LIFE IN THE SLOW LANE: AN AUTOETHNOGRAPHY OF IDENTITY DEVELOPMENT

FOLLOWING DISABILITY IN YOUNG ADULTHOOD

A Dissertation
Submitted to the Graduate Faculty
of the
North Dakota State University
of Agriculture and Applied Sciences

By

Jon Alan Kragness

In Partial Fulfillment of the Requirements
for the Degree of
DOCTOR OF PHILOSOPHY

Major Program:
Education
Option: Occupational and Adult Education

April 2015

Fargo, North Dakota

North Dakota State University
Graduate School

Title

LIFE IN THE SLOW LANE: AN AUTOETHNOGRAPHY OF IDENTITY
DEVELOPMENT FOLLOWING DISABILITY IN YOUNG ADULTHOOD

By

Jon Kragness

The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State

University's regulations and meets the accepted standards for the degree of

DOCTOR OF PHILOSOPHY

SUPERVISORY COMMITTEE:

Dr. Claudette Peterson

Chair

Dr. Thomas Hall

Dr. Christopher Ray

Dr. Gregory Sanders

Approved:

13 April 2015

Date

Dr. William Martin

Department Chair

ABSTRACT

The purpose of this manuscript is to view, through an autoethnographic lens, the role of adult education, distance education, and assistive technology on identity changes that take place when becoming disabled in young adulthood within the context of internal and external forces on the development of identity. Constructs were used to delineate the evolutionary sense of one's identity which includes: (1) once formed, one's sense of identity is relatively stable; (2) environmental variables and constraints will create shifts in identity; and (3) internal drives, abilities, and motivations play an important role in the evolution of identity. Each of these constructs was then examined at different levels of identity that included one's Public Identity, Private Identity, Personal Identity, and Self Identity. Information was gathered through a number of personal narratives and historical documents that could then be viewed through the lens of the constructs above.

By examining these constructs, findings indicated that successfully rebuilding identity after acquiring a serious disability was greatly influenced by strong supports and opportunities available and the internal capacity to make use of them. There was no one specific support that was the only catalyst in this rebuilding. Instead, the complete network of support including adult education, distance education, social supports, and family support was at the heart of successfully rebuilding identity.

occupied with this process. Ironically, my grandchildren have never known me when I'm not a graduate student.

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER 1. INTRODUCTION

Prior to young adulthood, the term "disability" was a descriptor that I was certainly familiar with, however the term for me was in the abstract and referred to others and those that should be helped. It wasn't until a catastrophic injury propelled me into the world of the "disabled" that I truly understood what that term meant. The transition from being the go-to person for all of the heaviest and most demanding physical tasks to that of having to rely on others for even the most basic physical tasks meant not just modifying my way of life, but instead, it became an entirely different life that was fully foreign and unfamiliar, and most of all, absolutely unwelcome. Over the course of the first few years following this injury, I experienced intermittent extended hospital stays and virtual warehousing of my life in between. As it became fully apparent that returning to my former life was not an option, the question of what was next continued to loom ever larger.

My disability was a result of hitting the sandy bottom of a lake head-first in a diving accident that caused my neck to break in the area of my fifth and sixth cervical vertebrae, often referred to as a C5/C6 injury, thus damaging the spinal cord in that area. This caused permanent damage to the central nervous system that is referred to as quadriplegia. Although most people are familiar with the term quadriplegia, it is often misunderstood. A common assumption is that quadriplegia indicates a total loss of function below the neck, but instead, quadriplegia more accurately refers to any neurological impairment of the four extremities ranging from mild to severe. In other words, for one person it may include total loss of use of all four limbs while for another on the other end of the continuum it might be a much milder impairment that could be evident by lacking dexterity or quickly tiring. There are also varying degrees of sensory loss due

to damage to the central nervous system. In my case, the damage was severe causing a loss of use of my legs and greatly limiting the use of my arms and hands.

While any damage to the central nervous system is serious, the level of injury will also indicate the term used to denote the level of damage. As mentioned above, quadriplegia involves all four limbs. This is where quadriplegia differs from paraplegia in that paraplegia involves only the lower part of the body below the arms. Although paraplegia is clearly very serious, it is often a blanket term that is used to refer to paralysis even though it ignores the ramifications of damage to function and sensory of the upper extremities. Even so, both conditions have varying degrees of motor and sensory loss creating a very different experience for every person whether it is a high-level spinal cord injury resulting in quadriplegia or a lower-level spinal cord injury resulting in paraplegia.

My identity closely identified with my hulking physical stature. Yet as a result of an injury, in just a few months I had lost more than 100 pounds eventually becoming thin and frail. The embarrassment of going out in public where I may run into others who knew me prior to this accident combined with a limited ability to work or socialize caused the future to begin to look incredibly dim. Thoughts of suicide occupied the majority of my time every day for years while trying to identify a plan that I could carry out despite my disability. This is not unusual among persons acquiring a spinal cord injury and suicide is often the cause of death. Approximately 5% to 10% of persons with severe disabilities use overt methods to commit suicide; however it is suggested that there are far more undocumented cases of suicide using covert methods (Kewman & Tate, 1998).

It is common when an individual experiences this type of injury to hear suggestions that they go back to school and "take up" computers. Having never been interested in education

beyond high school or in using computers, I found myself feeling as though I was being pushed into what I felt was the stereotype. I quickly came to resent this insistence and soon became very angry, not just about trying to cope with life after this injury, but with all the pressure to follow the stereotype. I felt that it was not only pushing me away from the interests I had loved before, but it also meant succumbing to following the notion of what must be done when you have a disability.

I began to feel that there was no viable alternative, and with a head of anger that was beginning to boil over, I defiantly felt forced to give in to the stereotype of attending higher education to overcome injury. When I finally decided to attend college a few years after the injury, it was driven by an incredibly intense anger all while displaying a smile and a friendly disposition to avoid angering those around me that I had to rely upon. This led to a covert personal self-destructiveness including the pledge that I would attend only as long as I finished with an A in every course and at the top of every class I took. If not, I would stop attending college. Originally I planned to take classes but to never actually finish the associate of arts degree. But after taking just a few courses the first year, the anger drove my completion of a BA in psychology four years later. Even the choice of majors was driven in part by interest, but perhaps even more so as a form of self-therapy.

While attending higher education itself was not enough to fully stem all of the underlying anger, it did bring a newfound appreciation for the power of education. Opportunities began to open up for both work and recreation that wouldn't have otherwise been possible. It became apparent that a return to graduate school would still be necessary to reach a competitive level of employment, but even then, it still might remain out of reach to become fully financially self-sufficient.

3

Education has never been more important than it is today, particularly for persons with disabilities. The information age is upon us and the need for skilled workers in the labor force places an unprecedented need for persons trained or educated to meet the needs of the modern workforce (Scheer & Lockee, 2003). More often than ever, a high school diploma will no longer suffice as one's ticket to a successful career. With the complexities of today's society, it is imperative that the educational system serves to provide transmissions of knowledge that cannot be acquired by personal or experiential learning alone (Dewey, 2007, p. 9). This means that workers must seek out continuing or higher education to remain competitive in today's changing workforce. There are many opportunities that will serve this population in preparing for the workforce.

The landscape of higher education is changing rapidly as Information and Communication Technologies (ICTs), and particularly the availability of the World Wide Web, are ever more present in our daily lives. For persons with disabilities, this becomes even more important than for peers without disabilities because things like productivity differentials, discrimination based on perceptions, or even disincentives within the traditional workforce serve as competitive barriers to work that is considered a Substantial Gainful Activity (SGA) when seeking employment (Officer & Shakespeare, 2011).

<center>***</center>

In the year 2000, there were 49.7 million, approximately 1 in 5, people in United States over the age 5 that had some form of a long-term or permanent disability (Bureau, 2009). Because of the additional challenges faced by these persons, they have frequently been an underserved population. Now, even persons that are place-bound, whether or not they have a disability, can utilize educational opportunities on even par with their counterparts attending

<center>4</center>

traditional bricks and mortar institutions. With the proliferation of the Internet becoming a widely available utility on a global scale, there are increasing opportunities for persons in their home, in institutions, and in remote locations independent of disability or geography.

As the number of students enrolled in distance education increases, so too do the number of students with disabilities that are taking advantage of distance education increase. For the most part, the increases in numbers are reflective of the increasing popularity of distance education programs and courses. There is, however, evidence that the number of students with mobility related disabilities are increasing in numbers more quickly than students falling into other categories of disability. Further, there is evidence that with age comes an increase in attendance of students that are seeking education through distance learning offerings (Radford & National Center for Education, 2011).

Postsecondary institutions have responded to student needs by providing learning opportunities through ICT's that has led to great deal of opportunity for students with disabilities that may not have otherwise been able to pursue higher education (Van Woerden, 2006). Despite this opportunity, persons with disabilities are often resistant to these opportunities because of poor accessibility, the cost of acquiring new equipment, the learning curve required to fully engage in new technologies, or the unreliable provision of accessible material. As a consequence, with any changing environment, these opportunities have not been without their challenges. It is incumbent upon the college or university to provide access to education, including distance learning opportunities, that is nondiscriminatory and does not prohibit an otherwise qualified student from participation because of disability (Seymour, 2005).

Adult Students

Adult learners, those that are not transitioning directly from high school but are seeking education following significant period of time since high school, bring with them unique learning needs. While arguably all students entering higher education are adults, those that have been members of the workforce and are entering higher education as a means of career advancement or job change frequently bring with them different student service needs than other students. Unlike their more traditional counterparts, those who have become adults prior to entering the higher education system frequently find themselves pursuing education because of changes that have necessitated a career change. This need for a career shift can be the result of the changing work environment or even work-related injury that restricts or eliminates their ability to continue in their present line of work.

These adult learners often have a far different view of what they expect from education than their classmates who are just exiting high school. There are a number of characteristics shared by adult learners that will be discussed in more detail later in this document. It is important to note, however, that there are generational differences even among students referred to as adult learners that will play a role in identifying the perspective from which adult learners view education. To view them as a single homogenous group is to ignore fundamental differences in their needs and views of education. By understanding these differences, educators can more effectively engage these students (Holyoke & Larson, 2009).

Students with Disabilities

Growth in student numbers also leads to a greater number of students with documented disabilities that are attending distance education offerings and are requiring support through a disability services office. At this time, 19.3% of civilian noninstitutionalized persons aged five

and over and United States report having a disability (Bureau, 2009). This brings approximately 11% of undergraduate students attending higher education that have self-disclosed the presence of a disability (Corbeil & Valdes-Corbeil, 2007).

For students with disabilities, there are many reasons for which persons choose higher education to meet their educational and career goals. Consider that it is widely acknowledged that disability is one factor that greatly plays a role in leading to poverty, however, the converse is also true where poverty can lead to disability. Impoverishing conditions that lead to that disability could include dangerous working conditions, menial labor jobs, poor nutrition, and lack of medical care among many others (D'Aubin, 2007; Mitra, Posarac, & Vick, 2011; Officer & Shakespeare, 2011, p. 10). While some of these factors may begin in childhood, many of them become additive throughout a lifetime whereby employment opportunities, particularly in adulthood, begin to dwindle.

It must also not go without mentioning the disabilities among adults that are a result of armed conflict (Officer & Shakespeare, 2011). Many veterans cannot return to former careers because of injury received while serving in the military, and higher education offers a way to pursue new career opportunities. Regardless of what brings students with disabilities to higher education, there is a great diversity of need for barrier removal to otherwise qualified students. As student numbers grow, the population of students requiring these services brings new challenges in removing barriers to higher education, particularly in distance learning environments. Having a disability that requires education or retraining as a means to relieve poverty or increase employment options becomes more attainable as distance education opportunities including courses, programs, and even degrees continue to grow with ongoing development of ICT's.

For students with disabilities, having ICTs available can add tremendous value to a student's success and overall college experience by fostering a greater sense of empowerment and improved self-esteem through allowing a greater level of independence. There remains reason for some concern, however, because dependency on ICTs is not without its own pitfalls. There is always a risk of technology malfunctions, hardware and software obsolescence, and the need to stay abreast of current technologies and upgrades that are inevitable but may or may not be as user-friendly (Seymour, 2005). This paradox becomes a balancing act where students with disabilities may wish to continue using a valued piece of aging technology but find that they must ultimately abandon it because of environmental constraints, lack of hardware or software support, or compatibility problems.

As a measure to stem discrimination, federal law requires postsecondary institutions to afford students with disabilities equal access to higher education. The most notable and furthest reaching of these is the Americans with Disabilities Act (ADA, 2011) and Section 504 (Jelinkova et al., 2008). Additional federal legislation that becomes important particularly in distance education is Section 508 (Lorenzo, 2007), The Telecommunications Act of 1996 (Oblinger & Oblinger, 2005), and the Assistive Technology Act of 1998 (Act, 2005). Taken together, these laws provide a foundation to remove disability related barriers to education for otherwise qualified students.

Although procedures for documenting a disability as well as definitions for making decisions regarding who is qualified for service through a postsecondary Disability Services Office can be challenging, the US government provides language through which to guide the process. The US federal government has identified persons with disabilities under the ADA by applying the following definition: "The term 'disability' means, with respect to an individual (A)

8

a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment" (Radford & National Center for Education, 2011, p. 14).

To receive disability services, students are expected to provide appropriate documentation of disability to qualify for disability services to a disability services office in higher education. However, acquiring appropriate documentation for providing services to students with disabilities in a distance education environment presents new challenges that are not part of providing an on-campus service. It may be a newly acquired disability that brings them to the educational system or they may have a chronic disability that is poorly defined and may not include documentation as necessary to guide the process of delivering appropriate accommodations to students. In either event, this population brings unique challenges in meeting their needs related to disability services as they continue to grow in numbers.

Assistive Technology

For many students with disabilities, assistive technology and assistive technology devices become integral if not critical parts of the barrier removal to their education. Federal law has provided a definition via the Assistive Technology Act of 1998 by identifying assistive technology with the following: "The term 'assistive technology' means technology designed to be utilized in an assistive technology device or assistive technology service" and by further defining an assistive technology device as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Act, 2005, p. 4). This definition includes high-technology like a sophisticated computer or piece of software but it also includes

low technology devices like a pencil grip or anything in between. In short, any piece of technology that removes a barrier caused by disability will fall under this definition.

One thing that is clear is the value of assistive technology to persons with disabilities in reducing or removing disability related barriers in the independent pursuit of education, independent living, and employment (Stumbo, Martin, & Hedrick, 2009). While this knowledge may well identify the need, many devices are very expensive or specialized whereby students may not have the means to acquire them. With education specifically, a particular course, instructor, or program may have a requirement where a student with a disability needs technology to gain access before being able to fully participate.

Disability Services Offices

Because of the varied nature of disability, even creating a platform that attempts accommodate all students by designing educational materials to incorporate the principles of Universal Design for Learning (UDL) alone cannot remove all barriers for students. Therefore, accommodation must be made on an individual basis. To provide equal access to otherwise qualified students, a Disability Services Office is responsible for providing accommodation to students that produce appropriate documentation of disability. These offices are charged with the responsibility to make accommodations to remove disability related barriers to education where universal principles fail to adequately meet their needs. This does not offer a blanket accommodation, but specifically provides for an accommodation of a documented disability that does not alter the curriculum or place an undue financial or administrative burden on the institution (Radford & National Center for Education, 2011).

Additionally, these offices may go by many different names and can be housed under academic affairs or student affairs depending upon institutional structure. These differences can

provide different viewpoints from which students are served while still meeting federal

requirements for access (Trubitt & Muchane, 2008). Lastly, institutional limitations in distance

education may share a great many of the same issues that are experienced with serving students

in a land-based environment, but it may also include many additional challenges unique to a

distance environment.

Definitions of Terms

Throughout this manuscript a number of terms are used that may have multiple or

esoteric meanings to some readers. To clarify the specific intent and of definition those terms,

the following section includes a definition of terms within the context in which they are used

throughout the script. While this list is not exhaustive for every relevant term in this text, it is

exhaustive in that it includes the terms most in need of clarifying the way the terms are used

throughout the remainder of this manuscript. The terms are included below.

Adult: A person who has left high school and begun taking on more freedoms and more

responsibility (Molgat, 2007).

Assistive Technology: "The term 'assistive technology' means technology designed to be

utilized in an assistive technology device or assistive technology service". (Act, 2005)

Assistive Technology Device: "The term 'assistive technology device' means any item,

piece of equipment, or product system, whether acquired commercially, modified, or customized,

that is used to increase, maintain, or improve functional capabilities of individuals with

disabilities" (Act, 2005).

Conceptual Framework: "A way of linking all of the elements of the research process:

researcher disposition, interest, and positionality; literature; and theory and methods" (Ravitch &

Riggn, 2012, p. 6).

Paraplegia: A neurological impairment of the central nervous system affecting the lower extremities beginning below the arms ranging from mild to severe from the first thoracic vertebrae and below (Lemay, Routhier, Noreau, Phang, & Ginis, 2012).

Personal Identity: Interpersonal exchange where there is an exchange only at the most intimate levels with others (Westerman, 2005).

Private Identity: Is more restrictive than a Public Identity whereby an individual is far more selective in choosing those with whom to be open about sharing with regard to others. This is akin to what Burkitt (2013) described in writing about Self and Others.

Public Identity: Sometimes described as a Persona, is that identity a person chooses to share openly with others (Leary & Allen, 2011).

Quadriplegia: A neurological impairment of the central nervous system affecting the four extremities ranging from mild to severe from damage caused to the cervical vertebrae (Lemay, et al., 2012).

Self Identity: Self-consciousness or self-awareness when recognizing the uniqueness of the core individual (Kaufman & Libby, 2012).

Theoretical Models

Several theoretical models were used to build a conceptual framework to provide a context for the study and also guide the analysis of data to be viewed. These theoretical models used in the development of the conceptual framework included the stages of grief (Kübler-Ross & Kessler, 2007), the Johari Window (Hensley, 1983), and the ABCX Family Stress Model (Gauthier Webber, 2011). Taken together, they help inform the development and structure of this manuscript. The following models were used in synthesizing and refining the conceptual framework providing structure in this manuscript.

Stages of Grief

Experiencing a catastrophic disability can lead to great stress and grief that places enormous challenges on one's identity. To better understand this process, Kübler-Ross and Kessler identified five stages of grief that one may imperfectly pass through when coming to grips with serious loss. These stages include denial, anger, bargaining, depression, and finally acceptance. They point out that these stages are not necessarily discrete and distinctive, but rather they may overlap as one moves along the continuum into finding eventual resolution to grief (Bolden, 2007; Kübler-Ross & Kessler, 2007).

This model recognizes the grieving process in a sequential manner that helps to understand the feelings associated with loss. This provides a roadmap for better understanding the grieving process and the mechanisms for coping that one will frequently experience when trying to come to grips with grief. They also point out, however, that these stages may overlap and it is not required for anyone to transition through all of the stages or even to pass that sequentially to successfully readapt (Kübler-Ross & Kessler, 2007).

Johari Window

When examining ones sense of identity, it is useful to view it through different lenses to fully understand the issue under study. One of the lenses that can provide meaningful insights to this process is viewing it through a Johari Window. The Johari Window allows one to put the context within a grid with four quadrants that considers what is known and unknown about oneself and also what is known and unknown by others. Broken down, this means that one quadrant is known by self and others (Open), another quadrant is known by one's self but not others (Hidden), another quadrant is known to others but not self (Blind), and the last quadrant is not known to self or others (Unknown) creating an area in need of discovery (Hensley, 1983;

13

Vazire, 2010; Wei-Wen, Cheng-Hui Lucy, Yu-Fu, & Yu-Hsi, 2012). An example of the Johari Window is illustrated in Figure 1.

	Known by Self	Unknown by Self
Known by Others	Open	Blind
Unknown by Others	Hidden	Unknown

Figure 1. Johari Window

This window is not meant to be static, but rather it is a dynamic representation whereby it will fluctuate with what is known by self and others about an individual. Because of this, the unknown section is usually quite large before a person has begun the journey of self-discovery. As this journey continues, the unknown area begins to get much smaller while the other areas continue to grow as other areas that are known to either self or others become clearer (Lowry, 2005).

The ABCX and Double ABCX models

The ABCX Model was developed to study stress and crisis among families to understand how they cope with a sudden stress or crisis inducing event. To better explain this: "The ABCX Model focuses primarily on pre-crisis variables of families: *A* (the crisis-precipitating event/stressor) interacting with *B* (the family's crisis-meeting resources) interacting with *C* (the definition the family makes of the event) produces *X* (the crisis)" (Gauthier Webber, 2011, p. 82). This model does, however, have some limitations in that it does not account for post-crisis stressors that may linger following a crisis event.

A variant of the ABCX Model was developed that included post-crisis variables to account for the ongoing challenges following an event and it was described it as the Double ABCX Model. This updated model could now be used to include stressors that were not only brought on by an event, but in addition, this model could be used to also acknowledge other stressors that appear as a result of the initial crisis. Simply said, this model now accounts for pre-crisis, crisis, and post-crisis variables that place demands on personal and family structures (Gauthier Webber, 2011).

Among the structures commonly studied with this method are families where one or more family members have a disability or for caregivers of a person with a disability (Pruchno & Patrick, 1999). In addition to family structures, this model provides a means to address ongoing stressors that arise during post-crisis for individuals. For example, acquiring a severe chronic disability creates stressors that extend far beyond the initial onset of disability, and as a result, there becomes a host of ongoing stressors that can be barriers to successful identity adjustment (Florian & Dangoor, 1994). Addressing these new stressors creates an impact on the ability to successfully re-examine one's own identity.

Conceptual Framework

To organize this manuscript, a conceptual framework is included to provide the reader with the context that guides the research process and allows a reader to identify how pieces fit together within the study. Creating this framework is a dynamic rather than static process mean that it has evolved his new discoveries are made and new data has been gathered. Ravitch and Riggn (2012) address the importance of this dynamic property of a conceptual framework throughout the research process by explaining how it allows a researcher continue to refine the process as new learning takes place. This framework also serves to organize the otherwise

15

somewhat unorganized fragments that are frequently seen in autoethnography and brings them together to organize them to create a coherent data base (Mitra, 2010).

This manuscript is based on a conceptual framework founded on the notion that a sense of identity, once realized, typically becomes a relatively stable core trait. This trait is not fully static but continues to evolve throughout one's life (Murugami, 2009). This stability creates a sense of identity through which one knows one's self and allows the pursuit of goals, commitments, and a sense of well-being. It also allows one to identify with personal values and belonging when reflecting and answering the question: "Who am I?" For persons who lack a strong sense of identity, the self may become fragmented and create a great deal of personal instability (Hopwood et al., 2009).

In most cases regarding one's identity, once formed, this is an evolutionary process that is slow to change, however; abrupt life changes can affect this process and create stressors that are capable of accelerating this process or even forcing one to accept a very different sense of self. The continuity in this process may be disrupted substantially if one is confronted with abrupt changes that require a new sense of self (Allemand, Steiger, & Hill, 2013). Take, for example, a person whose identity is tightly correlated with their work and then loses or must change their job, a spouse who is newly divorced, or a person with a newly acquired disability. While the core individual does not change from these changing circumstances, external conditions require a new vision of self, even if that new vision was not intentional or desired. By using constructs to represent the variables affecting one's identity, one can systematically identify relationships between constructs (Ravitch & Riggn, 2012).

This framework posits the notion that identity is influenced by internal and external elements by differing degrees that allow one to maintain a sense of identity from within and

16

within the context of environmental variables. This requires one to identify with an identity that is consistent with unified sense of self within the environmental context of current space and time. There are three key constructs that delineate the evolutionary sense of identity which include: (1) once formed, one's sense of identity is relatively stable; (2) environmental variables and constraints will create shifts in identity; and (3) internal drives, abilities, and motivations play an important role in the evolution of identity (Allemand, et al., 2013; Conley, 1985; Hampson & Goldberg, 2006; Hopwood et al., 2011). If one should try to ignore the importance of these constructs, the risk of cognitive dissonance increases as one's internal sense of self becomes conflicted when change is needed (Hopwood, et al., 2009).

