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A PHENOMENOLOGICAL STUDY OF LEADERSHIP: DEVELOPMENTAL PATHWAYS
OF LEADERS WITH DISABILITIES

By

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This project would not have been possible without the help of the leaders who shared their stories with me in this study. I am so grateful to these individuals. I feel fortunate that I had the opportunity to listen to the first-hand, lived stories and wisdom from these leaders who are well respected in their fields.

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I dedicate this dissertation to my parents, Masumi and Noriyoshi, and my brother, Shingo. My parents did not have the chance to attend college. Instead, they supported me and fully embraced my education. My core motivation to obtain a doctoral degree stemmed from my desire to thank my parents and give them a university graduation experience. For my brother who has worked so long, he needed a good reason to take a vacation by attending his sister's graduation. They will be at the commencement ceremony on May 17, 2014.

Abstract

Research on leaders with disabilities is largely limited in scope to civil rights and disability rights leadership. This qualitative research investigated how individuals with disabilities transformed themselves into leaders in the disability field. This research focuses on the leaders' perceptions of critical experiences and relationships that influenced them as leaders. A phenomenological approach was used to understand the lived experiences of six leaders with disabilities. Open-ended interviews with recognized leaders who had disabilities were analyzed by examining their narrative statements, resulting in a combined description of their lived experience.

The results of the analysis revealed that these leaders with disabilities made personal connections with others and found groups that were the right fit for them during their college years or immediately subsequent years. Furthermore, the results found the following essential themes: 1) childhood as an influential life experience, 2) commitment, confidence, resilience, and passion in leadership style, and 3) enjoyment of helping others. These themes were not independent of one another, but were intertwined throughout the lives of the six leaders with disabilities.

Through a deeper understanding of leadership development experienced by these leaders with disabilities, this study has implications for practice and further investigation. Higher education and elementary and secondary education can improve leadership skills training and opportunities for students with disabilities. I also recommend several future research topics, including exploring identity development among leaders with disabilities. This dissertation concludes with the recommendation that disabled people should be specifically included in leadership research.

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Chapter One

Introduction

Problem Statement

As societies become increasingly diverse in the United States and globally, organizations have recognized the importance of diversity and have been valuing the creative ideas and innovative accomplishments that diverse people contribute. Diversity brings a variety of personal experiences, values, and views that enrich all of us with a deeper understanding of the human condition. A deeper understanding of the human condition enables us to respond to rapidly changing societies with creativity and productivity. Organizations are increasingly promoting diversity and the participation of those who have diverse backgrounds, including those with disabilities. Leaders with disabilities are among those who significantly contribute to the development of our diverse nation.

As the United States grows more diverse, higher education recognizes its responsibility to educate students on the importance of diversity, inclusion, and equality. At the same time, colleges and universities have influenced the quality of leadership and have been producing citizens that make a positive difference in the society (Astin & Astin, 2000). Higher education recognizes its responsibility to expose students to different experiences, perspectives, and backgrounds so that students can adapt and succeed in an increasing diverse community and workplace. According to the American Council on Education, higher education institutions aim to "develop leaders for society through the educational process" (n.d., para.1). For many years colleges and universities have been integrating leadership development into educational programs (McIntire, 1989; Posner, 2004). Examples include: military sciences, business schools, educational leadership programs, public policy and leadership programs, internships, fraternities

and sororities, to name a few. Colleges and universities also offer short workshops or seminars for anyone, such as a student, faculty, staff, volunteer, supervisor, or community member who is interested in leadership. Kouzes and Posner (2002) asserted that, "leadership is everyone's business" (p.83). Leadership is not only about being in a formal position but about acting in a way that creates a meaningful difference (McCauley et al., 2008).

As the college student population becomes more diversified, it is becoming more important to develop the concepts of diversity and inclusion in leadership development. However, current literature on leadership development in higher education is largely lacking for specific diversity issues, such as disability (Sanlo & Chaves, 2013). Studies often discuss diversity only in the scope of gender and race or ethnicity (Coleman, 2012). A lack of focus on disability in the leadership literature not only appears in higher education, it also appears to be persistent across various disciplines. For instance, in the field of psychology Chin and Sanchez-Hucles (2007) criticized the special issue of the *American Psychologist*, which was dedicated to leadership, but failed to address the importance of diversity that includes disability status. In the field of business, disability is addressed in the scope of "diversity management" to prevent discrimination or to promote the participation of disabled workers (Thanem, 2008). Overall, disability appears to be forgotten in the leadership development literature.

Disability is part of diversity, which is defined by Giovannini (2004) as "any dimension that can be used to differentiate groups and people from one another" (p. 22). Age, gender, ethnicity, race, nationality, sexual orientation, religion, educational background, and disability are examples of differentiating elements. Like aspects of these dimensions, disability is a status that experiences prejudice, stigma, and discrimination. The Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 protect individuals with disabilities from discrimination.

Although disability is a dimension of diversity and brings benefits to different individuals, leaders with disabilities are understudied in leadership literature.

Recognized or not, individuals with disabilities have become leaders at all levels in the United States. A number of those who have disabilities have successfully emerged as powerful leaders at the local, state, national, and international levels. Justin Dart, Jr. was a leader of the international disability rights movement and the leading figure in passing the Americans with Disabilities Act. Judy Heumann has served as Special Advisor for International Disability Rights at the U.S. Department of State. I. King Jordan was the first deaf president of Gallaudet University. These individuals have made a meaningful difference and have contributed to our diverse society.

The researcher is curious if leadership development differs in leaders with disabilities from leaders without disabilities. Are there common themes among these and other individuals with disabilities in their experience of becoming leaders? What, if any, college experiences may have helped them to serve as a leader? Little empirical research has studied leaders with disabilities regarding leadership development. Exploring the lived experiences of leaders with disabilities is a good starting point to understand their leadership development, and it is currently lacking in the literature.

Purpose and Significance

The purpose of this study is to investigate how individuals with disabilities have become leaders and what influenced who they are as leaders. In particular, this study explores the important life events and relationships that influenced these individuals as leaders. Furthermore, this study aims to learn whether college experiences influenced their leadership development. In keeping with the exploratory aim of the study, a qualitative inquiry was utilized. For this study,

the researcher used a phenomenological method of research to understand leadership development of leaders with disabilities. In choosing this method, the researcher hopes to provide the reader an intimate, internal view of these experiences. Giorgi (2005) states that, "The goal of phenomenological analysis, more than anything else, is to clarify the meaning of all phenomena. It does not explain nor discover causes, but it clarifies" (p.77). This study provides detailed perspectives of these leaders' developmental and transformational experiences.

This study is significant in several ways. First, it expands literature in the area of leadership, leadership development, diversity, and disability, as well as in higher education. Noticeable gaps in the available literature led the researcher to focus her research in this area. Second, the researcher believes that her findings will help higher education institutions better understand the complexity of leadership development among diverse students, including students with disabilities. In this way, higher education may be able to improve student leadership development training and programs. The resulting information may enrich, expand and diversify the pool of leadership talents.

Design of the Study

This study is comprised of six chapters including this introduction, Chapter One. The structure of this study is as follows: In Chapter Two, the researcher presents a review of the literature by highlighting leadership, higher education and leadership, and disability and leadership. Chapter Three describes the rationale for using a phenomenological method to study leadership of disabled leaders. This chapter discusses participant selection, data collection, and data analysis, as well as the researcher's assumptions and biases that might affect the study and strategies to increase the accuracy of the study's finding. This chapter concludes with limitations of this study. Chapter Four presents data analysis and results of this study. The participants'

expression of their experience is organized and transformed in each step in the analysis with emphasis on the phenomenon - being a leader with a disability. The abstract phenomenological description is presented at the end of this chapter and captures only the essential features of the phenomenon. Chapter Five provides discussion by presenting primary themes evident in this study on experiences of leaders with disabilities. The themes are explicated through the earlier review of the literature in Chapter Two and by additional literature that the researcher reviewed after data analysis. Chapter Six offers implications for practice and recommendations for future research. This chapter suggests elements of leadership development in higher education, elementary and secondary education. This chapter also recommends future inclusion of disabled leaders in research and the research topics on leadership development and disabled leaders.

References and appendices follow these chapters. The appendices include, the explanation of this study, consent form, a sample email to potential participants, and the Levels 1-3 (verbatim transcripts, spontaneous meaning units, and narratives based on emergent themes) for each participant.

Definitions of Terms

For the purposes of this study, the following definitions apply:

Leaders. This researcher uses the generic definition of a leader provided by Oxford Dictionary of English (2003). It defines leaders as “the person who leads or commands a group, organization, or country” (para.1). The individuals in this study have served or currently serve some type of recognized role as leaders of a group of people.

Leaders with disabilities. Leaders with disabilities in this study are those who meet the definition of “*Leaders*” mentioned above and who have substantial limitations to major life activities. A substantial limitation to major life activities matches the definition of “a disability”

as stated in the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. In this dissertation, the words of "leaders with disabilities" and "disabled leaders" are used interchangeably.

College degrees. In this study, college degrees include: Associate's, Bachelor's, Master's, First-Professional (e.g., Education Specialist degree), and Doctoral degrees. Technical certificates, which are offered by two-year or vocational institutions, are purposefully excluded because these certificates do not award a degree.

Summary

This chapter presented disability as a dimension of diversity. Higher education aims to "develop leaders for society through the educational process" (ACE, n.d., para.1). As the United States grows more diverse, higher education recognizes its responsibility to develop the concepts of diversity and inclusion in leadership development. However, the researcher pointed out that the literature on leadership development is largely lacking for specific diversity issues such as disability. This study investigates how individuals with disabilities have become leaders and what influenced who they are as leaders. Further, this study explores whether participants saw college experiences as influencing leadership development for these individuals. This chapter described the significance and the terms that are used in this study, as well as the structure of this study. The findings from this study potentially add to the literature of knowledge of leadership development. This study also may contribute to the kinds of leadership education that is effective for college students. The next chapter will examine the relevant literature, including leadership theories, leadership training and skill development, and disabled leaders in the scope of leadership.

Chapter Two

Literature Review

This dissertation investigates how research participants with disabilities have become leaders and what influenced who they are as leaders. The researcher focuses on influential experiences and relationships that these leaders have had. This study also aims to explore whether college experiences influenced leadership development for these leaders.

There is a large amount of literature that discusses leadership theory, behaviors, and practices in business, education, military, religion, political, and civic settings. Gender and ethnic groups have also been discussed in leadership literature that addresses diversity. However, studies focusing on leadership and disabled leaders are sparse. As a result, a comprehensive literature review on the topic of leadership among the disabled has proven to be problematic. Hence, the first section of this chapter focuses on recent leadership theories and leadership development in organizations. Particularly, this chapter discusses personal qualities and skills that prove useful to leaders. This chapter then discusses current literature and research about disabled leaders, followed by leadership development in higher education.

Leadership

Leadership has been defined in many different ways, perhaps too many. Several hundred definitions of leadership have been introduced over the years and the terms “leadership” and “leaders” have been used interchangeably (Andersen, 2005). Many leadership concepts have been created, partially because scholars disagree about leadership concepts but also because there is a notion that leadership may mean something different to each individual (Jackson & Parry, 2011; Yukl, 2006).

Among these definitions, Peter Drucker, in the twentieth century, developed the concept of leadership in business and management. His leadership definition was simple; he stated, "The only definition of a leader is someone who has followers...without followers, there can be no leaders" (Drucker, 1997, p. xii). He asserted that leaders set examples, make the right decisions for their organization, not their own popularity, and produce results that make a difference. Furthermore, Drucker argued that leadership is not a title or position, but it is a responsibility to perform, improve and maintain standards and values to make a difference.

Other scholars such as Bass (1990) have defined a leader as the person who outlines a need for change, develops a vision for the future, and mobilizes followers to achieve the results. Bass argued that charisma is an essential component of leaders in order to intellectually stimulate and inspire followers. In Bass's perspective, charisma motivates followers to grow their own self-interest for the good of the organization and "excite their employees with the idea that they may be able to accomplish great things with extra effort." (p. 21).

Moreover, scholars have debated the differences between leadership and management. Almost sixty years ago, Drucker (1955) asserted that managers needed to perform leadership functions within their organizations. However, other scholars suggested that leadership and management are different functions that require different skills and different types of people. Recently, Bennis (2009) argued that leaders and managers are exclusively different because leaders are innovative, flexible, and long-term oriented while managers are stable, rigid, and short-term oriented. Yukl (2006) remarked on the differences between managers and leaders, stating that "Managers are concerned about how things get done, and they try to get people to perform better. Leaders are concerned with what things mean to people, and they try to get people to agree about the most important things to be done" (p.5). Knowing this distinction

between leadership and management is helpful for those who wish to go beyond management capacities and develop leadership skills and competencies.

Most recently, Maxwell (2013) offered a simple definition of leadership. That is, leadership "always means that people are going somewhere" to create a positive change (2013, p.48). Maxwell calls leaders "change agents" (p.5) who influence followers with credibility, trust, and other interpersonal skills, in order to develop followers that aspire to become leaders in their own way. Regardless of the similarities yet subtle differences in leadership definitions, simply put, leadership is leading others for change.

Leadership Theories

As the definition of leadership has developed, numerous theories of leadership have been proposed. Research has investigated what makes people become leaders and what helps them to be effective leaders. Studies have also tried to identify the essence of good leadership. It is clear from the research that effectively leading people is a complicated task. Theories have changed over time. Therefore, a chronological review of research and literature that explores the traits of effective leaders follows.

For many years researchers investigated the specific traits of leaders. In the earliest approach, Bernard (1926) examined personal, physical, and mental characteristics of leaders based on the idea that a leader was born, not made. His study was meant to identify people who were born with these attributes to be capable leaders. However, popularity of the trait approach became less attractive and faded in 1940's as research began focusing on how good leaders behave (Jackson & Parry, 2011).

In the 1950's and 1960's, researchers focused on what good leaders do, or leadership behavior, and their interactions with subordinates (Yukl, 2006). During this era, the assumption

continued that the person in charge is always the leader. In pioneering research, the Ohio State Leadership studies in the 1950's focused on behavioral differences between effective and ineffective managers. The Ohio State Leadership studies identified the types of leadership behavior and developed questions called "Leader Behavior Description Questionnaire (LBDQ)" to measure how often a leader used these behaviors to satisfy the group's needs (Halpin, 1957). These behaviors included being friendly and approachable, treating each group member equally, maintaining performance standards for the group, and emphasizing the importance of meeting deadlines (Halpin, 1957). The Ohio State Leadership studies took a behavioral approach and their LBDQ influenced future questionnaire research on leadership behavior in the U.S. (Yukl, 2006). In the late 1970's and 1980's, the focus shifted from the behavioral approach to more recent behavioral theories called transactional leadership and transformational leadership, and researchers, including James Macgregor Burns, further investigated leader behavior.

Burns (1978) noticed that some leaders engaged followers in reciprocal activity by rewarding them for completing tasks. He defined this behavior as transactional leadership. He also differentiated transactional leadership from leaders who motivate others by searching for and meeting their needs. He called this transformational leadership. Burns (1978) described the differences between transactional and transformational leadership as follows:

Transactional - leaders approach followers with an eye to exchanging one thing for another... the transform[ational] leaders look for potential motives in followers, seeks to satisfy higher needs, and engages the full person of the follower. (p.4).

Burns's idea of transformational leadership was later expanded and further described by Bernard Bass (1985). Bass held the view that transformational leadership style is effective and superior to transactional because the former inspires and intellectually stimulates followers. He also

suggested that transformational leadership broadens and elevates the follower's interest in the good of the group (Bass, 1985).

Transformational Leadership

Bass's expansion of Burns's work has become widely recognized in leadership literature. Bass summarized the characteristics of a transformational leader as: (a) having a charisma that provides vision and a sense of mission, instills pride, respect, and trust; (b) inspiring others through communicating with high expectations, using symbols to focus efforts, and expressing important purposes in simple ways; (c) intellectually stimulating others by promoting intelligence, rationality, and careful problem solving; and (d) considering individuals by giving them personal attention, coaching, and advice, and treating each follower individually (Bass, 1990, p.22). Bass's work was a groundbreaking for researchers who later studied transformational leadership.

Over the years, more scholars have offered additional characteristics to transformational leadership. In addition to Bass's summary of transformational leadership characteristics, Yukl (2006) identified a few other characteristics that are frequently discussed in the leadership literature. These characteristics are: (a) being able to articulate a clear and appealing vision; (b) being able to explain how the vision gets accomplished; (c) being confident and optimistic; and (d) leading people by example (p. 274-276).

Authentic Leadership

While researchers studied transformational leadership, a popular leadership publication came out in the late 1990's and early 2000's that brought attention to authentic leadership. Kevin Cashman's (1998) *Leadership from the Inside Out: Becoming a Leader for Life* and Bill George and Peter Sims's (2007) *True North: Discover Your Authentic Leadership* are among the popular

publications. Authentic leadership style and transformational leadership are similar in that they share common behaviors (e.g., intellectually stimulating, inspiring, motivating others). The distinctive difference is that authentic leadership is based on morality and a deep sense of self (Avolio & Gardner, 2005; Bass & Steidlmeier, 1999). Authentic leadership appeared in the leadership literature in the 1960's to describe how authenticity influences an organization through leadership (Gardner, Cogliser, Davis, & Dickens, 2011). Cashman (1998) asserted that effective leaders are authentic because they develop a strong self-awareness about their strengths, weaknesses, and areas of improvement. He suggested that authenticity could not be developed in a short period of time, but rather, requires "a lifelong commitment to self-discovery and self-observation" (p.44). Later, George and Sims (2007) summarized the qualities of authentic leadership styles by interviewing 125 leaders. They offered ways to discover and develop one's own leadership style as an authentic leader: knowing oneself and being true to oneself. George and Sims noted that not only knowing oneself but also, engaging in practices based on one's values and principles, building one's support team, and empowering others to lead are forms of authentic leadership.

Researchers have investigated characteristics of authentic leaders. Walumbwa, Avolio, Gardner, Wernsing, and Person (2008) suggested that authenticity increases as individuals advance their cognitive, emotional, and moral development. Particularly, these researchers identified self-awareness, transparency, moral perspective, and the ability to objectively analyze relevant information as distinguishing features of authentic leadership (Walumbwa et al., 2008).

While literature has focused on developing authentic leadership, Gardner, et al. (2011) pointed out that authentic leadership development could fully flourish if both leaders and

followers were authentic. They argued that the authenticity of followers is just as important as the authenticity of leaders and suggested further studies are needed in authentic followership.

The types of leadership that are most likely successful in an organization depend on context, such as the size, culture, purpose, structure, and history of an organization. However, understanding the characteristics of different leadership styles such as transformational and authentic are useful to us because the knowledge of leadership styles could help us gain awareness of our own strengths and weaknesses as well as areas for improvement. In the next section, the researcher briefly reviews commonly used methods of developing leadership skills and competencies: formal leadership training, feedback, and mentoring.

Developing Leadership Skills

Leadership training programs. As numerous books and articles on leadership and leadership development have been sold, leadership-training industries have also grown and become a big business. Many universities offer leadership seminars, courses, and training not only to students but also to managers, executives, or others interested in leadership. Large companies such as Apple, Google, Toyota, Exxon Mobil, and Mayo Clinic provide their employees with leadership development training courses.

However, some scholars are cautious about the effectiveness of leadership training programs. First of all, leadership development takes many years (Maxwell, 2013). Jackson and Parry (2011) believe that leaders learn about leadership primarily through experience, both in success and failure. There is also criticism that educational leadership training and programs only help to develop intellectual knowledge about leadership or about certain behavior and skills that can help individuals to lead others (Allio, 2005; Jackson & Parry, 2011). Bennis (2009) also argues that leaders are usually "self-made," not created by external forces such as training

programs. He stated, "Leadership courses can only teach skills. They can't teach character or vision... Developing character and vision is the way leaders invent themselves" (Bennis, 2009, p.35).

Although developing leadership skills and competency takes time, scholars have discussed some benefits of formal leadership training. Benefits of such leadership training programs include: helping the participants understand their own leadership styles; helping them to assess behavioral patterns of themselves and others; helping them increase their self-esteem; and helping them gain generic skills (Allio, 2005; Pledger, 2009). Yukl (2006) summarized the following contents that are found to be effective for leadership training programs: 1) role modeling effective behavior and interpersonal communication, 2) discussing difficult cases and receiving feedback and recommendation, and 3) simulating such cases. For specific interpersonal communication, Gardner (1989) suggested that improving written and oral communication skills would be one of the objectives in designing an effective leadership training programs because leaders need "exceptional command" of these skills to be effective (p.73). However, to increase effectiveness of training, program contents should be tactfully delivered to participants by providing clear content, concrete examples, and opportunities to practice (Allio, 2005; Yukl, 2006). In other words, the effectiveness of formal training programs depends on how well these programs are designed and implemented.

Feedback. Feedback has commonly been used to facilitate job performance and relevant leadership skills and competency on the job. Many organizations use multisource feedback, which is called '360 degree' feedback or 'multi-rater' feedback, as part of their leadership development programs (Atwater, Brett, & Charles, 2007). Multisource feedback is designed to provide behavioral feedback from multiple sources such as peers, subordinates, bosses, and

customers or other constituents. Feedback is useful when it is accurate, relevant to the person, easy to understand, and describes how the person can improve in areas of deficit (Yukl, 2006).

Over the years scholars have investigated the effectiveness of multisource feedback. Among these scholars, Brett and Atwater (2001) conducted an empirical study finding that negative feedback was not seen as accurate or useful by those who received the feedback. Their study also found that negative feedback caused resentment among the feedback receivers and that these receivers perceived such feedback as ineffective. Thus, Brett and Atwater recommended that negative feedback should be carefully delivered by providing follow-up activities such as one-to-one meetings.

Moreover, according to Yukl (2006), studies on the effectiveness of multisource feedback have shown inconsistent results; some studies found positive behavioral changes in leadership skills from multisource feedback while some studies did not find any improvement. Thus, Yukl suggested that further research is needed to adequately determine the effectiveness of multisource feedback and to learn how to use such feedback tools to enhance leadership skills.

Mentoring. Mentoring has also been used as a leadership development method. Organizations arrange formal mentoring and assign individuals to serve as mentors and offer advice and assistance to their mentees, who are called protégés (Hezlett, 2007). Informal mentoring is the process during which the mentee and mentor get to know each other on their own. This kind of mentoring is a special relationship that develops between the two people. Mentors are experienced persons who serve as "coaches, supporters, counselors, and educators" to provide assistance to less experienced individuals, called mentees or protégés for their development (Dziczkowski, 2013, p.351). Mentors coach mentees on how to use the skills that

they already possess. Mentors offer advice, listen to, and educate mentees by providing new ideas and additional support that mentees need (Dziczkowski, 2013).

Despite being used as a leadership development method, mentoring has drawn little attention in leadership training literature compared to formal leadership training programs. A study by Collins and Holton (2004) analyzed 103 empirical leadership development studies and discovered that only five percent of these studies focused on mentoring while eighty percent of these studies featured formal leadership training programs. One reason for such little attention on mentoring is probably due to mentoring's inconsistent success (Yukl, 2006). Stead's (2005) study on a formal mentoring program suggested that the significant costs, time, and commitments that organizations and individuals have to invest in mentoring could possibly lead formal mentoring programs to be unsuccessful. Further, due to the program's formality, formal mentoring programs might not succeed in helping mentors and mentees feel connected to one another (Hezlett, 2007).

To feel connected, trust is a crucial ingredient for effective mentor-mentee relationships (Hobson & Sharp, 2005). Researchers agree on the following additional key elements that make mentoring effective: 1) a clear process and responsibilities for mentors and mentees; 2) careful recruitment for well developed mentors who are committed, care for mentee's growth, and have the ability to establish positive professional relationships; 3) compatible pairing of mentors and mentees, and 4) proper training for mentors and mentees (Dziczkowski, 2013; Hobson & Sharp, 2005; Searcy, Lee-Lawson, & Trombino, 1995; Stead, 2005). These key elements should apply not only to mentors but also to mentees because an effective mentoring experience is based on relationships that involve trust, commitment and require reciprocal efforts. Two individuals need to be committed and trust each other to make the relationship work.

As discussed above, leadership development training and methods such as feedback and mentoring have been widely used. These training methods appear to help individuals gain self-awareness, which is an important element for developing leadership skills and characteristics (Cashman, 1998; George & Sims, 2007; Walumbwa et al., 2008). Characteristics such as authenticity influence leaders and followers, but diversity is also an influence in the workplace. Hence, the next section reviews literature on diversity and leadership. The researcher first reviews leadership literature that focuses on gender differences because gender is a form of diversity and a large body of literature has focused on gender and leadership. The researcher then reviews leadership literature on disability as diversity.

Diversity and Leadership

As society increasingly becomes diverse, organizations are recognizing the importance of diversity. Diversity takes multiple forms, which include, but are not limited to, disability, age, sex, race, ethnicity, religion, nationality, educational background, political views, sexual orientation, gender identity, and socioeconomic status. Most research has focused on gender. However, there is a small body of leadership studies focused on leaders with diverse backgrounds aside from gender (Chin, 2013; Klein & Mo, 2010). Diverse backgrounds and cultural influences, such as a leader's ethnic background, have been investigated to understand how a leader's ethnic minority status affects followers (Okoyi et al., 2009; Romero, 2005).

A substantial body of literature has discussed gender and leadership. Studies have debated whether there are differences between men and women in leadership behavior, effectiveness, and perception (Dobbins & Platz, 1986; Lauterbach & Weiner, 1996; Ridgeway, 2001). For instance, Watson and Hoffman (1996) found differences in the leaders' own perspectives, particularly in negotiation. Watson and Hoffman discovered that, compared to men,

women felt less confident and less satisfied with how they performed negotiations, although their performance brought about the same results as the men. In fact, when it came to the outcome of negotiation, there were no gender differences. The researchers tested whether their study would validate a common belief that "women are nicer, if possibly less effective, negotiators than men" (Watson & Hoffman, 1996, p. 80). Their results showed that both men and women who served as high-level leaders, demonstrated direct confrontation in their negotiation, while low-power leaders, regardless of gender, demonstrated soft persuasive negotiation styles.

Furthermore, Eagly, Johannesen-Schmidt, and van Engen (2003) analyzed 45 gender studies in leadership and reported a small difference between men and women in leadership styles. They found that women more often used transformational leadership styles than men did. They also found that women often demonstrated supportive behavior to followers and particularly supported followers with the development of skills and confidence.

Although these studies on different styles and perceptions between male and female leaders add valuable insight to diversity and leadership literature and practice, gender difference studies in leadership often have provided limited results and little agreement about how men and women actually lead (Dobbins & Platz, 1986; Eagly & Johannesen-Schmidt, 2001; Powell, 1990). As a result, some critics have concluded that there are no critical differences between men and women in the effectiveness of leadership behavior (Yukl, 2006). Additionally, critics have argued that organizations need to develop and promote both men and women in order to utilize the talents of men and women with various values, traits, and skills (Powell, 1990).

Male and female leadership styles have been the primary focus while the topic of disability in the leadership literature has only been addressed in two ways. First, it is addressed within the scope of "managing diversity" (Yukl, 2006, p.435). That is, organizations promote

diversity in the workplace for creativity and to increase talent but also to manage the workplace, such as mitigate distrust, conflict, low satisfaction, and high turnover (Yukl, 2006). The second avenue of discussion on this topic is that of preventing discrimination or promoting the participation of disabled workers (Thanem, 2008). Diversity literature has discussed providing accommodations to workers with disabilities and complying with the federal laws to prevent discrimination. Furthermore, diversity literature has promoted an understanding of disabilities and methods of accommodating disabled workers as ways to promote diversity at the workplace (Nafukho, Roessler, & Kacirek, 2010).

Recently, Chin (2013) investigated whether minority status influences leaders. Although this study did not include disability, it did include gender, race, ethnicity, and sexual orientation, and had notable results. Chin found that minority status could positively and negatively influence the way leaders exercise their leadership. Moreover, Chin's study found that leaders of color and women leaders more strongly embraced their ethnic and gender identities than did white male leaders.

Coleman (2012) reviewed scholarly articles on leadership and diversity published from 1972 to 2012 in the journal of Educational Management Administration and Leadership (EMAL). In the journal of EMAL, researchers used the term diversity to include gender, ethnicity, religion, sexual orientation, and disabilities. However, Coleman's literature review found that this journal primarily focused on gender and considered ethnicity an increasing interest in the area of diversity. Coleman also discovered that there was only one article in the journal on a leader with a disability (i.e., a mobility impairment). Due to this finding, Coleman strongly recommended that researchers and practitioners expand on the definition of diversity to include those who have disabilities.

Disability and Leadership

As Coleman's study (2012) suggested, disabled leaders are typically underrepresented and understudied in leadership literature. A miniscule body of literature has examined disabled leaders and their leadership development. Johnson (1999) stated, "the discussion of leadership for people with disabilities has almost been exclusively limited to self-advocacy focused on acquiring and defending a person's civil and human rights" (p.13).

Existing literature focuses on disabled leaders exclusively in the scope of disability rights. For instance, O'Day and Goldstein (2005) interviewed 16 leaders with disabilities to explore perspectives on advocacy issues that need to be prioritized for disability rights. In their study, these disabled leaders identified the following issues that need to be prioritized: the availability of affordable health care, employment, and accessible technology. Further, these leaders recommended that those who were engaged in disability rights activities should maintain consistent involvement in the political process, in order to build a strong disability rights movement and to pursue the identified pressing issues.

McCarthy (2003) conducted a similar study by interviewing 10 disabled leaders who experienced the disability rights movement. However, unlike O'Day and Goldstein (2005), McCarthy inquired on a more personal level by exploring the perspectives of the disabled leaders on advocacy issues that might affect their lives. McCarthy asked his research participants to reflect on personal experiences that they were proud of. Although the participants shared pride-producing experiences, McCarthy found psychosocial issues that continue to be challenging for people with disabilities: employment discrimination, oppression, and others' low expectation of their ability. McCarthy also found that these disabled leaders experienced the stereotype that "a life with a disability is worth less investment and protection than one without an identified

disability" (p. 221). He suggested that the disability community and professional community continue to work for social changes to eliminate the negative perceptions about people with disabilities.

Other scholars have discussed leadership in school as a way to support children with disabilities (King, Aguinaga, O'Brien, Young, & Zgonc, 2010; Kugelmass & Ainscow, 2004), or people with disabilities to advocate for civil rights in their communities (Caldwell, 2010; Powers et al., 2002; Shogren & Plotner, 2012). However, these studies did not investigate leadership development from a disabled leader's perspective.

Leaders with Disabilities and Leadership

Among the small body of literature that focuses on disabled leaders, Seekins, Shuttleworth, and Kasniz (2004) studied political leaders with disabilities in rural communities. Through interviewing 10 disabled political leaders throughout the United States, Seekins et al. found several strategies that these rural politicians used in order to be effective community leaders. Their study found that a non-confrontational manner in activism and advocacy, willingness to compromise, and ability to network were highly valued among these leaders when effectively achieving their disability-related agenda. Emphasis solely on disability did not work for these leaders in the rural political practice (Seekins, et al., 2004). More interestingly, their study found that many of these disabled politicians de-centered their disabilities in order to advance disability issues in their practice.

Similarly, Foster-Fishman, Jimenez, Valenti, and Kelley (2007) conducted a study on 21 leaders with disabilities in disability rights advocacy organizations in one state. Based on semi-structured interviews with these individuals, who were considered to be effective leaders, their study learned several lessons on how to facilitate leadership in the disability rights community.

These were: 1) leadership development occurs across the lifespan, 2) mentoring is important for promoting leadership, 3) an extensive network with diverse individuals and organizations is critical, and 4) leadership develops through practice (Foster-Fishman et al., 2007).

The disabled leaders in Foster-Fishman and colleagues' study (2007) indicated that they gained self-confidence through multiple experiences that helped them develop participatory skills, knowledge of the disabilities movement and the history of disability rights. These leaders also found it critical to have a mentor or a role model to help them develop leadership skills. Mentors demonstrated self-confidence and leadership competency in both formal and informal ways, which helped these leaders learn what effective leadership looked like. Furthermore, these leaders reported that they made efforts to find and build connections to be successful leaders. Identifying others who shared similar concerns was important for networking and building relationships.

Based on their findings, Foster-Fishman et al. (2007) suggested that leadership development for disabled leaders should integrate skill-building training with links to mentors, networks of other leaders, and opportunities to practice leadership skills in a real setting. These suggestions are congruent with general leadership development mentioned previously in this chapter.

Thus far, this chapter has reviewed leadership theories, diversity in leadership literature, disabled leaders in leadership literature, and leadership development training programs and methods. The purpose of this study is to understand disabled leaders' experiences while becoming and being a leader. In part, this study intends to learn whether college experiences influenced leadership development among disabled leaders. Therefore, the next section reviews literature on leadership development in higher education.

Leadership Development in Higher Education

American higher education has played a critical role in producing leaders across a broad range of academic disciplines (Astin & Astin, 2000; McIntire, 1989). Colleges and universities provide students with leadership training and educational programs. Leadership skills are valuable life skills and can be utilized in many areas of adult life (Astin & Astin, 2000). In terms of adult life, many higher education institutions have implemented Chickering's identity development theory into student development programs (Evans, Forney, Guido, Patton, & Renn, 2010; Garfield & David, 1986; Schuh, 1989). For this reason, the researcher describes this theory below.

Chickering's Identity Development Theory

Knowing oneself includes developing a sense of personal identity. Identity shapes how individuals think, act, and value themselves, as well as how they perceive and interact with the world around them. Chickering (1969) focused on developmental issues that traditional-aged college students commonly experience.

Chickering's identity development theory was based on Erik Erickson's idea that identity is shaped by how a person synthesizes experiences within the surrounding environment. (Evans et al., 2010). Chickering proposed that several critical developmental tasks, called "vectors," would advance students' psychological, physical, and intellectual development. Recently, Chickering and Braskamp (2009) re-examined the original identity development theory and suggested that four vectors are critical for current college student development. The first vector is called "moving through autonomy toward interdependence" (p.27). That is, students need to learn how to be reciprocal, committed, and compromise for the benefit of the larger community, not just for themselves. The second vector is establishing one's identity by gaining a wide range

of knowledge and experiences, which ultimately leads the student in developing a sense of what is important to them. The third vector is cultivating purpose. That is, students need to cultivate a sense of meaning and purpose in their lives. By doing so, this vector becomes a motivational factor that energizes students to action. The fourth vector is developing a capacity to control negative emotions, such as anger and fear. Chickering's theory has significantly influenced higher education institutions' understanding of students and the development of programs and services for students (Barr & Cuyjet, 1991; Evans et al., 2010). To assist students in gaining a wide range of knowledge and experiences, scholars have suggested a holistic approach to promote students' leadership development in addition to formal leadership development programs.

Holistic Leadership Development in Higher Education

Astin and Astin (2000) suggested that higher education institutions should practice a holistic and collaborative approach to leadership development. That is, higher education should implement leadership development opportunities not only through curriculum but also through service learning, student organizations, and community work. These activities include student employment on and off campus, internship, study abroad, volunteer work in the community, and involvement in student organizations and activities. In addition to institutional efforts, Astin and Astin proposed individual micro-level efforts for leadership development. For instance, they suggested that instructors could help their students by discussing how to apply the principles of shared purpose, collaboration, commitment, group learning, and division of labor to teams so that the teams could achieve their final goal (Astin & Astin, 2000). This perspective is similar to transformational leadership, discussed earlier in this chapter. The importance of collaboration, commitment, and group learning are congruent with the critical vectors that Chickering

suggested, which were described above. Faculty members usually have many roles, including serving on committees, chairing departments, teaching, researching, and advising, simultaneously. As a result, depending solely on faculty instructors may not be effective for micro-level efforts for student leadership development. Thus, to maximize the outcomes of these efforts, the responsibilities should be shared amongst other university staff and administrators.

Leadership Development Programs in Higher Education

Higher education institutions provide leadership courses and leadership training programs. According to Dugan and Komives (2007), since the early 1990's college student development has received exponential attention from higher education institutions. Over 1,000 leadership programs now exist on college campuses in the United States (Scott, 2004, cited in Dugan & Komives, 2007). Like other formal leadership training, researchers have questioned the effectiveness of such programs and suggested more investigation.

Although Avolio, Walumbwa, and Weber (2009) argued that leadership development is too complex to be accomplished through training programs, some empirical research on leadership and higher education has shown positive effects of such training for college students. Cress, Astin, Zimmerman-Oster, and Burkhardt (2001) found that these leadership-training programs have positive outcomes because, after completing the activities, students demonstrate improved leadership skills, knowledge of leadership theories, and developed self-awareness of both personal and societal values. Another study has shown that a one-day training session produced effects that were similar to a semester-long training program (Dugan & Komives, 2007). Further, Rosch and Caza (2012) found that short-term training fosters better understanding of leadership skills among participants and suggested identifying which skills should be targeted and included in a short-term program versus a long-term program. However,

these studies did not include college students with disabilities as their research participants. The lack of participation of people with disabilities in research was discussed earlier in this chapter. This issue is relevant to research on leadership training in higher education because college is a key time for students to develop competence, self-control, and sense of identity (Chickering & Braskamp, 2009). These elements are important both in the psychosocial development of college students and the leadership development.

Summary

In this chapter, the following three main topics were highlighted as literature review: 1) leadership in general, 2) diversity in leadership, 3) disability and leadership, and 4) leadership development in higher education. Various concepts of leadership and recent leadership theories were discussed. The researcher further explained transformational and authentic leadership styles and their characteristics. Formal training, mentoring, and self-help methods of knowing oneself were discussed as examples of leadership skill development and training. Leadership development training on college campuses was discussed by incorporating a theory of identity development in college-aged students. Although this chapter reviewed diversity issues, it was evident that leadership literature often does not represent leaders with disabilities. This demonstrates that this study on perspectives of leaders with disabilities will add insights into leadership development for this underrepresented and understudied population. In the next chapter, the researcher presents the methodology for this study by using a phenomenological approach in order to explore leadership development in disabled leaders.

Chapter Three

Methodology

This chapter describes the rationale and the process of qualitative phenomenological inquiry regarding the life experiences of college-graduated leaders with disabilities. The focus of this study is to understand the essence of their experiences as leaders. Phenomenological research was used in this study to explore the essential features of the life events and issues that brought these leaders to their leadership roles.

Lieblich, Tuval-Mashiach, and Zilber (1998) suggest that humans are storytellers by nature, and the stories we tell about our lived reality provide us with an understanding of who we are. In other words, stories can give us an idea of personal identity, personality, and the essence of our experiences. The participants in this study are the experts of their experiences. The researcher chose qualitative research for this study because little has been written about leadership development in people with disabilities. The researcher wanted to conduct the study in a natural setting to uncover the essence of experiences of leaders with disabilities as described by themselves.

Choosing the Phenomenological Method

This researcher chose the phenomenological approach described by Giorgi (1997, 2012) and Polkinghorne (1989) as the research method for this study to understand the lived experiences of individuals with disabilities who have become leaders. Phenomenological inquiry attempts to investigate the essential nature of an individual's experience of a specific phenomenon and to describe what and how they experienced this phenomenon (Creswell, 2007). In order to understand this phenomenon - being a leader with a disability - first, the researcher needs to know what these individuals experienced.

Patton (2002) offered the following explanation of phenomenological inquiry:

This [phenomenological approach] requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others. (p. 104)

This qualitative study investigates how these individuals describe their experiences of being leaders.

As Moustakas (1994) and Giorgi (1997) pointed out, it is critical for the researcher using a phenomenological approach to set aside his/her personal prejudgments, biases, preconceived ideas or knowledge of the phenomena as much as possible. This self-reflection process is called “bracketing” (Polkinghorne, 1989). The German philosopher Edmund H. Husserl originally developed this idea (Giorgi, 1997, 2005, 2012; Moustakas, 1994; Polkinghorne, 1989; Wertz, 2005). Priebe (1993) noted that, “His (Husserl’s) guiding belief was that to understand human phenomena we need to put aside our established views and assumptions and learn to “see” things as they present themselves in our experiences and to “describe” them in their own terms (p. 50). Bracketing is a challenging but essential practice because phenomenological research aims to elicit a phenomenon of the experience as it presents itself to the other person (Giorgi, 1997, 2012; Moustakas, 1994). For bracketing, this researcher identifies and addresses her own biases and assumptions in the section, “The Interviewer: The Instrument of Data Collection” found later in this chapter.

Participant Selection

For the purpose of this study, it was necessary to recruit disabled individuals: 1) who currently hold or previously held a leadership role and 2) who earned one or more college

degrees. Thus, this study used “*criterion sampling*” (Creswell, 2007), which in the case of this study means that all the participants meet these two criteria.

To understand the essence of the leaders with disabilities’ experiences, six leaders were recruited for this study. As the researcher, I carefully selected participants in order to gather data from those who have experienced the phenomenon of interest. The recruitment for leaders with disabilities was implemented after the University of Montana Institutional Review Board approved this study. I identified a few individuals who could meet the participation requirements. However, the number of those potential leaders with disabilities was small and I anticipated that it would be difficult to find a sufficient number of participants that met the criteria. Qualitative research needs good "key informants" who feel comfortable communicating with the researcher and are willing to reflect on their thoughts to provide information to the researcher (Gay, Mills, & Airasian, 2006, p.113). Thus, I asked for assistance to identify potential participants from several individuals who have worked professionally with disabled leaders and individuals with disabilities. After obtaining the names of potential participants, I contacted each of them and asked them to consider participating in this study. I further asked those individuals, who agreed or disagreed to participate in this study, to give me the names of additional potential participants by using a "snowball sampling" method (Patton, 2002). I acknowledge that in future research she might need to continue recruiting additional participants until redundancy in interview data occurs.

Characteristics of the Sample

The participants in this study were three men and three women all of whom held one or more college degrees and were nationally known for their work in the field of disabilities. These six participants were White and all had physical disabilities that impacted their vision or mobility.

The participants' ages ranged from late 40's to mid 60's at the time of the interview. One participant was the principle administrator of an international organization. One participant served as a board member of a national organization. One participant was a director of a research center at a private medical school. Three participants were disability services directors at a private or public university where the student population ranged from 5000 to 40,000. They were located in the Northeast, Midwest, South, and West of the United States.

Data Collection: The Interviews

The researcher conducted a face-to-face or phone-call, open-ended individual interview with each participant. Each interview lasted 45 to 75 minutes. The researcher asked participants an open-ended question: "Please take a moment and reflect on your important experiences or relationships in your life that led you to take your leadership role." The researcher also told the participants to: "Reflect on the events or activities that may have contributed or led you to who you are as a leader now." Depending on how the interview proceeded, the researcher asked the participants how they became leaders, what was unique about their experiences and how their experiences shaped who they were. These follow-up questions were used to clarify participants' responses. The researcher audio recorded interviews in order to preserve exact words and to be transcribed verbatim for later analysis.

The Interviewer: The Instrument of Data Collection

In qualitative research, the researcher is the "instrument" that collects data directly from the participants (Gay, et al., 2006; Morrow, 2005; Patton, 2002). It is critical for the researcher to identify the personal assumptions and biases that might affect the research findings (Creswell, 2003). This partially explains the need for the "bracketing" process as Priebe (1993) has noted above. By suspending or putting aside the knowledge and biases of the researcher, this study

aimed to faithfully understand a phenomenon at a deeper level. Bracketing is always partial, in that one's personal biases are not always visible to oneself.

