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Qualitative study: people with disabilities and internal barriers to work

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UNIVERSITY OF NORTHERN COLORADO

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The Graduate School

QUALITATIVE STUDY: PEOPLE WITH DISABILITIES AND INTERNAL BARRIERS TO WORK

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

Patricia Yeager

College of Natural and Health Sciences
School of Human Sciences
Program of Human Rehabilitation

August, 2011

This Dissertation by: Patricia Yeager

Entitled: *Qualitative Study: People with Disabilities and Internal Barriers to Work*

has been approved as meeting the requirements for the Degree of Doctor of Philosophy in College of Natural and Health Sciences in School of Human Sciences, Program of Human Rehabilitation

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ABSTRACT

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A great deal of work has been done over the past 40 years to make the built environment more accessible. Public awareness activities have been conducted to begin to change society's attitudes toward people with disabilities. Changes in government benefits now allow individuals to retain benefits while working. However, people with disabilities are still woefully unemployed. This study examined internal barriers to work that some people with disabilities on government benefits may experience.

Using qualitative methods, the researcher uncovered internal barriers to work among people with disabilities on government disability benefits. Data were collected through telephone interviews with six individuals with hidden disabilities, the majority of whom had acquired their disability as an adult. Using Anthony's (1994) suggestion to examine individuals with disabilities' willingness to change using the characteristics of self-efficacy, self-awareness, and current situation (quality of life), the researcher examined outside influences about disability (e.g., family, doctors, and society), whether they viewed themselves as a person with a disability, any thoughts and fears about going to work, and asked them to state their dream job.

Each case was coded, analyzed, and a case study was written about each individual’s experiences, thoughts, and fears about work and his or her quality of life. Negative thoughts about disabilities were noted as were his or her expectations about work and possible jobs. Individual and cross case analysis were conducted through the lens of Bandura’s (1986) thoughts about self-efficacy within social learning theory and the Ellis and Grieger (1977) rational emotive behavior therapy.

Results from the data suggest that this cohort of people with hidden and adult onset of disabilities need assistance in recognizing they have a disability, appropriately integrating their disability into their self-concept, information about their disability and career options, as well as role models for how to “be” with their disability and deal with society’s lowered expectations. Practice talking about their disabilities and negotiating for reasonable accommodations was also suggested. Implications and suggestions are offered for people with disabilities, rehabilitation counselors, independent living center personnel, and for systemic change. Directions for future research are also suggested.

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It takes a community to raise a Ph.D. To my J-Team of supporters (Judy Yeager, Jude Printz, Joann McLean, Joan E Warren, Judy Neal) and others I say thank you. Marilyn Gustin helped me to keep my perspective and learn to let go and trust. Jo-el Hibian and her partner Charles Hill were infinitely patient; they listened,

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CHAPTER I

INTRODUCTION

In the 21st century, expectations are changing for people with disabilities. With the creation and funding of Independent Living Centers (ILCs) in the late 1970s, the passage of the Americans with Disabilities Act in 1990, and various tinkering with the rules of Social Security to allow people with disabilities to work and retain some level of benefits, it is clear that "people living, working and participating in their communities has become the expectation and goal of many programs and policies" (Stapleton, O'Day, Livermore, & Imparato, 2006, p. 706).

Persons with disabilities are vastly under represented in the United States workforce. The 2007 Disability Status Report (Erickson & Lee, 2008) indicates that in 2006, 36.9% of people with disabilities of working age, using the American Community Survey's definition of disability, were working compared to 79.7% of the nondisabled population who worked. Adults who are not working because of their disability usually seek support through government benefit programs offered by Social Security. The monthly check is small, on average about $800, including all federal and state supplements (Livermore, Goodman, & Wright, 2007). Most importantly, access to health insurance is provided through Medicaid for those who have never worked. For those who have worked, but because of a disability no longer do, it takes a two-year waiting period and the spending down of all assets to a poverty level before Medicaid is made available. However, Medicaid health services become available to those who enroll and work through the Medicaid Buy-In program.

Once on the rolls of Social Security, it is often difficult to leave. In 1996 (the latest year this statistic was calculated), LaPlante, Kennedy, Kaye, and Wenger found that less than half of 1% of all recipients annually left the Social Security benefit rolls to work. In 2006, only 8% of persons with disabilities on Social Security were actively seeking work (Erickson & Lee, 2008).

In a more recent analysis of 2004 Social Security recipients, Livermore (2009) found that 40%, or about 4.5 million people, on the rolls indicated that they have goals for working. Livermore found that these recipients were "younger, more likely to be nonwhite and more educated" (p. 1). These individuals had been on the rolls for a shorter length of time, were more likely to have acquired their disability during childhood, had lower levels of other government benefits, and reported better health. Should these Social Security recipients find jobs, lessen their dependence on government programs, and contribute taxes, it could have a significant positive impact on their lives, contribute to the economy, and reduce spending in the Social Security programs.

Statement of the Problem

Given the laws that have been passed to remove barriers for persons with disabilities (e.g., 1964 Civil Rights Act, 1968 Architectural Barriers Act, 1970 Urban Mass Transit Act, 1973 Rehabilitation Act, 1975 Education of All Handicapped Act, 1988 Air Carrier Access Act, 1990 Americans with Disabilities Act, 1997 Individuals with Disabilities Education Act, and 2002 Help American Vote Act) and the Supreme Court decision ruling that segregation of people with disabilities is a form of discrimination (*Olmstead V.L.C.,* 1999), much has been done to improve environmental access. With the availability of personal assistance services, work incentive programs, accessible education facilities, assistive technology, and services to assist with job development and placement, there are a wealth of programs to help people with disabilities work but they are not leaving government assistance rolls. As of 2008, the employment rate of persons with disabilities, ages 16 to 64, remains a dismal 39.1% as compared to 77.1% of persons without disabilities in the same age group (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2009). Work over the past 30 plus years to address the social and environmental barriers that people with disabilities have faced are substantially increasing access to the community environment, but people are still not going to work.

In 1997 the National Council on Disability (NCD) wrote, "People fear most of all losing the medical benefits that can literally spell the difference between life and death" ("Barrier: Many People Worse Off," para. 1). The NCD provided a federal report that made recommendations to Congress about the barriers to work that people with disabilities faced. As a result of policy research and advocacy by the disability community along with others, The Ticket to Work and Work Incentives Improvement Act (TTW-WIIA), Public Law 106-170, was passed by Congress in 1999.

It is important to note that addressing the health insurance needs of people on Social Security benefits is a two-pronged effort. For those with disabilities who have never worked (Supplemental Security Insurance [SSI] recipients), the 1619(b) program was created a number of years ago that allows those recipients to work and keep their cash benefit and Medicaid health insurance up to an amount set each year by the state. For example, in Colorado the 2011 amount is $31,990, which is the amount the state calculates one would need to meet living expenses and pay for health insurance (Social Security Administration, 2011a). Social Security Disability Insurance (SSDI), the other prong, uses the Medicaid Buy-In program to serve persons with disabilities who have worked. This program allows SSDI recipients immediate access to Medicaid health insurance while they work up to a specific income level, which is determined by each state (B. MacDonald, personal communication, February 26, 2010). There is a lack of information about both of these programs among recipients (B. MacDonald, personal communication, February 26, 2010). For the purpose of this research, the term Medicaid Buy-In program will be used to refer to both programs for simplicity's sake. While the two groups take different routes, the goal of retaining health care benefits while working is the same.

Surely alleviating the fear of losing benefits would open the door for more people with disabilities to go to work. However, as of September 30, 2006, 39 of 51 states and territories had some sort of Medicaid Buy-In program in place, and only 67,480 individuals across the country were enrolled (Jensen, 2007). Gimm, Andrews, Schimmel, Ireys, and Liu (2009) reported that 200,000 people were enrolled in

Medicaid Buy-In programs between 1997 and 2007. While the program is growing, it is growing slowly.

In 2005, the California Foundation for Independent Living Centers conducted a survey of Californians with disabilities who accessed independent living services at 20 ILCs across the state. The survey asked the question: "If you had to *choose what MOST limits you from working* to your fullest ability, it would be" (Yeager, Kaye, & Reed, 2007, p. 146)? The survey was mailed to 14,000 randomly selected consumers, and 1,919 responses were received for a response rate of 12%. Choosing from an extensive list of 13 reasons and an open ended "other" option, 76% indicated that "my disability" kept them from working (Yeager et al., 2007). A majority of the respondents were people who had acquired a disability as an adult. Given the low usage of the Medicaid Buy-In program in California at that time, 1,850 enrollees as of December 31, 2005 (Jensen, 2007), the researchers expected that loss of health benefits would be the top reason. However, "loss of benefits, including health benefits," and all other reasons were cited by 20% or less, leaving one to wonder what the respondents meant when they chose "my disability." In reviewing the disabilities of the participants, none were deemed as severe as to preclude work altogether.

Livermore et al. (2007) examined the findings from the 2004 National Beneficiary Survey (NBS), a nationally representative sample of Social Security disability beneficiaries, to determine what characteristics, use of services, and work activity might be occurring. They found characteristics that were negatively associated with employment, which included:

> age 55 and over, being SSI only, having Social Security benefits greater than $500 a month, having low to moderate levels of other cash (0 – $499 per month), other (non-black, non-white) race, poor physical or mental health; having at least one ADL or IADL limitation requiring assistance and having a severe physical limitation. (p. 89)

Positive characteristics that were associated with employment included “childhood onset of disability, being male, having education beyond high school and obesity” (p. 89). The authors also explored the use of employment services and the number of Social Security recipients (both SSI and SSDI recipients) and found only 9% who reported that they used employment services. However, fully 30% of all beneficiaries expressed an interest in or intended to be off the program through employment within one to five years. There is a potential for significant savings in government benefit programs if more people with disabilities on benefits did follow through and engage in part- or full-time work.

Following up on the California Foundation for Independent Living survey finding about “my disability” as a top reason for not working, Kaye (2009), in a presentation at the 2009 American Public Health Association conference, presented data collected in a telephone survey of 1,017 working-age Californians with disabilities in 2007 to 2008. Kaye observed that in his study benefits seemed to be at the bottom of the list of barriers; perhaps more attention needs to be devoted to controlling pain, alleviating depression, and examining the unable to work mindset.

None of the data presented delve in to the internal feelings, beliefs, and experiences that people with disabilities may have about their ability to work. There appears to be little qualitative research into the mindset (Kaye, 2009) of persons with disabilities on benefits with regard to their ability to work. This study examined the mindset of a cohort of people with disabilities, either applying for or receiving government benefits, about any internal barriers that may play a role in their decision not to work. The American Heritage Dictionary defines the word mindset as a fixed way of thinking that predetermines an individual's response to or interpretation of a situation (Mindset, 2009). If individuals accessing benefits, who are relatively healthy and understand that they may keep their benefits while working up to a certain income level choose not to work, then, looking for fixed thinking and predetermined responses (Mindset, 2009, 2010) about work, may shed light on internal barriers to work for some people with disabilities.

Purpose

The purpose of this phenomenological study sought to describe the perceptions, experiences, and feelings that people with disabilities engage in when deciding not to go to work; these perceptions, experiences, and feelings may be the basis of a mindset about work held by people with disabilities, which may throw up internal barriers to work. On the other hand, some individuals may decide their lives are fine without work. By exploring these themes via telephone interviews with people with disabilities, who (a) are receiving government benefits or planning to apply, (b) have been informed of the availability of a Medicaid Buy-In program (or the 1619(b) program), and (c) are not working, I describe any internal barriers that impact their decision around work.

Research Question

Q What internal barriers impact the decision not to work for people with disabilities?

Rationale

While talking about persons with psychiatric disabilities and supported employment services, Anthony (1994) suggests that there are personal factors that can indicate a willingness to change: self-efficacy, self-awareness, and satisfaction with current situation. Anthony did not define current situation, but one could define the term using a quality of life (QOL) perspective (e.g., are you happy with your life as it is currently?). Given that willingness to change is a universal construct and not limited to persons with mental illness, Anthony's factors seemed to be a good theory to organize this qualitative study.

Two behavioral change theories may be helpful in assessing the self-awareness and self-efficacy of participants in this study. One is a practical, individual-based theory that can, with work, bring about a change in behavior. The other offers a more comprehensive look at not only the individual but the social context as well. This is important when considering a minority status group or individuals such as those with disabilities.

The practical, individual-based theory is rational emotive behavior therapy (REBT) founded by Albert Ellis. He is a pioneer in cognitive behavioral therapy, which posits "that people largely control their own destinies by believing in and acting on the values and beliefs that they hold" (Ellis & Grieger, 1977, p. 3). Becoming aware of one's self-talk is a major part of self-awareness and can lead to change. This may be helpful in creating strategies to change the thinking (self-talk) of people with disabilities regarding work.

The second theory concerns self-efficacy as developed by Alfred Bandura within his social cognitive learning theory. He defines self-efficacy as “the belief in one’s capabilities to organize and execute courses of action required to attain designated types of performances” (Bandura, 1986, p. 391). Belief in ability is separated from actual skills in this theory. Beliefs are influenced by social interactions and the environment. The social aspects of how self-efficacy is created or supported may help to guide strategies for helping people with disabilities actually go to work.

Anthony’s (1994) third personal factor, satisfaction with current situation, seems to refer to QOL issues. Are people with disabilities on benefits who choose not to work doing so because of their satisfaction with the quality of their lives? While there is no one definition of QOL (Brown, 1988), Parmenter (1988) defines QOL as the degree with which the individual makes choices to meet his or her needs and construct a “viable self in the social world” (p. 9). This description of QOL seems to fit this research study. By asking participants about satisfaction with their lives, this study found that for some individuals, work is not a means to meet their needs. If their current QOL works quite well, the choice to work may be unnecessary. This choice is an important factor for consumers and rehabilitation service providers to uncover and understand before embarking on an examination of internal barriers to work.

In the world of vocational rehabilitation programs, whose mission is to assist people with disabilities to work, it seems that focusing on the consumer’s beliefs of self-efficacy, self-talk, and satisfaction with life may not occur. This type of counseling is time intensive. There is a rush to place individuals into jobs, close the case, and make the agency's numerical goals (Herbert, 2004). Meeting placement goals are often a big measure of the effectiveness of the vocational rehabilitation agency. However, helping clients to examine their QOL decisions and deal with their internal barriers to work may improve their ability to choose work, as well as get and keep a job (Hanes, Edlund, & Maher, 2002).

If information gleaned from consumers/clients on what they tell themselves about their disability, their judgments about their ability to be successful at work as well as their thoughts and experiences around work could be elicited, counseling interventions could be created to help build a solid foundation for job seeking and placement activities for those who want to choose to work. While such counseling activities may slow down the placement process for vocational rehabilitation counselors, consumers may be more successful and more likely to continue working, assuming most all other factors are acceptable to the individual. Such factors include stable economy; relatively stable health conditions; access to health insurance, personal assistance, housing, and transportation; available adaptive equipment; and employer attitudes are at least neutral.

This phenomenological study of persons with disabilities, who are either on government benefits or considering going through the often arduous process of qualifying for benefits and are choosing not to work, may provide insight into their feelings and thoughts about work as well as the judgment they make about their ability to work. Providing insight to persons with disabilities about possible internal barriers to work that they may be creating, consciously or unconsciously, could be quite helpful in removing those barriers for those who want to choose to work. Counselors working with consumers could use these insights to assist consumers as they identify and work through their own personal barriers to work. Ultimately, the benefit of increased employment among people with disabilities will be to help lift them out of poverty, increase their QOL (if desired), and reduce the need for government benefits.

Delimitations

I sought to uncover the internal barriers to work that people with disabilities themselves create. To that end, this qualitative study focused on a group of six persons with physical or emotional disabilities of working age who were on or were seeking to qualify for federal Social Security programs and state or local assistance programs. In addition, all but one of the participants were relatively healthy as research has shown that poor health can inhibit job readiness (Erickson & Lee, 2008; Kaye, 2009; Livermore et al., 2007). While all of the participants had hidden disabilities, five of them acquired their disabilities as adults. Finally, participants had been exposed to a Medicaid Buy-In project (or 1619(b) program) in their community so as to eliminate fear of loss of health benefits as much as possible.

Anthony (1994) posits that satisfaction with one's situation should be examined as a possible impact on the decision to work. Cummins (1997) suggests that both quantitative and qualitative measures be used to measure QOL. Campbell, Converse, and Rodgers (1976) posit that satisfaction with a given life domain, such as work, is dependent on the attributes that make up that domain (work). It is dependent on the individual's subjective evaluation and the standard the individual holds for that attribution (Campbell et al., 1976). The authors go on to posit that life satisfaction is measured over a number of domains and that individual affect at the time may influence the decision about life satisfaction.

Gladis, Gosch, Dishuk, and Crits-Christoph (1999) suggest that both subjective and objective measures should be used to determine QOL. However, for the purposes of this study, I only looked at the subjective report of life satisfaction as a potential marker for readiness to change. I was only interested in the participants' view of their life satisfaction as it impacts on the decision to work.

As a qualitative study, this research was not generalizable to the larger working-age, unemployed disability community but provides rich details about the lived experience of this group of individuals, all of whom had hidden disabilities and five of the six acquired their disability in adulthood. Data from this study could be used to construct a well grounded survey of a much larger sample of the target population.

Definition of Terms

Ableism. This is defined by Hehir (2002):

> as the "devaluation of disability" that results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently rather than use spell check, and hang out with non-disabled kids as opposed to other disabled kids. (p. 1)

Hehir uses this term in his critique of education and children with disabilities.

Activities of Daily Living (ADLs). This refers to basic living tasks such as bathing or dressing, getting around the house, getting out of bed, and eating (Livermore et al., 2007). Human assistance is needed to complete these and other basic tasks essential to living. Services for persons with disabilities are often assessed from a functional limitation perspective in order to determine how severe the disability is and how much human assistance may be needed. This is often a cost borne by a government entity.

Americans with Disabilities Act (ADA). This is often called the civil rights act for persons with disabilities, which was signed into law in 1990.

Assistive technology. This is broadly defined as any device or equipment used to maintain or improve functioning, including devices used for mobility, seeing, hearing, communication, and performing everyday tasks (Technology Related Assistance for Individuals with Disabilities Act of 1988).

Built environment. This is a term of art used in the public right of way discussions that refers to anything manmade to improve living/travel conditions of human beings, including buildings, trails, sidewalks, etc. If someone takes a field in Iowa and puts in human-use features, not only must the feature be accessible but the public right of way (parking, sidewalks, etc.) must be accessible. It is an all inclusive term used in the Access Board deliberations (D. Brandon, personal communication, April 19, 2010).

Dysfunctionphobia. This is a term invented by Philip Patston (2007) in his article. He defines it as a fear of loss of body function that both nondisabled and those with disabilities experience.

Government benefits. These are federal and state government benefits (e.g., cash, health care, and food stamps) paid on a monthly basis to qualified persons with disabilities for support.

Instrumental Activities of Daily Living or (IADLs). This refers to other services that are "less fundamental but equally important activities such as getting around outside the home, shopping for personal items, and preparing meals" (Livermore et al., 2007, p. 88). A government entity may pay for these services, and volunteers are sometimes sought by nonprofit organizations to assist.

Job development. This refers to a service that is provided by vocational rehabilitation counselors or community-based counselors. It involves networking with employers to identify and/or develop jobs that could be done by specific clients with disabilities.

Job placement. This is an important service provided by vocational rehabilitation counselors and community based job counselors. It entails matching a person with a disability with job; helping the person get the job; and, in order for the activity to be counted as a placement, the employee must remain employed continuously for 90 days.

Medicaid Buy-In program. This refers to a program that is available to states who wish to participate. It allows persons with disabilities, who have a work history, to work and access Medicaid health care benefits until a certain income level is reached. Usually a gradual ramping off of the program is available. That is, as the person makes more money, he/she may pay a prorated share of cost, until the limit is reached. At that point, the person with a disability should be making enough money through work to purchase insurance and/or pay for personal assistance.

Mindset. The Merriam-Webster Online Dictionary (Mindset, 2010) defines mindset as a fixed state of mind. The American Heritage Dictionary of the English Language (Mindset, 2009) adds to this definition by describing mindset as an attitude that predisposes individuals to behave in a specific way.

Person with a disability. This is an individual who has a physical, mental, or emotional functional limitation. In the public data such as the Census or the American Community Survey, these are defined as sensory, physical, mental, self-care, ability to go outside the home, and employment.

In the world of rehabilitation services, persons with disabilities are referred to as clients in vocational rehabilitation agencies and community based employment agencies or as consumers in the independent living movement. In the government benefits programs, they are referred to as recipients.

Personal assistance. This is a collection of services used by persons with severe disabilities and includes assistance with ADLs and IADLs. Increasingly, this term is used in an employment setting to refer to support on the job such as reaching, filing, retrieving, note taking, and other activities. All of these activities are performed by someone else under the direction of the individual with a disability.

Phenomenological approach. This approach to qualitative research involves understanding "several individuals' shared experiences of a phenomenon . . . in order to develop a deeper understanding about the features of the phenomenon" (Creswell, 2007, p. 60).

Quality of life (QOL). A complex examination and discussion of satisfaction with meeting life goals in such settings as "work, home, school and community" (Goode, 1990, p. 46). The individual gives meaning and substance to the experience of satisfaction; what one experiences as satisfactory may not be to another (Taylor & Bogdan, 1990).

Rational emotive behavior therapy (REBT). REBT is a cognitive approach to psychotherapy and is the oldest form of cognitive-behavior therapy (David, Lynn, & Ellis, 2010). By identifying cognitive beliefs, challenging them, and working to change them, individuals can change their reality and behavior. Ellis' A-B-C (activating event, belief, consequence) (D-E [debating–efficient]) model is the foundation of REBT and modern cognitive behavioral therapies (David et al., 2010).

Section 1619(b). This program is a Social Security based benefit that allows people with disabilities, who have never worked, to work and keep their Medicaid health care benefit and cash benefits until they reach a level of income usually set by the state.

Section 504 of the Rehabilitation Act of 1973. This is a federal law that protects people with disabilities from discrimination based on their disability. It applies to all programs and services offered by federal programs and departments as well as any organization that receives federal funding. It defines the rights that people with disabilities have to participate and access programs and services (Office of Civil Rights, 2006).

Self-efficacy. This is defined as “the belief in one’s capabilities to organize and execute courses of action required to attain designated types of performance. It is concerned not with the skills one has but with judgments of what one can do with what one has” (Bandura, 1986, p. 391).

Self-esteem. This is defined by Bandura (2003) as “a judgment of one’s self-worth” (video).

Social cognitive theory. This is a complex explanation (theory) about human behavior developed by Alfred Bandura. It posits that human behavior is not solely driven by internal forces or external forces (Bandura, 1986). Bandura created a model of human behavior called triadic reciprocality.

Social Security Disability Income (SSDI). These are federal benefits paid out to workers who have worked and paid into the disability insurance program for at least 40 quarters. Income is based on salary and time worked. Recipients must wait two years to access the Medicaid health care system and must spend down assets to a poverty level. Recipients using this program will often have a share of costs for personal assistance services since these recipients usually receive higher monthly cash benefits.

Stigma. This term refers to the devaluing of individuals because they have characteristics that make them different from normal (Stigma, 2010). Goffman (1963) uses disability as a definition of a condition that brings about stigma or devaluation. People who are criminals look or act differently from the human expectation of normal and experience a separation from group or society as a whole. Stigma is negative and based on stereotypes, lack of information, and fear. It will interfere with the acceptance of the individual by others and by himself or herself.

Substantial gainful activity (SGA). This is a term used by Social Security. It refers to an incentive to allow people with disabilities receiving benefits to try working for up to nine months (historically) and make up to a certain amount of income. In 2011 that amount for nonblind individuals is $1,000 (Social Security Administration, 2011b). Often individuals will earn an income under the SGA and continue working while retaining full government benefits (including health care) for more than nine months. Changing the practice of working just to the cash limit is at the heart of the work incentives changes under the TTW-WIIA law.

Supplemental Security Income (SSI). This is a cash benefit paid out to persons who become disabled before they can work or before they have worked for 40 quarters. Access to Medicaid health insurance is provided along with personal assistance if needed. This benefit is means tested, and only individuals who have $2,000 and couples who have $3,000 or less may qualify, excluding a home and car (Social Security Administration, 2011a).

Triadic reciprocality. This refers to a model of human behavior based on "the behavior, cognition and other personal factors, and environmental influences that all act upon one another interactively as determinants of each other" (Bandura, 1986,

p. 23). Within this model, humans are influenced by their inner thoughts: societal and, to some extent, personal traits, as well as their environment.

Work incentives. These refer to a set of policies enacted by the federal government that encourage people with disabilities to work and still maintain their benefits such as their monthly check, health insurance, and personal assistance. After reaching a certain income level, they may pay a prorated share of cost until they earn up to a specific limit. At that point, they give up their benefits if they have reached an income level that supports their needs. Some may never reach that point but are able to work and receive benefits that, when combined, lift them out of poverty and increase their QOL while also allowing them to pay taxes.

Summary

Work is a fundamental, developmental life task that each individual must address. How one contributes to one's family, community, or the planet is a central question in one's life. For persons with disabilities, work increases one's ability to care for oneself and family, increases social connections, increases life satisfaction, increases one's physical and mental health, allows him/her to be a role model to others, empowers one to make a difference, and increases one's self-esteem (Yeager, Donnelly, Copeland, & Fraser, 2009).

Schur (2002) documented the economic impacts of work by showing that employment tends to improve the lives of minority groups including people with disabilities. Not only does it increase the household income of a person with a disability by 49% and have a positive affect on lifting that family out of poverty, it also alleviates social isolation and develops life skills in other areas such as community and political participation. Schur also found that employed persons with disabilities were more likely to feel included and respected.

Given all of the positive reasons to work, the rampant poverty that people with disabilities on benefits experience and the rising expectation that people with disabilities should work, this research may help the field pinpoint some of the internal barriers that people with disabilities erect regarding employment. This information is critical to people with disabilities; providing insight on the internal barriers that they may create could help them dismantle concerns about work. Such barriers and any strategies to address them could be developed and shared with not only individuals with disabilities but service providers and others who are working with them toward the goal of employment.