These constructs are further broken down by using a layered approach to examine each of these constructs in greater detail by viewing them through the lens of a Public Identity, Private Identity, Personal Identity, and a Self Identity. For working definitions, A Public Identity, sometimes described as a Persona (Leary & Allen, 2011), is that identity a person chooses to share openly with others. One's Private Identity becomes more restrictive whereby an individual is far more selective in those open about sharing with others. This is akin to the Open quadrant of the Johari window and what Burkitt (2013) described in writing about Self and Others. Westeman (2005) spoke of interpersonal exchange where there is an exchange with others that is very much like the Private Identity addressed herein. The term Self Identity in this manuscript is used to describe what Kaufman (2012) refers to as self-consciousness or self-awareness when recognizing the uniqueness of the core individual and is closely aligned with the unknown cell of the Johari window.

The descriptors included above are meant to illustrate a layered approach among these constructs in dissecting and identifying the outermost to innermost as one views the different

elements of identity. These layers are illustrated in Figure 2 showing steps on a continuum from most public to most private senses of identity. Figure 2 provides an illustration of the different layers of identity prior to introducing environmental variables because of the uniqueness of the individual experience. Once this baseline has been established, this model may be used to assess the impact of individual environmental factors to visualize the impact on identity.
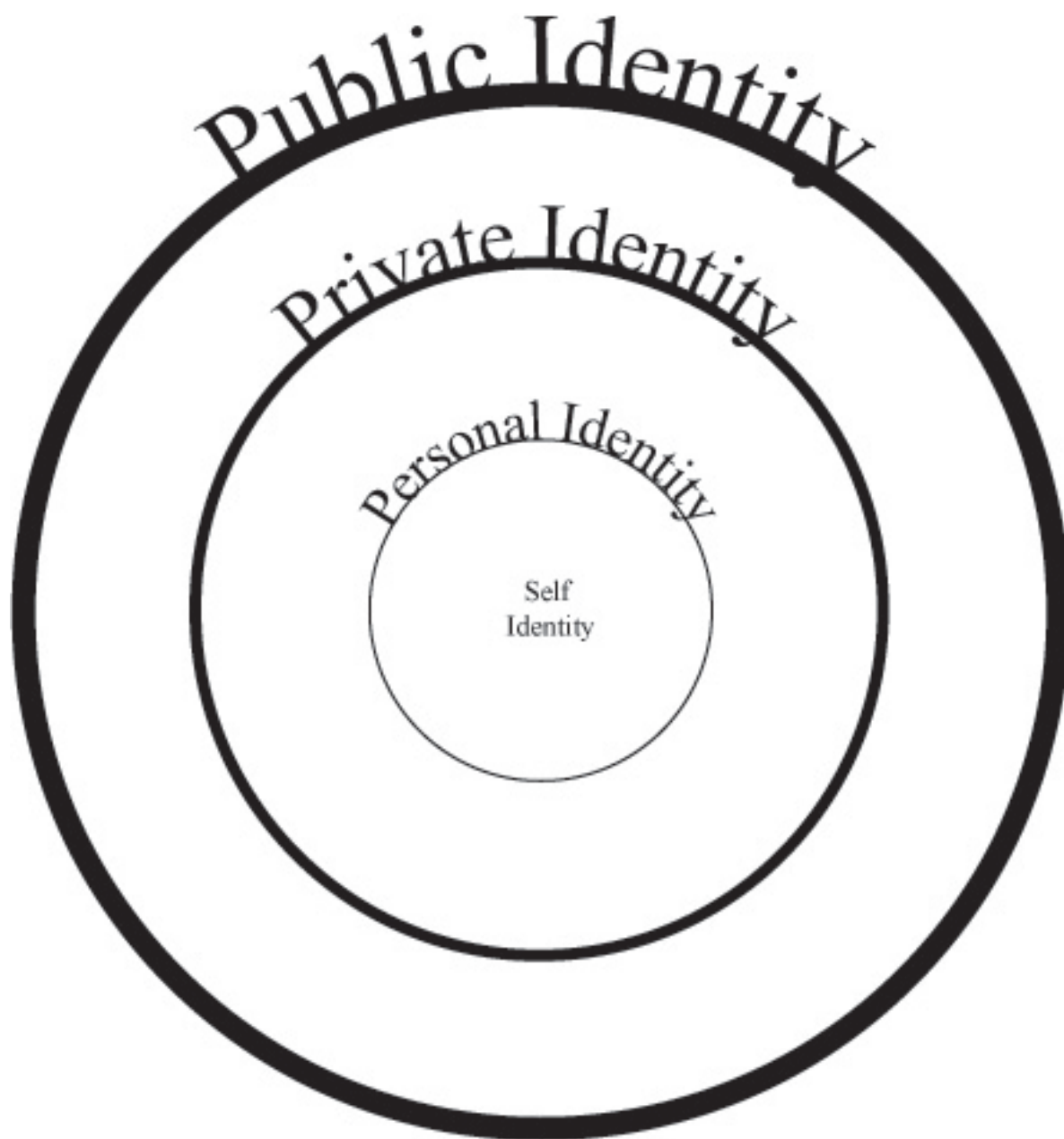
Figure 2. Layers of one's identity that protect one's sense of self.

Summary

The notion of identity is something that provides a sense of self and allows one to answer the question "who am I". While this notion may rarely be thought of consciously, it's a very important part of creating a sense of self. Despite being relatively stable, this sense of self may be substantially disrupted with sudden onset of severe and permanent disability. An acquired disability requires one to rethink many of the traits that have been identified with when making up one's sense of self. It's at this time that these traits that comprise identity must be reevaluated or realigned to this new reality for reshaping a sense of self.

There is a body of evidence that indicates an increasing need for higher and continuing education to secure an economically viable foothold in the employment market. Accessing higher education or retraining has been a challenge for adults seeking to change or advance in their careers, particularly for persons with disabilities. Adult learners, those that are not transitioning directly from high school but are seeking education following significant period of time since high school, sometimes do not have the flexibility or mobility to access traditional land-based education. Technological advancements allowing ever more robust models of remote delivery of education or distance education via Information and Communication Technologies (ICTs) has become a great resource in mitigating these challenges.

Despite these newfound resources, students with disabilities can be inadvertently denied access to their education by poor design or designs that unduly restrict access to materials because of a disability, even in a distance education environment. To serve and protect this population from discrimination by denial of access, there are a number of laws in place that require educational institutions to provide access to otherwise qualified persons, most notably the ADA and Section 504 of the Rehabilitation Act. One way to greatly improve access is to

implement Assistive Technology either through the institution or a student with disabilities to allow access to their education. This may provide the access necessary, however it must not be overlooked that course delivery models and ICT's need to include accessibility as part of the design for compatibility or they'll be rendered useless.

Ideally, a model that incorporates a Universal Design for Learning (UDL) allows access to educational materials for students with disabilities on par with their peers. In practice, this is not always achievable and an accommodation must be made. In this case, students can access services for students with disabilities that can make accommodations for accessing education to overcome loss of access because of disability. In higher education, this is not expected to relieve students from meeting the same goals and objectives as their peers, instead, is intended to provide disability related barrier removal to allow equal access to programs and education.

The purpose of this manuscript is to view, through an autoethnographic lens, the role of adult education, distance education, and assistive technology on identity changes that take place when becoming disabled in young adulthood within the context of internal and external forces on the development of identity. Chapter 2 provides a background and review of literature that provides context and information through this process. Chapter 3 addresses the autoethnographic methodology used to develop this manuscript. Chapter 4 provides a series of narratives that reflect lived experiences and provide a data source for this manuscript. Chapter 5 provides findings and conclusions of what this study found and what it meant.

CHAPTER 2. REVIEW OF LITERATURE

Sense of Identity

The notion of identity is something that creates an internal sense of stability through which one can identify traits, beliefs, and abilities that create a unified awareness of self. These characteristics need to remain relatively stable for one to find a sense of belonging within one's place in the world; if disrupted, a well-adjusted sense of self can be difficult to reestablish. While slow shifts in one's identity through day-to-day interactions are readily adjusted to, disruptions that are severe and or long-lasting can have a serious impact on one's identity. If disruptions are severe, that well-adjusted sense of self can be impossible to reestablish. In the case of acquiring a disability, this can force one to reconstruct one's sense of self and one's place in the world and cause a need to reevaluate what changes are necessary to develop a well-balanced sense of identity (Murugami, 2009).

Carol Gill (1997, p. 42) described four types of steps necessary to achieve an integration of disability while working toward a sound sense of identity within the intrapsychic, interpersonal, and social dynamics when attempting to regain one's sense of identity. She further suggests that there are four types of integration necessary that include: "(1) 'coming to feel we belong' (integrating into society); (2) 'coming home' (integrating with the disability community); (3) 'coming together' (internally integrating our sameness and differences); and (4) 'coming out' (integrating how we feel with how we present ourselves)". By using tools like the Johari Window or the identity model provided can help one learn where they are at in this process. Bringing these facets together helps to find a new sense of identity within a changed condition that is described by Murugami (2009, p. 4) as reaching a "reconstruction of normalcy in constructions of Self Identity".

21

While these guides help to understand the nature of what constitutes one's identity, they are but only one part of what makes up the entirety of one's identity. When navigating this process, the whole person, as it makes up one's identity, sees through a lens that includes past, present, and a future versions of how one sees oneself and their place in the world (Dunn & Burcaw, 2013). The importance of this was noted in a study where college students with disabilities were recruited then were primed by being identified as a person with a disability or as a student and findings indicated reduced autonomy when being identified by disability than when being identified as a student (Wang & Dovidio, 2011). This reinforces the notion that it is important to use person first language that acknowledges a person rather than their disability (*Publication manual of the American Psychological Association*, 2010, p. 76).

Identity development and maintenance is a complex process with many nuances that ultimately lead to a sense of wholeness. Successful rebuilding is in part dependent upon perceived ability to adapt and perceived severity of disability in aiding or hindering rebuilding of identity (Meyer & Kashubeck-West, 2013). In its totality, some level of integration of disability within one's overall sense of self most often leads to greater self acceptance and a sense of completeness in knowing oneself (Gill, 1997). Taken together, successful integration ultimately includes one's acknowledgment of disability as a component of a host of other internal and external traits that one can use to once again identify with their own sense of self.

Theoretical Models

Three theoretical models including the Kübler-Ross (1969) Stages of Grief, the Johari Window (Schneider, 1971), and the Double ABCX model of Family stress and crisis (Gauthier Webber, 2011) were considered in developing and revising a conceptual framework for this manuscript. The premise of these models are followed by a synthesis of constructs contained in

these models and are presented below representing the conceptual framework through which identity can be studied.

Stages of Grief

When considering grief and loss, the work of Elizabeth Kübler-Ross (1969) forged a pioneering effort to understand the cognitive and emotional process that one goes through when experiencing death. Her work in this area is developed a model that includes five stages that one experiences when facing death that include: denial, anger, bargaining, depression, and finally acceptance. Since then, this work has been expanded upon to recognize the impact of grief and loss that one may experience when passing through a traumatic and sustained event (Kübler-Ross & Kessler, 2007).

To better understand the nuances of each of these stages, it helps to have a brief description of each of them within the original context of the purpose for which they were developed that focuses on death. To exemplify this, an annotated a list is included below:

1. Denial. People believe that their loved one has died, but their denial is symbolic in that they cannot believe that their friend or family member will not, for example, be calling to say hello or returning from work at a certain time.

2. Anger. A person's anger is directed at the person who died or at oneself for being unable to prevent the loved one's death. The authors contend that once individuals are in this stage, they begin to recognize their ability to get through this difficult time.

3. Bargaining. Kübler-Ross and Kessler talk about the "what if" and "if only" mind-set wherein individuals who are grieving believe that they may have been able to control and thus prevent the loss of their family member or friend.

23

4. Depression. In this stage, the authors discuss the normalcy of feeling depressed and affirm the idea that such feelings are necessary for the healing process to begin.

5. Acceptance. At this stage, individuals are at a point where they recognize the current state of their lives, without their loved one, as the reality and can live with that understanding. (Bolden, 2007, p. 235-236)

Since this original work was done, this model has been used as the foundation for addressing many kinds of grief and loss beyond its original purpose of understanding the grieving process of death and dying. The work has often been used as a model to better understand ways to provide therapy to the family of a person with a closed head injury (Groveman & Brown, 1985), or therapeutic intervention for illness (Sarwer & Crawford, 1994). This model is also applied to addressing teen suicide prevention (Ross, 1997). While this list is not meant be exhaustive, it helps to illustrate the many uses for which this model can be applied.

This model provides a means of understanding the process of going through the acquisition of disability as a loss and frequently grieving process. By experiencing this loss, there is an impact on identity that must be processed while adjusting to a new vision of self. Severity of disability and individual differences will play a role in individual perception of the depth of grieving and loss; however, there remain many parallels to the loss described within the context of this model.

Of note within the context of this manuscript, rehabilitation therapists have adopted this model as a way to recover from significant loss. Gannon and Gold (1988) describe the rehabilitation process as a rebirth while using this model to help regain a new perspective on identity that is aligned with a person's current post-loss state. They approach it from a

perspective that parallels childhood development as one works through the stages of grief with the goal of reaching a changed but well-adjusted sense of one's identity.

The Johari Window

The Johari Window serves as a process of discovery for one's identity whereby each of the windows may change size throughout the discovery process. It allows for a visual representation of what is known about oneself and others that will vary throughout the process of self-discovery. It's the self-discovery that leads to a greater awareness in identity development as one critically looks at what is known or not known by the self and others. Typically, as one's discovery continues, the unknown area, or blind area, becomes much smaller thus strengthening one's ability to know one's self (Lowry, 2005).

These changes are important to recognize as they occur because they reveal clues about one's identity that provide useful insights to one's perspective. These insights reflect different individual strengths or weaknesses regarding interaction with others in self-image that vary with quadrant size. To this end, Holloman (1973) identified quadrants by number whereby Quadrant 1 represents a Public Identity, Quadrant 2 represents the Personal Identity, Quadrant 3 represents the Private Identity, and Quadrant 4 represents the Self Identity and he presented characteristics of persons exhibiting particular quadrant size that he described:

> Individuals with a large Quadrant 1 are less preoccupied with defensiveness and
> distortion generated by their attempts to ignore Quadrant 2 and protect Quadrant 3. These
> individuals also have interpersonal relations which are characterized by openness and
> trust, i.e., they let others know what they are feeling and how their behavior is affected by
> the behavior of others. (Holloman, 1973, p. 692)

Armed with this information, it's become possible to recognize some of the nonverbal cues taking place throughout the redevelopment of one's identity. From a nonverbal communication standpoint, this gives insights into one's identity that they may not be readily aware of. Instead, preparing a Johari Window to keep track of one's progress creates insights to changes taking place (Schneider, 1971).

The Johari Window can then be applied to different levels of identity and open up greater insights to each of the different layers and their relative changes or stability. As each of these quadrants are examined, greater insights emerge whereby fluid traits may show up in different quadrants while static traits will remain in place revealing core traits that are generally stable compared to more flexible characteristics. The following figure labels the respective quadrants with relation to where they fit within the conceptual framework in the context of this manuscript. As with the original Johari Window, the quadrant sizes will change as one goes through a period of self-discovery or experiences a significant life change. This is a learning process is continual and continues to provide new insights as new information is gathered.

	Known by Self	Unknown by Self
Known by Others	Public Identity/Open	Personal Identity/Blind
Unknown by Others	Private Identity/Hidden	Self Identity/Unknown

Figure 3. Johari window as it relates to the identity model.

The ABCX and Double ABCX Model

The ABCX Model provides a basis for most family stress models that are used to study the effects of crisis on families. In this model, A is the Crisis-Precipitating Event/Stressor, B is the Family's Crisis-Meeting Resources, C is the Definition the Family Makes of the Event, and X is the Crisis (Gauthier Webber, 2011). This model assesses the family's perception of a crisis or event and their ability to cope with it using the resources they have (Manning, Wainwright, & Bennett, 2011). Although this model could successfully be used to evaluate the family's perception of a crisis, it failed to account for ongoing stressors that were result of events caused by the initial crisis.

The Double ABCX Model takes into account ongoing stressors from an initial crisis and is noted for use in family stress models that include a pre-crisis, crisis, and post-crisis analysis. The pre-crisis in the Double ABCX is characterized identified using lowercase letters abcx to represent factors leading up to crisis with x representing the crisis. This state of pre-crisis can be thought of as a (Stressor), b (Existing Resources), c (Precipitation of the Crisis), x (Crisis) much the same as the ABCX Model. Following the crisis, or x, the post-crisis variables are denoted slightly differently to indicate how to post crisis relates back to the pre-crisis and described whereby variables in the: "Double ABCX Model include a pileup of stressors on top of the initial stressor (*aA*); existing and new resources (*bB*); perception (definition) of the initial stressor, pileup, and existing and new resources (*cC*); coping; and adaptation to the post-crisis variables (*xX*)" (Gauthier Webber, 2011, p. 87).

The difference between the ABCX Model and the Double ABCX Model is particularly important when understanding the effects of an acquired disability. While the initial disabling event can reasonably be studied using the ABCX Model to identify impacts created by a

disabling event, the newly acquired disability more often has ongoing stressors or even new

stressors created by disability. In some cases, both ongoing and new disability related stressors

may sometimes create even greater stressors than the initial event. This is where the utility of the

Double ABCX Model becomes particularly valuable in recognizing the ongoing events that take

place because the initial crisis but last far beyond the initial crisis.

This model has been used extensively to assess the stressors associated with disability

and the stress it places on the family. Where it has not been widely adopted is in the study of

Personal Identity and the changing dynamics experienced by a person faced with sudden onset of

a severe disability and the ongoing effects beyond initial crisis. While it was designed for use as

a family stress model, the ABCX model would also serve as a means to study the effects of

disability from crisis and on including lingering effects and effects caused later by disability.

While these models assess the ways that acquiring a disability impacts identity, there are

resources often available to help mitigate the successful realignment of identity. Among these

resources are adult educational opportunities for allowing a greater possibility for successful

paradigm shifts. Where these opportunities may have once been out of reach, they are now more

accessible to students through evermore offerings in distance education and access via assistive

technology. These changes help to remove many of the previously faced barriers in accessing

higher education by adults with disabilities.

Adult Students

Like many other disciplines, education has embraced technology as a way to offer more

effective service to an ever greater number of people. The purpose of this section is to consider

how formal education has adopted technology, particularly with regard to distance education,

and to consider what impact these changes have had on the adult learner as they now find

themselves interacting with technology more than ever before. This is perhaps true more for distance education than traditional classroom learning. The need for adult learners to increase their educational skills combined with the availability of distance learning opportunities has fueled incredible growth in this area meaning that many of the opportunities available to adult learners are now common in this format.

Distance education has been transformed from models such as correspondence school to more modern versions that included interactive television and the Internet among many other delivery modes. Online learning in particular is a method of providing learning opportunities that continues to grow in part because of the potential to attract greater number of students, reduce the cost of the delivery of education, and because it can leverage existing infrastructure (Moore & Kearsley, 2005). Together with a vast array of new technologies that are forever encroaching upon the traditional classroom, it is ever more important to recognize the role these technologies play in the process of education. One unfortunate side effect of this adoption of technology for adult students is that while formal institutions may be able to use existing structures to help keep costs down, students then must absorb greater cost in acquiring the technology necessary to take advantage of these educational offerings. This increases the risk of supporting an ever widening gap between rich and poor as less affluent adult students may have difficulty attaining technology such as computers or high-speed Internet access (Mitra, 2010).

Adults in Distance Education

Change seems to be one of the few constants in education. With every passing generation there is a taking for granted what is and has always been with regard to technology when seen through their eyes. Technological breakthroughs that amaze and draw wonder as if it is science fiction come to life will quickly become commonplace. Take for example two relatively recent

developments such as the Internet or wireless connections as examples of revolutionary technology that the current generation has never lived without (Oblinger & Oblinger, 2005). For adults there has been a profound impact on everyday life trough the development of these technologies, yet children and young adults have never known a world without them. It's important to understand how these differing viewpoints affect the perceptions and expectations of students when developing curricular material.

For the incoming generation of students that had not lived without many of these technologies, they are simply a part of everyday life. Computers, the Internet, and wireless technology are but a few of the expected technologies routinely used both academically and socially by students of today. There is no dichotomy between school and home largely because most of the students are not wowed by technology; rather it is simply a tool they use because it's convenient. Communication is on-demand, portable, and available virtually anytime, anywhere. Thus the lines between educational space and social space blur considerably as students may use portable devices for social communication in educational areas or classrooms yet they can use the same devices to acquire educational materials while sitting in a coffee shop or other social area. It's important that educators are cognizant of this variety of environments in which students may consume educational materials because of the potential environmental impact on learning (Oblinger & Oblinger, 2005). While it may be naïve to think that all educational material can be custom tailored to fit all spaces in which students may choose to work, recognizing the portability of information is in important step in developing learning material for networked generation.

Networks and portable devices have now become the norm and students are expecting them more routinely than ever before. Through their eyes, it is a technology that always has

existed. It is hard for them to imagine what a big deal it was in the late 1980s and early 1990s when many colleges and universities were getting their first student computer labs and in the mid to late 1990s when those labs became fully networked and Internet–connected. Today that has given way to wireless hubs and personal portable devices that can be used anywhere within range of the wireless signal. This has allowed students to receive their educational information with unprecedented flexibility in how and where they wish to learn to include many informal as well as formal learning spaces (Oblinger & Oblinger, 2005, p. 8.2).

Now, even the computer lab may become a thing of the past as we have known it. Students today are accustomed to having their own portable electronic devices and expect a wireless network connection to be available at their disposal regardless of their particular physical setting. Further, increasing use of collaborative work as a learning tool does not fit well with what has been a traditional college campus computer lab design. Instead, student work areas that are comfortable and allow convenient group work will more closely align with the current needs of students (Oblinger & Oblinger, 2005, p. 8.5).

The mobility of this information is perhaps no more important to anyone than persons who are place-bound and lack the ability to travel to a physical location to meet their educational needs. To better define place-bound persons, this includes anyone who lacks the educational opportunities they seek because of constraints that keep them from attending a traditional classroom. These can include geographic location, time, or family responsibilities among others. (Wilson, 1994). When developing policies and offering staff development this population should not be forgotten. With the prevalence of the Internet and other distance-learning opportunities, this traditionally underserved and growing population can now be reached effectively with high quality learning opportunities. Additionally, serving this group of students will provide

additional revenue to the school by increasing student numbers, an especially important issue for community colleges, many of which have been recently suffering from falling enrollment.

Place-bound students may differ demographically from their on-campus peers, but they share a need for high quality learning material. Courses that have been placed online without specifically utilizing sound design techniques deliberately intended for web delivery will be readily recognized and largely dismissed by students (Oblinger & Oblinger, 2005, p. 5.11). Instead, students today expect to play a much larger part in constructing and collaborating in their education rather than regurgitating what they've been told (2005, p. 11.12). This active process and apparent savviness of many of the students should not assume their ability to use and understand Internet services for academic purposes. Without properly educating these students on effective methods of evaluating Web content and finding reliable sources, many students struggle with finding quality information that can be depended on and may without this training simply perpetuate these problems by turning to peers for help. Further, as students are ever more immersed in a digital environment utilizing a wide array of portable devices both in their academic and personal lives, they increasingly come to rely on these various technologies (Corbeil & Valdes-Corbeil, 2007). Ultimately, educators will need to provide these materials in a greater variety of formats to accommodate a growing number of portable technologies that is changing the administrative needs of the infrastructure necessary to provide these services.