The researcher in this study is a doctoral student in the Department of Counselor Education at the University of Montana. She is originally from Japan and has lived in the United States for nineteen years as this dissertation was written. This researcher is bilingual in English and Japanese. She acknowledges she has worked with college students with disabilities for over twelve years in a university setting. Over the years her colleagues with disabilities have positively influenced her own understanding of having a disability. Through this, she has come to understand that disability is common, not extraordinary, and in fact, most individuals will experience either a temporary or permanent disability at some point in their lives. During the course of these years, this researcher has come to understand that her life long struggle with reading stems from a reading disability. This researcher has also experienced leadership roles. Her leadership skills developed through observing the positive and negative examples of leadership styles of others, by implementing good leadership styles in her own practice, and through learning from her own mistakes.

For example, from 2007 through 2010, the researcher met with a number of respected leaders with disabilities around the world through international conferences concerning disabilities. These leaders practiced effective communication, treated colleagues with respect and dignity, and appeared to have established a strong ethical foundation and sense of self-identity. This experience interested the researcher in learning more about leadership. Because of these professional and personal experiences, her preconceived ideas of characteristics of effective leaders with disabilities may potentially affect her data collection and interpretation process.

Data Analysis

This study focused on experiences of leaders with disabilities and treated descriptions as raw data in order to learn the essence of their phenomenon: being a leader with a disability. By using a phenomenological method, the researcher intended to clarify the meaning of human experience as it presents itself; the intention was not to explain or discover causes (Giorgi, 2005; Jenni, 1990). To analyze data, this study followed the protocol described by Giorgi (1997), Jenni (1990), and Polkinghorne (1989) and carefully paid attention to significant statements, generated meaning units, and developed an “essence” or abstract, non-situated description. This protocol included the six steps as follows:

Level One: Verbatim Transcriptions (Individual Protocols). This first step in the analysis is to read the transcript of each interview until the researcher understands its general sense.

Level Two: Spontaneous Meaning Units (Individual Protocols). The second step is to divide the transcript into sections called "meaning units." The meaning units appear when a subject/interviewee shifts the focus of attention during its interview. The researcher marks a forward slash "/" in the transcript to distinguish one meaning unit to the other so that the data can become manageable portions. Then, the researcher summarizes the meaning of each meaning unit by using the interviewee's words.

Level Three: Emergent Themes (Individuals Protocols). As the third step, the researcher simplifies each meaning unit by using largely his/her own language. This step reorganizes and partially transforms the data from the subject's words to the researcher's words. However, the researcher preserves many of the subject's words that were expressed in the original transcript.

Level Four: Transformations (Individuals Protocols). At this fourth step, the subject's expression of their experience is transformed into psychological language with emphasis on the phenomenon - being a leader with a disability. The researcher organizes each meaning unit by themes and describes the phenomenon for a single individual.

Level Five: Fundamental Descriptions (Combined Protocols). The fifth step is to combine the Level Four data from all participants and synthesize common themes that are shared by all or nearly all participants into a descriptive narrative statement. This statement includes concrete and specific information of the situated experiences that describe the phenomenon.

Level Six: Essential Description (Combined Protocols). The final step of data analysis is to create an abstract description that captures only the essential features of the phenomenon that participants in this study have experienced.

Protection of Human Subjects

Several safeguards were utilized to protect the confidentiality of this study's participants. First, the researcher obtained written, informed consent from the participants in the study. Consent forms informed participants that: (1) all of the information they provide would be kept confidential, except in cases of harm to oneself or others, (2) any identifiable names and features of the interview were removed or modified during the transcription process, (3) the researcher used codes and pseudonyms to conceal identities in transcripts, (4) audiotapes and interview notes were kept in locked files, (5) audiotapes would be destroyed once transcripts were verified for accuracy, and finally (6) transcripts, written interpretations and reports were available to the participants. Although the researcher implemented all of the above safeguards to protect the participants in this study, others may recognize the title or status of the participating leaders from the content of the experiences that were disclosed by the leaders. Prior to the time a potential

participant made a decision whether to participate in this study, the researcher explained this possibility in writing and provided them with the option of not remaining anonymous in this study. In the end, six individuals agreed to participate in this research. Three wished to remain anonymous and the other three approved their potential identification in the study. However, the researcher modified and removed identifiable details of all participants for purposes of consistency and to protect all participants' confidentiality.

Verification Procedure

The validity of a qualitative study is determined by the extent to which the data the researcher collects accurately represents what it is intended to represent (Gay, et al., 2006). As well, in order to establish “trustworthiness” in qualitative research, the following strategies were implemented in this study:

- 1) Spending prolonged time engaging with the participants (Creswell, 2003). This was achieved during each interview with the participants.
- 2) Clarifying the researcher’s assumptions and biases so that the reader can understand the researcher’s position and whether this position could unduly influence data collection and interpretation (Creswell, 2007). The researcher’s potential assumptions and biases were described earlier in this chapter.
- 3) Checking the phenomenological analysis and interpretation during the research process, which is called “peer review” (Lincoln & Guba, 1985). In this study, peer review was conducted through the dissertation committee, especially through the dissertation chair.
- 4) Using “rich, thick descriptions” (Guba, 1981; Lincoln & Guba, 1985) to state findings so that readers have adequate data to understand and interpret the phenomenological

description. This researcher used the participant's words in addition to psychologically-based language to bring out the essence of the experiences being described in the study.

Delimitations and Limitations of the Study

The purpose of this study is to investigate how individuals with disabilities have become leaders after college and what influenced who they are as leaders. Therefore, this study purposefully selected participants who met the following criteria: 1) has served in a leadership role and 2) has earned one or more college degrees. By using a phenomenological, qualitative method, the researcher focused on "individual, person-to-person interactions" (Gay, et al., 2006, p.402) with participants in order to understand the experiences of disabled leaders in a holistic and comprehensive way.

Although a qualitative approach may be a most appropriate strategy for this study, there are some limitations. First, the small sample size, which is the nature of a phenomenological study, makes it impossible to generalize the results. This study provides rich descriptions of disabled leaders' experiences and perspectives. The type of disabilities is also limited due to a small sample size. This study does not attempt to explore the behavior of a larger group, such as leaders with all types of disability, leaders in general, or leadership in a global perspective. Therefore, this study does not produce generalized knowledge about leadership for other people or other settings.

Secondly, this study had a limitation in participant selection. Subjects, who agreed to participate in this study, happened to be leaders with disabilities who were leaders of groups focused on disabilities and/or individuals with disabilities. As a result, this study unintentionally did not include disabled leaders leading a group of people who do not have a disability.

Thirdly, participants were not re-interviewed to assess if they had an adequate opportunity to express important elements during their interviews. This was due to the participants' busy schedules. However, given the time participants had during their interviews, the researcher did provide them for sufficient time and opportunity to express what they had to say without interrupting them.

Finally, the researcher is the data collection instrument for phenomenological research. It is also the qualitative researcher's job to interpret and analyze the data. This means that the researcher "filters the data through a personal lens" and cannot separate the personal interpretation from the data itself (Creswell, 2003, p.182). As a result, the researcher's assumptions and beliefs may affect the research findings. However, it is critical that the researcher identifies and discloses the personal assumptions and biases. By setting aside such assumptions as much as possible, the researcher may be able to see the phenomenon of the study "as if for the first time" (Moustakas, 1994, p.34).

Summary

Chapter Three described the methodology and rationale for the research design of this phenomenological study focusing on the development of leadership in individuals with disabilities. The research question grew from a gap identified in the literature review, which was presented in Chapter Two. This chapter describes the procedure of participant selection, data collection, and steps in the data analysis when using a phenomenological research method. Protecting participants and approval from the institutional review board were discussed. Further, this chapter addressed potential assumptions and biases the researcher herself may bring to this study, as well as four strategies likely to increase the accuracy of the study's findings. Finally,

this chapter discussed limitation of this study. The next chapter will describes data analysis and results of this study.

Chapter Four

Data Analysis and Results

In this phenomenological study, the individual interviews were conducted with six leaders with disabilities who have college degree(s) and have served or are serving one or more leadership roles. The researcher collected the data by having face-to-face meetings or phone interviews with the leaders. The researcher asked each of the six participants, "Please take a moment and reflect on important experiences or relationships in your life that led you to take a leadership role." The intention was to learn which of the leaders' essential experiences influenced them to be a leader.

Out of the six leaders, three participants in this study permitted the researcher to reveal their identities; the rest of the participants wished to remain anonymous. Thus, the researcher concealed information that would compromise the identities of all the participants.

This study used a phenomenological analytical method described by Giorgi (1997), and Jenni (1990), and Polkinghorne (1989). This method contains six steps, which were discussed in Chapter 3. These steps of the analysis are based on the individual interview data. Below, the researcher demonstrates the first four levels of analysis by using the interview with Participant One (S1).

Level One: Verbatim Transcription (Individuals Protocols)

Level One of the phenomenological analysis involves transcribing the audiotaped interview word for word, and thoroughly reading it until the researcher obtains a general sense of the participant's experience. As an example, the transcription below describes Participant One (S1)'s perspective of being a leader.

S1: Even when I have organizational power over others, such as my staff, I function more as a leader, we work as a team. My staff is encouraged to argue with me, to tell me when I am wrong and correct me, come up with their ideas. I always—I do everything that I can at the university to promote them, I send them out on speaking engagements instead of going myself, and let them develop. I'll teach them things and they come back and teach me things. We really totally work as a team.

S1: I look—there are sports coaches that will—let's say you get a new football coach, there's two kinds of football coaches; one will say here's the plan I am going to run, here are the plays I am going to run, here's this file of play that this team is going to do under my leadership. If I don't have the people that can do it, I will get rid of them and I will get people who can. There's another kind of coach that says, I'm going to look around and see what I've got, I'm going to see who's good at what and I am going to design plays and design a game strategy built around the talent I've got. That's the kind of coach I am.

Level Two: Spontaneous Meaning Units (Individual Protocols)

Level Two is the first stage in the data analysis of the "meaning units." At this step, the researcher divided the transcript into meaning units for all the six interviews. During this process, the researcher highlighted key words and significant statements. In order to better organize lengthy material, the researcher coded each meaning unit by numbering it, and then paraphrased each meaning unit.

Below is the example of Level Two for Participant One:

(Verbatim Transcription)	(Meaning Units)
<p>S1. 20. Even when I have organizational power over others, such as my staff, I function more as a leader, we work as a team./ 21. My staff is encouraged to argue with me, to tell me when I am wrong and correct me, come up with their ideas. / 22. I always—I do everything that I can at the university to promote them, I send them out on speaking engagements instead of going myself, and let them develop. / 23. I'll teach them things and they come back and teach me things. We really totally work as a team.</p>	<p>20. S1 functions more as a leader and as team member, even when he has organizational power over others. 21. S1 encourages his subordinates to argue with him, to correct him when he is wrong, and to come up with their ideas. 22. S1 promotes his subordinates at his institution by sending them out on speaking engagements and let them develop. 23. S1 teaches his subordinates and welcomes them to teach him, and he believes that he and his subordinates work as a team.</p>

<p>S1: 75. I look—there are sports coaches that will—let’s say you get a new football coach, there’s two kinds of football coaches; one will say here’s the plan I am going to run, here are the plays I am going to run, here’s this file of play that this team is going to do under my leadership. If I don’t have the people that can do it, I will get rid of them and I will get people who can. There’s another kind of coach that says, I’m going to look around and see what I’ve got, I’m going to see who’s good at what and I am going to design plays and design a game strategy built around the talent I’ve got. That’s the kind of coach I am./</p>	<p>75. S1 used sport coaches as a metaphor to describe his leadership. He tries to see who is good at what and designs plays and a game strategy build around the talent he has.</p>
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Level Three: Emergent Themes (Individual Protocols)

Level Three reorganizes the meaning units that were developed in Level Two for all interviews. At this step, the researcher simplified and summarized each meaning unit in her own words while the participants’ original language was still retained. At the same time, the researcher removed redundancies and other items that were not related to the researcher’s interest – understanding the development of leadership among college graduates with disabilities. The researcher also cleaned up the participant’s language so that a story could be told. Then, the researcher reorganized these themes and made a narrative to describe the essence of the participant’s experience as a leader with a disability. By using the interview with Participant One (S1), the narrative below illustrates S1’s vision as a leader.

S1 analyzes himself that he functions more as a leader and a team member. He encourages his subordinates to argue with him, to correct him when he is wrong, and to come up with their ideas. He promotes his subordinates by sending them out on speaking engagements and by letting them develop themselves. He teaches his subordinates and welcomes them to teach him. He and his subordinates work as a team. However, he sometimes has to make decisions on behalf of his team.

S1 used sport coaches as a metaphor to describe his leadership style. He tries to see who is good at what, and designs plays and a game strategy to build around the talent he has.

Level Four: Transformation (Individual Protocols)

In Level Four, the narrative that was developed in Level Three was transformed into the psychological meaning of college graduates with disabilities' transformational experience to leadership roles. The analysis of Participant One (S1) at Level Four illustrates this process.

For S1 a leader is a person who inspires people to follow his vision and provides both a purpose and a method for achieving that vision. He strongly values a team approach. As a leader, he sees himself as a team member, promoting and developing his subordinates. He leads them to be successful, and learns from them. He sees himself as a team coach who develops the talents of others. He tries to see who in his group excels at particular tasks and tries to utilize the strengths of his team members.

Level Four for All Six Participants

Participant One: Andrew (a pseudonym). Andrew is Disability Services Director in a public university in the Northeastern region of the United States. He was the first blind student to attend a public school in his hometown. He has a graduate degree. Before he became a disability services director, he was a vocational rehabilitation counselor for several years. He has also served the president of a professional national organization.

Level Four: Transformation. Making contributions to others is critical to Andrew. When he contributes to others' success, he finds the results enjoyable and rewarding. Helping others to raise their status and improve their lives is essential to him. He likes "straightening out messes" and helping others.

Andrew learned the value of contributions when he was a child. Growing up in poverty with not much hope in life, he was the first blind child in the mainstream classes in his school district. He received a lot of attention from teachers and other professionals. These individuals spent time with him, coached him and became role models for him. He watched these adults so that he could learn from their success.

Andrew continued watching and learning from others' success in his adulthood. When he was in college, others helped him find a job and directed him to pursue a graduate degree. These individuals helped him improve and encouraged him.

During his high school years, his academic performance was mediocre and his teachers believed that he would not succeed in college. However, he flourished in college, met academic success and made friends with instructors and staff. He found a niche in a higher-education environment.

Being persistent, steadfast, and determined is Andrew's leadership principle. He practices being a nice person: he is polite, attentive, dependable, eager to connect with people and hear what they think, sensitive to others' concerns, and willing to do small favors. By doing so, he engages with others and learns from them.

Andrew experienced fear when his employer and the institution were unsupportive. At that time, his ability to be a leader depended on his institutional support. Despite this fear during these challenging circumstances, he was able to lead and learn from such difficulties. He has resiliency and self control; he believes that it is his responsibility to transform impediments into positive learning opportunities for him.

For Andrew a leader is a person who inspires people to follow his vision and provides both a purpose and a method for achieving that vision. He strongly values a team approach. As a leader, he sees himself as a team member, promoting and developing his subordinates. He leads them to be successful, and learns from them. He sees himself as a team coach who develops the talents of others. He tries to see who in his group excels at particular tasks and tries to utilize the strengths of his team members.

Andrew works to make something better. He believes that a leader should serve his/her employees by making every day better. Leadership is another kind of service, and serving others is vital to him.

Participant Two: Brad (a pseudonym). Brad is the principle administrator of an international organization. He is blind. He resides in the Western region of the United States. While attending graduate school, he experienced that there were no accessible textbooks for him. He has been serving on various committees on the national and international level. He was recently awarded an honorary doctorate degree from a university for his accomplishments.

Level Four: Transformation. Developing and problem solving started Brad's career. He developed software that converted electronic files into an electronic book so that he could read. Since no one else was creating such books, the software that he created digital books accessible to him. He also became self-employed because he thought obtaining a job would be difficult. When Microsoft contacted him, he told them that he had just started a company even though he had not started it yet; he then offered assistance to Microsoft.

Moreover, Brad engaged in development throughout his career. He coined the term "Print Disabled." He developed Mathematical Markup Language (MathML) and standards and specification for technology. He created a single standard that would meet all people with disabilities' needs and would never bend to the design. As a result, he developed technology that is not only for the blind but also for people with other disabilities.

Throughout his career Brad reached out to others. When books were inaccessible to him for his graduate courses, he contacted publishers to obtain their electronic files of the books to use for himself and later for others. He reached out to several organizations for their help to start his own non-profit organization.

Brad has been progressive in developing accessible digital publishing. He saw himself as "way out in front" in the field. As a result, he encountered the fact that nobody in his graduate department held the view that accessible digital publishing was important. The field of digital books had no interest in recording for the blind when he first encountered it. However, no interest from those entities led him to start making accessible digital publishing on his own. Brad is confident. He was confident that it was the right thing to do to create accessible digital books and that better ways of creating accessible books needed developing. He also strongly believed that following content was crucial for creating accessible digital publishing.

Brad is a challenger. He took a challenging approach to create accessible digital books. He is also committed to creating accessible information. He spent at least \$10,000 of his own savings to start assisting Recording for the Blind with its merger. As his personal mission, he continues promoting accessible published material and accessible web information. To carry out this personal mission, he wants to find a person with passion and commitment to his mission of accessible information to take over his responsibilities.

Brad's strong beliefs led him to be a leader. He believes that accessible information should be useful to greater constituencies rather than just blind people. As a result, he created the single standard that would meet all people with disabilities' needs. To practice being a leader, he disseminates tasks to others and trusts them to get the tasks done. He hired two smart people to work with him whom he relies on for digital book production. Now that he has others to do technical tasks, he has moved into the role of managing, organizing, and finding resources for the organization so that he can keep things going.

Brad has responded to certain inquiries by taking opportunities to become a leader. For instance, he was approached by Recording for the Blind and asked to help them merge recording

books with computerized books. Also, Web Accessibility Initiative asked him to chair the steering counsel of the Web Accessibility Initiative; he accepted it. Several people approached him and encouraged him to run for president of the International Digital Publishing Forum (IDPF), which he did.

Connecting with his mentors was helpful for his flourishing with accessible digital publication. He found his niche through connecting with the Standard Generalized Markup Language (SGML) group members, who were influential to his career.

The following is a summary of Brad's leadership style: 1) advocacy, management, fundraising, and spreading the word about accessibility, 2) the outcome is more important than the organization names; as long as the outcome - ensuring that digital information is accessible for people with disabilities – is correct then the organization names are not as important to him. Making changes is also his leadership style. Under his leadership, the DAISY Consortium started focusing on putting text and audio together for a comprehensive reading experience for users. He has harmonized standards, merged DAISY into E-PUB, and worked on creating a single worldwide standard for digital publishing.

Participant Three: Colleen (a pseudonym). Colleen serves as Disability Services Director in a private university in the Midwestern region of the United States. She was the first blind child in a community organization. She obtained a graduate degree and worked as a counselor before she became a director. She has served on the board for national professional organizations.

Level Four: Transformation. Helping others improve is important for Colleen. She helps others develop their inner-personal strength and career choices. She enjoys helping others find what they are good at and guiding them to the activities that they like. Particularly, she enjoys

working to help students improve. She provides resources and tools, which help them accomplish their goals and become better students. She enjoys getting to know people, nurturing their skills, and helping them develop.

Critical skills for Colleen as a leader are knowing how to delegate authority, setting boundaries, being resilient, using her strengths, managing her time, supporting other leaders on a team, and handling issues, if they arise, such as when others do not approve of her decisions. She learned these skills in college by serving as a Residence Assistant and in student government. She believes these skills are important for leaders regardless of whether they have a disability.

Several individuals influenced Colleen as a leader. In her childhood, her parents and teachers influenced her by encouraging her to try different things and to become a leader. Her parents tried to instill confidence in her. While she was in college and entering adulthood, her mentor became a role model and inspired her to pursue a career in higher education. After she began her career, her colleagues became mentors for her; they guided and helped her handle difficult issues.

Colleen has just started a new job and is feeling some uncertainty because of interpersonal issues. Her current challenges include trusting an assistant she believes is incompetent, prioritizing tasks, and not having the right tools that she needs to succeed. For her, leadership depends on more than just the leader. A leader is only as good as the people and organizations that support the leader. Her leadership skills are currently hindered by a challenging assistant who requires a lot of guidance.

However, Colleen believes that a leader has to be able to take difficult situations and figure out what to do with the tools available. From her perspective, a leader has to prioritize tasks and see a difficult situation as an opportunity.

When Colleen identifies with others and listens to what they have to say they often believe in her and support her. She practices connecting with others, becoming an ally, and building alliances. She engages in these practices in pursuit of her passion: improving the institutional culture and the dominant perspective about disability on college campuses. A crucial part of this goal is to help others broaden their perception of diversity and see disability as another form of diversity.

Participant Four: Debra (a pseudonym). Debra is an administrator at a public university in the Western region of the United States. Before she became an administrator, she worked as a vocational rehabilitation counselor and obtained a doctorate degree. She has a physical disability that affects her mobility. She has served on committees and boards for national organizations that are related to disability and higher education.

Level Four: Transformation. Debra is a competent, effective, organized, and thoughtful leader. By tracing back to her childhood she can see what influenced who she is. She was the only child with a disability in her community. Her parents were supportive, creative, and innovative in order to provide her with opportunities that were comparable to her siblings and friends. They involved her in many activities and always asked how they could make things happen for her. They made sure that she could be independent. The community where she grew up was welcoming and inclusive. The community members were also creative and innovative. By growing up with her siblings, she was challenged, pushed to participate in activities, and taught to keep up with them. Her childhood experience shaped her to be independent, opinionated, competitive, active, and assertive.

Debra continued to be active throughout her high school and college years. Involvement in sports and politics increased her confidence and experience. Her mentor helped her connect to

others with disabilities. However, looking back her childhood, she realizes that she grew up in isolation, avoided being with other disabled people, and was privileged to be able do what she wanted. By interacting with others with disabilities, she began thinking about her own civil rights and started to value her identify as an individual with a disability. She found a niche in disability and that influenced her career.

As an effective administrator, it is important for Debra to find a balance, especially because she tends to have strong opinions and be assertive. Knowing what to say, when, how often, how, and to whom is critical for her to have balance. As a leader, she practices being fluent and familiar with what she is talking about to demonstrate her competence. She also adjusts her communication style and language depending on the audience so that she can effectively communicate with others. She engages others and gets them excited. Connecting, getting along, and engaging with people are inherent in her leadership principle.

Trusting others that Debra works with is her leadership element. She encourages others to take initiative and to come up with good ideas. She trusts and supports them by finding ways and resources for them to pursue their ideas. By doing so, she helps and serves others.

Debra's work consists of building and growing programs to make a difference. She values reframing the negative connotation associated with disability, and also changing people's perspective and behavior toward disability. She has been front and center of the actions taken to reframe disability in disability services on both state and national levels. She continues influencing others and helping them redesign and deliver services. As she gets older, she finds new areas where she wants to improve. For her, constant improvement is never-ending.

Participant Five: Emma (a pseudonym). Emma serves as a director of a research center at a private medical school in the Southern region of the United States. Her physical disability

affects her mobility. She obtained a doctoral degree after she worked for her mentor, who is a nationally well-known civil rights advocate. As a scholar and researcher, she has published more than 70 articles and book chapters.

Level Four: Transformation. In Emma's childhood, her mother was very supportive and encouraged her to be active in many different groups. She was the only child with a disability in her group. She was pushed onto a leadership platform at the age of nine. Since then, she became a leader for every group she belonged to.

Building sustainable organizations and systems are critical for Emma as a leader. By encountering the current crisis at work, she has gained an appreciation of sustainability in leadership. This appreciation for sustainability is rooted in her experience with one of the influential figures in her life.

Justin Dart Jr. significantly influenced Emma's life. He taught her how to strategize, get others to agree with what she wants to do, make right decisions for a group, stage events, organize people, and capitalize on the strengths of people who she is working with. More importantly, she learned from him how to help others find their own power and their own way to be successful in their lives.

Emma's academic advisor also influenced her life. He was encouraging and helped her develop a research career by opening doors for her in academia. He also helped her establish organizations and taught her how to conduct research by asking the right questions.

Equal opportunity and civil rights are critical components for Emma. It is her passion and mission to secure and sustain equal opportunity and civil rights for all. It causes her to be angry when others try to destroy these rights. It also concerns her that many people are not responding or doing anything when these rights are compromised.

As a good leader, setting a tangible, achievable, and proactive goal is critical for Emma. She also believes the importance of keeping the momentum going by finding another goal after each goal is achieved. Making others feel valued is also an element for her style of leadership.

The “non-violent communication” approach is important for Emma because it reminds her to value everyone’s right to talk even despite disagreement. She respects others by not shutting them down or interrupting them. She values when she can point out to others what and how they would benefit from doing the things that they are asked to do. She also uses positive, productive emotions to convince others to reach the goal.

Emma is resilient and sees difficult situations as opportunities for growth. By not having a good mentor in the women’s movement, she strives to advance women. By learning that cultural relevance is important, she wants to improve her cultural awareness. By experiencing a financial crisis at work, she wants to use this crisis as an opportunity to implement a revolution and to look for a different way to reach the same goal with much less money.

Participant Six: Frank (a pseudonym). Frank serves as a board member of a national organization for disability rights. He resides in the Western region of the United States. His vehicle accident at age 16 caused his mobility impairment. Several years after the accident, he attended a university and obtained a Bachelor's degree. He has served as the chair of various organizations as well as on the executive board and as an executive director.

Level Four: Transformation. Frank's passion is to improve the lives of people with disabilities. As a progressive liberal, he advocates for civil rights, particularly for minorities and people with disabilities. He becomes irritated and angry when people are treated unequally, abused or beaten, or perceived as unworthy. His passion has led him to become a leader in the civil rights field.

Frank's passion for civil rights started in his teenage years. He used to get engaged in discussion and arguments with his relatives about segregation. His family considered him "the black-sheep of the family." Seeing and hearing people being treated unequally prompted him to help others try and raise their status.

A turning point of Frank's life was the vehicle accident when he was 16 years old. After this accident he began using a wheelchair and others started telling him what to do, which made him feel powerless, aimless, and meaningless in his life. However, experiencing barriers led him to become resilient. This resiliency empowered him to determine his own protest and to stop using businesses that were not physically accessible to him.

By engaging in human services after college, Frank found his niche in civil rights and in working for people with disabilities. He connected with those who were like-minded and who helped him to become a better leader. Furthermore, he became a better leader by being involved in organizations and stepping into a leadership position when nobody volunteered for it. By not being afraid to take this opportunity he was able to flourish as a leader. Since then, others sought him out for his leadership; he has been involved in several national organizations as a result.

Several individuals became mentors and role models for Frank. These individuals instilled confidence in him, helped him to set a high bar, connected him with others at the state and national levels, taught him to be persistent, demonstrated love, compassion, and understanding, and inspired him to be a leader. He watched a role model practice her activism without fear, which empowered him to get involved in civil disobedience to order to pursue his passion: promoting disability rights.

Frank knows his own weaknesses. His areas of improvement include prioritizing from one task to another, learning how to say "no," and being able to follow through when he does say no.

As Frank gets older, he has changed his form of his advocacy to getting young people involved and educating them. He teaches young people about civil rights by developing materials and giving lectures; he hopes to pass on the importance of civil rights to the young generations.

Level Five: Fundamental Description

Level Five combines the data in Level Four for all participants. The researcher synthesized themes that were commonly addressed by the participants in this study. At this step, the researcher eliminated the perspectives that were presented by only one or two participants. However, there are some important themes that were uncommonly experienced by all participants. The researcher will address them later in the discussion chapter. Below is a summary of a fundamental description of college graduates with disabilities' transformational experience to leadership roles.

As leaders, the participants (Ps) work at high levels by finding strategies that can be broadly effective and influential. They build things up and grow them. They network and get involved in various activities. They connect and engage with others in order to accomplish their vision and goals. These leaders cultivate relationships and develop collaborative working relationships.

When Ps were asked to talk about their influential life experience, they first recalled their childhood. Ps' parents were supportive, provided opportunities for them to get involved in activities with other children and adults, and tried to instill confidence in them. Teachers and

people in the community also encouraged Ps to take a leadership role, spent time with them, and coached them. Those adults provided these leaders with a welcoming and inclusive environment.

During Ps' college years or immediately after college, they experienced a turning point in becoming leaders. During that time, Ps developed their own interest in a specific topic and found a niche that allowed them to flourish. At the same time, Ps connected with others by developing relationships and being inspired by them.

The way Ps have learned leadership is through accident, circumstances, and their mentors. Ps articulate their leadership principles and their roles as leaders. They believe that a leader needs a clear goal and vision of how a group of people can get there. They value positive change and make decisions and actions for the greater benefit. Ps have self-awareness and know their talent, personality, strengths and weaknesses. They trust and value the people who they work with. Consequently, they capitalize on the strengths of those people to get desired results.

Ps met mentors in adulthood. These mentors helped transform them to become better leaders. Ps perceived these mentors as their role models because the mentors demonstrated leadership by setting good examples. The mentors inspired Ps and showed them attributes and competencies of effective leadership. Ps interacted with, followed, and watched what the mentors did. As a result, Ps learned how to mobilize others to accomplish a mutual goal. These mentors also helped Ps connect with other people to develop other relationships.

Ps see difficult situations as opportunity for growth and improvement. When they encounter difficulties and crises, they handle these situations by maintaining an optimistic attitude and perspective. They transform impediments into positive learning opportunities. They are not afraid of failure and are willing to take risks. They have confidence, resiliency, and self-discipline by believing that "I could do good work in a bad situation."

Helping others, and making a difference are Ps' strong passion and commitment. Ps strive to improve the lives of others. This passion has been accumulated throughout their lives. However, this passion stemmed from their personal experience with inequality, which they encountered for themselves as well as on behalf of others. Ps are firmly committed to what they do and what they believe, all in order to improve equality and to make a positive contribution to others.

Level Six: Essential Description (Combined Protocols)

The final level of the Phenomenological analysis is Level Six: describing the essential features of the phenomenon - being leaders with disabilities. The researcher turned Level Five's fundamental description of the shared experiences into an abstract concept. The description in Level Six contains essential features of the phenomenon experienced by college graduate leaders with disabilities.

Level Six: Essential Description. Nationally well-known leaders with disabilities see themselves as broadly effective and influential. College years or immediately after college were a turning point for them in becoming leaders. During that time, they cultivated relationships with others and developed their own interests and commitment to a specific area which ultimately led them to find their own niche in the field. However, childhood was one of the influential experiences for leaders whose disability was present from birth. Their parents, teachers, and people in the community provided them with a welcoming and inclusive environment, where they were supported and encouraged to take a leadership role.

Leadership styles and skills were learned and developed by these leaders through accident, circumstances, and their mentors. Mentors demonstrated leadership by setting good

examples. These mentors inspired them, and they later connected with others to develop other additional relationships and skills.

Their leadership principles and their roles are clear in their minds. A directed goal and vision, including positive change, and decision making for the greater benefit are critical for them. They hold self-awareness of their personality, strengths, and weaknesses, trust, value the people who they work with, and capitalize on the strengths of those people in order to get desired results.

Difficult situations are opportunities for growth and improvement for these leaders. With their optimistic attitude and perspective, they transform impediments into positive learning opportunities. They are confident, resilient, and self-disciplined. They also have strong passion for helping others and making a difference to improve the lives of others. Their personal experience with inequality, which they encountered for themselves as well as for others, has enhanced their passion throughout their lives. Their firm commitment to what they do and what they believe drive them to improve equality and to make a positive contribution to others.

Chapter Five

Discussion

This phenomenological study attempted to understand the experiences of becoming and being a significant leader with six individuals with disabilities. The researcher explored the experiences and relationships that transformed and launched participants to leadership roles and that fostered their leadership development. Through the six-step phenomenological method of inquiry, this study extracted meaningful descriptions and common themes shared by these leaders. In particular, this study intended to learn whether college experiences influenced their leadership development. These findings suggest an affirmative answer; the college years did impact these leaders with disabilities. In this chapter, the researcher discusses in depth the leaders' college years as niche finding and relationship cultivating. Further, the researcher describes the following essential themes: 1) childhood as an influential life experience, 2) commitment, confidence, resilience, and passion in leadership style, and 3) helping others. These three themes are not independent of one another, but are intertwined throughout the lives of the six leaders with disabilities.

College Years: Niche Finding and Relationship Cultivation

The college years, or immediately subsequent years, influenced leaders with disabilities who participated in this study. The key significance was that they made personal connections with others and found groups that were the right fit for them. They developed relationships with others who became their mentors and role models and offered inspiration and support. The feeling of belonging and connection clearly exhibited during their college-age years of their lives served as a pivot point. Although some of the study participants experienced leadership activities

as children, learning leadership skills appeared to accelerate during, or immediately after college, by gaining experiences and reaching out to others with common interests or similar purposes.

For instance, Brad felt no one in his computer science graduate program understood his interest in creating accessible digital books. During his graduate studies, he attended conferences and discovered and made connections with a group of people who understood and shared this interest with him. Later, these personal and group connections led him into accepting a leadership role as he began connecting with mentors. He explained his excitement in finding a niche,

I went to some national—probably international conferences. This was in SGML, which is the predecessor to XML, the first HTML was written in SGML. I went to these meetings and there was immediate recognition in that community of how useful the marked-up text documents could be to people with disabilities. They just understood it. They got it right away where most people don't understand it. They really understood it. (Brad)

Finding a niche also led these six leaders with disabilities to find their passion in specific fields, although finding a niche was accomplished by trial and error. Debra, who identified herself as quite political, wanted to pursue a career in politics and then initially discovered a political career choice and lifestyle was not the right fit for her. As she continued gaining experience, she realized that having disability was also political. Discovering a passion for politics and advocating for those with disabilities, led Debra to pursue a leadership role in the field of disability advocacy representing those with disabilities. She explained,

I worked in Washington D.C. for a semester doing an internship but it became kind of clear to me that that really wasn't what I wanted—that political life. It was a little too dog-eat-dog for me. And then and I had some other experiences that really—I began to appreciate that the disability area was political too. Then all of a sudden it kind of—because I've worked at—I was involved at the Women's Rights Movement in the 70's, certainly the Anti-War Movement—and it just didn't click right away that the disability piece was also Civil Rights and that took me a little longer. (Debra)

As noted in Chapter Two, the college age is a critical time for identity and intimacy development as the initial stages of adult development occur during these years, according to Erik Erikson's theory of psychosocial development. Dating, marriage, family, and friendships are important during the young adult college ages and by forming relationships with others, individual experience intimacy (Erickson, 1964). The college ages establish one's identity and develop a sense of self in a social, historical, and cultural context through interactions with others (Chickering, 1969). In this study, leaders with disabilities appeared to develop a sense of self and direction through relationships with others and meaningful involvement. This study did not intend to discover identity development themes or generate a theory; however, findings suggest the potential for a focus for further study on identity development in leaders with disabilities and on leadership development comparisons between leaders with and without disabilities.

Childhood

Of six study participants, four had congenital disabilities. These four leaders felt their parents and other adults in their childhood positively influenced their leadership development by providing a welcoming and inclusive environment. Foremost, their parents played an important role in providing opportunities and instilling confidence in them. As children, these leaders felt supported, included, and encouraged to engage activities with both disabled and non-disabled peers and adults.

In addition to a welcoming and inclusive environment, the leaders experienced supportive adults as fostering their creativity. As a leader, Debra tried to be creative and inclusive when she worked with her team. She described how her parents and community members were creative and innovative and how she saw them as positive childhood role models.

My family was very creative and innovative and it was always about, “What is it that you want to do and how can we make that happen?.... it was a small town, really supported that, not that people didn’t recognize me as a disabled kid, which they did, but it was all. I was welcomed and included and everybody was real innovative and creative and supported that and just real welcoming. (Debra)

Andrew also commented that adults served as his role models.

I think I was the first mainstreamed blind child in my school system so I got a lot of attention from a lot of professionals in the system. I think that helped a lot—a lot of attention from role-model type people. (Andrew)

Colleen's parents not only encouraged her to try different activities, but also to assume leadership roles at an early age. She maintains that leaders must have had parents who encouraged them to be leaders during their childhoods. Her perspective illustrates as follows:

I think having—I mean anybody who is a leader, your parents are going to play a role because they are going to help you with, hopefully—well not everybody’s parents—I would say my parents—you know they tried to instill confidence in me to go—they encouraged me to try different things, to be a leader. (Colleen)

Unlike the four leaders with congenital disabilities, it is intriguing that Brad and Frank, who developed disabilities in adulthood, did not address their childhood experiences or supportive adults in their childhood. Instead, they spoke strongly about their adulthood relationships with those who shared interests with and expressed appreciation for the influence of mentors and role models in their adulthood.

Leadership development is affected by adult influence not only during the college years, but also during childhood (Komives, Owen, & Longerbeam, 2005). Influential adults can be family members, teachers, or others who serve as role models in leaders' childhoods. These role models often become mentors for the developing leader during childhood (Komives et al., 2005). In this study, the researcher questioned why Brad and Frank with acquired disabilities did not reflect upon their childhoods. The notable difference may have been that they have lived in two

worlds: the disabled and non-disabled world. Peer influence may have held stronger sway for Brad and Frank in adulthood, rather than in childhood. In this case, peers were those who shared interests with Brad and Frank and became their role models and encouraged Brad and Frank to take leadership roles. It is possible that leaders with acquired disabilities put more value on their adulthood role models as they began experiencing the disabled world as a young adult. The researcher suggests further research is necessary to examine this issue more closely.

Being a Leader: Passionate, Committed, Confident, and Resilient

A clear understanding of their leadership styles. It was evident that the leaders who participated in this study possess a strong understanding of their leadership styles including characteristics such as: a clear vision of leadership qualities and principles; encouraging positive change; decision making for the greater benefit; trust; seeing difficult situations as opportunities; and knowing their personality, both strengths and weaknesses. They also expressed their personal and social responsibility to improve the lives of others. Andrew articulated his style of leadership, stating:

...we work as a team... My staff is encouraged to argue with me, to tell me when I am wrong and correct me, come up with their ideas. I always—I do everything that I can at the university to promote them, I send them out on speaking engagements instead of going myself, and let them develop. (Andrew)

With a personal mission and clear vision of what is good for others, Brad focuses on his strengths to promote the mission by saying:

I rely on other people for the heavy lifting in the technical arena right now and figure that my time is best spent in advocacy and fundraising and management and leadership although it would be much more fun to get dirty with the technology and geek out. I still believe that right now my better role is in advocacy and management, trying to find fundraising and spreading the word. (Brad)

These characteristics of leadership styles are parallel to transformational and authentic leadership styles discussed in Chapter Two. Hence, the researcher further searched literature on

leadership style and disability leadership. A miniscule body of leadership literature on leaders with disabilities was found. However, the researcher found transformational and authentic leadership styles have been addressed in the context of special education and children with disabilities by a term defined as "self-determination."

There exists a large body of research on self-determination of children and college students with disabilities. Researchers have studied the effectiveness of self-determination skills utilized by children with disabilities and effectiveness of teaching such skills to these students (Martin & Marshall, 1995; Wehmeyer, 2007; Wehmeyer & Schwartz, 1997). Researchers have also investigated self-determination and college students with disabilities and their academic outcomes (Stoden, Whelley, Chang, & Harding, 2001; Thoma & Getzel, 2005).

In particular, Johnson (1999) compared the self-determination literature with leadership literature and found that the attributes, themes, and elements of self-determination were frequently cited as attributes of leaders. For instance, problem-solving, self-regulation, and personal control are attributes of self-determination and valued in the leadership literature (Johnson, 1999). The difference is that while self-determination focuses on individual actions toward personal goals (e.g., graduating high school and obtaining a job), leadership focuses on collective actions to achieve a common goal. Therefore, Johnson concluded that self-determination skills are transferrable to leadership skills. However, he also noted that existing literature had a limited view of potential leadership among people with disabilities and argued that people with disabilities should be assumed to take leadership roles in society (Johnson, 1999). It is intriguing for the researcher that a lack of attention exists in literature devoted to leadership development in adults with disabilities, while many studies focus on disabled children and young adults' self-determination, which share similar elements of transformational and

authentic leadership. Thus, the researcher recommends leadership of those with disabilities to be further investigated.

Helping others and making a difference as their passion and commitment. In this qualitative study, personal experience with inequality during their college years was a turning point for leaders with disabilities. Due to their experiences, they developed passion for helping others, for improving the lives of others and making a difference. Brad could not find textbooks that were accessible to him. Frank could not translocate to the places he wanted to enjoy for himself or with his peers. Debra witnessed those with disabilities characterized as persons to be pitied when she worked for Muscular Dystrophy Association at the Jerry Lewis Telethon. These leaders transformed their negative life experiences into something meaningful to them. As leaders, they proved their resiliency and transformed impediments into positive learning opportunities.

Dunn and Brody (2008) studied individuals with acquired physical disabilities and found that several attitudes and behaviors led individuals to life satisfaction. Their study shows those who reported higher satisfaction with their lives had positive personal qualities and a tendency to extract meaning from negative experiences. These individuals attempted to discover a way to reframe the situation, understand and adapt to changes from a negative event, such as losing a physical function. Although Dunn and Brody's study focused on individuals with acquired physical disabilities, positive personal qualities and optimistic attitude and view apply to those who have congenital disabilities (Mpofu & Harley, 2006) and do not have disabilities (Day & Harrison, 2007). It appears that leaders with disabilities in this study reframed their personal experiences with inequality to something personally meaningful.

Leadership Development

Leadership development is a lifelong process (Maxwell, 2013). No leader in this study reported that they had developed their leadership innately, nor learned from formal leadership trainings. Rather, they reported they had learned and continue to learn leadership through their experiences, and with colleagues, and mentors. Importantly, leaders in this study learned leadership principles and skills from their mentors and role models by watching and interacting with them.

As an example, Emma's mentor taught her how to lead a group of people and she felt privileged to have worked with him. She recalled:

I learned from him the tactics to use. How do you get a board to agree with something you want to do? How do you strategize? How do you decide what kind of an activity or strategy would be the right thing to use to get to the goal that you want to achieve? How to organize people? How to stage events? How to capitalize on the strengths of the people that you're working with. Really important leadership skills; really basic skills that you have to learn by watching a master. He was fabulous. He always made everybody on the movement feel valued. That's an invaluable skill to make people want to work with you. He used to ask people to do outrageous things, absolutely outrageous things, and people were so happy to do it. (Emma)

Similar to Emma, Frank feels privileged to have a handful of mentors in his life because they influenced his leadership and career path. His mentors taught him how to lead and set high standards for him. He characterized one of his mentors as follows:

I had the privilege of working with someone I considered to be one of my major mentors other than my wife, he was my boss at the time, he was always asking the question, "Why do we have to go to better before we get to best? I think professionally, [the name of a person] who was my boss at the Association for Community Advocacy which was the ARC, was the one that really instilled in me that going from straight to best. He was the one who really got me on that line. (Frank)

In a leadership study by Foster-Fishman et al. (2007), described in Chapter Two, leaders with disabilities valued mentoring, networking, and experiential learning opportunities of the leadership role as more effective than leadership development programs or trainings. These

leaders pinpointed a downfall of leadership development training by stating that such training fails to help individuals transform their learning through the process of leadership development (Foster-Fishman, et al., 2007). That they found formation leadership training and education ineffectiveness is congruent with similar criticism of general leadership training and education by Nirenberg (2003) and Allio (2005).