CHAPTER II

LITERATURE REVIEW

> Since time immemorial people, with disabilities, whether mental or physical, have been the subject of scorn, ridicule, fear, demonization, intolerance, ostracism, social and economic marginalization and, all too often, outright indifference. These practices have been universal and no nation on earth is guilt free. (Beverly & Alvarez, 2003, p. 27)

This kind of treatment from their fellow human beings does not easily translate into positive judgments about a work role that people with disabilities could make about themselves. When considering the question of why a large number of people with disabilities do not work today, there are several major strands to examine.

A historical perspective of disability approaches might be helpful. Each approach or model identifies a different definition of disability in a different institutional system (Scotch & Schriner, 1997) that identifies different problems that lead to different solutions. Following the historical perspective, several research perspectives are examined. A review of a variety of internal and external barriers that impact the decision to work provides context to this research project. Two quantitative research projects on health and why people do not work today are explored. Finally, several theoretical frameworks are used to provide a context to the data.

Historical Perspective of Disability Approaches

Medical Model

The medical model of disability views disability as an illness or injury (Scotch & Schriner, 1997) and was properly based in the health care institutions with health care professionals. That is, the role of medical intervention was to fix the problem (Scotch & Schriner, 1997) either through surgery, drugs, prosthetics, or other adaptive means so the individual could successfully execute daily living activities. Smart (2001) further explains that this model relied on physical symptoms to arrive at a diagnosis. Such a process required highly trained professionals to diagnose and prescribe treatments. Early on in the use of this model there were two outcomes: people either lived or died. One could reasonably assume that physicians were deeply committed to cure as the definition of success.

Medical treatments have come a long way, as evidenced by people with chronic illnesses such as diabetes (Smart, 2001) who may no longer die earlier than expected but generally manage their conditions successfully. However, the medical model did not envision the person outside of her/his biology; her/his family, employment, or community was not considered (Smart, 2001). The goal was to fix the pathology as best as possible. Sometimes the patient became the disease in the eye of the physician trying to cure the individual (Smart, 2001). Certainly stigma or society's attitudes were not considered by the medical model proponents.

Another important component of the medical model is that the medical experts were in charge of services and information; recipients were to trust the experts and follow their prescriptions (Smart, 2001). DeLoach and Greer (1981) called this the "omniscience of the experts" (p. 43). People with disabilities were not included in decision-making activities; rather, the professionals were the experts. A major focus of the independent living movement was to discard the medical model with its overwhelming medical presence as not only unnecessary but also adding to the barriers that people with disabilities faced (DeJong, 1984).

Functional or Economic Model

The functional or economic model of disability defines disability within the context of what function is lost and the impact of that lost function (Smart, 2001). Scotch and Schriner (1997) posit that the economic model views disability as an individual or labor force productivity issue. That is, the disability causes a limitation to participation in the labor force, and remedies should be focused on the individual's limitation as it relates to work. Thus, the definition of disability rests with the individual and his environment (Smart, 2001), particularly the work environment (Hahn, 1988/1993). However, what one person experiences as a significant disability may not be a disability at all to someone else in a different environment. Smart (2001) cites the example of Stephen Hawking, a famous theoretical physicist, "considers his disability, amyotrophic lateral sclerosis, which greatly limits his mobility and speech, to be an advantage because it allows him more time to think" (p. 38).

The functional or economic model of disability defines the disability as located in the individual but adds the component of vocational limitations as key. Medical professionals are still viewed as the purveyors of knowledge in their areas, as are experts with knowledge of adaptive equipment, speech and language practitioners, audiologists, and other allied health providers. However, there is a growing awareness of the individual with disabilities having different roles besides health (Smart, 2001). The recognition that environments have a role to play in defining disability is beginning to be felt. A new role, that of work or employment, is now being considered as well as the health/daily activities role. Finally, there is some recognition on the part of the professionals that able-bodied people are uncomfortable with people with disabilities, which may be a problem (Hahn, 1988/1993).

Minority Status Model

In 1985, Harlan Hahn argued that "disability is defined by public policy" (p. 294). He called for moving the locus of the problem of disability away from the individual and placing it in the social and political environments that are governed by laws and action. Hahn (1985) wrote that by acknowledging such a statement, disability became a legal issue needing a resolution either by way of action or money, which requires public response. Part of that response should be directed toward creating a consistent definition of disability. To make his point, Hahn (1985) cited Social Security as defining disability as the inability to earn a set amount of money while other agencies' policies looked at the ability to perform one or more specific major life activities as key to the definition of disability. These definitions point to different problems with different solutions.

At that point in time, the United States had no comprehensive public policy regarding people with disabilities (Hahn, 1985). Hahn (1985) argued that the environment was built for people who could function within a relatively narrow set of physical specifications: those who could hear, see, walk, talk, and learn at or above a certain level. All others were relegated to coping as best they could through the use of medical interventions, adaptive equipment, or not at all. By defining the disability within the context of physical barriers and prejudice leading to discrimination, laws could be crafted to expand the range of access so that more humans with physical and mental differences could be accommodated. Hahn (1985) called for looking at the interaction of the individual with the environment as the basis of a social and political approach.

With the passage of several early civil rights laws (e.g., Section 504 of the Rehabilitation Act of 1973 and Public Law 94-142 Education of All Handicapped Act in 1973), people with disabilities began to see that the physical and attitudinal barriers that kept them from participating in community life came from prejudice and stereotyping rather than functional limitations (Hahn, 1988/1993).

At the time, people with disabilities, as a group, faced the highest rate of unemployment, poverty, and welfare; they were also excluded and segregated from society's schools, housing, and transportation (Hahn, 1985). These were the same sorts of exclusionary issues that other minorities had experienced including being judged on the basis of "biological inferiority, stereotyping, stigmatizing, bias, and prejudice" (Hahn, 1985, p. 300).

Hahn (1985) posed the question of whether disability could be conceptualized as a civil rights issue. If so, then minority group status should be assigned to those with disabilities. Minority group status implies that a larger group of people experienced discrimination based on their inability to function successfully in a hostile environment created by prejudice. At this point in time, social policy did not recognize disability issues as being within its purview. As people with disabilities around the United States started to claim their status as a minority group in need of government laws and policies that removed barriers, progress in removing barriers began to occur (Hahn, 1985).

During the time that Hahn (1985) was writing, the disability civil rights movement was born. The movement began by calling for changes in both the attitudes of society and in the built environment that would increase access to education, jobs, housing, transportation, public rights of way, and the community as a whole. Demonstrations around issuing the regulations for Section 504 of the Rehabilitation Act of 1973 brought activists together from across the country who went on to work for the passage of other laws to codify nondiscrimination based on disability. Public attitudes were being assessed, and strategies for changing them through education were being developed.

Hahn (1985) also noted the need for a: (a) complete accessibility overhaul for the built environment, (b) vigorous enforcement of antidiscrimination laws, and (c) benefit payments to offset the extra costs of having a disability as components of a set of disability policies aimed at creating equality for persons with disabilities. Twenty-five years later, the International Building Code has a Chapter 11 section that codifies access in the built environment for all new buildings and significant remodels. The

Americans with Disabilities Act of 1990 (1991) and a host of other laws addressing access to the built environment, housing, transportation, education, and employment have been passed, and advocates are vigorous in their pursuit of enforcement. A number of tax credits for both those with disabilities and employers as well as businesses have been created to help defray the cost of disability.

Additionally, the *New York Times* (Elliott, 2010) reported on the launching of a major media campaign to promote disability equality using the tools of corporations by directing a $4 million ad campaign targeting those who influence hiring decisions in business through print, television, and outdoors and online advertising. This effort is the latest in a long line of efforts to change society's attitudes toward those who look or do things differently because of a disability. While ever so slow, work on changing the environment, whether with sledgehammers, lawsuits, or research and education, progress is being made.

Individual Civil Rights Perspective

Smart (2001) took the civil rights model out of the minority group and made it relevant to the individual. "There are three responses to people with disabilities: (1) charity, (2) preferential treatment and (3) compensation are based on the inherent inferiority of the individual" (p. 127). This presumes that the individual is inferior and needy when compared to able-bodied people (Smart, 2001). Again, the view of the nondisabled community is colored by the perceived limitations of the individual with a disability. Smart contends that policy makers and program directors do not consider self-empowerment, consumer choice, and respect for the individual when considering policy or programming for persons with disabilities. While these concepts are the tenets underlying the disability civil rights movement, the public has difficulty honoring them as the question of funding inevitably arises (Smart, 2001). The cost of access to the built environment: accommodations on the job or in schools, access to telecommunications, and even personal assistance to live independently are all calculated in dollars (Smart, 2001). Among all the minority status groups, costs are only included in the civil rights equation for people with disabilities and often to their detriment (Smart, 2001).

Human Variation Model

The human variation model gives society the responsibility for creating disability based on the variety of variations in the human body and mind as well as the decisions society makes about those variations (Higgins, 1992). “We make disability. Disability is not a natural quality of people or of their individual traits. Through responses to people with variations that we have made meaningful, within a world that we, often unthinkingly, built, we produce disability” (Higgins, 1992, p. 6). Disability gives context to the able-bodied, that is, without seeing the variations, one cannot recognize the social categories we have constructed (Higgins, 1992). The definition of disability is seen as the difference between the experience of the majority group (White, able-bodied men) and others. The experience of the majority becomes the standard by which we judge all others (Higgins, 1992). The institution where change must occur begins with all individuals and spreads to the political and community realms. If we expand our notion to include the wide variations within the human body and mind to accomplish tasks, institutions must develop a more flexible manner of dealing with disability. The individual and the institution are engaged in a dance of sorts to improve self-determination, create more opportunities, and enjoy a more full life (Higgins, 1992).

This concept is more easily seen in examples of learning disabilities. According to Higgins (1992), the first mention of anything related to our current term, learning disabilities, occurred in the late 1800s and was referenced as "word blindness" (p. 9). The term itself did not exist before the mid 1960s. At the time that educators began writing about learning disabilities, there was no recognition of problems with learning as a disability (Higgins, 1992). In 1990, the United States Department of Education reported that students with learning disabilities comprise the largest disability population in education (Higgins, 1992). Humans took that particular learning variation and created a disability, and as such, humans need to construct environments that allow for that variation.

Constructive Functional Diversity Model

Sutherland (1981) gives a hint as to the basis of the constructive functional diversity model, although it would be more than 25 years before the concept would evolve into a model. He declares of disability, "*It is the normal condition of humanity* [emphasis added]*"* (p. 18). Patston (2007), posited a more dynamic paradigm that builds on that statement. He embraces the range of functional diversity as a positive human trait instead of one that focuses on a narrow range as being normal. Patston's model removes the "us" and "them" approach by "recognizing that all people function in diverse ways" (p. 1626). He argues for the complete removal of the concept of differences from the norm. By removing divisive or stigmatizing labels, constructive functional diversity aims "to truly change the social mindset . . . to create one box only, labeled functional diversity in which all human beings sit, stand, lie, or otherwise exist" (p. 1626). However, within Patston's box, the context is critical for understanding what individual accommodations are to be made to allow each person to function at his or her best.

Summary of Models

From the medical model that treated people passively and only within the realm of sickness or health, we moved to the social or functional model that looked at the individual within the work and health arenas. Both models require professional experts to fix or ameliorate the disability problem. Following these models, the sociopolitical model positioned people with disabilities as a minority group who experienced stigma or prejudice that led to discrimination, both socially and in the built environment. In this model, laws, public education, and money are needed to change the built environment, public attitudes, and to enable people with disabilities to participate. Finally, society is beginning to understand that if one lives long enough, one will probably have a disability. This understanding could help society to construct a model of functional diversity with the flexibility needed to accommodate everyone.

Guiding Principles for Disability Research

Hahn (1985) called for an expansion of research on disability policy that would redirect inquiry away from functional limitations and medical interventions that focus on the individual as the locus of the problem. He proposed that disability research should be conducted within a multitude of disciplines including economics, politics, social work, and public health as well as the more traditional disciplines of rehabilitation, special education, and the medical fields (Hahn, 1985). The focus of disability research should be to look at the impact of living in a totally inaccessible environment coupled with the social stigma that able-bodied people (including researchers) hold toward persons with disabilities (Hahn, 1985).

Hahn (1985) called for research that asks people with disabilities about their experiences of living in an inaccessible environment where expectations are not high concerning what sort of future they could have. He called for research to stop looking at disability solely on an individual basis, which focused on the medical or vocational outcomes. Hahn (1985) suggested three foci for research: developing a common definition of disability across government agencies; examining the phenomena of people with disabilities coalescing into a minority group experiencing discrimination; and developing the laws, policies, and activism needed to change the environment.

The NCD's record of nearly 25 years of research on people with disabilities in this country serves as a good example of adhering to the minority status model by looking at public policy and its impact (or lack thereof) on the disability community. The NCD has issued at least four different reports on how research should be conducted and on which topics to focus. In 1984, its first report illustrated the glaring need for accurate demographics about the United States disability population so that effective policies could be constructed around actual needs. The report also called for research to identify effective technology and services to support people with disabilities (NCD, 1984).

In 1993, the call for research centered around structuring data collection that focused on the implementation of the four goals of the ADA, including people with disabilities in all facets of research, and calling for the construction and deployment of a disability supplement to the Health Interview Survey. This particular report noted that public policy had been responsible and successful in moving away from the medical model to a disability model of empowerment (NCD, 1992/1993, “Section 2: Conclusions,” para. 11). Finally, the 1993 report made the case for developing a field of study to examine disability policy through research.

In 1998, the NCD advocated for disability research that centered on demographics and goals. The NCD suggested that wherever gender and race/ethnicity was captured in the data, disagregation of disability type should also be recorded; for validity and reliability of data collected, people with disabilities should be involved in all aspects of the research, the 2000 Census should use the ADA definition of disability, and that disability issues be included in the short form of the Census questions as well. With regard to tracking the implementation of the ADA goals, the NCD called for research to be structured around the four goals of the ADA. Those goals are: “(1) equality of opportunity; (2) full participation; (3) independent living; and (4) economic self sufficiency” (NCD, 1998, “Orienting Disability Data Collection Activities,” para. 6). Together, the four goals focus on environmental barriers for people with disabilities.

The most recent ideas regarding disability research from the NCD were made public in a report released in 2004. The Council repeated its calls for organizing research around the implementation of the four goals of the ADA. It echoed the 1984 call for an accurate and official count of people with disabilities in the United States. Finally, it called for better questions on the 2010 Census and suggested that the American Community Survey and the Current Population Survey may be more effective tools to obtain more details about the needs of people with disabilities (NCD, 2004).

The NCD provided much information on the issue of who, what, and how disability research should be conducted. Firmly based in Hahn’s (1988/1993) call for examining the interaction of the individual with a disability and the environment, the NCD’s policy thinking and research has provided guidance on many laws, regulations, and programs that improve the life of people with disabilities.

Disability Theory in Qualitative Research

Qualitative researchers appear to have embraced Hahn’s (1985) suggestions when creating disability theory as a lens with which to view the disability experience using qualitative research techniques. Denhart (2008) describes three tenets of disability theory that she employed in conducting a qualitative study of the barriers that students with learning disabilities face in higher education: (a) meaning is constructed within a social context, (b) disability is a normal variation, and (c) it takes the voice of people with disabilities to deconstruct the experience (Higgins, 1992; McDermott & Varenne, 1999; Scotch & Schriner, 1997).

The first concept is rooted in the idea that disability must be understood within its social context as it is a product of social interplay between the person, the disability, as well as the social and physical community (McDermott & Varenne, 1999). The second tenet posits that impairments are normal all along the life span (Scotch & Schriner, 1997) and should not be construed as abnormal experiences. The last tenet and one critical to this study is that there is value in asking people with disabilities about their experiences (Hahn, 1985). The voice of people with disabilities must be included as active participants and as researchers to decode the meaning of disability and its impact in research (Higgins, 1992).

Summary of Disability Research Principles

I have chosen to focus on Hahn (1985), the work of the NCD, and the qualitative lens of disability theory to elucidate the disability research principles under which quite a bit of current research operates. Those principles include examining the interaction of the individual with the barriers that he/she faces in the environment, which leads to the designation of minority status and the need for public policies. Other principles include gathering accurate descriptive data regarding the status of the disability community through a variety of methods, organizing research around the four goals of the ADA, and implementing the principles of *Nothing About Us Without Us* (Charlton, 1998) in all areas of research. Following these principles gives people with disabilities power over and a voice with which to describe and make meaning about their experiences. While the focus of Hahn (1985) remains firmly entrenched in detailing and fixing the interaction between the individual and the environment, the question remains: What do people with disabilities tell themselves about meeting all of these challenges? Do those thoughts create their own barriers or support working toward change?

Research on adjustment to disability has tried to understand the psychosocial response to disability in a number of ways that will be explored in the review of literature on adjustment in the Internal Barriers to Work section. However, this body of research is beginning to advance new ways to research adjustment to disability that seek to understand the process as a much more dynamic one. Parker, Schaller, and Hansmann (2003) discuss the chaos and complexity theory of adjustment and call for both quantitative and qualitative research to look at the chaotic, nonlinear, abrupt, and the "cyclical or seasonal" (p. 240) behavior associated with adjustment to disability. Specifically, they call for quantitative researchers to gather information on adjustment over time among individuals. For qualitative researchers, Parker et al. suggest that sampling over time will yield rich descriptions of adjustment at the edge of chaos.

External barriers and the environment in which people with disabilities live provide an important foundation from which to look at internal barriers. Reaction to and dealing with those barriers often create the decisions people with disabilities make about coping with the world (Bandura, 1986). External and internal (or social and individual) barriers are important to research and change through increased knowledge.

Internal Barriers to Work

Internal barriers that impact people with disabilities' decision to work include adjusting to the disability (Dembo, Leviton, & Wright, as cited in Livneh & Antonak, 1997; Kendall & Buys, 1998; Parker et al., 2003; Smart, 2001; Wright, 1983), attitudes toward one's own disability (Charmaz, 1995; Graf, Marini, & Blankenship, 2009; Li & Moore, 1998; Marinelli & Dell Orto, 1984; Morris, 1991; Oliver, 1996; Vash, 1981; Weinberg, 1988; Wright, 1983), career barriers (Albert & Luzzo, 1999; Fabian, Beveridge, & Ethridge, 2009; Fitch, 2002; Kosciulek, 2004; Lent, Brown, & Hackett, 2000; Lent, Hackett, & Brown, 1996; Livneh, 2001; Wright, 1983), and health access and outcomes (Bolton, 1983; Cunningham & Hadley, 2008; Hanson, Neuman, & Voris, 2003; Kaye, 2009; Li & Moore, 1998; Sack, 2010).

Adjusting to Disability

A large body of research exists that examines the phenomenon of humans experiencing chronic illnesses and disabilities; that is, how does a change in function affect their "physical, psychological, social, vocational and economic" lives (Livneh & Antonak, 1997, p. 26)? This research is called adjustment to disability research or, in more recent times, adaptation or response to disability (Smart, 2001). The overall goal of adjustment/adaptation to disability can be summarized as successfully coping with and integrating a disability into one's core identity (Smart, 2001). Smart (2001) describes the literature on the successful adjustment to disability as having "a positive response as someone who is flexible, demonstrates active mastery, rallies social support and is capable of tolerating a degree of ambiguity" (p. 231).

Adjustment research has focused on trying to determine how individuals and groups make sense of their disability: What steps or process did they use, are there commonalities, and can such adjustments be predicted based on specific factors? The research has looked at the impact of disability on both individuals and groups of people who share a specific disability (Shontz, 1975).

Historical View of Adjustment Models

The following information on adjustment or adaptations models is presented as a historical look at the models that the rehabilitation field has developed, changed, been discarded, and built upon in the quest to understand how people adapt or adjust to disability. One of the most significant barriers to successful rehabilitation has been shown to be poor adaptation or adjustment (Putman & Adams, 1992).

Garrett and Levine (1962) studied the intersection of the person and the disability with the belief that different disabilities caused different reactions from individuals. Thus, deafness might cause a different reaction in people than say a spinal cord injury because different functions are affected. The psychological make up of each individual was considered along with the medical condition they were confronting.

Conversely, Wright (1983) put forth a set of principles that spoke to the common elements under which all people coped with their disability in the preface to the second edition of her book *Physical Disability, A Psychosocial Approach*. Wright incorporated human rights issues into her work and cautioned against the use of group information to predict individual adjustment patterns. Wright warned that one cannot reliably draw predictor variables to describe an individual’s progress toward adjustment from group study. In the end, while individuals are part of a variety of groups (e.g., family, others with same disability, community, etc.), each person creates her/his own path to adjustment.

Dembo, Leviton, and Wright (1956) conducted some of the first research on the social-psychological effects of disability and acceptance after World War II. Most of the pioneering work was conducted using qualitative research techniques such as interviews and role plays (Dembo et al., 1956). The researchers asked both those with injuries (amputations) and those without injuries a series of questions that examined the relationship between the two groups. The underlying relationship that describes the “social-psychological problems of the injured [can be described as] to consider someone unfortunate-to be considered as unfortunate” (Dembo et al., 1956, p. 19). In other words, in the relationship that bests describes the dynamic around disability is where one is viewing the other as unfortunate and the other is considered unfortunate. This creates an unequal relationship dynamic that can impact all interactions between the two (Dembo et al., 1956).

Dembo et al. (1956) explored the various responses that both those with injuries and those with out injuries experienced in dealing with the disability and focused on the degree of change in value for the individual with a disability. The research conducted explored a variety of ways to help the individual with a disability increase his or her view of his or her value (Dembo et al., 1956). Coming to terms with one’s own limitations, seeing oneself as having value because of other personal characteristics, experiencing success in other areas of life that diminish the physical loss, accepting that change in physical appearance does not diminish the individual and having control over his or her life are all part of the acceptance of loss process (Dembo et al., 1956).

Livneh and Antonak (1997) reported the Dembo et al. (1956) research as a coping model for successful adjustment to disability that looked at six characteristics:

> (1) emphasizing what the person can do; (2) assuming an active role in shaping one's life; (3) recognizing personal accomplishments; (4) successfully managing negative life experiences; (5) reducing limitations through changes in the physical and social environment; and (6) participating in and enjoying valued activities. (p. 6)

While there are many aspects under each of these characteristics that are examined throughout the adjustment literature, these six items represent the basic outcomes of successful adjustment.

Cognitive Restructuring

Wright (1983) defined acceptance of disability as "viewing the value loss as *non-devaluing* [emphasis added]" (p. 163). Nondevaluing of the individual despite a disability is the underlying foundation to Wright's work, and the author wrote extensively on the process individuals go through to get to the point of accepting their disability. Wright's theory of cognitive restructuring or values shifting as a response to disability describes four points. First, the person understands that she/he is more than just her/his disability. She/he has other talents and skills that can be used to create a wealth of responses to her/his environment. Second, she/he understands that she/he is more than just her/his body. She/he has self-worth outside her/his body or appearance, which is a big adjustment to make given American culture. Third, she/he does not deny the disability but sees it as a realistic part of her/his life, but only a part, not the sum of her/his life. Fourth, she/he can see her/his assets and focus on those rather than comparing herself/himself to others or focusing on just her/his losses (Wright, 1983).

Adjustment Variables

With the adjustment goals identified, researchers began to investigate variables that impacted adjustment to disability and built models for how such adjustment occurs. Livneh and Antonak (1997) use the term, chronic illnesses and disabilities (CID), as an umbrella term, acknowledging there are differences between those who acquire a congenital disability; those who have a sudden or traumatic disability that is generally stable after the initial onset; and those whose conditions are chronic and fluctuating, often eventually worsening or leading to death. The adjustment process has been found to be somewhat different in each group (Li & Moore, 1998; Livneh & Antonak, 1997; Smart, 2001; Wright, 1983).

The difference among congenital, traumatic, and chronic disabilities is a key concept for it defines the scope of the evolution toward adjustment. For those who are born with a disability or acquire it in early childhood, the disability is incorporated into their identity as they grow up. Those individuals have little or no experience of life without their disability so the issue they must face is the present stigma and difficulties attached to having a disability (Smart, 2001). Those whose disability occurs suddenly or traumatically a bit later in life must digest the changes in their self-concept; thus, they are dealing with the loss of function as well as stigma and current difficulties. Those whose disability is chronic and unstable are coping with the uncertainty of tomorrow as well as the stigma and difficulties of having a disability. These are important distinctions and may be especially relevant to a study about the decisions that people with disabilities make about work.

Livneh and Antonak (1997) reviewed the adjustment literature with an eye toward the variables that can affect adjustment to disability. Those include "disability or medical related variables, sociodemographic characteristics, personality attributes and traits, and features of the environment" (p. 153). Disability variables include the type and severity, pain, visibility, and treatment. Sociodemographic variables refer to the gender, age, ethnicity, socioeconomic status, religion, education, marriage status, and job status a person holds. Personality traits that impact the adjustment include self-concept, self-efficacy, self-control, resilience, personal attitudes about disability, ability to tolerate pain, cognitive skills, and coping styles. Environment variables are many. Livneh (2001) lists them as,

> sensory and social isolation, restricted mobility, architectural barriers, attitudinal barriers (degree of social stigma), frequency and duration of hospitalizations, available social support systems, available economic and institutional support (medical services, educational programs, and technological supports, political and religious groups), financial supports, living conditions, availability of job opportunities and accessibility of work sites. (p. 154)

Stages or Recurrent Processes of Adjustment

In contrast to current literature, which describes adjustment as overlapping stages, Livneh and Antonak (1997) described a stage approach as a method to observe the process that people go through when adjusting to a disability. This approach is based on the work of Kubler-Ross (1969) and Shontz (1975). Kubler-Ross studied people who were dying and found that there were five stages that individuals often experienced. Those stages are denial and isolation, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). Shontz does not cite Kubler-Ross in his work but one can see the influence. Shontz identified the stages that an individual often goes through to adjust to a different body image and changes in function. Those seven stages are shock, panic and disorganization, retreat into denial, internal and external anger, and finally, acknowledgment that leads to acceptance (Shontz, 1975). Both Kubler-Ross and Schontz note that individuals are likely to go back and forth between stages over an extended period of time. Livneh and Antonak restate Schontz's stages as "shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement and adjustment" (p. 20). Livneh and Antonak also posit that one stage should be successfully completed before moving on to the next one.