All these observations and plans for online or hybrid or distance course delivery consider the need for delivering high-quality educational materials, however, none of this is possible without the less glamorous yet critically important networking or cyberinfrastructure that must be available at the institutional level to support these robust learning opportunities (Jelinkova, et al., 2008). By sufficiently investing in this infrastructure, the institution positions itself to have

the resources to support the efforts of instructors and researchers that they depend on. This will allow instructors to build content rich courses that can be delivered on site or at a distance, and it will also allow the institution to attract high-quality researchers by offering sufficient infrastructure for data exchange and in both cases is transparent to the end user. And, high-quality and full-time instructors and researchers are important requisites to building student success according to Ruth, Sammons, & Poulin (2007) because an increase in part-time or adjunct personnel led to a decrease in student graduation rates. Of course it's important to communicate the capabilities of this infrastructure in plain English so as not to lose the target audience, in this case instructors and researchers, in the details of this conveying the capabilities of this infrastructure (Trubitt & Muchane, 2008).

Administrators must remain aware of the aforementioned changes in students and the technology employed to serve students of today in meeting their educational needs. Careful consideration of policies to support the needs of faculty, staff, and students with the infrastructure or "cyberinfrastructure" that is necessary to create a high-quality learning experience is essential in the educational institution of today.

While educational institutions, among other providers of adult education, continue to ride the wave of infusing ever greater levels of technology into education, it is the learners they serve that will ultimately consume the educational goods that they have to offer. Those in education must respond to the changing demographic as the average age of the population grows older and there is less adherence to the notion of longevity in a single career. Instead, there is far greater transience among careers in adulthood leaving today's adults in a position of seeking education to satisfy needs of future employers rather than seeking education only to fulfill current career requirements or need for advancement within their current position (Gordon, 1995). While this

33

demographic clearly does not represent the comprehensive pool of adult learners, it does

recognize the changes in educational needs that are evolving among the adult population.

For other career oriented adults, increasing their skills through continuing education that

may include taking a course, earning a certificate, or pursuing advanced degrees that may not

apply only the security of being more appealing to potential future employers, but they also

garner greater job security in their current workplace and tend to earn about 12% more than their

peers that have not acquired additional education (Kaplan, 1996). This scenario speaks clearly to

the need to recognize the increasing importance of lifelong learning to the adult learner. While

self-directed learning may meet the needs of adults in non-formal environments, it is the formal

learning environment that can accelerate the process and award a credential that can be used to

provide a standardized means of legitimizing what has been learned for current and future

employers.

Assistive Technology

This alone may not constitute cause for retooling the adult education paradigm, but

instead there are many indicators that suggest that this is but one component of a growing trend.

At this time, while the proportion of adults seeking education continues to escalate so too does

the average age of our population. This calls for us to rethink the Pedigogal model that has long

been in place to educate our children. Instead, we must better define adult learning models that

can be used effectively to serve the growing population of adult learners (Hernandez, Sancho,

Creus, & Montane, 2010). This paradigm shift can then be effectively supported through the

implementation of appropriate technologies to cater to the unique needs of the adult learner. Of

course, this technology cannot become the driving force behind the curriculum, but instead, it

must be used as a supportive medium from which we can enhance learning opportunities for adults.

There still remains a question of what influences adults and their acceptance or nonacceptance of embracing technology as an essential tool. For those adults that do not yet embrace technology, one often cited factor is the role of children, because of their familiarity and acceptance of technology, in adult acceptance of technology. Selwyn (2004) chose to investigate this further and found somewhat unexpected results. While children very often do play a role in adult acceptance of technology, it is usually only one factor of many and does not typically constitute a primary reason for acceptance or not. For this reason, while still a factor, the role of children in adult acceptance of technology is very often overstated.

Morris and Venkatesh (2000) found that, not surprisingly, younger adults were far more willing to accept new technology when necessary in the workplace. They found a linear rate of acceptance versus nonacceptance that showed greater resistance to adopting new technology as age increased. The evidence suggested that this was largely due to a greater degree of familiarity that younger adults had with other technology compared to their aging counterparts. They also found that over time these differences diminished greatly or faded entirely among all ages of adults. This point becomes particularly important in understanding the needs and abilities of adult learners when they enter a learning environment. While technology may be a welcome tool for accelerating a robust learning model, it will be of little or no value if thrust upon older adults too quickly. In fact, high levels of anxiety may be the first obstacle to overcome when introducing adult learners to new technology as part of their learning (Hughes, Pennington, & Makris, 2012).

Older adults are becoming an increasingly powerful demographic and may foster significant influence over electronic media both as an independent consumer and as nontraditional students. As they age, there is an ever greater loss of sensory and motor skills that can make it more difficult to access information that is readily available to others. Although they may not comprise a majority among electronic information consumers, at the same time, as a group they have amassed the financial resources to garner a great deal of attention from electronic content providers (Charness & Holley, 2004). For this reason, they must not be overlooked as a growing demographic of adult education consumers.

In light of this, when considering a design for presenting electronic information there are still some age-related differences worth noting. Phillips and Lesperance (2003) found that although working memory limitations in older adults did not differ significantly from that of younger adults when presented with distracters placed within text, semantic learning in older adults suffered far more than in young adults. These findings suggest that a straightforward design devoid of unnecessary artifacts will be more useful to adults across the age span. A well-thought-out presentation that implements a policy of universal design will provide benefits not only to the older population but also to young children in addition to persons with disabilities without sacrificing utility or preference by others. Therefore, innovations driven by this population brings with it a heavy carryover effect in terms of making electronic information more accessible and useful for everyone.

While in most cases the best technology remains effectively transparent to the end user, in cases where learners are required to directly interact with technology care should be taken to make sure the technology supports the learning and does not become an end in itself. One common characteristic particularly important across the span of adult learners is the need for

36

adult learners to understand the relationship between goals and objectives of their learning and the technology they are being asked to use (Meierhenry, 1982). Technology may also be used in creative ways that will involve many different learning styles of adult learners. Maule (1997) suggests that technology offers adult students the opportunity to interact at their own pace using a variety of sources that are readily available online.

Even among seasoned technology users, adult learning must still rely on core adult learning principles to be truly effective. MacDonald, Gabriel, and Cousins (2000) found that when using adult learning principles to train personnel in technology-based firms that learning was best retained and applied when there is a direct relationship between new learning and current responsibilities. Furthermore, it suggested the value of reflective work for adults and how it fits together with their new learning and then most importantly being able to apply what they've learned. For many, they indicated that this was the core of all learning that took place for them during the study.

There are, of course, mitigating factors that may affect access to and ability for adults to benefit from technology in education. For some, it may simply be little access to education or technology without a person or organization that can initiate an opportunity for education. An example of this exists in China where a large number of rice farmers have been able to escape poverty through distance education where they learned new more effective rice farming techniques. Without having had the opportunity of taking part in an educational broadcast that allowed them to reach education that brought them beyond the traditional methods they previously employed, these otherwise hard-working people would have remained in poverty despite their efforts (Rongxia, 2001). While this may relieve to a degree the depth of poverty suffered by these farmers, it may also speak to the increasing dichotomy between rich and poor

37

related to access of education. For some there may be other factors beyond their control that prohibit them from acquiring this form of distance education. Particularly in the poorest regions, Vadén and Suoranta (2009) point out that many times the basic infrastructure required to provide education via technology may be absent, citing the lack of electricity as one example of a barrier to persons in such areas.

While technology is forever encroaching upon the educational domain of adult learners, there still seem to be great advantages for some at the expense of others. Formal educational institutions can reduce costs and provide education to the masses relatively inexpensively by using much of their already existing infrastructure. This is caused a great explosion of distance learning courses and degrees being offered to a very large, even international, market. Even smaller schools can compete on a global scale in the virtual environment of computers and specifically the Internet. While it holds great promise for the masses and may be the key to relieving poverty for some, there are still others that continue to lack adequate access to this education thus potentially widening the economic gap.

Distance Learning

Distance education is not new. It has in fact been around in one form or another since the early days of correspondence study via the Postal Service, beginning in the 1880s described in greater detail below (Moore & Kearsley, 2005). Since that time, distance education has gone through continual revision of delivery methods whereby an unending evolution has taken place marked by a series of revolutionary events, namely the development of new technologies. Of these new technologies, perhaps none have been more influential in the delivery of distance education than personal computers and the Internet. Through their utility and availability, these technologies have come together to serve populations that were previously all but unreachable.

38

The following provides a brief overview of the prominent development stages of distance education. As one considers the beginnings of distance education and what technologies were available to support its delivery there has been an evolutionary process marked by five prominent stages. These are reflective of the technology of each era.

This first stage of distance education in the United States was embodied by the appearance of trains in the 1880s. This new technology, the trains, allowed regular inexpensive and reliable mail delivery whereby correspondence schools could use the postal system to communicate with students by exchanging written materials at a distance.

The second stage in this evolution came about in the 1920s as broadcasting radio signals became more popular and continue to expand with educational television programming began in the 1930s. Together, these new broadcast technologies brought a new dynamic to the technological capabilities of distance education.

The third stage began in the late 1960s and early 1970s whereby educators attempted to use many forms of media to create a more holistic version of distance education using what was referred to as A Systems Approach. Courses that used this approach made an effort to use many different forms of material may include print, broadcast such as radio and or TV, audio tapes, telephone conferences, and many more in addition to incorporating local study groups where possible or even allowing students to use on-campus laboratories during school vacations.

The fourth stage in distance education came about through teleconferencing in the 1980s and primarily embraced the notion of the traditional classroom in a distance format. One of its limitations was that it largely used a one-way system of delivery. This limitation, however, was quickly disappearing as two-way videoconferencing became more widely available in the 1990s.

The fifth stage began in the 1990s where the arrival of online education began to appear. This medium has been exploding popularity ever since and continues to do so. This has allowed educators and students to communicate in new ways and conduct course activities that were not possible in face-to-face classrooms or other distance formats.

By recognizing this historical perspective, it appears as though the time has come to acknowledge a new stage taking place in the late 2000s and early 2010s. Through the blending of devices and ubiquitous nature of digital connectedness there is now more than ever in emerging era of Digital Convergence. It is this convergence that will allow or arguably require educators to be cognizant of educational delivery in new and innovative ways. The lines between distance education and traditional education will continue to blur as both students and faculty increasingly use the same appliances and same services for the delivery of education in the classroom and at a distance as they do for their personal and educational lives.

Students and educators frequently use many of the same tools whether it's e-mail, Internet websites, or digital documents both for education and for pleasure. In addition, the appliances needed to access this information now come in a multitude of forms that will fit in a backpack or even one's pocket. And no longer are these devices stand-alone pieces of hardware that must be purchased specifically to accomplish a particular task but instead are embedded in everyday appliances, and even our cell phones.

As technology and student expectations continue to evolve the core mission of the educator remains the same in that it always requires a high-quality curriculum to be developed as a first priority while the technology remains a supportive medium. By understanding the changes that have taken place in the technology that has supported distance education we can better meet the needs and expectations of students as we look to the future. After all, despite the importance

of trains in early distance education, few educators or students today would agree that this level of technology would be sufficiently appropriate to effectively deliver high-quality distance education today. Instead, the collection of ICT's used today offer robust models for the delivery of distance education that will certainly be replaced as other communication technologies develop.

There are, of course, student needs for support no matter how robust the technology or delivery method may be. Within the model of distance learning, particularly in coursework offered via the Internet, there has long been recognition of the need for support services available to students. While there are frequently a number of supports available to distance of students, Scheer and Lockee (2003) found that by understanding the unique and specific needs faced by these students in geographically dispersed locations, educators can begin to more effectively serve their needs.

Universal Design

One of the most effective methods for serving the needs of all students is through implementing the concept of Universal Design (UD). The notion of Universal in this context refers to a forward thinking process of design that mitigates disability through design that minimizes or eliminates unnecessary barriers for as many persons as possible (Rose, Harbour, Johnston, Daley, & Abarbanell, 2006). It's very desirable to use these practices because it reduces the need for accommodation and creates a more inclusive environment. This is not a new concept; however, often the idea of UD first conjures up the idea of the removal of architectural barriers as a means to provide barrier free access to facilities. This does not tell the whole story in higher education, and it especially does not tell the whole story in a distance learning environment. In a learning environment, and especially the distance learning environment, the

41

goal is to create Universal Design for Learning (UDL) (Rose, et al., 2006). No matter how

desirable this concept may be, there are limitations to implementation that bring with it their own

challenges.

Instructor Training for Accessible Online Design

Creating challenges for consistency in design of distance education materials are the

different sources through which content is created. While the infrastructure for the ICT's may be

generated by an institutional design team and other outsourced programs that are contracted for

different courses or programs that are designed by the companies that market them, specific

courses and course content are frequently created by the faculty themselves. Problems can arise

if Faculty and other staff that are content experts in their respective area do not have sufficient

training or awareness of UDL principles to create or deliver courses accessible to all students in a

distance education environment (Burgstahler, National Center on Secondary, & Transition,

2002). The need for additional professional development for faculty was identified by Gladheart

(2010) through a survey showing a low percentage of faculty that were aware of methods to

improve accessibility in electronically delivered courses.

CHAPTER 3. METHODOLOGY

Although not necessarily widely used in research, autoethnography provides a methodology for this manuscript through which a researcher can provide a particularly thick narrative that may not otherwise be apparent while analyzing a body of qualitative notes. Where quantitative research carries value for measuring numeric data and other forms of qualitative research study the lives of others, they both lack the "I" that makes autoethnographic research unique by studying the self as a test subject. Through immersion in the study itself, one can fully explore the characteristics that make one unique while taking care to maintain the dichotomy between the fully engaged subject and the objective researcher (Mitra, 2010).

This type of research is useful in challenging or even dislodging the underpinnings of stereotyping by bringing the value and uniqueness of the individual to the forefront. Autoethnography gives voice to persons that may otherwise be ascribed to a group without their permission. Collectively, the body of autoethnographic works builds a literature base through which lived events and the nuances they carry demonstrates uniqueness of the individual despite any ascribed group affiliation (Hughes, et al., 2012). This uniqueness among individuals is brought to light as an identity separate from any prescribed group in contrast to the notion of stereotyping.

While one must acknowledge the risk of personal bias when acting as both researcher and research subject, it is fully as important to acknowledge the value of contributing to the body of existing literature the rich and nuanced thoughts, feelings, perspectives of the research subject. By studying one's own journey, the researcher can then be confident that a rich or thick description captures nuances that are important, but may be dismissed as unimportant if viewed by someone else. There is a concerted effort within the confines of this manuscript to strike a

balance that clearly denotes literature and objective information from the personal narratives that are included so as to breathe life of real-world experience within the context of research. Mitra (2010) stresses the importance of striking a balance between being over immersed and disinterested while suggesting that a good manuscript must be someplace in between.

Materials

To develop this study, resources were employed that captured the richness and depth of experience that were brought forth in some cases through memory and in other cases through documents that had been written earlier thus reflecting a historical snapshot. Resources herein referred to headnotes that consist of narratives retrieved from memory and from historical documents that are documents that were written as events happened in the past. These narratives use personal experience to illustrate and relate to scholarly literature throughout this manuscript.

Headnotes

This manuscript employs what is described by Wall (2008) as headnotes as one of the means to illustrate and bring life to literature in this document. These headnotes are akin to fieldnotes frequently used in qualitative research; however they differ somewhat in their genesis. Unlike fieldnotes that are frequently transcribed and recorded very soon after an interview, headnotes are more frequently taken from memory of lived experience and provided as the author remembers it. They include the researcher as participant to capture the experiences, emotions, memories, and performance when collecting data (Mitra, 2010). This can of course create risk of bias because of a possibility of reframing memories when placed within a current context whenever one is recalling previously unwritten or unrecorded information, however it remains relevant in that it still provides an accurate snapshot in how one's journey brought them to the current destination (Wall, 2008).

The use of headnotes for qualitative research provides a rich source of lived experience that cannot fully be captured faithfully and completely through the use of fieldnotes alone. The use of headnotes brings with them all of the context and nuances that extend beyond written accounts because they use data directly from memory without an intermediary that first transcribes the memories of others for research purposes. This method, in fact, may even carry greater value to researchers than the often-used fieldnotes (Wall, 2008). By including data gathered from headnotes, the researcher can conduct an intimate examination that includes a wide array of sources that acknowledge the role of the researcher is a part of the research process (Hughes, et al., 2012).

Historical documents

When carrying out autoethnographic research, it is incumbent upon the researcher to use a variety of resources through which to view the topic of study. Among the data used in this study were historical artifacts that provide a snapshot or record of data within the context of the time which it took place. Hughes (2012) notes the value of the historical context for autoethnographical research provided by including data captured at the time it initially occurred if one is to fully understand the context of the work. This data can come from a variety of sources depending upon what is available and could include audio or video recordings, documents, or clippings for example.

Historical documents, documents that were written during the period under study, are used to gather snapshots of thoughts, goals, and perceptions taken from real-time thoughts and beliefs of events written as they occurred. Because they were written at the time it occurred, these historical documents will allow one to identify biases that may be reframed by viewing memory through a current lens or they may be used to shed additional light on important issues

at the time or reinforce the accuracy of headnotes in their recollection. These documents were taken from applications to graduate school, leadership essay, and a transportation journal.

Literature

Throughout this manuscript, scholarly literature is used to provide a framework through which one can view the data related to becoming disabled as an adult and the impact on identity. This creates a contextual referent for environment and resources in which the journey of rebuilding identity takes place. Reviewing literature within this context creates a framework and common knowledge base through which both author and reader can share perspective on the topic under study (Randolph, 2009).

CHAPTER 4. A SERIES OF PERSONAL NARRATIVES

The following chapter provides a series of narratives that, together with personal accounts within this manuscript, were used to provide data used for the analysis of this study. Because autoethnography uses the researcher's personal story as a data source, these narratives become an integral part of the overall manuscript (Mitra, 2010).

This section begins with a series of headnotes that were transcribed for the purpose of creating this manuscript from memories of events and processes. These were essentially all created after the fact as accurately as possible to capture the nuances of lived experience with fidelity. The headnotes in this chapter begin with an account of my journey in higher education and the shift in my identity from brawny factory worker to scholar. They focus on several of the challenges I experienced along the way. One of those challenges was transportation and how that caused me to shift my focus to distance education. The headnotes then focus on my experiences with distance education and assistive technology in that context. I then address some of the barriers that exist in spite of assistive technology. I also include discussion about how assistive technology and distance education have developed my career in a completely new direction and made available many opportunities that I would never have considered in the past.

Becoming an Adult Student with a Disability

I had never embraced the educational system in my youth. Going to school was something that had to be done until high school graduation, and once that was done, it was time to find a good factory job and settle into a working routine that would last through retirement. Consequently, neither grades nor education carried great personal value, but instead, the goal was to find a way to graduation with as little effort as possible to simply obtain a diploma to be

considered a high school graduate for job seeking. At least that was my youthful viewpoint of education and its value.

Career choice had really never been a concern for me, because I felt confident that I knew what I wanted to do and what it would take to get there. I was content to work manual labor jobs while looking for a good paying position as a laborer in a factory where I could remain working until retirement age. Through a great deal of persistence, I found the work that I was looking for in a cheese factory in the town where I live. I began working there in 1983. Many of my coworkers were nearing retirement, and the wage was good, however a changing economy brought about the closure at this factory. This eventually led to work in a similar type of factory but this time requiring two and half hours of round-trip commute time each day.

After settling into my niche as a laborer in a factory where the work was primarily heavy labor, I hoped to remain there through retirement. In my free time, I had a passion for the outdoors that included hunting, fishing, skiing, and especially motorcycles. While I enjoyed many of these activities with a few friends I often chose solitude; however I was thrilled the birth of my son so I could share these experiences with him, even taking him for his first motorcycle ride through our neighborhood at only three days old. But I was required to create a complete change in perspective when a single catastrophic injury in 1987 made factory work and labor jobs unrealistic, and in fact, impossible. My disabling injury left me unable to perform even the most minor manual tasks. This became my abrupt introduction to being an adult with a disability with no apparent future in the workforce or the world I had known.

With no ability to return to manual labor in the workforce, I spent several years out of work despite having just reached early adulthood. Between 1987 and 1990 my life consisted of being warehoused at home with very limited transportation or social life alternated with lengthy

hospital stays. Because I require a vehicle that is capable of transporting me while positioned in my wheelchair, I need a special wheelchair accessible van. As a result, I became effectively homebound for all practical purpose for more than three years following my newly acquired disability. During this time, I had the extraordinarily good fortune to be offered the use of a retired ambulance that had a wheelchair lift installed in it for my use. So long as I had someone to drive the vehicle for me and tie down my wheelchair in the vehicle, I gained at least minimal ability to get around and had some form of basic transportation from 1988 until 1990.

Unfortunately I could only ride as a passenger and had to rely on others to drive me to my destination. This was a tremendous value and a life-changing opportunity, but it was still a cumbersome process and remained a last resort when transportation was absolutely necessary. Unreliable transportation would become particularly problematic even if I wanted to pursue a college education because without finding a driver, I could not attend class. In 1990 I decided to try to acquire a modified vehicle that I could drive myself. I achieved some independence with my first modified vehicle, which I drove for 16 years before having to replace it.

While there was abundance of loss and anger from all of these changes, it became even worse when returning to school began to look inevitable because the prospect of employment looked very unlikely in my lifetime. I still felt disdain for the educational system, including higher education. I felt contempt for the presumption that returning to school of any kind would be a fix all — or a fix for *anything* for that matter. Despite my hostility and anger, in 1990 I enrolled in the local community college. I made a pledge to drop out if I earned anything less than an A or if I did not finish at the top of every class I took. With a chip on my shoulder, I signed up for a single course without knowing what to expect.

My Initial Contact with Disability Services

When I began my journey in higher education, I was completely naïve to the entire process and had no idea what a stroke of good fortune I stumbled my way into quite early on. During one of my first visits to the campus, I was traversing a sidewalk near the administration building and could hear someone shouting something to me from across the campus. I stopped to see who it was, and I could see someone hurrying my way asking that I wait so he could introduce himself. He said that he noticed I was using a wheelchair and that he worked with disability services, an office that I had never before heard of, so he wanted to see how he could help while I was at the college. This provided my first knowledge and experience with these kinds of services in higher education and it played a pivotal role throughout my undergraduate career.

It was here that I first learned of the notion of reasonable accommodation. This provided a point of contact for which I could address barriers to my education that I faced because of disability. Most times, it was a relatively minor request such as being allowed to place answers for tests directly on a test sheet instead of filling bubbles on a Scantron sheet or getting a seat by the door to accommodate wheelchair access. However, no matter how minor some these changes may have been, it would not have been possible to successfully attend college without them. It's true that individual instructors may be willing to help where they could, but the process would have been piecemeal in a hit or miss fashion devoid of reliability or consistency for me or the instructors. This is critical because inconsistency becomes a kiss of death if there is no assurance of what to expect for either me or the instructors.

The same drive and competitiveness that fed my previous "work hard and play hard" attitude before my injury, came into play as a student. Although I did not plan to complete a

degree if I did not get the highest grades in the class, my drive caused me to sacrifice any social

life and many hours of sleep to excel in my classes. Having felt some sense of accomplishment

by completing the first portion of my college career with success and now able to drive, it was

toward the end of Christmas break that year I received two letters in the mail one day that

seemed to fly in the face of moving forward. One letter was from the college telling me my

college career had ended for nonpayment of tuition and not to return after Christmas break. The

other letter was telling me the state of Minnesota had once again canceled my driver's license for

failure to complete all required steps for full reinstatement before the expiration of the deadline.

Feeling both angered and defeated I contacted the college only to find they had failed to place

my financial file in the proper basket. I was told that I was in good standing and could ignore the

letter I received saying not to come back. I also called the state of Minnesota to find out why my

driver's license had once again been canceled since I had satisfactorily completed all the steps

that were required. After a great deal of prodding on my part they agreed to look into it only to

find they too had misplaced my file after receiving it and said to ignore the letter canceling my

license, and verbally stated that I was in good standing as a licensed driver in my state.

Even after resolving these issues, I was still angry in this role as an unwilling student.