Identity as Leaders with Disabilities

A major discovery of this study is that the leaders interviewed did not spontaneously address their own status as disabled. Rather, they spoke of leadership in the context of others with disabilities. As a result, being disabled appeared to fade into the background of their identity as a leader and their disabilities did not appear to be a primary focus of their social identities. In fact, one participant was somewhat confused by the researcher's topic - "leadership styles of disabled leaders." The researcher originally anticipated that research participants would bring their disabilities to forefront in the discussion of leaders with disabilities, yet not one was as interested in the topic as the researcher. This discovery was eye-opening for the researcher and made her see that she held an assumption that leaders with disabilities would regard their disability as primary self-identity in this context.

As discussed in Chapter Two, Seekins, et al.(2004) found disabled political leaders in rural communities did not focus on disabilities as their primary social identity. Instead, these political leaders focused on similarities. The study further discovered that political leaders used compromising, networking, persistency, and less-confrontational political strategies to accomplish their work. This study's findings appear to be congruent with Seekins and colleagues' findings.

Another perspective on disabled leaders' failure to mention their personal disability could be explained by Alston, Bell, and Feist-Frice's study of racial and disability identity development amongst African Americans (1996). They suggest that such social identities (being disabled or being of a specific race or ethnicity) are influenced and interchangeable by context (Alston et al., 1996). That is, an African American with a disability may identify him/herself as being disabled more than being African American when he/she is surrounded by others with disabilities. When the same individual is with a group of African Americans, the individual may likely become more aware of his/her racial identity than his/her disability identity. The researcher assumes that Alston and colleagues' perspective may apply to her research participants' social identities. Disability may not a primary identity, but social identities morph depending on the context.

Summary

This chapter comprehensively presented primary themes evident in this phenomenological study on experiences of leaders with disabilities. The researcher began with a description of leaders' finding a niche and developing meaningful relationships during, and immediately after, their college years. The researcher also noted leaders with congenital disabilities' important childhoods were influenced by supportive adults. This chapter further discussed leaders' passion, commitment, confidence, and resiliency, as well as their leadership development through their experiences and mentors and relationships with other colleagues. Finally, the researcher related identity development, which was manifested in this study, to studies on disabled leaders in rural communities, as well as racial identity development and disability identity development. In the next chapter, the researcher presents implications and recommendations for further study.

Chapter Six

Implications and Recommendations

This study explored six disabled leaders' experiences of being and becoming leaders. The intention was not to present generalizable results; thus, this study was small and exploratory. However, this study provided a comprehensive description of what influenced these particular individuals during their development as leaders. The findings revealed that human relationships played a significant role during the development stage, including the relationships occurring during the college years, or the years immediately following college. Family members, mentors, role models, and other adults facilitated the leaders' personal growth in becoming confident, passionate, and committed leaders. In this section, the researcher will suggest implications for higher education institutions, parents and teachers, as well as recommendations for future study.

Implications for Higher Education

An emphasis on relationships. The relationships developed during the college years, or the years immediately following college, influenced the six leaders with disabilities who participated in this study. During these years the leaders made personal connections with others and found groups in which they felt a sense of belonging. Traditional college age is a critical time for identity development, particularly through interactions with others (Chickering, 1964). As the findings of this study suggested, a sense of belonging and connection was critical for these six leaders with disabilities. Therefore, the researcher suggests that higher education institutions should emphasize the importance of relationship building and help their students with disabilities feel connected and meaningfully involved in order for them to develop a sense of identity.

The importance of making connections and belonging for college students is not a new topic; it is particularly associated with student-faculty relationships and has been widely discussed in literature on students' academic achievement (Anaya & Cole, 2001), motivation (Komarraju, Musulkin, Bhattacharya, 2010; Pascarella, Terenzini, & Hibel, 1978), satisfaction (O'Meara, Knudsen, & Jones, 2013; Pascarella & Terenzini, 1978), and sense of belonging and connections (Strayhorn, 2008 & 2010). This study not only offers strong support to the notion that connections made in college affect student success, but it also suggests that these connections are important for student leadership development. Thus, higher education institutions should consider students' interactions with faculty when exploring ways to structure or restructure the programs that provide leadership development opportunities for college students with disabilities.

Faculty members often serve as advisers for their students. Colleges and universities should consider having their faculty advisors serve as mentors and emphasize the meaningful connections that students can make. Higher education institutions also could consider promoting advising as a part of leadership training for students. However, student relationship building should not only be the faculty's responsibility. Faculty members work with many students and have numerous demands in addition to advising, including other roles in research, teaching, and service. Therefore, administrative assistants, residence hall staff, disability services staff, career and internship staff, and other support staff could all assist the faculty by developing meaningful connections with students who have disabilities to facilitate leadership development.

Goleman (1998) asserts that high levels of "emotional intelligence," which comprise self-regulation, adaptability, and resiliency, are absolutely necessary for leaders to possess because it enables them to better adapt to different and difficult situations while effectively working with

others. According to Goleman, taking time and being committed can help people learn emotional intelligence. Faculty members and staff should encourage and support students in the development of self-regulation, adaptability, and resiliency during interactions with other students, staff and faculty.

Higher education institutions already offer many opportunities for students to establish connections inside and outside of campus. Civil engagement opportunities, study abroad, internships, and student government are examples. Faculty and staff should continue encouraging students with disabilities to take advantage of these opportunities and emphasize that relationship development facilitates future relationships. Also, faculty and staff could teach students that relationships are reciprocal and they require effort to work. It is important to note that many of the suggestions discussed above are already happening at higher education institutions for the purpose of improving student academic achievement, motivation, retention, and satisfaction. The researcher asserts that these efforts can also benefit students with disabilities' leadership development.

Designing accessible leadership training. When designing leadership development training and programs, the curriculum should highlight relationship development. For example, the existing programs include interpersonal communication as a highlighted topic and provide participants with the opportunity to learn how to develop and maintain good relationships inside and outside of the classroom and college campus. As another example, the training organizer could include a respected disabled leader as a guest speaker to share his/her experience of cultivating relationships and leadership development.

While designing leadership training programs, the organizers should keep accessibility in mind as a key element. Making a program accessible is fundamental to prevent exclusion and

discrimination. However, it is common that organizers realize after the fact that accessibility was not considered, such as after a participant asks for a sign language interpreter or for information in Braille. Designing accessible content in the curriculum is as important as holding the event at a physically accessible location. The organizers must also provide sign language interpreters, use captioned multimedia during the program, provide alternative formats for handouts, and post the web information in an accessible way. The researcher also recommends that the promotional materials include a statement that the training program will provide reasonable accommodations upon requests.

Implications for Elementary and Secondary Education

It is evident from this study that supportive adults played an important role during the childhoods of the four leaders with congenital disabilities by providing opportunities and instilling confidence. Parents, teachers, and community members provided support and attention to these leaders when they were young and encouraged them to try different activities and to take childhood leadership roles. These findings are encouraging and can be useful to teachers, administrators, support staff, parents, and advocates for children and youth with disabilities.

As mentioned in Chapter Five, there exists a large body of research on self-determination in the context of special education and children with disabilities. The elements of self-determination are similar to transformational and authentic leadership styles (Johnson, 1999). The elements of self-determination are: a deep understanding of one's strengths and limitations, belief and confidence in oneself, and goal directed and self-regulated behavior (Field, Martin, Miller, Ward, & Wehmeyer, 1998; Pennell, 2001; Test, Fowler, Wood, Brewer, & Eddy, 2005). Teachers, administrators, supportive staff, and parents should help students acquire and exercise self-determination skills. Teachers could incorporate self-determination skill development into

their instructional strategies. Teachers and parents should also encourage children to get involved and socialize with others with and without disabilities. At the same time, these adults may want to challenge their children by setting high expectations and thereby, pushing the children to learn (Madsen, 2006). Just as supportive adults became role models for the disabled leaders in this study, educators and parents could also become role models for their children by helping them to develop meaningful relationships and leading them with examples. It is important that parents, teachers, and community leaders not assume that a child or youth with a disability will not want to participate in leadership experience. Encouraging all young people to lead, disabled or not, is an important part of human development.

Recommendations for Future Research

Identity development. This study raised several questions for researchers to investigate further leadership development for leaders with disabilities. By intentionally asking a broad question, this study explored the influential experiences and relationships of six leaders with disabilities. These leaders' identity issues became significantly apparent during the study. Thus, a case study or a grounded theory study on identity development in leaders with disabilities would be beneficial to the literature. The researcher suggests designing a comparative study on the course of identity development between disabled leaders and non-disabled leaders. Another future study could investigate identity development of disabled leaders who are persons of color or possible differences related to gender.

Further, the researcher suggests investigating how young adults develop identity after acquiring disabilities. This future study could investigate identity development based on the age of onset of the disability. Exploring influential childhood experiences of leaders with acquired disabilities might be also useful.

Including disabled leaders leading a non-disabled group. This study is limited to leaders with disabilities. However, participants who agreed to be participants in this study were leaders with disabilities who also happened to be leaders of groups focused on disabilities. As a result, this study unintentionally excluded disabled leaders leading a mixed group of people who may or may not have a disability. Therefore, the researcher recommends including disabled leaders leading a non-disabled groups of people in a future study to diversify study participants. Additionally, a future study could investigate emerging themes or issues that leaders leading a non-disabled or mixed group face when they assumed their leadership roles after they became disabled. Lanza (2007) reflected her own experience of going back to be a group leader after she experienced a stroke. In her article, Lanza described that the stroke made her feel less confident and more vulnerable to lead a group and she had to readjust her leadership style by learning how to let things go and delegate tasks to her co-leader. Understanding how leaders adjust their leadership styles after becoming disabled might add to our understanding.

Including disabled leaders in research. Through the literature review, the researcher was shocked to discover that studies on leadership and disabled leaders were sparse. For this reason, the researcher strongly recommends including more participants with disabilities in leadership research.

According to the World Health Organization (WHO & The World Bank, 2011), 15 percent of the world's population has one or more disabilities. Snyder and Dillow (2013) identified that students with disabilities represent 11 percent of the entire college population in the United States in the year of 2007-2008. Despite the existence of the disabled population, disability is not represented in the leadership and diversity research. The researcher has raised

three possibilities that are related to under-representation of disabled leaders in leadership research.

First, the minuscule presence of disabled leaders in leadership and diversity research may be due to the difficulty researchers have in being approved by the institutional review board, because the disabled population is considered a vulnerable category of subjects. Second, researchers may experience difficulty with securing adequate participants because some disabilities are perceived with negative stereotypes and stigma, which can discourage potential participants from identifying themselves. Disabled leaders may be hidden because their disabilities are invisible or because they fear public response to these disabilities, possibly in the form of negative stereotype, stigma, and discrimination. Consequently, such negative responses discourage individuals from identifying as disabled and perhaps from participating in research. The stigma of the disability is an ongoing problem in our society.

The United Kingdom faces a similar social problem: stigma of the disability. In 2011, the Office for Disability Issues, a part of the Minister of State for Disabled People in the UK, published guidelines to promote the inclusion of disabled people in social research because this population is often excluded from studies. These guidelines suggest involving disabled people throughout the research process, designing research that is accessible to people with different disabilities, and making data collection methods and result dissemination accessible (Farmer & Mclead, 2011).

Third, under-representation of disabled leaders in leadership and diversity research may stem from researchers' narrow definition of diversity. Perhaps, as Johnson (1999) suggested, researchers limit their view of leadership among people with disabilities exclusively in the scope

of disability rights. Expanding on the definition of diversity to include disabled participants is recommended for future research.

As a diversity study, Ball, Monaco, Schmeling, Scharz, and Blanck (2005) investigated the diversity plans, policies, and practices of the 100 most profitable businesses in the United States. These successful companies state in their policies that they value diverse employee backgrounds and are committed to promoting diversity in the workplace. However, this study found that only 42% of these companies included disability in their definition of diversity (Ball, et al., 2005). This finding is similar to Coleman's study (2012), which was discussed in Chapter Two, that leadership and diversity literature often do not include disability in the definition of diversity.

The findings of Ball et al. (2005) are troublesome because it creates a gap between what corporations include in their definition of diversity and how higher education institutions define diversity; the former excludes disability and the latter includes disability. Moreover, this gap may cause confusion for college graduates who received leadership and diversity training, because when they enter the business world they could recognize that disability suddenly disappears from the definition of diversity. It is also ironic that diversity management for businesses results in managing and preventing discrimination and lawsuits. Therefore, the researcher recommends expanding the definition of diversity in both business policy and higher education policy to include disability. In other words, organizations should carry what they say into action.

Conclusion

In conclusion, this chapter recommends implications for higher education and for elementary and secondary education to facilitate leadership development in children and young

adults with disabilities. This chapter also recommends several future research topics including identity development among disabled leaders. This chapter concluded with the recommendation that disabled people should be included in leadership research.

Alexander (2006) used the phrase, "the art of leadership" as a metaphor to describe leadership development (p.85). Mastering leadership is an ongoing and possibly lifelong process (Alexander, 2006; Maxwell, 2013). The experiences of the six leaders with disabilities in this study suggest that building relationships is crucial. This crucial element is congruent with leadership development in general. However, we have a lot to learn from leaders with disabilities. The researcher hopes that this study will intrigue others to learn from disabled leaders how to improve our understanding and practice of leadership and diversity.

References

- Alexander, J. (2006). The challenge of complexity. In F. Hesselbein & M. Goldsmith (Eds.), *The Leader of the Future 2: Vision, Strategies, and Practice for the New Era* (pp. 85-94). San Francisco, CA: Jossey-Bass.
- Allio, R. J. (2005). Leadership development: teaching versus learning. *Management Decision*, 43(7/8), 1071-1077.
- Alston, R. J., Bell, T. J., & Feist-Price, S. (1996). Racial identity and African Americans with disabilities: Theoretical and practical consideration. *Journal of Rehabilitation*, 62(2), 11-15.
- American Council on Education. (n.d.) Why invest in leadership development? Retrieved March 1, 2014 from American Council on Education website: <http://www.acenet.edu/news-room/Pages/Why-Invest-in-Leadership-Development.aspx>
- Americans with Disabilities Act of 1990, Public Law 101-336, 43 U.S.C., 2101-12132.
- Anaya, G., & Cole, D. (2001). Latina/o student achievement: Exploring the influence of student-faculty interactions on college grades. *Journal of College Student Development*, 42, 3-14.
- Andersen, J. A. (2005). Leadership, personality, and effectiveness. *The Journal of Socio-Economics*, 35, 1078-1091.
- Astin, A. W., & Astin, H. S. (2000). *Leadership reconsidered: Engaging higher education in social change*. Battle Creek, MI: W. K. Kellogg Foundation.
- Atwater, L. E., Brett, J. F., & Charles, A. C. (2007). Multisource feedback: Lessons learned and implications for practice. *Human Resource Management*, 46(2), 285-307.
- Avolio, B. J., Gardner, W. L. (2005). Authentic leadership development: Getting to the root of positive forms of leadership. *The Leadership Quarterly*, 16, 315-338.

- Avolio, B. J., Walumbwa, F. O., & Weber, T. J. (2009). Leadership: Current theories, research, and future directions. *Annual Review of Psychology, 60*, 421-449.
- Ball, P., Monaco, G., Schmeling, J., Schartz, H., & Blanck, P., (2005). Disability as diversity in Fortune 100 companies. *Behavioral Sciences and the Law, 23*, 97-121. doi: 10.1002/bsl.629
- Barr, M. J., & Cuyjet, M. J. (1991). Program development and implementation. In T. K. Miller, J. Winston, Roger B. & Associates (Eds.), *Administration and leadership in student affairs: Actualizing student development in higher education* (2nd ed., pp. 707-739). Levittown, PA: Accelerated Development.
- Bass, B. M. (1985). *Leadership and Performance Beyond expectations*. New York, NY: The Free Press.
- Bass, B. M. (1990). From transactional to transformational leadership: Learning to share the vision. *Organizational Dynamics, Winter 90, 18*(3), 19-31.
- Bass, B. M. & Steidlmeier, P. (1999). Ethics, character, and authentic transformational leadership behavior. *Leadership Quarterly, 10*(2), 181-217.
- Bennis, W. (2009). *On Becoming a Leader*. New York, NY: Basic Books.
- Bernard, L. L. (1926). *An Introduction to Social Psychology*. New York, NY: Henry Holt and Co.
- Brett, J. F. & Atwater, L. E. (2001). 360° feedback: Accuracy, reactions, and perceptions of usefulness. *Journal of Applied Psychology, 85*(5), 930-942.
- Burns, J. M. (1978). *Leadership*. New York, NY: Harper & Row.
- Cashman, K. (1998). *Leadership from the Inside Out: Becoming a Leader for Life*. San Francisco, CA: Berrett-Koehler Publishers.
- Chickering, A. W. (1969). *Education and identity*. San Francisco, CA: Jossey-Bass.

- Chickering, A. & Braskamp, L. A. (2009). Developing a global perspective for personal and social responsibility. *Peer Review, 11*(4), 27-30.
- Chin, J. L. (2013). Diversity leadership: Influence of ethnicity, gender, and minority status. *Open Journal of Leadership, 2*(1), 1-10.
- Chin, J. L., & Sanchez-Hucles, J. (2007). Diversity and leadership. *American Psychologist, 62*(6), 608-609. doi:<http://dx.doi.org/10.1037/0003-066X62.6.608>
- Coleman, M. (2012). Leadership and diversity. *Educational Management Administration & Leadership, 40*, 592-609.
- Collins, D. B. & Holton, E. F. III. (2004). The effectiveness of managerial leadership development programs: A meta-analysis of studies from 1982 to 2001. *Human Resource Development Quarterly, 15*(2), 217-248.
- Cress, C. M., Astin, H. S., Zimmerman-Oster, K., & Burkhardt, J. C. (2001). Developmental outcomes of college students' involvement in leadership activities. *Journal of College Student Development, 42*(1), 15-27.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Day, D. V., & Harrison, M. M. (2007). A multilevel, identity-based approach to leadership development. *Human Resource Management Review, 17*, 360-373.
doi:10.1016/j.hrmr.2007.08.007
- Dobbins, G.H., & Platz, S. J. (1986). Sex differences in leadership: How real are they? *Academy of Management Review, 11*, 118-127.

- Drucker, P. F. (1955). *The Practice of Management*. New York, NY: HarperCollins.
- Drucker, P. F. (1996). Foreword. In F. Hesselbein, M. Goldsmith, & R. Beckhard (Eds.), *The Leader of the Future: New Visions, Strategies, and Practices for the New Era* (pp. xi-xv). San Francisco, CA: Jossey-Bass.
- Dugan, J. P., & Komives, S. R. (2007). *Developing leadership capacity in college students: Findings from a national study*. A report from the Multi-Institutional Study of Leadership. College Park, MD: National Clearinghouse for Leadership Program.
- Dunn, D. S., & Brody, C. (2008). Defining the good life following acquired physical disability. *Rehabilitation Psychology, 53*(4), 413-425. doi: 10.1037/a0013749
- Dzickowski, J. (2013). Mentoring and leadership development. *The Educational Forum, 77*(3), 351-360. doi: 10.1080/00131725.2013.792896
- Eagly, A. H., & Johannesen-Schmidt, M. C. (2001). The leadership styles of women and men. *Journal of Social Issues, 57*(4), 781-797.
- Eagly, A. H., Johannesen-Schmidt, M., & van Engen, M. L. (2003). Transformational, transactional, and laissez-faire leadership styles: A meta-analysis comparing women and men. *Psychological Bulletin, 129*(4), 569-591. doi:http://dx.doi.org/10.1037/0033-2909.129.4.569
- Erickson, E. H. (1964). *Childhood and Society* (2nd ed.). New York, NY: W.W. Norton & Company.
- Evans, N. J., Forney, D. S., Guido, F. M., Patton, L. D., & Renn, K. A. (2010). *Student development in college: Theory, research, and practice*. San Francisco, CA: Jossey-Bass.

- Farmer, M. & Maclead, F. (2011). Involving disabled people in social research: Guidance by the Office for Disability Issues. Retrieved from Office for Disability Issues website:
<http://odi.dwp.gov.uk/docs/res/research/involving-disabled-people-in-social-research.pdf>
- Field, S., Martin, J., Miller, R., Ward, M., & Wehmeyer, M. (1998). *A practical guide for teaching self-determination*. Reston, VA: Council for Exceptional Children.
- Foster-Fishman, P., Jimenez, T., Valenti, M., & Kelley, T. (2007). Building the next generation of leaders in the disabilities movement. *Disability & Society, 22*(4), 341-356.
- Gardner, J. (1989). Leadership development. *NASSP Bulletin, 73*. doi:
10.1177/019263658907351512
- Gardner, W. L., Coglisier, C. C., Davis, K. M. & Dickens, M. P. (2011). Authentic leadership: A review of the literature and research agenda. *The Leadership Quarterly, 22*, 1120-1145.
- Garfield, N. J., & David, L. B. (1986). Arthur Chickering: Bridging theory and practice in student development. *Journal of Counseling and Development, 64*, 438-491.
- Gay, L. R., Mills, G. E., & Airasian, P. (2006). *Educational research: Competencies for analysis and applications* (8th ed.). Upper Saddle River, NJ: Pearson.
- George, B., & Sims, P. (2007). *True North: Discover Your Authentic Leadership*. San Francisco, CA: Jossey-Bass.
- Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research. *Journal of Phenomenological Psychology, 28*(2), 235-261.
- Giorgi, A. (2005). The phenomenological movement and research in the human sciences. *Nursing Science Quarterly, 18*(1), 75-82. doi:10.1177/0894318404272112

- Giorgi, A. (2012). The descriptive phenomenological psychological method. *Journal of Phenomenological Psychology, 43*, 3-12.
doi:<http://dx.doi.org.weblib.lib.umt.edu:8080/10.1163/156916212X632934>
- Giovannini, M. (2004). What gets measured gets done: Achieving results through diversity and inclusion. *The Journal for Quality & Participation, 27*(4), 21-27.
- Goleman, D. (1998). What makes a leader? *Harvard Business Review, 76*, 92-102.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology, 29*(2), 75-91.
- Halpin, A.W. (1957). Manual for the Leader Behavior Description Questionnaire. Columbus, OH: The Ohio State University. Retrieved March 9, 2014 from Fisher College of Business website:
<http://fisher.osu.edu/supplements/10/2862/1957%20LBDQ%20MANUAL.pdf>
- Hezlett, S. A. & Gibson, S. K. (2007). Linking mentoring and social capital: Implications for career and organization development. *Advanced in Developing Human Resources, 9*(3), 384-412. DOI: 10.1177/1523422307304102
- Hobson, A. J. & Sharp, C. (2005). Head to head: A systematic review of the research evidence on mentoring new head teachers. *School Leadership and Management, 25*(1), 25-42. doi: 10.1080/1363243052000317073
- Jackson, B., & Parry, K. (2011). *A Very Short, Fairly Interesting and Reasonably Cheap Book about Studying Leadership*. Los Angeles, CA: Sage.
- Jenni, C. C. (1990). *Men's perceptions of their former wives in the joint custody family: A phenomenological analysis*. Available from ProQuest Dissertations and Theses database. (UMI No.9023492)

- Johnson, J. R. (1999). Leadership and self-determination. *Focus on Autism and Other Developmental Disabilities, 14*(1), 4-16.
- King, L. H., Aguinaga, N., O'Brien, C., Young, W., & Zgonc, K. (2010). Disability in higher education: A position paper. *American Annals of the Deaf, 155*(3), 386-391. doi: 10.1353/aad.2010.0019
- Klein, K. M., & Wang, M. (2010). Deep-level diversity and leadership. *American Psychologist, 65*(9), 932-934. doi: <http://dx.doi.org/10.1037/a0021355>
- Komarraju, M., Musulkin, S., & Bhattacharya, G. (2010). Role of student-faculty interactions in developing college students' academic self-concept, motivation, and achievement. *Journal of College Student Development, 51*(3), 332-342. doi: 10.1353/csd.0.0137
- Komives, S. R., Owen, J. E., & Longersbeam, S. D. (2005). Developing a leadership identity: A grounded theory. *Journal of College Student Development, 46*(6), 593-611. doi: 10.1353/csd.2005.0061
- Kouzes, J., & Posner, B. (2002). *The leadership challenge* (3rd ed.). San Francisco, CA: Jossey-Bass.
- Kugelmass, J. & Ainscow, M. (2004). Leadership for inclusion: A comparison of international practices. *Journal of Research in Special Education Needs, 4*(3), 133-141. doi: 10.1111/J.1471-3802.2004.00028.x
- Lanza, M. (2007). Reflection: Returning as a group leader after a severe disability. *The Journal for Specialists in Group Work, 32*(3), 210-223. doi: 10.1080/01933920701431628
- Lauterbach, K. E., & Weiner, B. J. (1996). Dynamics of upward influence: How male and female managers get their way. *Leadership Quarterly, 7*(1), 87-107.

- Leader. (2003). In *Oxford Dictionary of English* (2nd ed.). New York, NY: Oxford University Press.
- Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative Research: Reading, analysis, and interpretation*. Thousand Oaks, CA: Sage.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Madsen, S. R. (2007). Developing leadership: Exploring childhoods of women university presidents. *Journal of Educational Administration, 45*(1), 99-118. doi: 10.1108/09578230710722476
- Martin, J. E., & Marshall, L. H. (1995). Choicemaker: A comprehensive self-determination transition program. *Intervention in School and Clinic, 30*(3), 147-157.
- Maxwell, J. C. (2013). *How Successful People Lead: Taking Your Influence to the Next Level*. New York, NY: Center Street.
- McCarthy, H. (2003). The disability rights movement: Experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin, 46*(4), 209-223.
- McCauley, C. D., Palus, C. J., Drath, W. H., Hughes, R. L., McGuire, J. B., O'Connor, P. M. G., & Velsor, E. V. (2008). *Interdependent leadership in organization: Evidence from six case studies*. Greensboro, NC: Center for Creative Leadership.
- McIntire, D. D. (1989). Student leadership development: A Student Affairs mandate. *NASPA Journal, 27*(1), 75-79.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA Sage.
- Mpofu, E., & Harley, D. A. (2006). Racial and disability identity: Implications for the career counseling of African Americans with disabilities. *Rehabilitation Counseling Bulletin, 50* (1), 14-23.

- Nafukho, F. M., Roessler, R. T., & Kacirek, K. (2010). Disability as a diversity factor: Implications for human resources practices. *Advances in Developing Human Resources, 12*(4), 395-406. doi: 10.1177/1523422310379209
- Nirenberg, J. (2003). Toward leadership education that matters. *Journal of Education for Business, 79*(1), 6-10.
- O'Day, B. & Goldstein, M. (2005). Advocacy issues and strategies for the 21st century: Key informant interviews. *Journal of Disability Policy Studies, 15*(4), 240-250.
- Okozi, I. F., Smith, K. L, Clark, L., & Sherman, R. M. (2009). Leadership styles of ethnic minority leaders. American Psychological Association, August 2009, Retrieved from <http://www.apa.org/pi/oema/resources/communique/2009/08/ethnic-leaders.aspx>
- O'Meara, K., Knudsen, K., & Jones, J. (2013). The role of emotional competencies in faculty-doctoral student relationships. *The Review of Higher Education, 36*(3), 315-347. doi: 10.1353/rhe.2013.0021
- Pascarella, E. T., & Terenzini, P. T. (1978). Student-Faculty informal relationships and freshman year educational outcomes. *The Journal of Educational Research, 71*(4), 183-189.
- Pascarella, E. T., Terenzini, P. T., & Hibel, J. (1978). Student-faculty interactional settings and their relationship to predicted academic performance. *The Journal of Higher Education, 49*(5), 450-463.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Pennell, R. L. (2001). Self-determination and self-advocacy: Shifting the power. *Journal of Disability Policy Studies, 11*(4), 223-227.

- Pledger, C. (2007). Building manager effectiveness by combining leadership training and organization development. *Organization Development Journal*, 25(1), 71-76.
- Polkinghorne, D. E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), *Existential-Phenomenological Perspectives in Psychology: Exploring the Breadth of Human Experience: with a Special Section on Transpersonal Psychology*. (pp.209-225). New York, NY: Plenum Press.
- Posner, B. Z. (2004). A leadership development instrument for students: Updated. *Journal of College Student Development*, 45(4), 443-456.
- Powell, G. N. (1990). One more time: Do female and male managers differ? *Academy of Management Executive*, 4(3), 68-75.
- Powers, L. E., Ward, N., Ferris, L, Nelis, T., Ward, M., Wieck, C., & Heller, T. (2002). Leadership by people with disabilities in self-determination systems change. *Journal of Disability Policy Studies*, 13(2), 125-133.
- Priebe, R. M. (1993). *Voc talk: Stories from the back of the school*. Available from ProQuest Dissertations and Theses database. (UMI No. NN88234)
- Rehabilitation Act of 1973, Public Law 93-112, Section 504, 29 U.S.C., 794.
- Ridgeway, C. L. (2001). Gender, status, and leadership. *Journal of Social Issues*, 57(4), 637-655.
- Romero, E. J. (2005). The effect of Hispanic ethnicity on the leadership process. *International Journal of Leadership Studies*, 1(1), 28-43.
- Rosch, D. M., & Caza, A. (2012). The durable effects of short-term programs on student leadership development. *Journal of Leadership Education*, 11(2), 28-48.
- Sanlo, R., & Chávez, A.F. (2013). Our vision of identity and leadership an academe. In A.F. Chávez & R. Sanlo (Eds.), *Identity and Leadership: Informing Our Lives, Informing Our*

- Practice* (pp. 3-7). Washington, DC: National Association of Student Personnel Administrators (NASPA).
- Schuh, J. H. (1989). A student development theory to practice workshop. *Journal of Counseling and Development, 67*, 297-298.
- Searcy, S., Lee-Lawson, C., & Trombino, B. (1995). Mentoring new leadership roles for parents of children with disabilities. *Remedial and Special Education, 16*(5), 307-314. doi: 10.1177/074193259501600507
- Seekins, T., Shuttleworth, R., & Kasnitz, D. (2004). *Rural civic leadership and disability: Positive perspectives on participation and advocacy*. Missoula, MT: The University of Montana Rural Institute.
- Shogren, K. A. & Plotner, A. J. (2012). Transition planning for students with intellectual disability, Autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Development Disabilities, 50*(1), 16-30. doi: 0.1352/1934-9556-50.1.16
- Snyder, T. D., & Dillow, S. A. (2013). *Digest of Education Statistics 2012* (NCES 2014-015). National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education. Washington, DC.
- Stead, V. (2005). Mentoring: A model for leadership development? *International Journal of Training and Development, 9*(3), 170-184.
- Stodden, R. A., Whelley, T., Chang, C., & Harding, T. (2001). Current status of educational support provision to students with disabilities in postsecondary education. *Journal of Vocational Rehabilitation, 16*, 189-198.

- Strayhorn, T. L. (2008). Sentido de pertenencia: A hierarchical analysis predicting sense of belonging among Latino college students. *Journal of Hispanic Higher Education*, 7(4), 301-320.
- Strayhorn, T. L. (2010). Majority as temporary minority: Examining the influence of faculty-student relationships on satisfaction among white undergraduates at historically black colleges and universities. *Journal of College Student Development*, 51(5), 509-524. doi: 10.1353/csd.2010.0007
- Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education*, 26(1), 43-54.
- Thanem, T. (2008). Embodying disability in diversity management research. *Equal Opportunities International*, 27(7), 581-595. doi: 10.1108/02610150810904292
- Thoma, C. A., & Getzel, E. E. (2005). "Self-determination is what it's all about": What post-secondary students with disabilities tell us are important considerations for success. *Education and Training in Developmental Disabilities*, 40(3), 234-242.
- Walumbwa, F. O., Avolio, B. J., Gardner, W. L., Wernsing, T. S., & Peterson, S. J. (2008). Authentic leadership: Development and validation of a theory-based measure. *Journal of Management*, 34(1), 89-126. doi: 10.1177/0149206307308913
- Watson, C., & Hoffman, L. R. (1996). Manager as negotiators: A test of power versus gender as predictors of feelings, behavior, and outcomes. *Leadership Quarterly*, 7(1), 63-85.
- Wehmeyer, M. L., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children*, 63, 245-255.

- Wehmeyer, M. L. (2007). *Promoting self-determination in students with developmental disabilities*. New York: The Guilford Press.
- Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology, 52*(2), 167-177. doi: 10.1037/0022-0167.52.2.167
- World Health Organization & World Bank (2011). *World Report on Disability: Summary*. Geneva, Switzerland: World Health Organization.
- Yukl, G. (2006). *Leadership on Organizations* (6th ed.). Upper Saddle River, NJ: Pearson.

Appendices A-C
Forms for Interview

Appendix A: Institutional Review Board checklist and application

THE UNIVERSITY OF MONTANA Institutional Review Board (IRB) for the Use of Human Subjects in Research CHECKLIST/APPLICATION

IRB Protocol No: 53-11

At The University of Montana (UM), the Institutional Review Board (IRB) is the institutional review body responsible for oversight of all research activities involving human subjects outlined in the U.S. Department of Health and Human Services Office of Human Research Protection (www.hhs.gov/ohrp) and the National Institutes of Health, Inclusion of Children Policy Implementation (<http://grants.nih.gov/grants/funding/children/children.htm>).

Instructions: A separate registration form must be submitted for each project. IRB proposals are approved for three years and must be continued annually. Faculty members may email the completed form as a Word document to IRB@umontana.edu. Students must submit a hardcopy of the completed form to the Office of the Vice President for Research & Development, University Hall 116.

1. Administrative Information

Project Title: A Phenomenological Study of Leadership: Perspectives of Leaders with Disabilities.

Principal Investigator: Mika Watanabe, M.A.

Title: Doctoral Candidate

Email address: mika.watanabe@umontana.edu

Department: Counselor Education

2. Human Subjects Protection Training (All researchers, including faculty supervisors for student projects, must have completed a self-study course on protection of human research subjects within the last three years (<http://www.umt.edu/research/complianceinfo/IRB/>) and be able to supply the “Certificate(s) of Completion” upon request. Add rows to table if needed.

NAME and DEPT.

Mika Watanabe, Counselor Education, Principal Investigator, Human Subjects Protection Course
10/23/2009

Cathy Jenni, Counselor Education, Faculty Supervisor, Human Subjects Protection Course
9/26/2008

3. Project Funding

Is grant application currently under review at grant funding agency? No.

Has grant proposal received approval and funding? No.

Is this part of your thesis or dissertation? Yes

If yes, date your successfully presented your proposal to your committee. December 10, 2010.

4. Purpose of the Research Project (not to exceed 500 words): Briefly summarize the overall intent of the study. Your target audience is a non-researcher. Include in your description a statement of the objectives and the potential benefit to the study subjects and/or the advancement of your field. Generally included are literature related to the problem, hypotheses, and discussion of the problem's importance. Expand box as needed.

Despite American higher education's ongoing role in producing future leaders, the importance of leadership and the shortage of leaders with disabilities has been discussed in scholarly literature (Johnson, 1999; Foster-Fishman, Jimenez, Valenti, & Kelley, 2007). The purpose of this qualitative research is to investigate how college graduates with disabilities transition to the role of being leaders. A phenomenological approach will be used to understand the lived experiences of 6 to 8 adults with disabilities who have achieved leadership positions at the state or national level. Semi-structured interviews with participants will be analyzed by looking at significant statements, generating meaning units, and developing an unifying description that includes the experience of all subjects, with a focus on subjects' undergraduate college years. The findings from this study may expand the literature in the area of leadership in people with disabilities. Additionally, the outcomes of the study have the potential to enhance programs in higher education that help college students with disabilities develop the capacity for leadership.

5. IRB Oversight

Is oversight required by other IRB(s) [e.g., tribal, hospital, other university] for this project? No.

6. Subject Information:

a. Human Subjects (identify, include age/gender):

Participants in this qualitative study will be 6 to 8 men and women who 1) have achieved state or national level leadership to advocate for disability rights, 2) who have publicly identified them that they have a disability, 3) have held a leadership position at least three years in their respective organizations at the time of the interviews, 4) earned one or more college degrees, 5) experienced limitations during their college years due to their disabilities, 6) are at least 18 years of age.

b. How many subjects will be included in the study? Between 6 to 8 total.

c. Are minors included (under age 18, per Montana law)? No.

d. Are member of physically, psychologically, or social vulnerable population being specifically targeted? Yes.

If yes, please explain why the subjects might be physically, psychologically or social vulnerable:

Historically, people with disabilities have often experienced physical, psychological, and social barriers when participating in research. For example, some written research protocols and interview questions have not been in accessible formats for individuals with visual impairments who use screen-readers. The PI will ensure that the interview process and information provided

to participants are accessible to the interviewees. None of the individuals in this study will have cognitive functions that could otherwise compromise their ability to fully understand and consent to the nature of the research, the questions, or the research procedures. None of the research questions will be potentially traumatizing.

e. Are there other special consideration regarding this population? No.

f. Do subjects reside in a foreign country? No.

g. How are subjects selected or recruited? What is inclusion/exclusion criteria? (Attach copies of all flyers, advertisements, etc,- that will be used in the recruitment process as these required UM-IRB approval)

Participants will be recruited through word of mouth and via email invitation through disability organizations such as Digital Accessible Information System (DAISY) Consortium, National Federation of the Blind (NFB), Association on Higher Education and Disability (AHEAD). Eligible participants will: be age 18 or older, have a disability, have publicly identified themselves as having a disability, hold one or more college degrees, have achieved state or national leadership to advocate for disability rights, and will have held their leadership position at least 3 years in their respective organizations at the time of the interviews. Participants who are younger than 18, without a disability, and whose disability was acquired after they graduated college will be excluded.

h. How will subjects be identified in your personal notes, work papers, or publications: (may check more than one).

Identified name and/or address or other

(Secure written [e.g., ICF] or verbal permission to identify; if risk exists, create a confidentiality plan.)

Confidentiality Plan

(Identity of subjects linked to research, but not specific data [e.g., individuals identified in ICF but not included in publications]; identification key kept separate from data; or, data collected by third party [e.g., Select Survey, SurveyMonkey, etc.] and identifiers not received with data.)

Never know participant's identity

(An ICF may be unnecessary [e.g., anonymous survey, paper or online] unless project is sensitive or involves a vulnerable population.)

i. Describe the means by which the human subject's personal privacy is to be protected, and the confidentiality of information maintained. If you are using a Confidentiality Plan (as checked above), include in your description a plan for the destruction of materials that could allow identification of individual subjects.

Participants will have the choice of whether they would like to participate anonymously. For those who wish to participate in this study anonymously, the following plan will be implemented:

Participants will be informed regarding the limits of confidentiality including communication through personal computers being traceable before they agree to participate in the study.

Deidentifying all data and keeping all files in password protected or locked devices will mitigate these confidentiality risks. During the interview, notes taken by the investigator will be labeled with an identification number rather than a participant's name. Any identifiable names and features of the interview will be removed during the transcription process. The investigator will use codes or pseudonyms to conceal identities in transcripts. When face-to-face meetings occur, interviews will take place in a private room. All confidential material will be stored either in a locked cabinet or in a de-identified form on a secure hard drive.

All research participants will be asked to review a copy of their completed interview transcript and make any changes or corrections necessary for anonymity and for privacy. The researcher will incorporate the participants' suggestions until they feel comfortable, or omit the section.

j. Will subject(s) receive an explanation of the research – separate from the informed consent form (if applicable) – before and/or after the project? Yes.

7. Information to be Compiled

a. Explain where the study will take place (physical location not geographic. If permission will be required to use any facilities, indicate those arrangements and attach copies of written permission):

Interviews will take place at a location of the participant's choosing (such as in their office a private meeting room or in another location where both the participant and the researcher feel private and safe). Interviews will be conducted through a face-to-face meeting or by using a telephone and Skype, an Internet phone service.

b. Subject matter or kind(s) of information to be compiled from/about subjects:

Participants will be asked for demographic information for purposes of describing the interviewees.

c. Activities the subjects will perform and how the subjects will be used. Describe the instrumentation and procedures to be used and kinds of data or information to be gathered. Provide enough detail so the IRB will be able to evaluate the intrusion from the subject's perspective (expand box as needed):

The Principal Investigator (PI) will send participants, who agree to participate in the study, an information packet containing the informed consent form. The participants will be asked to complete the form and to send it back to the PI via fax, postal mail or electronic scanning/email. In addition to the written consent form, a verbal consent will be recorded before each interview

session. Before answering questions all participants will be informed of the purpose of the study, the approximate time of the interview, the right to decline or stop the interview at any time and privacy issues concerning the participants.

An individual, face-to-face or phone interview with each participant will be conducted for approximately 60 minutes by the PI. At the beginning of the interview, participants will be asked to answer demographic questions (see the attached Interview Protocol). And then, the PI will ask participants open-ended questions such as, “please tell me about important experiences or relationships in your life that led you to take your current leadership role.” Depending on how the interview proceeds, the PI may ask the participants what experiences and relationships primarily in their college years influenced their growth as a leader, what challenges they encounters and how they overcame such challenges that influenced their leadership development (see the attached Interview Protocol). Follow up questions will be used to clarify participants’ responses. All participants will be asked to review a copy of their completed interview transcript and make any changes or corrections necessary for anonymity.

d. Is information on any of the following included? (check all that apply):

- Sexual behavior
- Drug use/abuse
- Alcohol use/abuse
- Illegal conduct
- Information about the subject that, if it became known outside the research, could reasonably place subject at risk of criminal or civil liability or be damaging to the subject's financial standing or employability.

e. Means of obtaining the information (check all that apply). Attach questionnaire or survey instrument, if used:

- Field/Laboratory observation
- In-person interviews/survey
- Telephone interviews/survey
- Blood/Tissue/Urine/Feces/Semen/Saliva Sampling (IBC Application must be submitted)
- On-site survey
- Medical records (require HIPAA form)
- Main survey
- Measurement of motions/actions
- Online survey (attach Statement of Confidentiality)
- Use of standard educational test, etc.
- Examine public documents, records, data, etc.
- Other means (specify)
- Examine private documents, records, data, etc.

f. Will subjects be (check all that apply):

- Videotaped
- Audio-taped
- Photographed

_ N/A

Explain how above media will be used, who will transcribe, and how/when destroyed:

Digital recording will be used to record interviews in order to preserve exact words for later analysis. The researcher's computer will have recording software and will be used in connection with Skype. The Skype application will be utilized to call land line, cellular, and internet based phone numbers. All audio files created through this process will be secured in a password protected digital folder on the same computer. Any external data backups of these files will also be contained in a non-public, password protected drive.

If this drive or computer is accessed over any wireless servers, access will be through networks based on security process such as the WPA format (Wi-Fi Protected Access). No information will be created or sent over unsecured, public networks. Finally, when materials are electronically sent between the participants and the researcher, formats which provide end-to-end encryption will be utilized. One example includes new settings in Gmail.