Trieschmann (1988) disagrees with the stages approach. In her review of a number of research projects and papers, written between 1954 and 1981, that examined the stages of adjustment people with spinal cord and other types of disabilities experienced, she raises the concern that the belief in stages and mourning may have biased researchers to look for such reactions to a disability. Trieschmann states that the descriptions are "based on the clinical impressions of the particular author, and that no data have been presented in any of these articles to demonstrate reliably and validly the existence, sequence, or duration of these stages" (p. 69). She posits that professionals using a stage model may be putting people with disabilities in a catch-22 position by implying something is wrong if one does not have a psychological reaction to a disability.

Using antidotes from several individuals with spinal cord injuries, Trieschmann (1988) shows the progression of hope as related to the life options that are available. One individual, injured in World War II, stated that he did go through a deep depression after acquiring his spinal cord injury because he was told that he would be “dependent for the rest of his life with no hope of marrying, having a family and would die in two years” (Trieschmann, 1988, p. 71). Yet, a study completed in 1967 of a group of persons with spinal cord injuries indicated much less depression (Taylor, 1967). An explanation of the different reactions offered by Trieschmann was that people with spinal cord injuries had far more options (in 1967 as opposed to 1944) and, thus, hope for a life that they could create.

Kendall and Buys (1998) also take issue with the stages approach. They fear that professionals will focus on the model, expect individuals to follow it, and label those who do not as abnormal. This does not serve the client well (Kendall & Buys, 1998). After reviewing a number of models, Kendall and Buys posit that most models have three stages in common: initial shock, followed by stress and anxiety, which leads to acceptance.

Rather than a step-by-step progression through the stages, Kendall and Buys (1998) describe a “recurrent process” (p. 16). That is to say, adjustment is messy. People go back and forth between the various steps that recur based on changes in the disability or the environment or upon receipt of new information about either. Kendall and Buys build the recurrent process on the schema model set by Beck (1967). Schemas are defined as beliefs we hold about ourselves, others, and the environment. These schemas must be recreated to accept changes in our world, including physical and mental changes. Often individuals will continue to hold faulty schemas (causing denial and/or depression) until they can adequately reconstruct a schema about themselves and the change that has occurred (Kendall & Buys, 1998). This reconstruction requires new information that can lead to a more realistic view of one’s life. Because this is an iterative process, people move back and forth between extreme positions until they reach an equilibrium state of acceptance (Kendall & Buys, 1998). This repetitive process can be represented as circular or pendulum-like in motion (Livneh, 2001).

Further, Livneh (2001) collapses the stages model from eight categories to three. The categories are “Antecedents, Process and Outcomes” (p. 152), each having a number of outcomes and criteria that are organized around the QOL construct of which employment is one aspect. This model still outlines a step-by-step process that leads to adjustment.

Adjustment Models Become Flexible

Livneh (2001) acknowledged that the literature on adjustment could be captured among three models. The first two, stages and recurrent, have been discussed above. Livneh and Antonak (1997) argue the need for a model that has discrete steps as being useful to research. However, there is room for a more fluid and dynamic view of adjustment that emphasizes the individual process rather than generalizing an adjustment process across the all persons with disabilities. Such a model would be more in keeping with the independent living construct that emphasizes consumer self-direction and acknowledges the large impact of the environment around the individual.

The third model appears to incorporate more of the independent living philosophy. Livneh (2001) described it as an "idiosyncratic or individually-folding model" (p. 159). This model is based on the unique reactions of each individual; so unique as to defy the development of any sequence of adaptations that could be generalized to the disability population as a whole. This appears to be a more contemporary modern view that incorporates consumer choice and direction.

Catastrophe, Chaos, and Complexity Theories

As can be guessed by the names of these theories, Parker et al. (2003) call for new adjustment/adaptation models that are "able to explain complex, multidimensional, nonlinear and discontinuous behaviors" (p. 236) that occur in the adjustment process. The characteristics listed above are good descriptors of what happens when individuals go through the process of adjusting their self-concept to include all that having a disability entails. It makes sense to develop models that try to capture that essence. Catastrophe, chaos, and complexity theories are based on "mathematics, physics, biology, economics and psychology" (Parker et al., 2003, p. 234).

Catastrophe theory (Parker et al., 2003) looks at the impact that one or more control factors have on a specific dimension as a way to show why some individuals go through the adjustment period smoothly and others do not. Parker et al. (2003)

used the example of catastrophic reaction as the outcome measure to illustrate this theory. High levels of stress and psychosocial instability were the two factors impacting the reaction. Using a pictorial model, the authors showed that as levels of stress (from other sources) increased and psychosocial instability (such as marital issues or lack of family support) occurred, adjustment to disability could be predicted to slow down or stop completely.

Chaos theories (Parker et al., 2003), which include fractals and complexity systems, are even more interesting. Chaos theory is "capable of addressing, nonlinear, random and unpredictable events over time" (Parker et al., 2003, p. 237). One of the hallmarks of chaos theory is the butterfly effect, which posits that when something small happens in one place its effect is much larger in another. The butterfly effect could be used to describe the effect of how a change in eyesight, even a small one, could lead to much larger impacts elsewhere in the person's life such as transportation, information gathering, etc. The process is chaotic in that it may be different for each person in a seemingly similar situation and may lead to many other impacts in a random, nonlinear manner. Each person's process is distinct from other individuals' processes.

Fractals are found wherever chaos, turbulence, and disorder exists (Parker et al., 2003) and indicates an object (or event) that lies between the three dimensions in which we experience our world. Drodge (2002) relates fractals to career counseling.

> Knowing that a small shift in a variable can alter the pattern [of one's career] is a powerful metaphor for seeing the possibility of human change. Altering some aspect of one's cognitions, feelings, or behavior can trigger a cascade of changes resulting in a more positive career, a new fractal of living. (p. 59)

Fractals are a way of elegantly expressing a model for the hoped-for outcome.

Complex systems are a systems approach to chaos, which may seem contradictory. However, out of chaos comes a different order. Parker et al. (2003) indicate that complex systems refer to open and closed systems. Stages or recurrent models of adjustment are closed systems that generally come to a complete standstill. Open systems, such as chaos, operate on the edges of chaos and are more likely to bring in new information or events. Chaos is disorganizing, but it leads to change in the system. The saying, things have to fall apart before they can get better, is a way of describing complex systems and chaos. Parker et al. uses the example of a breadwinner whose recently acquired disability brings chaos to the family as they each struggle to redefine their role in the family system. There is chaos during the struggle but the outcome is a new (and often better) order in the system.

Catastrophe, chaos, and complexity theories can be useful for counselors working with people with disabilities who are in the process of adjusting or adapting to their physical, mental, or emotional changes. Whatever the outcome, the counselor’s role is to help the individual navigate the chaotic process of change as a normal part of life. Drodge (2002) defines normalizing as engaging the client in a “rational discussion about the natural, widespread state of uncertainty in human affairs, the world and perhaps the universe” (p. 58). If the counselor can see chaos as a pathway to change and help the client experience it in that manner, both will see chaos as a normal reaction to change that is not to be avoided but directly engaged (Drodge, 2002). Perfecting the skill of riding the waves of change will lead to better adaptive behaviors rather than pathology (Parker et al., 2003).

Attitudes Toward Self as an Internal Barrier

If a person with a disability has absorbed society's negative beliefs about the disabled, then clearly this attitude could be a barrier to work. DeLoach and Greer (1981) wrote that society's attitudes toward people with disabilities could be more disabling than the actual medical condition. It is difficult to develop a positive view of oneself when family, medical personnel, and society devalue the individual because he/she is not physically normal (DeLoach & Greer, 1981). Meyerson (1963) observed that psychological maladjustment to disability occurs when the individual accepts the negative views about disability from others. Weinberg (1988) studied people's feelings about their disability using the interviews of 30 people with disabilities, published autobiographies of people with disabilities, and published essays or interviews of people with disabilities. The researchers grouped reactions to disability among a continuum of three points: bitter, accepting, and transcending based on the ability to achieve the goals they set for themselves. Weinberg observed that the bitterness group fit with society's beliefs about disability. These individuals "believed that disability is the worst thing that had happened to them" (p. 149). Inability to live independently, work, and/or marry led them to view their lives as tragic. People with disabilities whose reactions coalesced around accepting their disability came to see their limitations as merely an inconvenience. Mostly, individuals with disabilities were able to achieve their goals, but when unable to attain a goal, then momentary bitterness could surface. Finally, transcending the disability is what happens when people embraced their disability: when they realized they would be different without their disability and did not want that difference. Weinberg suggests that society might find these people "startling" (p. 151).

Vash (1981) posited that devaluation based on disability was the foundation for psychological problems that could arise upon acquiring a disability; however, acceptance was the solution. Devaluation is the process that happens when others perceive a person with a disability as less than or different in a negative way because of that disability. The type and severity of the disability makes a difference in the scope of work needed to adjust. However, learning to accept the disability in the long run aids in the adjustment. Vash went on to describe the transcendence of disability as coming to the point of seeing the disability as aiding in one's personal growth. When a person can embrace the disability as a positive part of her/his personal growth as a human, the individual has transcended the limitation. Weinberg (1988) and Vash both demonstrate this concept by reporting on individuals with disabilities who would not give up their disability if a cure was available.

Charmaz (1995) examined how chronic illness and disability affect individuals' views of themselves and their goals for the present and the future. She looks at the model of adapting to changes caused by illness and disability. As the individual grows to accept the impairment, he or she starts the process of changing his or her life in ways that are acceptable. "Adapting shades into acceptance" (p. 657). Charmaz suggests there is a flow to living with illness and disability. "After long years of ignoring, minimizing, struggling against and reconciling themselves to illness, they adapt as they regain a sense of wholeness, of unity of body and self in the face of loss" (p. 658). This description could be seen as adding to the details of the continuum that Weinberg (1988) describes. There is a flow to living with the disability as it changes or as life circumstances change. The challenge is to be able to adjust to changes in functional capacities or one's life circumstances but not consumed by those changes.

Jenny Morris (1991) wrote a book on prejudice and disability that examines the intersection of how people with disabilities view themselves and how others view them. A feminist who acquired a disability a bit later in life, she wrote about the experience from a political point of view. "Disabled people are not normal in the eyes of non-disabled people" (p. 7). She defines normal as what society has defined as acceptable and desirable. She acknowledges that people with disabilities are physically different and that those physical and intellectual differences can mean that there are other needs that must be attended to for the person to have a good QOL. The point Morris makes quite elegantly is that society drenches people who have disabilities with devalued messages based on differences that become absorbed, if those messages are not questioned.

> One of the biggest problems for disabled people is that all these undermining messages, which we receive every day of our lives from the non-disabled world which surrounds us, become part of our thinking about ourselves and/or our thinking about other people. (p. 22)

They believe our lives are not worth living because of a disability (Morris, 1991).

Oliver (1996) also speaks to the connection between disability acceptance and understanding the impact that society and its inherent physical barriers impose on people with disabilities. He describes his own path to understanding his disability as it intersects with the environment and values of society. By confronting those devaluing messages and focusing on changing the environment, he came to understand his disability within a political dimension as well as a personal one.

Up to this point I have been describing individual models and responses to attitudes towards one's own disability. By explicating the impact of society's negative view as well as the problems caused by political decisions (e.g., the cost of including people with disabilities) and the built environment, Morris (1991) and Oliver (1996) point to the impact that society's beliefs have as extremely limiting to the individual.

Li and Moore (1998) conducted a survey of 1,266 adults with disabilities in the United States in order to examine the relationship between acceptance of disability and a host of demographic variables (e.g., gender, age, education, etc.), the disability itself, and several psychosocial factors such as self-esteem and social support during an adjustment period. Their results echoed earlier studies that showed there was a strong connection between self-esteem and acceptance of disability. Both Wright (1983) and DeLoach and Greer (1981) suggest that adjusting well to a disability will assist in integrating in society. Successfully incorporating one's disability into one's self-image and joining the disability movement with pride may be needed for empowerment that leads to integration into society (Li & Moore, 1998).

Li and Moore (1998) linked their findings about the formation of self-concept and acceptance of disability to the social environment. Stigma and prejudice based on disability create social and physical barriers to participation. Some individuals found these social barriers too difficult to overcome. "The more they believed they would be devalued and discriminated against the less likely they were to accept disability" (p. 22).

To look at a much more recent study about acceptance of disability, Graf et al. (2009) conducted a qualitative study of 78 individuals with spinal cord injuries who were invited to fill out a demographic survey online and type 100 words about living with a disability. They found that 27% of the group felt that the negative attitudes of people without disabilities impacted self-esteem. These attitudes were displayed through "unequal treatment, unwanted attention, being ignored or patronized, and the spread affect as some non-disabled persons believed participants with disabilities also had a mental disability" (Graf et al., 2009, Discussion section, para. 55).

Attitudes are both an internal and external barrier. In this section, my goal was to establish that external attitudes often lead to the need to become conscious of and reject those internally absorbed negative stereotypes as one engages in the process of adapting or adjusting one's self-esteem to include disability. As a summary of the internal attitudes effect, Patston (2007) writes about dysfunctionphobia, a term he has created that is defined as a fear of loss of function:

> We are all influenced by the values, beliefs and attitudes that condition us from birth. Often these are subconscious and we have little awareness of them, but most often our response to impairment and disability is negative. It is not just non disabled people who exhibit dysfunctionphobia—many people who are impaired either fear or dislike their own functional deficit and/or the possibility of further loss of function. (p. 1627)

Career Barriers

While Bandura (1997) was not speaking directly about people with disabilities, he certainly included their issues when writing about the difficulties of choosing a career path. Bandura (1997) posited that people had to think about their capabilities, their interests, the short and long term prospects for various occupations, how accessible potential careers might be, and, importantly, the identity they wanted to establish through work.

It is important to look at how adjustment impacts the opportunity for work. It is clear that people with disabilities are more successful when they have incorporated their disability into their self-concept. "The individual's self concept and perceived ability to perform an occupation are critical" (Marinelli & Dell Orto, 1984, p. 25) to the successful career development of persons with disabilities. From that foundation, they are better able to grapple with the challenges of work. While Bandura's statement above was written about people without disabilities, it rings true for people with disabilities.

As indicated earlier, there is a difference in this task depending on the timing and severity of the disability (Livneh & Antonak, 1997; Smart, 2001; Wright, 1983). For those who acquire the disability at birth or as a young child, the disability is a part of their self-concept. They have no knowledge of life without a disability. Those who receive a disability later in life must process the changes that occur in every aspect of their lives. If the disability is stable, they are dealing with letting go of the past. If the disability is a chronic disability that changes over time, then it is a much more difficult process. Not only is the individual processing the current change but is unsure of what might happen next in the course of the unstable disability. Regardless of when the individual receives his or her disability, developing a career path or changing it requires confronting lowered expectations and negative attitudes.

For individuals who acquire a disability at birth or early childhood, the educational system can often be a barrier to figuring out a career path. Hehir (2002) cites ableism attitudes throughout the educational system that can cause students with disabilities and their families to focus on changing the disability. Rather than working with the assets that the student has, clinicians, teachers, and others are focused on changing the disability so that the student can learn and do in the same manner as students without disabilities. This misdirects students' energy away from exploring what they can do, given their assets. Hehir quotes Greg Smith, activist and talk show host, in defining "ableism as the devaluation and disregard of people with disabilities" (Smith, 2001, as cited in Hehir, 2002, p. 16).

When the environment is welcoming (e.g., accessible facilities, interpreters, tutors, positive attitudes from teachers, etc.), when students with disabilities are given clear feedback about their skill mastery (Hehir, 2002), and when adults around them are pointing out what they can do as opposed to what they cannot (Smart, 2001), students are more able to clearly consider vocational goals.

Disabilities are an influence on the aspirations of youth and young adults in the realm of setting career goals (Feldman, 2004). I would argue that disabilities (the actual physical, emotional, or cognitive limitations) also impact the adjusted career goals of adults who acquire a disability during their working years. Saunders, Leahy, and Frank (2000) speaks to the negative effect lowered aspiration levels have on vocational choices. Lowered aspirations occur when children and youth with disabilities are unable to see themselves in a variety of work settings and are continually exposed to negative beliefs from able-bodied adults and children around them about what he or she can do. Kaye (2009) found that adults with disabilities may have the same lowered aspiration experience but from different sources (e.g., health care professionals, government benefits workers, and family members).

While there are numerous career and vocational development theories to explain how and why people make the career choices that they do, I will narrow my focus to social cognitive career theory (SCCT) (Lent, 2000; Lent, 1996) since self-efficacy is a major focus of my research project. SCCT follows Bandura's social cognitive theory by incorporating self-efficacy, outcome expectations, and goals into a career theory. Lent (1996) propose that people make career choices based on what they think they can do (irrespective of skill level), their expectations of being successful and the intentions or goals that they set for themselves. Self-efficacy and expectations are impacted by beliefs and experiences while goals "related intimately to self efficacy and outcome expectations" (Lent, 1996, para. 9).

Albert and Luzzo (1999) posit that there are "*perceived* [emphasis added]" (p. 431) career barriers that should be considered in SCCT. Perceived barriers are barriers that the individual believes to be in place, regardless of reality. These barriers do directly affect the career decisions of an individual (Albert & Luzzo, 1999). While the authors referred to studies conducted with women and minorities that indicated they would not choose a career if they felt the barriers to be insurmountable, the authors did not refer specifically to persons with disabilities. However, Albert and Luzzo did indicate that some people do not get to make career decisions under the best circumstances. Financial considerations, educational limitations, little family support, and other conditions such as discrimination do inhibit career choices (Albert & Luzzo, 1999). Certainly this is applicable to those who acquire a disability at birth or during childhood. Albert and Luzzo agree with Corbiere, Mercier, and Lesage (2004) that it is both self-efficacy and career barriers that significantly influence the choice of careers and actually pursuing a job.

Lent (2000) take up the issue of career barriers and SCCT by equating barriers to environmental effects, which is one of the three variables in Bandura's triadic reciprocality model. "Physical attributes features of the environment and particular learning experiences influence career-related interests and choice behavior" (p. 36). SCCT posits that career decisions are impacted by objective factors such as the quality of education or financial supports and perceived environmental factors such as opportunities, barriers, and resources available to the individual (Lent, 2000). Barriers are defined as a negative influence, something that hinders development. However, Lent (2000) indicate that it is important to examine how the individual interprets and acts (or not) on the barriers that he/she encounters. In other words, the individual bears some responsibility for how he/she perceives and responds to those barriers. Interestingly, career barriers are discussed throughout the article as barriers that may confront women and minorities as well as anyone who has experienced oppression without naming people with disabilities. In their conclusion, Lent (2000) call for more research on individuals' beliefs about what they will encounter in pursuing a particular career path.

Perhaps as a response to the Lent (2000) research direction, a study to examine career barriers was conducted with 99 individuals with disabilities attending orientation programs conducted by the Maryland Division of Rehabilitation Services (Fabian et al., 2009). Using a shortened version of the Career Barriers Inventory, the investigators found that, for this sample, the majority perceived that there were multiple career barriers. The top barriers included "lack of career information or inadequate career decision making skills," "my physical health," and "losing my health insurance benefits" (p. 46). In addition to the inventory, the investigators also collected demographic information including a work history, if any. While this is a small sample, Fabian et al. (2009) found that the perceived barriers to work rating increased the longer the individual was unemployed. Alternately, the 20 who were working (but seeking better employment) rated career barriers lower. Clearly, being in the workforce helped participants see career barriers in a more realistic manner.

Kosciulek (2004) offers another view of challenges to work that people with disabilities face. He references a presentation by Bruyere et al. (2002) in which she presented data that indicated few work skills, poverty, and underemployment or unemployment were the causes of poor vocational adjustment. In addition, Kosciulek addressed the construct of "negative worker self concept" (p. 41) that can be experienced by those who grew up with a disability and had few, if any, opportunities to create a vocational identity. It also impacts those who acquire a disability later in life as negative worker self-confidence can be a product of negative societal attitudes toward people with disabilities.

Castification is a third barrier that Kosciulek (2004) identified, which states that some barriers people with disabilities face come from service providers and organizations who use functional limitations to determine who gets what services (i.e., eligibility interventions, etc.). Such “paternalistic” (p. 42) behavior by service providers allows them to direct their clients’ services rather than allowing the client to assert his or her needs. This behavior does nothing to foster empowerment (Kosciulek, 2004) and self-efficacy.

Whether one is born with the disability or acquires it later in life, negative social attitudes toward disability may be equally important as the disability itself in shaping the choices that people with disabilities make (Kosciulek, 2004). It seems a miracle that people with disabilities are employed at all given the daunting barriers of negative attitudes in education, lack of positive career development expectations, and perceived career barriers. Add the castification issues that occur in some disability related helping programs and it becomes easier to see why some people with disabilities either do not try to access work or give up.

Health Care Access and Outcomes

Health status plays an important role when thinking about employment. Bolton (1983) and Fabian et al. (2009) mention high correlations between self-perceived good health status and employment in studies both authors conducted with people with disabilities. Bolton's study examined psychosocial factors that influenced vocational outcomes (e.g., employment) among 211 former vocational clients. Fabian et al. explored the perception of barriers to career choice among 99 persons with disabilities who attended an orientation session for vocational rehabilitation services.

However, the Kaiser Family Foundation reported in 2003 that "adults living with disabilities face considerable challenges in the health care system" (Hanson et al., 2003, p. 22). Researchers conducted a national random telephone survey on health care experiences with 1,505 adults, aged 18 to 64, who fell into one of five insurance categories: private insurance, Medicaid, Medicare, Medicaid and Medicare (dual eligible), and no insurance. Respondents experienced a wide variety of permanent physical and/or mental disabilities. Researchers found that those without insurance and those respondents on Medicare often delayed or went without health care, equipment, or preventative care. The pharmaceutical needs of Medicare recipients were met, however. Those without insurance often delayed or went without prescriptions. Medicare also caused significant reimbursement problems for recipients trying to access other services such as "mental-health care, dental care, equipment and home health services" (Hanson et al., 2003, p. 22). Medicaid recipients did receive a wide array of services at a low copay cost but were subject to the whims of state legislatures' budget cuts during lean times. While private insurers seemed to be the most generous, high copay amounts and lack of specific services that people with disabilities needed (e.g., personal care services) created barriers to health care that led to a good health status.

Cunningham and Hadley (2008) conducted a study to look at the impact of physician income, ownership, and size of practice on willingness to serve adult Medicaid recipients and the uninsured (charity work). While the study did not break out specific groups other than adults, it is assumed that people with disabilities were automatically included in the definition of adult Medicaid recipient as well as the uninsured. The authors state that a reduction in the number of physicians treating Medicaid and charity patients can be traced to financial issues and changes in the ways a practice is managed (Cunningham & Hadley, 2008, p. 91). The authors' research found that higher reimbursement rates increased physicians' participation. This finding did not correspond with increased consumer use of in-office physicians, which could be attributed to consumer characteristics such as willingness to seek out care (Cunningham & Hadley, 2008). Cunningham and Hadley found that physicians whose income had decreased and those who changed their practice arrangements (small or solo practices to large group practices with salaried doctors) were less likely to take Medicaid recipients and the uninsured.

The *New York Times* (Sack, 2010) reported that Medicaid reimbursements were only 72% of Medicare reimbursement rates in 2008. Sack reported that Medicare rates are lower than the private insurance rates, which underscores the problem with Medicaid reimbursement. Sack pointed out that President Obama and the Senate Republicans have agreed on the point that reimbursements may have to increase in order to keep physicians' services available to Medicaid recipients. With so many states in dire fiscal straits, Medicaid services and rates have been on the budget chopping block. For example, Michigan not only cut reimbursement rates by 8% but eliminated dental, vision, podiatry, hearing, and chiropractic services for adults (Sack, 2010).

With health care practitioners increasingly not taking on additional Medicaid recipients and/or dropping existing consumers, difficulty in obtaining needed services, equipment, and/or prescriptions, as well as accessing related services such as dental or mental health counseling, people with disabilities' health may be declining as a result. Li and Moore (1998) found that chronic pain or multiple disabilities became a barrier to successful attitude adjustment which can, in turn, affect one's judgment about being able to work. In the face of declining access to health services, an individual's declining health status can be seen as a primary barrier to work.

External Barriers to Work

> I—and most disabled Americans have been exhorted that if we work hard and "overcome" our disabilities, we can achieve our dreams. . . . It is a lie. The truth is that the major obstacles we must overcome are pervasive social prejudice, systemic segregation, and institutionalized discrimination. Government social-service policies, in particular, have forced millions of us to the margins of society. Those policies have made the American Dream inaccessible to many disabled persons. (Longmore, 2003, p. 230)

As Longmore (2003) points out, there are many barriers that people with disabilities face on the road to employment. Those include the attitudes of others, including employers; physical barriers; policy barriers; and a host of specific employment barriers such as transportation, housing, education, accommodation and access to assistive technology, corporate culture issues, and inadequate or erroneous counseling on a variety of issues.

Attitudes of Others

Yuker and Block (1979) defined attitude as "an emotional reaction to something or someone" (p. 17). The authors described an attitude as having three components. The first is the emotional component of being either positive or negative. The second is a belief component that may or may not be rooted in truth or fact. The third is an action component; the individual usually acts based on emotion and belief. If one likes someone or something, one moves toward it. If one does not like something, one will move away or avoid it (Yuker & Block, 1979). Thus, if someone (or group) is negatively perceived as being different and stereotypes or beliefs about that difference are held by the perceiver, then the perceiver moves to exclude or ignore the individual or group.

Humans tend to have a negative view about people who are different. Yuker and Block (1979) state that the "problem is not so much the obvious physical difference but the fact that the perceived difference often carries with it some degree of perceived inferiority" (p. 21). People with disabilities whose functional limitations cause them to accomplish daily and life tasks in a different manner are looked at negatively and often avoided (Higgins, 1992; Smart 2001; Wright, 1983). Wright (1983) describes this as "difficulty stem(ming) from the expectations that a person must eat a certain way or dress a certain way, *ways of behaving prescribed by society* [emphasis added]" (p. 6). When the expectations of society are narrowly defined (e.g., must be able to walk, talk, see, hear, and learn in a certain way) and the physical environment also reflects that narrow definition (e.g., must be able to use steps, see and read directions and signs, hear signals, and use high counters and narrow doors), then people who do not fit the expectations are excluded. Given limited information or contact, people often let the functional limitation be the most salient point about the individual. Thus, the limitation in one area of function spread to other functions. Wright called this the negative spread effect that leads to assumptions about other personality traits based on the functional limitation.