Each semester when I received awards and honors for my good grades, I would take a bottle of

Southern Comfort on onto my deck and drink it as I set the certificates on fire and dropped them

off the edge of the deck to burn. Because of the anger that was driving me – as well as support

from disability services – eventually I was faced with the unexpected and unplanned reality that I

was graduating. In spite of my pledge to drop out if I earned anything less than an A or did not

finish at the top of every class I took, I completed my associate of arts degree in 1993. The

ongoing anger drove me to transfer to Minnesota State University and complete a Bachelor of

Arts degree in psychology in 1995. The choice of majors was driven in part by interest, but perhaps even more so as a form of self-therapy.

After completing these degrees, I began to question what was next. After being turned down for the graduate psychology program at North Dakota State University (NDSU), initially I continued my studies at home for fear of losing my newly gained education. Then I began some volunteer work in order to give back. This was a turning point in my life. The work I was doing applied the formal training I had prepared for as an undergraduate and also included a great deal of technology and computer software.

I created an unpaid internship at the Fergus Falls Treatment Center in my hometown. Because this site was a mental health facility, I developed and proposed an internship to help me take what I had learned as an undergraduate clinical psychology major and put it to work in the real world. This was important to me since the program I completed did not have an internship component. My proposal met a great deal of resistance because the union was concerned that I would be taking away someone else's job by working as a volunteer. After lengthy negotiations, they allowed me to work with patients who were Mentally Ill and Chemically Dependent (MICD) as long as my work did not interfere with paid positions. This of course meant that there were limitations in what I was allowed to do, but they did grant me full access to patient records, patient meetings, and other daily activities in that area. While there, I also taught classes to both staff and patients on mental illness in addition to co-facilitating some MICD groups. Lastly, I was asked to develop analytical spreadsheets by the psychology department that would score data from tests they gave. Unfortunately, the spreadsheets I created were not used for long because they replaced the skills required of a person specially trained for scoring them thus meaning that the spreadsheets would eliminate someone's job.

52

While volunteering at the Regional Treatment Center, I was also asked to provide written weekly reports for my assessment of accessibility around the campus. The facility is very large thus making a divide and conquer system the only viable means of addressing these needs. By taking one section or one area at a time, recommendations could be generated there were detailed enough to be meaningful. I was also asked to inspect the satellite facilities around the region and generate written reports for the accessibility of those as well. It should be noted that these were not necessarily reviewed to see if they were compliant with state or federal law, but instead, they were from a usability perspective to see if they actually work for someone that uses a wheelchair and has severely limited mobility.

At the same time that I was volunteering at the treatment center, I also felt driven to return to the college where I began my higher education experience and offer to work as a volunteer to try and give back because of all they had done for me. Throughout college I had spent time working with and serving various organizations and even chaired the bookstore committee. When I finished college, it was of utmost importance for me to give back to them for what they meant to me as I began my education; because I did not have the financial means to provide a donation, I chose to volunteer my time. The timing was right in that they had a great deal of need for the skills and education I had acquired. This provided an excellent venue for me to feel that I could create some parity in all they had done for me.

I found myself returning to the Disability Services office where my experience allowed me to help the office and current students in finding creative ways to meet their assistive technology needs. The computer skills I learned related to assistive technology became a very large part of what I could offer to the college, this department, and students. Shortly after I began volunteering, I found myself putting in 60 to 80 hours per week and often more preparing

documents for students in electronic formats at a time when publishers were otherwise unwilling to provide them. This involved scanning and using Optical Character Recognition (OCR) to convert entire textbooks into electronic texts. Because of the technology of the day, this was a very slow process and the resulting files would have to be saved to a floppy disk and driven to a student at an out-of-town location.

At around the same time, we undertook an initiative to become the first two-year college in the country to offer wireless Internet and network access to students. The intent was to use this technology in a way that allowed students with disabilities that otherwise had difficulty using the library and other traditional print resources the opportunity to have the same information available to them that other students have long enjoyed. Even though a few short infrastructure delays meant that it was among the first, but not the first, it provided a new level of information freedom for students with disabilities that was rarely seen at the time. While wireless Internet and network services are a staple of colleges and universities today, this system was initially begun for students with disabilities and it now provides the backbone for the wireless network on that campus today. With the completion of this project, I presented this technology and co-authored an article for Closing the Gap, the premier conference for assistive technology.

Working ever closer with persons and organizations that needed hands-on knowledge of useful assistive technologies, I began volunteering for other persons and organizations to help identify and serve their assistive technology needs. Eventually, I was contacted by the Minnesota STAR Program (a System of Technology to Achieve Results) to help rate and disseminate state grants for assistive technology. This program is operated by the State of Minnesota and is responsible for overseeing the technology needed for persons with disabilities throughout the state. After serving the grant process, I was asked to join their advisory Council where upon I

applied and was appointed by the governor to serve. I remained a member for approximately 10 years and served as Chair of the advisory Council for two years.

As I continued to volunteer, many of the people I came into contact with either knew somebody or knew an organization that needed computer training or software development that I could provide. At first, this was primarily work I could do from home or through some other informal means. Over time this volunteer work using computers and computer software led to my first paying working since becoming disabled. Eventually, I was asked by the college to work for them as a contractor under the Center for Lifelong Learning where I would teach an occasional evening Computer Science class in addition to going on-site to provide customized computer training and custom software development. While flattering, I had not viewed any of my work as employable or worthy of pay. With some substantial financial earnings limitations, the most severe of my angst was in a clear belief that I had come to feel I was unemployable and was being offered pay for something that therefore had no value and I should do for free.

This was a substantial paradigm shift because of my lack of identity as a person working and receiving pay for those efforts. Eventually the work I was asked to do the college was negotiated at a fair rate because they said the structure they need to work with required payment to me and therefore accountability for the services they were providing through my work. While limited in scope, this became the first paid work I had taken on since leaving my work as a laborer in the factories. Despite the anxiety, there was a degree of empowerment that I gained by having paid employment even though it was relatively small in scope. Through this work, my perspective began to realign with a fair compensation for a fair work. I taught in a contract capacity from 1997 to 1999. Still, the majority of my work was volunteerism that had become a sense of civic duty and provided a great deal of fulfillment by contributing to others.

My work had begun to be more focused on computers related to both hardware and software eventually earning a reputation for quality work. Settled in with my contract work for the college and volunteer work I was doing, I was very surprised within a couple of years to receive a call from the college asking me to begin teaching as a faculty member at the college in place of the contract work I had previously been doing. I was asked to teach several courses in computer science and business.

Feeling a great deal of trepidation, I asked for a few days to think it over to see whether I could manage it, particularly since my formal education was limited in both those fields at that time. When I replied to them with the news that I felt I could take on about half of what they're offering, they said thank you and immediately set me up with all of the courses where they needed help, including the ones I was trying to turn down. With only a couple of days to prepare to teach several college courses, and having never taught as a faculty member before, I found myself fully immersed and working feverishly to present a quality education to the students I was serving. Considering that this meant I had to effectively write all of these courses from scratch with very little notice while teaching them, the task was formidable say the least, even for seasoned faculty members. It became a trial by fire trying to stay ahead of the students while developing the courses throughout the semester. With this, my role changed from a contractor to an employee effectively starting my career in higher education. I embraced the fruits of higher education rather than rejecting it in anger. My drive was channeled into more constructive activities related to employment and education. I held this position for 10 years at the college where I began my experience in higher education.

The transition from student, to volunteer, to employee wasn't always a smooth process. There were numerous challenges to my new role that were in some ways unexpected. I found in

part, disability seemed to be acceptable as a student, but I could feel a presumption by many of my former instructors that were now peers struggling to see me as a viable colleague. Most of them were still very polite, friendly, and helpful, but clearly didn't see me as a qualified colleague. This presumption was clearly exacerbated by still seeing me as a student or volunteer that wasn't really qualified or was serious about the service I was providing.

Because I began working as faculty prior to the Student Information Systems that are widely used today, it was very difficult for me to carry books or notes or other materials for lecture and demonstrations not to mention assigning and collecting student work so I needed to find a different way to manage materials. To make this work for me, I taught myself how to develop webpages where I could place all student work and assignments, and students could submit their work to me as electronic files via e-mail attachments. Using standard technologies that were universally available was a critical component in allowing me to return to work in an environment where a disability would otherwise have been a substantial barrier. Using the Internet in this way provided barrier free access for me and a strong learning environment for the students I served.

As faculty, I began teaching at the two-year community college with a BA degree just as many others had. When I joined the faculty I had completed my undergraduate work but had not undertaken any graduate study. Contractually, this was allowed for the short term, but eventually I needed to return to graduate school for a graduate degree or give up my position as a faculty member at the college. At that time I was relatively content in my faculty position and I wanted to continue in the position. So I accepted that I needed to pursue graduate work and the time came where it was necessary to search for a graduate program that met my current needs and areas of interest. The search initially appeared futile when trying to find a program that was

57

geographically accessible, that I could afford, and that met my interests and needs. As a stroke of good luck, a friend referred me to a Master's program within an hour's drive of my home. Better yet, the school had just developed a new initiative to offer their entire program through various forms of distance education. The degree itself was in Educational Leadership with an emphasis in educational technology which aligned with the work I was doing in higher education. This looked like it would be a great fit for securing a permanent position in my current role and would also allow me to develop more robust models of course delivery, particularly those that are being provided via distance education.

This leadership essay that I wrote as part of my application to the Master's program marked a paramount shift in vision from the role of a laborer conditioned to adhere to the guidance provided by leadership to one of providing the very leadership that had been so important to successful factory work. With new insights and changed perspective, it now became more important to provide the leadership I had long been trained to follow (See Appendix A for complete essay).

The leadership essay described my vision for how people interact and respond depending on internal and external motivators. Recognizing these differences and motivators serves as a foundation to providing effective leadership for others. This also asserts the belief that by providing a structure and support that allows others to work in ways that work best for them; they will be more satisfied in both their work and the end result. In addition to describing the leadership style to which I aspired, these insights allowed me to better understand how to provide this leadership effectively as a newfound role in my career opportunities in addition to my shift in my own identity.

Further exemplifying the shift in identity is my stark transition from laborer to leader by making the decision to attend graduate school with the intent of building a stronger foundation for a career in higher education. This included a great deal of reflection and searching to find graduate programs that would align well with my current career aspirations. While this would be a natural transition for many, it was a complete reversal of my entire self-concept whereby graduate school was something I sought out and embraced. A statement of professional goals that was written as part of a successful application to the Master's program provides evidence of a newfound identity (see Appendix B). This historical document illustrates the change in vision I have experienced in how I have come to see myself and where I belong.

The Educational Leadership program allowed me to develop course materials and provide many new insights within my present work environment. Students in my classroom had the benefit of many new tools and learning models that I could not have provided prior to beginning this graduate program. It also provided the professional credentials and skills that allowed me to greatly expand the service I could provide to colleagues. I found myself in the midst of greater roles for meetings and in the decision-making in my workplace. While still limited in the amount of time I could be paid for the work I was doing, the work experience I was gaining became more valuable to me than lost earnings. There appeared to be a new model on the horizon for my continued employment whereby career building carried at least some promise for a chance at possible financial independence.

While working, I continued to volunteer for a number of organizations with increasing levels of responsibility. I did this in part to serve and in part to being a career-building process that would allow me to seek higher-level positions that I could not otherwise attain without gaining valuable experience. These included local, regional, and state nonprofit organizations

that serve people with disabilities. Those organizations needed input regarding technology and also needed a connection with higher education. By being involved in some of these simultaneously, it provided an outstanding networking opportunity to coordinate events with several organizations.

Between 2004 and 2007 I completed the Master of Science degree in Education Leadership with a concentration in Educational Technology through Moorhead State University. This is one of the first times that I had truly stepped back to consider my views on personal leadership and define a style that I believed in and could pursue as I developed a leadership essay (Appendix A). This created a framework for which I could identify with to align with the more consistently and apply principles of the leadership activities I had alluded to in my application letter to MSUM (Appendix B). By that time I was having significant problems with the adapted van that had allowed me to attend school, but this program was offered through distance education. Eventually I realized that I would need to complete a doctoral degree to fully accomplish the career building opportunities that I was currently involved with. While the position I held at that time did not require a doctoral degree, this terminal degree would allow me to apply for future positions and enhance my marketability and career goals. So when I graduated from the Master's program, I immediately identified my interests and goals (Appendix C) whereby I entered a doctoral program at NDSU that was offered at a distance using an Interactive Video Network that allowed me to participate synchronously in doctoral-level distance education.

This is followed by another statement of professional goals that was written near the completion of the Masters program, and this second statement is part of the application to a

doctoral program (Appendix C). These documents together provide further evidence of the shift identity from that of a laborer to one of a professional interested in leadership roles.

In 2009, after 10 years of teaching computer science at the college where I had begun my experience in higher education, I gave up my faculty position to accept a position as the Director of Disability Services upon the retirement of my friend, mentor, colleague, and former director who supported my early career in higher education. I have continued that position while working on my doctoral degree. This allowed me to further serve students with disabilities with assistive technology or other collegiate accommodations as appropriate under the law. As the director, it also afforded me the opportunity to build a program to serve students while providing assistive technology to mitigate the barriers they face in their education. This is vitally important at a two-year institution because the students' initial experience will often determine whether or not they continue in higher education.

Unlike high school, these students are expected to self disclose these disabilities to me as a provider so I can work with them to identify appropriate service within a higher education environment. Because high school and college operate largely under different disability related legislation the responsibility is now upon the student to self disclose rather than the schools' responsibility to identify, therefore it can be a difficult task at best for students to ask for service. Creating an even greater challenge is that when I accepted the disability services position I had to create the office from scratch with little or no resources. Even the office space I had at the time offered no privacy even when students frequently need to disclose sensitive medical information to allow me to provide service. Having experienced similar situations, I insisted on private office space for nearly three years before it was granted.

If I can provide a sound footing through my office, many students may persist that otherwise would not. I also know firsthand the power of appropriate intervention through assistive technology and that allows me to counsel students and recommend solutions to disability related barriers to their education that are appropriate without overburdening them with unnecessary technology.

Having been a consumer of disability services throughout my work as an undergraduate, I learned how important the removal of disability related barriers to education really was. This barrier removal allowed me to remain competitive, and even excel. Although federal law requires postsecondary institutions to afford students with disabilities equal access to higher education, the wording of the legislation does not tell the entire story. Curb cuts are not enough to remove disability-related barriers to education. Invention of technology for modified vehicles for transportation and assistive technology for learning also does not tell the entire story. This narrative continues with a deeper description of some of the significant barriers, including transportation, assistive technology, classroom climate and obstacles, and challenges doing research that I have faced on the journey. The narrative will then close with a discussion about how distance education can mitigate these barriers.

Transportation Challenges

In order to take advantage of reasonable accommodation offered through disability services that would allow me to become a successful student, I had to be able to get to the campus. Transportation presents its own challenges when one is fully dependent upon a wheelchair and must remain in the wheelchair, even while in a vehicle. While the options for transportation are improving somewhat, there has historically been either no available wheelchair accessible transportation or unreliable wheelchair accessible transportation, particularly in rural

areas. This creates a far greater dependence on personal vehicles for transportation when faced with mobility challenges. In order to have reliable transportation that is wheelchair accessible it is necessary to have a personal vehicle. Having it adapted for safe use is not as simple as it may sound.

Prior to my injury, I was accustomed to operating nearly every vehicle type licensed for the road ranging from tractor-trailers to motorcycles and including off-road vehicles. After my injury, my driver's license was immediately canceled through a standard protocol because my injury was neurological in nature. Before I could consider driving, I had to go through a long multilayer process to once again reacquire my driver's license. There was a letter required for medical approval from my primary rehabilitation physician, a required driving evaluation, a standard written test that is taken by new drivers, specialized driver's training to learn how to operate a vehicle using hand controls, and last there had to be a behind-the-wheel test equivalent to what new drivers must complete and pass. Even if I could meet all of the requirements, there were still a question of how to pay for a very expensive vehicle on limited income, and even more than that, there was always the possibility that I may have been unable to safely and independently operate a vehicle with my limited mobility no matter how modified or custom it may be for my needs. After completing all these steps, I received notice of cancellation for failure to complete these steps prior to the deadline despite having completed everything on time. After extensive prodding of the state licensing bureau, they acknowledged that they had failed to handle my file properly and immediately reinstated my license in good standing.

During this time, I had ordered a vehicle specially modified to meet my driving needs. In just under two months of vehicle build time following this preparation, I was able to take delivery on a wheelchair accessible van custom-built for me to drive for daily transportation as

well as attending college. It allowed me to drive while seated in a wheelchair using hand controls with highly modified steering and brakes among many other adaptations. Even after having a great deal of experience with driving a wide array of vehicles, once this vehicle arrived, I took specialized training to help become familiar with the hand controls. This training was enormously helpful because of the substantial change in the way this vehicle behaved relative to unmodified vehicles.

This brought a newfound level of freedom that had been absent for the years following my injury. Perhaps one of the more bitter pills to swallow was the widespread assumption I was often confronted with – but even more often alerted to from friends that had been hearing others talk – was an apparent widespread belief that some mystery pool of money found its way to buying a new vehicle for me out of pity following my disabling injury. In truth, because of the specialized nature of the vehicle it became essentially the equivalent cost of buying three brand-new vehicles with no outside financial support, causing a great deal of personal hardship in financing my transportation.

Because these vehicles become extraordinarily expensive — and because disability often limits income and resources substantially as it did in my case — I drove this vehicle for a great many years well beyond its otherwise serviceable life. Because of the cost of a wheelchair-accessible van with hand controls and other secondary controls necessary for me to safely operate it, I maintained the same vehicle for 16 years, putting nearly a quarter million miles on it. As a student and on a limited income this meant constant care, maintenance, and bodywork to stifle rust and other road hazards in an effort to avoid excessive wear and the threat of a need to replace it. Unfortunately, repairs were frequent and ran high often exceeding monthly income

leaving little for anything else. Repairs alone ultimately cost much more than the vehicle itself by the time it was retired. Eventually, it became clear there had to be some way to replace it.

I owned this initial vehicle from 1990 to 2006. It carried me through the entirety of my undergraduate work, through my educational hiatus where I began to return to some work, and into my graduate work. Eventually the maintenance began to be so overwhelming that it was clear it was not going to function for me any longer. It was bittersweet coming to grips with retiring this vehicle since it had become deeply embedded in my life and had been fully built around my needs more and more with every passing year. In some ways, it was more like an old friend full of memories but it was time to say goodbye. While replacement is typically very expensive for a vehicle, and especially for these heavily modified vehicles, I had the extraordinarily good fortune of working with Vocational Rehabilitation at the time my vehicle's useful life was coming to an end.

When it became impossible to continue maintaining my initial vehicle, I was very fortunate in working with the Minnesota Department of Vocational Rehabilitation which agreed to cover the cost of vehicle modifications, provided I would find the personal resources to buy a brand-new vehicle for modification. Unlike the two months required for my first van, the time it took to complete this process from beginning approval through having a new vehicle in the driveway eventually became measured in years. While much of this change in vehicles was a positive move, there were some issues that were recurring and not getting resolved. Unfortunately, within a few years, the second van developed a steering problem because of the vehicle primary controls modification. The power steering would seize up every couple of months from a failed seal that would require pouring copious amounts of fluid back into the system long enough to make a trip to the dealer in a major city for repairs. Perhaps most

troubling is that the steering itself never did work properly. The vendor consistently failed to keep records regarding this repeated problem, so they always treated it as a one-time problem. This was a serious issue where the steering would bind so the vehicle could not be turned until it was rolled forward or back. This became highly problematic and dangerous in tight areas such as parking lots or in traffic. After exhausting all efforts for repair, the steering was deemed unrepairable and a safety risk.

Fraught with steering problems and lacking the intimate bond the first vehicle and I had, it was clearly time to start the process all over again. This time, licensing was not an issue but driving evaluations and equipment checks have become part of the routine when shopping for a different vehicle. Having long been something of a *motorhead,* car shopping had always been a process I looked forward to and I embraced it as a sort of personal statement and long upcoming relationship. Now, with all of the modifications and changes I need in a vehicle, it simply becomes a long arduous task. A job well done can bring a renewed freedom, but the process becomes wearing.

The timing, funding, and political climate were right at the time I needed to replace this vehicle and therefore some of the cost for me to acquire another modified vehicle could be relieved by Vocational Rehabilitation Services. Because it was a safety issue, Vocational Rehabilitation agreed to fund the vehicle modifications for a third new vehicle, again with the stipulation that I find personal financial resources to purchase another new vehicle. When the time came to move forward in acquiring the next vehicle, the standard protocol requires going through a full driving evaluation to see if my needs had changed. If those needs had changed, what those new needs were. It is also necessary to investigate changes in vehicle manufacturing.

At the completion of the evaluation, a decision needed to be made identifying the manufacturer of the vehicle that I planned to modify. Because of my height, there were only a total of only three different manufacturers that met the interior height requirements for me to safely operate the vehicle. Once I made that decision, the recommendations developed by the evaluator could be completed taking into account nuances unique to my chosen manufacturer.

Despite having fulfilled necessary obligations on my part, the finished results of the evaluation could not go out for bids because of a state government shutdown that took place just as the evaluation was ready for release. This meant that all progress came to a halt while the state worked out its budget since the first stage of the project was reliant on Vocational Rehabilitation sending a bid out for the adaptive equipment in this vehicle. To further complicate matters, the state implemented a new data system for all state services during the shutdown leaving state employees unable to process a request like this until they received further training. This wait became particularly frustrating because protocol required sending this job out for bids, but in reality, there was only a single vendor that had the tools to meet all the requirements contained within the bid. Because of this, the process was quite arbitrary yet caused significant delay while I continued to drive a vehicle that had been deemed unsafe to operate. After a host of bureaucratic delays that resulted because of state budgetary issues with Vocational Rehab as a funding source, the process to order this most recent new vehicle was able to finally get underway.

With the bid once granted, the time came to order a new vehicle so that work could begin in the process of modifying and fitting the vehicle to safely meet my driving needs. Finding financial means to acquire another new modified vehicle is no small task only a few years after the last one. The associated costs can vary greatly depending on individual needs which can

range from small adaptations or technologies to substantial vehicle rebuilds. For more substantial projects, it becomes most practical to begin with the new vehicle rather than a used one because of the cost of adaptations equipment, however this also means the overall vehicle cost rises at the same time. The cost of replacing the vehicle remained substantial since the financial support is specifically for anything disability related, and they do not cover the cost of any part of the new vehicle itself. Used vehicles are not an option because of the high cost of specialized equipment that was designed to accommodate another person with different mobility challenges. There is also a limited useful lifespan of vehicles that are not new when they are modified. Somehow, personal funds must be found that are substantial enough to purchase a brand-new vehicle on typically very limited incomes — I was no exception to this typically limited financial capacity. To further exacerbate the process of finding a cost effective vehicle to modify, there are usually very few suitable vehicles for modification available to the consumer making the market extremely narrow and selection very small. Further creating challenges is the fact that because I am very tall even though I am now sitting in a wheelchair; even the wheelchair accessible vans on the market typically will not allow enough headroom for me to sit in the driver area. This means low-cost options are simply not available.

Having found one manufacturer that offered a vehicle with sufficient headroom for me to sit in the driver area, I was able to begin the process of having a new vehicle built that would once again fit my specific needs. This time, however, the process was somewhat different because I had financial support for the adaptive equipment from the state of Minnesota through Vocational Rehabilitation Services. This created a number of bureaucratic delays in finalizing the process and sending the vehicle modifications out for bids. The result was that I needed to purchase my vehicle through whichever vendor that supplied the most competitive bid for this

job. Unfortunately, the vender did a very poor job of keeping me informed of the process or any information about the vehicle, modifications, or other details. Much of the information about the vehicle I had just purchased was completed unknown until the first day I was inside the vehicle, had paid for it, and was taking delivery. In the meantime, I had to pay for the new vehicle chassis months before they would begin work on the modifications. Between the limited earning capacity created by disability and substantial cost, a large barrier exists in replacing vehicles, even if for safety issues.