A digital recorder will be used for a face-to-face interview. A professional transcription service who ensures strict confidentiality will transcribe the recorded interviews. The transcription service will not be allowed to keep any files and will need to sign a confidentiality agreement before serving in this role. Data will be kept in a confidential and locked area by the PI and will be destroyed once transcripts are verified for accuracy.

g. Discuss the benefits (does not include payment for participation) of the research, if any, to the human subjects and to scientific knowledge (if the subjects will not benefit from their participation, so state):

This study may expand the literature in the area of leadership in people with disabilities and help improve leadership development programs for college students with disabilities. Participants may feel good about contributing to the project. However, participants will not receive direct benefits or compensation from participation.

h. Cite any payment for participation (payment is not considered a benefit):
No payment for participation.

i. Outline, in detail, the risks and discomforts, if any, to which the human subjects will be exposed (Such deleterious effects may be physical, psychological, professional, financial, legal, spiritual, or cultural. As a result, one can never guarantee that there are no risks – use “minimal.” Some research involves violations of normal expectations, rather than risks or discomforts; such violations, if any, should be specified):

Participants are not intentionally exposed to any risk. Any psychological, physical, social, or legal risks that participants may encounter is not greater than those ordinarily experienced in daily life. No questions regarding violence, abuse, sexuality or sexual history will be asked during the interviews. However, the researcher will initially inform the interviewees that if any information is disclosed about a child being abused or neglected or that an older person or a

person with a developmental disability has been subjected to abuse, sexual abuse, neglect, or exploitation, then the researcher may be required to report this information to the appropriate authorities. If interviewees do not agree to this procedure, they will be excused from the study. The researcher has earned a Master's Degree in Counseling and has been trained in issues surrounding mandatory reporting.

j. Describe, in detail, the means taken to minimize each such deleterious effect or violation:

Participants may withdraw from participation or pause or stop the interview process at any time without penalty or further questioning. All data pertaining to withdrawn participants will be deleted from the audio recordings and all written notes will be destroyed. No data from removed participants will be included in the data analysis.

8. Informed Consent

An informed consent form (ICF) is usually required, unless subjects remain anonymous or a waiver is otherwise justified below. (Templates and examples of Informed Consent, Parental Permission, and Child's Assent Forms are available at <http://www.umt.edu/research/complianceinfo/irb/forms.aspx>).

- A copy of the consent/assent/permission form must be offered to all subjects, including parents/guardians of subjects less than 18 years of age (minors).
- Use of minors

All minor subjects (under the age of 18) must have written parental or custodial permission (45 CFR 46.116(b)).

All minors from 10 to 18 years of age are required to give written assent (45 CFR 46.408(a)).

Assent by minor subjects: All minor subjects are to be given a clear and complete picture of the research they are being asked to engage in, together with its attendant risks and benefits, as their developmental status and competence will allow them to understand.

Minors less than 10 years of age and all individuals, regardless of age, with delayed cognitive functioning (or with communication skills that make expressive responses unreliable) will be denied involvement in any research that does not provide a benefit/risk advantage.

Good faith efforts must be made to assess the actual level of competence of minor subjects where there is doubt.

The Minor Assent Form must be written at a level that can be understood by the minor, and/or read to them at an age-appropriate level in order to secure verbal assent.

Is a written informed consent form being used? Yes (attach copy)

Is a written parental permission form being used? No.

Is a written minor assent form being used? No.

The Principal Investigator agrees to comply with all requirements of The University of Montana-Missoula IRB, the U.S. Department of Health and Human Services Office of Human Research Protection Guidelines, and NIH Guidelines. The PI agrees to ensure all members of his/her team are familiar with the requirements and risks of this project, and will complete the Human Subject Protection Course available at <http://www.umt.edu/research/complianceinfo/irb>.

Principal Investigator's Statement

I certify that the statements made in this request are accurate and complete. I also agree to the following:

- If I receive approval for this research project, I agree to inform the IRB in writing of any emergent problems. I further agree not to proceed with the project until the problems have been resolved.
- I will not make any significant procedural changes to procedures involving human subjects without submitting a written amendment to the IRB and will not undertake such changes until the IRB has reviewed and approved them.
- It is my responsibility to ensure that every person working with the human subjects is appropriately trained.
- I will not begin work on the procedures described in this protocol until I receive notice of approval from the IRB.
- I will keep a copy of this protocol (including all consent forms, questionnaires, and recruitment flyers) and all subsequent correspondence.

Signature of Principle Investigator: _____ Date: _____

Attachment: Interview Protocol

Explanation of Research Study to Participants

Thank you for agreeing to participate in this research study. The purpose of this study is to understand how college graduates with disabilities transition to the role of leaders. I am interested in your reflections on important experiences and relationships in your life that led you to take a leadership role.

I would like to inform you that this interview will be recorded for accuracy and later analysis. I will later conduct verbatim transcription for the interview. Is this fine by you?

If yes, begin recording the interview.

Let me go over the requirements and consent forms. You should have a copy of the consent form with you. Is this correct?

Read over consent form with the participant. Answer any questions and ask the participant to state consent to participate.

I will begin the interview by asking you some background questions about yourself. Then I will ask you a research question.

Participant Demographic Information

During the first 5 minutes, I will ask you a few questions to gather demographic information. This information will not be used directly in the data analysis. However, it will be used to organize the data that will be collected during the interviews. I will begin.

What is the title of your current leadership position?

How long have you held this leadership position?

What is and are your college degree(s)?

When did you receive your college degree(s)?

What was or were your major(s)?

Interview Question

Now we will move onto the interview question. Would you take just a moment to reflect right now on important experiences or relationships in your life that led you to take your leadership role? You can say whatever comes to mind.

Possible other questions:

What were some of the challenges or obstacles? And how did you overcome them?

Tell me your accomplishment as a leader that you are most proud of. Who supported you?

When you think about your years in college, were there relationships or experiences that influenced your growth as a leader?

During the interview, I may ask probing questions which may include:

What does that mean?

Can you explain that to me in more detail?

Describe what that was like for you.

Appendix B: Participant information and informed consent form

TITLE:

A phenomenological study of leadership: Perspectives of leaders with disabilities

PROJECT DIRECTOR:

Mika Watanabe, M.A., Doctoral Candidate
Department of Counselor Education
University of Montana
Missoula, MT 59812
Phone: 406.243.6535
Email: mika.watanabe@umontana.edu

FACULTY SUPERVISOR:

Cathy Jenni, Ph.D., Professor
Department of Counselor Education
University of Montana
Missoula, MT 59812
Phone: 406.243.2608
Email: cathy.jenni@mso.umt.edu

Please read this information carefully before you make a decision whether or not to participate in this study. This consent form may contain words that are unfamiliar to you. If you read any words that are not clear to you, please ask Mika Watanabe for clarification.

PURPOSE:

The purpose of this qualitative study is to investigate how college graduates with disabilities transition to the role of leadership. You must be 19 years of age or older to participate in this study.

PROCEDURES:

Participants who agree to take part in this study will have the choice of whether they would like to participate anonymously. They will be asked several background questions and will then be asked to complete an approximately one-hour face-to-face or telephone interview. The interviews will be audio recorded and transcribed. Each participant who wishes to remain anonymous will be assigned a number or study name so that they cannot be identified as individuals. To insure confidentiality, all research participants will be asked to review a copy of their completed interview transcript and make any changes or corrections necessary for anonymity. Any or all parts of interviews may be quoted in published reports of this research.

RISKS/DISCOMFORTS:

You will not intentionally be exposed to any risk. You will be asked questions regarding your life experiences. This may trigger the memory of unpleasant events. If you should feel distressed during the interview and wish to pause or stop, please alert Ms. Watanabe so that she can act accordingly.

BENEFITS OF PARTICIPATION:

Participants will not receive any form of payment or service in compensation for participation. The only known benefit is that this study could contribute to a body of knowledge that informs development for future leaders with disabilities.

CONFIDENTIALITY:

To protect confidentiality, the researcher Mika Watanabe will take several precautions to ensure privacy for those participants wishing to remain anonymous.

Any information obtained during this study which could identify you will be kept strictly confidential. The data will be stored in a locked, private location and only the researcher and her dissertation committee members including Faculty Supervisor Dr. Cathy Jenni will have access to the data. The interview will be transcribed by a professional transcriptionist. During transcription and data analysis, you will be assigned a pseudonym.

Near completion of data analysis, the researcher will send you the interview transcriptions for you to review, and allow you to edit material that you feel compromises your confidentiality if you wish to remain anonymous or if you would like to restate responses. The researcher will incorporate your suggestions until you feel comfortable, or omit the section.

The information obtained in this study may be published in scientific journals or presented at scientific meetings, but the data will be reported in anonymous form. The audiotapes will be destroyed after this study is completed.

There are conditions under which confidentiality may be breached. If you speak with the researcher indicating the intention to harm yourself or someone else, as the law mandates, appropriate individuals may be contacted.

COMPENSATION FOR INJURY:

Although we do not foresee any risk in taking part in this study, the following liability statement is required in all University of Montana consent forms.

In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement or compensation pursuant to the Comprehensive State Insurance Plan established by the Department of Administration under the authority of M.C.A., Title 2, Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Claims representative or University Legal Counsel. (Reviewed by University Legal Counsel, July 6, 1993)

VOLUNTARY PARTICIPATION/WITHDRAWAL:

Your decision to take part in this research study is entirely voluntary. You may refuse to take part in or you may withdraw from the study at any time without penalty. You may be asked to leave the study for any of the following reasons: (a) failure to follow the Researcher's instructions, (b) a serious adverse reaction occurs which may require evaluation, (c) the Researcher believes it is in the best interest of your health and welfare, or (d) the study is terminated.

QUESTIONS:

You may wish to discuss participating in this study with others before you agree to take part. If you have any questions regarding your rights as a participant, you may contact the IRB Chair at The University of Montana Research Office at 406.243.6670. If you have any questions about

the research now or during the study, please feel free to contact the Project Director Mika Watanabe and/or the Faculty Supervisor Dr. Cathy Jenni at 406.243.2608.

PARTICIPANT'S STATEMENT OF CONSENT:

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

Printed (Typed) Name of Participant

Participant's Signature

Date

ANONYMITY: Please sign one of the following statement. You may change your mind at a later date.

I do wish to remain anonymous in this study.

Participant signature

Date

I do not wish to remain anonymous in this study.

Participant signature

Date

Appendix C: Sample Email Letter to Participants

Dear potential participant name:

As part of my doctoral dissertation research, I am planning to conduct interviews with a small number of local or nationally recognized leaders with disabilities. These people [will name them] have suggested your name as someone who may be interested in participating in this study. I am asking you to consider being a part of this study.

The purpose of this qualitative study is to investigate how college graduates with disabilities transition to the role of leadership.

Participants who agree to take part in this study will have the choice of whether they would like to participate anonymously. They will be asked several background questions and will then be asked to complete an approximately one-hour face-to-face or telephone interview. The interviews will be audio recorded and transcribed. Each participant who wishes to remain anonymous will be assigned a number or study name so that they cannot be identified as individuals. Further to insure confidentiality, all research participants will be asked to review a copy of their completed interview transcript and make any changes or corrections necessary for anonymity and for privacy. I will incorporate the participants' suggestions until they feel comfortable, or omit the section. Any or all parts of interviews may be quoted in published reports of this research.

During a one hour interview, I will be interested in learning: important experiences or relationships in your life that led you to take your leadership role; critical events or activities you think may have contributed or led to your leadership development; what you feel contributes to/impedes transformation. I also would like to learn your experiences in your college years that influenced your growth as a leader. I will also be interested in any recommendations you may have for other leaders with disabilities whom I might be able to interview.

Thank you for your consideration of this project. I look forward to hearing from you.

Sincerely,

Mika Watanabe, Doctoral Candidate
Department of Counselor Education
College of Education and Human Sciences
University of Montana
Missoula, MT 59812
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Appendix D

Data Analysis

Andrew: Levels One to Three

Andrew (S1): Level One and Two (Spontaneous Meaning Units)

<p>Please take a moment and reflect your important experiences or relationships in your life that led you to take your leadership role.</p> <p>S1: My leadership role—my current leadership role or leadership broadly? Do you mean my current position and what got me there? Is that what you're looking for?</p> <p>I will just follow as you start, whatever is important for you.</p> <p>S1: Okay. 1. I think there are two major pieces that led me to my current profession, maybe three./ 2 .One is that I found out very young that something I wanted to do in life—something that I was concerned about in life was helping to raise the status and do work that would improve the lives of others. That was...(Call ended)./</p> <p>I'm sorry. We got disconnected.</p> <p>S1: 3. I'm not sure where that came from but I knew about it very young. At first, when I was young, I thought I wanted to go into some form of the ministry. But, that didn't work out and that really wasn't for me anyway./ 4. The next thing that I discovered when I was in my 20s was that I could be seen by others as a leader./ 5. The way I found that out was through summer employment; I worked for something called the Neighborhood Youth Corp, which was a federally funded program at the time that took teenage children from low income families and get them summer employment. I was a supervisor—I was in my 20s and in college so they made me a supervisor. We worked at a book bindery in the school of in [a city] where I grew up./</p> <p>6. The kids had jobs restoring text books that were rented to the children in the school and</p>	<p>1. S1 has 3 major pieces that led him to his current leadership position.</p> <p>2. When S1 was very young, he decided to do work to help raise the status and improve the lives of others.</p> <p>3. During S1's childhood, he wanted to pursue a career of the ministry, but this did not work out and he realized that the ministry career was not for him.</p> <p>4. During S1's 20s, he discovered that others saw him as a leader.</p> <p>5. S1 had summer employment when he was 20s in his college. The employment was to work with teenagers from low income families and to supervise them binding books in the town where he grew up.</p> <p>6. S1 supervised the children restoring textbooks after they were damaged. He also</p>
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<p>then turned in and then would be rented out again the next year but they came back damaged. So we would restore these text books to like-new condition. And then we also did other book binding projects. / 7. We had a big job that came in and the guy that I reported it to brought it to us and he said, "Okay, do a first run of this job." It came back with terrible quality; pages upside down, out of order, bad quality. He said, "We can't accept this. You're going to have to tear this apart and run it again." I said, "Okay, kids, you guys know the job. I want one of you to work as an inspector."/</p> <p>8. So the job will come off the line, it will be inspected, every book that we put together will be inspected for quality. So, we did that for a day. The guy I report to came and picked them up, brought them back the next day, and he said, "The quality is no better." I said, "Okay, you guys, we're going to get this quality thing down if I have to have one person putting it together and everyone else inspecting it." "Let's start out with two inspectors. So it will come off the line, an inspector will inspect it, the second inspector will catch errors that the first inspector missed." That worked./</p> <p>9. Why? The kids were able to explain why it worked themselves. They were willing to forgive production errors because anybody can make errors. They were willing to forgive errors that the first inspector made and not catching the errors that the production people made. But they weren't willing to accept errors that an inspector of an inspector made. So the inspector would always take pride in catching errors that the first inspector didn't catch. Meaning that the first inspector would work extra hard to catch errors in the first place./</p> <p>10. By the time we got to two inspectors, our quality rate actually equaled [a name] quality rate three days. That led me to believe that I had some leadership potential because all of</p>	<p>supervised these children to bind other books.</p> <p>7. S1's senior employer told him that quality of the books the bindery produced was unacceptable. Thus, S1 told the children to work differently and suggested that one of them acted as an inspector for quality control.</p> <p>8. S1 was told by the senior employer that the quality was the same as before. Thus, S1 proposed having two inspectors instead, and this strategy worked.</p> <p>9. S1 concluded the success and quality of the bookbinding work came from children's pride in what they did to assure quality.</p> <p>10. S1 started believing that he had leadership potential from this experience because he did it intuitively.</p>
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<p>that was intuitive./ 11. I wasn't a business major; I didn't know anything about industrial psychology. But, it occurred to me, and I started thinking, what is leadership all about? It occurred to me that you're only a leader if people follow you by definition. /</p> <p>12. Leadership is not a quality that you may possess if you're really a leader. Nobody happens to be following you but you're a leader, no, that's not true. People either follow you or they don't and if they don't then you're not a leader./ 13. They don't always follow—no one can be a leader all of the time. No one is going to get people to follow them all of the time because the leader is always going places that people want to follow./</p> <p>14. What leadership has to do is articulate a vision of what it is going to be like when we get there? What is a reasonable way we can expect to get there? Why is it going to be better for you when you get there?/</p> <p>15. It's not about me; it's about the place where we are going and how we're going to get there and how it's going to benefit you. That's at the root of leadership./ 16. I discovered from those kids—these were kids who couldn't read a ruler. These were not successful kids. They were poor, poor, poor kids. I was teaching them how to use a ruler. High school kids couldn't use a 12-inch ruler./</p> <p>17. Anyhow, lots of other things began. I was interested in always in the sociology of power when I was in college. I was a sociology major in undergraduate years. It became obvious to me that there are lots of differences between leadership and power./</p> <p>18. Some powerful people aren't good leaders and some good leaders aren't necessarily powerful./ 19. It occurred to me that I was much more interested in leadership than power./ 20. Even when I have organizational</p>	<p>11. S1 did not study business or industrial psychology in college, but this summer employment experience led him to think about leadership and to believe that a leader is a person who other people follow.</p> <p>12. S1 defines a leader as a person who others follow.</p> <p>13. S1 believes that no one can be a leader all the time and a leader always goes places that people want to follow.</p> <p>14. S1 believes that a leader has to be able to articulate a vision of what it will be like when the group gets there and a vision of what a reasonable way should be used to get there, and the reason why getting there is better for the group.</p> <p>15. S1 believes leadership is about the place where the group is going, how the group gets there, and how it benefits the group.</p> <p>16. S1 learned leadership elements from working with the children who were poor and academically unsuccessful.</p> <p>17. S1 recalls many things began after his summer employment experience. S1 started realizing that there are differences between leadership and power.</p> <p>18. S1 believes that some powerful people are not good leaders and some good leaders are not necessary powerful.</p> <p>19. S1 started realizing that he was more interested in leadership than power.</p>
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<p>power over others, such as my staff, I function more as a leader, we work as a team./</p> <p>21. My staff is encouraged to argue with me, to tell me when I am wrong and correct me, come up with their ideas. / 22. I always—I do everything that I can at the university to promote them, I send them out on speaking engagements instead of going myself, and let them develop. / 23. I'll teach them things and they come back and teach me things. We really totally work as a team./ 24. Sometimes I have to make decisions on something. How did I get here?/</p> <p>That was another question I wanted to ask.</p> <p>S1: 25. One of the things that happened with me was that I discovered that my best environment was the public university. That was the environment where I could flourish./ 26. I was a very mediocre high school student. I graduated from high school thinking that I didn't have a potential to go to college./ 27. I got out in the world and found out that I couldn't find a job so eventually I went to college anyway./</p> <p>28. But I flourished in the public university. I really participated in it./ 29. I wasn't just a student; I was a very good student. I made friends with the instructors and staff. It just fit me like a glove./ 30. Eventually you've got to graduate and go out into the world. I wanted to work in the steel mills and I did that for a few years, in personnel work, human relations work. And then I was laid off from the steel industry like everybody else./</p> <p>31. And then I got a job with the State as a Vocational Rehabilitation Center as a Counselor and that went okay./</p> <p>32. I had a good time with that job and I learned a lot but I felt I was on the wrong side of the desk because I felt like it was a power thing and not a leadership thing. I was just spending the people's money on people trying</p>	<p>20. S1 functions more as a leader and as team member, even when he has organizational power over others.</p> <p>21. S1 encourages his subordinates to argue with him, to correct him when he is wrong, and to come up with their own ideas.</p> <p>22. S1 promotes his subordinates at his institution by sending them out on speaking engagements and letting them develop.</p> <p>23. S1 teaches his subordinates and welcomes them to teach him, and he believes that he and his subordinates work as a team.</p> <p>24. S1 has to make decisions sometimes on behalf of his team.</p> <p>25. S1 discovered that his best environment was the public university where he believed he could flourish.</p> <p>26. S1 was academically mediocre in high school and thought he did not have the potential to go to college.</p> <p>27. S1 could not get a job after high school and eventually went to college.</p> <p>28. S1 flourished in, and participated in, the public university he went to.</p> <p>29. S1 academically performed well, and made friends with the instructors and staff.</p> <p>30. After college graduation, S1 worked in human relations work in the steel industry but was laid off after a few years.</p> <p>31. S1 got a counselor position at a state vocational rehabilitation center and the work went okay.</p> <p>32. S1 enjoyed the vocational counselor work, but he felt this job was a power position not a leadership one.</p>
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to get them to get better and get ready for jobs and stuff./ 33. But then at [a college], [a state], a Disability Services Director position came open and I applied for it and I got it over 85 others. I kept that job for, I think, seven years./ 34. And then this job here in [a city] came open and I had always wanted to work at a full-service university with housing, PhD degrees, the whole research one thing going on. I was just at a regional campus there at [a city]. I applied for this job and got it. All along I was really active and I had—I think that's basically my story./

Going back to your story about being a book bindery during your summer employment. It sounds to me that that's the time that you enjoyed learning to be a leader.

S1: Yep.

Who encouraged you to take the leadership? Or is there significant others in your life that support you to take that leadership role? Did someone facilitate your value of leadership in your life?

S1: 35. No. I think that it was never expected of me. I think I found that by accident./ 36. I will tell you that when I was a child—I think I was the first mainstreamed blind child in my school system so I got a lot of attention from a lot of professional in the system. I think that helped a lot—a lot of attention from role-model type people./

37. I was kind of a gentle child for the most part, cooperative. I had my tough times from the sixth grade to the sophomore year of high school like every kid. I think the attention that they spent with me—that they spent on me and the time that they took with me and the care and the coaching that they gave me, undoubtedly helped./ 38. I think when I was young my church experience helped all of that./ 39. I really liked watching professionals.

33. S1 applied for a Disability Services Director position in a small university, was accepted, and held the position for 7 years.

34. S1 later became a Disability Services Director in a large university.

35. S1 recalls no one expected him to become a leader, but he learned leadership by accident.

36. S1 received a lot of attention from professionals in his school system because he was the first blind child in the mainstream classes. S1 also thinks that a lot of attention from those who became role-models for him were helpful to him.

37. Although S1 had tough times from six grade to the sophomore year of high school, he spent time with his role-model type people who coached him.

38. S1 recalls his church experience helped develop his leadership.

39. S1 enjoyed watching professionals.

<p>I don't know where I got my curiosity./</p> <p>40. My mother said that my first complete sentence was a question./ 41. Just the curiosity I had about others and getting a big charge out of seeing people do better. When someone around me succeeds, even if I don't have anything to do with it, if I see people that are successful in what they do, I get a big charge out of that./</p> <p>42. If I get to contribute to their success, I get an even bigger charge. I don't know where that comes from./ 43. I do know that after I had that book bindery experience, then a couple years later, my college got a student-support services programs—we called it special services in those days—they were looking for peer counselors and tutors to work in that program. The director of it happened to be a friend of this person that I reported to in the book bindery and so my name came up that way. He said, "I'd hire this guy anywhere. Take him." I got lucky and got this job doing para-professional work when I was a junior in college./ 44. I stayed with that program all the way through graduate school. That's how it all tied together./</p> <p>45. And then from there, I minored in Industrial Management in graduate school. One of my teachers there knew a lot of industrial people and he got me into the steel mill work./ 46. You get to know people and practice being very nice. That's another one of my principles of leadership; practice being a nice person./ 47. People can't resist nice people. That was one of my mottos. Practice being a very nice person./</p> <p>48. And I found you can get more done that way. I don't try to get people to like me but I just like them. Some people will like me in return./</p> <p>You're saying that being a nice person is a</p>	<p>40. S1's mother said his first complete sentence was a question.</p> <p>41. S1 enjoys seeing people succeed and people who are successful in what they do.</p> <p>42. S1 gets excited when he can contribute to other people's success.</p> <p>43. When S1 was in college, someone recommended him and as a result he got a para-professional job in a student support service program.</p> <p>44. S1 maintained his para-professional work through graduate school.</p> <p>45. S1 studied Industrial Management in graduate school and his instructors got him into the steel mill industry.</p> <p>46. S1's leadership principle is to practice being a nice person.</p> <p>47. S1 believes that people cannot resist nice people and being a very nice person is one of his mottos.</p> <p>48. S1 also believes that being nice can get more things done and he likes people and some people will like him in return.</p>
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<p>key?</p> <p>S1: Oh, most assuredly.</p> <p>The definition of a nice person is...</p> <p>S1: 49. Polite. Attentive. Eager to hear what's on people's minds. Sensitivity to their concerns. Small favors—not big favors but small favors. Being dependable. Being someone that is there who will listen to people and reflect genuine concern and respect for them. Soliciting other people's views without punishing them for that when they express them. Being a little entertaining and engaging in small talk. Being non-judgmental. Not using punishment but using encouragement. I think those are some properties of being a very nice person./ 50. I think it is the easiest thing in the world to do. It's much easier to be a nice person than it is to be a bitter and ugly person. Why some people choose that other path, I have no idea. I tell you, I don't. I don't know what goes into that./</p> <p>Where did you learn those things? Who taught you?</p> <p>S1: I don't know. It was just things that I picked up.</p> <p>Over the years?</p> <p>S1: 51. I just liked people who were like that. When I was young, I knew what old people were cool and who weren't. I wanted to be around the cool ones. Now, I'm old, and young people think I'm cool. I get along just fine with the young people. /When I can't, I will have to retire. I will retire before then./</p> <p>52. You know, it's not about age. It's not about anything but connecting with people.</p> <p>When you think about your years in college—so you went for a bachelor's degree and a master's degree—during those college</p>	<p>49. S1 defines a nice person as being polite, attentive, eager to hear what's on people's minds, sensitive to their concerns, does small favors, is dependable, listens, reflects genuine concern, respect, non-judgmental, and shows encouragement.</p> <p>50. For S1 being a nice person is easier than being a bitter person.</p> <p>51. S1 thinks young people think that he is cool, nice person and he gets along with these people.</p> <p>52. S1 believes connecting with people is important.</p>
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years, were there any relationship experience that influenced your growth as a leader?

S1: 53. I think I got a little bit from everyone. I used to like to go visiting a lot./ 54. At this particular school, [a college] campus, it was not the main campus in [a city]. But at this campus, teaching was—people were hired for their desire to teach. So they wanted people who would be there. When you walked up and down the halls of offices at [a college], teachers were in and doors were open. You could go see people and I did./ 55. I had my regular route between classes or times when I was studying and got tired and needed a break. I just walked around and visited teachers. If the teachers weren't around, I would visit with the secretaries. If the secretaries weren't around, I would visit with the cleaners. (laughing)

I can imagine that.

S1: I don't care. I just engaged with people and learn from everyone. I would see what they were doing and emulate some of that./ 56. By getting a charge out of other people's success, I became successful myself./

I'm going to shift the focus a little bit. Tell me what accomplishment, as a leader, that you are most proud of.

S1: 57. I like straightening out messes. (laughing) I like introducing change in a broad way. I don't like nipping at the edges and making little improvements. I like to come into a job and have it be a total and complete mess and then help everyone around get that mess cleaned up. My promise to my supervisor is that I am not done yet. But before I leave, I want to be sure that I don't leave her a mess. That's my goal in life./ 58. What I'm most proud of is, is the fact that I got to be president of [an organization]./

53. S1 learned connecting with others from everyone and used to like to visit others.
54. At the college campus where S1 was, instructors were accessible for him to visit.

55. S1 engaged with people, learned from these individuals, and emulated some of the actions of these people.

56. S1 learned from other people's success and became successful himself.

57. S1 enjoys introducing change in a broad way, straightening out messes, and helping others. S1 wants to help his supervisor before he leaves his position.

58. S1 is proud of having served as president of a professional organization.

<p>59. During my presidency, I got to reorganize the board and give them a whole different look at what their responsibilities are. I feel like that different look has carried on today./ 60. In fact, I was at a board meeting this [month] because [a person], the president of [an organization], has asked me chair the Committee, it's a new standing committee. The committee chair of these new committees went to do strategic planning with the board—we got to sit in with the board./ 61. What I was able to convince the board when I was president was that their structure was all wrong. It had a Director of Membership, a U.S. Director, and an International Director, Training Director, all these director positions on the board that were defined by job titles. I said, “That’s not how a board ought to be structured. What you guys are doing is being little volunteer professionals. That’s not what a board is for. A board is supposed to be a management, a leadership body. You need to be stripped of all these titles and they all need to be directors at large./</p> <p>62. And then we can organize and figure out what kinds of work that we can do that will help organize and manage the work of our members. We needed to function as leaders who lead the membership in doing the work of an organization, not sitting in our meetings, and then going home and staying up all night and doing it all ourselves.” That worked. That model has held today. That was 10 years ago. I feel like that was a major accomplishment./</p> <p>63. I feel like—I’m so fortunate. I grew up in abject poverty, on welfare, living in a federal housing project, with not much hope of anything in life. To go from that, to the top designated leader of your professional organization and be known internationally—you get to travel to places like [a country] and [a country] and do presentations for [an organization] and get to know people in other parts of the world—to go from where I started to get that far, I felt so privileged to have filled</p>	<p>59. S1 reorganized the organization's board and its responsibilities that have continued still today.</p> <p>60. S1 recently attended the organization's board meeting because he was asked to serve as Chair of a committee.</p> <p>61. S1 convinced the organization's board that its structure was wrong.</p> <p>62. S1 believed leaders are those who lead the membership, not doing everything by themselves. This model was introduced by him ten years ago and the organization had retained this model today. S1 feels this change was his major accomplishment.</p> <p>63. S1 feels fortunate about his opportunity because he grew up in poverty with no much hope in life. As the leader of the organization, he had opportunities to visit foreign countries and to get to know people in other parts of the world.</p>
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<p>that role./</p> <p>Sounds like you did a nice job too, to practice straightening up messes. It seems to me that the organization for that large national organization like [an organization] is a lot of work.</p> <p>S1: It wasn't.</p> <p>Why not?</p> <p>S1: 64. I suppose it was. It didn't feel like it. I don't busy myself with a million tasks. That's not how I work. I try working at high levels. Trying to find the things that we can do that will have a broad effect. I'm not interested in a whole bunch of work. I've never been known to be a laborious kind of leader. I'm not one of these 15- or 18-hours a day, up in the morning—that's not me. I don't work that hard./</p> <p>How did you make this reorganization successful?</p> <p>S1: 65. I went in with a well-prepared plan that I presented to the board about what we were doing wasn't working. People knew things weren't working but they didn't know why. I gave them that explanation; our view of our job with what our responsibilities actually are, are two different things. We need to change our views to meet where our responsibilities really are, which is leadership not work, leadership and government. We really had to lead and govern the association not to do all the work. The director of membership, there shouldn't be a director of membership that's a board member who's responsible for the number of members that you have and again service to those members. That's professional work. Right now we have a director of member services that is that person's job. That's how it should be./</p>	<p>64. S1 does not see himself as a "laborious" leader by doing things by himself. Instead, he tries working at high levels by finding things that can be broadly effective.</p> <p>65. S1 prepared a plan to present to the board. He provided them with an explanation of what was not working when they did not know why. His explanation also pointed out that the board's responsibilities should be leadership and government.</p>
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Sounds like you presented your vision and plan to the board.

S1: 66. Yeah. They agreed to it. I was given a grant for board development by a secret source, that I don't even know—I suspect who it was—I think I know who it was but I wouldn't tell. I got [a person] who used to run [an organization]. I got her to come and facilitate our strategic planning that went on the year after my presidency. I got it initiated. That carried forward to these changes that we have made on the board and they've done a couple of strategic planning sessions since then. That was how we followed up to be sure it was put into place./ 67. The other thing that I am proud of is when I came here 14 years ago, it was just me and an administrative assist and a competent person that was hired as a counselor and that was all we had to run the office. The office was highly dysfunctional. The two people here hated each other. They're subsequently gone and I've been able to build it up now to where we have seven people./ 68. The way I did it, instead of having counselors that are responsible for case loads, I said that I will do all the case load work that I can but any specialization that we have here is going to be specializing in service not in disability./ 69. There's nobody that's working for me that hasn't—there's only one person working for me that has a disability background so we have a person who is in charge of auxiliary aids and services. She is—her background is in Fine Arts. She has a master's degree in Fine Arts and MSW majoring in educational media. What a great idea for an auxiliary aid services person, educational media, right?

Yeah.

S1: Our testing services coordinator is a counselor by training./ 70. We have a woman that I had my eye for years, even when I first met her when she was a graduate student, doing her PhD in Rehabilitation Science. She

66. S1 was given a grant for board development. He also initiated the board's strategic planning with a facilitator. Because of his initiation, a few strategic planning sessions have been conducted since then.

67. S1 is proud of building up his office from two staff to 7 people in the last 14 years.

68. S1 re-organized his office by specializing in service not in disability.

69. S1 has a limited number of staff who have a disability background. Examples include a staff handling auxiliary aids and services has Fine Arts background and MSW in educational media. His testing services coordinator has a counseling background.

70. S1 hired a person as a counselor, whose background is rehabilitation.

<p>has a long background as an occupational therapist and she was doing her PhD work on how students with physical disabilities plan for success in an environment that isn't necessarily accessible. How they respond to the outcome of their plan in terms of whether their plans were successful or unsuccessful to get through all of that to get to a positive finish such as graduation. She learned enough from that that she also talked to people who don't have physical or mental impairments or learning disabilities. I was able to hire her as a counselor./ 71. We have since changed her title to Participation Consultant. She helps people that are really having problems that threaten to cause them to fail or drop out of school; she works with them to formulate plans for success and stay in school./ 72. She has put together the only universal yoga program that we know about in the United States. She got certified as a yoga instructor; she's got four other yoga instructors./ 73. In fact, they just came back from [a state] working with a guy named [a person] who is a paraplegic. He is a Yogi. He teaches yoga to disabled people. We have a program that we call Universal Yoga where our students that we work with that have disabilities and other students who don't—anyone in the world can come and take our Universal Yoga class and they can all interact together./ 74. The motto is "Safe, Welcoming, and Comfortable." We want to make sure that people practice yoga safely but we want to make sure that people who don't have the physical or mental ability to do all of the strenuous tasks of yoga can still benefit from what yoga is in its essence. We did a program two years ago and it is the only—we're the only people in the world doing this. There are other programs that other people saw what we were doing and it is starting to pick up around the country. There a couple other start-up programs. [A person] has totally put that together with my support. It would've never happen without [a person] but that's kind of how I work./ 75. I look—there are sports</p>	<p>71. This counselor, as Participation Consultant, helps students having problems and failing or dropping out of school. She works with these students to formulate a plan for success.</p> <p>72. The participant Consultant is a certified yoga instructor and includes a yoga program for individuals with disabilities.</p> <p>73. S1's institution provides a class called "Universal Yoga."</p> <p>74. This class focuses on being "safe, welcoming, and comfortable." He believes that his institution is the only one that provides such programs that are put together by his staff.</p> <p>75. S1 used sport coaches as a metaphor to</p>
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coaches that will—let's say you get a new football coach, there's two kinds of football coaches; one will say here's the plan I am going to run, here are the plays I am going to run, here's this file of play that this team is going to do under my leadership. If I don't have the people that can do it, I will get rid of them and I will get people who can. There's another kind of coach that says, I'm going to look around and see what I've got, I'm going to see who's good at what and I am going to design plays and design a game strategy built around the talent I've got. That's the kind of coach I am./

I see. If I summarize right, you are the coach who gathers your team member's strengths and utilize those strengths. Am I right on that?

S1: Yeah. Yeah. /76. You give me five people to fill five positions and that's going to be a different place to work at then if you gave me five different people. But either way, they're going to be successful and they're going to meet our obligation to the university in their own way./

Shifting a little bit. You shared told me great stories as a leader. I wonder, though, a leader can be quite challenging depending on the situation. I am assuming you have a couple of challenges or obstacles in the past or even currently. If you have one, would you share it with me? Your experience that you felt was a big challenge for you.

S1: 77. Yeah. I wouldn't give you the first nine years—I wouldn't do over again the first nine years of my employment here in [a city] for anything. I would not do those over again./ 78. I was brought here sort of under false pretenses. I was told that the university knew that it didn't have a good program, that it had neglected the Disabilities Service Program here, which had been a good program for

describe his leadership. He tries to see who is good at what and designs plays and a game strategy build around the talent he has.

76. S1 would utilize different people's talents to meet the department's obligation and be successful.

77. S1 would not want to repeat his experience of the first nine years in his employment.

78. S1 felt that he was hired under false pretenses. The institution told him that it wanted to get the Disability Services program back together like it used to be.

years, in the 70s and 80s. And then it was allowed to languish during the late 80s and 90s. I was told that they wanted to get that back together. But the truth is, while there were people in the community who wanted that, the administration did not want it./ 79. The first thing that they did was put my office under the Health Services Department. I worked for a person that did not understand the work that we do, did not understand me, misrepresented me to the management of the institution./

80. We have a permanent appointment system here where you work for seven years but if you don't get permanent appointment at the end of that seven years you have to leave the university. I lived under the constant threat of not having permanent appointment and they wouldn't tell me what their intentions were. In fact, they managed to delay it for two years beyond that and eventually human resources caught up with them and made them give me permanent appointment./ 81. I lived under constant fear of not getting that against the backdrop of a vice-president who did not want to change, did not want disabled students to succeed here, was a very bigoted kind of person. I had to endure that and put that up against my desire to improve and see people do better./ 82. I had many, many sleepless nights living in fear. I tried to get a better job at a better university a couple different times and I made it to the finalist but I couldn't get those jobs. So I kind of got stuck here./ 83. As soon as I got my permanent appointment, five years ago, everything turned around. They saw that I was here, they couldn't get rid of me, and then they started working with me more and I have been able to get way more done. I am happy. Those first nine years I would not do over again. I regretted every minute of them./

You were in fear for a long time. How did you overcome this feeling of fear at that long?

79. However, the institution located S1 under health services and his administration misrepresented him to the management of the institution.

80. S1 lived under the constant threat of not having permanent appointment and the administrators would not tell him what their intentions were.

81. S1 lived under constant fear because of a vice-president who did not want to change, did not want disabled students to succeed. He had to endure the vice-president and held his desire on hold to improve the services.

82. S1 had many nights that he could not sleep because of the fear. He tried to get a job somewhere else but could not get it and felt stuck in his institution.

83. S1 got his permanent appointment 5 years ago. Since then things changed; people started working with him, which made him happy.

<p>S1: 84. By believing that I could do good work in a bad situation. This is something that goes back to high school. It took me a long time to figure out when I was a kid but I figured out that I couldn't blame what I didn't learn on bad teaching. I stopped caring who my teachers were and whether I thought they were smart enough for me because I was smarter than most of them and I knew it. I stopped caring about all of that. It's not their job to teach me, it's my job to learn. It's my job to find out what they know that I don't and try to learn that. It's my job to get their evaluation of me and help me to learn better. I don't care if I like them or not./</p> <p>85. I don't have to like my boss, I don't have to like my teacher to do a good job. I've stuck with that. I don't have to be in a situation that's perfect for me to do good work. I will strive to do good work./</p> <p>86. I will take my reward—because we have to have rewards—you can't go on in a bad situation, you've got to have rewards. I took my rewards and knowing my intent was good, knowing that I was helping students and that they appreciated it. I took my successes in small places./</p> <p>87. I saw them as great. It was during that time that I became president of [an organization]. Do you know why I ran for the president of [an organization]?/</p>	<p>84. S1 believes in himself that he can do good work in a bad situation. He learned that he could not blame what he did not learn from a bad teacher. He stopped caring who his teachers were. He believes that it's his job to find out what they (teacher/boss) know and what he can try to learn from them.</p> <p>85. S1 believes that his good work comes from himself not from a situation that would be perfect for him to do good work.</p> <p>86. S1 takes rewards and success to strive good work in a bad situation.</p> <p>87. S1 recognized that these successes and rewards were important when he became president of the organization.</p>
<p>No.</p> <p>S1: 88. I figured they couldn't fire their president of [an organization]. I said this university cannot touch me as long as I am involved with [an organization]. I ran for totally selfish reasons. I believed that there were things that I could do to contribute but that's why I did it./</p> <p>So it was win-win situation for [an organization] and for you as well.</p> <p>S1: It was certainly a winning situation for me.</p> <p>These are very empowering stories. It</p>	<p>88. Although S1 decided to become president of a professional organization for a personal reason, he believes that he could contribute to the organization.</p>

<p>sounds to me you are practicing persistence.</p> <p>S1: I would say, sure.</p> <p>Or any other word I should have come up with?</p> <p>S1: 89. No. I think it is that these are not— stories like that are not sad stories, they are just stories about life because these kinds of things that I ran into are things that you run into in life. There are always going to be things that can hold you back but you can't take those as excuses./ 90. Not only persistence but steadfastness. Determination...determination to see something to be better./ 91. I got up in the morning and I came here today to make something better. I take someone into my office to talk to them; I want to be something that made their day better. I don't get to excuse myself because my boss doesn't like me and my boss doesn't think I should be doing what I'm doing. I don't get that excuse./ 92. The person that's come to see me is entitled to more than that. I always think of my responsibilities to the people I serve. That's another concept of leadership that it absolutely vital. Leadership is just another kind of service. It's not about making people do stuff and having the glory of people getting behind you and falling in line, it's is just another form of service. I've been aware of that for a long time./ /93. When I talk to people who I supervise, what I want to know from them is what do I need to do? What do you need me to do so that you can do your job better? You can do it easier? You can do it with comfort, assurance and that there is purpose in all of it. What can I do? /</p> <p>It sounds like serving is an element as a leader for you?</p> <p>S1: Yeah./ 94. To me, that's an essential.</p> <p>I really appreciate you sharing and your</p>	<p>89. S1 believes there are always things that would hold him back in his life. However, he believes that he could not take these as excuses not to be successful.</p> <p>90. S1 believes in persistence, steadfastness, and determination.</p> <p>91. S1 believes his work is to make something better and to make his employees' day better.</p> <p>92. S1 believes his responsibility as a leader is to serve the people, which is absolutely vital. He believes that leadership is another kind of service, not making others work and having the glory of people getting behind him are falling in line.</p> <p>93. S1 wants to know from his employees what he needs to do for them to do their jobs better. He wants to provide his employees with comfort, assurance, and purposes.</p> <p>94. To S1, serving is an essential as a leader.</p>
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wisdom and your story that I can learn from. Thank you very much.

S1: You're most welcome. It was fun. It's not very often that someone calls you up and says, "Talk about yourself for an hour." (laughing) I get to do that.

Level Three (Narrative Based on Emergent Themes)

Andrew recalls three major experiences that led him to his current profession. One was from his childhood. When he was very young, he decided to work to help others to raise their status and improve their lives. He thought about pursuing a career of ministry, however, he later realized that this career was not for him.

During his twenties in college, Andrew noticed that others saw him as a leader. He learned leadership elements from his summer job in college. On this job, he worked with teenagers from low income families and supervised them to conduct book bindery in a school of the town where he grew up. These children were academically unsuccessful. His job was to supervise these children who restored damaged textbooks and to bind other books.

One day Andrew's senior employer told him that the quality of the book bindery that he supervised was unacceptable. Andrew directed the children to work differently and suggested that one of them acted as an inspector for quality control. However, this trial did not improve the quality; his senior employer pointed out the quality was the same as before. After a trial, he intuitively directed the children to work differently and suggested that two of these children act as inspectors for quality control, which improved their work.