Wright (1983) noticed that attitudes toward people with disabilities were similar to other minority groups. That is, lowered expectations and preconceived ideas based on group stereotypes were attributed to individual members of the groups (Yuker & Block, 1979). The lack of context—knowing the individual personally—contributes to the negative spread effect. When an able-bodied person gets to know someone with a disability, that contact allows the able-bodied person to correct stereotypes and often leads to the diminishing of the disability to the point it is not noticed. Other personal characteristics, skills, and knowledge come into view (Higgins, 1992; Smart, 2001; Wright, 1983), and the person with a disability becomes an individual. Yuker and Block (1979) offer another view of context that is based on society's view of work. As work becomes less physical, the view of disability becomes less negative.

Yuker and Block (1979) identified status as an important concept in attitudes. Those who were perceived to have status through job title, socio-economic means, education, or other measures were perceived more positively. Those with status were perceived to have more opportunity and perceived more positively. People with disabilities are perceived as devalued, which may lead to less opportunity being available to them (Yuker & Block, 1979).

Smart (2001) lists 10 sources of prejudices toward people with disabilities, which are many of the same prejudices aimed at other minority groups. The first source is "economic threat" (p. 76): the fear that the individual will be a burden on the family or society and consume scarce resources with no corresponding contribution. Second is the "safety threat" (p. 83): Will people with disabilities become violent, destructive, aggressive, or antisocial and threaten the physical safety of others or will they be contagious or contaminate the environment? "Ambiguity of the disability" (p. 85) is the third threat: stereotypes based on lack of information or context lead able-bodied people to guess about how to interact with people with disabilities. This is an uncomfortable state that leads to devaluing the person with a disability. Fourth, the "salience of the disability" (p. 88) refers to what Wright (1983) and others describe as the tendency to see the individual's disability as the primary characteristic of the person. Fifth is the "spread of the disability" (p. 90), which was discussed earlier. These prejudices can be ascribed to other minority groups as well (Smart, 2001). A person's gender, race, or sexual preference could be inserted wherever "person with a disability" is found above.

The next five sources of prejudice are germane only to people with disabilities who are arguably the most discriminated group throughout history (Beverly &

Alvarez, 2003; Smart, 2001). "Accountability for the cause of disability" (Smart, 2001, p. 101) is the sixth source of prejudice: people who are thought to have caused their disability (e.g., drinking or taking drugs that leads to an accident, engaging in unsafe activities such as rock climbing, motorcycle riding, etc.) endure more stigma than those whose disability was caused through no fault of their own. Those who could correct their disability (e.g., cochlear implants) but choose not to are viewed with increasing stigma. Seventh, "moral accountability for management of the disability" (Smart, 2001, p. 107) refers to society's expectation that people with disabilities follow the rules about containing the effects of their disability. That is, they should do whatever is needed to ameliorate the functional limitations, ignore discrimination, and have a cheerful attitude no matter what. The eighth source of prejudice, negatively "inferred emotional consequence" (Smart, 2001, p. 109) is that people without disabilities assume that having a disability is the worst thing that could happen and is unendingly tragic. Ninth is the "emphasis on beauty, fitness and youth" (Smart, 2001, p. 113), which can lead to employers refusing to hire people who look different because it might distress coworkers and customers. The more attractive, fit, and, to some extent, youthful the person with a disability is, the more access to privileges and a better QOL is possible. Finally, the last source of prejudice is the "fear of acquiring a disability" (Smart, 2001, p. 115): the presence of a disability forces people without disabilities to confront the notion that they are not in control of life or their bodies (e.g., the longer one lives, the more likely one will experience a disability).

Thomas (2001) criticized much of the measurements of attitudes toward people with disabilities as uni-dimensional. That is, attitudes about the disabled were held constant across all members of a disability group or across all disability groups. “This practice has sometimes led researchers and practitioners to erroneously assume that a single dimension can account for perceptions of an individual with a disability” (p. 3). Thomas conducted several experiments designed to capture perceptions of disability across a variety of related dimensions. His conclusion was that there are three dimensions underlying the perceptions of able-bodied society about those with disabilities: overtness of the disability, risk, and the person with a disability’s response to the disability. Thomas recommends that individuals with highly visible or less understood (overt) disabilities and those who work with them should conduct strategies to educate others about the disability and reduce ambiguity about it. The second dimension is risk to others: is the disability contagious? More information is needed to combat this bias. Third, how the individual with a disability responds to the limitations of the disability will influence others. Thus, the better integrated disability is in the individual’s self-concept—the more accepting, even transcending her disability, the more comfortable others will be.

There has been a great deal of research over the years that focused on employer attitudes toward people with disabilities as employees. Havranek (1991) found that attitudes of employers are critical to employment status. Studies examining the barriers that people with disabilities face in securing employment list employer attitudes as a significant barrier (Livermore & Goodman, 2009; Loprest & Maag, 2001; NCD, 1997). The scope of my review of the voluminous employer attitudes literature will be limited to summarizing the current thinking on employers' attitudes in order to provide context to the study I am proposing.

Hernandez, Keys, and Balcazar (2000) conducted a review of the literature on employer attitudes toward workers with disabilities from 1987 to 1999 and looked at how ADA rights might impact those views. Unger (2002) conducted a review of the literature from 1992 to 2000 on employer attitudes towards the employment potential of persons with disabilities.

Both reviews found positive and negative attitudes across the literature. Inconsistencies in the findings could be a product of variations in how the research was conducted (telephone or paper and pen survey), regions of the country, and that much of the research was conducted with people other than the front line supervisor (Unger, 2002). Hernandez et al. (2000) found that while there were successes in improving general attitudes toward workers with disabilities, overall the results were mixed. When global attitudes about people with disabilities were assessed, employers were positive. When negative attitudes toward a specific disability were assessed, attitudes continued to be negative, which may be based on stereotypes rather than actual experience (Unger, 2002). Otherwise, their findings were similar. Employers, in general, supported the idea that people with disabilities should be included in the workplace. Positive prior contact with people who have specific disabilities encouraged employers to hire people with those types of disabilities again. Those with physical disabilities were more likely to be hired than those with mental health or cognitive disabilities. Hernandez et al. (2000) found the literature to show less of a relationship between employer attitudes, employer education, and company size, which is a change from previous research findings. The most salient point, however, is that both studies found that while employers agreed that people with disabilities should be hired, that belief did not readily translate into action.

Berry and Meyer (1995) advocated for examining the feelings of coworkers as well as employers along the dimensions of attitudes and situations relating to potential coworkers with disabilities. They used the Attitudes toward Persons with Disability (ATDP) scale, Form A (Yuker, Block, & Young, 1966), provided hypothetical situations of contact with people with disabilities using the Multiple Affects Adjective Checklist (MA ACL) State/Today Form (Zuckerman & Lubin, 1965), and constructed a questionnaire to determine "behavior and cognitive reactions" (p. 215) to the disability and the contact. One's attitude about people with disabilities and discomfort with the situation at hand were found to be related to negative responses to contact with a coworker with disabilities (Berry & Meyer, 1995). While situational issues need to be addressed in training employers and coworkers to reduce their anxiety and hostility while in uncomfortable situations, it all seems to start with the negative attitudes that employers and coworkers bring with them. "Negative attitudes predict negative reactions regardless of situations" (p. 218).

Physical Barriers

Sutherland (1981) catalogues the barriers people with disabilities face by way of anecdotes. Access to the physical environment including steps, heavy doors, and transportation; “If we can’t get there, it doesn’t matter if we can get in” (p. 23). He speaks of not finding curb cuts at all four corners of an intersection or throughout a path of travel from point A to B, making a path of travel explicit for those with visual impairments, access to public toilets, access to public transportation, access to information through interpreters, captioning for the deaf and hard of hearing, and attitudes held by the nondisabled public. Having an attitude of being helpful goes along way toward creating access; “Almost any place becomes accessible if the people in the place want it to be” (p. 27).

Sutherland (1981) catalogues discrimination in education through lowered expectations and discusses the learned role of helplessness that people with disabilities acquire in the face of all the environmental obstacles. He observes that the role of learned helplessness is central to the oppression of individuals. Finally, as a summary of Sutherland’s anecdotal approach to documenting barriers, he reduces the barriers to the central one of access—to respect, dignity, and inclusion in society.

From the first report in 1984, which laid out the values and standards of policy for people with disabilities to multiple reports issued each year, the NCD has been a major convener and documenter of research on the impacts of discrimination and lack of access for people with disabilities. Started as the National Council on the Handicapped, which subsequently changed to the National Council on Disability, this body both leads and documents the remarkable history of the policy work accomplished using the minority status of disability as its guiding principle. The issues have remained basically the same over the nearly 25 years of the council’s work. One can see the changes in emphasis or specific group, but overall the issues mentioned in 1984 are still with us. These issues include access to education, changing obsolete public attitudes, employment, single entry point for information and services, expanding laws—in 1984 the recommendation was to add disability to the Civil Rights law of 1965, accessible communities, removing disincentives to work and social participation, improving research—gather accurate information about people with disabilities and identify effective technology and services for people with disabilities, prevention of secondary disabilities (health issues), continuum of support services to live independently, minority inclusion, and international cooperation on disability issues (NCD, 1984).

de Blacazar, Bradford, and Fawcett (1988/1993) constructed an early rigorous research project that consisted of quantitative data from 13,000 people with disabilities across 10 states and included qualitative data from local focus groups. The authors identified 18 issues as major problems by Americans with disabilities and, interestingly, reported on solutions suggested by the respondents and participants themselves. Those included:

> access to and the affordability of assistive technology devices; accessibility of businesses in the community; lack of consumer discounts much like senior discounts; community support and responsiveness (family and government services to help people with disabilities); disability rights and advocacy; employment accommodations, disincentives and training, employment discrimination; employment opportunities, handicapped parking; healthcare (affordability and availability); housing affordability, availability and accessibility; insurance for auto, life and liability for persons with disabilities; insurance for health care, medial portrayal and public information about people with disabilities; public access (rights of way and path of travel issues); social services failure to serve people with disabilities effectively; transportation (availability and affordability); and the affordability of utility bills. (pp. 5-13)

In 2002, a study of the work incentives implementation efforts in Oregon, Vermont, Wisconsin, and Washington state identified transportation, housing, personal assistance, child care, and access to long term supports as being physical barriers to work (Hanes et al., 2002). As a part of its 1997 Report on Employment Barriers, NCD identified similar physical barriers that impact individuals' ability to work. Those stubborn barriers include transportation, health care, housing, and livable communities, along with community based services and supports. Educational gaps are also mentioned in this list.

Over the years, the physical barriers have come down to transportation and housing which taken together could be seen as livable communities with the community based services and supports (e.g., personal services) that are needed to stay in one's home and go to work. Livermore (2009) lists inaccessible workplaces as a barrier, but recent reports from the NCD have not highlighted public rights of way (e.g., curb cuts and sidewalks) and building access as major issues.

Policy Barriers

Hanes et al. (2002) characterize Social Security disability policy in this country as in "maintenance mode" (p. 4) between the enactment of Title II (SSDI) in 1956, Title XVI (SSI) in 1972, and the 1619 Work Incentives in 1980. Even with the large increase of younger people with disabilities enrolling in Social Security programs during the 1980s, the policy inertia continued into the 1990s. In 1996, the decision was made to not cover those whose disability involved substance abuse, which resulted in a large drop in the numbers of beneficiaries; but since then, the rolls have steadily increased given that substance abuse is often a secondary disability (Hanes et al., 2002).

In 1997, the NCD submitted a report to Congress, *Removing Barriers to Work,* which would be the first of several examining barriers to work and suggesting solutions. The 1997 report posited that "hundreds of thousands of the millions of working age SSI recipients and DI beneficiaries want to go to work and would do so except for the many barriers that still exist" (NCD, 1997, "Conclusions," para. 1). In this report, loss of health care benefits was one of the top issues that prevented people with disabilities from going to work. The other barriers involved various benefit rules, losing benefits eligibility if one worked, and overpayment of benefits by Social Security. Included among the 15 action proposals were developing a ticket to work program so that consumers had a choice in vocational/employment assistance providers, removing the marriage penalty, compensation for disability-related work expense, and designing a benefits program that supported work.

O'Day (1999) echoed many of the NCD barriers but simplified them into problems with program eligibility (either you could work full-time or you could not), loss of medical coverage, confusing and arbitrary benefits rules, and lack of choices for vocational services. O'Day also called for incentives to employers to be limited to actual costs of hiring a person with a disability (e.g., accommodations and increased health care premiums). She called for the elimination of these policy barriers so that people with disabilities could work and keep the cash and/or health benefits they needed.

In 1999, the TTW-WIIA was created to do several things, one of which was to establish a Medicaid Buy-In program. This federal-state partnership allowed states to create a program whereby people with disabilities receiving Social Security benefits could work and keep their cash benefits (up to a set amount) and keep or obtain health insurance through Medicaid.

> States have the option of using these grants to raise the income limits for Medicaid eligibility, disregard some earned and unearned income, raise asset limits, exempt certain assets, and charge premiums on a sliding scale in extending the availability of Medicaid coverage to people with disabilities who work. (Hall & Fox, 2004, p. 38)

This law would allow people with disabilities to work for more than just the 9-month trial work period as they either reduced their dependence or worked their way off public benefits entirely.

Barriers Specific to Employment

Other barriers documented in the literature include transportation while searching for work (Loprest & Maag, 2001) as well as actually getting to and from work (Livermore & Goodman, 2009; NCD, 1997). Education gaps (Livermore & Goodman, 2009; Livermore, Stapleton, & Roche, 2009; Loprest & Maag, 2001; NCD, 1997) and training or education that allows people with disabilities to compete in the workforce (Hernandez, 2009) have been documented. Accommodations on the job (Livermore & Goodman, 2009; Loprest & Maag, 2001; NCD, 1997) and lack of funding for assistive technology on the job (O’Day, 1999) have been identified as barriers as have disability-unfriendly corporate cultures (NCD, 1997). Several reports documented inaccessible workplaces and inflexible work arrangements that allow for meeting health care needs (Livermore & Goodman, 2009; Livermore et al., 2009; NCD, 1997). Hernandez (2009) documented the negative experiences based on ethnicity that African-Americans and Latinos with disabilities have had with vocational counselors and employers. Latinos experienced a language barrier as well.

The lack of counseling on various issues or even erroneous counseling deserves special mention. Livermore and Goodman (2009), Loprest and Maag (2001), NCD (1997), and O'Day (1999) all speak to the lack of appropriate career information and counseling, good job placement services, and job search and interview skills as barriers. O'Day and NCD (1997) use this lack of quality vocational services to call for a program that allows people with disabilities to pick where and from whom they wish to receive their vocational services. The Ticket to Work program of the TTW-WIIA bill that passed in 1999 was created to allow consumer choice in where vocational services can be obtained. In addition, there is a need for more and better information about the impacts of work on benefits and health care (Livermore & Goodman, 2009; NCD, 1997). Finally, a qualitative study in Kansas (Hall & Fox, 2004) of eight participants of the Working Healthy program (Kansas' Medicaid Buy-In program) found that participants had been told by their health care providers that they could not work. Kaye (2009) also found that a vast majority of his respondents were also told by the medical establishment that they could not work. Uninformed health care providers as well as government benefit workers (Kaye, 2009) represent a very large barrier.

My Disability is the Barrier: Two Studies

Oregon, Vermont, and Wisconsin study. Early in the history of implementing the Medicaid Buy-In program across the country, The Robert Wood Johnson Foundation funded a project studying the implementation of work supports for people with disabilities in Oregon, Vermont, and Wisconsin. An applied research project with an experimental design was developed to observe and evaluate three different approaches to systemic change that would allow people with disabilities to go to work. A control group that received no interventions was established in each state and a separate state (Washington) that was not planning any work incentives implementation activities also acted as the state level control group.

One of the research questions was, “Do individual knowledge, attitudes, and beliefs about employment after disability impact earnings and sustained employment” (Hanes et al., 2002, p. 14). Using the Employment Barriers Scale at three different times over the life of the three-year grant, focus groups, and key informant interviews, the project reported that the “single biggest barrier to employment is the individual’s disability and its related contingencies, one of which is a lack of confidence in income-producing capacity” (Hanes et al., 2002, p. v). Additionally, across all three states, it was noted that consumers’ fear of losing benefits increased with more information about the work incentives program (Hanes et al., 2002). Results from focus groups and interviews were not reported separately from the overall report, but it does not appear that questions about what participants told themselves about work and their judgments about work were asked.

California study on why people with disabilities do not work. In Chapter I, I described a paper survey among 1,900 ILC respondents in which the majority of working age participants cited “my disability” as the primary barrier to work. Following up on the question of how my disability keeps people from working, Kaye (2009) queried a random sample of 1,017 Californians with disabilities through a telephone survey process. His data, presented at the 2009 American Public Health Association conference in Philadelphia, offered some insights.

The respondents in this survey were all people with disabilities: 39% were employed, 10% were not employed but looking, and 51% were not participating in the labor force. Thirty-six percent were on some sort of public benefit program. Participants’ disabilities included mobility impairments, cognitive impairments, mental health issues, and sensory impairments. Sixty-six percent of the nonworking respondents indicated that health reasons prevented them from working. Other reasons for not working included family responsibilities (10%), cannot get hired, discrimination (nearly 4%), and preference was for not working (3%). Again, health is the major reason for not working (Kaye, 2009).

Some of the reasons nonworking respondents gave for why their disability prevented them from entering the workforce included can no longer perform prior job (nearly 92%), disability/health issues use too much time and energy (82%), believe they cannot work at any job (74%), told they could not work (66%), and cannot get hired because of disability (60%). Those who were told they could not work indicated by an overwhelming majority that health care professionals gave them that verdict

(97%) with 25% hearing it from Social Security or other government program staff (Kaye, 2009).

When those who were not in the labor force were asked to be more specific about why they cannot work, the vast majority said they could not do the job tasks (90%), nearly 87% indicated they experienced frequent illnesses, 85% said they suffered from a lack of stamina or experienced fatigue, nearly 75% cited frequent pain, and 65% indicated they had personal care needs that precluded work (Kaye, 2009).

For the question of what it would take for respondents not in the work force to go back to work, the answers were reported by those on SSI or SSDI benefits and those who were not. Overwhelmingly, for those on government benefits, their health had to get better (94%), 81% wanted the guarantee of being able to return to benefits if they had to leave the job, and 67% wanted to keep their benefits while they worked (Kaye, 2009).

For those not working and not on government benefits, they too reported that their health had to get better as the top reason (nearly 77%), while 74% indicated that the employer would have to give them a chance, and 72% indicated that the job would have to have full health benefits. Other reasons cited include ease of returning to benefits if job does not work out (44%), want to keep benefits while working (38%), and, finally, transportation (an environmental barrier) appears on the list as being cited by 35% of those with disabilities who do not work currently (Kaye, 2009).

From the data, Kaye (2009) posited that there seemed to be two different disability groups within the population: those whose health and disability were stable and those who experienced debilitating illness, fatigue, and pain. The first group seemed to be a minority as a majority of the participants blamed their disability and health as the factor most responsible for not working.

Kaye's (2009) conclusions focused on three areas: "bad advice, heath and public policy" (PowerPoint slide 1). He observed that nearly all the respondents were told they could not work and at least two-thirds of them were told by health professionals. It appeared that none of the respondents had been given information about assistive technology, accommodations, or shown others with disabilities working successfully. Clearly, bad or, at the very least, poor advice had been given to the respondents about their options for work.

Health is a major barrier to working with illness, fatigue and pain affecting a major proportion of those not working, based on Kaye's (2009) sample. Several questions were posed: Was diminished health the cause or the effect of not working and what was the role of depression in keeping people from working? In Kaye's (2009) presentation, he wondered about the "unable to work mindset" (PowerPoint slide 26) that those not in the labor force exhibited and suggested that this be explored further. His research also leads one to wonder how rehabilitation professionals and disability advocates could help the health care professionals to better understand that people with disabilities can work with the proper training, assistive technology, and other employment supports.

With regard to public policy, Kaye (2009) recommended that promoting wellness before health declines as essential to helping people with disabilities go to work. He also argued for the inclusion of mental health services as a component of improving health care. Making people with disabilities and employers aware of the resources and possibilities for work is also important. Finally, it would be important to intervene before someone loses or leaves a job because of their disability.

While health may seem to be an internal barrier, it can also be construed as an environmental barrier due to lack of access to good health care, good nutrition, and personal assistance services that help prevent secondary disabilities. While people with disabilities can exercise some control over their health, in this day and age of managed care or lack of health professionals who accept Medicaid, it presents a very difficult barrier that must be adequately addressed in order for employment to become an option.

Theoretical Foundations

> Psychology can not tell people how they ought to live their lives. It can however, provide them with the means for effecting personal and social change. (Bandura, 1986, p. 46)

Anthony and Personal Factors

Anthony (1994), in writing about employment services for people with mental health issues, calls for investigating personal factors that indicate readiness for change and that are conducive to vocational interventions. He lists those factors as “personal preference, satisfaction with current situation, commitment to change, self-efficacy, environment awareness and self awareness” (p. 11). Johannesen, McGrew, Gress, and Born (2007) reduce Anthony’s list to self-efficacy, self-awareness, and satisfaction with current situation and echoes Anthony's suggestion that these be examined as meaningful targets of research for impacts on consumers choices around work.

This research project proposes to examine self-efficacy, self-awareness, and satisfaction with current situation. The first two personal factors readily lend themselves to discovery through a qualitative process. Identifying satisfaction with current situation seems to be a marker for readiness to change. It could be equated with a QOL theoretical perspective that can be examined through both qualitative and quantitative processes. For the purposes of the research project, a qualitative process will be used since the project is probing subjective perspectives about self-efficacy and self-awareness around the decision of whether or not to work.

I propose to use two theories of human behavior to examine and understand the data on self-efficacy and self-awareness (Anthony, 1994) from this research project. The first is social cognitive theory developed by Alfred Bandura. For this project, I focused on Bandura's (1997) concept of self-efficacy. It builds on the notion that people's beliefs affect their behavior but expands to include the social and environmental effects that also impact people's behavior. As the literature has shown, discrimination (social) and inaccessible communities (environment) can have an enormous impact on the behavior of people with disabilities. The second theory of human behavior, REBT, was developed by Albert Ellis. It focuses on the individual's responsibility for his or her behavior and techniques for changing it.

The third factor that Anthony (1994) suggested, satisfaction with current situation, calls for an examination of consumers' QOL. QOL concerns itself with both the subjective and objective measurements of happiness (affect), satisfaction (cognitive), and sense of well being (Bishop, Chapin, & Miller, 2008,). Measures of QOL are both personal and subjective (happiness, well being, and satisfaction) as well as conditions that can be measured objectively (Bishop et al., 2008; Brown, 1988; Halpern, 1993; Schalock, 1990). These objective conditions include "health, wealth and comfort" (Bishop et al., 2008, p. 49). For this research project, I limited my examination of QOL to asking about satisfaction with life. This line of inquiry may uncover a motivation to support or deny the need for work.

Bandura and Self-Efficacy

Bandura (1986) seems to have built his social cognitive theory on the same thought causes behavior premise as Ellis by situating social cognitive theory within the individual. He posited that human thought is the basis for human behavior but expands his theory of human behavior through understanding how social forces influence the individual, small groups, and large groups (Davidson Films, 2003). He developed a model for this interaction called the Triadic Model of Reciprocal Causation (Bandura, 1986). This model shows the interplay between "behavior, cognition and other personal factors, and the environment" (Bandura, 1986, p. 23) that explain human behavior. Through the model, Bandura (2003) demonstrates that humans not only shape their environment but are shaped by that environment as well (Bandura, 2003).

According to Bandura (1986), while people can learn through trial and error, most of their learning occurs by observing others. "Much social learning is fostered by observing the actual performances of others and the consequences for them" (p. 47). This has implications for people with disabilities in terms of what values and expectations are modeled to them about their ability to contribute and fit in the community.

Perceived self-efficacy, according to Bandura (1986), "is defined as people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances" (p. 391). A key point here is that it is one's judgment of one's skills, not the actual skill that one possesses, that determines the self-efficacy of an individual. One may know what one needs to do to be successful, and that success may even bring rewards such as money; but, if the individual does not think he can do it, he probably will not even try (Bandura, 1986).

In general, people are not self-efficacious in all areas of their lives (Bandura, 2003). Rather, they excel in some areas and are less successful in others. Self-doubt can occur when exposed to circumstances that undermine their beliefs about their abilities (Bandura, 1997). People with disabilities find themselves in this situation frequently when trying to navigate the community, learn or engage in social activities in a less than accessible built environment, or when confronted with society's beliefs about their abilities.

"People who doubt their capabilities . . . shy away from difficult tasks in those domains" (Bandura, 1997, p. 39). They dwell on their perceived shortcomings, are unable to motivate themselves to try, and give up easily in the face of obstacles (Bandura, 1997). They diagnose the problem as their "deficient aptitude" (Bandura, 1997, p. 39). On the other hand, resilient people, those with high self-efficacy, look at a task as a challenge to be mastered (Bandura, 1997). They challenge themselves and remain committed to see the challenge through. They increase their efforts when faced with obstacles and remain focused on the task at hand by thinking strategically. Failure is not taken personally but a sign that they must make more of an effort to succeed (Bandura, 1997).

There are four ways to develop or improve self-efficacy according to Bandura. The first is mastery, actually trying and succeeding in a task, which is the most powerful way to create strong efficacy (Bandura, 1997). Second, social modeling or seeing others like themselves being successful is critical. Third, people are persuaded by the beliefs of others that they can do it, which could be called social persuasion. The fourth way focuses on understanding one's physical and emotional state: being able to accurately read and manage one's physical and emotional state, which helps with coping with depression and stress (Davidson Films, 2003, p. 8).

Albert Ellis and Rational Emotive Behavior Therapy (REBT)

REBT is a very pragmatic and active therapy model. REBT focuses on helping the individual see his view of an issue and change it for the better, thus, creating a change in behavior. The model can be used as a short or long term therapeutic tool that is taught to individuals who can use the process whenever needed.