Throughout the process, a number of build problems took place that further pushed back delivery dates. The process became years long, and despite having taken delivery of the vehicle more than a year ago, there is still work to be done before it will be fully complete.

With the bid once granted, the time came to order a new vehicle so that work could begin in the process of modifying and fitting the vehicle to safely meet my driving needs. As a matter of preparation, accessible equipment manufacturers were contacted prior to ordering so that parts would be available when needed for extensive modification of this vehicle. Of even greater importance, one of the key elements, namely the power steering, used an entirely new system creating concerns that the technology not be available to modify the steering in the way I need by reducing the effort necessary to steer. After both the evaluator and the vendor contacted the manufacturer for the steering modification, they both received assurances that the technology was available to make this work. At that point, the vehicle was ordered and delivered only for the manufacture of the steering modification to announce that they weren't yet able to modify this new technology quite yet, but rather it was coming soon. The wait began first for weeks, then the wait turned into months, and after nearly a year of promises by the manufacturer, it was clearly time to change manufacturers and start over with entirely different vehicle.

To get this project back on task, the dealer agreed to absorb the cost of removing any installed equipment from the original vehicle and place in a different vehicle from a different manufacturer. The state agreed to allow them to continue the project without rebidding since nothing else would change. At this point, I was able to order another vehicle to begin the build process all over again, this time with one that had an older style tried-and-true power steering technology that can be easily modified. With that, there began another wait for the vehicle to arrive at the dealer and for work to start all over again. When it did arrive, there were a host of delays once again but this time from a variety of sources. In some cases, the technicians doing the work were on vacation or out hunting, there were many times the project was held up for several employee illnesses, and on the vehicle itself, there were a number of defective parts that had to be returned several times. One case was with modified interior switches that had to be shipped to a distant manufacturer to be hand wired and returned. As things will go with hand built customized parts, there were some that didn't work and needed to be shipped back and forth several times causing weeks of delay. Unfortunately, because they're hand wired, the same switches had to be shipped each time because there are no ready to go manufactured parts that can be exchanged. This is the one example; however there were many more similar stores throughout this process.

With this entire project taking more than two and half years to complete, the vehicle still needed to be custom fitted to me before I could operate it. When the vehicle was essentially completed, the last thing necessary before taking possession was to have a final fitting so the vehicle is set up properly for me, and then it needs to be checked over by a representative from Vocational Rehabilitation and a driving evaluator that will see that I can operated safely. This will typically take a few hours or possibly most of the day to complete. Instead, it took the entire

70

first day, the entire second day, and an entire third day to complete. The time and adjustments seemed endless, but the importance of the final product being set up properly far outweighed any other inconvenience.

Well into the evening on the third day of fitting, the time finally came to take possession and begin a nearly three-hour journey back home. Having been in the shop all day, stopping for dinner on the way home for the first meal of the day only made sense. Stopping about 10 miles down the road, I parked in front of a restaurant fully intending to go in for dinner. Instead, the vehicle malfunctioned leaving me stuck inside. With the stroke of good fortune, I called the technician and found he had not yet left the shop and he agreed to try and repair it before going home. He contacted the manufacturer engineers for guidance who had also long been home from work for the evening, and the local technician was able to get troubleshooting advice from them. After some time, they were confident the repair they had made would cure the problem, and I arrived home in the early hours of Saturday morning. After three days, the same problem came up as I was headed to work whereby I had to return to the dealership that was nearly 3 hours away for emergency repairs. This time, they took effectively all of the components that contained the malfunction and replaced them as a single unit and there have been no further malfunctions to date.

All told, the process start to finish took more than a year and a half to complete. The cost of my most recent vehicle was nearly $110,000 by the time it was completed and ready for delivery. Of this, I was responsible for roughly half of the cost of the core vehicle while the other half was the cost of vehicle modifications and adaptive equipment.

Despite the enormous wait time and barrage of problems with the build process, the final result was second to none. I now have reliable transportation I can safely operate for a very long

period of time. I enjoy a newfound level of safety and freedom that I had not known in either of my prior wheelchair accessible vehicles. Fear of driving because of safety issues has now been replaced with optimism and security when driving. No longer afraid to bring passengers in case of safety concerns while driving, I can once again place confidence in my driving ability for arriving safely and comfortably whether for work or pleasure. Furthermore, the trade-off for financial hardship is offset by the renewed ability to pursue work and not be concerned that vehicle problems will prohibit me from fulfilling my obligations.

With financial resources still at a minimum, it was vitally important to have the help I received from the Minnesota Department of Vocational Rehabilitation to defray the cost of the accessible equipment and vehicle modifications. Without the support of Vocational Rehabilitation in financing the cost the adaptive modifications of this vehicle this whole project would not have been possible. I owe an incredible gratitude to all of those that helped make this happen, because without them, I could not have financially supported the entire project with the vehicle and necessary modifications together.

For all the challenges this project endured, it has also brought with it a great deal of valuable learning and information for those persons working in the Vocational Rehabilitation offices at both the state and local agency levels. Despite some of the unusual roadblocks encountered during this vehicle building process, I have heard countless times from persons at all levels how much stronger the system will be for supporting modified vehicles because of what they have learned about the building needs of some of the more complex vehicles. I've been assured many times the challenges I have faced will help many others for a long time to come.In this capacity, their help has actually been a part of my ability to share with others.

Personal Utility of Assistive Technology, the Early Years

Although I had resisted the recommendation to go back to school so that I could "take up computers," I had long been interested in technology and all the things it can do. It appeared that assistive technology would be a perfect fit for my newly acquired disability in finding creative ways to mitigate manual limitations. Working with occupational therapy, a deluge of fancy braces, devices, utensils, fishing and other recreational adaptive technologies, computer hardware and software, and countless other gadgets was recommended as a means to return to at least some parts of a normal life and undertake regular daily activities. There became a steady supply of both handmade and recommended commercial products.

Now armed with seemingly countless devices and pages of additional recommendations, the reality of utility these devices could provide became readily apparent. Most of them were very bulky hence making it difficult to transport them. This became problematic in having the correct device available when it was actually needed. At best, these devices often did not perform as intended meaning they were often as much in the way as they were help. Ultimately, this led to my rejection of the host of additional recommended devices not only for lack of utility, but also because of the cost involved to acquire this additional equipment that had so far shown no use in addition to the reality that it would take a trailer to haul it around so it is available when needed. Through this, I became a technological minimalist for devices that were specialized, and instead, I sought out universally available technologies so as not to become more dependent than necessary on specialized equipment.

Assistive Technology

My first experience with assistive technologies left me extraordinarily underwhelmed in finding any sort of utility for large numbers of marginally useful adapted appliances. The genesis

of this experience came from very energetic and enthusiastic occupational therapists that had been recently educated and couldn't wait to demonstrate what they had learned. However, they fell short in experience with everyday tasks and practical limitations. The new ideas and boundless energy created a more human guinea pig type experience for me while they were trying out what they had learned.

Now lacking the manual dexterity to manage eating utensils in the way that one normally would, there was a host of braces, special plates, and adapted drinking glasses none of which worked very well. Even the brace required silverware to fit within it, and while this can be maintained at home, it frequently did not work at all if relying on silverware available in a restaurant or other venue. This brace would be required for nearly everything I did ranging from eating a meal to signing documents. It did work somewhat for these purposes, however I would have to have someone willing to remove it so I could operate a wheelchair for mobility and I would have to keep it with me in case I needed to use it again later. This was a cumbersome process that left me dependent on this brace and having someone always near me that could help me put it on and take it off. Any independence that was gained by use of this device was negated by the dependence on others to manage the brace.

Fortunately, I had traveled to the University of Minnesota for a neurological evaluation related to my injury and needed to sign a document. The person behind the desk saw me struggling to put on and use my brace for this and showed me an effective method for holding objects independently without a brace so I could sign documents, pick up small objects, and hold silverware all without being dependent on any braces. This became a watershed moment for me in finding effective means of using everyday items that are available regardless of venue in an adaptive way rather than being dependent upon an ineffective piece of technology. This small

change allowed me to see assistive methods in a new way that created enormous levels of freedom and utility by using conventional items differently.

Although I remained severely limited in my ability, my newfound knowledge was pivotal in helping me see things differently whereby everyday objects can be used creatively. Even though I initially had an aversion to computers, upon entering higher education they were an obvious tool of education that was at that time coming-of-age as a basic need for everyone. There were initially many challenges in trying to overcome obstacles created by my limited dexterity. Prior to this, my only experience with computers had been when an ambitious occupational therapist fashioned some crude typing sticks out of malleable plastic and put them in the braces I had come to loathe. It was obvious that this was not going to be a solution for completing college work, and I had to find another way to use standard computer equipment. Computers were new to our desktops but software had not yet become robust or overly sensitive to disability needs. I had discovered accessibility features available on Apple computers and they were very useful because they were built-in and available as part of the standard operating system. This meant that even though it was an adaptive piece of software, it was universally available on that platform.

For the first time, computers became a user-friendly means of communication. Even more importantly, my limited dexterity that precluded my ability to handwrite documents became manageable in other ways. Now, by using a computer, I was able to write my own papers without having to dictate them thus opening a whole new opportunity educationally. Prior to that, I found dictation to be extremely difficult for me, and I learned nothing about punctuation or document structure. Even if I dictated with punctuation, it was very difficult not to have changes made for better or for worse by the person taking dictation. In addition, I found the

thought process in developing a coherent piece of work was much stronger when I could write my own documents, not that I ever enjoyed writing them.

Beginning with Apple's release of the first color laptop computer, I found it difficult to be without having a computer available to me. Since software was still relatively primitive for the consumer market, I came to embrace the challenge of developing creative workarounds to transform the resources I had via a computer into creative solutions. In some cases, I was able to create macros, templates and other shortcuts to speed up my work when those computing capabilities were rare. I was also able to create statistical functions to expiate the time consuming demands for calculating results in statistics courses. This allowed me to enter raw data for much of the routine work and have a result appear immediately. Without this, it would've been nearly impossible to keep up with the amount of data entry required for undergraduate statistics course. Unfortunately, because the functions I created resided within the laptop computer in a single file, they were lost to a hard drive failure when the computer was damaged during transport. Being nearly done with statistical requirements for completing my program, it became impractical to re-create them yet very difficult to finish the course without them.

As software continued to evolve, there became ever larger numbers of useful software titles that often had greater sensitivity to a broader audience that included access that supported disability related needs or even included specific accessibility tools. From here, a number of companies also developed software solutions that were specifically designed to accommodate disability related needs. This led to increased availability and greater opportunity of adaptive software and computer related solutions.

With all things, there are some downsides. One of the tools I use frequently is Dragon NaturallySpeaking voice recognition software for dictation. In fact, this manuscript has largely

been created by using the software. For all its utility, there is no shortage of challenges in applying this particular software, especially for large projects. For instance because we typically speak different than we write, it forces a complete and coherent thought to be spoken without pause, interruption, or change in direction that often accompanies normal speech. Therefore, this software uses what it refers to as an "utterance" during dictation to mathematically aid in word choice and order based on the user's personal speech profile to correct for dictation that may be a bit unclear to the software. This system works very well in most cases, however it can lead to some very bizarre results that are easy to miss in proofreading that can leave a reader scratching their head in bewilderment over what the author may have been trying to say. These are just a few of the functional challenges that are a hallmark of this otherwise very useful software

There are frequently other technical glitches that can create havoc with this and other specialty software. Dragon NaturallySpeaking has historically had a relatively short time after each version release where they continue to support their product. This means that if it's necessary to change an operating system to a newer version, update supportive software such as Flash, or perform other system updates, the manufacture of the software often failed to remain compatible with these updates for a reasonable amount of time following a version release. This means that a very expensive software program must be updated frequently to remain viable.

Of course Dragon NaturallySpeaking isn't the only software that provides greater accessibility to accessing the computer, and it's not the only one that sometimes has trouble getting along with other software. As new tools are developed and installed on the computer resulting conflicts often become so overwhelming that it requires a complete system reload often including formatting the hard drive. This creates an enormous number of logistical challenges that typically results in at least a week of full-time work to restore, and a very patient personnel

support system to help with locating all of the relevant software. Once inventories have been completed of relevant and necessary software, all of the installation codes must be located and then a support system must be in place to help physically load discs with software one after the other until the system is once again functional assuming all goes well. Unfortunately, because of the invasive nature of these software solutions, it's all too common to have installation failures that require starting over midway through the process.

While many of these technologies are becoming more useful and more commonplace throughout the general population, there are still a number of new barriers created while trying to remove others. Aside from the learning curves often required to use them effectively and their sometimes marginal usability, there are also the technological challenges of software conflicts, excessive costs that can quickly make these software solutions out of reach, and the sometimes cumbersome nature of slowing down productivity just to get a minimum amount of access. Taking these challenges with a host of other software challenges that compound one another, these solutions offer access but often at the cost of productivity and usability. In short, they can be a huge source of frustration, but thank goodness for them and their utility.

Even as an undergraduate, I conducted research. When doing research, literature provides a foundation for understanding the context in which research is to be carried out. It sets the stage and provides the reader with an understanding of the problem that is under study. Knowing this, all aspiring researchers must learn the art of identifying appropriate literature to incorporate into research in order to set a sound foundation for the problem they intend to study. With the myriad of potential sources, it becomes incumbent upon writers to seek out and utilize quality information from work that has already been done and is related to the topic. This is not only true

for beginning researchers, but it is preparation for becoming a research writer and also an informed research consumer.

This core element brought its own challenges in both retrieval and manipulation of literature, particularly before electronic information became widely available. When I was an undergraduate and beginning to perform research there was very little electronic information available. It was the norm to use card catalogs while spending time in libraries skimming over tables of contents of journals and other reference materials to identify literature related to one's area of study. Even the more advanced electronic information that was available typically included only abstracts that had to be printed while the electronic access itself was not allowed to leave the library, even through the network, because of licensing restrictions.

This left a great many challenges to gathering materials for writing a review of literature necessary for any research and created a dependence upon others for the physical manipulation of the objects I reviewed. The simple task of retrieving journals from shelf meant that I had to ask someone to be available to take them off the shelf; it also required their patients while I reviewed them for relevancy. Once I could find relevant materials, I would have to ask someone to photocopy the information and eventually bind it in a ring binder so I could read it at a later time. For items not housed in the local library, it still meant having to identify appropriate materials and asking someone to fill out interlibrary loan forms then retrieve and bind materials upon their arrival.

With materials in hand, there were still many mundane challenges in managing the large quantities of paper documents. Turning pages, while not impossible, could often take as long as the actual review process itself. What's more, searching through mountains of paper to locate a passage or salient point within a document could often be an exhausting undertaking. And if a

page or pages should come loose the entire body of literature may become unusable until finding someone to straighten it back up. Countless are the times where I've had work to complete that is dependent on literature in a paper format that has fallen, is just out of reach, underneath something, or otherwise found its way out of my grasp. When this happens, all work requiring that literature must stop until someone else is available to gather it for me. Even though these challenges remain today, they've gotten much better since my undergraduate days in the 1990s with the prevalence of the emerging electronic technologies and subsequent information.

It quickly became apparent as I started my research journey as an undergraduate that it would be important to incorporate electronic information to the greatest extent possible as a way to overcome challenges faced because of disability. I became very tech savvy and found creative ways to access and exchange electronic information where possible to reduce the need for physical documents both in their acquisition and submission as much as possible. While this was helpful, data exchange like this was still in its early stages and not yet widely accepted as a viable means of data exchange.

For me perhaps one of the greatest tools made available for research came of age during the hiatus between my undergraduate and graduate work. During that time, there has been a flood of electronic information made available that has removed a great deal of the need for dependence on others when acquiring literature for research. While books are just now becoming ever more available in electronic form, research journals have been greatly increasing the literature widely available electronically at a tremendous rate. This clearly doesn't relieve the task of reviewing literature as a researcher, but instead, it provides far more tools that are readily available to act as a researcher on par with others not challenged by disability. In short, the

evolution of literature in electronic format has been a key element for a great deal of barrier removal.

As this format and the tools to read it continue to evolve, there is ever greater promise for creating a much more level playing field for learning to an ever more inclusive audience of learners. This growing opportunity brings with it, of course, additional challenges not seen with traditional paper documents, albeit it's a reasonable trade-off. One must note that as with any electronic information, it becomes dependent on electronic device to display it. Should this device fail, there may be no way to view this information until the device is repaired or replaced. That said, the wide availability of devices and frequency of networked information is also continued to mitigate the risk of data loss because of this unless the device or software is specialized for accommodating a disability. For me, the vast majority of electronic hardware and software is off the shelf so it is relatively replaceable, however some persons' repair or replacement can be very burdensome.

Electronic devices to view documents aside, the software they run carries a large impact on utility of electronic documents. I have found that usefulness of electronic information for me depends greatly upon my needs and abilities of the device and software in which I'm viewing it. While some appliances and software work very well for reading, they fall short in manipulating electronic information in a meaningful way for research. The personal computer is the most readily available electronic appliance that I can manipulate and use for electronic documents, however it is cumbersome given the current technology I have available for highlighting or otherwise making notes on electronic documents. Other portable electronic appliances have utility however again are dependent upon the software application used for document viewing. Unfortunately, all too frequently electronic documents that have been marked up and highlighted

on one appliance may fail to display the information on a different appliance that lacks the same software.

Despite the availability of all of this electronic information, there are times that it is still important to travel to physical destination. This can be for education, work, meetings, recreation or other reasons. Maintaining physical presence is also important to relieve some of the isolation that can occur when chronically interacting only from a remote location. This, however also creates challenges in finding appropriate transportation with restricted or limited mobility.

Barriers

Even after mastering the challenge of transportation and learning to use assistive technology, attending a physical college campus brings its own challenges when facing disability related barriers. Once there, many doors were beyond my ability to open so I would have to sit in the hallway and hope someone came by to open it for me. Upon entering the classroom, I had no way to manage books, pencils, pens, or any other of the standard tools for academia all while in fear that my slightest move during class could trigger a muscle spasm capable of throwing me face first on the floor. Fellow students were very polite and friendly, however all of these newfound challenges served to drive a barrier between making any real social connections.

Some of these barriers can be very obvious whereby a narrow doorway or limited space may block access to an area. There are, however, many far more serious nonobvious barriers that can create difficulty when attending a physical campus. Whether obvious or nonobvious, barriers can quickly derail the learning process by directing attention to the barrier rather than education.

Perhaps one of the most serious impediments for me attending a physical campus is rooted in the simple room temperature and air movement. In my case, the spinal cord injury I sustained included damaged the autonomic system that regulates body temperature. This can

result in inappropriate body responses such as sweating and shedding heat during cold temperatures or conversely from the body being in distress to the opposite where the body is conserving heat on hot days even when the body temperature increases to feverish levels. . One way to mitigate this is through use of dressing in layers, but without the ability to independently add or remove layers is needed this is a solution that works marginally well at best. There are additional measures that can be employed, but unfortunately, it tends to be an insidious process with an extremely slow recovery that can take much of a day to complete.

Because of this, environment plays a large role in determining systemic core temperatures. Cold is the most frequent problem because the lack of mobility exacerbates the ability to control temperature where not only is my body's normal thermostat is not functioning properly, but the lack of physical movement also fails to generate normal or even sufficient levels of internal heat. Living in Minnesota, this becomes particularly problematic in the wintertime. In addition, I am unable to easily slip into a coat, hat, gloves and boots. As a result, I usually move between buildings or from my car to a building without wearing outdoor gear. Ironically, sustained time in air-conditioning or cool evening temperatures can also lead to difficulty maintaining sufficient body temperature.

The effects of this cooling are frequently far more than discomfort or inconvenience; instead they regularly require me to make substantial changes to daily activity. As my body's core temperature falls, there a number of effects that begin to become apparent depending on how cold I have become. Typically the first signs of cold are from hands and legs that chill to numbness, then a feeling lifelessness and pain. If the reduction in core temperature continues, this is followed by slowed or sluggish thought and often in non-articulate speech. In summer the level of chill is typically less severe, but in winter it becomes very serious yet happens frequently

during extended periods in cool environments or traversing outside. It also leaves skin susceptible to frost burns, especially from hand controls in a vehicle or other outside objects that must be handled.

I have found that if I surround myself with extreme heat prior to entering a cool environment it helps to prolong function for longer periods of time than would otherwise be possible. At the same time, even a few hours in a very cool environment may require 10 to 12 hours or more to recover. This is true even if later surround myself with extreme heat, with extreme being typically 90° to 110°. On rare occasions I find a sauna when traveling where my wheelchair fits through the door so that time may be reduced to 30 to 45 minutes at temperatures of 180° or so. Using extreme temperatures to counteract the effects of unreasonable raising or lowering body core temperature is helpful but contains its own pitfalls. Even though it is nice to warm up more quickly, it typically results in uneven warming and creates risk of burns to areas like my ears and lungs.

Unfortunately, while I may enjoy it, extreme heat brings its own perils if I am exposed too long. It's often prudent to dress very warmly and wear many layers when planning to be in an environment in which I have no thermal control for extended periods of time. Even in summer the air-conditioning can make it very difficult to stay warm on a hot day if there's a need to be inside for extended periods. As a result, traveling on a hot day to and from campus or finding areas that are unusually warm can quickly lead to a great deal of thermal distress from too much heat. This can cause a feeling of panic, racing thoughts, and speaking very rapidly in a near pressured fashion. If the heat becomes too extreme, it can even lead to lightheadedness, difficulty with vision, and feelings of nausea. In the educational environment, this means that one's attention shifts from the learning process over to a feeling of self-preservation needs that trump

all else. In extreme cases, this can result in extreme rises in core body temperature causing a very high fever that needs to seek a cool environment to recover to a normal temperature. This would not be an overwhelming problem because of the layers I tend wear, however my disability limits my movement substantially enough that I'm not able to remove the layers independently and must wait for assistance to remove them, typically after returning home.

It's reasonable that we all need some degree of thermoregulation within our environment to allow one to remain productive. In my case, the window or degree of ability to adapt to variances in environmental temperatures over extended periods of time is greatly reduced because of my diminished lack thermoregulation abilities. Through distance education, the ability for me to alter my environment as necessary is greatly enhanced allow me to focus on education or work without being impaired by thermoenvironmental differences that would not be apparent to others. This way, my focus can remain on the task at hand without the distraction of self-preservation needs taking precedent over academic abilities. Case in point, I'm sitting in a small room with a space heater near my legs as I write this manuscript so as not to be distracted by a cool room and falling core body temperature.

Advantages of Distance Education

Though arguments for the benefits of distance education when dealing with mobility limitation can be many, there are obvious advantages but there are also many nonobvious advantages as well. Some of the more obvious advantages may include not needing to deal with physical access to buildings or different floors that may require steps or lack appropriate elevators or ramps. This also eliminates challenges with transportation to and from a physical campus or addressing foul weather problems. There are also no concerns that a desk or doorway may be too small or inappropriate or difficult to reach. At times, someone placing one well

meant wastebasket or rug may eliminate the ability to reach a door opener or to even leave room by maneuvering adequately with a wheelchair. While this is certainly not intended to be an exhaustive list of possible challenges, it illustrates a few of the barriers that one may think of with regard to mobility impairment while attending a physical campus.

There are, however, a host of other challenges that manifest when attending on-campus courses that have serious implications related to learning that are frequently not recognized readily by most people. Perhaps one of the most serious impediments to attending a physical campus is rooted in the simple room temperature and air movement.

Giving Back – From Consumer to Provider

Having been a consumer of disability services throughout my work as an undergraduate, I learned how important the removal of disability related barriers to education really was. I was probably more fortunate than most to work so closely with this department for many years prior to my appointment as director, however, there remained many challenges of acclimating to the service provider side of disability services. While it was not unusual to be invited to student interviews for service or to be invited to many other aspects of what is expected in this role, operating without having someone to fall back on became a challenging experience. Many of the activities I had done seem to be more closely related to my particular areas of interest and did not necessarily reflect the full range of disabilities within the student population requesting services. From here, my initial learning curve became very steep.