Andrew learned from this experience that the children's pride in their work improved their quality of book bindery. The children's pride led them to be successful. This experience also made him believe that he possesses leadership potential. He did not study business or industrial psychology in college, however, this summer experience with the children made him think about leadership. This experience also led him to believe that a leader is a person whom people follow.

Andrew believes leadership is not a quality that the individual possesses, but the individual will be called a leader when people follow him or her. He also believes a leader has to be able to articulate a vision of what it will be like when the group gets there, a vision of what a reasonable way is to get there, and that the reason of getting there is better for the group. In other words, he believes leadership is about the place where the group is going, how the group gets there, and how it benefits the group.

After his summer job in college, he started realizing that there are differences between leadership and power. He observed that some powerful people were not necessarily good leaders and some good leaders were not necessarily powerful. He began being interested in leadership rather than power.

Andrew analyzes himself in that he functions more as a leader and a team member. He encourages his subordinates to argue with him, to correct him when he is wrong, and to come up with their ideas. He promotes his subordinates by sending them out on speaking engagements and by letting them develop themselves. He teaches his subordinates and welcomes them to

teach him. He and his subordinates work as a team. However, he sometimes has to make decisions on behalf of his team.

Over the years, he discovered that he could flourish in a public higher education institution as his best environment. When he was a high school student, his academic performance was mediocre and his teachers thought he would not succeed in college. He tried to get a job after high school but could not obtain a job, which led him to go to college. However, he flourished going to a university because he academically performed well, made friends with instructors and staff, and felt that the university environment was right for him.

After graduation from the university, Andrew had a human-relations job in the steel industry and was laid off after a few years. Later, he obtained a rehabilitation-counselor position at a state vocational rehabilitation center. Although he enjoyed the counselor work, he felt that this job was rather more about power than leadership. He applied for a Disability Services Director position in a small university and held the position for seven years. Later, he became Disability Services Director in a large university.

By looking back on his experience, he feels he learned leadership by accident while no one expected him to become a leader. When he was young, he received a lot of attention from teachers and other professionals because he was the first blind child in the mainstream classes of his school. A lot of attention came from adults who were role models for him. These adults spent time with him and coached him.

Andrew was involved in church when he was growing up. This experience also helped him develop leadership. Particularly, he liked watching successful people so that he learned from them. He enjoys seeing people succeed and observing what these successful people do. He also enjoys when he can contribute to others' success.

During his college years, someone recommended to a college official to hire him as a para-professional employee and he maintained this job through his graduate school. His instructor in college recommended to him to study Industrial Management in graduate school and he pursued it.

His principle on leadership is to practice being a nice person: being polite, attentive, eager to hear what people think, sensitive to others' concerns, doing small favors, and being dependable. He believes that people cannot resist nice people. He likes people in general and practices being a nice person. He believes that being nice can get more things done. He likes other people and some people like him in return. Being nice to others is easier for him than being bitter.

He thinks that young people think he is cool and nice, and he gets along with these people. Connecting with people is important to him. He learned this principle from every person he with whom interacts. As an example, he as a college student used to visit instructors, staff, and anyone on campus. He engaged with people, learned from them, and emulated their success. In other words, he learned other people's success and became successful himself.

Andrew enjoys introducing changes to others in a broad way, straightening out messes, and helping others. He wants to help his supervisor before he leaves his current position.

He is proud of having served as a president of a professional organization. He reorganized its board and its responsibilities, which have continued still today. He is convinced that the way the board was structured was wrong. Leaders are those who lead the membership, not doing everything by themselves. He introduced his view of leadership to the organization ten years ago and organization changed. He feels that this change was a major accomplishment for him.

This accomplishment is significant to Andrew because he grew up in poverty with not much hope in life. As a leader of the organization, he had opportunities to visit foreign countries and to get to know people in other parts of the world.

Andrew does not see himself as a "laborious" leader by doing things alone. Instead, he tries working at high levels, by finding things that can be broadly effective. He implemented this practice at the organization's board meeting. He well-prepared a plan to present to the board. He provided the explanation of what was not working when the board did not know why. The explanation also pointed out that the board should be responsible for leadership and government. He was given a grant for board development. He initiated the board's strategic planning with a facilitator. Because of his initiation, several strategic planning sessions were conducted and this practice carries on since then.

Andrew is also proud of building up his department/office from two staff to seven people in the last fourteen years. He re-organized the office by specializing in service, not in disability categories. Only a few of the staff have a disability background. For example, the auxiliary aids and services staff and the test service coordinator have counseling backgrounds. He recently hired an individual with a rehabilitation counseling background and assigned her to help students formulate a plan for success and stay in school. Her job is called "Participation Consultant" and she is certified as a Yoga instructor and conducts a yoga program for individuals with disabilities. He is proud that his staff put together this program, which is the only one in this country.

Andrew used sport coaches as a metaphor to describe his leadership style. He tries to see who is good at what, and designs plays and a game strategy to build around the talent he has.

He would not want to repeat his experiences in the first nine years in his employment. He felt that he was hired under false pretenses. The institution told him that it wanted to get the Disability Services program back together like it used to be. However, the institution located him under health services and his administration misrepresented him to the management of the school. He lived under the constant threat of not having a permanent appointment and the administrators would not tell him what their intentions were. He had many nights that he could not sleep because of the fear. He tried to get a job somewhere else but could not get it and felt stuck in his institution.

Andrew got his permanent appointment five years ago. Since then things changed; people started working with him, which made him happy. He has believed in himself that he could do good work in a bad situation.

He figured out that he could not blame what he did not learn from bad teaching. He stopped caring whether he liked the teacher or his boss. He believes that it is his job to find what they (teacher/boss) know and what he can try to learn from them.

He believes his good work comes from himself; not from a situation that would be perfect for him to do good work. He takes rewards and success in order to strive for good work in a bad situation. He also saw these successes and rewards as great. He took rewards while he was the president of the organization.

Although Andrew's motivation came from a personal reason to run for the president of the organization, he believed that he could contribute something to benefit the organization. He believes there are always things that would hold him back in his life. However, he believes that he could take these as successes, not excuses. He believes in persistence, steadfastness, and determination.

Andrew's work is to make something better. He also believes that his mission is to make the day of his employees better. His responsibility as a leader is to serve the people, which is

absolutely vital to him. He believes leadership is another kind of service, not making others work and having the glory of people getting behind him and falling in line. He wants to know from his employees what he needs to do for them to do their job better. He wants to provide his employees with comfort, assurance, and purpose. For him, serving is an essential function as a leader.

Appendix E

Data Analysis

Brad: Levels One to Three

Brad (S2), Level One and Two (Spontaneous Meaning Units)

<p>Would you take a moment to reflect on important experiences or relationships in your life that led you to take your leadership role?</p> <p>S2: 1. Some of the things that caused me to move into a leadership role; one was absolute necessity where I didn't have books available to me as a graduate student in Computer Science. The available resource was Recording for the Blind, at that time, in the mid 80s. There was no books. They didn't have materials./</p> <p>2. I started to contact some publishers and asked for the files that drove their printing presses./</p> <p>3. As a graduate student, I wrote software that converted into an e-book. That was the first e-books that were created. I recognized the importance and significance of this and how this helped me with my talking computer and the ability for the book to read it to me. The first piece was major recognition that this was super important./</p> <p>4. I went to the university—to [an organization] serving people with disabilities. They had research programs there. I talked to them about what I did. They were very encouraging, helpful. The Foundation of [an university] was very helpful as well./</p> <p>5. I started to develop that technology in concert with standards. Instead of doing it in a proprietary way, I went to use standards and specifications./ 6. I went to some national—probably international conferences. This was in SGML, which is the predecessor to XML, the first HTML was written in SGML. I went to these meetings and there was immediate recognition in that community of how useful the marked-up text documents could be to</p>	<p>1. When S2 was a graduate student in Computer Science in the mid 80s, the Recording for the Blind [the organization that created audio formats of books for those who are blind and visual impaired] did not have books that he needed. This caused him to move into a leadership role.</p> <p>2. S2 contacted publishers to obtain their electronic files so that he could listen to the information by using his talking computer.</p> <p>3. As a graduate student, S2 developed software that converted electronic files into an e-book. By developing the software and obtaining files from the publishers, he created the first e-book. This experience was "super important" for him because it enabled him to read books.</p> <p>4. S2 approached a University Foundation, which served people with disabilities. He told them that he created e-books and they were encouraging and helpful to him.</p> <p>5. S2 became interested in developing standards and specifications for technology.</p> <p>6. S2 went to national and international conferences, and attended meetings related to SGML [Standard Generalized Markup Language]. He found that the SGML community immediately recognized usefulness of the marked-up text documents that S2 was emphasizing. The community understood the</p>
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people with disabilities. They just understood it. They got it right away were most people don't understand it. They really understood it./

7. Charles Goldfarb came up to me and said—he invented SGML. He is the father of Markup Languages. He said, "For the first time, what I've created is being used for humanitarian purposes," and he thanked me. That was pretty amazing./

8. Another important piece was that another gentleman called, name Yuri Rubinsky. He was the head of the SGML working group at that time. He was a tremendous, dynamic, person who understood the need for accessibility. He published a book in 1992 on Christopher Columbus, 500-year anniversary of Christopher Columbus. It was first available for people who were blind. Later that day, it was published for the sighted community. Pretty amazing stuff. We all did it using the Markup./

9. I can't underemphasize the importance of Yuri Rubinsky in this whole process. He was a terrific leader. He helped us get involved and move forward./

10. Another piece was that living in Missoula and being a blind person, I thought that it was going to be real hard to get a job. So, I created my own job. I started my own company called Computerized Books for the Blind, as a non-profit, and started making books for people. This is still while I was a graduate student and tried to finish up my Computer Science degree./

11. One thing led to another and the company was formed. A huge uptake throughout the world. A lot of intonation, creating a new technology created digital magazines and newsletters and kept people up to date./

12. I had very little funding—had no funding for it. As a non-profit, it was very difficult so money was very hard to come across. There were a few donations coming in from blind people who were getting books. The National Science Foundation really helped and process was a beginning of how e-books are made for math today.

usefulness while most people did not understand it.

7. Charles Goldfarb, who invented SGML and the concept of markup languages, thanked S2 for his efforts in educating others about the usefulness of the mark-up texts for people with disabilities. Goldfarb's recognition to him was an amazing experience.

8. Another important person for S2 is Yuri Rubinsky who promoted SGML. Rubinsky was a tremendous, dynamic person who understood the need for accessibility. Rubinsky published a book that was coded into Braille and reproduced on voice synthesizer, and it became the first accessible book for blind people.

9. S2 cannot underemphasize the importance of Yuri Rubinsky's work. For S2, Rubinsky was a "terrific" leader and helped others start creating accessible electronic books.

10. As a blind person, S2 felt that living in the city of Missoula and obtaining a job would be difficult. He started his own non-profit company called, "Computerized Books for the Blind" and created books for blind people while he studied in a graduate school, trying to complete his computer science degree.

11. When S2 was forming his company, new technology came out to create digital magazines and newsletters, which kept people up to date.

12. S2 had very little funding for his non-profit company. The National Science Foundation provided S2 with \$50000, called "SGER [Small Grants for Exploratory Research]", a high-risk grant. This grant required him to explore how to create e-books for math and science. This process was a beginning of how e-books for math are created throughout the

<p>They provided a \$50,000 SGER grant, it's a high-risk grant. They wanted me to explore how to do math and science with the books I was doing. Actually, that was the beginning of how we—including math in e-books today. It started the focus on Math ML that is being used today throughout the world for accessibility./ 13. The National Science Foundation money went a long, long way in this domain. / 14. I knew I had to build my own company and started with this non-profit. It was very, very difficult to move this forward. In '91, Recording for the Blind recognized the work that I was doing and wanted to merge the computerized books for the blind with recording for the blind./</p> <p>15. Well, I had never received a paycheck yet. It was '91 and we had spent at least \$10,000 of our savings getting this going so I agreed to the merger. July 1, 20 years ago, I got my first paycheck and we did the merger./ 16. The name Computerized Books for the Blind went away and it was just Recording for the Blind. Later, in '96 I think, they added the word "Dyslexic" to their name; Recording for the Blind and Dyslexic. Recently, they changed their name again to Learning Ally./ 17. I'm still employed by Recording for the Blind—by Learning Ally. They've got me subcontracted to the DAISY Consortium./</p> <p>18. Before I go into that aspect, I think the significant piece is that Yuri Rubinsky died unexpectedly and I think he was 43. He was the champion. He was the hero. Intellectually guiding things, strategically moving accessibility into SGML and XML and to the web—the World Wide Web was just forming at that time and he was just a critical piece of that and he died. It shattered me, personally, that he died./</p> <p>19. The other thing that I recognized was that there wasn't anybody else to lead this effort, access to published information. I didn't want the job of being the leader of accessible</p>	<p>world. It is called "Math ML [Mathematical Markup Language]"</p> <p>13. The National Science Foundation money was very helpful to develop Math ML.</p> <p>14. When S2 was having a difficulty starting his non-profit company in 1991, S2 was approached by Recording for the Blind because this organization wanted his assistance to merge the computerized books with recording books, which were created for the blind.</p> <p>15. S2 spent at least \$10000 of his savings to get started assisting Recording for the Blind for before this organization provided him with a paycheck.</p> <p>16. After the merger the organization changed its name to Computer Books for the Blind, but later changed again to Recording for the Blind. The organization recently changed its name to Learning Ally.</p> <p>17. S2 is still employed by Learning Ally, but is subcontracted currently to the DAISY Consortium.</p> <p>18. Yuri Rubinsky unexpected died when he was 43. This sudden death shattered S2 personally because Rubinsky was a hero for S2. Rubinsky intellectually guided others and strategically integrate accessibility into SGML, XML, and the World Wide Web.</p> <p>19. After Rubinsky's death, S2 recognized that no one was leading the effort for accessibility in published information. As a result, S2 decided to carry over Rubinsky's effort for</p>
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publishing but there wasn't anybody else to do it so I had to take it./

Let me clarify this. The person passed away while you were still a grad student or after that?

S2: 20. It was after I had stopped taking graduate courses. I never got my master's degree. I didn't finish—in my mind, I finished the work but not in the university's mind. I thought that all of this work was worthy of a Master's in Computer Science./ 21. There was not a whole lot of interest in the Computer Science Department. In part, I think this is why, many years later in 2007, I was awarded the PhD because of all my work in the field of accessible digital publishing and that recognition./ 22. Way back then, it didn't exist, it wasn't important, nobody was doing it. I was way out in front. When Yuri died, the leadership role he was playing was lost. That's when I started to take over so to speak or continue to promote accessible publishing and the accessible web./

23. The web accessibility initiative was just forming. So I was promoting that. [A person] was elected as—or put in the position of the International Program Office of the Web Accessibility Initiative. She asked me to chair the steering counsel for the Web Accessibility Initiative. I agreed to do that. I've been in that role ever since./ 24. I don't know when I started it but I was the first chair of Web Accessibility Initiative steering counsel. I was one of the authors of the WCAG 1.0 guidelines./

25. In 1997, the DAISY Consortium was forming and they looked for a project manager. They did not have an employee and I had been looking at what was going on at the DAISY Consortium and the kinds of things that were going on at Recording for the Blind with the web, with digital books, and with audio, and

accessible publishing [an approach to design books or information are available in alternative formats] although he did not want to take on this leadership role.

20. S2 took leadership for accessible publishing and stopped taking graduate courses. As a result, he did not receive a Master's degree in Computer Science. However, he thought all of his work in accessible digital publishing was worthy of the degree.

21. Many years later in 2007, S2 was awarded a PhD and was recognized because of his work in the accessible digital publishing.

22. When S2 was a graduate student, nobody saw accessible digital publishing as important. He was "way out in front" of accessible digital publishing. When Rubinsky died, his leadership role was lost. This prompted S2 to take over Rubinsky's role and to continue promoting accessible publishing and accessible web.

23. When the web accessibility was forming, S2 took a leadership role. A person, who held a position of the International Program Office of the Web Accessibility Initiative, asked S2 to chair the steering counsel for the Web Accessibility Initiative. He holds this position currently.

24. S2 was the first chair of the Web Accessibility Initiatives steering counsel and was one of the authors of the WCAG [Web Content Accessibility Guideline]1.0 guidelines.

25. In 1997, the DAISY Consortium was looking for a project manager. S2 researched what was going on at the DAISY Consortium and learned that their focus was audio. S2 focused on navigation and the text. Later, DAISY Consortium focused on putting text and audio together for a comprehensive

the synchronization of text and audio. DAISY was primarily audio in the early days; I was more of a text-oriented person focusing on the navigation and the text. We ended up with this opportunity to merge text and audio to provide a comprehensive reading experience./

26. I checked with my boss at Recording for the Blind and he said that it was okay for me to apply for this position. In a competitive process, I ended up getting the job in '97. At that point, DAISY Consortium has subcontracted me from Recording for the Blind ever since. I still have a foot in Learning Ally but the line share of my time is devoted to the DAISY Consortium./ 27. In '99, this whole e-book effort started and I had a philosophy of follow the content. That's the most important thing when you're talking about access to information; you've got to follow that information. When this e-book started up with Microsoft and Adobe and Intertrust and all these different—I don't think Google existed at that time. We started to participate in it./

28. The NIST, National Institute on Standards and Technology was starting to help drive this forward. Because of government involvement, there was an emphasis on accessibility. Plus I knew a ton about the business and about e-books so I stepped into, pretty much, a leadership role in the newly forming e-book industry./

29. I was one of the founding members and one of the first board members, the first chairman of the board of, what was then, the Open E-Book Forum. That changed its name to the International Digital Publishing Forum 5 or 6 years ago./

30. The bubble burst in the tech sector in 2003. Many of these companies went out of business. The interest in e-books dropped but didn't go away. It hasn't been until the last 3 or 4 years that the whole interest in e-books has exploded./

reading experience for users.

26. After checking with his boss at Recording for the Blind, S2 applied for the project manager position of the DAISY Consortium and got the job in 1997. He still holds this position. Although he still works for Learning Ally, much of his time is devoted to the DAISY Consortium.

27. In 1999, the e-book effort started. S2 had a philosophy of following the content, which is important for access to information. When the e-book started up with Microsoft, Adobe, Intertrust, and other companies, the DAISY Consortium began participating in the e-book effort.

28. S2 was very knowledgeable about e-books and stepped into a leadership role in the newly forming e-book industry when the National Institute on Standards and Technology (NIST) started emphasizing accessibility.

29. S2 was a founding member, board member, and the first chairman of the board of the Open E-book Forum. This forum changed its name to the International Digital Publishing Forum (IDPF) 5 or 6 years ago.

30. In 2003, the tech bubble burst and many technology companies went out of business. However, the interest in e-books did not go away. S2 observed that the strong interest in e-books has exploded in the last 3 or 4 years.

<p>31. Last year, at the end of 2009, there was an election for board members, I was still on the board of the IDPF, and there was an election for president. One person from Adobe was running for president and several people called and said, “We think you should run for president.”/ 32. I said, “Oh, God, just what I need is more things to do.” I saw this as an opportunity to drive accessibility even further into the digital publishing space. I ran for president and then won./ 33. Starting right at the end of 2009, beginning 2010, I was the president of IDPF. It was a non-paid position, just a board volunteer position with that group, the secretary general of the DAISY Consortium and still chair of the steering counsel of the Web Accessibility Initiative./</p> <p>34. Every position myself in terms of accessibility in the line of where is the content coming from; we need to make this content accessible to people with disabilities, and then moving it forward. A couple of times, I have agreed to testify when there were issues surrounding access information. I saw that that was in keeping with my personal mission to make published material accessible and that the laws need to back it up./</p> <p>35. Several times I accepted to be an expert witness in cases that involved access information by people with disabilities./</p> <p>36. I wish there was somebody else that could take all of this over. (laughing) It is a lot of responsibility but honestly there still has been nobody stepping up to take over. That’s one of my concerns and one of the things I would like to do is find a person with a passion and commitment to the mission of accessible information to have them take over./</p> <p>37. There’s other people, of course, who have that passion and commitment and people who are technically far, far, far better than I am. I am not on the cutting edge of understanding all the technologies anymore. Twenty years ago I</p>	<p>31. In 2009, S2 was approached by several people asking him to run for president for IDPF.</p> <p>32. S2 ran for president because he saw this as an opportunity to drive accessibility even further into the digital publishing. He won the election and became president for IDPF.</p> <p>33. In 2010, S2 became the president of IDPF, a non-paid volunteer position. He also continued to be the secretary general of the DAISY Consortium and the chair of the steering counsel of the Web Accessibility Initiative.</p> <p>34. It is important for S2 to ensure making content (information) accessible to people with disabilities. He testified in court when issues regarding access information were addressed. He believes that it is his personal mission to make published material accessible. He also believes that the laws need to support accessible information for all.</p> <p>35. S2 testified as an expert witness in cases that involved access information by people with disabilities.</p> <p>36. S2 wishes that someone else could take some responsibilities from him because he already has lot of responsibilities. He sees nobody as stepping up to take over the responsibility of ensuring that published material are accessible. That is one of his concerns. He wants to find a person with a passion and commitment to the mission of accessible information and have the person to take over S2's responsibility.</p> <p>37. S2 recognizes that his technological skills and knowledge are out of date. He feels fortunate to have a staff that is absolutely committed to accessibility and has the</p>
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was but today I'm not. Fortunately I have people like [a person] who is our [a job title] in the DAISY Consortium who is absolutely committed to accessibility and who has all of the technical understanding. I moved into a role where we are trying to manage, organize, find enough funding for the organization to keep things going./

It sounds like your leadership role started from your feeling of necessity to create accessible books to you. There was a personal reason. Then you met several important people in your life, including Yuri and then you had a personal mission to promote that accessible information. Now, here you are. What helped you to have that strong passion and to take leadership roles?

S2: 38. I remember when I created the first accessible books. It was a book on WordPerfect, Lotus, and Dbase; some of the basic manuals on applications that were being used at that time. Mastering WordPerfect, Mastering Dbase, and Mastering Lotus 1-2-3, from the publisher Sybex. I saw these books and I said, "These are absolutely terrific."/ 39. I was a kid—I call myself a kid at 35 or 36 years old—and I started talking to Recording for the Blind. I said, "Are you guys doing this?" They go, "What are you talking about?" Text files of books. I talked to people very high up and they didn't have any clue of what I was talking about. They actually wrote me a letter saying that they had no interest in doing this. They are not going to do it./

40. I talked to every organization around about this and there was nobody doing it. The Computer Science Department was really not interested in it. There was nobody doing it. At one point, it was over the summer of '88, and was saying, "I should just forget this." This is turning into an obsession with me—making these books, making them better, trying to get more books./ 41. There was no company

necessary technical understanding. S2 moved into a role of managing, organizing, and finding resources for the organization to keep things going.

38. S2 remembers when he created the first accessible books by himself. He thought the creation of these digital books was "absolutely terrific."

39. S2 was young and calls himself "a kid" at the age of 35 or 36 when he approached Recording for the Blind. He talked to his superiors in the organization about creating accessible digital books, however, they had no interest in it.

40. S2 approached various organizations and discovered that no one was creating accessible books. He realized that he needed to start making accessible books, making them better, and trying to get more accessible books. This became his "obsession."

41. S2 thought about stopping his obsession -

formed at that time. I said that I should stop this. This is crazy. I should get my degree, finish, go out and get a job, be a normal guy. I said to myself, the problem is that I am right. I know I am right. I know this is good. I just totally have this belief that this is the right way to go in something that must be developed. Part of it was confidence that I was right. Of course, they say, the road to hell is paved with good intention. I would do it completely differently today if I was doing it. It was still right./

42. Later that summer, Microsoft, who had requests for things like this from other blind people throughout the world, they said, "Can you give me your text book?" There was nobody to get the text files. They didn't want to give these files out to anybody. They wanted an organization to be there that they could turn to and distribute those files through a secure—a normal channel—not necessarily secure but a normal channel. I said, "Well, I will start a company. I mean, I started a company." They said, "What's the name of the company?" I said, "Ahhh...Computerized Books for the Blind." (laughing)/

43. It is funny because there was a phone call [his wife] took a message—she said that it was from a Ms. Dos.—MS Dos. I was trying to find out who the heck in Microsoft called me about this. I finally did get in touch with that person and ended up—I never formally incorporated the company. I just said that's the name, I created some letterhead, and later added the term—Computerized Books for the Blind and Print Disabled. I had put "handicapped" in there for a little bit but I thought that handicapped was an old-fashioned term. So I pretty soon changed it to Print Disabled. Actually, that was the time that Print Disabled was coined. So I started the word "Print Disabled."/ 44. The reason was because I recognized it that there was more than just blind people that could benefit but all the people with dyslexia and learning disabilities

making accessible books- when no one was doing this. He thought it (making accessible books) was crazy. However, he had the confidence that creating accessible books was the right thing to do and that the right way to create accessible books needed to be developed. The path he took was very challenging. However, he still believes that his decision to pursue devoting himself to accessible information was the right one.

42. Microsoft approached S2 because the company was looking for an organization that could help Microsoft distribute text files. S2 told Microsoft that he just started a company, although he has not yet, and that he could help Microsoft distribute the text files. He made up his company's name as he was talking to the person at Microsoft.

43. S2 fondly recalls that one day his wife received a call for him from someone named "Ms. Dos," which turned to be someone from Microsoft (MS Dos). He got in touch with the caller. He created a letterhead, named his company as "Computerized Books for the Blind and Print Disabled." It was at this time that he coined the term "Print Disabled."

44. S2 coined "Print Disabled" because there were more than blind people who could benefit from accessible books. An example includes people with dyslexia and learning disabilities.

<p>that “Blind” was a much too limited. I invented the word “Print Disabled” and started the company./</p> <p>45. I worked under [a university] as a project from [a university] until it was formally incorporated/merged with Recording for the Blind, in '91./</p> <p>It’s bold in my word to contact a large organization like Microsoft and other organizations. Who supported you perhaps by saying, “Go ahead, you have a confidence, you know it’s right. Go for it.” Is there anyone that supported you for that?</p> <p>S2: 46. [A name], who was the head of [an organization], gave me an office at the university. That was it. It was an empty room. I found an old, broken down chair and used it and I scavenged up a desk to put in there. He gave me a phone. I had to really watch it with long-distance phone calls. (Inaudible) foundation and thought that this was a terrific project that could bring funding in. So there was some support from there and some encouragement./</p> <p>Any family members or a mentor to support you?</p> <p>S2: 47. It wasn’t until it got connected with Yuri Rubinsky and the SGML group that I started to see mentors and people who could advise. A lot of it was in the technology itself./</p> <p>48. Things like Zip—everybody knows zip today but it was something that was just getting going and taking the books and zipping them onto a diskette and mailing them out. Trying to find the money to buy diskettes to mail to people and buying unformatted diskettes and having all my children remember sitting there formatting diskettes. I paid them a penny a piece—child labor. How old was[a child], she is 33 now, so she was 12 or 13 years old and putting these things in and reading,</p>	<p>45. S2 worked as a project manager for a university until his project was formally merged with Recording for the Blind in 1991.</p> <p>46. The University provided S2 with an empty room and a phone. He had to find a desk.</p> <p>47. S2 began connecting to his mentors and people through Yuri Rubinsky and SGML group.</p> <p>48. S2 recalls that he used to manually zip the files onto a diskette and mail it out with his children's help. The process was complicated because there was no internet or CD Rom discs back then.</p>
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<p>putting them in and reading. It was very complicated. It wasn't like distributing it on the internet, even CD Rom didn't exist back then./</p> <p>49. Using my own computers to do these and then needing bigger computers to who saw what I was doing and thought it was cool. [A person], [a person] who are still working in the computer science field, understood what I was doing. I hired both of them at one time to work for me and going after really smart people like [a person] and [a person] to work with me and really relying on those people. I was technically really, really, really good./</p> <p>50. Once companies started stuff and I started contacting publishers asking them for files, trying to get permissions, learning about copyright—oh my, God, copyright./ 51. SCC is running today in Geneva, Switzerland, the old copyright exception. I've been involved with those activities in the United Nations. Adhering to copyright law, obeying the laws, doing this appropriately. Learning about all those kinds of things meant I had less time to focus on the real technical details./</p> <p>52. If it is one thing that I miss it's not being as in touch with the technical details of XML and XML Processing as I would like to be. I rely on other people for the heavy lifting in the technical arena right now and figure that my time is best spent in advocacy and fundraising and management and leadership although it would be much more fun to get dirty with the technology and geek out./ 53. I still believe that right now my better role is in advocacy and management, trying to find fundraising and spreading the word./</p> <p>Based on what you said, you have a leadership role, which is a global level. You have more than 20 years of that leadership role or multiple roles. By looking back, pick one or two of your accomplishments that you are most proud of as a leader.</p>	<p>49. S2 used his own computers to create accessible books. His technical skills were very good. However, he hired two smart people to work with him and relied on these people.</p> <p>50. S2 started contacting publishers, asking them for electronic files, and trying to get permission, and learning about copyright. 51. S2 has been involved in copyright exception activities in the United Nations. The more he became involved in copyright law, the less time he had to focus on the real technical details.</p> <p>52. S2 misses the technical details of XML and XML Processing. However, he relies on other people for technical knowhow while he spends his time in advocacy, fundraising, management, and leadership.</p> <p>53. S2 believes he is best suited to the roles of advocacy, management, and fundraising, as well as spreading the word.</p>
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<p>S2: 54. I think what I am most proud of is the harmonization of standards./ 55. It's easy to go out and create something, ignore standards, and build it. This is why it is easy for a company to say, okay, I'm going to build a product and I don't care about anything else. I build it and you don't have to ask anybody else how to do it. They can move forward. When you work with standards, you're working towards a single standard that is going to solve the complex problems not just simple problems but the complex problems./ 56. The first piece was there was this split between the DAISY Consortium and other organizations like Recording for the Blind. I moved into a leadership position with the DAISY Consortium and merged—brought those pieces together, those groups together./</p>	<p>54. S2 is most proud of harmonizing standards. 55. S2 finds it hard but rewarding when harmonizing standards because the standards solve the complex problems.</p>
<p>57. When Library of Congress here in the United States started an activity to build a standard for digital talking books, they were going on a separate standards path. What I did with DAISY was moved the DAISY technical developments under NLS and the National Instructional Standards Organization (NISO)./ 58. Again, instead of—one standard is always better than two; that's a principle./</p>	<p>56. S2 moved into a leadership position and brought two organizations together.</p> <p>57. S2 moved the DAISY Consortium's technical development under the U.S. Library of Congress and the National Instructional Standards Organization (NISO) when the Library of Congress started to build a standard for digital talking books.</p> <p>58. S2 believes that as a matter of principle, one standard is always better than two.</p>
<p>59. First doing DND and DAISY and NLS and NISO and now—so DAISY essentially became the NISO standard and people still call it DAISY World Wide. Now what we're doing is merging DAISY into E-PUB and having a single worldwide standard for digital publishing where the disability and the mainstream community are the same.</p>	<p>59. S2 is now involved in merging DAISY into E-PUB and having a single worldwide standard for digital publishing where the disability community and the mainstream community share the same standard.</p>
<p>60. The converging on single standards that are going to meet everybody's needs, I'd say is my biggest accomplishment and something that I'm most proud of and never bending to the design that would meet all people with disabilities needs./</p>	<p>60. As his biggest accomplishment, S2 is very proud that he created a single standard that would meet all people with disabilities' needs.</p>
<p>61. There's a lot of time so there's pressure to</p>	<p>61. S2 would never accept technology that was</p>

focus only on blind. I never would accept technology developed just for the blind that wouldn't include people with other disabilities. I wouldn't do that. I think that is the biggest accomplishment./

It sounds like your leadership brought other entities together and then work toward an outcome or the missions. It's almost like a merging and then everybody started working together.

S2: 62. The outcomes are very important. The names of the organizations and the standards are less important. The outcomes are what is most important. I could see that the word "DAISY" as E-PUB becomes more rolling off of everybody's tongue. This Christmas when all the e-book devices are (inaudible) DAISY will probably not be mentioned but EPUB will. That preservation of that word "DAISY," which I am very proud of and I have a lot of investment in, is not as important as the outcomes of reaching people with disabilities./

63. Last week, Apple, at their big conference in San Francisco, announced support in the I-Book 1.3 for text audio synchronization. It's on my iPhone right now and it's DAISY. Nowhere in any of the publications or the press does it talk about DAISY. Some people know where all this came from and how it evolved. It doesn't matter who gets credit for it just as long as the outcome is correct./

That's part of your leadership style?

S2: It is. I've said many times that it doesn't matter who gets credit for this as long as it gets done./

64. I've seen several times where I've initiated something, came up with something, designed it, and then somebody else in the group would say, "Well that was my idea," and they take credit for it. That's fine. I don't care. It doesn't

developed just for the blind people. His biggest accomplishment was that he developed technology not only for blind but also for people with other disabilities.

62. For S2 the outcomes are more important than names of the organizations and the standards. He values the outcome of reaching people with disabilities rather than the name recognition. For instance, "EPUB" [electronic publication] will be recognized by many people even though EPUB uses the DAISY Consortium's technical standard, in which he invested in and he is very proud of.

63. For S2 it does not matter who gets credit for making information/technology accessible such as Apple's text audio synchronization as long as the outcome is correct. That is accessible for people with disabilities.

64. S2 has initiated things and designed them, and later someone took credits for it. S2 is happy to give credit to those people as long as it gets done.

<p>matter who gets credit for it. I'm more than happy to give credit to anybody who thinks they invented it./ 65. With the e-book thing, when I talked with Microsoft, I wasn't the only blind person in the world who had thought of this. There are other blind people who are using computers, who are contacting Microsoft, "Could I get this book on disk? Could I get this somehow?" I wasn't the only one who thought of it but I was the one who did it and formed a company. I had a small board here when I formed that company that was very encouraging. That was terrific./</p> <p>(An interruption occurred for the next meeting for S2.)</p> <p>It looks like our time is up. Thank you for sharing those stories and who has facilitated your roles in the leaderships.</p> <p>S2: You're welcome.</p>	<p>65. S2 was not the only blind person, or person with disabilities, contacting Microsoft requesting accessible materials. S2, however was the one to form a company to create electronic files that worked with Microsoft.</p>
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Level Three (Narrative Based on Emergent Themes)

In the mid 1980s, Brad, who is blind was a graduate student in Computer Science. Recording for the Blind, an organization that created recording textbooks for blind and visual impaired, did not have books for his study. As a result, he was not able to read materials that he needed. This experience ultimately became a turning point for him to move into a leadership role.

As a graduate student, Brad developed software that converted electronic files into an electronic book. He contacted publishers to obtain their electronic files so that he could listen to the information by using his talking computer. At that time, he created the first electronic book, which later became known as an "e-book." This experience was extremely important to him because creating e-books enabled him to read books. Also, he saw himself as "way out in front" of accessible digital publishing back then.

Brad remembers when he created the first accessible books by himself. He thought the creation of these digital books were "absolutely terrific." Nobody in his department saw accessible digital publishing as important. At that time he was about 35 or 36 years old and approached Recording for the Blind. He talked to people at higher levels in this organization about creating accessible digital books. However, Recording for the Blind had no interest in digital books.

He approached various organizations and discovered that no one was creating accessible digital books. He realized that he needed to start making accessible digital books, making them better, and trying to acquire additional books. This became his "obsession."

Brad thought about stopping his obsession - making accessible digital books- when no one was doing this. He thought that making accessible books by himself was crazy. However, he had confidence that creating accessible digital books was a right thing and that a proper way to create accessible books needed to be developed. He took a challenging approach. However, he still believes that devoting himself to create accessible information was the right decision for him.

As a blind person, Brad felt that living in the city of Missoula and obtaining a job would be difficult. Thus he thought about becoming self-employed. First he contacted an organization that serves people with disabilities, and a university foundation and told them that he created e-books. He received some support and encouragement from both organizations. One provided him with an empty room and a phone, though he had to find a desk. Then he started his own non-profit organization and created books for blind people while he was trying to complete his graduate degree.

He fondly recalls an incident before he established his organization. One day his wife received a call for him from someone named "Ms. Dos," which turned out to be someone from Microsoft (MS Dos). He got in touch with the caller. Microsoft approached him because the company wanted an organization to help Microsoft respond the requests for text files and distribute those files to the requesters. He told Microsoft that he just started a company, although he has not started yet, and that he could help Microsoft distribute the text files. He made up his company's name as he was talking to the person at Microsoft. He created a letterhead and named his company. It was at this time that he coined the term "Print Disabled." He believed that not only blind people could benefit from accessible books. An example includes people with dyslexia and other learning disabilities.

Brad recalls that he used to manually zip the files onto a diskette and mail it out, using help from his children. This process was complicated because there was no Internet or CD Rom back then. He used his own computers to create accessible digital books and his technical skills were very good. However, he hired two smart people to work with him and relied on these people for digital books production as well.

As he was establishing his organization, new technology came out to create digital magazines and newsletters. He had very little funding for his organization. As a result, he applied for a grant from the National Science Foundation (NSF). He received a high-risk grant of \$50000 from NSF, called "Small Grants for Exploratory Research (SGER)." This grant required him to explore how to create e-books for math and science. This exploration was a beginning of Mathematical Markup Language (Math ML)--how e-books for math are created now. SGER was very helpful for him to develop Math ML.

Brad started leading the effort of accessible publishing and stopped his graduate studies. Consequently, he did not receive a Master's degree in Computer Science. However, he thought all of his work in accessible digital publishing was worthy of the degree. In 2007, many years later, he was awarded a PhD and was recognized because of his work in the accessible digital publishing.

In 1991, he was struggling with running his organization. He was approached by Recording for the Blind and was asked to help Recording for the Blind merge recording books with the computerized books. He agreed to take on this request. He spent at least \$10000 of his savings to start assisting Recording for the Blind for its merger even before RFB provided a paycheck for him. Shortly after, Recording for the Blind changed its name to Computer Books for the Blind but this name did not last. Recording for the Blind changed its name a few times and he continues to be employed by this organization.

While Brad was operating his organization, he became interested in developing standards and specifications for technology. He went to national and international conferences, attended meetings related to Standard Generalized Markup Language (SGML). The SGML community immediately recognized the usefulness of the marked-up text documents that he was emphasizing and talking about. This community understood the usefulness of the marked-up text while most people, whom he talked to, did not understand it. He began connecting his mentors through the SGML group, who were influential in his career.

A major figure in SGML thanked him because he educated others that the mark-up texts were useful to people with disabilities. This person's acknowledgement was an amazing experience for him.

Another leader and mentor in the field was a tremendous, dynamic person who understood the need for accessibility. This person published a book that was coded into Braille and reproduced on voice synthesizer, and it became the first accessible book for blind people. He cannot underemphasize the importance of this mentor's work. For him, this person was a terrific leader and helped others start creating accessible electronic books. This person intellectually guided others and strategically integrate accessibility into SGML, XML, and World Wide Web.

Brad's mentor unexpectedly died when he was in his early 40s. This sudden death shattered him personally because he was the hero for him. After the death, he realized that no one was leading the effort for accessibility in published information. As a result, he decided to take over his mentor's role and to continue promoting accessible publishing and accessible Internet.

When the web accessibility was forming, he took another leadership role. A leader in the International Program Office of the Web Accessibility Initiative asked him to chair the steering counsel for the Web Accessibility Initiative. He has been holding this position still now. He was the first chair of Web Accessibility Initiative's steering counsel and was one of the authors of the Web Content Accessibility Guideline (WCAG) 1.0 guidelines.

The DAISY Consortium was looking for a project manager. He researched what the DAISY Consortium was doing and learned that they were focusing on audio while he focused on the navigation and the text. He applied for the project manager position and was offered this position in 1997. Later, the DAISY Consortium started focusing on putting text and audio together for a comprehensive reading experience for users. Brad still holds this position.

In 1999, the e-book effort started. The National Institute on Standards and Technology (NIST) started emphasizing on accessibility. He believed that following content was crucial for information accessibility. When Microsoft, Adobe, Intertrust, and other companies started the e-books, the DAISY Consortium began participating in this e-book effort. Because he was very knowledgeable about e-books, he stepped into a leadership role in the newly forming e-book industry. He became a founding member, board member, and the first chairman of the Board of the Open E-book Forum. This forum changed its name to the International Digital Publishing Forum (IDPF) 5 or 6 years ago.

In 2003, many of technology companies went out of business. However, the interest in e-books did not go away. He observed that the strong interest in e-books has exploded in the last 3 or 4 years.

In 2009, Brad was approached by several people and encouraged to run for president for IDPF. He saw this as an opportunity to drive accessibility even further into the digital publishing. He was elected and became president for IDPF, an unpaid volunteer position. He also continued

to be the secretary general of the DAISY Consortium and the chair of the steering counsel of the Web Accessibility Initiative.

It is crucial for him to ensure making content accessible for people with disabilities. He testified as an expert witness in court when cases addressed accessible information for people with disabilities. He believes that it is his personal mission to make published material accessible. He also believes that the laws need to support for ensuring accessible information.

Brad wishes that someone else could take some responsibility from him. He sees nobody is stepping up to take over the responsibility of making accessible published material. That is one of his concerns. He wants to find a person with a passion and commitment to the mission of accessible information and have the person to take over his responsibility.

He acknowledges that other people possess more of the latest technological skills and knowledge than he does. He feels fortunate to have his staff that is absolutely committed to accessibility and has technical understanding. By having others to do technical tasks, he moved himself into a role of managing, organizing, and finding resources for the organization to keep things going.

When he learned about copyright as he contacted publishers, he asked them for electronic files and tried to get permission. He has been involved in copyright exception activities in the United Nation. The more he became involved in the copyright law, the less time he had to focus on the real technical details.

He misses the technical details of XML and XML Processing. However, he relies on other people for the technical aspects while he devotes his time in advocacy, fundraising, management, and leadership. He believes that he does better job in advocacy, management, and fundraising, and spreading the word about accessibility.

Brad is most proud that he has harmonized standards. For instance, he moved into a leadership position and brought two organizations together when these two organizations used different standards. He moved the DAISY Consortium's technical development under the U.S. Library of Congress and the National Instructional Standards Organization (NISO) when the Library of Congress started building a standard for digital talking books.

As another example, he is involved in merging DAISY into E-PUB and having a single worldwide standard for digital publishing so that the disability community and the mainstream community share the same standard. He finds harmonizing standards to be difficult but rewarding because the standards solve the complex problems. It is his principle that one standard is always better than two.

As Brad's biggest accomplishment, he created the single standard that would meet all people with disabilities' needs and never bending to the design. He would never accept technology that was developed just for the blind people. He is very proud that he developed technology not only for blind but also for people with other disabilities.

Outcomes are more important for him than names of the organizations and the standards. He values the outcome of reaching people with disabilities rather than name recognition. For instance, "EPUB" [electronic publication] is be recognized by many people even though EPUB uses the DAISY Consortium's technical standard, in which he invested in and he is very proud of.

He has initiated and designed things, and later someone took credits for them. For him it does not matter who gets credit for making information and technology accessible. An example is Apple's text audio synchronization. He is happy to give a credit to those people as long as things get done and the outcome is correct - ensuring information accessible for people with disabilities.