REBT is organized around an A-B-C (D-E) model: A indicates the Activating event, B refers to a strong held Belief or belief system, and C is the emotional or behavioral Consequence. D refers to actively Debating or disputing one's irrational beliefs, while E refers to acquiring more Efficient (healthier) beliefs to replace the irrational ones (David et al., 2010). When an activating event occurs there will be a consequence, but what the response will be and how positive or negative it is will be up to the individual. If one has wrecked one's car (activating event), there is a consequence such as not having personal transportation or needing to find the money to repair it. However, the belief that the individual holds about how awful it is or what a bad person he/she is for wrecking the car causes the emotional upset, not the event itself. Ellis and Grieger (1977) describe "the central theory of REBT (as Epictetus observed some 2000 years ago): The things that occur do not upset you—but your view of those things does" (p. 7).

The effectiveness of this theory is that once one accepts what he or she believes about an event, and not that the event itself causes one's feelings, one can "enormously increase your power over your own emotions" (Ellis & Greiger, 1977, p. 8). If a person can tune into her/his self-talk or beliefs about a specific event, she/he can control how she/he responds and behaves as a result. For people with disabilities who have absorbed society's limiting beliefs about what is possible while living with a disability, REBT (and its techniques for uncovering and conquering irrational beliefs) could be very helpful in changing behavior.

REBT offers a number of techniques, including gathering information to support or refute the belief and debating oneself on the rationality of that belief, to assist individuals in making personal changes. For the purposes of this study, I only used the A-B-C model of this psychological theory to help uncover what people with disabilities believe or tell themselves about their disability and work.

Quality of Life (QOL)

Increasing the function of individuals with disabilities has been the singular focus of rehabilitation outcomes; historically, the method of measuring improvement has been whether employment has been achieved (Fabian, 1991). However, Chan, Rubin, Lee, and Pruett (2003) call for including QOL as one indicator of a successful rehabilitation outcome for consumers that may or may not be linked to vocational goals. Rubin, Chan, and Thomas (2003) posit that part of the motivation of consumers to seek rehabilitation services rests on the assumption that life will improve as a result.

Historically, QOL has concerned itself with surveys of population well being based on objective social criteria that can be easily measured in large scale groups such as wages, cost of housing, and unemployment (Cummins, 1997). However, in the 1960s a shift to examine the individual perspective took place (Cummins, 1997) as researchers began to recognize the critical role of the individual's assessment of QOL.

Literature indicates that there is no one definition of QOL in general (Brown, 1988; Dennis, Williams, Giangreco, & Cloninger, 1993; Fabian, 1991). Brown (1988) states that assessing QOL is complex and should be viewed holistically. That is, it examines all aspects of day to day living and is based on the individual's perception of his or her life. Another definition for QOL centers on the difference between an individual's met and unmet needs; the larger the gap the poorer the QOL (Brown, Bayer, & MacFarlane, 1988).

Parmenter (1988) defines QOL as the degree to which and individual constructs his or her own values and sustain a sense of self in the community. What one person perceives as adding to his or her QOL, another person may not value at all (Brown, 1988; Taylor & Bogdan, 1990). Goode (1990) speaks of both those with and without disabilities when he describes achieving a higher QOL as being able to satisfy one's own goals in important life areas such as employment, education, community, and in the home while still meeting society's expectation in those areas.

Halpern (1993) observes that there are important dichotomies underlying these definitions that need examination. First, there must be a personal or subjective measure of QOL as well as the objective or societal measure. Second, there is often tension between what the individual values or chooses and societal norms. Third, personal needs must be contrasted with societal expectations; and fourth, personal choices must be included in planning program outcomes. In terms of outcomes, Halpern identifies three that are usually represented in any QOL taxonomy: "physical and material well being, performance of adult roles, and a sense of personal fulfillment" (p. 490).

Edgerton (1990) adds the concept of sense of well being to the definition of QOL and indicates that service providers and society cannot impose their beliefs of what makes up an appropriate lifestyle. "Society should provide options-it should not impose standards" (p. 158). George (1979) posits conceptual differences among terms, that is, defining happiness as a fleeting affective state; life satisfaction is defined as how well one has met one's expectation of life; and well being is defined as a much broader view of satisfaction with the nature and quality of one's life.

Cummins (1997) defines QOL as being composed of seven domains: "material well being, health, productivity, intimacy, safety, community and emotional well being" (p. 132). QOL can be assessed through both subjective and objective measures of life; the objective incorporates "norm-referenced measures of well being" (Cummins, 1997, p. 132), and the subjective is based on measures of individual perceptions of well being that are based on satisfaction (Cummins, 1997). The author goes on to present a cogent argument for what measures of satisfaction and QOL must be the same for both those with and without disabilities. To do otherwise often sets expectations for minority groups, such as people with disabilities, to have an acceptable (to the measurer) lower QOL (Cummins, 1997).

Another conceptualization of QOL looks at three measures: social, psychological and "goodness of fit/social policy" (Schalock, 1990). Social measures include health, social welfare, connections with others, living standards, education safety, housing, and leisure. Psychological factors are personal reactions to life experiences. Personal satisfaction is based on the positive feelings individuals have about their lives (Schalock, 1990). Goodness of fit social policy is defined by Murrell and Norris (1983) as the relationship between the person and the environment. The better the fit between resources and stressors, the higher the QOL. Meaningful work is mentioned as a component of QOL (Bishop & Allen, 2003; Cummins, 1997; Edgerton, 1990; Schalock, 1990). However, Halpern (1993) and Myers and Diener (1995) found that occupational success (an objective criteria) and satisfaction (a subjective measure of happiness) are unrelated. In other words, life satisfaction is not dependent on employment or achieving occupational goals.

Bishop et al. (2008) described the lack of clarity among the concepts that fall under the umbrella of QOL that makes measurement difficult. Much work has been done to try to measure subjective and objective criteria of QOL. Diener, Emmons, Larsen, and Griffin (1985) advocate for asking whether people are satisfied with their lives as a whole and not just over various domains. Deiner et al. developed the Satisfaction with Life Scale that asked questions such as,

> In most ways my life is close to my ideal; the conditions of my life are excellent; I am satisfied with my life; so far I have gotten the important things I want in life; if I could live my life over, I would change nothing. (p. 72)

However, Edgerton (1990) calls for both qualitative (subjective) and quantitative (objective) measures of QOL over time for a truer picture of life satisfaction.

In summary, QOL considerations have been added to the outcomes measures of rehabilitation services (Bishop et al., 2008). QOL is both subjective and objective and social services providers must be mindful not to impose their cultural values on the people that they serve. Individuals are best able to answer the question: Am I satisfied with my life? The answer to that question should drive program development and the delivery of services for the individual (Halpern, 1993).

Summary of Literature Review

In my review of the literature that focused on factors impacting people with disabilities' choices about work, I examined a number of different areas to provide a context to the research question: What do people with disabilities (particularly those on benefits) tell themselves about their ability to work?

I examined a number of models of disability that shifted the responsibility for the problems of disability from the individual to society and the environment. Wherever the problem of disability is placed (e.g., medical, economic, or social), a different set of problems and solutions were identified. From the 1980s forward, there has been a strong push to conduct research on the interaction between the individual and the environment, which has led to many improvements in society and the built environment. This direction continues today. However, such improvements still have not led to increases in the employment rate of people with disabilities. What are the barriers, then?

The internal barriers to work include adjustment to disability (e.g., successfully incorporating functional changes into self-concept); personal attitudes toward disability, expectations, and work; early life experiences with work development tasks; and better health outcomes that lead to stable lives.

The external barriers to work include stubborn negative public attitudes (including employers); governmental polices that are in flux (e.g., Social Security benefits, access to assistive technology, and not enough money for programs); physical barriers that, while improving, still exist (e.g., accessible, affordable housing, transportation, and education); as well as effective health care that is widely available. Such health care needs to better address pain, fatigue, and depression issues (Kaye, 2009).

While so much of the research has been conducted with an eye toward the interaction of the individual with her/his environment, there is a dearth of research that asks people with disabilities directly about their feelings and beliefs concerning their ability to engage in work. This qualitative study focused on the individual for she/he bears responsibility for her/his reaction to the disability. Hanes et al. (2002) state, "We believe attitudes and beliefs relate to work outcomes in significant ways" (p. vi). Through the examination of the lived experience about the mindset (Kaye, 2009) that a cohort of people with disabilities on benefits have toward work, we can learn more about the attitudes and beliefs of individuals with disabilities struggling with the decision to work. Asking the question, "Are you satisfied with your life?" may provide insight into a motivation that affects the choice of whether to work at all.

Uncovering this information and sharing it with consumers may help them revise their decisions around work. Such information could lead to the development of strategies for intervention. The psychological theories of social cognitive theory (e.g., what judgments are you making about your skills?) and REBT (e.g., what are you telling yourself about the situation?) and QOL assessment may help in understanding the mindset of people with disabilities on benefits who want to work but do not.

CHAPTER III

METHODOLOGY

This research project was qualitative in nature and followed the steps of a qualitative approach. Crotty (1998) suggests that every research project must address four elements before starting to gather data. These four elements informed and guided the design and execution of the research as well as provided the theoretical lenses that were used to make sense of the data. Epistemology refers to how we know what we know (Crotty, 1998). Guba (1990) calls this the researcher's worldview and defines it as "a basic set of beliefs that guide action" (p. 17). Theoretical perspectives speak to the specific theories that guide the researcher (Crotty, 1998) in his or her work on that particular research question. Methodology is the "plan of action" (Crotty, 1998, p. 3) that guides the choice of the next element. The final element is method or the means by which we collect the data (Crotty, 1998).

For this project to uncover and make meaning of the internal barriers that people with disabilities on benefits may construct around working, I used constructivism as my epistemology. Two theoretical perspectives guided my research approach: postmodernist theory and disability theory. The methodology or plan of action I used to conduct my research was phenomenology. Interviews with individuals was the method I used to conduct the study. This chapter explains in more detail each of these elements as they related to the actual project.

The Four Elements of Research Design

Epistemology

Creswell (2007), in his definition of epistemology, poses the question: How does one know what one knows? Because this research sought to uncover and examine the internal barriers to work that some people with disabilities construct out of their experiences, I used constructivism as my world view (Guba, 1990).

Crotty (1998) describes constructivism as making “useful interpretations” (p. 47) of what is constructed in the mind. Crotty reminds us that there is no one true statement about what is real or what exists. Human beings make meaning out of what is before them, otherwise the objects do not exist (Crotty, 1998). Fish (1980) adds a social component to this world view in that he suggests that the culture in which humans live greatly influence the construction of meaning for each individual. In this research project, I studied the meaning that people with disabilities make about their ability to work. The American culture, while changing, historically has not encouraged independence, acceptance, and work for people with disabilities as discussed in Chapter II.

Theoretical Perspectives

The next element in research design, according to Crotty (1998) is identifying the theoretical perspectives used to guide the methodology. The two theoretical frameworks used to make meaning of the data that I collected during this research project are postmodernist and disability theory.

Rue (1994) describes postmodernist perspective as having no absolute truth or values. That is to say, there is no right truth or “public truth” (p. 272) that everyone can or must subscribe to. Our individual truth, or as Rue labels it, our “private truths” (p. 272) are influenced by our experiences. “That is, individuals of the same age, sex, race, class and language group may be expected to perceive and to reason in diverse ways that reflect their diverse experiences” (Rue, 1994, p. 272). The postmodernist view, as Rue describes it, is that there is no one universal truth or interpretation. Everything is open to individual interpretation and everyone is free to choose their private truth as long as there is no requirement for everyone to interpret the universe in the same way. The universe has no meaning, but humans give meanings to the universe (Rue, 1994). In other words, there is no one true or right way to understand a phenomenon; we must respect the various interpretations that each human brings to his or her private truth.

The theoretical perspective of the postmodernist underscores the need to understand the personal truth of the individuals with disabilities who choose not to work. Those individuals may have constructed internal beliefs and judgments about work that would seem to be influenced by their experiences. Uncovering these beliefs and asking about their meanings from the participants who experience them could unlock personal interpretations and allow the individual and the researcher to better understand the beliefs as they are shared. Sharing them with others allows people with disabilities to perhaps uncover their own private truths about the choice to work.

The second theoretical view I used as a guide for my research process was disability theory. As discussed in the literature review, there are three tenets that comprise disability theory. The first is that meaning is constructed within a social context (McDermott & Varenne, 1999); certainly thoughts and judgments about an individual's ability to work are rooted in a social context. The second tenet is that disability is a normal variation (Mertens, 2003; Scotch & Schriner, 1997) as researchers now view disability as one facet of the human existence and not something that is shameful or unusual. The third tenet is that it takes the voice of people with disabilities to deconstruct the experience (Higgins, 1992), which is why I chose to use a qualitative approach with disability theory as one of two theoretical lenses for the research question at hand.

Methodology

Transcendental or psychological phenomenology (Moustakas, 1994) is the study of the "appearance of things, of phenomena just as we see them and as they appear to us in consciousness" (p. 49). It begins with a scientific study of the thing or phenomena itself and focuses on making both real and alternative meanings about the phenomenon which lead to understanding the essence of the experience (Moustakas, 1994).

"Evidence from phenomenological research is derived from first-person reports of life experiences" (Moustakas, 1994, p. 84). Moustakas (1994) calls for the bracketing of the researchers' experience, knowledge and biases so that researchers come to the phenomenon with fresh eyes; we cancel out our judgments and previous knowledge in order to more purely experience the participants' phenomenon ourselves. Psychological phenomenology or "searching into the meaning of something" (Moustakas, 1994, p. 60) involves bracketing researchers' knowledge and judgments so that researchers can see more clearly what is in front of them as well as what is inside the researchers. It includes engaging in reducing the participants' statements into incomplete statements and themes that include textural descriptions and reflections which lead to a rich description of the essences of the experience or phenomenon (Moustakas, 1994).

The phenomenon that this research examined was that of people with disabilities choosing not to work even though the environment has changed enough to make that choice more viable. Choosing a life of benefits and poverty over work and prosperity may indicate that there are internal barriers keeping some individuals from working. By asking questions of individuals experiencing the phenomenon of choosing not to work, I uncovered those barriers and made meaning of them so that individuals with disabilities who are struggling with the question of work may benefit from the insights of the participants in this research project. The participants' insights may trigger an awareness of the barriers that other individuals with disabilities may create for themselves and lead to a reassessment of their choice not to work.

Moustakas (1994) calls for the researcher to bracket his or her personal experiences of the phenomenon. The values of the independent living movement include promoting peer experience and encouraging the sharing of that experience with others. Having spent my adult life in the independent living movement, also known as the disability civil rights movement, peer sharing is an important part of my values as a person with a disability and as a researcher. Everyone has something to share, a perspective to add to the picture, and my goal was to give voice to those perspectives. Given my strong bias toward work as a part of a successful life, I knew that I must use care to not allow alternative views of life success to be overshadowed or dismissed. By stating my bias here and reflecting in writing on my biases as I conducted the research helped me to bracket my beliefs and allow all perspectives to be explored. My focus was on gathering the data from participants in the community to create the essence of the internal barriers that some people with disabilities carry when thinking about engaging in work.

Research Methods

As it sometimes happens in research, real life meets the research design and changes need to be made. Originally, the design was centered on two focus groups. Technical requirements that arose from the state vocational rehabilitation agencies of California and Utah led me to abandon those two organizations as recruiters for focus groups. I then tried to bring together a focus group in California using other recruiters. It was agreed by my committee that I would do one focus group in California since that state’s work incentive program is so robust. The World Institute on Disability (WID) continued as a recruiter and four ILCs in the Bay area also agreed to become recruiters for the focus group. Each sent me an e-mail formally agreeing to recruit for this research project.

ILC benefits counselors working with persons with disabilities considering work agreed to look through their recent cases for possible candidates. Several counselors hold regular initial workshops to orient groups of people to the incentives programs; those venues were the most effective at finding potential focus group members. Recruitment was conducted through November, December, and part of January. However, only four people had agreed to participate by mid January; not enough to conduct the group. Given the difficulty of pulling a group of people together, a key decision was made by my committee chair and faculty member with expertise in qualitative research that the method should shift from focus group to individual interviews in order to facilitate the completion of this dissertation.

Rather than a multi-site bounded case study, the research project became a multiple-case bounded study (Yin, 2003) using phenomenology to look at the phenomenon "within its real-life context particularly when the boundaries between phenomenon and context are not clearly evident" (p. 13). The phenomenon examined was any internal barriers to work that may be evident in people with disabilities, on benefits, who had been introduced to work incentive programs but still felt reluctant to work. The context I sought to understand included their disability and how it impacted work in the minds of the participants, that is, the statements they heard from their families, doctors, and society make about work and people with disabilities and their own thoughts and/or fears about work. Asking about their QOL and its impact on the decision to seek work highlighted their motivations to work or not. These contexts became the structure for organizing the information gathered, a strategy that Yin (2003) suggests.

Description of the Researcher

In qualitative research, Merriam (1998) calls the researcher the "primary instrument for gathering and analyzing the data" (p. 20) so personal biases can be problematic. One way of dealing with such biases is for the researcher to declare his or her personal stance at the beginning. My personal stance is that of critical inquiry in that I am most interested in empowering people to overcome the barriers of race, class, gender (Fay, 1987) or, in this instance, disability. I used phenomenology to guide my research methods and critical inquiry to use the data collected to inform people with disabilities about potential internal barriers that they may be consciously or unconsciously creating toward work. Sharing the research from this project may help some people with disabilities to re-examine their decision to work with an eye toward confronting personal internal barriers.

Moustakas (1994) also calls for a personal examination (bracketing) of the researcher's judgments and preconceived ideas about the phenomenon prior to gathering data. Having acquired a moderate hearing loss at the age of two and not receiving adaptive equipment until I began school, my speech was impacted as were my social skills. Growing up in West Virginia in the 1950s and 1960s, there were few children with disabilities that were visible and very few services. My family was at a loss as to how to address my disability; having a hearing aid that was disguised under head bands and wearing a hairstyle that hid my hearing aid were the strategies my family used to deal with my disability. My parents and I never talked about my disability while I was growing up. Stereotypes at that time indicated that I was too different to have a “regular” life. Their advice focused on getting an education and getting a job as I might not find a husband. Work was held up as an extremely important way to be successful.

I graduated college with a teaching degree, got married, and then decided to attend graduate school. One of my husband’s medical school friends had a lower arm amputation and was considering becoming a psychiatrist. He told me about the scholarship program for master’s level rehabilitation counselors at West Virginia University. I applied and was accepted. Enrolling in a program where I would learn about disability and work was the beginning of coming to terms with my disability; for the first time it was a good to have a disability.

My entire career direction has been shaped by the fact that I have a disability. My work has focused on creating access to education and community services that allow individuals to build their lives in a community that is barrier free and accepting. Vocational rehabilitation services are focused on the goal of finding individuals with disabilities work. That is the definition of success for rehabilitation counselors; for me, providing a service that I believe would have such a positive impact on others’ lives was extremely gratifying. While I did not work as a vocational rehabilitation counselor within the state agency, my work with several colleges in the late 1970s and 1980s focused on making higher education accessible to persons with disabilities. I believe that education is critical to successful employment so making those college campuses and programs accessible was important to me. After leaving higher education, I went to work for a large metropolitan city and county government that had a long commitment to making sure municipal services were accessible. Here, I could work to make the community physically accessible and open up career opportunities for persons with disabilities. The last 20 plus years of my work life have been spent in the ILC milieu where I worked with individuals directly on their life goals. I have advocated and organized at the local, state, and national level for communities to be accessible, usable, and welcoming of people with disabilities. My mantra has been, and continues to be, "We need to make these changes so that people with disabilities can work, make their own choices, and create a life!"

It is no surprise that my research interests would include looking at the internal barriers to work that some individuals with disabilities create. I tend to look at research with an eye toward improvement; I want to use the information from this research to help individuals tear down their own barriers to work, if they choose to do so.

In summary, this was a multiple-case, bounded study, using the lens of postmodernism (Rue, 1994), disability inquiry (Higgins, 1992; McDermott & Varenne, 1999; Mertens, 2003; Scotch & Schriner, 1997), and psychological phenomenology (Moustakas, 1994) to uncover the essence of internal barriers to work that some people with disabilities may construct for themselves. My primary audience for this research was my community, people with disabilities. Secondarily, rehabilitation professionals and service providers may find this information useful as they work with people with disabilities to consider employment options. The goal of this research was to uncover insights from the data that I collected and make meaning of those insights in order to help others with disabilities consider work.

Participants

The criteria for participation in the individual interviews included being on or about to go on government disability benefits, not currently working, being between the ages of 18 and 36, health status did not preclude work and had been exposed to Medicaid Buy-In programs, and reluctant to try work.

Participants for this study were recruited from a larger group of individuals who had attended group meetings about the availability of work incentives or who had a relationship with a benefits counselor. These individuals had been exposed to the availability of a work incentives program, which allowed them to keep their healthcare (Medicaid) and some cash benefits while working. Since the purpose of the study was to look at internal barriers to work, I wanted to interview people with disabilities who understood that the health care barrier had been removed but yet still chose not to work. Other environmental barriers may be mentioned, but the health care one is hard to remedy if a work incentives program is not available.

Originally, I had specified an age range of 18 to 36; however, that proved to restrict the recruitment too much. Several recruiters indicated that there were older people who otherwise met the requirements and asked me to reconsider. The literature (Livermore et al., 2007) suggests that individuals who have been on benefits as much as 10 years or more were much less likely to go to work. Thus, the criteria to be on benefits less than 10 years rather than an age limit seemed a good compromise. It was decided that the criteria for this recruitment effort was limiting enough, and I would not look for specific disability types, ethnic groups, or any other criteria other than the ones already stated.

As it turned out, it proved to be difficult to find people to agree to talk to me regarding fears about work. One recruiter indicated that perhaps this was a sensitive and painful area to explore (B. MacDonald, personal communication, March 1, 2011). One of the interviewees indicated that it was “confrontive” (Molly). “It is like those things that float around in your subconscious and you are kind of half aware and then when you are out there and reading the transcript it is like wow it is really there” (Molly). Ten people either did not respond or stopped responding when I further explained through e-mail or by telephone that this was a study about internal barriers to work and that we would be talking about fears that might keep them from working.

Recruitment

While recruitment methods originally focused on finding participants for a focus group, those who did agree to participate were invited to be interviewed via telephone rather than come to a meeting. Three of the original participants agreed, and one did not return my telephone calls. Recruitment continued through the rest of January and into early February before enough participants agreed to be interviewed by telephone. Participants were recruited through two postings on the Northern California Disability listserv; four people responded initially but did not respond again after receiving the consent form. The WID distributed an e-mail invitation to participate first in a focus group but later in the interviews to its interns who were to look for individuals. WID then posted it on their Facebook page and sent it out to the network of benefits counselors across the state. Additionally, WID sent it out to individual consumers on a private e-mail list. One referral resulted but she did not meet the criteria.

The Independent Living Resource Center–San Francisco (ILRC-SF) was the most successful in finding and referring participants. The benefits counselor there was very interested in the study and felt the information would be valuable. She announced the study in her periodic initial workshops on working with benefits. Those who responded as interested were given my contact information and consent form. They either e-mailed me or had the counselor fax me their consent form with their signature and contact preferences.

Given the difficulty of finding interviewees, I contacted an alumnus of the human rehabilitation program at the University of Northern Colorado who works in Wisconsin and manages a large benefits counseling program among other duties. None of his counselors had individuals who met the criteria, but he sent the invitation out to three organizations locally in Wisconsin. None of these organizations were able to identify potential interviewees. I contacted the director of the Kansas State Rehabilitation Services for assistance. He, in turn, contacted an organization focusing on employment and youth as well as an ILC that provided employment services; neither were able to come up with potential interviewees.

Thinking of populations rather than agencies, I contacted an AIDS activist in San Francisco, who is also a researcher. He identified three people who fit the criteria: two followed up, and one actually participated. Lastly, the ILC in Santa Barbara identified one participant who interviewed. This gave me six participants to interview; upon completing the fifth and sixth participant interviews, I found no new information and concluded that I had reached saturation (Creswell, 2007).

Changing the method of data collection from focus group to individual interviews meant that parts of the recruitment process needed to change. The consent form needed to be reworded and the recruitment letter became an e-mail. The demographic form I used to collect information about disability, age of onset, ethnicity, gender, and contact information remained the same. Each participant was to receive a gift card to thank them for their time and contribution. I raised the gift card amount from $35 to $50 to reflect the additional time and focus of an individual interview. See Appendix A for the consent form, Appendix B for the demographic survey, and Appendix C for the e-mail recruitment message that I used to help recruiters identify individuals who could qualify for my study. At the request of several recruiters, a letter format of the invitation was also developed (see Appendix D). This was handed out at meetings to individuals who fit the criteria.

Recruiters either gave interested individuals my consent form and invitation letter with my contact information or e-mailed them the same information. Individuals either e-mailed me or had the counselor fax me their signed consent form with contact information, and I followed up with an e-mail and/or a telephone call. I explained the study and the criteria. One person had been on benefits for much longer than 10 years, so I did not accept her. Five others met the criteria and agreed to talk about their thoughts and fears around work. One individual had just applied for benefits and after several conversations, it became apparent that she would not be mentally able to focus on work for at least a year; however, she could articulate her thoughts and fears so she was included as a participant.

Method

Prior to starting the recruitment of participants, I submitted an Institutional Review Board (IRB) application to the University of Northern Colorado's board for review and approval. That application, based on conducting focus groups, included the cover letter; a copy of the recruitment letter; the informed consent letter; the demographic information form; a sample follow-up letter stating date, time, and place for the focus group; and the question route or focus group and individual interview guide. When it became apparent that the research process would have to change to individual interviews, some minor changes needed to be made. Given that the purpose of the research, participants, and questions asked remained the same and the only changes were to move from focus groups to individual interviews and make minor revisions to the consent form and recruitment materials, my committee felt there was not a need to resubmit the IRB application.

As the recruitment process unfolded and after the potential participants contacted me via e-mail or through a faxed or mailed consent form, I followed their preference for contact. I either called or e-mailed them to explain the research project, the process of telephone interviews that would be digitally recorded, the transcript and the review process as well as confidentiality, and the gift card for their time. The consent and demographic survey forms were e-mailed as needed. I collected all consent forms either by mail or by fax. Demographic forms were returned to me by e-mail.