Despite knowing enough about disabilities to realize that many of them are unseen, it came as a surprise to realize there were really very few students that came to see me for an accommodation related to a mobility or dexterity impairment. This created a substantial paradigm shift my notion of the population I would be serving. My initial feeling of relative

confidence and competence as a service provider quickly transformed to a feeling of anxiety and uncertainty for a period of time while I broadened my understanding of the field. Through time, education, and experience I found that by far the majority of students to come to see me for services have a disability that one cannot see or even detect at a glance and many times the students with an apparent disability that can be seen never feel a need to request any service through me or my office at all.

Graduate Study

Even though I completed an undergraduate degree in psychology, the activities I was involved in became deeply embedded in computer technology. While remaining a minimalist, I found that both high technology and low technology could be truly valuable assets in becoming more productive and aid in living a more satisfying life. I continue to selectively use additional assistive technology items albeit with a least possible approach. Even my vehicles are rich with assistive technology devices that allow me to drive, but again, with the least necessary. My experiences have made me a firm believer in the power assistive technology for relieving some of the challenges I've faced because of disability.

Assistive technology is an exceedingly important tool in mitigating the effects of disability that must be carefully considered before using. Without providing proper training, assessment, and developing substantial buy-in by the consumer, the best technology in the world becomes a pile of burdensome, expensive, and useless junk. Is most useful to provide this support and consult with the consumer to avoid initial rejections of assistive technology. By identifying the least invasive tools that can be used in the widest array of circumstance provide the greatest level of independence that can be garnered via technology.

When possible, using universally available tools in creative ways allows the greatest level of independence because it dispenses with the need to arbitrarily manipulate a large number of specialty gadgets. Perhaps the greatest experience in learning about the creative ways to reduce the dependence on specialty assistive technology came during a meeting at the University of Minnesota. It is at that meeting that I learned to all lands without the use of a brace reducing my dependency on others. This was a very simple adaptation, but it had a profound impact on my life in seeing items and tools around in a different way. With this, I was able to embrace just a few very valuable technologies while casting a way others as useless this creating levels of freedom I had not known since becoming disabled.

This is when I learned that by initially investigating readily or universally available low-tech solutions, the same tool can then be used creatively in many ways reducing the level of dependence on others. I even learned about a feature called "Sticky Keys" that at that time was newly available function on all Macintosh computers allowing me to virtually press and hold a function key. This meant I could use a shift key for typing uppercase characters on a keyboard without the use of specialized technology or software. This universality can serve as a launching platform in learning new and creative ways to use assistive technology for home, recreation, in education.

As my repertoire of assistive technology and creative uses for it continued to expand, it developed into an opportunity to share that newfound information and use creative problem solving with others. Having a venue to share this newfound information was an important step in conducting assistive technology assessments. For me, working in higher education and serving state and regional assistive technology organizations provided that venue. While the in my role

as faculty, I transitioned to the position of Director of Disability Services at the college where I had gotten start and continued to work.

The undergraduate degree I had initially held when I began working in higher education did not provide the necessary credentials required to allow me to remain in my position indefinitely. The next step was to enter graduate school to secure a long-term position where I can continue to serve others and continue working with technology. I'm now able to provide service to students while remaining a minimalist in the use of technology.

Paradigm Shift in Employment

Feeling self-assured, I had certainly thought, but never put much creative thought into what I was going to do to earn a living throughout my life. Having shunned any non-manual career choices, and completely avoiding anything that required additional education beyond high school, I looked forward to manual labor with the hopes of landing a factory job that would last until retirement. Securing a factory job, I worked there for several years before disabling injury left me unable to continue work, particularly in a manual labor environment.

After a few years of recovery in staying at home, I angrily and begrudgingly entered the higher education system with no intent to ever finish. Instead, I became swept up in the stream of the educational process and completed an undergraduate degree within a few years. This unintentional graduation left me feeling internally as I needed to find a way to give back to those that were so supportive throughout my education. This led me to begin a number of volunteer positions in an effort to give back and put my newfound education to work. Around the same time, I self-created an internship at the Fergus Falls Regional Treatment Center to continue my education and put my classroom knowledge into a real-world environment.

While working, I continued to volunteer for a number of organizations with increasing levels of responsibility in part to serve, and in part two begin a career building process that would allow me to seek higher-level positions that I couldn't otherwise seek without gaining that valuable experience. These included local, regional, state, and nonprofit organizations that serve persons with disabilities, needed input regarding technology, and needed a connection with higher education. By being involved in some of these at once, it provided an outstanding networking opportunity to coordinate events with several organizations.

Educationally, I also realized that would need to complete a doctoral degree to complete the career building opportunities I was currently involved with. While the positions I held did not require this degree, this degree will allow me to apply for future positions and enhancement my marketability and career goals. At the conclusion of this program, I plan to volunteer for search committees that include positions similar to which I'm interested in to get the inside track on hiring for those positions.

Historical Documents

In addition to the data gathered through the headnotes provided in this manuscript, there are also three historical documents included that capture a snapshot of my perspective within the context of the time they were written. Including these documents provides an opportunity to reduce the risk of bias that can exist when recording headnotes. Since they were written as they happened, there's no contextual influence to skew the perspective of these writings. These three historical documents consist of a Leadership Essay (Appendix A), an application to a Masters program (Appendix B), and an application to a Doctoral program (Appendix C).

The leadership essay describes my vision for how people interact and respond depending on internal and external motivators. Recognizing these differences and motivators serves as a

foundation to providing effective leadership for others. This also asserts the belief that by providing a structure and support that allows others to work in ways that work best for them; they will be more satisfied in both their work and the end result. In addition to leadership style, there are two application letters to graduate school included also expand upon leadership style and activities.

This leadership essay marks a paramount shift in vision from the role of a laborer conditioned to adhere to the guidance provided by leadership to one of providing the very leadership that had been so important to successful factory work. With new insights and changed perspective, it now became more important to provide the leadership I had long been trained to follow. These insights now allowed me to better understand how to provide this leadership effectively as a newfound role in my career opportunities in addition to my shift in my own identity. The entirety of this essay is provided in appendix A.

Further exemplifying the shift in identity is my stark transition from labor to leader by making the decision to attend graduate school with the intent of building a stronger foundation for a career in higher education. This included a great deal of reflection and searching to find graduate programs that would align well with my current career aspirations. While this would be a natural transition for many, it was a complete reversal of my entire self-concept whereby graduate school was something I sought out and embraced.

A statement of professional goals that was written as part of a successful application to a Masters program that provides a historical document as evidence of a newfound identity (Appendix B). This historical document illustrates the change in vision I've experienced in how I've come to see myself and where I belong. This is followed by another statement of professional goals that was written near the completion of the Masters program, and this second

statement is part of the application to a doctoral program (Appendix C). These documents

together provide further evidence of the shift identity from that of a laborer to one of a

professional interested in leadership roles.

Career Development

Still severely limited in physical ability and financial earnings limits, the choices I made

became far more ingrained in not only what service I could provide, but how do things fit with

long-term financial independence. The reality that there'll always be many things I'm not able to

do means to me that I feel the need to compensate by always being prepared far better than

others that may be interested in the same work. Also, I will have to make a very large leap in

income before I can afford to work even a little more. Because of this, I needed to find ways to

become a part of substantial and accountable organizations and initiatives that will build a solid

foundation of work experience in addition to exceeding any degree requirements for positions in

which I'm interested.

To gain this experience, I chose to attend many professional conferences that provide

both experience as well as professional networking. This opened additional opportunities to gain

other work experiences while continuing to provide service. To help foster grant writing ability, I

agreed to serve on a state granting committee to help select appropriate grantees for state funding

of assistive technology initiatives. I also applied and was selected to serve on a statewide

assistive technology Council for many years. While serving, I gained leadership experience by

agreeing to chair the organization and speak on their behalf for two years. As chair of this

Council, my duties included developing the council agenda to identify priorities, doing several

TV and public speaking appearances as well as hosting an annual awards ceremony at the state

Capitol rotunda for Minnesota residents exhibiting excellence in assistive technology throughout the state.

I also joined a number of local councils and committees that serve my community as well as the region of the state in which I live. This also created a great number of professional networking opportunities while volunteering to serve. In addition, I joined a second Board of Directors that serves a large part of the state of Minnesota. This position provides personal accountability and responsibility for a regional nonprofit organization. All told, there are varying levels of responsibility and accountability in the work I'm doing in addition to the volunteer work I continue to do. Relative to career building and looking forward to higher-level administrative positions, I have varying levels of responsibility that range from policymaking in some cases, in other cases only oversight, in other cases nonbinding advisory, down to smaller levels of being fully responsible for budgets. This brings with it varying levels of responsibility for a combined total that reaches approximately $20-$25 million per year. Despite a substantial amount of money and responsibility, I'm not compensated for the majority of my time for those organizations and instead draw only a part-time wage from the college where I currently work.

After approximately 10 years of teaching computer science as a faculty member, I transitioned my role and accepted a position as the Director of Disability Services in the college where I work. My friend, colleague, and mentor who had been the Director of Disability Services since I was a student there, announced his retirement whereby I was asked to help write a job description and then if I was interested in his job. I had hoped to put this off for a while, but the opportunity had arrived and I accepted this position, leaving most of my duties as faculty behind. I felt this position however provided me the opportunity to continue my career building while I

put my education and experience together working with distance education and assistive technology.

Working in a small college, taking on the position of Director means that I am responsible for making determinations for eligibility for disability services as appropriate under federal and state law in addition to institutional policies. I'm also responsible for all budget management and department purchasing for my area as well as all decisions for my department. Also, I am responsible for managing work-study students and for other campus wide decisions related to disabilities and interpretation of federal and state laws for all five campuses within the college when there's no other clear policy guidance within our college. Having established a solid foundation in this position for several years, I now look forward to completing the last stage of my doctoral program and to joining hiring committees for other high-level administrative positions to better be prepared for applying for them.

Having a position like this has also been tremendously valuable for me by allowing the flexibility to set my schedule in a way that works for me, within reason. Having a disability has required me to do an enormous amount of planning ahead even for some of the more routine tasks. I've converted the records my office keeps to an institutional electronic record-keeping system that I can manage independently, although I do still need to plan ahead for some types of paper documents that still sometimes come in. I can manage some of these, but if they happen to fall on the floor, need to be scanned, or are folded tightly, or even if they're just unbound they will create a significant challenge for me to manage.

The work environment can also present a number of challenges that require a great deal of planning. There is the ever looming possibility that someone borrowed something I need for my job but failed to return it, and it may be something I'm unable to retrieve because of the

weight, size, or other property. Even more, environmental temperatures create a huge challenge with the lack of internal thermoregulation on my part making it necessary to plan ahead for what the room temperature may be before I arrive for the day. Most frequently, after a few hours in a work environment it's not unusual to spend 8 to 10 hours trying to re-warm my core body temperature so I can return to functional levels. Unfortunately, it's very difficult to lose that many hours in a day making it necessary to find a work environment off campus where it's extremely warm to try and regain a normal body temperature.

Technology is one of the keys to being an effective and productive individual in my workplace. We all tend to use some form of technology in our normal work day whether it's the computer on our desk or the vehicle we drive to work. There are many great tools available when they work, but we all need to find alternatives when they don't. Unfortunately, while most people simply find an alternative tool or take a different vehicle, I must rely on the ones I have. For example because most vehicles aren't equipped to allow entrance where passengers are able to remain in a wheelchair while inside the vehicle, I need to use my own vehicle for transportation. I take great care to make certain that is as reliable as possible, but as vehicles will go, sometimes they breakdown. There've been a number of times that I've either not been able to get my workplace because of a technology breakdown in my vehicle or even arrive at work only to find that my vehicle malfunctions when I arrive not allowing me to exit it independently. If this happens, I have no recourse but to search for someone that can either repair the vehicle or at least bypass the automatic systems to allow me to get out. There are just some things that all the planning in the world cannot fully circumvent.

I'm extraordinarily fortunate that I have enough flexibility in the workplace meet my needs, but eventually I need to find work that will pay substantially more. Realizing that my

nearly completed graduate program would make a very good fit for the work I was doing, it clearly would not suffice for a high-level administrative position or the like unless I continued through a doctoral program. During the evolution of this process, I still provide a vast majority of my efforts for free or as a volunteer but it has been enormously valuable in establishing a substantial work record, and presumably, a solid educational foundation at the conclusion of this doctoral program. The benefits of providing these services have been perhaps more useful to me and how I see the world and work with others than to any of the others with whom I work. I certainly hope that through this process the time spent has been valuable to others along the way.

Summary

The headnotes in this chapter begin with an account of the paradigm shift required one's internal being and the importance of managing one's exterior image as much as possible. There is a substantial need for self-awareness that affects not only what others see from the outside in but also what is seen from the inside looking out. Managing these dynamics as much is possible helps to guide the perception others have on abilities, albeit in an imperfect way. While limitations related to disability may be permanent, the perception of how to deal with them and mitigate them to the greatest extent possible is an area with which there is more control. While there may not be a particular solution for many of these challenges, by using creative problem solving there is often a way to lessen the impact of a given challenge. Finding ways to successfully live with disability is necessary to be well-adjusted to one's new identity, however this does not require someone's disability to be a primary feature of Self Identity.

CHAPTER 5. FINDINGS AND CONCLUSIONS

The purpose of this manuscript was to view through an autoethnographic lens the influence of a severe physical disability acquired in early adulthood within the context of internal and external forces on the development of identity. To do this, a theoretical framework was used to examine these effects systematically. This framework posits the notion that identity is influenced by internal and external elements by differing degrees that allow one to maintain a sense of identity from within and within the context of environmental variables. This requires one to identify with an identity that is consistent with unified sense of self within the environmental context of current space and time. There are three key constructs that delineate the evolutionary sense of identity which include: (1) once formed, ones sense of identity is relatively stable; (2) environmental variables and constraints will create shifts in identity; and (3) internal drives, abilities, and motivations play an important role in the evolution of identity (Allemand, et al., 2013; Conley, 1985; Hampson & Goldberg, 2006; Hopwood, et al., 2011). If one should try to ignore the importance of these constructs, the risk of cognitive dissonance increases as one's internal sense of self becomes conflicted when change is needed.

Reflecting from chapter 1, these constructs are further broken down by using a layered approach to examine each of these constructs in greater detail by viewing them of a Public Identity, Private Identity, Personal Identity, and a Self Identity. For working definitions, A Public Identity, sometimes described as a Persona (Leary & Allen, 2011), is that identity a person chooses to share openly with others. One's Private Identity becomes more restrictive whereby an individual is far more selective in those open about sharing with others. This is akin to what Burkitt (2013) described in writing about Self and Others. Westeman (2005) spoke of interpersonal exchange where there is an exchange with others is very much like the Private

97

Identity addressed herein. The term Self Identity in this manuscript is used to describe what

Kaufman (2012) refers to as self-consciousness or self-awareness when recognizing the

uniqueness of the core individual.

　　　　While there is an intermingling of the effects on one's identity among these constructs to

form the entirety of one's identity, they've been broken down into discrete units. By looking at

each of these units individually in detail, their meaning will be reviewed and summed in the next

section. The environmental stressors imposed on the layers of one's identity are illustrated in

Figure 4. This figure was developed for this manuscript to illustrate how severity and duration of

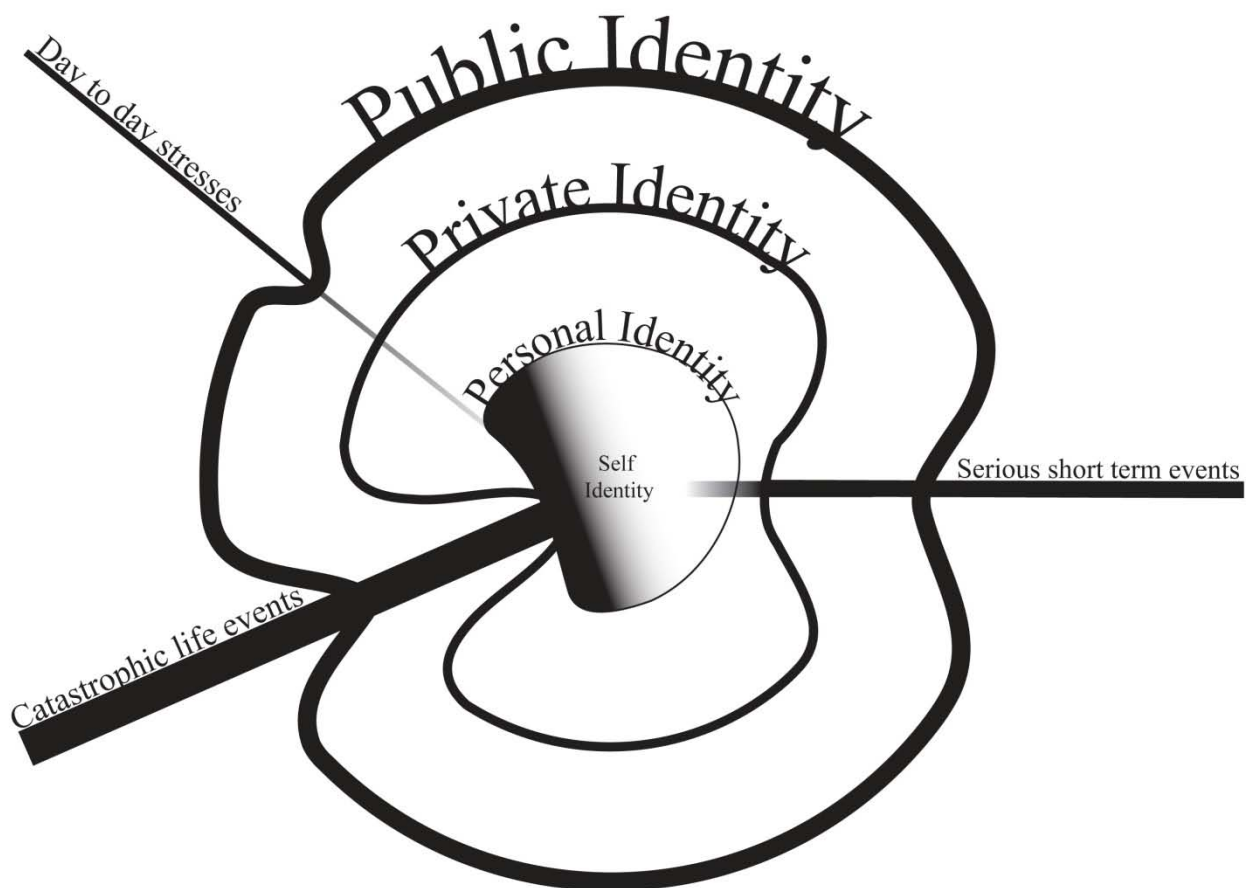these environmental impositions will affect the impact on one's identity.

Figure 4. Increased event severity leads to greater impact on identity.

Figure 4 also illustrates the impact of events and their ability to create change among the different layers of one's identity. These are not meant to create discrete categories among events, but instead, they are representing points on a continuum of events that lead to influencing a coherent sense of identity. Further, these examples of events should be seen as general guidance because of differences in subjective interpretation of life events. For this manuscript, definitions of these events are included in the following text.

Day-to-day stresses are meant to include those things most people deal with every day. It could be conflict among relationships, challenges at work, or traveling in heavy traffic. With disability, these may be compounded with ongoing daily challenges that could include wheelchair problems, temperature regulation problems, condescending or dehumanizing treatment by others among many more. Most of these things will not have a lasting impact from day to day. They may, however, begin to take a substantial toll if they once become chronic and out of control. At this point, the effects become additive and may have substantially more impact on identity.

Serious short-term events are those that may have serious consequence but allow some hope for recovery. Events in this area of the continuum begin to take a more substantial toll on identity because of the impact to everyday life. These may include a serious accident with prolonged recovery, ongoing pressure wounds that will not heal, loss of a job that is closely identified with and so on. All of these events require a somewhat different vision of identity that may get mostly recovered once the event has passed. This occupies the middle area upon the continuum that is substantial but not necessarily life altering.

Catastrophic life events are those that are so serious that a full recovery will never be possible. In this case, the initial event acts as a catalyst for long-term life changes that are beyond

99

the control of the person experiencing them. Events like this will ultimately require a realignment of all of the layers of identity to successfully avoid cognitive dissonance. Unlike the other events, this can be a single event that carries lasting impact it will not end with a full recovery of prior abilities therefore requiring a shift in perspective.

The continuum of events will look different for every individual; however the general premise is true for all persons. Rather than expecting anyone event to follow exactly along a point, this model can be applied within the confines of the perspective of the person using it to identify where their data points should fall upon the continuum. In some cases, it may be valuable to add points to this model for identifying circumstance more closely related to an individual. Once this has been done, one can begin to assess the impact of events as they relate to each of the categories as this author has done below using accounts from the data in chapter 4.

(1) Once Formed, One's Sense of Identity is Relatively Stable

Public identity

Despite a strong association with strength and physical stature, my injury initially took a huge toll on my self-image as that strength and stature withered away. This caused the initial and complete disruption in how I presented my Public Identity. The enormous weight loss and loss of strength left a sense that there was nothing left without reclaiming what was lost. Through this experience, there's been a shift in priorities from physical to cognitive self identification priorities while managing only those physical characteristics still under one's control.

What has not changed is a desire to remain articulate and maintain a strong self-awareness of how others see me. I remain aware of the importance of striving to control this image both personally and professionally. There are certainly things that are not under my

specific control, but for those that are, I continue to manage a sense of my vision of normal as best I can.

Private identity

The evolution of my Privatel Identity has caused changes in relationships with those whom I am close to and my interactions with them. Interactions that were once highly physical and interactive with the environment and others have now largely given way to much more intellectual discourse and more selectiveness in identifying activities that allow me to interact.

What has not changed dramatically is my association with a small number of people close to me as opposed to large groups of people I'm loosely associated with. Instead, it has changed only moderately whereby a relatively small social circle became a somewhat smaller social circle. Essentially all of the existing friendships changed, however the new social circle is smaller but much more tightknit.

Personal identity

For better or for worse, my Personal Identity has come to place far greater value on timeliness and on preparation, and perhaps even helped to sharpen leadership skills. I'm now forced to think about what's next, at least for the short term, to avoid getting into something I can't get out of. This has had a great deal of carryover effect with planning preparation in both the work and educational environments.

Evidence of this shift is apparent in the need for planning is demonstrated by the need for temperature monitoring and preparation to avoid extreme shifts in core body temperature. While it is common to have a need for preparation, the importance of this preparation has been increased for me as a way to mitigate some of the new and ongoing challenges that I face. While

I have always been sensitive to timeliness and preparation, there is a heightened sense of importance to compensate for unforeseen challenges.

Self Identity

Interestingly, this shift has not largely disrupted the perspective or motivation to excel when confronted with a task. Perspective remains strong with regard to exceeding standards for most things while seeking out excellence. Prior to disability, my drive was focused on primarily physical tasks with those being my strongest interests and tools available. Following disability, through a very slow process those drives continue to remain strong, however I've had to readjust their focus from physical tasks to those that are primarily cognitive. Even though this is a large shift, the core values and Self Identity remained generally intact.

Evidence of this is apparent by viewing the passion that I had when faced with a task. Whether it was the determination presented at completing large and heavy tasks or if it was the pursuit of academics and later time whether through anger or ambition, the drive to excel and exceed has never waned. While the vision of this identity has changed around the types of task, the internal sense of what drives me has not.

(2) Environmental Variables and Constraints will Create Shifts in Identity

Public identity

In this context, disability creates barriers to maintaining a public façade of sorts that will force a shift in how we portray ourselves to others. It becomes difficult or perhaps even impossible to control the image we project to others and how they view us, even though it's not unusual for one to make an attempt to manage the image they portray to others. This is evident in all of the health and beauty aids available, weight loss and diet ads, fitness ads and so on

intended to manage one's outward or Public Identity. Even those traits that are not easily changed including looks or height form part of our Public Identity.