Appendix F

Data Analysis

Colleen: Levels One to Three

Colleen (S3), Level One and Two (Spontaneous Meaning Units)

Please take a moment and reflect your important experiences or relationships in your life that led you to take a leadership role.

S3: 1. Well you know, I have had a lot of different leadership roles but that is a really huge question. I mean, that is really general because I don't that people just wake up one day they have, like you are aware of, people don't just all of a sudden have leadership role. I mean, I have been having a leadership role since I was a little kid.

Would you tell me more about when you were little and then you took a leadership role?

S3: Well, (long silence) like I think I was the President of my 4H Club when I was a kid or what else did I do? You know, I was on the Student Council when I was in Junior High or things like that./ 2. I think having—I mean anybody who is a leader, your parents are going to play a role because they are going to help you with, hopefully—well not everybody's parents—I would say my parents—you know they tried to instill confidence in me to go—they encouraged me to try different things, to be a leader./ 3. I think that I had that experience probably in school to different teachers or that kind of thing where they encouraged me towards being a leader./

Would you tell me a little bit more about what you did in 4H Club where you said that the parent encouraged you to take a leadership but particularly your parents....

S3: I really don't know what to say, I guess, I mean it was just a 4H meeting and I was elected for President and I ran and I was elected, I guess. (silence)

1. S3 has had a lot of different leadership roles. She started being a leader when she was a child. She served as the President of her 4H Club and she later served on the Student Council when she was in junior high school.

2. S3 personally believes that parents play a role to help their children with becoming leaders. Her parents tried to instill confidence in her and encouraged her to try different things to become a leader.

3. Not only S3's parents but also her teachers encouraged her to be a leader.

You also took a leadership in the Student Council. And what year are you?

S3: Um, I really don't remember—maybe 8th grade or something like that. Yeah, maybe 8th grade. (silence)

I see. What other leadership experiences did you take when you were growing up including like your college years?

S3: 4. Oh college years. Okay that's a little easier. I would say well—when I was in college I was a sophomore I was in Student Government. I was elected to the Student Government for that. I was an RA in college for a couple years. Do you know what an RA is?

Yes.

S3: Okay. I was an RA for a couple of years in college and so those are a couple of leadership roles.

I see. When you were in Student Government or being an RA, which is having to deal with some student issues in the dormitories. Can you tell me particularly, what types of things you learned and perhaps you could say, "Yeah, I'm still using the skills as a leader now."

S3: (Long silence) This is hard. (long silence) What kind of skills did I learn—I mean, just so broad you could be so abrupt on it, it's kind of like—because I am sorry I—maybe I shouldn't be doing this right now, I feel like I'm being kind of abrupt with you and I don't mean to be but—

No, no.

S3: It's just hugely broad./ 5. Any leader whether they have a disability or not, would be able to tell you they learn all kinds of things

4. S3 served as a Residence Assistant (RA) in college for a couple years and served in student government when she was a sophomore in college.

5. S3 believes that leaders, with or without disability, learn a wide variety of things from being a leader (learn from their experience).

<p>being a leader./</p> <p>6. Like, as an RA you learn how to delegate authority, you learn how to set boundaries, you learn how to have resilience, you learn how to play to your strengths, you learn how to handle it when people don't approve of decisions that you make, you learn how to support other leaders on a team, you learn how to manage your time. Is that the kind of stuff you're talking about?</p> <p>Yes, definitely.</p> <p>S3: I know but it's just so general that I feel like I'm not—I mean there's nothing unique about that though—it's pretty just standard leadership stuff. I mean it's—yeah so, those kinds of things.</p> <p>I see. Those things like delegating, boundaries, and being a team, managing time, those kinds of things that you just mentioned—I'm assuming that those are important to you to be a leader now.</p> <p>S3: Oh, of course they are and that's why I mentioned them because that was your question. Yep.</p> <p>Is there anyone or any relationship who encouraged you to take on those leaderships when you were in college?</p> <p>S3: Let me think about it. Well, yeah I think probably a Resident Director probably did or—I don't really remember or that one I guess. I can't—one person doesn't come to mind. I think I had some mentors and leaders and things like that but—</p> <p>Tell me more about your mentor.</p> <p>S3: 7. Well, there was a mentor who was—she was [a position] and then later she became [a position] at the institution and she is someone</p>	<p>6. S3 learned how to delegate authority, set boundaries, have resilience, play to her strengths, manage her time, support other leaders on a team, and handle the issue when people don't approve of decision she has made. She believes that these are so general and nothing unique about being a leader with a disability.</p> <p>7. S3 had a mentor, who became an administrator at a college. S3 observed this mentor as a good leader. This experience made</p>
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that I felt like she was a really good leader. I saw her working in a college setting and I thought maybe I could do that as well./

She was a good model to you.

S3: Good moral?

I am sorry. We are having a communication problem. I said she was a good example.

S3: I don't think I understand what you are getting at?

Okay. I said that your mentor demonstrated a good example.

S3: Yeah, yeah, she was a good example.

Would you share with me what other leadership roles you took after you graduated from college with a bachelor degree?

S3: 8. Well, I was in [a position] for a couple of years so I was [a position] and I worked alongside another [position] so I did that for a couple years. // Then I went and got my Master's in counseling and then I worked as the Coordinator for [an organization] in [a state]. // Then I was a Disability Specialist at [a university] for several years. Then I became the Director of Disability Services at [a university] and I worked there for over 10 years./

During those years with those leadership roles, what are some challenges or obstacles that you experienced?

S3: Let me think about that. Are you thinking of obstacles specific to disability or just any obstacles?

Any obstacles, yes.

S3 think that she could follow this mentor's path and could work in a college setting.

8. After she obtained a bachelor's degree, S3 worked for a couple years. Later she went to a graduate school and received her Master's in counseling, worked as the Coordinator for an organization. After that, S3 became a Disability Specialist and later held a Disability services Director position for over 10 years.

<p>S3: 9. I would say—what obstacles did I experience? That is such a good question because I feel like I am experiencing a whole bunch of obstacles right now./ 10. When I agreed to do this, I didn't know I would be. Let's see, what would it be, like—maybe it's funny because usually people have believed in me in some way except, but still obstacles would be sometimes not having the tools and the resources that I need./</p> <p>11. And I guess I am thinking specifically about disability, but I think it's true for people without disabilities too, but—not having the resources that I need, or getting into a situation and thinking that it might turn out—thinking that it looks like it would be one thing but it ended up being something else and then kind of having to “regroup”. If that makes sense? Let me give you an example. Is that what you were going to ask?</p> <p>Yes.</p> <p>S3:12. Like, maybe that's a too general way to put it—but sometimes interpersonal things can be a barrier. Like when I first worked in [a position]—maybe I won't have you use my name. Anyway, when I first worked in [a position], I ended up working with someone who was really challenging to work with. We just saw things very differently and in a lot of ways it was good working with him, but he was someone that a lot of people would find him hard to work with, I don't think it was just me. It was kind of like, “Is the opportunity worth the headache?"/ 13. Which is kind of the situation I'm in right now too in a certain way. It's kind of like—it sounds like a really negative way to put it—but it's kind of like, “Is the advantage and the opportunity that this leadership opportunity provides worth dealing with the obstacles that are involved?” So I think that's really big./</p> <p>14. I'm trying to think—like I remember the</p>	<p>9. S3 feels that she is currently experiencing obstacles as a leader.</p> <p>10. S3 is currently experiencing something different by taking a new leadership position. She sees that people believe in her. However, she experiences obstacles because she sometimes does not have the tools and resources that she needs.</p> <p>11. Whether the person has a disability or not, S3 believes that it's challenging for people not to have resources they need to succeed. By changing a job, she is having unexpected situations and dealing with adjustment by "regrouping" herself.</p> <p>12. S3 believes that interpersonal issues can be a barrier. In the past, she ended up working with someone who was really challenging. This individual had different views of things and other people found him hard to work with. She wondered, "is the opportunity worth the headache?"</p> <p>13. S3 is currently in a difficult situation at work with a new interpersonal issue. She wonders whether this difficult situation could be the opportunity for her to grow.</p> <p>14. During a summer in her college, she did an</p>
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summer that I was in college between my Junior and Senior year, I did an internship because of my undergraduate degree and so I did an internship, and I stayed with [a person] and his wife that summer. Well it turns out once I got there for a couple days I found out that he wasn't very happy in his work and things weren't going very well and his daughter had ended up getting pregnant out-of-wedlock. I didn't find out any of this stuff until I was there. So their marriage was—he and his wife were struggling in their marriage and stuff like that. So that was really something—to kind of move into that. I think my own—sometimes a barrier for me is that I—I think our biggest obstacles are personal ones./ 15. It's kind of like—sometimes I think it's easy to think of a situation as like this situation shouldn't be the way it is. You know, you can think that way a lot and then it doesn't help you be creative to get out of it. There are those kinds of barriers—/

So, if you don't mind—

S3: Go ahead, I knew you were going to ask me about that one—I would if I were you—

You said that one of the challenging things are personal relationships—

S3: 16. I think that personal attitudes and motivations—/

Personal attitudes...

S3: 17. Personal attitudes. I am in a situation right now where I am frustrated because right before I took my position they decided that they were going to discontinue [a position] and so now I am working by myself. So what happened is—and this is why I am a little off-kilter today is because what happened is they told me when they hired me—I mean I agreed to it because it was already decided, and I thought, “Well I can figure this out and I'll

internship and stayed with a person and his wife. She discovered that he was unhappy with his work and his marriage and having family issues, which negatively affected her internship experience. Other people's personal issues became a barrier for her.

15. Although S3 tries to think differently to manage difficult situations, some situations are difficult to be creative to get out of.

16. S3 thinks others' personal attitudes and motivations are her current challenge as a leader.

17. S3 is frustrated that her institution decided to discontinue the assistant position immediately before she started working as a director. As a result, she is working by herself in her department. Because of this situation, she feels that she is not balanced during this interview.

change this changed over time and this or that.”/ 18. Well another thing they did is they hired a student worker to help me out like doing a reading or different things like that and they knew I would rather hire my own but they wanted to make somewhat sure that someone was there when I got there./ 19. But the thing is he is really bad. I think he is probably the worst work-study person I have ever had./

Oh no.

S3: 20. And I am brand new there and the problem is that he is really—he is just, I mean I hate to say it, but—so I talked to him the other day because I thought, “I have to get to know this guy better and know his deal.”/ 21. He just doesn’t follow through. I know this is getting really specific, but I think it relates to the other things, you know what I mean. So he doesn’t—I could say to him, “I want you to do these four things” in the two hours that he has and he might do one or two of them and then not get the other things done but not tell me why he didn’t get them done. And they are things that he should be able to get done./

22. Like today, I asked him to—we have all these students that use alternate text. You know what that is, right?

Yes.

S3: I said, “Look at this whole big list of all our students and there’s ones that have little “a’s” that use alternate text and I want you to make a separate document for me that shows—that just lists the students who use alternate text. So I don’t have to go through and find each one. You know what I mean? Well, he did except—and you know this sounds really picky but—so he made the document and he emailed it to me but it didn’t even have a title on it—you just open the open the document and it’s just got the names. That’s really small, okay. It’s just that everything that we do, he like-he

18. S3 does not appreciate that her institution hired a student worker for her rather than allowing her to hire someone that suits her.

19. S3 believes that this student is the worst student employee that she has ever had.

20. Because S3 is brand new to her institution, she feels obligated to deal with this unqualified student employee, instead of firing him.

21. S3 is frustrated that this student worker does not follow through and does not get things done.

22. S3 thinks that this student worker does not follow directions, does not complete tasks, and is unmotivated.

went over to another college and learned how to scan the other day because he was scanning. Their coordinator did training with him and all this and he came back so I had him do a practice document for me to see how he would do it but this guy is an English major. He scanned it and he didn't spell check it or anything and it there were problems and it could be he could say, "Well I didn't know I was supposed to do that." But the thing is, he did know because they went over that stuff with him. I think that he is just not very motivated./ 23. So here is how it all relates to leadership, okay. How it relates is, I know in this position, where I would love to fire this person except that he hasn't really done anything worthy of firing./ 24. Because you know that if you want to fire someone, you have to really tell them exactly what you expect and they have to really not do it. You can't just fire someone for making these kind of mistakes because he just makes a different one each time./

25. The problem is the person who hired him is [a position] and I don't think [a person] even really even interviewed him. What I heard through the grapevine is that he is some relative of his or she knows his parents or something stupid like that. So now when I need someone more than you would believe, I'm in this situation, and I have to figure out, do I tell [a supervisor] this—do you know what I mean? Like what do I do?/ 26. And this guy that I talked to the other day and I said, "Tell me about some of your other work experience?" And he said to me, this guy is [an age], he was [a year of a college] last year, he said he has never had a paid job in his life before and his mom would not let him work in high school because his grades were too poor.

Oh no.

S3: (Laughing) Here's my deal. What could get in the way for me as a leader is me is how

23. As a leader, S3 wishes to fire this unmotivated student worker but she cannot find strong reasons for terminating him.

24. Firing someone is not easy. As an administrator, S3 feels obligated to tell her employees exactly what she expects and the employees do not do it at all before she decides to fire them.

25. The way this student employee was hired is problematic to S3. A person hired him through a personal connection. He was hired without an interview. S3 wonders whether she should report this to her supervisor.

26. S3 realized that this student never had a paid job in his life, and his grades were poor. She needs to rely on this student employee as her tool but she cannot. S3's co-worker even told S3 that she would not hire this student. Being stuck with working with this unqualified student employee is bugging her.

am I going to approach this? Right now, I am feeling very frustrated about it. I know it is very small because I know he is only going to be working for me during the summer anyway and then he will be done. But, it is really bugging me—

Because that is your tool.

S3: It's my tool. And I don't like it and I want to tell [a supervisor], "Have him work for you! And we'll see how you like it!" And even [a position] —because I report to the Office—she even said, "Well, I wouldn't have hired him. I wouldn't want him working in my office."/ 27. And I've talked to her—so I left her a message this afternoon and just said, "I'm wondering if we could do some creative problem solving and if we might talk about this soon because I'm continuing to find that I don't know he's a really good fit." Or maybe I just need to deal with it./ 28. Because the thing is if can't really manage him, then it makes me look bad, in a way. So I'm giving all of this a good example of 1) giving him the right tools, 2) me giving—because I'm already feeling double-minded about this decision that I made about this decision to move in my job./ 29. I'm doing better this week than the last two weeks, so this could really get in the way for me as a leader—not so much just this specific student worker but that I really want an assistant like I had before./ 30. When I took this job and I don't have that and now I'm kind of regretting that I made the decision a little bit. I know this is not what you wanted to hear probably in your interview, but it kind of—I think how I lead is going to be how do I manage this situation?/

Right.

S3: Does that make any sense?

Yes it does. You have been in that position for only two weeks. It doesn't seem to be a pleasant way to start with the new position.

27. S3 has decided to consult with her supervisor about this student worker. She left a phone message. However, at the same time, she wonders if she should just deal with this issue alone.

28. If S3 cannot manage this student worker, it would make her look bad. She has been giving this student worker the right tools. At the same time, she is feeling "double-minded" about her decision to take her current job.

29. S3 really wants a capable assistant like she had previously.

30. S3 is regretting her decision to accept her current position because she does not have the right administrative assistant. The student worker is not a good fit, is not focused on what he is doing, and is not adjusted; he does not have the right skills for his duties.

S3: I know it. I was like, “This is crazy you guys.” But see, they thought—I mean, to me you’d think—and the thing is you can’t tell him—well I can’t fire him—what I would say is he is not a good fit. Because he is just not focused on what he is doing, he is not adjusted. He doesn’t have the right skills to be—you know it’s just really stupid things./ 31. Like this afternoon I said, “So you’re going to do these things. I have to leave a little early at 3:15 because I’m in a meeting or whatever.” He’s like, “Well I have a doctor’s appointment at 3:30 and I need to go.” Which is fine except he should have told me before—which is fine, but he also told me he was going to be gone for 3 days on the second day and I’m just like—it’s just common sense that he doesn’t have and I am supposed to trust him with really personal and—trust him with this stuff and so I am struggling with it. Anyway, that’s kind of a side note. That I am kind of like—so how I manage this and how I am perceived as a leader/ 32. Here is another thing. You asked about obstacles, is the whole idea of what level of priority or how much weight do you give others perceptions? I think that really affects whether you are a good leader./ 33. Like am I a better leader if I just say, “You know what, this is not working you guys and I am really sorry. I know that you gave this guy the job for the summer, but the assistant told me that she didn’t even interview him.” So, I mean it’s kind of her fault. But, anyway—so, that’s an example.

That’s a good example.

S3: It’s like okay, so I am being straight with her, no maybe a better leader for me would be that maybe I can really whip this guy into shape, not literally whip him, you know what I mean, but maybe I can really teach him a whole bunch and then he will be a better student leader for someone else. But I am having to pay such a high price to do that./

31. S3 struggles with managing this student worker and wonders how she is perceived as a leader as she handles this difficult situation. She is having difficulty trusting him because he is not reliable.

32. S3 believes that good leaders know what level of priority they have to take and how much weight to give others perceptions.

33. S3 struggles with balancing how much weight she should give her opinions or perceptions versus those of her colleagues. She also struggles with prioritizing the potential value of training this student worker for his future because she has to pay a high price to train him.

Right.

S3: 34. And that is what is so unfair to me is that, yeah I love students, I can help them develop, but I already have enough stuff I am trying to learn right now without having to do that. Why would you possibly hire someone whose has never even had a job? Even when they were in high school the only thing he ever did was he said he babysat a couple of times. This guy has never had a boss before.

It seems to me that you are unfortunately given an unqualified or under-qualified auxiliary aid.

S3: Yes. And he even said—I asked him about his strengths and weaknesses and he said that disorganization was one of his weaknesses. And that is one of things we have to do right now is get this office organized./ 35. So I think a leader—when I was saying that do not know which of your questions it fits under, but a leader is someone who has to be able to take the situation like I’m in and figure out is it better to try and work with the tool that’s there or to say, “You know what this ridiculous and stressing me out.”/ 36. Now to be fair, these people are letting me have an hour with their administrative assistant like 4 days a week. She is going to do some stuff for me. So probably I can make it through and I can just forget about this whole thing with the student leader./ /There are some things I could get him to do that don’t require a whole lot of—like he’s making brown labels on files—okay he’s able to do that. You know what I mean, so maybe I just need to let it go and just work through it and not make a big deal out of it because if I make a big deal out of it then we have to find someone else and I have to interview them and then this guy is out of a job and—anyway. So what other questions do you have?

It sounds like you want to move to a little more positive side.

34. S3 enjoys working with students. It is important for her to help students' development. However, she feels that she has enough things to do as she just started her new job.

35. For S3, a leader has to be able to take the difficult situations, like she is in now, and has to figure things out with the tools available.

36. S3 now feels that she needs to let it go by having this student worker to do a simple job while she utilizes an administrative assistant's help to operate her department.

S3: 37. What would make me really happy is if I could have him become a better student worker. Because then it would be like I am really helping him develop. So that would be a leadership—because you were asking about the barriers and I was saying not having the right tools or the inter-personal challenges, I think that can be there sometimes. I think those are big ones./

When you had inter-personal challenges in the past, how did you overcome those?

S3: 38. Well, I think it really depended on—it's not that I've had a lot of them, but I'm just giving you as an example—in one of the leadership positions, I think we realized after we worked together for two years, that we just weren't really super compatible. We liked each other as friends, but didn't work well together./

39. I think in that situation and in other times, just communication. It's ongoing communication./ 40. And I think not having the right tools like—getting back to that like right now in this job they use a program called [a name] for their email and calendaring and everything and it's way less accessible than Outlook. So it takes maybe three or four keystrokes to do what would have taken one in Outlook./

Oh wow.

S3: For someone who is using reading software, so it's one of those things. So that can be a barrier sometimes if you don't have the right tools./

41. But then I think getting back to what you talked about before like the people that influence—like in this position right now, one of the people that influenced me was the Executive Director of [an organization]. I mean, because you know because I have been on the Board of [an organization] the last several years, that's been a leadership position.

37. For S3 leadership requires helping others develop, having the right tools and the inner-personal strengths. She would be happy if she could help this student worker to develop and become a better student worker.

38. S3 had an experience that she and her colleague did not work together because they were not compatible, although they got along well as friends.

39. To overcome personal challenges, S3 believes that communication is important.

40. Regarding communication, it is important for S3 to have the right tools. Currently, she is having communication difficulties because her institution's e-mail and calendar systems are hard to use with the screen reader that she uses.

41. S3 has been serving on the board for an organization for the last several years. During these years, the Executive Director of an organization positively influenced her. She also had a mentor who encouraged her apply for a board member position to serve as a leader.

And there I had a mentor that really—[a person], he really encouraged me to run for that. That’s who I should talk to about this actually that we are talking about. Do you know him?

Yes.

S3: I wonder what he would do?

You mean how to handle this Under-qualified Auxiliary Aid?

S3: Yes, the Under-qualified auxiliary aid. I love how you put that. (Laughing).

S3: See part of the issue is that part of this person’s job isn’t really an auxiliary aid because the sighted director would probably get a work study person too, so it’s kind of a merge thing.

I see.

S3: That’s interesting. Under-qualified auxiliary aid. That’s going to be my new title, “UAA”. That is great. I love it. What other questions do you have for me?

Okay. This is my last question. Thinking about your leadership roles including being part of a board member, tell me what accomplishments as a leader are you most proud of? I know it’s a very big question, but—

S3: 42. But it’s a good one because I have been thinking about it. I think leaving [a university], because I was the first Director of Disability Services that [a university] had and I feel like I’ve been able to change—really have an impact on the culture and beliefs about disability in the organization. I know I have because they changed the job description from when I first came, even after I left and they want their new Director to affect the campus

42. At her previous institution, S3 made an impact on the culture change and beliefs about disability. She enjoyed it. As a proof, this institution has changed the job description of Disability Services Director, which she held prior to her current job, in a way that this position affects the campus culture and the campus.

culture and the campus—you know (inaudible) or whatever you want to say./ 43. I think I am proud of the fact that I've been able to change people's perceptions about disability and to help people at [a university] see disability as another form of diversity and to include disability in their reconciliation efforts. Because they talk about reconciliation a lot and usually they just mean racial reconciliation which is fine. But then what I want to say is, "Why don't you just say racial reconciliation then? If you're going to make it broad then use the "r" word. I mean, if you're just talking about race, then say that." But it's broader than that, so I feel that I have been able to have an impact on that and people have said that I have./ 44. By teaching [a name of class], I have been able to affect students on some of the career choices./

45. One of my students is a Disability Services Specialist at [a university] right now. Another student ended up going into Disability Advocacy and, see that's what I really care about is helping people find or guess what they are good at and being called to those things./

It sounds like you have changed people or the organizational culture. Who supported you?

S3: 46. Well, that is a good question. I think some of what I did—one of the things I like to do is I like to find things that people are going to see—I like to give them resources and tools that are going to help them./ 47. That's what I'm even trying to do with this work study now. I said to him the other day because he wants to be an English teacher which man, he needs to work on a lot of stuff if he wants to be an English teacher. I said, "You want to be an English teacher, a good thing to start to do is when you start something, put things away when you are done." Or whatever, I can't remember, maybe it wasn't even that—but the example is I like to give people tools so when

43. S3 is proud that at her previous institution she changed people's perceptions about disability and helped people see disability as another form of diversity. She also helped people broaden their perception of diversity, beyond issues of race.

44. S3 has affected students in their career choices by teaching a course on disability in society.

45. S3 enjoys and cares about helping others find what they are good at and guiding them to the activities that they like.

46. S3 likes to provide resources and tools that help people accomplish their goals.

47. S3 is trying to work with her student worker and give him some experience so that he may be able to accomplish his goal: becoming an English teacher.

I—who supported me would be./ 48. I think people supported when they realized I was trying to identify with them and listen to what they had to say. I went to this anti-racism weekend that they had at [a university] and it wasn't about disability at all, but it was about looking at racism and privilege and all those kinds of things. So I think part of it is becoming allies and building alliances and things like that. I think people that have supported me are people like—well I think different faculty members there did./ 49. And to be honest, when I first started there as Director of Disability Services, the position was in the President's Office. I wasn't literally in the President's Office, but I reported to the Office of the President. That made it easy for me to get certain things done because I could just say, "We really should do this and the President Executive Assistant would say, "Well do you think we really need to do that?" and I would say, "Yeah" and he would say, "Okay, do it." So he almost never said no to me about stuff. So I got that support I guess.

Wow, that's nice.

S3: I know. Then I got here and I got moved down the food chain a little bit and more into the organization and more into the student life office. So it's interesting./ 50. Then I'm thinking of the other kinds of positions—even when I was an RA when I was in college, I think I got the support of the people who hired me, they never said, "We don't know if you can you really do this." Even when I was in [a position], even with this guy who was hard to work with, but he still was the one, he was in charge and he asked me to come and work with him. I was recruited for all those things. This is the first thing—I'm trying to think—even being at [a university], yeah I was recruited for that, but I—it was different, it wasn't like someone called me up and said, "Oh, come and work here" or kind of thing. Whereas my last job at [a university] before that, I was really

48. S3 learned that people support her when she tries to identify with them and listens to what they have to say. She believes becoming an ally and building alliances are important.

49. S3 also recognizes that the close proximity to the authorities such as President allowed her to influence the university culture easily. At her previous institution, the Office of the President and President Executive Assistant asked for her opinions and supported her. At her current institution, she feels that she was moved down the food chain. As a result, she feels the close proximity to the decision makers makes a difference.

50. S3 has been recruited by various people for a variety of positions. Even when she was an RA in college, she received support from the individuals, who hired her, and believed her ability. A man, who was hard to work with, asked her to work with him. Her previous institution also recruited her to work for them.

<p>almost kind of recruited into it.</p> <p>I see.</p> <p>S3: 51. Then on [an organization]'s Board, we kind of all support each other. Does that kind of get out what you are looking at?</p> <p>Yes, definitely. It sounds to me, that you made organizational change in your previous institution, you had several people who supported you, and those people trusted what advice you've given to them.</p> <p>S3: 52. Yeah, they did. They really—you know what helps though is that we kind of have a legal situation that came up pretty fast when I started there. I had suggested to some people that they handle a situation in a certain way and they didn't. Actually, and if they had, then this legal thing probably wouldn't have happened. So it kind of gave me some—I sort of had a platform because of that situation right from the start. There were some things like that and I think. / 53. The thing is where I am at now, I am probably feeling a lot more alone again because I had all of that support and everything and now I am back to—I am more on my own./ 54. I would say I have had people that have believed in me, and have given me the tools that I've needed./</p> <p>You mean as a Disability Services provider?</p> <p>S3: 55. Yeah, Disability Services provider but even when I worked at [an organization]. You know what's funny, the woman that I hired to be a reader for me there, she and the Chief of the Board, she is on the Board of Directors for the Organization right now or something like that.</p> <p>Oh, wow.</p> <p>S3: I saw her name, she is actually Chairman of the President—she's like the Chairman of</p>	<p>51. On the organization's board, she feels that everyone on the board supports each other.</p> <p>52. The organization's board members helped S3 deal with a legal case at her institution. They guided her to handle the difficult cases like this, which became a platform for her.</p> <p>53. She feels alone and on her own at her current job.</p> <p>54. S3 feels people have believed in her and have given her the tools that she needed.</p> <p>55. S3 hired a female student as her reader 17 years ago. Later this woman became successful and now serves as Chairman of the Board.</p>
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the Board for the Organization now or something and she was a reader for me like you know 17 years ago or something, she was my reader. She was just a student—you know, isn't that funny?/

Lucky you.

S3: 56. I know. That kind of stuff has happened to me a lot. Where, because I like being able to claw into people and give them skills and help them develop. And maybe that's why I'm serving this student so much is because I don't want to give up on him, but I don't know if I have the energy because I don't know if he's really invested. I need a sense from him that he really wants to grow and learn how to do a good job./

I see.

S3: I guess I'm figuring that out as we're talking about it a little bit, do you know what I mean?

Yes. Is it helping you?

S3: Just what you wanted. Therapy—counseling on the side. I love the interview but oh well. Two birds with one stone.

You are torn because of your previous experience, you provided a tool for people and then people took those opportunities but right now you just started a position and it's been chaos and you feel like, "I don't have the time to invest in this person yet."

S3: That is exactly.

I appreciate your stories—I have picked up some leadership essence from what I heard today from you. That is exactly what I was looking for. Now, I am finished with the interview with you.

56. S3 likes to get to know people, give them skills, and help them develop. She realizes that's why she continues working with this student worker. She hopes to get a sense from him that he wants to grow and to learn how to do a good job.

<p>S3: That's good.</p> <p>Thank you for your time.</p>	
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Level Three (Narrative Based on Emergent Themes)

Colleen started taking a leadership role when she was a child. She served as the President of her 4H Club and later on the Student Council when she was in junior high school. Colleen believes parents play a role to help their children become leaders. Her parents tried to instill confidence in her and encouraged her to try different things to become a leader. Her teachers also encouraged her to be a leader.

When Colleen became a college student, she served as a Residence Assistant (RA) for a few years and served in student government. By serving those roles, she learned how to delegate authority, set boundaries, be resilient, play to her strengths, manage her time, support other leaders on a team, and handle issues when people did not approve of decision she made. She believes that these skills are general and are not only for a leader with a disability.

During college Colleen was mentored by the Dean of Student Life. The Dean later became Vice President for Student Affairs at a college. She observed this mentor as a good leader. She wanted to follow this mentor's path and wanted to work in a college setting.

When Colleen served as a student staff, she worked with someone who was really challenging. This individual had different views of things and other people found him hard to work with. She wondered, "is this opportunity worth the headache?"

One summer, Colleen did an internship and stayed with someone and his wife. She discovered that he was unhappy with his career and his marriage and having family issues, which negatively affected her internship experience. Although Colleen tried to think differently to manage difficult situations, some situations did not help her be creative to get out of them.

After Colleen obtained a bachelor's degree, she held a job for a couple years. Later she went to a graduate school and received her Master's in counseling, and worked as the Coordinator for an organization. After that, she became a Disability Specialist and later held a Disability services Director position more than 10 years.

Colleen recently took a new leadership position at a different college. She is experiencing interpersonal difficulties at work. She is frustrated that her institution discontinued the assistant director position immediately before she started working as the director.

She does not appreciate that a student worker was hired for her rather than allowing her to hire someone that she chose. She thinks that this student is the worst student employee that she has ever had. Because she is new to her institution, she feels obligated to deal with this unqualified student employee, instead of terminating him.

Colleen is frustrated that this student worker does not follow directions, does not complete tasks, and is unmotivated. She would like to fire the student but she cannot find strong reasons for terminating him.

The way this student employee was hired is problematic for her. A person hired him through a personal connection without interviewing him. She wonders whether she should report this to her supervisor.

Colleen realized that this student never had a paid job in his life and his grades were poor. She needs to rely on this student employee as her tool but she cannot. The office manager even told her that she would not hire this student. Being stuck working with this student employee is troublesome to her.

She decided to consult with her boss about this student worker. She left a phone message. However, at the same time, she wondered if she should just deal with this issue alone. She wonders whether this difficult situation could be the opportunity for her to grow.

Colleen wants a capable administrative assistant as she had at her previous institution. She regrets her decision to accept her current position because she does not have a right administrative assistant. The student worker is not a good fit, is not focused on what he is doing, and is not adjusted; he does not have the right skills for his duties.

Colleen struggles with managing this student worker and wonders how she is perceived as a leader to handle this difficult situation. She is having difficulty trusting him because he is not reliable. She struggles with balancing how much weight she gives others (her colleagues) her opinions or perceptions. She also struggles with prioritizing the potential value of training this student worker for his future because she has to pay a high price to train him.

Colleen feels that she needs to let things go by having this student worker do simple jobs while she utilizes an administrative assistant's help to operate her department. She wants to give that student employee experience so that he may be able to accomplish his goal: becoming an English teacher. She would be happy if she could help him to develop and to become a better student worker.

Colleen sees that people believe in her. She has learned that people support her when she tries to identify with them and listens to what they have to say. She believes becoming an ally and building alliances are important. Colleen also recognizes that the close proximity to the authorities such as the President allowed her to influence the university culture. At her previous institution, the Office of the President and President's Executive Assistant asked for her opinions and supported her. At her current institution, she feels that she was moved down the food chain. As a result, she feels the close proximity to the decision makers makes a difference.

Colleen has been recruited by various people. Even when she was an RA in college, she received support from the individuals, who hired her, and believed in her ability. Her previous institution also recruited her to work for them.

At her previous institution, Colleen changed the institutional culture and beliefs about disability. As a result, this institution has changed the job description of Disability Services Director, which she held prior to her current job, in a way that the Director affects the campus culture and structure. She is proud that she changed people's perceptions about disability and helped people see disability as another form of diversity. Colleen also helped people broaden their perception of diversity to include more than racial distinctions. She has affected students in their career choices by teaching a course on disability and society.

Colleen has served on the board of a professional organization for the past several years. Her mentor encouraged her to apply for a board member position. During those years, the Executive Director of the organization positively influenced her. She feels that everyone on the board supports each other. In the past, those board members helped her for a legal case at her institution. They guided her and helped her handle the difficult cases, which became a platform for her career as a disability services director.

Regardless of whether a person has a disability or not, Colleen believes that it's challenging to lead when you don't have the resources needed to succeed. However, for her, a

leader has to be able to take the difficult situations, like she is in now, and has to figure things out with the tools the leader has. She also believes that good leaders know how to prioritize things.

It is important for Colleen to have the right tools for communication. She feels that people have given her the tools that she needed. Currently, she is having communication difficulties because her institution's e-mail and calendar systems are hard to use with a screen reader that she uses.

Colleen's leadership requires helping others develop their inner-personal strengths and having the right tools for their jobs. She enjoys working with students. For instance, she hired a female student as her reader and helped her develop 17 years ago. Later this woman became successful and now serves as Chairman of an organization. Colleen enjoys helping others find what they are good at and guiding them to the activities that they like. She also likes to provide resources and tools that help people accomplish their goals. She likes getting to know people, nurturing their skills, and helping them develop.

Appendix G

Data Analysis

Debra: Levels One to Three

Debra (S4), Level One and Two (Spontaneous Meaning Units)

<p>Please take a moment and reflect your important experiences or relationships in your life that led you to take your leadership role.</p> <p>S4: 1. I was raised—I mean, I am 60-years old and I was raised then in the 50's in a very small town in [a state] where there wasn't a lot going on relative to disability./ 2. I might have been the only disabled kid in town, so I really have to attribute a lot, not only to my family, but to that community and my friends and neighbors in that small [a state] town./</p> <p>3. My family was very creative and innovative and it was always about, "What is it that you want to do and how can we make that happen?" I would say my dad especially was all about making sure that I had comparable opportunities that my three brothers did but also as my friends in town. I mean just as an example, when everybody started to ride bikes and I couldn't ride a bike, then he said, "We'll get you a horse." And of course it was a small town so I could ride that horse anywhere I wanted to. Then he also bought me a cart that I could hook the horse to so that I could have my friends with me with the horse. So I used that horse like other kids used bicycles. I mean we literally would ride it to the swimming pool, pack it up and go swimming, and then go home./ 4. So I had—he was very—both of my parents were very—what's the word I'm looking for? Very, anxious, probably is the right word. But set on making sure that I could be independent. Everything kind of went around that so when my friends started ice skating, my father figured out a way that I could wear ice skates over the top of my shoes connected to my braces. He put sandpaper on my crutches so that I could figure out a way to be on the ice with my friends. It was just—that was just continuous./ 5. Again, this was in the 50's when they really didn't have any real</p>	<p>1. S4 grew up in the 1950's in a small town where disability was not prominent.</p> <p>2. S4 believes that she was the only child with a disability in that small town and had to attribute to her family, friends, and neighbors in that town.</p> <p>3. S4's family was creative and innovative to include her in activities and to enable her to do these activities by asking, "what is it that you want to do and how can we make that happen?" Especially, her father made sure that she had comparable opportunities to her brothers and her friends in town. Due to her disability, she could not ride a bike. As a result, her father gave her a horse so that she had transportation.</p> <p>4. S4 recalls that her parents were very anxious about her but they made sure that she could be independent. For instance, her father creatively put sandpaper on her crutches so that she could figure out a way to be on the ice with her friends for ice skating.</p> <p>5. S4's parents significantly supported her. As an example, her father modified a car so that</p>
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<p>connections to disability. We weren't political, there weren't any—there was no civil rights movement going on. It was just from their personal places and what they wanted for me. When it came time for me to be able to drive a car, my father went out and discovered hand controls which again, he would have had no reason to know about that. He made sure that I had controls at 14 so that I could drive. I just really attribute to that early and the whole community, like I said, it was a small town, really supported that, not that people didn't recognize me as a disabled kid, which they did, but it was all/ 6. —I was welcomed and included and everybody was real innovative and creative and supported that and just real welcoming./ 7. I would say that from a very early age I was real independent and also opinionated and pretty assertive about saying this is what I was going to do and this was how I was going to do it. I feel like I got a lot of that from my parents and friends and the community./ 8. I think that, again, probably like any trait, you always have to find a way to channel it and certainly, I had to learn how to channel my opinions and assertiveness because there were periods in my life I think when I might have been too aggressive./</p> <p>9. I am very political and don't mind sharing that with whoever will listen. I have had to find ways to channel that to be effective./ 10. I certainly appreciate that I have a had a good, strong foundation for being able to speak up and share what I thought and felt and didn't have a lot of shyness about that. I would say that was very important in my early years. Does that make sense? /</p> <p>Yes it does. It sounds like your parents definitely helped you to shape up what is important elements for you, it sounds like.</p> <p>S4: 11. And of course I have three brothers and I think that probably had an impact too because again, they were really pretty insistent that I</p>	<p>she could drive at age 14. She was doing activities other children did. The whole community supported her and the parents' efforts.</p> <p>6. S4 felt that she was welcomed and included by her community and that everyone was innovative and creative. The community sincerely welcomed her.</p> <p>7. In her a very early age S4 learned to be independent, opinionated, and assertive. She believes that she learned from her parents, friends, and the community.</p> <p>8. S4 learned how to channel her opinions and assertiveness because there were periods in her life where she was too aggressive.</p> <p>9. S4 is very political and does not mind sharing her views. She has learned how to be effective to convey her political views.</p> <p>10. S4 believes she has a good, strong foundation of being able to speak up and this came from her early years. Not being shy about speaking up and sharing her thoughts have become very important elements in her early years.</p> <p>11. Grown up with three brothers, S4 felt that she was pushed and pushed herself to participate, keep up with them, and do things</p>
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<p>participate and keep up with them and do things with them. I was pushed and I pushed myself. Again, I just feel like that was an important experience for a young, disabled kid in terms of how I was going to handle my future./</p>	<p>with them. Being challenged was an important experience for her. She believes that this experience influenced her future.</p>
<p>Did you have those similar experiences later on in your life?</p>	
<p>S4: 12. Yeah because when I was in high school, I was on the Student Council. I was President of the PEP Club. I was in Choir. I was on the community swim team, and even with swim team, they let me participate. I have had to—when we raced, I couldn’t dive off the thing, I had to be in the water and start out, so of course, I very seldom won, but I was part of a swim team./ 13. I’m just not sure that all of that happens all the time for kids. Some of it is that in a small town, some of it is me and my confidence that I think I got thinking, “I can do this” and “It’s okay that I do it a little differently” and “You can figure that out.” Like I said, I don’t think I was mean about it. I think people like me, so I wasn’t overbearing, but I was pretty clear about wanting to try stuff./</p>	<p>12. When S4 was in high school, she served in leadership positions and actively participated in swim team, choir, and PEP Club, which taught young children basic sport skills. For swimming, she seldom won but participated in a team by modifying the way she started swimming in the pool.</p> <p>13. By growing up in a small town, S4 gained confidence to be able to join activities by doing things differently or by figuring things out. She thinks that she was not mean to others or overbearing. However, she clearly showed to others that she wanted to try things.</p>
<p>14. So when I went to college, I was President of my freshman class in college. I worked for a Congressman in [a state]. So I mean I just—kind of just kept continuing those kinds of roles—I’ve had them all along./ 15. I think it took me a little longer to appreciate that I wanted to be a leader relative to disabilities. I was headed in a different direction. I was more political. I wanted to be working in Washington D.C. My major was history. I thought maybe I would be a history professor or Political Science, so I was really headed in that direction and through my college years as I worked on campaigns. I was a manager on a political campaign for a US Senator from [the state] who won, which was great./ 16. I worked in Washington D.C. for a semester doing an</p>	<p>14. S4 continued taking leadership roles in college, including working for a Congressman.</p> <p>15. It took a little longer for S4 to want to become a leader relative to disabilities. Before that, she was political and wanted to work in Washington, D.C. She served as a manager on a political campaign for a US Senator from her state during her college years.</p> <p>16. S4 worked in Washington, D.C. as a one-semester long internship. During that time, she</p>

<p>internship but it became kind of clear to me that that really wasn't what I wanted—that political life. It was a little too dog-eat-dog for me./</p> <p>17. And then and I had some other experiences that really—I began to appreciate that the disability area was political too. Then all of a sudden it kind of—because I've worked at—I was involved at the Women's Rights Movement in the 70's, certainly the Anti-War Movement—and it just didn't click right away that the disability piece was also Civil Rights and that took me a little longer. I didn't kind of arrive at that until I was kind of later in my 20's. I think I was like 27 or 28 when it kind of started to click and then that's when I really got comfortable working in this area./</p> <p>18. Then I've done different work both more individual counseling work, but then once I got my Doctorate it moved more into administration and I knew I wanted to kind of in higher ed. I liked this mix of administration and teaching. I find it a little more interesting than just one or the other./</p> <p>19. Since I've been doing this work, again, I've been very involved in the Disability Rights Movement, President of my Professional Association. On campus, I am the Chair of Committees, I am President of the Association of Women's Faculty, it's just kind of who I am. I take those roles. I can trace it back to my roots./</p> <p>Let's go back to like you said, when you are your late 20's, you were very active politically and then you thought about going to the political arena. Also you were involved in the Women's Rights Movement and you shaped it to disabilities, is there anyone who helped you to go that route?</p> <p>S4: 20. Yeah, there are a few key moments for me. One is I was working actually—this is</p>	<p>realized that a political life was too "dog-eat-dog" to her, meaning that the political life was too tough to her.</p> <p>17. S4 began to realize that disability was political. She was involved in the Women's Rights movement and the Anti-war movement in the 1970's. Later, perhaps when she was in her late 20's, she started engaging in disability-related activities and started feeling comfortable with working in the disability area.</p> <p>18. After S4 worked as a counselor, she obtained a doctoral degree and became an administrator in a higher education institution. She liked being an administrator and a teacher at the same time.</p> <p>19. Since S4 moved into an administration job, she has enjoyed being involved in the Disability Right movement has enjoyed serving as a leader for her professional associations and for her university. She feels that she can trace her leadership back to her roots.</p> <p>20. S4 recalls she met with a mentor while she was working for the Muscular Dystrophy</p>
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going to sound really strange where I am at politically, but I was working for the Muscular Dystrophy Association in [a state]. I had a wonderful mentor in that Association who was very political in the Disability Rights Movement in [a city] but at the period it was kind at the '76-'77 when there was a group in [the city] called the Atlantis Group and they were all about "independent living" and they were chaining themselves to buses to make sure the buses were accessible. The mentor of mine connected me to them and I can remember at first just feeling real confused a little bit about, "Wow I had never really thought civil rights for myself." /

21. I had always felt like I'll do what I want when I want. And my first real awakening for the status of disabled people in the United States and globally too. It was eye-opening that this is not a given for everyone that—and I realized how privileged I'd been, really. So that was wonderful./ 22. Also during that same time I got involved in sports./

23. That is one thing, growing up I had been real active, but it was always active with non-disabled people so I ice skated with my friends, I rode horses or I might play baseball and basketball, but it wasn't with other disabled people./ 24. Around that same time because there was a lot going on in [a state] with wheelchair sports, and not just wheelchair sports, I would say adapted sports, and there was a big club and again, this was just something that I had not done before was to be affiliated with other disabled people. / 25. I had grown up in isolation and I just hadn't—part of that is our history. We don't want to hang out together because we are so stigmatized, right. I had kind of avoided that, but this was all kind of evolving for me./ 26. I kind of got involved in this sports club and involved with all other disabled people. I learned to ski which was the most amazing thing to me that I was downhill skiing and using outriggers and full-length leg

Association. The mentor was very political in the Disability Rights movement and connected her to a group called the Atlantis Group that was promoting independent living for people with disabilities. [Atlantis Community in Denver, was started by Wade Blank and that was a beginning of ADAPT.] This experience led her think about her civil rights.