Once the forms were either confirmed as mailed or actually received, I offered to meet with them on Skype so that they could see me and we could get to know each other a bit. I also sent them a link to my website where they could see a picture of me and read a little about my background. Two people met with me on Skype, and we had a general conversation about my work, my background, and their background. Several others indicated that they looked at my website. This may have helped to make the participants more comfortable to talk to me openly by telephone.

I used a toll free conference telephone line that allowed me to digitally record the conversation. By the time the interview was conducted, I had talked to each of the participants at least once if not twice by telephone, and we had exchanged information by e-mail. I disclosed to each person that I had a disability, and we talked about the potential for this research to impact others with disabilities. Each person seemed comfortable in the conversation. They knew when the recording started and stopped as it was announced by the automated conference service. After the recording, we often had a bit more conversation in which I took notes. I contacted each person with their transcripts by e-mail and by telephone. First interviews ranged from 36 minutes to 1 hour, 20 minutes. Second interviews ranged from 20 to 40 minutes in length. Transcripts were typed up from each recording.

Each participant reviewed his/her initial transcript. Only one made more than cursory changes; her interview was a bit of a challenge to transcribe as she jumped from subject to subject. Most of the changes made by participants were fixing typographical errors and filling in details such as name of the town lived in before accepting the transcript as accurate. Each initial transcript was accepted by the participant.

Follow-up interviews were conducted with four of the six participants. One person did not respond to repeated requests for a follow-up interview. The second individual, who was happy not working, answered several factual follow-up questions by e-mail. The other four interviewees participated in a follow-up interview that mainly consisted of clarifying work history, disability, dream jobs, and other details.

Individual Interview Questions

Originally, the focus group questions were reviewed and contributed to by a group of researchers and people with disabilities in the field. The original questioning route was externally reviewed by a team of nine individuals to help ensure the validity of the focus group questions. The group included five individuals with different disabilities, two nationally known disabilities researchers, one of whom has substantial experience as a qualitative researcher.

When the decision was made to shift from a focus group to individual interviews, that meant the questions needed to be reviewed as well. The original questioning route gave me 13 questions as suggestions for guiding the discussion in the focus group.

While Krueger and Casey (2009) discuss two methods of conducting focus groups, I found their perspective to be relevant to individual interviews. The "questioning route" (p. 37) is marked by a conversational feel. That is, the questions flow naturally, usually from easy and general to more thoughtful and specific. The topic guide route is a list of topics or issues to be covered without specific questions being developed. While topic guides are usually the choice of nonprofits and academic researchers (Krueger & Casey, 2009), I chose to develop a conversational guide or the questioning route. This forced me to think through the information I wanted to collect and help make sure I asked good questions. The conversational feel of the discussion fostered comfort in opening up and make the experience a pleasant and thoughtful one.

Working with my committee chair and the faculty member with qualitative research expertise, we reviewed my questions and reduced them to 10 questions that were to be used for guiding the interview (see Appendix E). The path toward identifying participants' thoughts, feelings, and fears, as well as asking about what others told them about work was the same for the interview as it would have been for a focus group.

First, an introductory set of questions that included inquiries about family status, education level, and interests were asked as a way of easing into the conversation. Second, I inquired about work: had they worked, what was the work activity, and where? For those who had not worked, the question was reframed to ask about their dream jobs. I wanted to know what employment participants had in the past and what they thought about those past jobs. For those who had not worked, the question was reframed to ask about their dream job. My goal was to get them to create a picture of working and remembering what it was like or what they thought it might be like for participants who had not worked. Third, I asked about their disability and work. What was the impact of their disability on their ability to work? I asked why they did not work, which elicited many exterior barriers such as disability, education, attitudes of others, and loss of benefits. Fourth, I asked how they rated their QOL and if that had any impact on their decision to work. My goal here was to begin the task of uncovering judgments they were making about their ability to work, which may provide a view of their internal beliefs about work. Then, I ended by summarizing the points made by the interviewee and asked for any last reactions.

While conducting the first interview, I added a direct inquiry about fears about work as the question about what do you hear yourself saying about work was too broad. I also asked if each person considered himself or herself a person with a disability as it became clear during the course of the interviews that most of the participants were struggling with the issue of disability identity.

The follow-up interview questions were derived from what was lacking in the original transcripts or thoughts I had after reviewing the interview. Generally, the follow-up interviews occurred 10 to 14 days after the interview; depending on the availability of the transcript and the participant These were also transcribed.

Phenomenologically based studies describe and examine the lived experience of the individuals affected by the phenomenon at hand; as such, phenomenological studies seek to use the words of the affected individuals to describe the phenomenon as the participants live and describe it. This study sought to find out what thoughts (Ellis & Grieger, 1977) people with disabilities who do not work have about working and the judgment (Bandura, 1997) they make about their ability to work. Additionally, the study inquired about life satisfaction among the participants.

Postmodern constructivist theory posits that individuals make their own meaning (Rue, 1994). For that reason, I chose to conduct individual interviews as my method to gather information. My questions asked individuals to share their thinking about their disability, how it impacts their ability to work, what others told them about work and disability, their QOL, and their dream job to explore the meanings they are making about work.

Data Collection

Data collection and data analysis in qualitative research is best done together (Merriam, 1998). That is, after each data collection activity (individual interviews, demographic information collection, the writing of field notes, etc.), I reviewed the data with an eye for how to improve my data collection and what additional questions or insights I needed to pursue with the next data collection activity.

The data for this project consisted of six initial interviews and four follow-up interviews, demographic survey collected from each participant, and my journal of reflection and documenting the process. A transcriptionist was hired to provide the transcripts of the 10 interviews. In addition, my attitudes about people with disabilities and work, I kept a journal that included my written field notes describing (a) each telephone conversation, (b) my reflections after each interview, and (c) any administrative issues that came up during the research process. The demographic survey gave me descriptive information such as age, gender, income, disability, and ethnicity, which helped paint a more complete picture of the participants. The digital recording were transcribed so that I could code the interviews for themes to answer my research question.

All data were kept confidential. Each participant was asked to pick a pseudonym, which was used during the interview so that his or her anonymity was preserved. Each participant was referred to using his or her chosen name throughout the research project. All data were stored in a locked file cabinet located in my office. After the study is completed and my dissertation accepted, the participant information, recordings, will be shredded and recycled. This will include interviews, demographic forms, and the names and addresses to mail gift cards that were used as incentives for the interviewees' participation.

Data Analysis

> Data analysis in qualitative research consists of preparing and organizing the data (i.e., text data as in transcripts or image data as in photographs) for analysis, then reducing the data into themes through a process of coding and condensing the codes, and finally representing the data in figures, tables or a discussion. (Creswell, 2007, p. 148)

While the quote above concisely outlines the steps of data analysis used in phenomenology-based research, there is much more to be considered. The issues of trustworthiness, credibility, authenticity, transferability, dependability, and confirmability were addressed just as in quantitative research the issues of internal and external validation, reliability, and objectivity are addressed (Lincoln & Guba, 1985). Creswell (2007) recommends using two strategies at a minimum to address validity and reliability. As I describe the strategies that I used, my analysis procedures become clear.

After conducting the initial interview, I typed up the participant's story as I had experienced it and included some observations. This document became the basis for the case study provided in Chapter IV. After receiving the transcript of the first interview, I listened to the interview while following along on the typed transcript. I made notes on each section and/or underlined for the facts of that person's story. Then I went back and filled in the gaps and details that were missing in each case study.

As I was writing the case study, I was also revisiting the transcript to code for the answers to my original questions around what they had learned about disability from family, doctors, and society, if anything; did they consider themselves a person with a disability; thoughts and fears about work; QOL issues; and their dream job. These conversations were very fluid, so often the answers to these questions were in various parts of the transcript, and some were found in the second interview or in an e-mail or conversation I had with the participants. Answers to these questions were then highlighted in ink or specific highlighter color for ease of finding them.

I then began a series of four written iterations of, first, answers to the questions, then the themes began to be apparent in the second iteration. Each iteration was either hand written or typed and included quotes. Oddly enough, the kinetic experience of writing and typing those quotes helped me to see the themes, their relationship to each other, and the implications they have for rehabilitation counselors and independent living staff. During the fifth iteration, it became apparent that the family and friends, doctors, and society could be collapsed into outside influences. This iteration became the themes as shown after each case study. These themes were placed into a table in Chapter IV so that analysis across the participants could be considered. Finally, I went back to the themes and wrote a short analysis of each person's themes as they related to the research question.

Trustworthiness

Merriam (1998) defines trustworthiness by asking the question, "How can the consumers of research know when the research results are trustworthy?" (p. 198). Merriam suggests that examining the validity and reliability of the research will address the trustworthiness of the research at hand. Lincoln and Guba (1985) ask the questions, "were the interviews reliably and validly constructed; was the content of the documents properly analyzed; do the conclusions of the case study rest on the data?" (p. 378). Firestone (1987) suggests that it is necessary to provide the reader with enough description and detail of the research data and the process to allow a decision to be made about trustworthiness and its components.

Internal Validity or Credibility and Authenticity

Merriam (1998) posits that internal validity deals with the how the findings match the data collected. Lincoln and Guba (1985) call this credibility and authenticity. Examining the original source of the data (e.g., transcripts, journals, written memos) can give a sense of whether the findings matched the data and answered the question of whether or not the researchers answered their research question.

Merriam (1998) suggests several research strategies to strengthen the internal validity or what Lincoln and Guba (1985) call credibility and authenticity. First, I bracketed my beliefs and judgments about the phenomenon at hand in order to limit my biases (Merriam, 1998; Moustakas, 1994). Readers can see my bracketing in the Researchers Stance section of this chapter. Digital audio recordings were made of all interviews, and transcripts were typed up from those interviews. All six participants reviewed their initial transcript and made changes or accepted it as produced. Second interview transcripts were often shorter and focused on facts such as a fuller exploration of their work or disability history as well as any missed questions. It was very difficult to get the participants' attention after the first interview. The first interview was far more content laden and deemed to be the most important transcript to be reviewed by the interviewee.

Once transcripts were approved, coding completed, and themes developed, three of the six initial interviews and themes statements were sent to Dr. Jana Copeland, Rocky Mountain Disability and Business Technical Assistance Center director and employment specialist. She is also a researcher and a person with a disability. Dr. Copeland agreed with my coding schema and suggested added emphasis on two descriptors: all have hidden disabilities and all live in very expensive geographic locations (coastal regions of California). She also raised the issue of connection with others as being limited with a number of the respondents as a possible theme. Because this research focuses on work barriers and not so much the social isolation of individuals, I did not include it as a full blown theme.

Bracketing my beliefs, having the participants review their transcripts for accuracy, and inter-rater reliability are the three strategies I've used to strengthen the internal validity (Merriam, 1998) or credibility and authenticity (Lincoln & Guba, 1985) of my research process.

External Validity or Confirmability

In qualitative research, Merriam (1998) posits that the ability to reproduce the same results is not the goal of external validity. Rather, the goal is to provide enough information that the reader can determine whether his or her situation is enough like the phenomenon being researched that the findings are helpful. To that end, rich thick descriptions assist the reader in making that determination (Merriam, 1998; Lincoln & Guba, 1985). In Chapter IV I have provided a detailed case study for each of the participants interviewed. The thick, rich descriptions should provide the reader with a wealth of information about the individual and the experiences he or she is having around disability and work. Readers can examine the case study and the themes to determine for themselves whether the themes are an adequate representation of the phenomenon these individuals are having.

In addition, peer reviewers were invited to review the themes and my conclusions. The reviewers who were asked to examine the data included two benefits counselors from the ILCs and a disability researcher, all from California. The only reviewer to respond was the researcher. I am particularly pleased to have Dr. Kaye's review as he was the coprincipal investigator on the original research that surfaced the research question central to this dissertation (Yeager et al., 2007). In addition, he pursued his own research on the subject (Kaye, 2009). The complete text of his comments can be found in Appendix F. Dr. Kaye agreed with my themes and had two observations. First, the participants' experience really underscores the need for keeping people who have worked connected to their employment networks from the start of a disability. Waiting so long for vocational rehabilitation interventions is not helpful. In addition, their age and ability to keep up with technology really impacts their ability to make their way back to work. Second, Kaye remarked on how nontraditional this group is for being recruited from ILCs. Perhaps researchers should now be focusing on people with hidden disabilities and no role models.

Triangulation

Triangulation of more than one data source is a method for confirmability of the research. In this project, the digital recordings and transcripts, the demographic survey that each participant filled out, and my journal of reflections are the three data sources. Finally, the literature review on acceptance of disability, in particular, Beatrice Wright's (1983) work on disability and self-concept sheds light on the phenomenon, in addition to Ellis' (Ellis & Grieger, 1977) work on negative self talk and Bandura's (1997) work on self-efficacy.

Summary of Strategies for Trustworthiness

Readers of my research project should be able to determine the trustworthiness of my research through a variety of strategies. To validate my research, I bracketed my beliefs and experiences; provided rich, thick descriptions of the phenomenon, participants, and their thoughts; and asked individual interviewees to review their transcripts. Another researcher reviewed half of my transcripts for interrater reliability. I also used a peer examiner (Merriam, 1998) to review my findings as I developed the themes.

To address the reliability of the research findings, I provided a journal of my field notes describing the participants, the conversations we had, my reflections about those conversations, and administrative decisions made throughout the research process. Finally, I triangulated the research findings and the field notes with the literature review to provide multiple methods of data collection and analysis.

Summary

The ultimate goal of this study was to identify the thoughts and judgments made by people with disabilities who were not working, in their own words. In Chapter IV I paint a picture of the internal barriers to work that these participants experience using the description of the phenomenon and the themes using the statements of the participants. I make meaning of these themes using the theoretical lenses that rational emotive behavioral therapy (Ellis & Grieger, 1977) and social cognitive theory (Bandura, 1986) offer to view the internal barriers. In Chapter V the final results describe the essence (Moustakas, 1994) of the internal barriers to work that these participants described.

The insights gleaned from the participants in this study may be helpful to other persons with disabilities who are fearful of working, particularly those whose disability is hidden and acquired as an adult. The insights may also be helpful to service providers in the field who wish to develop strategies for helping people with disabilities identify their own personal barriers to work. With the number of people with disabilities receiving Social Security increasing and 40% (Livermore, 2009) wanting to go to work, but do not, such a question, asked directly of consumers, may help us better understand why not. The qualitative processes detailed in this chapter serves as the map that leads to the end goal.

CHAPTER IV

DATA

Chapter III discussed the process for collecting the data and analyzing it. This chapter provides a case study for each of the participants and two tables that display the salient data collected for analysis. At the end of each case study is an analysis of that case. At the end of the chapter a cross participant analysis is provided. Chapter V reflects on what the participants told me and its meaning for the field.

Participants

The demographic information that follows and contained in the case studies is from the demographic survey that each person filled out prior to the interviews. The six participants all have nonvisible disabilities; one person with epilepsy becomes a visible person with a disability when experiencing a seizure but, in general, the group does not have immediately visible disabilities—both the interrater reviewer and the peer reviewer commented on the fact that all the participants have hidden disabilities (J. Copeland, personal communication, April 20, 2011; H. Kaye, personal communication, April 26, 2011). Another striking observation is that all but one acquired his or her disability as an adult. The peer reviewer indicated that this is a nontraditional group of individuals that typically do not use ILCs for other services so they do not (a) identify themselves as disabled, (b) typically do not have role models, and (c) do not typically show up in research other than surveys (H. Kaye, personal communication, April 26, 2011).

Table 1 shows participants' ages range from 24 to 57, two are male and four are female. Ethnicity ranges from Asian to Caucasian with one person reporting mixed heritage that includes Asian, Native American, and Hispanic. Two are on SSI, three are on SSDI, and one recently applied for SSDI. Two individuals have used workers compensation and one has a disability retirement pension from the city in addition to SSDI. Time on benefits ranges from just submitting an application for benefits to 9 years. All live in coastal cities in California, which are among the most expensive in California (J. Copeland, personal communication, April 20, 2011).

Table 1

Demographic Information

Name[a]	Gender	Age at interview	Disability	Benefits	Time on Benefits	Ethnicity
Alice	Female	34	– Bipolar – Drug addiction	SSDI	Just submitted application to Social Security	Asian
Joan	Female	24	– Epilepsy	SSI	7 years	Asian/ Native American/ Hispanic
Molly	Female	51	– Fibromyalgia – Depression	SSI	3 years	Mixed European
Sam	Male	54	– HIV +	SSDI and SF Disability	7 years	Caucasian
Suzanne	Female	57	– Limited mobility – Degeneration of cervical spine – Depression	SSDI	8 years	Caucasian
Bob	Male	54	– Bilateral thoracic outlet – Syndrome with dystonia	SSDI	9 years	Caucasian

[a] Names changed to preserve anonymity.

Data—Case Studies

The following section describes each of the six people who participated in the study. At the end of each study are the themes from the interviews arranged into six topics: outside influences, sees self as a person with a disability, thoughts and fears about work, QOL issues, other themes, and their dream job. Outside influences address the external influences that may have played a part in their thoughts about work. These include family and friends, doctors, and society at large. An analysis of each participant's themes can be found in the data analysis section of this chapter.

Alice

At the time of the two interviews conducted, Alice was a 31-year-old Asian woman who has just successfully submitted her SSDI Benefits application in December 2010 for multiple mental and physical health issues of which bipolar disease is the most serious. She has a dual diagnosis as she has been self-medicating for years with drugs. Nearly homeless at the time of our interview, she is the most precarious in terms of having basic needs. It is a testament to her value of work, that in the month she applied for federal benefits she attended a workshop on how to work while on SSDI benefits where she was recruited for this research project. In reality she will probably not be able to work for at least a year; however, she clearly articulated fears about work, described her dream job and has the education for it, and articulated a healthy sense of integrating her disability into her self-image. For those reasons, her interview and data are included in the study, even though her current health status precludes work for now.

Alice describes herself as “a woman without a country” as she was born in Taiwan, which is not considered a true country with a separate culture. She immigrated with her parents and two older siblings when she was 6 years old. Alice sees this event, the resulting lack of a feeling of belonging and her parents’ culturally induced inability to address her childhood emotional health as setting the stage for the disabilities that have occurred in her life. She indicated that she was an “unplanned baby” so her parents had not saved up money for her education. From an early age, she knew that she had to take care of herself financially and be ready to support her parents if needed. Alice saw the sacrifices her parents made for the children to succeed in this country and vowed they would never have to worry about money again when she grew up.

She had problems as a child immigrating to America; she experienced Attention Deficit-Hyperactivity Disorder (ADHD) as well as major depression, and these issues were not addressed. At age 12 she acquired an eating disorder that made the depression much worse. She bounced between deep sadness and extreme energy between the ages of 12 and her mid 20s. During high school she began to smoke to help cope with the depression. After she got into college she experimented with heavier drugs to help medicate her mood swings and found a combination that worked for her.

Growing up, Alice was always fiercely competitive; she had a strong drive to succeed at whatever she tackled even though she suffered through anorexia and severe mood swings. As a child she played the violin and guitar. She loved music but did not consider music to be a viable way to support herself. She began to take college classes in high school and was able to finish her bachelor of arts and master of arts in business in four years. She chose business because she saw it as a skill that "helped me to develop [into] a person that could protect myself but also always have a career so that I am not going to ever worry about financial stability like my parents did." It was her intent to provide for not only herself but her parents, too.

In June 2001, at the age of 20, she took a job as an investment banker at a bank in New York City to show that she could excel right out of the university. She describes her life as going from manic to depressive states and now understands that she has bipolar disease. Not understanding that she had an illness she self-medicated with drugs acquiring a co-disability of addiction. In March 2002, after 9 months on the job and the events of 9/11, she was one of many financial specialists who were let go in New York. She traveled internationally and resumed her interest in music for a time, then went back to San Francisco.

In September 2003, Alice then went to work for a major accounting firm for about 18 months and began studying for her Certified Public Accountant (CPA) license. She put in the hours needed to take her exam and passed it. She left that firm in April 2005.

Her next job was with a video game producer; she worked from April 2005 to April 2006. Alice was the accountant and finance person; a one-person office handling all the accounting and finance work for an electronic games developer. She liked that she interacted with every department in the organization. Her last and best dream job was working with a startup airline company that became famous for its inexpensive flights. She admired the founder who was featured as an entrepreneur at the time. From April 2006 to December 2008, she worked during the start-up, launch, and post launch mode of the airline before her body crashed and she left the company. “And that is when my body was fighting me and I didn’t even know it consciously that it was dying to get out of the business world. It was done.” She had pushed her body as far as it could go. At the end of 2008 she was finished with a business career.

In 2009, she went to England to earn a certificate in digital music engineering, having made the decision to focus on music rather than the business world. Early on during her stay in England, Alice had an abortion that triggered post traumatic stress symptoms. She did not have the place or support to process that loss, which triggered severe emotional distress. While it was difficult to cope with that and get her certificate, she did persevere and finish her education. She also tried to find a job in England with no success. It was here that Alice figured out that she had bipolar disease. Alice found that emotional stress triggered more physical symptoms that worsened the bipolar disease. In 2010 she came back to San Francisco, thinking that she would get a job and health benefits so that she could start to deal with the mental health and physical issues.

Alice tried desperately to get work, but by this time her emotional health was causing physical problems. She contracted a deadly staph infection on her skin, which left blisters on her face and body. These were very painful and unsightly. She found that employers would not hire her. In retrospect, she knew they were right not to hire her as she was too sick to work but needed work for health insurance. Alice did try to work by taking a job for 10 hours a week in an upscale animal hotel. She received animals that were being boarded for a length of time, a job that she really liked. However, Alice found that just working 10 hours a week to be exhausting. This exhaustion was very anxiety producing; she had always been able to work 80 to 90 hours a week in a demanding job but now she could not even do 10 hours in a fun, nonthinking job. The more she tried to work and then failed, the more anxious she became, which led to more stress and physical symptoms that kept her from working. Most concerning, she could not get health insurance. What was happening to her?

After spending down her assets and liquidating all of her retirement accounts to live and get some medical care including a few emergency room visits that were very expensive, she finally was poor enough to qualify for the City of San Francisco's indigent treatment clinics. It was here that she found formal confirmation that she was bipolar. She put together her own application for SSDI in early December 2010 and is awaiting the final disposition of the application. With the help of her parents and doctors, she has been assigned to a case worker at Social Security who is reviewing her file. Alice feels that she is very likely to be successful in getting SSDI. While Alice is waiting for her award, back pay, and monthly check, she is receiving treatment for her physical conditions and starting to work on the bipolar issues, including detoxification of her drug addictions.

Alice talked about her fears of going to work. Outside of the recorded conversation, she indicated that she fears going to work because she will be so self-conscious of who and how she used to be at work and that person is no longer there. “And that, in and of itself, will make me uncomfortable. . . . Everything about me is different because of all the disabilities.” She believes she will be very self-conscious of what she needs to do to keep her balance; she needs an unstructured environment and wonders if employers will be open to that requirement. Alice indicated, “I actually did go back to work and it was difficult.” The pet hotel job for 10 hours a week was too exhausting. “There comes a time when your disability does get in the way.” Alice wonders if she can work: Can she be productive in the traditional way that employers want?

Alice’s dream job would be to work for herself as a digital music engineer and produce music. That way she can work at her own pace and manage her disability as needed. But first she must detox and get her bipolar disease under control. Her doctors are encouraging her to take a least a year to treat her dual diagnosis before considering work; however, they are optimistic that she can work. Her parents do not want her to work but come and live with one or the other (they are now separated) and focus on getting her health back. Her siblings are in shock as they had no idea she was sick. Her view of society’s view is that “people with disabilities can’t do things.”

When asked about society’s views of people with disabilities Alice felt that the word disability, “for most, would be quite a negative thing” and she blames the media for their one-sided portrayal of people with disabilities. Alice felt that the media generally focused on only those with visible disabilities. She felt that people should be educated about both physical and emotional disabilities. Alice indicated “there is a wide variation of [disability]. Right? And you may be good at one job and may not be good at another . . . people have a very first level-surface level [understanding of disability].”

I asked Alice what she thought of her ability to work, and her answer revealed that she had not let the notion of a disability over take her entire self-image.

> I do not feel that I am any less capable than I guess right now where I am . . . what I have been through has made we a more deeper person and more understanding. And has made me probably more capable. Once I overcome these physical disabilities [symptoms] like getting tired too fast and all that stuff. But in terms of my intellect and creativity inside, I didn’t lose it.

Alice went on to list several positive personality traits that have been deepened because of this experience. She is relieved in a way to have the diagnosis as it ties her experiences in life together in a way that makes sense,

> I started smoking in my teens and drugs in my 20s. Now I know why because I was so chaotic inside and on no medication because I didn’t know. Nobody did. Yet I was accomplishing a lot of things, more so than a lot of my peers. Well, now we know why. I was in mania.

The current turmoil and instability in Alice’s life, her anguish at not being able to support herself and having to rely on others was very evident. Right now, her QOL suffers because she is struggling to get her basic needs met and get the health care to address her disability so that she can start her dream job.

Theme: Outside influences. Alice credits the lack of having a national identity—she didn’t fit in while trying to assimilate along with parents who were culturally not prepared to provide the emotional support needed for this transition as the beginnings of her disability. “I have experienced a lot of culture clashes between eastern, west and because of where my parents grew up I did not have any emotional support . . . it is not really something as important in the Asian culture." Her fears and anxieties were exacerbated by the tendency toward bi-polar disease and depression in her family genetics, another influence on her thoughts about work.

In terms of thoughts about disability, her parents were reluctant to accept that she had a mental health disorder fearing that others would think they caused it. "[It is hard for my parents to accept a mental disability]. They did not want people to think their daughter was crazy and they had caused that." However, they now believe that she should not work but focus on getting her health back. Her doctors, who are very new to her, are "in full support of me taking at least a year off [to recover]. . . . They are not discouraging [about work] at all."

Alice sees society not having a good understanding of disability, particularly hidden disabilities. "I think the word disability is interpreted in so many ways . . . it would be quite a negative thing. . . . But I think people need to be educated about what disability really means. That is it could be physical, mental or both. . . . Most people react negatively . . . because they don't quite understand it."

Finally, Alice sees having a hidden disability may be more difficult than a visible one. "People think you are lying or being lazy or something" when they cannot see your disability.

Theme: Does she see herself as a person with a disability? While Alice was relieved to have confirmation of her disabilities and a diagnosis that made sense to her, she sees her disabilities as having made her a different and better person.