While severity or type of disability matters, the ability to manage your Public Identity may be abruptly compromised and unwelcome. For me, the shift was particularly substantial because of the polar opposite Public Identity of typically the largest and strongest man in the room to becoming one of the weakest and physically least capable of any persons in the room. This loss of ability to control the public image brought with it a loss of respect and confidence of others in many contexts.

Whether through a barrage of environmental challenges like blocked access panels, hot or cold rooms, or other environmental challenges, it becomes the additive effect that create some shift of one's sense of Public Identity. The challenge of not appearing overly frustrated or angry along with avoiding areas that are potentially problematic, can lead to some sense of isolation and social avoidance.

Private identity

My Private Identity, that identity which I share among those close to me, was forced to build a new vision of how I could interact with others. There was a clear shift in those with whom I could associate and how I would interact with them. This meant that I had to find a way to surround myself with persons more interested in urbanized accessible activities or that were more interested in social interaction rather than physical types of interaction. Being very slow to give in to a new paradigm, this was a very difficult shift.

The loss of physical stature also created rifts in work and professional relationships. Again, this disability created an alienation from the work I had been doing and the activities I had long enjoyed and forced a new reality within my Private Identity that was without my

choosing. Through this process there has, however, been a shift in many of the new relationships I've come to embrace.

Within the reduced size of this social circle, some of the post injury friends have built ramps or made other accommodations so it is easier to socialize. This is a substantial change from the circle of friends I had prior to becoming disabled, however it still aligns with the smaller more intimate group of persons that I choose to associate with.

Personal identity

The Personal Identity shift that I've experienced throughout this process is probably the most profound change that I've experienced through this entire process. The transition necessary from my initial rejection of education and academic pursuit has been enormous. While this has not been a quick or easy process, it has been an extraordinary shift in how I see myself and my place in the world. To find a path that largely abandons all things that had been clung to so tightly and find alternative pursuits has been a seemingly insurmountable change.

As discussed earlier, the shift from physical laborer to academic, from go-to to dependent, from large in stature to largely wasted, has required a substantial paradigm shift. This record a new vision of Personal Identity that is congruent with the ability I have post injury. Despite rejecting this reality, I found ways to move forward within a reduced set of abilities through which I could still maximize the resources I retained.

Self identity

My sense of Self Identity was very strong prior to becoming disabled. In some ways, this became problematic with the difficulty in change that is inevitable following a disabling injury. This created a great deal of resistance in adapting to necessary changes that are now a reality and have become a part of everyday life. This nearly broke any sense of Self Identity I had come to

know. In the absence of physical ability, it was an enormous struggle to rediscover who I am in the absence of most of the capabilities I had always relied upon. It took a number of years to realize that I had the same internal drives and abilities albeit with a different way to carry them out. This did not take place overnight, but it was really facilitated by the availability of education, particularly distance education, higher education, and support system I had available me.

Many of these challenges took place before slowly beginning a rebuilding process that is now far more malleable. In any event, it has been a growing process, albeit a very difficult and painful one at times. Once discovered, much of my sense of identity was restored largely through new vision of self.

(3) Internal Drives, Abilities, and Motivations Play an Important Role in the Evolution of Identity

Public identity

For me, physical stature and passion created a need for high energy, high risk activities that ultimately led to an injury causing permanent disability. These passions still exist despite manifesting in different ways. Rather than pursuing the physical activities I had previously enjoyed, I've now turned to finding alternative pursuits. Priorities in this area have begun to focus more on internal traits and identifying more clearly how to remain valuable and viable in the larger setting.

Over time, I have channeled those passions and drives into other pursuits that strive for the extreme. As an entering college student I channeled my feelings of anger driving me not only excel academics, but my anger also drove me to exceed most reasonable measures of success. At that time, this academic excess was fueled largely by a need to be defiant in my disdain for the

educational system that was ultimately and inadvertently providing a sound foundation for future educational pursuits. The unintended results were part of the building process a renewed vision of identity.

Private identity

This has clearly been a difficult area to navigate when trying to balance interdependence with independence. It's been important to realize the value of letting one's guard down to accept help in ways that are sometimes very difficult to swallow, and yet it's fully as important to remain cognizant of identifying the difference between tasks that may be difficult and should be done by oneself and those that simply will require the assistance of another. Too much dependence leads to a renewed sense of dependence and becoming less valued as a person while futilely struggling with unachievable tasks leads to being mired down in tasks may be impossible. It's here where one must be highly self-aware to know the difference.

The transition I experienced moving from a very hands-on do-it-yourself person for tasks to having to ask for help for even minor items was a substantial change. While this may not have been nearly as problematic for a few things or a short time, it required a substantial period of realignment to begin a sense of normalcy.

Personal identity

The process of rebuilding my Personal Identity was very difficult and slow. There was a deep-seated rejection of this change that nearly became insurmountable. While this steadfastness nearly stood in the way of progressing from coming to grips with the loss of my interaction with the physical world, it is also become a driving force in recognizing the change that has come with disability. While there is still a measured rejection of desired change, this change has taken place nevertheless whereby it has begun to supplant the long-held notion of Personal Identity.

My need for patience and persistence became ever more important while learning to move the speed of other's schedules. Whether it is the experience of delays that take place when having a vehicle built or waiting for help from someone else, without determination nothing is going to happen.

Self Identity

My Self Identity became severely challenged when forced to change abruptly. However, the core values driving the anger during adjustment was very much a redirected passion that existed prior to injury and continues to exist today, even if the direction it takes has been changed. It was the same passion driving risk-taking leading to injury that later turned to anger ultimately to be refocused on a different type of work and education. Finding ways to take this productive energy that turned to anger and return it to other productive pursuits is an evolutionary process that continues yet.

Even if it's not my first choice in where I focus my energy, I still get deeply immersed in whatever I'm doing. Long hours of factory work may require different skill sets than those required in education, however I still find the personal need to put in long hours for my current work at hand just the same as I always had.

Discussion

When considering the impact of significant change and its role with regard to the various levels of one's identity, it's helpful to first break down different lenses through which we see ourselves. By using a theoretical framework to examine the contents of the narratives in this document through this theoretical framework, we can better understand the themes that may otherwise be obscured.

Perhaps the most noteworthy observation, although not surprising, is that the more central the layer of identity, the more stable it is. This area is highly resistant to change, and while it may be impacted by serious events, the core of one's identity remains even if the perspective manifests in different ways. With an abrupt change like acquired disability, this can be a slow and difficult process, however with time and support the sense of self can remain. Conversely, the less central the layer of identity is the more it can be adapted to meet the changing conditions one is faced with. This is not to suggest a complete abandonment of a sense of identity prior to an event, but instead, it suggests that the ability to adapt increases as it becomes less a part of the central portion or core of identity.

While these changes may range from something seemingly insignificant to something much more profound, none of these changes are related to disability alone or in a vacuum but instead are influenced by many other factors. In some cases, there are tools available throughout this time of identity adjustment helping to lead to positive results while in others there can be restrictive factors that further exacerbate the disabling condition. Taken together, they create the winds and pressures of context in the environment through which these shifts take place that will play a role in how far or how little this sense of identity can develop as it plays on one's inherent strengths and weaknesses.

In my case, I've had the extraordinarily good fortune to experience many positive and supportive persons and organizations that helped bring about generally positive change. Even where I chose to initially reject some of the support that was available to me early on, the foundation of the support I had allowed me to move forward and begin to rebuild. This knowledge has allowed me to seek out support in many ways that would not have been available

to me without that initial foundation. Even where I've come to rely less on many supports, there are still a number of supports that have been critical in this process of moving forward.

The key outcome of the support I've received has been to foster a great deal of opportunity that is ever growing, even today. Whether through education, employment, or resources to pursue new avenues through opportunities, there have been opportunities presented that were far outside of my pre-disability paradigm. The cost of education would likely have been too high for me while living on a very limited income. Vehicle replacement for both the vehicle and modified equipment would otherwise make travel to and from work or school beyond my financial means, and most of all, the support of the people and organizations around me that have been available as a measure of safety have allowed to begin new ventures that would otherwise have been unreachable.

All of the opportunity and support alone cannot fully account for finding a successful path to navigate. If it didn't require internal ability and motivation, anyone with privilege should be successful by virtue of privilege alone. For me, there is an internal drive that while manifesting itself in different ways, whether through anger or productive activity, created the energy and need for excelling in the pursuit of excellence. The most difficult process was changing the focus of what activities I could take part in and using the anger I had faced while using it in non-self-destructive ways to purposefully begin the rebuilding of a new and altered identity.

This change meant that there became a need to use the tools that were still available to me and created an identity less focused on physical stature and tools and now became more focused on cognitive skills. This newly realized skill set eventually came to be valued as a means to reclaim a new sense of identity. It also eventually brought with it the realization that informal

learning alone was not going to be sufficient to rely upon for this skill set. Instead, after a begrudged entry into higher education it became acutely apparent that formalized education in higher education system is going to be a necessity.

Without realizing it at the time, informal education had long been a byproduct of my curiosity and drive. As I struggled to reclaim an identity, the higher education system left me with a niche where I could once again be competitive, and even perhaps excel. There were certainly disability related barriers that were problematic throughout my higher education experience, but there were ways to mitigate the worst of the effects through support systems available including the Disability Services offices. At least in the academic environment, I could return to competitiveness and work on par with others. As an undergraduate, most of these problematic areas were environmentally related, and while not insurmountable, created substantial challenges in attending colleges.

Some of the greatest opportunities for graduate work came via distance education in formats that were simply not available during my undergraduate work. With the growth of opportunities presented via distance education, it opened doors to programs and locations in ways that would never have been available to me because of geography and environment even just a few years earlier. Now, this technology and method of course delivery has become commonplace and is widely accepted as a viable method of garnering a high-quality education.

Even in the face of catastrophic disability, there is still hope for successful adaptation to a disability they can be facilitated through using positive framing in reevaluating one's circumstance. By providing a positive support system and positive counseling the speed and likelihood with which a successful vision identity can be rebuilt is greatly enhanced, and it's possible that the end result may be even more successful than a predisability state (Dunn &

Dougherty, 2005). It further elevates the likelihood of successful transition by incorporating

realistic positive reflection within the self and from others by revealing portions of the unknown

area identified in the Johari Window (Wei-Wen, et al., 2012).

Recommendations

- Before attempting to implement new technologies, take the time to earn sufficient buy-in by consumers.

- Identify a comprehensive positive support system

- Validate and respect decisions and actions on par with others

- Recognize personal value as an individual

- Recognize that disability may be a trait, but it does not define the person

- Realize there will be setbacks

- While some may suffer a disability, it's inappropriate to assume all persons with disabilities are suffering

- Accommodations or supports rarely make things easier than they are for persons without disability

- Even with accommodations, persons with disabilities often have additional barriers to overcome

- A disability in one area does not necessarily render one disabled in other areas

    When studying disability, there's a wealth of research that addresses the impact on the

family, social structures, and other supports that become necessary when addressing an acquired

serious disability. This body of literature provides a record of meeting the challenges faced when

presented with disability and also identifies successful coping methods to help make the best of

challenges that are faced. These supports are absolutely critical for successful development of

one's identity following disability, and will be a very large part of rebuilding of Personal Identity. If these supports become overstressed it impedes the process successful adjustment for both individual and affects social support of the individual and those around them.

An area where the literature is currently lacking is in addressing the impact an acquired severe disability has on one's own sense of identity. By better understanding the role of identity within the context of disability, a more informed support system can result in returning to a capacity that is as productive as possible. Because this study carried out an in-depth autoethnographic methodology rather than studying large sample, the generalizability of this work on its own will be limited. Because there is a lack of this type of literature, however, more research is needed that will allow other researchers to aggregate results through meta-analysis or other methods to allow greater generalizability.

A lack of generalizability should not be construed to imply minimizing of value to this population; on the contrary, it is the personal nature of the genuine story for better and for worse the lens value to this work. A narrative can be a powerful tool in conveying positive message to persons having become disabled, caregivers, and healthcare professionals that form the support team. The narrative message provides a gateway through which real examples of real experiences that are critical in reforming ones sense of identity (Smith, Tomasone, Latimer-Cheung, & Martin-Ginis, 2014).

As this body of literature grows and becomes further analyzed, it will bring with it additional value to a host of others including professionals that are providing direct or indirect services for individualizing best practices, for caregivers and family members that are adjusting to a new means of interaction, and perhaps most importantly, there can be greater insights for individuals that have experienced a serious disability when reclaiming a new and healthy sense

of identity. Resulting research should be geared specifically for each of these target groups because of the different needs to create a comprehensive understanding of the changes that need to take place for successful rebuilding of an individual's identity.

Summary

It's valuable to recognize that this manuscript uses an autoethnographic methodology to study the effects of disability on one's developing identity beginning in young adulthood to draw conclusions about how changes in one's identity are impacted by disability. This process is very personal and can be affected by a host of different variables that will impact each person somewhat differently, however without a literature base that includes these experiences there is no way to capture the changes and processes through which one passes.

Finding a way to successfully navigate shifts in identity brought about by abrupt change is no small task and carries with it a myriad of nuances. While it's incumbent upon the affected person to find ways to navigate through this process, the level of support available will become a guiding force in how successfully one is able to adapt to change. There are many ways that support may manifest and there is not a single source that can encompass all areas, instead, a support network that includes formal and informal support creates the greatest likelihood of a successful transition in one's identity.

Formalized support remains the most recognizable and comes in many organized forms through organizations, advances in technology, and in legislation. These may include vocational services, educational services, and other service providers that are in place to provide support. In many cases, the legislation provides an overarching onus upon organizations to provide this support as a minimum standard. With these standards, there has been a general movement that

has encouraged many, perhaps not all, but many organizations to provide support beyond the minimum the law requires and provide support and services where economically feasible.

Digital information and network services have further created opportunities to transition a once again self-reliant sense of identity formation by making far more content available to all persons at an increasingly rapid pace. Now, education may become in many cases free of geographic or environmental restrictions through the digitization of delivery modes. There is a new level of access to materials and resources independent of disability that is unprecedented relative to even just a few years ago, and having education and educational content available helps to rebuild a sense of self-worth and independence while preparing for a viable workplace experience.

Metacognitive Review of Developing this Manuscript

The development of this manuscript brought with it many challenges both anticipated and unanticipated. No matter the level of planning ahead or preparation for the development of this document, there remained many of the challenges brought forth in this manuscript and some that were not.

In most cases, environmental concerns were not at issue in managing thermoregulation because of the independent nature of this type of manuscript. This subtle opportunity was extraordinary valuable in managing my environment. There were many other challenges, several of which were included in this manuscript, in the development of this work.

Some of the more difficult challenges not included in the earlier pages of this manuscript centered on the personal nature of this work. Because of this personal nature, while there are a great many examples in narratives throughout this text, it would sometimes becomes difficult to remain on task with including themes only derived from the written work. Even though there

were countless other narratives that could have been added, the overall findings would not have changed a great deal, only the narratives used to arrive at those findings. The sample included in this manuscript is meant to be representative of the much larger picture.

Another substantial unanticipated phenomenon was the vivid level of memories that these experiences forced me to relive, sometimes joyful, and many times very painfully. While it certainly has been a very learning and growing experience to complete this process, I expect these experiences parallel those of many others that may find some value to these experiences coming to light.

Disability – New Means of Daily Living

Acquiring disability requires a substantial paradigm shift whereby in many ways it becomes life in the slow lane where even spontaneity requires planning ahead. Now rather than loading up the motorcycle at the last minute for a weekend of off-road racing on a motocross track or testing performance abilities of a snowmobile because there's a new fallen snow, I must now plan ahead for even the most mundane of adventures. Unless I can arrange a travel companion travel is limited by the round-trip range of the vehicle, time is limited by how long I can prepare for food water and restroom breaks, and overnight travel is not an option without pre-arranging a travel companion.

Social abilities also suffer from mobility limitations despite the best of intentions. While friends may come visit me because I've created an accessible environment, it's very difficult to visit them. Having one or more steps required to enter their home, as most homes do, creates a barrier that I'm unable to pass. Even the few homes of friends were I can visit; temperature or other environmental constraints where I don't have control can quickly derail a visit despite the best of intentions. Lastly, where I've always preferred active social interactions like hunting,

115

fishing, motorcycle riding and racing, snowmobiling, downhill skiing and so on, my social interactions are now forced to be primarily passive with visiting or watching movies the most common because it's among the few things I'm able to do socially.

Perhaps this is why there is an ongoing struggle for identity in both one's self-image and one's outer more public image. When President Franklin D. Roosevelt became partially paralyzed, he recognized the ramifications of others' perceptions of him in light of disability. Some may argue that he simply wanted to hide his difficulty standing and need for leg braces, however his protection of his public image by concealing his disability where possible was very important in maintaining public confidence in his leadership abilities. While one may argue that physical strength and stature may not define leadership abilities, the perception of those abilities is quickly eroded with loss of physical ability.

While in a professional environments, I typically have not had a great deal of difficulty with overt lack of confidence in my work or leadership because of disability. I have on the other hand experienced being treated as feeble and inept on many occasions. One such incident took place when I reached the interview round when applying for work only to be politely but quickly dismissed by interviewers after meeting me in person. I've also had many other exemplary experiences similar to that like a time I was shopping and an older man walked up and patted me on the head and told me how good it made him feel to see "cripples like me get out once in a while." These kinds of experiences continue to happen surprisingly often and are vivid reminders that no matter how accomplished, no matter how hard working, no matter how dedicated, to many there is simply no overcoming the perceptions of others. While I can move on without fixating on what others think of me, it does take a toll on the way others perceive me, in both

social and professional opportunities, and other subtle nuances that one typically takes for granted.

As I write this document, I am confronted again with some of the challenges created by limitations of mobility and dexterity. Needing a resource to continue my work that is located on the bookshelf next to me, I'm unable to remove it from the bookshelf to examine its contents despite seeing it right next to me. Instead, I'll need to make note of the materials I need and then I can ask someone to place within my reach for the next time I need them. In the meantime, the other book I'm using has not yet had the back broken or pressed open; as a result it continues to flip itself shut whereby I lose hold of the pages and need to repeatedly start over in my search for information within its pages. Nearly 15 minutes is lost in a futile search where I must refocus my efforts to a different section based on what materials are available to me.

It sometimes becomes difficult when reviewing day-to-day challenges living with a major disability not become fixated on the problems; however I refuse to accept the role of the victim because of these challenges that I face resulting from disability. It is not to say there are no lingering frustrations that will sometimes boil over, but I choose not to allow this to define me but rather to drive me. To me, to say that I have accepted disability is to say that I've accepted defeat. Instead, I choose to move forward in spite of these challenges while acknowledging that it will continue to be an obstacle, yet it is a part of my everyday life.

REFERENCES

Act, A. T. (2005). *Assistive Technology Act of 2004*. (Pub. L. No. 108-364).

ADA. (2011). *Americans with Disabilities Act Title II Regulations: Part 35 Nondiscrimination on the Basis of Disability in State and Local Government Services*. Department of Justice, Civil Rights Division.

Allemand, M., Steiger, A. E., & Hill, P. L. (2013). Stability of personality traits in adulthood: Mechanisms and implications. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry, 26*(1), 5-13. doi: 10.1024/1662-9647/a000080

Bolden, L. A. (2007). A Review of On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss. [Book Review]. *Counseling & Values, 51*(3), 235-237.

Bureau, U. S. C. (2009). *Disability Status: 2000*. Retrieved from http://www.census.gov/hhes/www/disability/disabstat2k/disabstat2ktxt.html.

Burgstahler, S., National Center on Secondary, E., & Transition, M. M. N. (2002). *Bridging the Digital Divide in Postsecondary Education: Technology Access for Youth with Disabilities. Information Brief*.

Burkitt, I. (2013). Self and others in the field of perception: The role of micro-dialogue, feeling, and emotion in perception. *Journal of Theoretical and Philosophical Psychology, 33*(4), 267-279. doi: 10.1037/a0030255

Charness, N., & Holley, P. (2004). The New Media and Older Adults: Usable and Useful? *The American Behavioral Scientist, 48*(4), 416-433.

Conley, J. J. (1985). Longitudinal stability of personality traits: A multitrait–multimethod–multioccasion analysis. *Journal of Personality and Social Psychology, 49*(5), 1266-1282. doi: 10.1037/0022-3514.49.5.1266

Corbeil, J., R., & Valdes-Corbeil, M. E. (2007). Are You Ready for Mobile Learning? *EDUCAUSE Quarterly Magazine, 30*.

D'Aubin, A. (2007). Working for Barrier Removal in the ICT Area: Creating a More Accessible and Inclusive Canada. [Article]. *Information Society, 23*(3), 193-201. doi: 10.1080/01972240701323622

Dewey, J. (2007). *Democracy and education*. Tedington, Middlesex, UK: Echo Library.

Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology, 58*(2), 148-157. doi: 10.1037/a0031691

Dunn, D. S., & Dougherty, S. B. (2005). Prospects for a Positive Psychology of Rehabilitation. *Rehabilitation Psychology, 50*(3), 305-311. doi: 10.1037/0090-5550.50.3.305

Florian, V., & Dangoor, N. (1994). Personal and Familial Adaptation of Women with Severe Physical Disabilities: A Further Validation of the Double ABCX Model. *Journal of Marriage and Family, 56*(3), 735-746. doi: 10.2307/352882

Gannon, S., & Gold, J. R. (1988). Rebirth: The rehabilitation process. *Professional Psychology: Research and Practice, 19*(6), 632-636. doi: 10.1037/0735-7028.19.6.632

Gauthier Webber, J. (2011). *Individual and Family Stress and Crises.* Thousand Oaks, CA: SAGE Publications, Inc.

Gill, C. (1997). Four types of integration in disability identity development. [Journal]. *Journal of Vocational Rehabilitation, 9*, 39-46.

Gladhart, M. A. (2010). Determining Faculty Needs for Delivering Accessible Electronically Delivered Instruction in Higher Education. *Journal of Postsecondary Education and Disability, 22*(3), 185-196.

Gordon, K. (1995). The United States: Developing the workforce. Organisation for Economic

    Cooperation and Development. *The OECD Observer, 197*(48).

Groveman, A. M., & Brown, E. W. (1985). Family therapy with closed head injured patients:

    Utilizing Kubler-Ross' model. *Family Systems Medicine, 3*(4), 440-446. doi:

    10.1037/h0089672

Hampson, S. E., & Goldberg, L. R. (2006). A first large cohort study of personality trait stability

    over the 40 years between elementary school and midlife. *Journal of Personality and*

    Social Psychology, 91(4), 763-779. doi: 10.1037/0022-3514.91.4.763

Hensley, W. E. (1983). An Examination of the Johari Window as a Research Tool and a

    Theoretical Model.

Hernandez, F., Sancho, J. M., Creus, A., & Montane, A. (2010). Becoming University Scholars:

    Inside Professional Autoethnographies. *Journal of Research Practice, 6*(1).

Holloman, C. R. (1973). Characteristics of Interpersonal Relations in Municipal Government.

    The Academy of Management Journal, 16(4), 691-695. doi: 10.2307/254702

Holyoke, L., & Larson, E. (2009). Engaging the Adult Learner Generational Mix. *Journal of*

    Adult Education, 38(1), 12-21.

Hopwood, C. J., Donnellan, M. B., Blonigen, D. M., Krueger, R. F., McGue, M., Iacono, W. G.,

    & Burt, S. A. (2011). Genetic and environmental influences on personality trait stability

    and growth during the transition to adulthood: A three-wave longitudinal study. *Journal*

    of Personality and Social Psychology, 100(3), 545-556. doi: 10.1037/a0022409

Hopwood, C. J., Newman, D. A., Donnellan, M. B., Markowitz, J. C., Grilo, C. M., Sanislow, C.
A., . . . Morey, L. C. (2009). The stability of personality traits in individuals with
borderline personality disorder. *Journal of Abnormal Psychology, 118*(4), 806-815. doi:
10.1037/a0016954

Hughes, S., Pennington, J. L., & Makris, S. (2012). Translating Autoethnography across the
AERA Standards: Toward Understanding Autoethnographic Scholarship as Empirical
Research. *Educational Researcher, 41*(6), 209-219.