21. S4 always felt that she would do what she wanted when she wanted. After she learned the status of disabled people in the United States and other countries, however, she realized doing what individuals want was not for everyone and how privileged she had been to be able to enjoy it.

22. During that same time, S4 got involved in sports.

23. When S4 was growing up, she enjoyed being active and enjoyed ice skating, horse riding, basketball, and baseball. But she did these activities only with non-disabled people.

24. Around the same time when she was involved in Atlantis Group, wheelchair sports became popular in the state where she was living. Thus, she became involved in adapted sports with other disabled people and joined a adapted sports club.

25. S4 realized that she grew up in isolation and that she avoided hanging out with other disabled people.

26. S4 got involved in an adapted sports club with other disabled people and did downhill skiing by using outriggers and full-length leg braces.

<p>braces and it was wonderful. /</p> <p>27. I competed and won a gold medal two years in a row for my downhill skiing. That experience of just being around with and socializing with other disabled people, both with sports and politics was really incredible for me./ 28. That period is when I appreciated how problematic the Jerry Lewis Telethon was and I was working for that organization./</p> <p>29. All of that came together and helped me appreciate the real good work that needed to be done in this area and how much I valued my identity as a disabled person and how appreciative I was at having disabled friends and colleagues. So that was a real turning point for me. That was in my late 20's. / 30. That's also when I went back and got my Doctorate in Human Rehabilitative Services and really headed in a more professional direction./</p> <p>I see. During those 30 years, what are some of the challenges or obstacles as a leader?</p> <p>S4: 31. Well, I think for me, it's got to be pretty personal right? I would say for me, it was really and I don't know if this will make sense, but I had a mentor once that told me kind of a couple years into my administrative role that I needed to learn how to "dipsy-doodle"./</p> <p>What is "dipsy-doodle"?</p> <p>S4: 32. Well, he wouldn't really tell me but he would say, "You figure it out, but this is what you've got to learn."/ 33. And what I think I came to appreciate is that it was—"dipsy-doodling" was really learning about what to say, when to whom. I think that was a really—again a very important piece for me because I think I started out, especially as an administrator in the disability arena because I had been such an activist./ 34. I was struggling to find a balance between activist and</p>	<p>27. S4 competed and won a gold medal two years in a row for her downhill skiing. Being around other disabled people doing sports and politics was incredible for S4.</p> <p>28. When S4 started spending time with other disabled people, S4 was working for Muscular Dystrophy Association and realized how problematic the Jerry Lewis Telethon was.</p> <p>29. Having disabled friends and colleagues led S4 to realize the real "good work" needed to be done and to value her identity as a disabled person. She was in her late 20's.</p> <p>30. It was also in S4's late 20's when she went back to university and received her doctorate in Human Rehabilitation Services and headed in a professional direction.</p> <p>31. During her early administrative career, S4 had a mentor who told her that she needed to learn how to "dipsy-doodle."</p> <p>32. S4's mentor just said, "you figure it out, but this is what you've got to learn."</p> <p>33. S4 has learned what "dipsy-doodling" is about: what to say and when to say it and to whom. This was a very important piece for S4 to switch from being an activist to being an administrator in the disability field.</p> <p>34. S4 struggled to find a balance between being an activist and an administrator.</p>
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administration, maybe being too much of an activist that was comfortable for a Higher Ed Institution, if you know what I mean?/

35. So in order for me to really be effective, I needed to kind of learn how to advocate and how much to advocate and when./

36. Almost like a dripping faucet, right? When do you turn the drips up and when do you slow them down? Who do you do that to and with?/

37. Gosh, I just learned so much both from this mentor who just—that's all he told me is, "You need to learn how to dippy-doodle."/

38. But he was a mentor to me in a lot of ways and I came to appreciate how important that was because I think I became a pretty effective Administrator./

39. In [a state] where I was at, our program grew exponentially in the 14 years I was there and not to brag, but we really built a program. The same has been true here the last 12 years. We have really had some impact./

40. I think that is something—again, I still have to struggle with that, that is not something all of a sudden I learned it and I've got it down./ 41. You go into a new environment or with new people, or a new department, and I have to constantly kind of think about that issue about, "What do I say, when do I say it, how often do I say it, how do I say it" /

42. —all in ways that will be effective and ways that will be heard and ways that engage people in my cause or in my work. How do I get them excited about it? So I think that is a constant challenge. For me anyway, I think it's fun and it's good work, but it's not something that I can just forget about. I always have to think about it and pay attention./

It sounds to me that challenge has taught you to be an effective communicator. That is

35. In order for her to be an effective leader, S4 needed to learn how to advocate and how much to advocate and when to advocate.

36. S4 used a metaphor of using a dripping faucet to find a balance, when to drip up and down; whom do you do that to and with.

37. S4 feels that she learned a lot from her mentor who told her to find that balance.

38. S4 feels that this individual was a mentor for her in many ways and that she became an effective administrator thanks to him.

39. S4 is proud that she, as an administrator, built and grew exponentially her programs both in her previous institution in fourteen years and current institution in twelve years. She believes that she has made some impact as a result.

40. S4 still struggles with practicing "dippy-doodle."

41. When S4 goes into a new environment, with new people, or a new department, she constantly thinks, "what do I say, when do I say it, how often do I say it, and how do I say it."

42. S4 has to remember and pay attention to how she engages others and get them excited. This is a constant challenge. However, she enjoys thinking how to deliver her messages so that people get excited.

my word though.

S4: 43. Yeah, it is. I mean, yeah, it's what you say, how you say it, when you say it. It's all of that. I need to be fluent, relative to what I'm talking to about./

44. I've got to be able to have different language with different audiences. It's all of that. So, yeah, I think it's huge./

45. Some of it is, I hate to say it, but some of it just comes down to personality. Am I going to exhibit and air or a climate that is going to want people to be connected, right? Am I easy to get along with or am I a jerk, right? I just think all of that is so important relative to being a leader because I see a leader as really as kind of engaging people in good work, right?/ 46. People have got to get excited by it and see it as important and fun and challenging. So that is part of my task is, "How can I get that message across?" Like I said, it's been challenging for me over the years and I continue to work on it and some days it works and other days it doesn't./

On self-examination of a scale of 0-5, with 5 which is "I'm perfect, I'm mastering it," where are you in terms of what you are saying?

S4: 47. I would say, I'm 60-years old, I would never think that I have arrived. In some respects, sometimes I think the older I get, I see new areas that need to be improved that I wasn't aware of before. It just seems that it is never ending./ 48. I don't know, I think I and the people around me would say I am a fairly competent, effective leader in the disability arena. Like I said, I do take on leadership roles outside of disability, and I think people do see me as pretty organized and thoughtful./ 49. I think one thing that I really believe in is I believe in—I don't know if this makes sense, but I really believe in trusting the truth, that

43. S4 thinks it is important to be fluent and familiar with what she is talking about so that she will know what, how, and when to say things.

44. S4 thinks it is important to have different language or expression with different audience to effectively communicate.

45. S4 believes that being a good leader requires the ability to connect, get along, and engage people in good work.

46. S4 believes that a good leader makes others excited by helping them see things as important, fun, and challenging. Her task is to figure out how she gets her message across to others. She continues to improve her skill.

47. S4 is now 60 years old. She sees new areas of improvement as she gets older and believes that her improvement is never ending.

48. S4 believes that she is a fairly competent, effective, organized, and thoughtful leader both in and outside of the disability arena.

49. S4 believes in "trusting the truth." It is not really about her, this is about everyone. She believes that everybody needs to take initiative, come up with good ideas, and try them out.

isn't really about me, this is about all of us. Everybody needs to take initiative, come up with good ideas, try them out and what I need to do is see supportive of that and find ways that people feel encouraged to do that because that is how we all get ahead, it isn't really just me./ 50. I think that I really trust people who either report to me or who are on a committee with me. I never feel that I have to do it all or that I am the only one who can do this. I appreciate that I have some skills, but man, it's like other people have such good ideas that I would never have thought of. / 51. So it's like being really supportive of that good idea and let's figure out how we can bring it to fruition. What can I go and what resources do you need? So I think that's been an important piece for me to learn./

You trust people.

S4: 52. I do. I really trust them. I trust that their idea is a good one most of the time and that it's worth pursuing./

53. I am sure that there have been times when I've said, "I'm not sure that's such a hot idea" because I'm sure that I have, but that's not my standard. I usually see an idea as having some good pieces and that it just maybe needs some work. 54. I am sort of this way as a mother too, I have two daughters. I mostly like to say, "Yes." I don't like to say, "No." I like to say, "No" when I have to say, "No." Most of the time I like to be able to say, "Yes, let's do that", "Let's try that", or "That's a good idea" so that when a "no", there's a good reason./

I see. This might be a good segment to go to the next question. As a leader, you talked about your confidence, trusting other people, and making an effort to effectively communicate. Please tell me the accomplishment that you are most proud of.

S4: 55. I would say that probably what I am

Her role as a leader is to be supportive of her colleagues' ideas and find ways that they feel encouraged to take actions for their ideas.

50. S4 really trusts people who either report to her or who are on a committee with her. She never feels that she had to do it all. She lets others come up with good ideas that she would never have thought of.

51. S4 sees that her role is to be supportive of good ideas and to figure out how her team can bring it to fruition by finding out what resources they need.

52. S4 really trusts her team. She also trusts that her team's ideas are good most of the time and they are worth pursuing.

53. Even if an idea does not meet S4's standard, S4 usually sees it as having some good pieces and needs some work to make it to be a good idea.

54. Most of the time S4 supports her colleagues' ideas rather than rejecting them. However, when she says "no" to these ideas, there is a good reason.

55. Through her engagement with disability,

<p>most proud of is that, again within my small pond, okay because I have to appreciate that I am working in kind of a small pond which is disability-related stuff not like it's huge, but I would say what I am most proud of is that I have—kind of early on in my learning and in my engagement with disability, really appreciated that disability needed to be reframed. People needed to think differently about it./ 56. We all had a kind of a negative connotation of disability and recognized that the service-industry was a big culprit in keeping disability framed as a bad thing./</p> <p>57. The very services that we have to be helpful are our biggest problems. Does that make sense?/</p> <p>58. So whether it's rehab counseling or even like my office here at the University, Disability Services and Higher Ed, or Special Ed or I mean—there's just such a huge service industry around disabilities and that I appreciated very early how important the service industry is to how disabled people get defined and conceptualized in our society and that we were the biggest culprits in keeping it framed negatively./ 59. Within my small pond of Disability Services and Higher Ed, I have I think really had an impact on what our profession is doing relative to what our practices are in Higher Ed and how do we design and deliver our services in ways that frame disabilities differently. I don't know if this is making sense to you?/</p> <p>It is making sense to me.</p> <p>S4: 60. Okay, good. So, we were doing that in [a state], we are going that in [a state]. Through our professional association [an organization], I feel like I have been front and center on that issue. / 61. We, as service providers, are a big part of the problem. If we don't start thinking differently and behaving differently, this is not going to change. I feel probably most proud</p>	<p>S4 realized that disability needed to be reframed. People needed to think about disability differently. She is proud of her realization.</p> <p>56. S4 thinks that disability had a negative connotation among many people and the service-industry facilitated that having a disability was a bad thing.</p> <p>57. S4 thinks that helping services are the biggest problems for a negative connotation of disability.</p> <p>58. S4 realized that how the service industry defines and conceptualize disability is a key to eliminate a negative notion of disabilities.</p> <p>59. S4 is proud that she impacted her profession (a disability services in a higher education institution) to redesign and deliver services in ways that frame disabilities differently.</p> <p>60. S4 is proud that she has been front and center in reframing disability in disability services in higher education on the state and national levels.</p> <p>61. S4 believes that services providers are a big part of the negative connotation of disability and need to change. She is proud that she has played in brining this issue to the forefront.</p>
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about the role that I have played in bringing that to the forefront./

It sounds like you are the driving individual to make this culture change. Am I right?

S4: 62. I have been real consistent in my message that we have to think differently about disability and then we have to behave differently./ 63. And behaving differently means we have to design services that don't look so medical-model, right? And that we have done that on the service-guide of the house./ 64. We talk differently, we say, "We don't believe in the medical-model" but then we do all of this stuff that just reinforces medical-model thinking about disability. For example, we have—you look at websites and they are filled with compliance language. My thing is we have to change that narrative on campus. We have to change it from a compliance narrative to a social-justice narrative. I feel like I have been real consistent in that message over the last 20-25 years./ 65. They certainly didn't have it when I first started, but have developed it and that now is beginning to take root at least within Disability Services and higher ed. If you go to the national conferences you will see a lot more concurrent sessions about Social Justice and Universal Design, reframing disability that just wasn't there at all 15 years ago or 10 years ago./ 66. I just am now involved with a national project where we are bringing in—we brought 25 service providers together over the course of 3 years where we have summer institutes and technical assistance all designed to help them think differently and then change their practices in their offices. We are just seeing wonderful changes happening. So, again, I am most proud of that./

I see. It sounds like a very moving experience and that is very inspiring.

S4: Thanks.

62. S4 strongly believes that people need to think and behave differently about disability.

63. S4 facilitated designing services to behave differently.

64. In the last 20 to 25 years, S4 has been consistent with her belief that disability services providers have to change to a social-justice narrative from a compliance model or a medical-model about disability.

65. S4 sees more social justice and Universal Design in Disability Services in higher education in the last 10-15 years.

66. S4 is now involved in a national project that brings 25 service providers together for three years of summer institutes and technical assistance. They are designed to help the service providers think differently about disability. She is proud to be involved in this national project that facilitate change disability services' practices.

<p>Thank you so much for your time and sharing your stories.</p> <p>S4: Well you are welcome. I hope it was helpful.</p> <p>It was very helpful.</p>	
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Level Three (Narrative Based on Emergent Themes)

Debra grew up in the 1950's in a small town where disability was not prominent. She believes that she was the only child with a disability in that small town.

Debra's family was creative and innovative. They always asked her what she wanted to do. They also asked themselves how they could make things happen for her. Her family included her in many activities, which enabled her to do those activities. Especially, her father made sure that she had opportunities that were comparable to her brothers and her friends. For example, she could not ride a bicycle due to her disability. As an innovative solution, her father gave her a horse so that she could have transportation like other children who rode bicycles.

Debra recalls that her parents were very anxious about her when she was young. However, they were very supportive of her and made sure that she could be independent. For instance, her father creatively put a piece of sandpaper on each of her crutches, which enabled her to be on the ice with her friends to ice skate.

As another example, her father modified a car for her so that Debra could drive at the age of 14 like other children. The modifications to the car enabled her to have good control of the car while she was driving. At a young age, Debra was doing the activities that other children were doing. The whole community supported her and her parents' efforts.

Debra felt that she was sincerely welcomed and included by her community. She also felt that everyone in the community was innovative and creative. She appreciated the support from her family, friends, and neighbors in her community.

At a very early age, Debra's parents, friends, and community members taught her to be independent, opinionated, and assertive. She believes that in her early years, she gained a good, strong foundation for being able to speak up. Not being shy about speaking up and sharing her thoughts became very important in her childhood.

Debra felt that growing up with three brothers pushed her to participate, so as to keep up with them and do things with them. Being challenged was an important experience for her and she believes that this experience influenced her future.

When Debra was in high school, she served a leadership position on the student council and actively participated in the swim team, choir, and PEP Club, which taught young children basic sport skills. For swimming, she seldom won but participated in a team. Through these experiences, she gained confidence to be able to join activities by doing things differently or by figuring things out. She does not think she was mean or overbearing to others; however, she clearly showed others that she wanted to try things.

When Debra was growing up, she enjoyed being active; she enjoyed ice-skating, horse riding, basketball, and baseball. But, she only did these activities with non-disabled people. She then realized that she grew up in isolation and that she avoided hanging out with other disabled people.

Debra continued taking leadership roles through college. At one point, she worked for a Congressman in her state. She was politically-minded and wanted to work in Washington, D.C. As a result, she served as a manager on a political campaign for a US Senator from her state. She worked in Washington, D.C. for a one-semester long internship. During that time, Debra realized that the political life was too "dog-eat-dog," meaning that the political life was too tough for her.

Around the same time that she was involved with the Atlantis Group, wheelchair sports became popular in the state where she was living. Thus, she became involved in adapted sports with other disabled people, and eventually joined an adapted sports club.

Debra was also involved in the Women's Rights movement and the Anti-war movement in the 1970's and through these experiences, realized that disability was political. Later, in her late 20's, she started engaging in disability-related activities and started feeling comfortable with working in the disability area.

She met with a mentor when she was working for the Muscular Dystrophy Association. The mentor was very politically involved with the Disability Rights movement and connected her to a group called the Atlantis Group [Community], which was promoting independent living for people with disabilities. This experience led her to think about her own civil rights as a disabled person.

Debra always felt that she could do what she wanted when she wanted. After she learned the status of people with disabilities in the United States and other countries, she realized that she was privileged to be able to do what she wanted. She also realized how privileged she had been to enjoy this freedom in her life.

Debra became involved in an adapted sports club with other disabled people. She enjoyed downhill skiing and by using outriggers and full-length leg braces, she competed and won a gold medal two years in a row for her downhill skiing.

At the same time, Debra was working for the Muscular Dystrophy Association. As she spent time with other people with disabilities, she realized that the Jerry Lewis Telethon was problematic to her and those other individuals with disabilities.

Being around other people with disabilities for sports and politics was an incredible experience for her. Having disabled friends and colleagues made her realize that the real "good work" needed to be done for people with disabilities. She also started valuing her identity as a disabled person.

She started wanting to become a leader for others with disabilities. She went back to school at the university level and received her doctorate in Human Rehabilitation Services, which led her to become an administrator in higher education.

Debra has enjoyed being involved in the disability rights movement. As an administrator and a teacher, she has served as a leader for her professional associations and for her university. Her propensity to lead can be traced back to her roots.

Debra believes herself to be very political and does not mind sharing her views with others. There were periods in her life where she was too aggressive when sharing her opinions. Over the years, she has learned how to be effective when conveying her political views. Debra has also learned how to control her opinions and her assertiveness.

Early in her career, her mentor told her that she needed to learn how to "dipsy-doodle." He just said, "you figure it out, but this is what you've got to learn." She has learned what "dipsy-doodling" is all about: knowing what to say, when, and to whom. This was a very important lesson for her while she was switching from being an activist to being an administrator.

It was difficult for Debra to find a balance between being an activist and an administrator. However, in order for her to be an effective leader, she needed to find balance between her roles. She needed to learn how to advocate and how much to advocate and when to advocate. It was like using a dripping faucet and finding a balance- when to drip up and down, who do you do that to and with.

She learned a lot from her mentor and feels that he mentored her in ways that helped her to become an effective administrator.

As an administrator, Debra is proud to have built and grown her programs, both in her previous institution, where she spent fourteen years, and her current institution, where she has been for twelve years. She believes that she has made some impact as a result of her work.

However, she still struggles with practicing "dipsy-doodle." When she goes into a new environment, with new people, or a new department, she constantly has to think, "what do I say, when do I say it, how often do I say it, and how do I say it." She has to remember and has to pay attention to how she engages others and getting them excited. This is a constant challenge. However, she enjoys thinking about how to deliver her messages so that people get excited. She also believes that it is important to Being fluent and familiar with what she is talking about helps her know what, how, and when to say things.

It is important for Debra to adapt her language and style depending on the audience. In order to effectively communicate with different audience, she believes it is important for a leader to connect, get along, and engage with people. She believes that a good leader excites others by helping them see things as important, fun, and challenging. Her task is to figure out how to get her message across to others, which is a skill she continues to improve.

Debra is now 60 years old. As she gets older, she finds new areas where she can improve and believes that improvement is never ending.

She believes that she is a fairly competent, effective, organized, and thoughtful leader both in and outside of the disability arena.

She believes that success is not really about her; it is about everyone. She believes that everybody needs to take initiative, come up with good ideas, and try them out. Her role as a leader is to be supportive of her colleagues' ideas and find ways to encourage them to develop their ideas and take action.

Debra never feels that she had to do it all and trusts the people who either report to her or who are on a committee with her. She allows others to come up with good ideas, some of which she would never have thought of.

Debra believes that her role is to be supportive of good ideas and to figure out how her team can bring it to fruition by finding out what resources they need. To show her support, she trusts her team. She also trusts that her team's idea is good and that the idea is worth pursuing. Even if an idea does not meet her standard, she usually sees it as having some good pieces but needing some work to make it become a good idea. Most of the time she supports her colleagues' ideas rather than rejects them. However, when there is a good reason to reject an idea, she sometimes has to say "no." Through her engagement with disability, she realized that disability needed to be reframed and that people needed to think about disability differently. Debra thinks that disability had a negative connotation among many people and the service-industry portrayed

having a disability as a bad thing. Particularly, she thinks that the service industry's view of disability is one of the biggest reasons for the negative connotation of disability. Particularly, she thinks that helping services are the biggest problems for a negative connotation of disability.

She believes that changing how the service industry defines and conceptualizes disability is a key to eliminate the negative view of disabilities. She is proud that she impacted her universities by redesigning and delivering services in ways that frame disabilities differently.

Debra strongly believes that people need to think and behave differently about disability. She is proud that she has been front and center of reframing disability in disability services in higher education on the state and national levels. She contributed to bringing this issue to light and facilitated new ways of designing services that work differently with individuals with disabilities.

In the last 20 to 25 years, she has been consistent with her belief that disability services providers have to change to a social-justice narrative from a compliance model or a medical-model with regard to disability. She has seen more social justice and Universal Design in Disability Services in higher education in the last 10-15 years. She believes that she contributed to this change.

Debra is currently involved in a national project that has brought 25 service providers for three years through summer institutes and by providing technical assistance to them. This national project is designed to help service providers think differently about disability. She is very proud to be involved in this project and again, in facilitating changes in disability services' practices.

Appendix H

Data Analysis

Emma: Levels One to Three

Emma (S5), Level One and Two (Spontaneous Meaning Units)

<p>My question to you is broad. I want to know critical moments or important experiences in your life that shaped up who you are as a leader. Would you take a moment and think about those important experiences and relationships that led you to become a leader?</p> <p>S5: How far back do you want me to go? Do you want me to go back to my childhood?</p> <p>I will just follow wherever you are going. If you feel like childhood comes into your mind then go for it.</p> <p>S5: 1. When I was a child, my mom was really supportive of me and she encouraged me to really active in all kinds of different groups. I remember I was just starting to get involved in 4-H. Are you familiar with that?/</p> <p>Yes.</p> <p>S5: 2. This was an inner-city 4-H group of girls. I think I was, oh wow, I might have been like 9 or 10 years old. I was really, really young. It was a group of girls that were anywhere from 6 years old up to 15 years old./</p> <p>3. The first meeting I ever went to, in my whole life, they elected me president. (laughing) I don't know why./ 4. I was the only disabled kid in the group and I don't know what they thought that gave me the qualification./ 5. I didn't know anything about 4-H, I didn't know anything about how to be a leader. Here I was just pushed onto the leadership platform./ 6. I went to my mother because she was there and she said go for it. Well, okay. So I served as president of this 4-H club. I was 9 years old and that's pretty much how I got started./ 7. I learned quick (inaudible) in my fire. I didn't even know how to conduct a meeting. The leader in the club was teaching me how to conduct a meeting and</p>	<p>1. When S5 was a child, her mother was very supportive and encouraged of her to be active in many different groups.</p> <p>2. S5 was 9 or 10 years old when she became involved in 4-H.</p> <p>3. S5 was elected as president of an inner-city 4-H group for girls at the first meeting she ever went in her life.</p> <p>4. S5 was the only child with a disability in the group.</p> <p>5. S5 did not know anything about 4-H and felt like she was just pushed onto the leadership platform.</p> <p>6. S5 was encouraged by her mother to serve as president of the 4-H group and that is how she started becoming a leader.</p> <p>7. S5 quickly learned to conduct a meeting by learning from the leader of the club.</p>
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how you make a motion—how to take a move on motion./

When you were at age of 10-16?

S5: No, that was the range of ages in the group. I think I was 9 years old.

Wow.

S5: Can you believe that?

No, but that's a wonderful experience.

S5: 8. If you believe in karma, I was just destined. (Inaudible) from there with every group that I have ever belonged to I was always president of it. What can I say?/ 9. So that was one thing about leadership but it took me a long time to learn what leadership really means./ 10. I'm not sure I'm ever wearing—one critical element of leadership and that is sustainability./ 11. Along the years, I learned how to organize. I've taken courses, I've studied under some really masterful organizers in all kinds of different venues. I've learned some fantastic techniques./ 12. I will go into a little more detail about some of the most meaningful leaders that I've been privileged to study under. The one thing that I really don't think I ever learned is how do you get an organization to sustain itself. That's hard. The one of the most critical and most impactful leaders that I ever worked with Justin Dart. Have you heard of him?/

Oh, yes. I love to meet with his wife because I'm from Japan.

S5: Oh! Okay. Are you Japanese?

Yes, I am.

S5: Oh, okay.

I read a background of Justin Dart. If I

8. S5 became a leader for every group she belonged to.
 9. Even though S5 had many experiences as a leader, she feels that it took a long time to learn what leadership really means.
 10. For S5 one critical element of leadership is sustainability.
 11. S5 learned how to organize all kinds of different venues and gained fantastic techniques.
 12. S5 worked with Justin Dart and she believes that he is one of the most critical and most impactful leaders for whom she has ever worked.

recall, he was the first person in Japan to hire women in the late '60's.

S5: 13. He's not only a good man, he mobilized women. He was a real trouble maker. He was in Mexico and he started a Free Speech Center in Mexico. He was making a lot of problems for his father who was this really conservative republican leader. Justin, at that time, was a liberal democrat. His father was trying to get him out of his hair so he gave him this mission impossible which was starting Tupperware in Japan./

That's right.

S5: 14. He would joke about what would be more impossible than trying to sell plastic pots to Japanese women. He discovered the greatest source of wealth that Japan had and that was the uncapped resource of their own women./

15. They had the women just sitting at home waiting on their men, and when he came there, he was teaching them how to sell things, how to organize, to get into support groups. They were doing this in small groups. Each group was part of a bigger group—you know how Tupperware works—that was his strategy that he did everything he did./ 16. He started with small groups of people; he showed them how to have things in their own power, their own capacity to be successful. Selling plastic pots was only the means for being successful./ 17. He always stressed about- What do you want to do with your life? Where do you want to go? This is just the way that you're going to get there./ 18. He built an empire over there. He brought Tupperware from zero up to something like a six million dollar industry in two years, which in Japan, in the 1960's, was amazing. It was a miracle./ 19. I'm not sure how much you know about his philosophy but he has this concept called the revolutionary industrial union or RIU. You have to change your ways when you sell first before you can change the world. When he was having this

13. S5 recalls that Justin Dart was a good man and mobilized women. He was a troublemaker and his father gave him a difficult task, which was starting Tupperware in Japan.

14. S5 recalls that Justin Dart discovered the great source of wealth that Japan had untapped resource in their own women.

15. Dart moved to Japan, taught women how to sell things, how to organize, and to get into support groups.

16. Dart started with small groups of people, showed them how to have things in their own power, their own capacity to be successful.

17. Dart always stressed what individuals want to do with their lives, where they want to go.

18. Dart built Tupperware in Japan as a six million dollar industry in two years. It was a miracle.

19. S5 admires that Justin Dart changed his own way and then changed the world. He gained Disability rights movement by organizing things to pass the ADA.

revolution, he spent his life studying about revolutionaries. He spent a lot of time studying [a name] and [a name] and Thomas Jefferson, all the revolutionaries along in history. He was a big fan of history. He realized that all of these people had to conquer their own demons first and change their own ways and then they were able to change the world. That's what he did in Japan and that's what he did in America when he came back here and he really gained the Disability Rights Movement with organizing power to pass the American Disability Act./ 20. I was very blessed to work for him at that critical moment in history. I got to know him just as he came back to the United States. This was in 1980. He and Yoshiko came back from Japan in the late '70's, I believe, and they were in Washington first then they moved to Austin, TX. That's when I met him./ 21. And then I started working for him in 1980. He invited me to come and live with him and his family and the ladies that they were helping. They would bring over Japanese ladies who were dealing with some kind of difficulty in their life and then he would help them, again, find their own power and be a success in their lives. Those ladies were helping me as my attendant and I was helping Justin as his assistant to help him organize his meetings and write—we did a lot of writing together./ 22. I helped Yoshiko was organizing the household. I used to do the grocery shopping. It was amazing. That was the most incredible four and a half years that I lived with them. That was the turning point for me./

Justin Dart was your mentor and someone you admired. Do I understand right?

S5: 23. Oh, yeah. Definitely, yeah. Also he—I mentioned that he was very radical, revolutionary disruptive kind of person. Sometime between the time he quit Japan Tupperware and the time that he came to the United States, there was a span of about 10 years, that he and Yoshiko lived up in the

20. S5 feels blessed to work for Dart at that critical moment.

21. S5 observed that Dart helped individuals, who were in difficulty, by finding their own sense of power to be successful in their lives. These individuals also helped S5 as her attendant, and S5 helped Justin Dart with organizing his meetings and writing.

22. S5 helped Dart's wife with organizing the household. S5 recalls the 4 1/2 years of living with Dart and his wife was the turning point for her.

23. S5 remembers that Dart changed himself for the 10 years when he and his wife lived in the mountains of Japan. S5 remembers that he changed his own behavior and lost about 200 pounds.

<p>mountain; they lived up on the side of Mount Fuji for that period of time and he did a lot of reflection. He really changed, really changed. He did a lot of thinking about how he could change his strategies and what does it take to make the change happen. He himself lost about 200 lbs. He was extremely obese. He lost an incredible amount of weight. You can imagine what kind of a revolutionary of his own behavior that must have taken. He realized that he was going to die and he could get control of his life. He did. Everybody was so amazed at how skinny he always looked./ 24. I thought if you only knew what he went through to get down to that weight. I really need to write more about my experiences with him because he was really amazing. I learned from him the tactics to use. How do you get a board to agree with something you want to do? How do you strategize? How do you decide what kind of an activity or strategy would be the right thing to use to get to the goal that you want to achieve? How to organize people? How to stage events? How to capitalize on the strengths of the people that you're working with. Really important leadership skills; really basic skills that you have to learn by watching a master. He was fabulous./ 25. He always made everybody on the movement feel valued. That's an invaluable skill to make people want to work with you./ 26. He used to ask people to do outrageous things, absolutely outrageous things, and people were so happy to do it. He would call them at midnight and say we really have to have a meeting. Can you call these 20 people and schedule a meeting for tomorrow at 2 o'clock? They would do it. I would tell him, "Justin, that was outrageous." He said, "Yeah, but they did it and they're happy to do it. That's because they love me so much because I make them feel valued. They're not doing it for me," he would say, "they're doing it for themselves."/ 27. He would always point out to them what they would benefit from everything. How they were going to benefit. So everybody felt they had an investment in what they were</p>	<p>24. S5 learned from Dart: how to get a board to agree with something she wants to do, how to strategize, how to decide what kind of activity/strategy would be right for the goal, how to organize people, how to stage events, how to capitalize on the strengths of people that you are working with. S5 believes that these important fundamental leadership skills could be learned by watching a master. Dart was a master of these skills.</p> <p>25. S5 recalls Justin Dart made everyone feel valued and believes this is an invaluable skill to make people want to work with you.</p> <p>26. S5 remembers that Dart asked people to do outrageous things and people were so happy to do it. She recalls that Dart used to say, "That's because they love me so much because I make them feel valued" and "they're doing it for themselves."</p> <p>27. S5 recalls that Dart always pointed out to others what and how they would benefit from doing things that Dart asked. S5 stayed up until 4 in the morning to get ready for the meeting</p>
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doing for him. I was (inaudible). I wouldn't even do this. (Inaudible). I was the one who had to stay up until 4 o'clock in the morning finishing all that work and getting ready for that meeting the next day. That's what I did for him for four years. I worked so hard you can't imagine./ 28. At the same time, I had another job and he encouraged me to go back to school and that's when I did my doctorate. I did an amazing amount of work. I was doing all the food shopping. I would wheel myself up to the corner—it wasn't the corner but I was a mile away in the food store, and then I would buy the groceries and the clerk at the food store would literally get some twine and tie the bags onto my wheelchair and then wheel it home. When those sidewalks (inaudible) side of the road we didn't (inaudible). Just ridiculous. It is the stuff you remember./

You had a wonderful example and you learned a lot from Justin Dart. Now you are a leader of various organizations and positions. What principles do you practice as a good leader?

S5: Just one?

No, no. Maybe a few.

S5:29. The most important one is to know what your goal is. That's really hard. Every group I am involved in is trying to change the world. That's not a good goal. It's not achievable. Yeah, you have to be a little more specific./ 30. Justin had this one goal of passing the Americans Disability Act. The whole time I worked with him and even afterward, because I stopped working, was when I moved to Houston, in 1984, he was doing all the preparatory work for it. The Americans with Disabilities Act didn't get passed until 1990 so that was laying the ground work for it then. But it always with that goal in mind./ 31. People with disabilities need a law to protect their civil rights. That is a very tangible,

that Dart was calling. She worked so hard for Dart.

28. S5 remembers that while she was working hard for Dart, she started her doctoral study. She remembers going grocery shopping in a wheelchair was difficult, but a good memory.

29. S5 believes that knowing a specific goal is most important.

30. Dart had a goal to pass the Americans with Disabilities Act, which actually passed in 1990. He was doing the preparatory work when S5 stopped working for him in 1984.

31. Dart had a tangible, achievable goal.

achievable goal. Changing the world is not achievable. He knew it was and he worked toward it./ 32. The only thing he said to me is beware when a person achieves their dream. Because what if you have it, what do you do next? It's really, really hard to keep the momentum going after you achieved your goal because you have to find another goal./ 33. I think the disability white woman is suffering now is because all they're doing is defending. It's no longer the proactive, aggressive kind of a movement; it's a defensive movement and it is much harder to get your momentum up for that. It is hard to be on the down side. In the '80's we were on the upside; we were fighting hard to our goal./ 34. Organizing a goal is the best thing. I think there's some fault in the leadership today; they don't have a proactive goal. I admire ADAPT, and that was another organization that I learned a whole lot from. I learned a lot from Wade Blank. Do you know him?/

No, I don't.

S5: He was a leader in ADAPT. Are you familiar with that?

Yes.

S5: You must know [a person].

That's right. [A state] has a chapter of ADAPT and yes.

S5: That's right./ 35. ADAPT is a national organization and their headquarters was in Denver and Wade Blank was the organizer that got it all started in Denver and then it fled nationally. Back in the '70's and '80's, Wade Blank was the organizer so I learned a lot from him too. Now, ADAPT is focusing on getting this—what do they call it—humanity support. It is part of the affordable healthcare. When you're trying to get rid of the institutional (inaudible). That's a very tangible goal so I

32. Dart taught S5 the importance of keeping the momentum going by finding another goal after the goal is achieved.

33. S5 sees that the current disability movement as defensive and aggressive, rather than proactive.

34. S5 sees that the leadership should have a proactive goal. ADAPT is a good example of such proactive goal.

35. ADAPT focuses on "humanity support" which is part of affordable healthcare. S5 admires ADAPT because that organization is working so hard for its tangible goal.

<p>really admire them working so hard working for that one goal. That's wonderful./ 36. Even when they achieve it, they're going to have a lot of work to do to enforce that goal. I think having that one goal is important./ 37. You ask about other principles. More recently I adopted the principle of non-violence. I have become more serious about it. It is very difficult because non-violence goes beyond using guns. Obviously we don't use guns. It also goes into your behaviors and the way you communicate. A non-violent means communication is very difficult./ 38. I have always had a problem with (inaudible) in that they use some very violent communication techniques like shouting down speakers, chanting so that someone didn't have a chance to talk. Those are techniques that were used in the Civil Rights Movement. That is legitimate in certain context./ 39. I was at meetings where they didn't want people to have the podium (inaudible) by chanting and shouting so we couldn't be heard. That's violent. I'm trying to be more careful now./ 40. I still lose my temper. I get very, very angry about things because it is so frustrating now. We're living in times that are right (inaudible) fascism. We're seeing factious things happen especially here in [a state]. It's terribly frightening./ 41. We're living in times when (inaudible) to the 1930's with the rise of the Nazism. It's very, very similar./ 42. For me, being a progressive democrat, and valuing things like prestige and equal opportunity and civil rights, the majority of the population of [a state] is dedicated to eradicating those things that I hold dear. How am I not supposed to get angry? What am I supposed to do when they're angering me? And to not have violent communication is my most difficult struggle right now./ 43. Especially when I am doing work around health care reform; I have a goal there and I have to keep telling our organization, "Let's go out and just try to preserve Medicaid," we're pushing for national health insurance for everybody. There's not going to be a part-time system where some</p>	<p>36. Even when the goal is achieved, work to enforce the goal is also important. Having one goal is important.</p> <p>37. A non-violent communication is difficult but important to S5.</p> <p>38. S5 used to shout down speakers and chanting, which she calls "violent communication techniques."</p> <p>39. S5 encountered some people chanting and shouting at meetings.</p> <p>40. S5 loses her temper and gets angry.</p> <p>41. Some activities, which are happening in her state, frightened S5 and reminded her of 1930's Nazism.</p> <p>42. S5 is a progressive democrat and values equal opportunity and civil rights. However, S5 feels that many of the people in her state appear to want to destroy these opportunity and rights, which make S5 angry.</p> <p>43. Currently, S5 is pushing for national health insurance for everyone as her goal. S5 observes that prejudice against people with disabilities come out during this debate and that fact makes her angry. However, she tries to maintain a non-violent communication approach, which is challenging for her.</p>
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people get 2nd or 3rd degree health care, but we all get the same health care. National health insurance is our goal. We get so much bias, so much prejudice and reaction to what we're trying to do, and it's based on lies, it's based on misinformation, and frankly it's based on racism too. A lot of prejudice against people with disabilities comes out and it just makes me so angry. So I am trying to maintain a non-violent communication approach and it is so hard for me. I try to keep the principles of non-violence./

Does non-violence mean not aggressive?

S5: 44. Not necessarily. You can be aggressive. You have to draw the line at when you disrupt the rights and equality of other people. My life should not—how do I say this—honoring my rights should not make me dishonor your rights. If I—by pushing for my rights, I'm advocating your rights then I've committed an act of violence. So when I'm shouting you down so you can't talk, I committed act of violence because you have the right to talk just like I have the right to talk./ 45. If I truly believe in free speech, then you have just as much of a right to talk than I do. As much as I disagree with you and as much as I think what you believe is based on lies, you still have a right to talk.

So it's a balance act of honoring people's rights.

S5: Right. I can be aggressive. I can be—aggressive is a forceful advancing of your rights. I can be forceful. It's like two bulls in a ring and they lock their horns. You understand?

Yes.

S5: Both of them are being aggressive and they're not really getting anywhere if they've got their horns locked. A more possessive

44. It is important for S5 to honor her rights and other people's rights. She draws the line between disrupting the rights and quality of life of other people.

45. S5 believes that people should have a right to talk despite disagreement. She can be aggressive and forceful to advance her right and those of others.

approach is convincing, to convince somebody. You really don't get there with aggression you get there by convincing. I like to think they get there by logic but in this day and age people are not convinced by logic. Some people are. People who were raised to think logically can be convinced by logic but 60% of the population in [a state] was not. Those are the ones that elected (inaudible). They don't know the first thing about logic or else they wouldn't have elected him. The man is evil. Anybody who elects somebody who's evil is not basing their vote on logic; they're basing it on something else./ 46. I put it as fear. Now when you've got somebody who's acting on fear, then you have to use a different approach entirely. Just an example, we had a little girl visiting our house yesterday—you heard my dog in the background and she has a very, very loud bark and she is harmless—this little girl was so afraid of my dog and I tried to reason with her. I tried to tell her that she has a very loud bark but she is a sweet dog and come and pet her, she won't hurt you. That little girl would have nothing to do with my dog. Just the presence of my dog terrified her. Logic is not how you approach somebody at that level of terror. That's the state of Texas and the United States right now; people are reacting to everything on the basis of fear. So we can't use logic. Somehow we have a new dimension but we have counter it with productive emotions, not emotions based on fear and tribalism./ 47. Justin used to talk a lot about tribalism and barbarism. He used to call our society "technology and power barbarism." I'm afraid that's what we got. The internet is such a valuable tool for social networking and communication but the barbarians are using it too. They're empowering the fear-based campaign. I'm afraid that too many of us who don't respond to fear campaign are just sitting back and letting them have free reign. People who were not raised to think rationally are falling victim into that. And then they elect (inaudible) into political power and that is

46. S5 observes that people are acting out of fear regarding the national healthcare insurance for everyone. As an example she recently met a girl who was afraid of S5's sweet-tempered dog just because the dog has a loud bark. She feels that Texas, where she lives, and the United States in general are acting on the basis of fear.

47. S5 is afraid that too many of us, who don't respond to a fear campaign, just don't do anything. She believes that is seriously dangerous.