> I have done a lot of self reflection the past two years and I have come to the conclusion that I am someone who never had a country and identity really.

> And who I really am is actually a combination of my disabilities. And I don't see that as a bad thing even though I have suffered a lot for it. It has made me become who I am; a much stronger, empathetic person. . . . If anything I think what I have been through has made me a more deeper person and more understanding.

Alice has a healthy perspective about having a disability. She seems to understand that this is just one part of her.

> Right now I can say that I am not less about than what I was before. If anything, I think that what I have been through has made me a more deeper person and more understanding. But in terms of my intellect and creativity inside, I didn't lose it.

Upon reflection in my journal, I believe that Alice is successfully integrating her functional limitations into her self-image in a positive way.

Theme: Thoughts and fears about work. Alice sees her disability as changing her for the better and for worse—she is uncertain as to how to manage that change with potential employers. "I am definitely not the same person when it comes to work in terms of my energy level and mental level . . . everything is different about me as a person because of all the disabilities." On the other hand, "My empathy has really, really increased . . . [my disabilities have given me] a better understanding of people, a better ability to handle problems at work or even prevent [them by anticipation]."

"I am afraid I will be different. I will be self-conscious about how different I am now" (personal communication, January 29, 2011). Alice speaks to her fear of being different and remembering who she used to be—a woman who could work 80 hours a week. "I didn't know I had [bipolar disease]; therefore, I wasn't conscious of my behavior. But now I do know I am definitely going to be conscious of my behavior. And that in and of itself will make me uncomfortable." Alice is struggling with how she will be as a person with a disability at work.

Will employers accommodate her needs? "I realize that what I have is quite peculiar." Alice feels that working in a "[highly structured] environment is really unhealthy for me."

Finally, Alice did try to work and was unsuccessful. "I actually did go back to work and it was difficult. It does get to a certain point where your disability does get in the way." Having a history of being unsuccessful while working with a disability can be a detriment to trying it again. In Alice's situation, she realizes that she must get her physical and mental disabilities addressed before trying to work again.

Theme: Quality of life. It did not seem appropriate to ask this question directly because at the time of the second interview all of her life savings had been spent trying to meet her basic needs while she looked for a job. She was unable to keep a job because of her health. Finally, she was about to become homeless while waiting for benefits to kick in. But I believe that for this smart, accomplished and competitive woman, work will be important to rebuilding her QOL. "I do know I need to work because you know I am adult. I need to be responsible and one of the things is you need to be able to financially support yourself."

Theme: Other. Lack of access to health care impoverished her before she could get help. Alice had to liquidate all of her savings including retirement before getting the comprehensive help she needed to document, begin treatment of her dual diagnosis, and successfully apply for social security benefits.

Theme: Dream job. With a Masters in Business Administration (MBA) and CPA license, her business experience ,and having trained as a digital music producer and performer, Alice would "like to be my own independent artist with my own label and have musicians that work with me and DJs and be doing my own performances out." Alice feels being self-employed will be key to maintaining the kind of work environment that will accommodate her functional limitations.

Joan

One interview was conducted with Joan, who is 24 and of mixed race, that is, Asian, Hispanic, and Native American (demographic survey). She has lived a very sheltered life because of medical issues. She had extreme asthma in childhood, which often hospitalized her. She spent most of her childhood in hospitals and was home schooled. While Joan's asthma became much less of an issue after the age of 16, she developed epilepsy (which is not well controlled and rheumatoid arthritis [RA]), perhaps because of the long-term use of steroids during childhood. She spoke in a soft voice and apologized often for not having the right words or being able to communicate as well as she would like. She has been on SSI for seven years.

Joan indicated that at this point in her life she physically feels "the best I have ever felt." She used to use a cane and should have used a wheelchair but just refused to get into the chair. She proudly explained that her mother told her she is a very strong person for refusing the chair. Her RA is in remission, so for now she does not use a cane. She is breathing fine but her epilepsy is not under control. She has a seizure about once a month, which can affect her for around three days. "Whenever I have a seizure, particularly a big one, it puts me through a depression." She is usually very fatigued afterwards and confused. She withdraws socially and it takes time to get back up emotionally.

Because of the lack of expectations from her family and receiving most of her primary and secondary education in a hospital or home schooled setting, Joan has had limited contact with the outside world. She was an average student in her high school years and berates herself for not being a better reader. Joan's interests include art and gardening.

Recently, she completed two semesters of college, against her parents advice. She took general education and art courses. Joan indicated that she loved going to school and seeing that there was a much wider world out there. On the other hand, she experienced panic attacks when she did not know how to handle situations and people with whom she came into contact.

Her parents worry about any work that could cause Joan to lose her benefits.

> And my family is so protective. They don't want me to get a job. They still think I need someone to you know help me out all the time. So I am trying to prove to my family that I can do it. At the same time I am trying to convince myself I can do it.

Joan has heard the message very clearly from her parents that she is too fragile or sick to be able to take care of herself. The parents' life plan for Joan is to live with them until they die at which time she will go to live with her older sister. The SSI that she receives gives her access to health insurance and her medications, which are quite expensive. She does not have access to her benefits check and has no knowledge of how it is spent.

> One of my biggest goals is to actually be independent and live on my own and have my own job. I am still not able to take care of myself yet. I am just kind of afraid. . . . It is a big step from just being at home with my family.

However, Joan's parents,

> repeatedly tell me how I am unable and I am disabled. So it kind of put my mindset on I can't do it. I am disabled but I just have to change the way I think. It is more of a mental kind of battle at the moment to get out there and think I can get through college and get a job.

Joan did try to work at one point. Her aunt hired her to come in to answer the phones and take messages. Her aunt is "a hard business woman. . . . She was always frustrated with me because I needed extra help in understanding. . . . I didn't know how to handle like phone calls and simple things." Joan does not think she is very smart.

When asked about her dream job, she indicated that it needed to be with a small employer who would understand her disability and training needs. "I can't picture myself doing anything bigger than that." When asked if she thought she would finish college she indicated, "I really don't know." She would like to work in a plant shop. She can see herself talking to people, ringing up their purchases and making change. She sees herself "smiling and more pumped up." When asked what it would be like for her to work, she said, "I think it would be great. I would feel more comfortable in my surroundings [with a little support]. But I think [work] would actually help my confidence."

Joan indicated that her fears about work center on lack of experience. Several of her friends and family say that she has to be able to socialize with people and not run away from conflicts with others. Her aunt scared her when Joan made mistakes answering the phone. But she just didn't know how. Her family has told her that she is "not the best." Joan indicated that people "usually see me as like 16 on the way I communicate and act. . . . I still act like a child. Like I need help."

Another fear she has is the impact of work on her insurance and social security. Her father takes care of all that, but she is afraid she might lose access to her medication. Her doctors seem to still see her as living at home and not going out much. One doctor did tell her about a program for people with epilepsy who want to work. She was thrilled to hear about it and is in the program. Joan is trying to work with the program "but my family doesn't want me to do it and they are afraid I will lose my social security."

Joan sort of sees herself as a person with a disability but more thinks that it is "automatically in my mind that I can't do it other [rather?] than using the disability." Joan indicated that she is "kind of determined like I can work. I think it is more like, oh that is my dream. But I feel like I can work. I can get out." The last two lines were spoken in a very strong and different voice than the rest of the interview.

Joan's lack of experiences in the work world, that many people get as a teenager coupled with her parents complete belief that she cannot work, is quite a barrier to overcome. Joan somewhat reluctantly sees herself as having a disability, which is a negative attribute, but thinks her deficits can be overcome through more experiences in the outside world. While her basic needs are being met, her need to contribute and grow into an adult seems to be thwarted by her parents' attitudes. Her QOL is filled with frustration at the moment.

> I am not really fully satisfied because I am depending on others. And it seems at the moment all the income I guess, social security—it does go to my—I guess I have an account but my parents control it.

Theme: Outside Influences. Overwhelmingly, Joan's parents' belief that she is too disabled to work has influenced Joan's view of working. However, Joan is struggling to reject that view.

> My family is so very protective. They don't want me to get a job. They still think I need someone to help me out all the time. So I am trying to prove to my family that I can do it. At the same time I am trying to convince myself I can do it.

In addition, her parents are fearful that Joan will lose her health insurance; "they are afraid I will lose my social security."

Joan's friends with disabilities, mainly those she knows from her lengthy stays in the hospital, are not independent either. Her doctors for the most part, see her as being at home, although one physician did suggest she try a program "for people with epilepsy if they want to pick up a job and have help." She is trying to follow up on that referral. She has not "thought much about" what society says about people with disabilities, although "that is how they probably see me."

Theme: Does she see herself as a person with a disability? Joan is only 24 years old and has not been much exposed to the outside world. She cannot articulate her own thoughts about her view of herself. She does consider herself "a person with a disability" but cannot expand on that view. She indicated that her parents "repeatedly tell me how I am unable and I'm disabled so it kind of puts my mindset on I can't do it."

Theme: Thoughts and fears about work. Joan has fears about her competence to handle work and new experiences.

> It scares me . . . when I try something new I start to kind of panic and it just brings on another seizure. I am kind of afraid of going out there and having an episode where I won't be able to do my job. Just getting out there is kind of intimidating. . . . I fear I won't be able to, you know, keep it up and actually go forth and do it.

Her seizures, which are not controlled, are a barrier to work, "it puts me through a depression." She feels that she sometimes still "acts like a child" and will not know how to handle every day issues. "Since I don't go out very much, I am so afraid that if I have a panic attack or anything that is too overwhelming. I am afraid and don't know how to deal with situations."

Joan shares her parents' fear of losing her social security and medical insurance if she works. "I would like to work but if I lose it [social security], then I can't afford my medications."

In spite of all the fears she has, she believes she can work. In a very strong voice, different from the rest of the interview, she declared, "Oh that's my dream. But I feel I can work. I can get out." Joan indicated it is a matter of changing her mindset. "I have to change the way I think. It is a mental battle at the moment to get out there."

Theme: Quality of life. Joan does not experience a good QOL because she is dependent on others who don't expect much from her and she has no income herself.

> I am not really fully satisfied because I am depending on others. . . . And that is one of the main problems I am having. An it seems at the moment, all the income, I guess social security. . . . I have an account but my parents control it.

This must be very frustrating for Joan given the developmental stages of autonomy that she is not achieving. “It is not very encouraging [to have people not expect much].”

Theme: Other. It is striking that she has no information about services or supports for people with epilepsy and seems to have no one championing her rights or abilities to become independent. After the interview but before the end of our telephone call, I asked Joan about her resources and knowledge about epilepsy. She indicated that she did not know any of the resources I named such as service dogs for people with epilepsy and the Epilepsy Foundation websites (personal communication, February 2, 2011).

Theme: Dream job. “I would like to work in a [plant] nursery . . . I can’t picture myself doing anything bigger than that.”

Molly

Molly is 51 and lives on a boat in the San Francisco area. She has been diagnosed with fibromyalgia since 2003 and started receiving SSI three years ago, in 2007. Her parents immigrated to America but she declined to name the country from where they came (demographic survey). She was born here in America, but the family returned to their native country when she was 11. She has one older brother and two younger sisters. Molly went to primary school in America but graduated from high school and attended a university overseas. Molly stated that her family engaged in satanic ritual abuse in which she was the target during her childhood. She indicated that her mother was addicted to drugs when Molly was born. She spent her childhood on drugs but no longer does them. Molly has been straight for 20 years through Narcotics Anonymous (NA). Her parents are alive but living in another country. She has very little if any contact with them or her siblings as “they would be extremely detrimental to my well-being.”

Molly indicated that she is quite smart and was accepted in art schools both in Europe and America. She attributes the stress of the childhood abuse as the cause of her disability. She has multiple personality disorder and is working to re-integrate herself. She is on a waiting list for mental health services. While studying philosophy in Europe in 1989, she collapsed and was diagnosed with pain and fatigue, which kept her in bed for eight months. She was unable to finish her philosophy degree. Molly worked several typical student jobs during her first stint in college: “selling magazines, or in a little kiosk, or working in the food place at the student mess hall. Just stuff like that. Nothing that would lead to a career.” Molly thought that she would get a degree and a real job but that did not occur.

She then moved back to America and got accepted to several art schools here. Half-way through her Masters in Fine Arts degree, she collapsed again. She was able to finish the degree in 2004, but it took more time than expected and she has not been able to work since then. She was diagnosed with fibromyalgia in 2003 and started receiving benefits in 2007. Receiving the diagnosis gave her “relief” and clarity about her life, “Oh! I am not crazy.” Molly researched fibromyalgia and was not surprised to find that “eight to ten of them went through some sort of abuse. Well, duh.”

Molly describes the impact of her disability: “Well, there is chronic pain and then there’s insomnia and then there is fuzziness, inability to concentrate, and then there’s depression. So between all of that it is hard to function.” There are some treatments but the only type that she is interested in is the anti-inflammatory drug. She does not want anything that “affects my mind because I feel like I don’t want to get any fizzier than I am.” Molly’s disability is quite unpredictable day to day and she finds that she is more able to work in the afternoons and evenings as opposed to the mornings.

When asked about her feelings about having a disability she responded,

> I try not to think about it. It makes me feel worthless, it makes me feel extremely frustrated and angry because I know I’m smart, intelligent, I’m articulate, I’m creative, and I’m talented and I can’t do anything with it . . . because of all these health issues.

She worked hard to “make sure nobody notices” her disability, which took quite a bit of energy until she couldn’t do it any more and got sick the first time in 1988.

Taking a pragmatic approach to the question of work, Molly indicates that she is interested in teaching.

> Well it is one thing that comes to mind because it is something I am qualified for and it isn’t like flipping burgers. . . . I paid a lot of money to get a good education and it would be nice if that would connect to something I would do.

Molly relayed an experience that gave her an insight about work. While at NA one day after her art classes, she had her sketch books and she played with the kids that were waiting for their parents. She enjoyed drawing and thought maybe she should be an art teacher. She likes kids and loves art. “But I don’t want to do it on a volunteer basis. I help people all the fricking time voluntarily. I want something real. Something for me. Something that has my name on it."

When asked about her fears about going to work in the first interview, Molly could not respond directly. "I am drawing a big blank here." She indicated that she is "always terrified of everything" but does not tell herself anything. She just "freezes . . . just like a pinball machine. It goes on overload . . . that doesn't help for me. I can't go there in my head. I can only go there in person and see what happens."

Molly described resistance as another barrier when talking about looking for work. "It is like trying to drive with the brakes on. Doing anything, like, it is so hard. It is harder for me than for other people." When asked for an example she talked of trying to do something and "after eight or ten times of getting a no or not even being noticed . . . I don't have it in me to keep doing that."

However, during the second interview, I asked the same question again, and her response was much more descriptive.

> All the old voices that always told me I was worthless and no good, blah blah blah. . . . It is like this committee that is always criticizing everything. It is mom's voice and my dad's voice and my main abusers. They are yelling at me about how it is never going to work.

Molly talked about not wanting to engage with the tape but remove it altogether.

During the first interview Molly could not respond to the question of what a dream job might look like.

> I don't know. I can't do that. I always need parameters. I don't want to get my hopes up and then get them crammed again. . . . I can never predict how I am going to feel. So making that kind of commitment [9 to 5 job] and having to call in sick all the time is really what keeps me from trying to find something like that.

After the recording of our interview, she called me back, through Skype, to tell me that she had a dream in which she was working with vulnerable kids and animals to prevent abuse.

In the second interview, Molly indicated that she had had a breakthrough in thinking about work. “Things have been shifting and changing.” She decided after attending a psychic healing program that she had been too limiting what she thought about work.

> What I have been putting out there is not so much along the lines of what I think I should be doing or what I could be doing. I am limiting my possibilities . . . I have decided [I want to do] what I need to do and what I came here to do. . . . I am just being open to being guided to what it is. Does that make sense?

Molly described herself as having had blinders on when it came to thinking about what work she wanted to do. Now she is going to take several aptitude tests at her next Department of Rehabilitation appointment and see what they indicate. Molly really wants what is right for her in terms of work so she doesn’t “just lock myself into a certain area but see what comes up.”

For Molly, it is important to contribute, “Like, if I don’t feel useful, I don’t want to be here.” During her first interview she indicated that,

> for me personally at this point if I could just do something even for a few hours a week where I felt like I was contributing. You know, part of a regular life. . . . I hate feeling useless . . . for me, paid work does make a difference.

When asked about her QOL, she indicated, “that would be no. I want a real life.” SSI is “enough not to die on,” but Molly wants much more. “I want freedom. I want independence. I don’t like being dependent on anyone.”

Theme: Outside influences. Molly's outside influences about work focus on her parents and other abusers who have become "the [critical] committee [in my head] always told me that I was worthless and no good and it was never going to work." Society and doctors seem not to have had an influence on her views about working as a person with a disability. However, Molly has a strong internal drive to work and contribute, which powers her through her struggles with fibromyalgia and multiple personality disorder. "This was my big hope of being able to be self-supporting through my own contributions and to be able to participate in society."

Theme: Does she see herself as person with a disability? This is a label that Molly doesn't want to think about or accept as it is devaluing. "It makes me feel less than, it makes me feel worthless, it makes me feel extremely frustrated and angry because I know I am smart, intelligent, I'm articulate, I'm creative, and I'm talented and I can't do anything with it."

Theme: Thoughts and fears about work. Fear of rejection and disappointment leads to resistance for Molly, which makes it hard to try working.

> I am always working against [my own] resistance. It is like trying to drive with the brakes on. Doing anything, like, is so hard. It is harder for me than most folks. . . . After eight or ten times of getting a no or not even being noticed, it is like why would I—I don't have it in me to keep doing that. . . . [When thinking about work] . . . I cannot think about work . . . everything freezes, like a pinball machine. It goes on overload and everything freezes.

Molly is determined to work as she sees employment and the recognition from it as a form of validation. "It is a form of validation . . . it is a very concrete way to value your contribution." She sees work as a way to "participate in society."

Theme: Quality of life. Molly does not experience a high QOL and believes that purposeful work that pays enough to give her independence and freedom is the key.

> I want a real life. [Lack of quality of life] I think is not having a sense of purpose or a sense of usefulness . . . and a connection to regular society. . . . Like, if I don't feel useful, I don't want to be here. . . . I have always just wanted to be normal. . . . But being on SSI, I mean, it is just enough not to die on.

However, Molly needs more money to live a regular life.

Theme: Other. Lack of access to other forms of mental health therapy to help her integrate her multiple personality is striking. The medical field is focusing on drug therapy as opposed to talk therapy. For someone who was born with chemical addictions and successfully struggled to shed them, she is seen as noncompliant.

> The total therapy thing is like everything is being flushed down the drain with all the drugs and all that. I am on two waiting lists [for talk therapy]. The first thing they want to do is they want to put you on pills and when you don't want to get on pills you are noncompliant.

Theme: Dream job. At first, Molly couldn't be specific: "I don't want to get my hopes up and get them crammed again." After more probing, Molly firmly indicated that "something like teaching would work" as she could see herself teaching art to children which would combine her Masters in Fine Arts degree and love of children. She felt that teaching could provide her with a flexible enough schedule to accommodate her fibromyalgia. Later in a personal conversation Molly shared a dream in which she did work that protected children and animals. In the second and final interview, Molly indicated that she had a break through. "Things have been shifting and changing. . . . I am limiting my possibilities [and think] I am just open to be guided to what it is [that I should be doing].” Later that week Molly was to go to her Department of Rehabilitation counselor and take some interest and aptitude tests. She was open to the information it might give her.

Sam

Sam is 54 years old and has been on city disability retirement first, then SSDI for four years. He lives with a partner in San Francisco and has contact with his two sisters. Sam acquired the HIV infection around 1982, and while this played a role in his physical deterioration later in life, he did not take drugs to counteract it at the beginning. He and his doctor had an agreement that he would consider medications when he had two consecutive low T-cell counts. That would not actually occur until 2006.

Sam has lived in northern California all of his life. He grew up on a farm in the Central Valley with an older sister and younger brother and sister. His father was a farmer and his mother (who grew up in the Bay area) often took them to San Francisco to experience the arts, music, and culture. Sam knew from about the age of five that he wanted to live in San Francisco. At the age of 17 he left home to attend college and did not return to live in the Central Valley. His mother died of a stroke when he was 21. His father lived a long life and died of complications with Alzheimer’s disease at the age of 93.

Between 1975 and 1980, Sam got a Bachelors of Arts degree in film making, which he never used. However, he acquired clerical skills through work study so when he graduated from college, he got a clerical job with the United States Public

Health Department as a “stop gap measure.” That clerical position lasted for 10 years (1980 to 1990), and he was promoted up the ranks to the executive secretary position in the federal agency located in San Francisco. The stress of the job became more than he wanted and the director was unpleasant, so he stepped down to go back to school.

Sam loved gardening so, in 1988, prior to leaving his position with the United States Department of Public Health, he went to the San Francisco City College to get an Associate of Arts certificate in horticulture, which he completed in 1991. He went to work in 1990 as a city gardener in San Francisco and worked there for 15 years. He loved the job but long term exposure to pesticides, repetitive motions, and lots of walking on uneven surfaces for those 15 years caused his body to break down. Sam became susceptible to a lung fungus (Aspergillus), and had problems with his hands, arms, and feet. After working to ameliorate some of the physical issues and suffering from several lung infections that took quite a while to heal, Sam decided that perhaps he should look at another career. In 2003 he went back to City College to study nursing.

As the Aspergillus fungus became a worker’s compensation issue, Sam left his city gardener position in 2005 and finished his nursing training. Sam loved being a student and was the student representative to the faculty senate where he presented student issues for the two years he was there. In 2005 he took a full time position as a nurse at San Francisco General Hospital. He did his internship in the Step Down Unit and was hired to work in that unit. The Step Down Unit deals with people who are stepping down from the Intensive Care Unit or stepping up from the Emergency room.

It is very fast paced with lots of sick, contagious, and sometimes combative patients. Sam felt he was a good nurse and was particularly good at patient interactions which were not encouraged by management. It was here, after three and six months on the job, that Sam's T-cell count "went into the toilet." Sam then went on medication for HIV that, it turns out, had an interaction with the anti-fungal medication controlling the Aspergillus. Sam left the nursing position in November of 2006.

The impact of the drug interaction was that Sam lost some cognitive functions: his ability to do simple math, his judgment was impaired, and his immune system was suppressed. These are all very serious issues in a nursing environment where one must calculate medication doses, make quick decisions, and be in contact with contagious patients. The stress of the position, being exposed to very sick people with contagious illnesses, and Sam's own suppressed immune system led his doctor to recommend that he take disability retirement from the city of San Francisco. He received his disability retirement from the City in February 2007 and secured SSDI by May of the same year. He has not worked at all since November 2006.

When asked about his thoughts on going back to work, he replied, "That I am actually happy not" to go back to work. Sam felt that retirement agreed with him. He did not have a problem with boredom, and felt his life was pretty complete. "I don't miss my identity as a worker." Currently he manages the house by taking care of things and seeing that household duties are completed. He has a partner and spends time reading, going to movies, and working on his computer (personal communication, February 16, 2011). Sam likes his time to himself and not being on a schedule set by others. He gardens and works to maintain his health (yoga for breathing and weight training for osteoporosis and the effects of HIV medications). He has friends that he spends time with. These activities are how he has reconstructed his life and identity. When pressed for what he might do if he had to go back to work, Sam indicated that he has very good interpersonal skills and could do other things besides gardening or nursing. However, he is not interested in pursuing those options now.

Sam indicated that his income meets his needs. He has friends who are desperate for work and feels it is better for him not to take a job from them or anyone who is fully able bodied and needs to work. He describes himself as very adaptable so he can live on the amount that he gets from the city's disability retirement system and SSDI. He is happy not to work but mentioned that often others "directly express envy" because they, too, would like to be retired, even though they do not see or understand the disability aspect of his retirement.

In terms of fears about work, the only fear Sam talked about involved fear of re-injury through face-to-face contact with sick people. He travels very infrequently by airplane because of his vulnerability to lung infections and the difficulty with healing those infections. Sam's family (two sisters) has been very supportive of his activities to manage his disability and decision not to pursue working. He is not in contact with his brother.

When asked via e-mail if he saw himself as a person with a disability, he indicated "Yes, I do see myself as a person with a disability, albeit one that I‘ve adapted my life to" (personal communication, March 9, 2011). It appears that he has integrated his disability into his self-image in a balanced manner. He seems content with his life and his satisfaction comes from the freedom he has and his role of taking care of the household.

Themes: Outside influences. Family members have been supportive of Sam's decision not to work. "My sisters have really been supportive of what I have been going through and how I have been having to deal with it." Doctors have supported him in dealing with his disability, but given his choice not to work, they don't seem to play a role in reasons for not working. Sam has a positive view of his life with a disability so society seems not to have played an overly negative role or he has dealt with the stigma.

Theme: Does he see himself as a person with a disability? Sam does see himself as a person with a disability "albeit one that I have adapted my life to" (personal communication, March 9, 2011). Sam seems to have a realistic view of his disability and limits its impact on his self-esteem. He sees his life as complete without work and has constructed a new identity that accommodates his functional limitations without limiting his life satisfaction.

Theme: Thoughts and fears about work. Sam feels that retirement has agreed with him and when asked what comes to mind when you think about going back to work, "that I am actually happy not."

Expressing concern for others who need work, Sam indicated that he doesn't want to take a job from someone else if he doesn't need it. "I'm not particularly interested in filling this spot in the labor market. I am not taking a position away from someone else who is able bodied . . . and wanting to work. I am lucky . . . I have enough to meet my needs."

Finally when pressed to name any fear he might have about work, he indicated that he was fearful of re-injury or causing re-occurrences of lung disease with contact with sick people. "The fear or thing that would prevent me {from working} is just coming into contact with sick people." When questioned about face-to-face contact, Sam replied, "yes, that is something I try to avoid."

Theme: Quality of life. Relatively young at 54, Sam is happy not to work after 30 years of high level clerical, gardening, and nursing careers. "I don't miss my identity as a worker. I feel like I manage the house now." Sam has reconstructed his identity around other life activities. He gets his satisfaction from keeping his own schedule, tending his small garden, maintaining his health through specific exercise, friends, movies, and hosting a yahoo group for former nursing classmates in addition to being the keeper of the household. When asked if he felt his life was pretty complete, he responded, "yes, I feel like it is. Yes."