Jelinkova, K., Carvalho, T., Kerian, D., Knosp, B., Percival, K., & Yagi, S. (2008). Creating a
five-minute conversation about cyberinfrastructure. *Educause Quarterly, 2,* 78-82.

Kaplan, K. (1996, August 19). Never too late for old dogs to learn new techs, *Los Angeles Times,*
p. 5.

Kaufman, G. F., & Libby, L. K. (2012). Changing beliefs and behavior through experience-
taking. *Journal of Personality and Social Psychology, 103*(1), 1-19. doi:
10.1037/a0027525

Kewman, D. G., & Tate, D. G. (1998). Suicide in SCI: A psychological autopsy. *Rehabilitation
Psychology, 43*(2), 143-151. doi: 10.1037/0090-5550.43.2.143

Kübler-Ross, E. (1969). *On death and dying*. New York: New York Macmillan.

Kübler-Ross, E., & Kessler, D. (2007). *On Grief and Grieving: Finding the Meaning of Grief
Through the Five Stages of Loss*. New York: Scribner.

Leary, M. R., & Allen, A. B. (2011). Self-presentational persona: Simultaneous management of
multiple impressions. *Journal of Personality and Social Psychology, 101*(5), 1033-1049.
doi: 10.1037/a0023884

Lemay, V., Routhier, F., Noreau, L., Phang, S. H., & Ginis, K. A. M. (2012). Relationships

    between wheelchair skills, wheelchair mobility and level of injury in individuals with

    spinal cord injury. *Spinal Cord, 50*(1), 37-41. doi: 10.1038/sc.2011.98

Lorenzo, G., Oblinger, D. & Dziuban, C. (2007). How Choice, Co-Creation, and Culture Are

    Changing What It Means to Be Net Savvy. *EDUCAUSE Quarterly Magazine, 30*.

Lowry, M. (2005). Self-Awareness: Is It Crucial to Clinical Practice? *The American Journal of*

    Nursing, 105(11), 72CCC-72DDD. doi: 10.2307/29745936

MacDonald, C. J., Gabriel, M. A., & Cousins, J. B. (2000). Factors influencing adult learning in

    technology based firms. *The Journal of Management Development, 19*(3/4), 220-240.

Manning, M. M., Wainwright, L., & Bennett, J. (2011). The Double ABCX model of adaptation

    in racially diverse families with a school-age child with autism. [Report]. *Journal of*

    Autism and Developmental Disorders, 41(3), 320+.

Maule, R. W. (1997). Adult IT programs: a discourse on pedagogy strategy and the Internet.

    Internet Research, 7(2), 129-152.

Meierhenry, W. C. (1982). Microcomputers and Adult Learning. *Training and Development*

    Journal, 36(12), 58.

Meyer, J. M., & Kashubeck-West, S. (2013). Well-being of individuals with late-deafness.

    Rehabilitation Psychology, 58(2), 124-136. doi: 10.1037/a0032197

Mitra, R. (2010). Doing Ethnography, Being an Ethnographer: The Autoethnographic Research

    Process and I. *Journal of Research Practice, 6*(1).

Mitra, S., Posarac, A., & Vick, B. (2011). Disability and Poverty in Developing Countries: A

    Snapshot from the World Health Survey *Social protection and labor*.

Molgat, M. (2007). Do Transitions and Social Structures Matter? How 'Emerging Adults' Define
Themselves as Adults. [Article]. *Journal of Youth Studies, 10*(5), 495-516. doi:
10.1080/13676260701580769

Moore, M., & Kearsley, G. (2005). *Distance Education: A Systems View* (2nd ed.). Belmont:
Wadsworth.

Morris, M. G. V., V. (2000). Age differences in technology adoption decisions: Implications for
a changing work force. *Personnel Psychology, 53*(2), 375-403.

Murugami, M. W. (2009). Disability and Identity. *Disability Studies Quarterly, 29*(4).

Oblinger, D. G., & Oblinger, J. L. (2005). Educating the Net Generation. *Educause*.

Officer, A., & Shakespeare, T. (2011). World report on disability: The World Health
Organization and The World Bank.

Phillips, N. A., & Lesperance, D. (2003). Breaking the waves: Age differences in electrical brain
activity when reading text with distractors. *Psychology and aging, 18*(1), 126-139.

Pruchno, R. A., & Patrick, J. H. (1999). Effects of formal and familial residential plans for adults
with mental retardation on their aging mothers. [Article]. *American Journal on Mental
Retardation, 104*(1), 38-52.

Publication manual of the American Psychological Association. (2010). (6th ed.. ed.).
Washington, DC: Washington, DC : American Psychological Association.

Radford, A. W., & National Center for Education, S. (2011). Learning at a Distance:
Undergraduate Enrollment in Distance Education Courses and Degree Programs. Stats in
Brief. NCES 2012-154: National Center for Education Statistics.

Randolph, J. J. (2009). A Guide to Writing the Dissertation Literature Review. *Practical
Assessment, Research & Evaluation, 14*(13).

Ravitch, S. M., & Riggn, M. (2012). *Reason & rigor : how conceptual frameworks guide research*. Thousand Oaks: Thousand Oaks : Sage Publications.

Rongxia, L. (2001). Distance education helps farmers get rich. *Beijing Review, 44*(4), 21-24.

Rose, D. H., Harbour, W. S., Johnston, C. S., Daley, S. G., & Abarbanell, L. (2006). Universal Design for Learning in Postsecondary Education: Reflections on Principles and their Application. *Journal of Postsecondary Education and Disability, 19*(2), 135-151.

Ross, A. (1997). Preventing teenage suicide in New York. *Crisis: The Journal of Crisis Intervention and Suicide Prevention, 18*(1), 12-16. doi: 10.1027/0227-5910.18.1.12

Ruth, S. R., Sammons, M. & Poulin, L. (2007). E-Learning at a Crossroads—What Price Quality? *EDUCAUSE Quarterly Magazine, 30*.

Sarwer, D. B., & Crawford, I. (1994). Therapeutic considerations for work with persons with HIV disease. *Psychotherapy: Theory, Research, Practice, Training, 31*(2), 262-269. doi: 10.1037/h0090227

Scheer, S. B., & Lockee, B. B. (2003). Addressing the Wellness Needs of Online Distance Learners. *Open Learning, 18*(2), 177-196.

Schneider, J. E. (1971). Mino to Mino Communication: Nonverbal Influence? *Theory into Practice, 10*(4), 259-263. doi: 10.2307/1475752

Selwyn, N. (2004). Exploring the role of children in adults' adoption and use of computers. *Information Technology & People, 17*(1), 53-70.

Seymour, W. (2005). ICTs and disability: Exploring the human dimensions of technological engagement. [Journal]. *Technology and Disability, 17*, 195-204.

Smith, B., Tomasone, J. R., Latimer-Cheung, A. E., & Martin Ginis, K. A. (2014). Narrative as a Knowledge Translation Tool for Facilitating Impact: Translating Physical Activity Knowledge to Disabled People and Health Professionals. *Health Psychology*. doi: 10.1037/hea0000113

Stumbo, N. J., Martin, J. K., & Hedrick, B. N. (2009). Assistive technology: impact on education, employment, and independence of individuals with physical disabilities. *Journal of Vocational Rehabilitation, 30*(2), 99-110.

Trubitt, L., & Muchane, M. (2008). In Plain English, Please: Effective IT Communications. *EDUCAUSE Quarterly Magazine, 31*.

Vadén, T., & Suoranta, J. (2009). A definition and criticism of cybercommunism. *Capital & Class*(97), 159-177, 180-181.

Van Woerden, K. (2006). Mainstream developments in ICT: Why are they important for Assistive Technology? [Article]. *Technology & Disability, 18*(1), 15-18.

Vazire, S. (2010). Who knows what about a person? The self–other knowledge asymmetry (SOKA) model. *Journal of Personality and Social Psychology, 98*(2), 281-300. doi: 10.1037/a0017908

Wall, S. (2008). Easier Said than Done: Writing an Autoethnography. [Article]. *International Journal of Qualitative Methods, 7*(1), 38-53.

Wang, K., & Dovidio, J. F. (2011). Disability and autonomy: Priming alternative identities. *Rehabilitation Psychology, 56*(2), 123-127. doi: 10.1037/a0023039

Wei-Wen, C., Cheng-Hui Lucy, C., Yu-Fu, H., & Yu-Hsi, Y. (2012). Exploring the Unknown: International Service and Individual Transformation. [Article]. *Adult Education Quarterly, 62*(3), 230-251. doi: 10.1177/0741713611402049

Westerman, M. A. (2005). What Is Interpersonal Behavior? A Post-Cartesian Approach to

    Problematic Interpersonal Patterns and Psychotherapy Process. *Review of General*

    Psychology, 9(1), 16-34. doi: 10.1037/1089-2680.9.1.16

Wilson, G. A. (1994). *A Three College Collaborative Teacher Preparation Program*, Chicago,

    IL.

APPENDIX A. LEADERSHIP ESSAY

I believe leadership requires one to have a clearly developed set of principles from which a vision for the future can be drawn. Through that vision one can enlist the efforts of others to achieve a unified end. Most people, especially in an organization where people routinely behave in primarily a theory Y model of motivation, will work best in an autonomous manner when there is a clear vision to work toward. This will help dispel both overt and covert lack of acceptance among those asked to carry out the vision.

I would like to bring that vision forward to pursue an emerging area in education. As the paradigm continues to shift toward student convenience in education, I believe we're going to continue to integrate a growing number of delivery methods for student learning. My vision of leadership for personal future professional pursuits is to oversee the direction of distance learning in higher education. Although this may appear to be a somewhat abstract aspiration considering that this position does not even exist at this time in the institution within which I work, I believe it will be an essential position as alternative learning delivery methods continued to proliferate.

The next major step will be utilizing my leadership style to most effectively meet my goals. On the Leadership Effectiveness & Adaptability Description inventory we took earlier this semester, I scored very highly on participating and selling with a very low score on telling and delegating. I felt this particular inventory provided a great deal of enlightenment for me in terms of understanding more clearly why my personal style of leadership has been more effective in some settings than others. I normally try to use the least amount of directive necessary to complete a task which is intended to allow others to plot their own course as much as possible. In reality, I believe this inventory has helped to understand how this leadership style may need to be

more directive in some cases until those involved are better prepared to work in a highly participative mode.

Although I believe in a participative model of leadership wherever possible, I feel I've learned the value of being far more directive when working with people that aren't yet prepared for the participative style. Initially, I plan to restructure some of my introductory courses that I currently teach to give more direction in getting started. Throughout the courses I plan to slowly revert to a more independent style as students become more prepared to complete the work. As I move into positions of greater leadership I plan to take this new knowledge with me.

There are number ways in which a leader may hold power within an organization. How one uses power will largely influence the health of the organization. When possible, an ideal rewards system would create a supportive scenario where one could discover measurable success where they previously believed they could not succeed. This will foster the desire to continue with greater success. By doing this, the pitfall of working just for the reward and eroding the internal good feelings can be avoided.

If and when one uses a coercive power to force compliance, it must be used with care to avoid backlash. In the case where someone is clearly working outside or against an organization there may be times it becomes the best course of action to keep the organization healthy. Is useful have a level of expert power available to help stay on task. There may be times when the organization begins drift from its vision and through use of expert power leadership can redirect the course to keep an organization growing and moving in the right direction. By acknowledging and exercising in a legitimate power source and organization will have a face or an icon to look to for leadership. This acknowledgment carries with it the expectation that people will comply when asked.

The notion of referent power is probably more easily thought out in terms of how a leader presents himself. Much of this will probably be from everyday interactions and casual contact. A major key to leading others lies in cultivating a nonthreatening and nonjudgmental dialogue by listening. As Covey states in his book <u>The Seven Habits Of Highly Effective People</u>, "seek first to understand and then to be understood". By building a community of trust and respect, people feel free to express their thoughts without fear. Too often leadership can be closed out from what is happening in the rest of the organization by making a few snap comments to or about others that will erode genuine dialogue. Leadership may find themselves with a room full of "yes-men" that covertly lack acceptance of the leadership vision.

I also believe in a great deal of personal freedom in that if allowed, people will be the most creative and productive if the leadership recognizes and appreciates the skills and diversity others possess. Whether working in groups or as individuals there are often a great deal of ideas and methods that can and will be created by fostering that personal freedom within the structure of the organization.

Further, I believe in a process of on the spot decision making wherever possible. Persons should have authority and responsibility to make decisions regarding day-to-day problems that affect them directly without having to consult others. Initially this may require additional time and or training on the part of the organization to properly prepare employees, but in the long run it should provide a stronger base from which to build. I feel this will further build motivation by acknowledging appreciating the capabilities of people within the organization.

My personal motivation primarily comes from within. I find the amount of pay for particular job or the rewards for particular milestones are of little value to me personally so long as I have enough to meet my basic needs. If those needs are reasonably met, I find my time is

spent toward feel I can make the greatest difference in serving others. I believe this is reflected in the fact that I spend fully half to two thirds of my time in a volunteer capacity where I feel my service will have a positive impact on others. These volunteer hours often come at the expense of other paying work, but again, when I finish a project, serve on a committee, or donate time and talent for it is needed is what I feel the greatest sense of fulfillment.

I feel that understanding the needs of others is paramount to motivating them. Leadership needs to take a proactive role in identifying these needs to make certain their efforts to provide motivation in workplace are not in vain. Some inference for these needs may be drawn from demographics. If for example an organization was made up largely of persons nearing retirement, offering the opportunity to become a member of a soccer team may not be much of a motivator. Conversely, an organization comprised largely of younger people may be highly interested in the social experience created by the opportunity to participate on the soccer team.

Much can also be said for showing appreciation for the individual's efforts in making the organization what it is. One relatively constant motivating factor is the desire people have to be appreciated. Whether this is shown formally or informally it is the essential to reassure people that what they do is important, necessary, and appreciated.

It is very important to have a supportive environment from others within an organization. Many times this support can be built, but it is not necessarily implicit, nor should be taken for granted. This includes support from other leaders in the organization as well as those looking to leadership. As part of the supportive environment, it is important for me to seek out an organization that believes in reasonable accommodation. By that I am not suggesting any sort of special favor, but rather an understanding that mobility and dexterity are not among my strongest

skills, but neither are they my identity. I acknowledge these issues and as my calling card bring with me my strengths.

I believe people working in an organization will be reflective of the leadership and policies all that organization. If allowed, those working in an environment that nurtures and appreciates the inner drives of individuals

That is not to suggest a laissez-faire style of leadership of the organization which can lead to anarchy of sorts, but rather that people will respond to best to a well-defined organizational structure with clear values and vision that allows as much personal freedom as possible. Research has also shown that once an individual has committed themselves to working for an organization they will seek to reduce cognitive dissonance by speaking more highly of the organization, and in effect the begin to feel better about the organization in which they work. It is believe this helps reduce anxiety created by working in an organization that one does not believe in. By understanding this concept, leadership can and should set the stage through policy and action whereby employees can create the positive workplace they desire.

Over time I have come to put into practice many of the beliefs that I discussed. If anything, I probably carried out many of my beliefs about the internal motivation of individuals to a fault. I do rely heavily on the belief that people are highly motivated from the inside. While I do believe this is true for most, there seem to be some people that carry with them and apathy that seeks a more theory X solution. I do however believe that through positive affirmation most people will strive to reach a greater level of achievement and to retain the desire to repeat achievements that would be possible if I were to revert to a more coercive strategy.

A very good example of a leader that facilitates individual growth is Dr. David Seyfried, the Director of the Center for Students with Disabilities at Minnesota State Community and

Technical College - Fergus Falls. As the director for the center, Dr. Seyfried is taken a department that is frequently seen as a government mandated service that creates a drain on the system and turned it into one of the leading departments on campus. As one example, during the North-Central accreditation visit last year the progressive nature of this department and the environment that creates were cited twice by the accreditation team as being exemplary toward which this college should strive. Especially noteworthy in that comment, is the fact that no other departments were singled out by name. As is with his leadership style, if asked, he would routinely show evidence of how the students using this department have made it what it is.

When asked, he said the most important book to influence his leadership style has been, How To Win Friends And Influence People by Dale Carnegie. Citing this book as a source of influence came spontaneously and without hesitation. It has been a very important tool in shaping this vision of leadership. He followed this with his personal definition of leadership which is "the ability to enable people to produce their best in a nonthreatening environment".

An excellent example of the leadership style Dr. Seyfried exhibits lies in his role with regard to the installation of the first wireless computer network in the country to be installed on a community college campus. The entire process, from its inception through its implementation, was a student driven project. Furthermore, the particular group of students carrying out this project all had some form of disability and had each long lived with a stigma that suggested they are consumers but not contributors. Because of this, many of them could not envision themselves successfully carrying out a project of this magnitude.

Upon completion, the system was demonstrated at Closing the Gap in Bloomington, Minnesota by the students that had created it. This was followed by an article that was written by the students and published on the front page of the Post conference publication. This space is

sought-after nationally as a way to publicize cutting-edge technology. To be published front page

is quite an accomplishment.

APPENDIX B. LETTER TO MSUM ADMISSIONS ON PROFESSIONAL GOALS

To: MSUM Graduate Admissions

4/14/04

Re: Essay on professional goals

I am applying for the Master of Science in Educational Leadership: General Leadership with Educational Technology Emphasis degree program. Completing this program, I feel, will allow far greater opportunity for me to contribute to students, learning, and the public than I can offer today. I have been working with technology by serving on committees, providing customized and individual software training, and using/teaching technology in the classroom for many years.

I have a wide and varied experience with technology inside and outside the educational environment. I was published in 1998 April-May "Wireless Laptops for Disabled College Students" *Closing The Gap* Volume 17 Number 1. This is the foremost publication in computer tech for people with special needs, and it is an international publication for users and inventers. This article showcased a campus-wide wireless network we put in place at the Fergus Falls Community College. Since then the college has been renamed: Minnesota State Community and Technical College-Fergus Falls (MSCTC). When initially installed, it was a pioneering effort at a 2-year college.

From June through August 2003 I served as interim Project Manager for the Assistive Technology Network (ATN) of West Central Minnesota. My position with the ATN was to oversee the technology needs of persons with disabilities in a nine-county region of West Central Minnesota. This included arranging technology clinics by bringing services from Gillette

Children's Hospital to Fergus Falls, Alexandria, and Detroit Lakes to reduce hardship for those who would otherwise need to travel to the Metro area for services.

In April 2004 I accepted an advisory position with The Minnesota STAR (A System of Technology to Achieve Results) program as the voice for Greater Minnesota technology needs for persons with disabilities. I also serve on CTIC (Community Transition Interagency Committee) of the Otter Tail Family Services Collaborative. My role on this committee is to address the technology and services available to students with disabilities as they enter college.

I currently hold an adjunct faculty position at MSCTC–Fergus Falls where I teach computer applications. I have written and taught courses using Microsoft Office Professional applications including Word, Excel, Access, PowerPoint, and FrontPage. Spring semester 2004 I am teaching Desktop Publishing using Adobe PageMaker and PhotoShop. I deliver all of these courses in the traditional face-to-face classroom using the web for support. All course work is submitted electronically via email or email attachments with the exception of documents that must be printed specifically to compare onscreen to printed versions.

While I enjoy the work I'm currently doing as an adjunct faculty member, I am highly motivated to further my education to secure a permanent position at MSCTC or similar institution. I have for many years found the technology field to be both interesting and challenging. I believe this is an excellent opportunity to be a part of the move to place additional educational content online.

Upon completion of the Master of Science in Educational Leadership: General Leadership with Educational Technology Emphasis degree, I would like to continue to serve in education. I believe this degree will allow me to pursue a permanent and more robust role in an

institution of higher education. In addition to my current professional goals, I maintain an educational goal of ultimately earning a Doctoral degree.

APPENDIX C. LETTER TO NDSU ADMISSIONS PROFESSIONAL GOALS

To: NDSU Graduate Admissions

1/26/07

Re: Professional goals

I wish to apply to the Doctoral Program in Education offered at North Dakota State University. At this time, I have finished all but the last portion of my field research in the MSUM Master of Science in Educational Leadership: General Leadership with Educational Technology Emphasis degree program at MSUM and plan to graduate in the spring of 2007. I chose the research over the portfolio route in this program in an effort to begin the process of developing sound theory in the quest to pursue doctoral studies. From here, I would most like to pursue the occupational and adult education option at NDSU to further my education.

I believe that completing this degree will allow me to greatly expand not only my ability to perform tasks in the work environment, but to elevate my ability to question not only if something works why it works and to use that knowledge in the classroom and beyond. While I enjoy the work I'm currently doing as an adjunct faculty member, I am highly motivated to further my education to secure a permanent position at Minnesota State Community and Technical College - Fergus Falls or other institution.

During my first semester of providing classroom instruction, I realized that there is a wealth of opportunity in utilizing network resources to create a more robust learning environment. At that time, there were relatively few resources available and content need to be generated largely through the development of a personal web site that was made available to students via the Internet. While this was a very useful tool, it lacked the data driven decision-making and relied primarily on student feedback and classroom observations to drive further

development. This wasn't a bad system, but I very quickly realized there was much to learn as I continued to develop classroom materials.

Around this time, I also served as interim Project Manager for the Assistive Technology Network (ATN) of West Central Minnesota. My position with the ATN was to oversee the assistive technology needs of persons with disabilities in a nine-county region of West Central Minnesota. This included arranging technology clinics by bringing services from Gillette Children's Hospital to Fergus Falls, Alexandria, and Detroit Lakes to reduce hardship for those who would otherwise need to travel to the Metro area for services. In April 2004 I accepted and maintain an advisory position with The Minnesota STAR (A System of Technology to Achieve Results) program as the voice for Greater Minnesota serving the assistive technology needs for persons with disabilities. I also serve on CTIC (Community Transition Interagency Committee) of the Otter Tail Family Services Collaborative. My role on this committee is to address the technology and services available to students with disabilities as they enter college.

Throughout my work with the ATN, STAR, and CTIC among others, there is a recurring issue with how to engage learners who are unable to attend the traditional classroom by offering alternative delivery methods. One area I'm particularly interested in is finding ways to serve students with disabilities that have frequently been difficult to reach or are effectively place-bound. Upon hearing numerous anecdotal accounts of post-high school learners who were frequently not afforded educational opportunities because of geographic or mobility constraints relating to their disability, I visited the research literature and discovered that most literature studying Place-bound persons does not address the particular needs of persons with disabilities.

In light of this, I believe that Place-bound learners with disabilities are a traditionally underserved population, and judicious use of technology will allow many persons to take an

138

interactive role with other students in the absence of geographical constraints. A well-developed curriculum employing universal design can be available to all students without the typical segregation that Place-bound learners often face. The many benefits to these persons may be rather obvious, but other more traditional learners will also reap the benefits of interacting collaboratively with persons outside of their usual learning environment.

I feel the knowledge of these needs combined with the proliferation of network connections and personal computers underscores the efficacy of computer-based distance education to reach underserved populations. To that end, understanding that education is ever-changing, I feel it's important to remain abreast of current movements within education but also that it's very important use data driven decision-making to avoid the pitfalls associated with following trends. By remaining cognizant of sound educational principles and current research on pertinent topics, one can identify and provide leadership when faced with shifts in educational needs.

I have for many years found the distance education and computer-aided course delivery field to be both interesting and challenging. I believe this is an excellent opportunity to further develop alternative classroom delivery that will embrace distance education and computer-based instruction. A well-developed program will bring all students together without the constraints that geography has long imposed while driving learning opportunities that extend beyond the classroom walls and that cannot be replicated in a traditional classroom.

Upon completion of the doctoral program in education at NDSU, I would like to continue to serve in higher education. I believe this degree will allow me to pursue a permanent and more robust role in guiding and developing policy for alternative delivery methods. In support of my

current professional goals, I have long maintained an educational goal of ultimately earning a

Ph.D. in Education and believe that I'm ideally positioned to make it happen at this time.