<p>seriously dangerous. So, you're asking about principle anyhow./</p> <p>Yes.</p> <p>S5: 48. My other principle is, in addition to being non-violent, it was (inaudible). Let me think about this. This is good, I should write this. My other principle would be to use positive productive emotions to convince people to join our campaign./ 49. I got a lot of different campaigns that I work on but the principles are all the same. I've got the campaign of Advance Women with Disabilities, I've got the campaign to work toward national health insurance and I've got the campaign to prove research on health for women with disabilities and the whole disability rights thing. But it is all the same strategy. Somehow we have to get people to join us using productive, positive emotions./</p> <p>Your principles have been implemented in various areas. Those principles have been influenced by your mentor, Justin Dart. Am I on the right track?</p> <p>S5: Yes. I've had other mentors as well.</p> <p>Who are those people?</p> <p>S5: 50. My academic advisor at the [university] was very influential. And he was just the opposite of Justin Dart.</p> <p>In what way?</p> <p>S5: He was very academic, soft spoken, mild mannered. (laughing) He tolerated me.</p> <p>You saw the opposite side from Dustin Dart.</p> <p>S5: Opposite, absolutely. The opposite. He was so encouraging of me. He really helped me along with my career. My career has been as a researcher./ 51. Justin helped me as an</p>	<p>48. It is a principle for S5 to use positive productive emotions to convince people to reach her goal.</p> <p>49. S5 conducted many different campaigns. However, she always uses positive, productive emotions as an effective method to further her campaigns.</p> <p>50. S5's academic advisor at the university was very influential in her development. She recalls that his temperament was the opposite of Justin Darts. His approach as an advisor was to encouraging and helped her research career.</p> <p>51. While S5 learned from Justin Dart to be an</p>
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advocate. My academic advisor's name is [a person] at [an university] in [a city]. He opened doors in academia for me. He helped me get established in organizations. He encouraged me to travel. He gave me my first break when I had to present at an academic conference. He taught me some skills to do good competent research. He taught me how to ask the right questions. How to approach research when you don't even know what the question is what you should be asking. That is more valuable than anything./ 52. The biggest pitfall I see. It burns me up when I have to review articles where the researcher is asking a question that is irrelevant. If they're irrelevant therefore they're finding is irrelevant and therefore what they've done is a waste of tax payer dollar and a waste of my time because they never took the time to ask the right question./ 53. When I work with doctoral students and when I teach, I focus so heavily on that. If you don't know what the question is then ask people in your population that you're studying. Ask them, listen to them. That's what you're doing right now and that's why I am a strong advocate of quality research./ 54. That's how we got started in our women's research. We started with interviews. We didn't know what to ask. Nobody had every studying this before. No one ever knew science. All that was out there was anecdotal, hearsay, that was it. But we got together—well we didn't get together, we individually went to 31 different women and we just listened. Issues arose that we never anticipated. From that, we based almost 20 years of research./

It sounds to me that you had a great example from an advocacy point from Justin Dart but you also had a wonderful mentor and a good model from an academic side.

S5: Yes.

I would say that you are very lucky.

advocate, she learned from her advisor to be successful in academia. He opened doors in academia for S5, helped her get established in organizations. This advisor also taught her to present at an academic conference and to conduct good competent research, and to ask the right questions.

52. S5 gets frustrated at research that asks irrelevant questions. She thinks that such research is a waste of tax payer dollars and a waste of her time because the researcher did not take the time to ask the right question.

53. S5 values asking questions and listening to people when the researcher does not know what to ask. She claims she is a strong advocate of quality research.

54. S5 started women's research by conducting interviews. She went to 31 different women and just listened to what they had to say. Then issues arose that S5 never anticipated.

S5: I am. I can't tell you how lucky I am.

You took opportunities and then learned from those opportunities. You are practicing what you learned from those mentors.

S5: Yeah.

That's wonderful.

S5: 55. The one area that I don't have a good mentor and I wished I did and that's someone in the women's movement. I just picked it up here and there but I don't have a good mentor. I can't say when I have a question I go to this person because I don't have that person./

Is it because of the lack of female leaders? Why would that be?

S5: 56. I came into it very late. I was so obsessed with disability rights, I never was aware of my women's rights. I learned about that. I was well into my 40's. That's pretty late to be coming into your womanhood. I'm not talking about sex. Sex was there but who am I as a woman beyond my sexual being./ 57. Who am I as a woman and what does it mean to be a woman and the powers that come with womanhood? Why is a woman different than a man? How is a woman different from a man? How is a woman made different to respond to stimuli different than a man? I never understood that and I have only learned that from work./ 58. There's been no groups. The women's rights—women's movement has not been open to me./ /It's not their fault necessarily. I know other women who have intimately—who live on the west coast or east coast. Here, in the central part of the country, it's not been an opportunity that's been open to me./ 59. Disability Rights was totally male dominated; there were no—there were definitely women leaders but they weren't talking about feminism. They were always

55. S5 feels that she does not have a good mentor in the women's movement. She would ask other for suggestions but does not have a specific individual to ask for guidance.

56. S5 was "so obsessed" with disability rights and learned about her women's rights in her 40's. She believes that it was late for her to come into her womanhood.

57. By learning about the womanhood, S5 questions, such as "who am I as a woman, why is a woman different than a man, how is the woman different to respond to stimuli different than a man."

58. S5 feels that the women's rights or women's movement was not open to her. Although she know other women who have been involved in the women's movement, she feels that she did not have an opportunity to get involved in the central part of the country where she lives.

59. S5 saw that disability rights issues were heavily male dominated. There were women leaders in the disability rights; however, these women focused on disability, not women or

<p>talking about disability rights. (Inaudible) make sense. We were always disabled first./</p> <p>60. We could name all the heavy-hitter women like [a person]and [a person] and [a person] and all these really heavy women disability rights movement and they will probably feminist in their own right but what have they done to advance women in the movement? Nothing. For me, that's another source of anger./</p> <p>I see.</p> <p>S5: 61. By working (inaudible) I have come together with a lot of very powerful women and every time we hold an event, every time we do anything (inaudible) result of our research, we get a huge positive response from women. I'm just not as successful in organizing that. This is sort of my work that can be done./</p> <p>Thank you for sharing your experience with me. To me it's fascinating. I also feel like I learned how you shaped up your leadership from your experience and philosophy.</p> <p>S5: Sure. It's my pleasure. You didn't ask me about my failings as a leader.</p> <p>No, I did not.</p> <p>S5: You didn't think I would want to go into.</p> <p>No. I don't want to take up your time. If not, please tell me some failing stories. It is helpful to know your successful and unsuccessful stories.</p> <p>S5: You learn as much from that (failure), right?</p> <p>That's true.</p> <p>S5: Yeah. I have two short ones. 62. One is I went on a luncheon tour of Japan, actually I did</p>	<p>feminism.</p> <p>60. S5 thinks of several women who have been very active in disability rights. However, she thinks that these women did not advance women in the disability rights movement. This makes her angry.</p> <p>61. S5 met with many powerful women through her work and received a large amount of positive response from women. However, she feels that she is not as successful as she wanted to be and there is room for improvement.</p> <p>62. S5 has two incidents that she considers failures from which she learned lessons. One</p>
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it twice. It was a two month-long luncheon tours of Japan that Justin helped me set up. This is after I moved to [a city] I was working here at [an institution] but I still had very strong ties to Justin and Yoshiko and to Rehab International so it started with their conference. I went to that in Japan in 1989 or something. I tagged onto that a tour. So I went around to different cities in Japan. I went to [a city]./ 63. I talked to different groups of people with disabilities and also to some of the groups and rehabilitation professionals. I was doing it in Japanese because I was studying Japanese at that time as well. They were so impressed having an American speaking Japanese. It was really fun./ 64. That's when (inaudible) independence. Not one of them said to me independence. I saw that in the 1980's, in Japan, that was really at the beginning of the Japanese independent living movement. I realized there that many of the people who were listening to me were either writing me off as somebody who didn't what she was talking about or actually got angry with me about not understanding their situation. That was the first time I got an awareness of what works for me and what works here in the United States isn't necessarily going to work in another culture. That was an awakening for me at that cultural relevance./ 65. One of the times I went I was doing a fellowship and I was studying about attendant care. I was trying to figure out how do people in Japan with physical disabilities get their attendant needs met. I was discussing that a lot of them had friends helping them. They didn't teach them anything; they just had friends helping them. They came up with this notion that helping is a natural extension of friendship. That just shook me to my core. I never could understand that. That is such a cultural thing. It wouldn't work, ever, in my cultural circle here in the United States. So I think that cultural awakening is a real important part of the development of a good leader. I think I'm a little better but I still have a really long way to go in (inaudible) in

was her visit to Japan for a two month-long luncheon tour in late 1980's.

63. S5 talked to different group of people with disabilities and rehabilitation professionals.

64. While she was traveling in Japan, no one mentioned independence to her even though it was at the beginning of the Japanese Independent Living movement. Some of these individuals did not want to listen to her and became angry with her because they thought she did not understand their situation. From this experience, she learned that things that work in the United States are not necessarily relevant to another culture. This experience was "an awakening" for her about cultural relevance.

65. When S5 was studying about personal care attendance for Japanese people with physical disabilities, she learned that their friends helped them and that helping is a natural extension of friendship in Japan. She thinks that cultural awareness is an important part of the development of a good leader. She believes that she needs to improve in this area.

everything I do./ 66. The other one I just want to go back briefly about sustainability. I'm at a crisis point right now in my research and in my work because my work with Women with Disabilities because the money is not there. My office at [an institution] is without money starting January of next year./ 67. I'm either going to have to pursue what I want to do without money and thankfully, with Justin, I learned some good things for doing that so I'm going to be implementing some of those ideas. Money (inaudible) is always relatively easy. I ran (inaudible) anywhere from \$750,000 a year to \$1 million a year to fund my research in the center we've been running. Now I'm down to zero./

Wow!

S5: 68. Yes, yes. Because it's just me and physically I'm not able to do the traveling needed to make those connections. I don't have the stamina to stay up all night and write grant proposals when the deadlines are very tight. I just can't do that anymore. I'm having to really change my strategy. I'm having another chance now to implement this revolution. I need this to look for a different way to reach the same goals but trying to do it in a much, much, much less money./ 69. So to reconceive this notion of sustainability. Justin always used a frightening example of (inaudible) who had his revelation start in a cave with one mimeograph machine and that's how the Chinese Revolution started. It had nothing to do with what he was printing; it's got all to do with his strategy. He did it with no budget. If he can do it I can do it./

I see, you have been empowered.

S5: Yeah, I've been empowered. I'm creative now. Thank you. Good luck with your dissertation.

Thank you so much. I appreciate your time.

66. The other failure experience is related to sustainability. Currently, she is at a crisis point in her research and work because she has no funding starting next year.

67. S5 has to decide what to do without money. However, she feels thankful that she learned ideas of how to deal with crisis in the past from her mentor Justin Dart. Thus, she plans to implement those ideas.

68. S5 has come to a conclusion that she needs to change her strategy. She sees this difficult time as another chance to implement a revolution. She feels that she needs this opportunity to look for a different way to reach the same goals with much less money.

69. S5 believes that she can handle this difficult time and make it sustainable because her mentor demonstrated an example. He started his own revolution with no budget.

Level Three (Narrative Based on Emergent Themes)

When Emma was a child, her mother was very supportive. Her mother encouraged her to be active in many different groups and she joined 4-H when she was nine years old. At her first meeting, she was elected as president of an inner-city 4-H group for girls. That meeting was the first meeting she ever went in her life.

Emma was the only child with a disability in this 4-H group. She did not know anything about 4-H and felt like she was just pushed onto the leadership platform. Her mother encouraged her to accept the president position for the 4-H group. She quickly learned how to conduct a meeting from the leader in the club. Since this experience, she became a leader for every group she belonged to.

Even though Emma had many experiences as a leader, she feels that it took a long time to learn what leadership really means. For her one critical element of leadership is sustainability. She learned how to organize all kinds of different venues and gained fantastic techniques.

Emma worked with Justin Dart Jr. For her Dart is one of the most meaningful leaders that she studied under. She believes that he was one of the most critical and most impactful leaders that she ever worked.

She recalls that Dart was a good man and mobilized women. He was also a trouble maker for his family who was conservative republican. His father gave Dart a difficult task which was to establish Tupperware in Japan. Dart moved to Japan. He discovered that many Japanese women were staying at home waiting for their husbands come home. He saw these women as the great source of wealth that Japan had not have discovered. Dart taught those women how to sell things, how to organize, and how to get into support groups. He started with small groups of women, showed them how to do things by themselves and how to succeed in their own capacity.

Emma recalls that Dart always stressed what individuals wanted to do with their lives and where they wanted to go in their lives. He built Tupperware in Japan as a six-million-dollar industry in two years. She admires that Dart practiced the concept of the revolutionary industrial union (RIU) and changed his own way and then changed the world. She remembers that Dart drastically changed himself during those ten years when he and his wife lived in a remote mountain village in Japan. She recalls that he changed his own behavior and lost about 200 pounds of his weights. She believes that his practice empowered him to move the Disability rights movement forward and to help pass the Americans with Disabilities Act of 1990.

Emma feels blessed that she had worked for Dart at the critical moment in the United States' history. She started working for him in 1980 when he and his wife Yoshiko moved to Texas after they returned to the United States from Japan. Dart invited her to live with him, his family, and some women who were helping him. She observed Dart helping others, who were in difficulty, by finding their own power and finding their own way be successful in their lives. These individuals also helped her as her attendant, and she helped Dart with organizing his meetings and writing. She also remembers that she helped Yoshiko with organizing their household. Living with Dart and Yoshiko in four and a half years became the turning point for Emma's life.

She learned from Dart: how to get a board to agree with something she wants to do, how to strategize, how to decide what kind of activity/strategy would be right for the goad, how to organize people, how to stage events, how to capitalize on the strengths of people that you are

working with. She believes that these important fundamental leadership skills could be learned by watching a master. Dart was a master of these skills.

She recalls Dart made everyone feel valued. She believes making people feel valued is an invaluable skill as a leader. She remembers that when he asked people to do outrageous things, people were so happy to do his request. She recalls that he used to say, "That's because they love me so much because I make them feel valued" and "they're doing it for themselves."

Emma recalls that Dart always pointed out to others what and how they would benefit from doing things that he asked. She stayed up until 4 in the morning to get ready for the meeting that Dart was calling for. She acknowledged that she worked so hard for him but it was rewarding.

She started her doctoral study while she was working for Dart. She remembers how difficult it was to go to grocery shopping with a wheelchair. However, such small thing became a good memory for her because it was rewarding. She worked with Dart until 1984.

Emma believes that a good leader knows setting a tangible, achievable goal is critical. Dart had a specific goal: passing the Americans with Disabilities Act. He also taught her the importance of keeping the momentum going by finding another goal after the goal is achieved.

She perceives the current disability movement as defending and aggressive rather than proactive.

She believes that leaders should focus on one proactive goal. It is critical for her to continue the work to enforce the goal after the goal is achieved. For example, ADAPT, a grassroots disability rights organization, is currently focusing on "humanity support" which is a part of the affordable healthcare in the United States. She admires ADAPT's significant effort to achieve its tangible proactive goal.

She perceives her as a progressive democrat. She values equal opportunity and civil rights. Some activities that are occurring in Texas, where she resides, have frightened her and have remind her of the 1930's Nazism. She feels that some people in Texas appeared to destroy the equal opportunity and civil rights. Those behaviors make her angry.

Currently, Emma is pushing for national health insurance for everyone as her goal. She and her team receive bias, prejudice, and strong reaction from others to what they are trying to do. She observes that prejudice against people with disabilities have come out and has made her angry. However, she tries to maintain a non-violent communication approach, which means she tries not to shut down speakers or not to interrupt them by chanting. This approach is challenging for her to practice. However, this communication style is important to her as a leader.

It is important for her to honor her rights and other people's rights. She can be aggressive and forceful to advance her right and others. She draws the line between disrupting the rights and quality of other people. She believes that people should have a right to talk despite disagreement.

Emma observes that many people are acting on fear regarding the national healthcare insurance coverage for all US residents. As an example on people's acting on fear, she recently had a girl who was afraid of Emma's sweet-tempered dog just because the dog had a loud bark. She feels that her state and the United States overall are currently acting on the basis of fear regarding the national healthcare topic. She is afraid that too many of people don't respond to fear campaign. She believes that is seriously dangerous that many just do not do anything about it.

It is a principle for her to use positive productive emotions to convince people to reach her goal. She conducted many different campaigns. She always uses positive, productive emotions as an effective method to encourage others to join her campaigns.

Addition to Justin Dart Jr., her academic advisor at her university was very influential to her. She recalls that his demeanor was opposite from Dart and he was encouraging and helped her research career.

While Emma learned from Dart to be an advocate, she learned from her advisor to be successful in the academic field. This advisor opened doors in academia for her, helped her get established in organizations. This advisor also taught her to present at academic conferences, to conduct good competent research, to ask the right questions.

She becomes frustrated at research that is asking irrelevant questions. She thinks that such research is a waste of tax payers' dollar and a waste of her time to review it because the researcher did not take the time to ask the right question. She values asking questions and listening to people when the researcher does not know what to ask. She claims her as a strong advocate of quality research.

In the past, she conducted her research on women by interviewing thirty one women. She visited those women and just listened to what they had to say. As a result, her research brought up interesting issues that she never anticipated.

She feels that she does not have a good mentor in the women's movement. She would ask other for suggestions but does not have a specific individual to ask for guidance. She was "so obsessed" with disability rights and learned about her women's rights in her 40's. She believes that it was late for her to come into her womanhood. By learning about the womanhood, she questions, such as "who am I as a woman, why is a woman different than a man, how is the woman different to respond to stimuli different than a man."

She feels that the women's rights or the women's movement was not open to her. Although she knows other women who have been involved in the women's movement, she feels that she did not have an opportunity to get involved due to where she lives. She also believe that disability rights issues were heavily male dominated. There were women leaders in the disability rights; however, these women focused on disability, not women or feminism. She thinks of several women who have been very active in disability rights. However, she thinks that these women did not fully advance women in the disability rights movement. She met with many powerful women through her work and received positive responses from women. However, she feels that she is not as successful as she wanted to be. Advancing women is an area of improvement for her.

Emma has learned a lesson from two incidents. One was her visit to Japan in last 1980's while she was engaging in luncheon tours for two months. She talked to different group of people with disabilities and rehabilitation professionals in Japan. During her visit no one mentioned independence to her even though it was at the beginning of the Japanese Independent Living movement. Some of them did not want to listen to her and became angry at her because they thought she did not understand their situations in Japan. From this experience, she learned that things that work in the United States are not necessarily relevant to another culture. This experience was "an awakening" for her to recognize the cultural relevance.

By interacting with people with disabilities in Japan, she also learned friends of people with physical disabilities helped them as their personal care attendants. She learned that helping is a natural extension of friendship in Japan. She believes that cultural awareness is an important part of the development as a good leader. Increasing cultural awareness is another area of improvement for her.

She has learned a lesson from her experience that is related to sustainability. Currently, she is at a crisis point in her research and her work because there will be no funding next year.

She has to decide what to do without funding. However, she has some ideas to handle this crisis and plans to implement them. She is thankful to her mentor Justin Dart Jr. because he taught her to deal with crisis. He showed her a good example of his revolution with no budget.

By encountering the current crisis, Emma has concluded that she needs to change her strategies. She perceives this difficult time as an opportunity to implement a revolution. She feels that this crisis will give her an opportunity to look for a different way to reach the same goal with much less money. She also believes that she can handle this difficult time and can make it sustainable.

Appendix I

Data Analysis

Frank: Levels One to Three

Frank (S6), Level One and Two (Spontaneous Meaning Units)

I am interested in learning your important experiences or relationships in your life that led you to become a leader. Would you tell me the title of the leadership position or positions that you have or had?

S6: 1. You know, I feel like I have been around for so long. I have been involved in a lot of groups and at one time or another seem to gravitate to the top. Usually because or often times because nobody else will. I have been on several Boards and been the President of the Boards. [An organization] actually back before it was [an organization], I was the President of their Board. I was on the State Independent Living Council in a leadership capacity there. I am currently the President of the Board for [an organization]. I think more importantly than that are my less formal, at least as far as titles go, forms of leadership./ 2. I am part of an organization called ADAPT that is a National organization fighting for disability rights and primarily right now fighting with Congress to end the institutional bias in long-term care. I have been involved with ADAPT since 1993 and have gotten over the years to a position where I am probably one of 10-12 folks that are considered kind of the core-leadership group for the nation. We kind of set the agenda for meetings—it's kind of hard to explain, but we kind of lay out the outline for strategic meetings that ADAPT will come to and then a larger group of folks will then decide what we are going to do./ 3. I am part of that leadership and often times when we do, at least twice a year, we have National actions or we will go to Washington D.C. or somewhere else and have protests and engage in civil disobedience./ 4. Often times I will be one of the leadership that are directing people, contacting the police, contacting the press, and being in that sort of situation. The leadership part, a lot of that

1. S6 has been involved in a lot of groups and has gravitated to the top. He has been on several boards and President of the boards because often times nobody else would take on such leadership roles. He has served leadership roles for three state organizations.

2. S6 has been involved in ADAPT, a national organization that fights for disability rights and for ending the institutional bias in long-term care for people with disabilities. He is one of 10-12 individuals in the core-leadership group. This group lays out the strategic outline for ADAPT.

3. S6 is part of the leadership and is involved in national actions in Washington DC and elsewhere conducting protest and engaging in civil disobedience.

4. S6 takes a leadership role by directing people, and contacting the police and the press. He holds this leadership role since he became involved in ADAPT. S6 observes that participants in ADAPT come and go. He has

really came from just being involved for as long as I have. People come and go so you kind of rise to the top and also having the passion./ 5. I have been in human services for most of my adult life and have worked with folks with really significant disabilities. A lot of folks who have been in institutions, nursing homes, group homes and then moved on to their communities./ 6. I am very concerned about the policies that we have that keep people with disabilities down, particularly people with cognitive disabilities or communication disabilities that keep them down and keep them incarcerated for nothing other than the crime of having a disability. So it really is a passion for me and I think that is what has kind of led me to the top as well as being somewhat of a policy wonk. I like to get in there and understand what the policies are: federal, state, and local and how we can change them and make them better./ 7. Then having quite a bit of experience in being involved in developing policies and changing policies in one way or another related to folks with disabilities. Did that make sense? I start to ramble sometimes.

Where did this passion come from?

S6: 8. Well, I was injured when I was 16 in a car accident. It was the end of my junior year in high school. For probably about 8 years, maybe 10 years, I think I was going through the world sort of aimlessly. Didn't really know what I wanted to do./ 9. A year post-injury I was over here going to college and everybody else was directing my life, "You know, this is what you should take. You're in a wheelchair now you have to find a desk job." Being told by Deans that I can't do that because nobody would hire me./ 10. So it was very frustrating and I remember multiple times, but once over here or actually several times over here, in my enjoyment going out and enjoying the community and going to local taverns and often times being carried into a place because it

risen to the top and maintaining his passion.

5. S6 has been in human services for most of his adult life and has worked with individuals with significant disabilities, who have been in institutions, nursing homes, group homes, and eventually moved to their communities.

6. S6 is very concerned about the policies that affect people with cognitive disabilities and communication disabilities. These policies keep those individuals down and incarcerated them just because they have a disability. Changing such the policies is his passion and led him to be a leader. He likes to understand the federal, state, and local policies and to make them better.

7. As a result, S6 has many experiences in developing and changing policies that are related to people with disabilities.

8. S6 was injured by a car accident when he was 16 years old during his junior year in high school. He went through "the world of aimless" about 8 to 10 years after this accident. He did not know what he wanted to do in his life.

9. S6 went to college one year after the car accident and felt that everyone else was directing his life. He uses a wheelchair and was told by Deans at the college that nobody would hire him.

10. S6 enjoyed going out to the community and going to local taverns. However, these locations were not accessible, and he was often carried down the steps to get to these places. He got to the point that he thought that those places should be accessible if they wanted

wasn't accessible. Actually, I was going to school before they had the lift into [a college cafeteria] so I had to be carried down the steps to get in and eat.

Because there was no lift to get to the college cafeteria?

S6: At that point there wasn't. Often times you would come in from the back and in the winter it was icy. The friends who were carrying me down would slip. I would crash and freak everybody out inside. We thought it was funny, but there were enough of those instances that I got to the point that I thought, "If somebody wants my business, they will make their place accessible."/ 11. It was sort of my own protest that I was no longer going to go into businesses that weren't accessible. 12. The only sort of deviation that I would make from that is if it was somebody's home. We are still a long way away from accessibility in single-family houses, but I don't visit a lot of my friends because they aren't accessible./ 13. That was kind of the beginning of it and I think the passion not only came from my protest, but the more that I got jobs in Disability Services./ 14. I worked for a Center for Independent Living back in [a city] area and worked with a lot of folks who, again, had significant disabilities and didn't have the services that they needed./ 15. Then I moved on and worked for an Association for Retarded Citizens, ARC, in [a city] and there I was working with folks who couldn't speak, who had been in institutions, had been abused, had been in nursing homes. I got to realize that folks were much more intelligent than anyone gave them credit for./ 16. I had the privilege of working with someone I considered to be one of my major mentors other than my wife, he was my boss at the time, he was always asking the question, "Why do we have to go to better before we get to best?"/ 17. There is no reason why somebody has to go from an institution to a nursing home to a group home to their own

business and him as a customer.

11. As his own protest, S6 stopped going to or using businesses that were not accessible to him.

12. S6 accepts the fact that many single-family houses are still not accessible. However, he does not visit a lot of his friends because their houses are inaccessible.

13. S6 believes that his passion came from his personal protesting experience and his employment in disability services.

14. S6 worked for a Center for Independent Living in Detroit and worked with people with significant disabilities who did not have the services that they needed.

15. Then, S6 started working for an Association for Retarded Citizens (ARC) and worked with people who could not speak, have been in institutions, have been abused, and had been in nursing homes.

16. S6 considers his wife and his boss at the time as his major mentors. This boss always asked the question, "Why do we have to go to better before we get to best?"

17. S6 believes that somebody can go from an institution to his or her own home, instead of first going to an institution, nursing home or

home. They can go from an institution to their own home./ 18. Then in school, there is never—people with disabilities always have to prove that they are worthy of something better. Where the general population, you have to start out with the assumption that you are good, then you get pushed back if you are not. So it just didn't seem right./ 19. Again, I was with [a name], my boss, I was able to get connected with a lot of people at the state and national level in [a state] across the country that held those same beliefs and, again it's like when you're working with and becoming friends with the most significant disabilities then it's like if we can do it for them, someone who has a spinal cord injury, it's no big deal./ 20. Or someone who has a single digit IQ, get them to be able to live in their own home and have their own job, then there should be no problem with getting someone who uses a wheelchair and is a paraplegic or quadriplegic. I think that's where really the passion came from. I've always been just "civil rights" minded./ 21. I remember having—I have a bunch of relatives that live in [a city]. I remember being a young teenage and they would come up and visit and I would get into discussions/arguments about segregation./ 22. It didn't make sense to me why black kids had to go to one school and their kids had to go another and I would say, "Well, why can't the black kids go to the school that you're kids go to?" "Oh their schools are fine." And I would say, "Why don't your kids go there?" "Well, we don't want to do that." So I have always been going against most of my families' policies and what they would consider the black-sheep of the family./

In a good way.

S6: I think so, but—and I think they probably do, for the most part now looking back.

Did somebody influence you, in a good way, to be a black sheep?

group home.

18. At school, S6 believes that people with disabilities always have to prove that they are worthy of something better. He believes that it seems to be wrong that people with disabilities are assumed that they are not good.

19. Through S6's boss, he was able to get connected with many people at the state and national level. He got connected with those who held the same beliefs and became good friends with those who have significant disabilities.

20. S6 has been "civil rights" minded because he wanted to improve quality of life for someone who is paraplegic or quadriplegic, who has a single digit IQ or who uses a wheelchair.

21. S6 recalls that as a young teenager he used to get into discussions or arguments with his relatives about segregation.

22. S6 did not understand why black children had to go to a different school. He has always been going against most of his families' policies. He has been considered as "the black-sheep of the family."

<p>S6: Not early on, as I said. 23. To a large degree, from a Civil Rights perspective, I have just always sort of been progressive liberal or whatever label you want to put on that./ 24. I think professionally, [a person] who was my boss at the Association for Community Advocacy which was the ARC, was the one that really instilled in me that going from straight to best. He was the one who really got me on that line./ 25. There are a number of folks. My wife, [a name]. She has been working in disability for probably longer than I have, or at least as long and her expertise is Social Security. She has been fighting for folks that people would say, “No, they don’t deserve the Social Security.” Again, she fights and ensures that they get all of the rights they are entitled to. From an advocate perspective, there’s not a stronger advocate. She is kind of like a pit-bull, once she gets a hold of your arm, she’s not going to let go until you say “yes.”/ 26. I think the one other person—there really are so many, but I think once, for me and I think for a lot of people, once you get to a certain point where you are headed in a direction that it’s going to end up being a leading role or into leadership, then you start to surround yourself—and I think that if you are a good leader, then you surround yourself with other people who are like-minded, but also that ask questions about what you are doing that also make you a better leader. For me, that is so true with ADAPT./ 27. The founder of ADAPT was a person named Wade Blank who was a reverend and he was involved in the Civil Rights movement back in the ‘60’s. He was at Ken State when the shootings happened in the early ‘70’s and sort of wanted to get away from all that and move to Colorado and started moving people out of nursing homes./ 28. I got to meet him once before he and one of his sons passed away. They were on a vacation and the son got caught in a riptide and got pulled down. Wade went in to save him and he got caught and they both drowned. That was</p>	<p>23. S6 sees himself as progressive liberal from a Civil Rights perspective.</p> <p>24. S6 believes that his boss at the Association for Community Advocacy, was influential and instilled in him the idea of going straight to best.</p> <p>25. S6 also believes that his wife, also influenced him. His wife has been working in disability and Social Security for longer than he has. S6 compares his wife's advocacy style with a pit bull - once she gets the person, she will not let go until the person says "yes."</p> <p>26. S6 got to a certain point where he was headed in a direction and started to surround himself with like-minded individuals. He believes that he surrounds himself with other people who are like-minded, asks questions about what he is going to make him to be a better leader. He experiences this through ADAPT.</p> <p>27. S6 remembers the Reverend Wade Blank, who was involved in the Civil Rights movement in the 60's. Blank started moving people out of nursing homes in early 70's in Colorado.</p> <p>28. S6 met Blank once before he and one of his sons died from being drowned by trying to save his child in a riptide. His meeting Blank occurred 4 months after he became actively involved in ADAPT.</p>
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about 4 months after my first ADAPT action./ 29. But he was somebody that immediately when you saw him there was like love, compassion, understanding, he was just one of those people that he was a born leader and instilled in other the power to be leaders themselves./ 30. Starting with him and then other folks, there are people in [a state] and people in [a state] and people just all over the country that I think that we are just all called "mentors" to each other and we continue to grow as the movement grows and continue to try and find new ways to do things. There are a whole bunch of people—very few though, [a person] and my wife, Wade Blank, but nobody really early on. It was pretty well into my professional life before./ 31. I guess I always felt like I was—I was always asking the questions. I don't know, now that I think about it, very unusual and puzzling because I just always feel like people, regardless of what demographic label you put on them, people should be equal and it really irritates me when anybody is not treated equal and in particular is abused or beaten or whatever and it's something that I have always, always held deep down. Maybe it's one of the things that come from my Catholic education that's a good thing. Most of the things were not so good. The scars of getting up early to be an altar boy. Again, I ramble.

This is great. I have another question for you. Because you have years of experience to take leadership roles from various organizations, would you share with me the challenges or obstacles you have encountered as a leader and how you have managed those challenges?

S6: 32. Probably the biggest challenge is prioritizing from one group to another or one task to another. I am not very good at it./ 33. I think that's probably one of my biggest—one of the things I need to work on most continually is 1) learning how to say, "No"

29. S6 recalls that Blank had love, compassion, and understanding, and was a leader, and inspired and empowered others to be leaders themselves.

30. S6 met many individuals in several states, and all over the country. These individuals called themselves "mentors" and he and they continued to try and find new ways to do things. As a summary, his boss, his wife, and Wade Blank were influential individuals to his professional life.

31. S6 always feels that people should be equal regardless of demographics. He gets irritated when someone is treated unequally, in particular being abused or beaten. Such issues are very troubling to him.

32. The biggest challenge for S6 is prioritizing between one group and another or one task and another. He believes that he is not good at it. 33. S6 believes that he continually needs to learn how to say "no" and to be able to follow through when he says, "no."

which I think I have gotten better at, but when I don't say, "No" it's being able to follow through./ 34. A lot of times I find myself agreeing to do something and agreeing to do too many things and not having the time or the energy./ 35. Particularly as I am getting older and having the time or the energy to be able to complete what I need to which probably doesn't make me a very good leader. I think that's the biggest thing and it's one of the reasons why I feel so strong about getting more young people involved./ 36. As I am getting older and seeing a lot of my friends who are getting older, we are breaking down and we need someone to come in behind us./ 37. One of the things that I have been quite involved with in the last 10-15 years is developing materials that illustrate and document our history and the history of the Disability Rights Movement and trying to teach other people, particularly younger people where I've come from, where people before me have come from and where younger people sort of what they have missed and what we have done has helped them to get to where they are going./ 38. It's still a constant struggle I think for all generations and particularly for people with disabilities and any minority, we are certainly nowhere near "everybody is equal now and we don't need Civil Rights anymore, we are all equal."/

You are working on documenting the history of the Disability Right movement and to pass it on to the younger generation. It sounds like a big task.

S6: 39. It's not so much documenting, it's really collecting materials. We have quite a library of books, music, poetry, just all kinds of posters and things like that. I do quite a bit of just training on disability culture and disability history. It's having it and sharing it more than documenting it.

It sounds like an information depository or

34. S6 finds himself agreeing to do too many things and not having the time or the energy to complete everything.

35. As he gets older, S6 strongly feels that it's important as a good leader to get more young people involved.

36. S6 is getting older and seeing others getting older. He believes that older people need someone to come in behind them.

37. In the last 10 to 15 years, S6 has been involved in developing materials that illustrate and document the history of the Disability Right movement to teach other people, particularly younger people.

38. For S6 it is a constant struggle that not everyone is equal or does not have equal civil rights, particularly for minority including people with disabilities.

39. S6's project is collecting and sharing materials such as books, music, poetry, posters, to teach young people about the disability rights movement. He provides training on disability culture and disability history.

library, so to speak.

S6: People much brighter than me are documenting it. I just collect it and share it.

Sharing is important. Here is another question for you. Over those years of your leadership roles, what is the most experience that you are most proud of?

S6: 40. I think that the thing—well I will share two and one of them is very general. I think my participation with ADAPT and sort of getting to a leadership position with ADAPT./ 41. Getting to the point where I was willing to get arrested engaging in civil disobedience in order to bring about or trying to bring about social change./ 42. Probably I could pinpoint it down to one specific, the first action that I went to in San Francisco. We had been then for 3 days and I was—when the police come by they give you 3 warnings and the third warning is your last and you are going to get arrested. I had always up to the last day been able to get out of the fray and not get arrested./ 43. The third day I was sitting there next to what ended up becoming a very good friend of mine, [a person], who just passed away, but she was an author/poet from [a city]. She had a real significant disability and I can't tell you what it is but she was on a ventilator and pretty much the only thing she could do, I think she could move one finger and her eyes. Other than that, she could operate her power wheelchair./ 44. She was going toe-to-toe with the police who were in riot gear on these big motorcycles, they had their shotguns at their sides and this was San Francisco and they are notorious for not being very nice policemen. I was sitting with her and when she didn't move, I didn't move. That sort of—I had a lot of people come up and tell me what an inspiration I was when I was playing tennis or gotten through with a road race or something like that in a wheelchair. She was an inspiration./ 45. Anybody can play tennis, but going toe-to-toe with cops was

40. S6 is proud that he participated in ADAPT and getting to a leadership position with this organization.

41. S6 was willing to get arrested by engaging in civil disobedience in order to bring social changes.

42. S6 remembers the incident when he went to San Francisco to engage a civil disobedience.

43. On the third day of this activity, S6 sat next to an author and poet, who later became a very good friend of his. She had a significant disability, was on a ventilator, and her mobility was extremely limited.

44. For S6 she was an inspiration because she practiced her activism for disability rights without showing her fear in front of the police.

45. Her action of going to toe-to-toe with the police inspired S6. This changed him and was

<p>inspirational to me. I think that's what really changed or was a trigger for me./ 46. So I think that was something that I was very proud of that I got that first arrest that led to god knows how many others./ 47. Then I think the other that I am very proud of is I was the Executive Director for [an organization] for [years]./ 48. I got the job or asked to take the position when the former Director—there were some problems with the former Director. I really enjoyed being in a broader Civil Rights scheme of things than just disability./ 49. I really looked forward to working with ethnic minorities, women and gay/lesbian, although they weren't protected, but working with just across the board Civil Rights./ 50. What I quickly found out was people with disabilities were discriminated against more than anybody else or at least they were more likely to report the discrimination. It sort of backfired on me./ 51. I thought that we did a really good job during those years and brought some really good cases and had several significant lawsuits that even today are still held up in our precedent across the country for the way to bring out certain types of litigation and how to fight for certain types of accessible housing. Those are a couple of things that I am very proud of./</p> <p>Thank you for sharing those experiences.</p> <p>S6: You're welcome.</p>	<p>a trigger for him.</p> <p>46. S6 was very proud himself when he was arrested for the first time because his experience led many people to follow his lead.</p> <p>47. S6 is also proud that he was the Executive Director of an organization for several years.</p> <p>48. S6 was asked to take the Executive Director position. He really enjoyed working on broader civil right issues, not just disability, by serving in this position.</p> <p>49. He looked forward to working with ethnic minorities, women, as well as gays and lesbians. He enjoyed working on civil rights across the board.</p> <p>50. By serving as the Executive Director, he realized that people with disabilities were discriminated against most and were more likely to report the discrimination. This finding made him angry.</p> <p>51. S6 is very proud that the organization did a good job during those years under his leadership. His organization brought good cases and lawsuits that became precedents across the country.</p>
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Level Three (Narrative Based on Emergent Themes)

Frank has been involved in human services for most of his adult life. He has worked with individuals who have significant disabilities, and have been in institutions, nursing homes, group homes, and have eventually moved into their communities.

He became involved in many organizations and gravitated to the top. He has been on several boards and served as President of boards because often times nobody else would take such leadership roles. He has served as leadership roles for various state and national disability organizations.

Frank has been involved in ADAPT, a national organization that fights for disability rights and for ending the institutional bias in long-term care for people with disabilities. He is

one of the ten to twelve individuals who work in the ADAPT's core-leadership group. This group lays out the strategic outline for ADAPT. As a leader in this group he is involved in national actions in Washington D.C. or somewhere else to conduct protests and to engage in civil disobedience.

Frank's leadership role includes responsibilities such as, directing people, contacting the police and the press, and being in the protest activity. He has held this role ever since he became involved with ADAPT. He observes that ADAPT's participants come and go. He has risen to the top by maintaining his passion for civil rights. He believes that his passion came from his personal experience as a protester and his employment with disability services, which will be described below.

When he was 16 years old, he was injured by a car accident. This accident occurred during his junior year in high school. He went through "the world of aimless" about 8 to 10 years after this accident. He did not know what he wanted to do with his life. One year after the car accident he went to college and felt that everyone else was directing his life. He uses a wheelchair. Deans of the college told him that nobody would hire him.

Going out into the community and going to local taverns were enjoyable for Frank. However, these locations were not accessible, and he often had to be carried down the steps to get to these places. He got to a point where he thought that those places should be accessible to him if they wanted his business as a customer. He began his own protest and stopped going to and using businesses that were not accessible to him.

Later, Frank started working for a Center for Independent Living and worked with people with significant disabilities who did not have the services that they needed. Also, he worked for the Association for Retarded Citizens (ARC) and worked with people who could not speak, have been in institutions, have been abused, and had been in nursing homes.

Frank is "civil rights" minded. He wants to improve quality of life for those who are paraplegic or quadriplegic, who have a single digit IQ, or who use a wheelchair. He believes that those individuals can return home from an institution instead of to a nursing home or group home.

He recalls that as a young teenager he used to get into discussions and arguments with his relatives about segregation. He did not understand why black children had to go to a different school. He has always gone against most of his families' policies. He has been considered "the black-sheep of the family." From a political perspective, he is an advocate for civil rights and considers himself a progressive liberal. For him it is a constant struggle that not everyone is equal and does not have equal civil rights, particularly for minorities, especially people with disabilities.

For instance at school, he has experienced people with disabilities feeling like they always have to prove that they are worthy of something better. He believes that it is wrong that people with disabilities assume that they are unworthy.

Frank always feels that people should be equal regardless of demographics. He gets irritated when someone is treated unequally, in particular, being abused or beaten. Such issues are real troubling for him.

He is very concerned about policies that affect people with cognitive disabilities and communication disabilities. These policies keep individuals down or incarcerated just because they have a disability. Changing these policies is his passion and has led him to be a leader. He works at understanding the federal, state, and local policies and wants to make them better. Consequently, he has had many experiences in developing and changing policies that are related to people with disabilities.

Frank started surrounding himself with people who are like-minded and who ask questions about what will make him become a better leader. He experiences this with ADAPT.

He met many individuals in all over the country. These individuals called themselves "mentors" and he continues to work with them to try and find new ways to do things.

Frank's former boss at the Association for Community Advocacy, his wife, and Wade Blank at ADAPT have been influential individuals in his professional life. His former boss and his wife have been his major mentors. Frank remembers that his former boss always asked, "Why do we have to go to better before we get to best?" The boss instilled in him that going straight to the best without compromising the quality is important.

Through his former boss, Frank was able to connect with many people at the state and national level and across the country. He connected with those who held the same beliefs and became good friends with people who have significant disabilities.

Frank believes that his wife also influenced him. She has been working for disability issues for longer than he has. He compares her advocacy style with a pit bull - once she gets a hold of the person, she will not let go until the person says "yes."

Frank remembers the Reverend Wade Blank, who was involved in the Civil Rights movement in the 60's. Blank started moving people out of nursing homes in the early 70's in Colorado. He met Blank once before he died while trying to save his child from a rip tide. His meeting with Blank occurred 4 months after he became actively involved with ADAPT. He recalls that Blank expressed love, compassion, and understanding and as a leader, he inspired and empowered others to be leaders themselves.

The biggest challenge for Frank is prioritizing one group to another or one task to another; and believes that he is not good at it. He believes that he continually needs to learn how to say "no" and to be able to follow through when he does say, "no." He finds that he often agrees to too many things and does not have the time or the energy to complete them.

As he gets older, he strongly feels that it is important to get more young people involved. Not only is he getting older, but also others are getting older. He believes that older people need someone to come in behind them. In the last 10 to 15 years, he has been involved in developing materials that illustrate and document the history of the Disability Right movement so as to teach others, particularly young people. For his project, he collects and shares materials, such as books, music, poetry, posters, to teach young people about the disability rights movement. He also provides training on disability culture and disability history.

Frank is proud of his participation in ADAPT, especially his leadership position with ADAPT. He has gotten to the point where he was willing to get arrested by engaging in civil disobedience in order to bring social changes. He remembers the incident when he went to San Francisco to engage in civil disobedience for disability rights.

On the third day in San Francisco, Frank met and sat next to an author and poet, who later became a very good friend of his. She had a significant disability, was on a ventilator, and her mobility was extremely limited. For him she was an inspiration because she practiced her activism without showing her fear in front of the police and their shotguns. Her action of going toe-to-toe with the police inspired Frank. This changed him and triggered something for him. He was very proud himself when he was arrested for the first time because his actions inspired many people to follow.

Frank is also proud that he served as the Executive Director of a state organization for several years. He was asked to take the position by others. As the director, he really enjoyed working on broader civil right issues, not just disability. He looked forward to working with

ethnic minorities, women, and gay and lesbian people. He enjoyed working to promote civil rights across the board.

By serving as the Executive Director, Frank realized that people with disabilities were more likely discriminated. These findings made him angry. He is very proud that the organization did a good job under his leadership. His organization brought good cases and lawsuits that have become precedents across the country.