Sam's income from his disability benefits is adequate. "I am in a situation where I have an income from my disability . . . I am lucky. My financial situation has worked out that . . . I have enough to meet my needs." Because of health issues, Sam does not travel very much and lives a relatively simple lifestyle.

Theme: Other. Envy from others who see his lifestyle as easy and wish they could do the same while at the same time not understanding the work Sam puts into maintaining his health and avoiding sick people. "Sometimes I get a lot of directly expressed envy . . . they just see it as someone who doesn't have to work anymore and don't necessarily read all the reasons behind it."

Theme: Dream job. If he were to consider work, Sam would like to do something that uses his interpersonal skills. "If I were in a situation where I could use interpersonal communication skills I could see my self doing that." The only caveat is that he must avoid sick people as much as possible. If Sam came to me for career guidance one of the jobs I could see for him would be a telephone-based nurse advocate and coach helping people understand their diagnosis and options for a medical facility or health insurance company.

Suzanne

Suzanne is 57 years old and has three adult children, one of whom has a developmental disability. This particular son lives independently and the State of California pays her a little money each month to help him live in the community. She is divorced. She acquired depression as a disability at the age of 27, and repeated neck injuries caused degeneration of the cervical spine at age 35. Her major source of income is SSDI, which she has received for the past 8 years for both the spinal degeneration and the depression.

She has received worker's compensation support for rehabilitation in the past and currently does some elder-care work on a part time basis which aggravates her physical disability. She is very careful about staying under the cap of how much she is able to earn without losing her benefits.

Suzanne's clinical depression started at the age of 27 while she was raising her children, and her cervical spine injury first occurred around the age of 35 while she was working in an accounting office. Suzanne enjoyed research and digging through accounting files to find information. Lifting boxes of paperwork, however, caused her first neck injury. She stated that this injury, made worse through picking up and moving her son with a disability, causes her a great deal of pain. She feels that the depression and chronic pain are related. At the age of 35 she went back to school to get her General Educational Development (GED) and took adult education courses in computers, business and communication, all of which she enjoyed.

She continued to work, however, and had a position as the department manager of a craft store. Here she had some assistance with lifting heavy things. However, she was required to get up on small footstools or ladders to put things away. One day in 1999, at the age of 45, she got up on a footstool that was broken but she did not know it. She fell and re-injured her neck and her back. At this point, she could no longer work at all. Her employer tried to insinuate that she was not really hurt enough to trigger a worker's compensation claim and she wondered if she was exaggerating it.

Suzanne was off work for eight months and tried to take care of the injury by going to a chiropractor but could not afford to continue treatment. She then went to a doctor who indicated that she needed to have this injury looked at (i.e., file for workers compensation). While she had a great deal of difficulty thinking of herself as a person with a disability and needing help, Suzanne could no longer work at all because of the pain and had no means of support. In October 2002 she got federal benefits. They are not enough to live on and she wants to work to supplement them or even get off entirely. So she has worked on and off as an eldercare provider to supplement her benefits. However, she has also re-injured her neck repeatedly in this line of work.

In 2003, while on SSDI and worker's compensation, she looked into getting her nursing degree as those with a Registered Nurse (RN) status can generally avoid heavy lifting or get help from others. The college-required internship requires the ability to lift 60 pounds independently. She knew she could not do that and decided not to pursue nursing.

Suzanne's next education goal was to try computers. She spent nearly two years studying computers. With two children at home and financial aid's preference for going full time, it was difficult but she tried to finish the program. Suzanne found that it was difficult to sit for more than an hour although she really liked the training program. She ended up not receiving her certificate of completion for the training course.

Because of her disability, she has learned to exercise and meditate to help her deal with her depression. Her spiritual life is very important to her. She has to monitor and reduce how much time she can spend on the computer to minimize her pain.

Her dream job would be to work in accounting or in the health and wellness industry. She talks about what she needs on the job but wonders if employers will allow it. She was unaware of the term reasonable accommodations until I briefly explained the term. This dream job would involve computers and accounting, ergonomically sound furniture and computer set up for her disability (stand up tables with stools really appeal to her), regular breaks, and exercise time/equipment available. Suzanne really values working in a team environment where people respect each other. She feels that she learns and grows best in a team environment so that is a part of her dream job.

Her family has been very encouraging about her working. Suzanne and her son were studying computers at the same time, and he was very supportive in tutoring her and offering encouragement. All that her doctors told her about work was that she should avoid heavy lifting.

She has several fears about work. First, she believes that she might be too old for employers to consider hiring her. “I’m too old and they want younger people and now the competition is huge.” Second, she is afraid that she is not technologically up to date. Third, she is fearful of re-injuring her neck if she is not allowed to get up and move around. Fourth, she fears telling employers that she has participated in workers compensation. “I was a legal liability.” When asked on an employment application about worker’s compensation, Suzanne felt that she had “workplace leprosy” by telling the truth and was not hired. Finally, she is fearful of asking for an accommodation for her disability; she wonders how she will find an enlightened employer who will accept her at her age, with her technological disadvantages, and give her the accommodations she needs to work.

Suzanne received mixed messages about people with disabilities as a child. There were several people in her family who had disabilities, most notably a cousin with a developmental disability. But it was somewhat secretive. "She wasn't hidden inside or anything but I remember that I didn't know . . . I actually still don't know to this day exactly what her disability was . . . I remember her and I liked her." On the other hand, she remembers being in the cafeteria at school and seeing children with disabilities segregated from the other kids.

> I would see the children with disabilities, developmental disabilities and physical. They would sit in a certain area of the cafeteria especially if there were behavioral issues. . . . And, I would go and talk to them . . . and I actually felt empathy because they were like in the corner. . . . It wasn't quite right the way it was taking place.

Finally, Suzanne remembered several people with disabilities in her childhood with a great deal of admiration and affection.

> I had a neighbor with polio and I had a good friend . . . she had quite stunted growth. She was like my really good friend. They were quite empowering because they were actually very empowered, very strong people. [The neighbor with polio] had a strong but calm presence. And then my good friend was—she was very outgoing and very energetic.

I asked Suzanne about her QOL and whether her ability to work impacted that quality. She indicated that while her life was good, that is, her emotional and social life was good, she has good feelings, her social support network is good, but her life is not comfortable.

> I want to keep learning and growing . . . I have outgrown the work I am doing [eldercare] and I am not able to advance in the work I was doing, it is not even covering basic expenses and it is not working for me physically and emotionally anymore.

Suzanne indicated that while she could make $930 a month gross (but must pay taxes) with the $836 that she received from SSDI, it was not enough for the area in which she lives.

Theme: Outside influences. Suzanne's family has been very supportive over the years of her getting an education and working. Doctors only limited her work choices by indicating that she was not to lift anything. Suzanne has a mixed view of disability; she saw individuals with disabilities in her childhood who were empowered and those who were devalued because they were different. "I didn't have a bad association . . . I didn't have a lot of association about it . . . I remember feeling empathy because they [special education kids] were like in the corner. . . . No, it wasn't quite right." As a child, she regarded a neighbor with polio and a young girlfriend with dwarfism as empowered. "They were actually very strong empowered people . . . I was thinking how are they doing this? I mean they didn't let it take them down completely." Finally, in an employment situation she experienced co-workers trying to minimize her injury and limitations. "They tried to downplay it so then I started thinking, am I just complaining here? I ended up feeling like I was a weakling and I was exaggerating." For Suzanne, compassion and respect are important as she saw others and experienced it first hand, "[people with disabilities were] not treated with respect and compassion."

Theme: Does she see herself as a person with a disability? Suzanne sees herself as a person with an injury primarily who reluctantly claims the label disability to get the services she needs. "I see myself as a person who is injured and depression can be disabling. Things are categorized and sometimes you only get help if you allow yourself to be in a category . . . and accept a label." About accepting assistance, Suzanne observed, “That was just very painful and humiliating . . . and then I see all these people with raging needs and then there is me. I have to ask for help also.”

Theme: Thoughts and fears about work. Age is a barrier. Suzanne feels that she is too old to go back to school and employers will not hire her. “I am too old to go back to get my certificate . . . and they want younger people . . . now the competition is huge.” In addition, not being up to speed on technology is a barrier, “I am over 50. So I walk in being that and being out {of touch} with some technology.”

Fear of re-injury is something Suzanne struggles with in her current work as an elder care provider. “You’ve got to pay attention. . . . It can undo things if you are not careful [speaking of re-injury].”

How to speak about your disability and ask for an accommodation when you are viewed as a liability for having participated in workers’ comp were big issues for Suzanne.

> I was afraid to say I need accommodations. It was perceived as this liability. This is trouble. . . . We are not touching this person. . . . To tell someone I had gone through workers’ comp is like . . . workplace leprosy. I will keep it to myself.

Finding an enlightened employer willing to accommodate her needs seems to be a barrier (my reflection during the first interview).

Theme: Quality of life. Suzanne does not feel she has a good QOL because she does not have the income she needs and is not working and growing in the field she would like to be in.

> I want to keep learning and growing-I have outgrown the work I am doing and I am not able to advance in the work I was doing. And I have learned that even

> though I like helping other people . . . it is not even covering the basic expenses.

Theme: Other. Work incentives are not enough to really encourage work.

> The amount you are allowed to work is pretty low. It is something and I am glad it is there [but it is not enough]. [From SSDI, I receive] $836 . . . and you are allowed to make $930 a month . . . and that is gross. That is before taxes.

Living in a southern California costal town on this amount is difficult.

Respectful communication is important for team work and individual growth on the job. “When you are in an environment where the team is communicating in a respectful way and is respectful of each other. . . I think everyone learns something from each other and everyone advances.

Not being accommodated after maternity leave [pumping milk in the workplace] was a big issue; “It became an issue that needed to be addressed in the workplace.”

> Disability organizations and information are so helpful. It is a huge support to have the local Independent Living Center or any other disability advocate agency that help the person learn about the benefits. . . . disabled student services on campus was a positive experience.

Stigma is finally being addressed: “[We have come a long way]. Yeah, because we are talking . . . we can talk about this. We are talking about this openly.”

Theme: Dream job. Suzanne’s dream job would incorporate accounting, computers, and research without heavy lifting of boxes or other items. She is also interested in health and fitness. I summarized the characteristics of Suzanne’s dream job during the first interview, which she enthusiastically accepted: working for an enlightened employer that is looking after the well being of his/her employees by offering ergonomically designed furniture and situations that allow your physical disability to be accommodated. And there is exercise with perhaps a quiet room. This is an employer who recognizes that people are more productive when they are treated with respect and their well being is as important as the bottom line of the business.

Bob

Bob is 54 years old. His parents have passed away, and he has one brother. He is single. Bob acquired an on-the-job injury, thoracic outlet syndrome with dystonia, while working as a paralegal and has been on SSDI for nine years.

He grew up in Ohio, moved to Utah, and later settled in San Francisco. He studied architecture, photo journalism, and music (guitar) but did not finish a four-year degree. While in Utah and teaching guitar as an adjunct professor at a university, he was involved in an auto accident that broke his arm and curtailed his music career. He enjoyed the job—he liked both the classroom and individual teaching experience, demonstrating how to play the guitar, and sharing information about music. It used his writing skills, ability to explain things, and involved working directly with others. He thought that he was set for a career before the auto accident changed all that.

After the accident he went for career counseling and aptitude testing to see what careers he should consider. One test ranked his creative and analytical thinking as perfectly split between the two. Bob's counselor indicated that they did not have jobs for people with that profile. So, he decided to choose to focus on his analytical, information processing skills and trained as a paralegal. Bob finished a two-year training program in Utah over three years.

He worked at a small Utah firm right after completing his training and then moved to San Francisco to work in a medium sized firm (150 attorneys) that specialized in litigation. He found that he really enjoyed the people there, the research, and the writing but did not like extreme stress around deadlines created by the attorneys. He worked long hours at the computer without getting up or moving around much, did not have an ergonomically correct work space and eventually his body rebelled. Bob worked at the legal firm from 1994 to 2004 but the last several years were spent on worker's compensation getting treatment and not working at the firm.

After four years of working as a paralegal in San Francisco, at the age of 40, he was diagnosed with bilateral thoracic outlet syndrome with dystonia. This is an injury that involves the muscles of the body found between the clavicle and the first rib. Important blood vessels and nerves are found there and if muscles are overused they can collapse on the veins and nerves with very painful results. Blood does not circulate and nerve endings burn and tingle in the hands, arms, and forearms. Muscles become " ropey." Certain body types (tall and thin through the chest and shoulders) are prone to this condition. It can be further aggravated by poor ergonomic work space design coupled with long hours at the computer. Surgery, physical therapy, massage, and biofeedback are all treatments for this syndrome. The goal is to rebuild that part of the body so that veins and nerves, muscles, and the skeleton are better able to function normally. Worker's compensation benefits were used and it took five to six years of surgery, body work, healthy eating, and reduced stress to achieve a measure of health and consider working again.

The functional impact of this is that Bob cannot use the computer or sit for long periods of time. He must exercise and maintain his health to be able to function and he must keep his stress level low. While Bob does not look like he has a disability, the inability to use a computer and sit for long periods of time makes it challenging for him to think about work.

Bob admits that he has a number of blocks in his head about working. Being able to use a computer seems to be a major part of just about any job these days and that is something he needs to reduce or avoid. In some ways that limitation has become more of a barrier than the actual injury for Bob.

> I almost try to ignore computers . . . it has caught up with me. I realized I am really out of date in terms of communicating with people. And ways that people typically communicating now I don't do it—I'm starting to feel pressure from that.

Bob did try a voice activated computer system some years ago with less than positive results. However, he admitted that he needed to look at that equipment again.

Bob indicated that he has fears around what to tell employers about his disability. "Because when I think of going in to the workplace at large it seems kind of intimidating to define myself for other people and tell them what I can and can't do." Bob does not see himself as a person with a disability,

> I guess I see myself as a person with an injury. An injury that is not going to go away so I guess it is a disability . . . such an odd and unusual injury and the diagnosis is so tenuous on it depending on what doctor you actually go to.

If Bob cannot see himself with a disability that he can describe and talk comfortably about his limitations, it becomes difficult to think about looking for or going to work.

He fears re-injuring himself and wonders how employers would accommodate his need for less stress, not sitting or using the computer for long periods of time, and time to exercise which keeps his injury under control. The thought of telling employers about his disability is disquieting. “You don’t want them to think of you as being disabled or … think you can’t do the job.” He also mourns the loss of time. At 54, he wonders if he can reinvent himself and get back in the “loop I was in . . . with my work connections).” He mentions the complexity of disability insurance and work, expressing the common fear of losing his benefits. More specifically, he fears losing his health insurance and access to medications.

He found it hard to respond to a question about his dream job, stating, “To think in terms of my dream job at this point is very farfetched because having a disability . . . you know the road just gets narrower and narrower rather than looking more and more open.” Bob remembers himself as he was before the injury and thinks about what he cannot do now. It stops him from thinking any further about work.

When pressed to think about work and his interests, Bob indicated that perhaps going back to teaching music (with an emphasis on guitar) at a community college might work. He thought that he could publish some of his teaching materials as friends have encouraged him to do. Bob knew that teaching was something that he loved doing; it involves lots of movement and one does not play for long periods of time so it could accommodate some of his physical requirements. He believes that his way out of his dilemma may lie in a part time job in teaching music, which will give him flexibility with his time and his body as well as exercise his mind and allow him to contribute to others. The income he earns could supplement his Social Security benefits.

Some of his friends think he should work at anything and stop letting the disability prevent him from having a life; he has lost several friends over this. Other friends think he should volunteer to see if he can get back into a more structured life. His doctors have told him he cannot work in the field of paralegal services, but are neutral on the subject of work otherwise. They told him that he has made a remarkable recovery given the injury he sustained working as a paralegal.

In the first interview, Bob was asked what society says about disability, "I think society doesn't want to think about people with disabilities. I think a lot of people don't want to believe it can happen to them. So I think [people with disabilities] are ghettoized a little bit." During the second interview, I asked Bob what he heard from others about people with disabilities. He indicated that he remembered from his childhood that he was told not to stare at a person with a disability. "I had the message that people with disabilities can't take care of themselves . . . what happened to them was sad. And also that they are different and they are not like other people."

Bob feels his QOL is compromised by relying on benefits for an income and he has become isolated.

> I don't really have a lot of money to do things. I kind of feel stopped in my tracks and I'm 54 and other than the injury I'm healthy so I have some time left. So satisfaction is what is driving this idea of returning to work for me because I am not satisfied...it seems that it is a core issue to a person to have some kind of meaningful work and have a way of supporting themselves.

Theme: Outside influences. Thinking back to when he was a child, Bob remembers getting theses messages about people with disabilities: ”People with disabilities can't take care of themselves; what happened to them was sad, they are different and not like us.” Currently Bob's family (just a brother now) has no input on the subject of his working with a disability. Bob's doctors have been very low key about his returning to work but have been clear that he cannot return to the paralegal position in which he was injured. “[The doctor]} asked what I thought I would do. He didn't really say you should never work or you should work . . . I had to take care of myself and be careful. He said that I could not go back to the job I had.”

Friends, however, have had lots to say on the subject of Bob's hidden disability and not working. His friends range from sympathy to anger over his not working and may not really understand the impact of his hidden disability. He has lost friendships over it.

> Friends and people who are close to me think I need to do something with myself. . . . I have had people who were less sympathetic to me give me a hard time and say: you are making this harder than someone who is blind. . . . I can tell from the things they say—don't have any knowledge of my injury which is pretty obscure anyway.

In terms of what society thinks about people with disabilities, Bob believes that people don't want to think about people with disabilities or accommodate their needs.

> I think they turn a blind eye. I think of all the people who can't use [the Internet and computers] and how no one is stopping so much to think about that. So I think they [people with disabilities] are kind of ghettoized a little bit.

Theme: Does he see himself as a person with a disability? Bob “waffles” on considering himself a person with a disability. He sees himself as a “person with an injury that is not going to go away." Bob views his limitations on using his hands have led to a loss of identity and it stops him from thinking about what work he could do.

> It kind of led to a loss of identity because I had identified with my job [paralegal] and I identified with being a musician [guitar] and I couldn't do it. . . . You start to think, now I have a limitation and then you stop thinking about what you might do.

Bob thinks that perhaps having an invisible disability makes it harder to deal with. "I struggle a bit in seeing myself that way [as a person with a disability]. And maybe part of that is because I don't have a disability that people can see or people understand very clearly."

Theme: Thoughts and fears about work. Bob has deep concerns around what he can do given this functional limitation.

> I have had a lot of trouble . . . coming up with a way to work [that does not rely on his hands]. . . . I have been stuck trying to get back to work . . . [dealing with] this disability has created a lot of barriers . . . I think about it and what I can't do and I stop."

"I feel pretty guarded about what I could and couldn't do. I think that is an inner fear for me." Bob is struggling with how to explain his disability and what accommodations he might need. "Somehow it is being able to come up with a definition for what I can and what I can't do and find out how to work with that . . . when I think of going into the workplace at large, it seems kind of um intimidating to define myself for other people and tell them what I can and can't do."

There is a fear of being pre-judged as incompetent because of a disability that makes Bob want to not speak up about his disability to a potential employer.

> I think about getting back into the work place and you know you kind of don't want them to think of you as being disabled or you don't want them to fire you or think you can't do the job . . . there is a danger of doing more than you should. Do you tell them you have an injury? Do you tell them you can't do things? That gets to be a bit of a barrier.

Bob also has fears of re-injury and given his long road to rehabilitation it is understandable. "It is kind of tricky because anytime you have injured yourself, you have second thoughts about using that part of your anatomy. . . . I have fears of re-injury to some degree." Combine this with not knowing how to explain your disability or what accommodations would work; one can see how this fear could keep Bob from working.

Loss of time and age are another barrier that Bob contends with. Will employers hire him at his age or is it too late? "Also I feel a sense of loss and how much time I have lost." He talks about not being a kid anymore: "Thinking of age and not being a kid but still that doesn't stop everyone."

Bob realizes that he is not up-to-date in electronic communication skills and wonders how that will work given the prevalence of computers in the work place and his specific limitations.

> I realized I am really out of date in terms of communicating with people. And ways that people are typically communicating—now I don't do . . . I kind of wish they [computers] would go away and I know they aren't going to.

"The complexity of disability insurance when you return to work is frightening because I don't want to lose medical benefits unless something else is in place . . . because I need them." Bob's fear is not just about losing benefits but also about the complexity of the regulations and how to ensure that he is complying with all the requirements.

Bob is trapped by his social isolation and lack of financial resources; he wonders how to get back into the mainstream. It is risky trying and risky not; he's stuck.

> Being disabled has made me very isolated. You get out of the workplace, you become less social. You have less money and so you lose the social resources. . . . I am out of the loop I was in and kind of removed from the connections I had. Scared of the risks I see that I would have to take to get back in there. . . . The alternative is sitting here. No I am not happy with that.

Theme: Quality of life. Bob is missing having a purpose in life and a way to connect with others. He also does not have enough income to meet his needs.

> I have become very isolated. I don't really have a lot of money to do things. I kind of feel like I am stopped in my tracks and I'm 54 and other than the injury I'm healthy so I have some time left. Satisfaction is what is driving this idea of returning to work for me because I am not satisfied . . . seems like it is a core issue to a person to have some kind of meaningful work and have a way of supporting themselves.

Theme: Other. Dreaming about a perfect job is difficult when one believes the disability diminishes options.

> To think in terms of my dream job at this point is very farfetched because of having a disability . . . you know the road just gets narrower and narrower rather than looking more and more open. Especially having been through a few careers already.

When I reflected to Bob that starting with limitations when dreaming about a job doesn't work, he understood immediately. "It just shuts you down doesn't it?"

Invisible disabilities may be harder to deal with in Bob's mind. "I think the average person would think I was just fine which is kind of strange you know.

Invisible disabilities . . . so I get a whole range of advice on what I should do [from people who don't understand my limitations]."

Theme: Dream job. Bob would like to be self-employed as a music teacher focusing on the guitar (where you can play and teach with lots of variety back and forth) and produce instructional books for teaching music. He can see himself teaching at a community college or similar type of environment.

Data Analysis

The data of qualitative research rests on the themes or essences that come from the interviews, the demographic survey each individual filled out, as well as my field notes and journal of reflection. The case studies written in the last section reflect information from the demographic surveys, the digital audio interview(s), and transcriptions. Following each case study were the themes identified and organized by the question they answered. Table 2 follows over the next several pages and displays the salient points for each participant. An analysis of each case is then provided followed by a cross participant analysis.

Table 2

Themes Across Participants

Outside influences	See self as person with disability	Thoughts/fears about work	Quality of life	Other themes	Dream job
Alice					
– Lack of having a national identity--she didn't fit in. – Family genetics. – Parents reluctant to accept she had a mental health disorder fearing others would think they caused it. – Society has a negative understanding of disability, particularly hidden disabilities. – Hidden disability may be more difficult than a visible one.	– Relieved to have diagnosis and confirmation of her disabilities. – Sees her disabilities as having made her a different and better person.	– Disability changing her for better and for worse. – Struggling with how she will be as a person with a disability at work. – Will employers accommodate her needs? – Did try to work and was unsuccessful- disability does get in the way.	No, lost all savings and was about to become homeless. However, supporting herself financially is important to her self-esteem.	Lack of access to health care impoverished her before she could get help.	With an MBA and CPA license, her business experience and having trained as a digital music producer and performer, Alice would "like to be my own independent artist with my own label and have musicians that work with me and DJs and be doing my own performances."

(*table continues*)

Table 2 (*continued*)

Outside influences	See self as person with disability	Thoughts/fears about work	Quality of life	Other themes	Dream job
			Joan		
– Joan’s parents’ belief that she is too disabled to work. – Joan’s friends with disabilities are not independent either. – Her doctors see her as being at home. One doctor referred her to an employment program for people with epilepsy, dismaying her parents.	Considers herself “a person with a disability” (but hasn't thought much about what that means).	– Fears about her competence to handle work and new experiences. – Her seizures, which are not controlled, are a barrier to work. – Fear of losing her social security and medical insurance. – Believes she can work.	No, because she is dependent on others who don’t expect much from her and she has no income herself.	She has no information about services or supports for people with epilepsy and seems to have no one championing her rights or abilities to become independent.	“I would like to work in a [plant] nursery. . . . I can’t picture myself doing anything bigger than that.”

(*table continues*)

Table 2 (*continued*)

Outside influences	See self as person with disability	Thoughts/fears about work	Quality of life	Other themes	Dream job
Molly					
The critical committee [in my head] always told me that I was worthless and no good; it was never going to work.	A label that Molly doesn't want to think about or accept as it is devaluing.	Fear of rejection and disappointment leads to resistance. Cannot think about work. . . . Everything freezes–Like a pinball machine. It goes on overload and everything freezes." Determined to work as employment and the recognition from it is a form of validation.	No. Believes purposeful work that pays enough to give her independence and freedom is the key. "I want a real life." Needs more money to live a regular life.	Lack of access to other forms of mental health therapy.	Wanting to use her Masters in Fine Arts, Molly first talked about teaching art to children; upon further reflection she has decided to see what her skills and aptitude tests reveal when she takes them at the Department of Rehabilitation.

(*table continues*)

Table 2 (*continued*)

Outside influences	See self as person with disability	Thoughts/fears about work	Quality of life	Other themes	Dream job
Sam					
– Family members have been supportive of Sam’s decision not to work. – Doctors . . . don’t seem to play a role in reasons for not working.	Sees himself as a person with a disability “albeit one that I have adapted my life to.”	– Retirement has agreed with him. – Doesn’t want to take a job from someone else if he doesn’t need it. – Fearful of re-injury.	Yes, happy not to work. Has constructed an identity around other life activities. Income from benefits is adequate.	Envy from others who see his lifestyle as easy.	If he were to consider work, would like something that uses his interpersonal skills but he must avoid face to face contact with sick people.

(*table continues*)

Table 2 (*continued*)

Outside influences	See self as person with disability	Thoughts/fears about work	Quality of life	Other themes	Dream job
			Suzanne		
Suzanne has a mixed view of disability; she saw individuals with disabilities in her childhood who were empowered and those who were devalued because they were different.	Sees herself as a person with an injury who reluctantly claims the label disability to get the services she needs.	– Age is a barrier. – Not being up to speed on technology is a barrier. – Fear of re-injury. – How to speak about your disability and ask for an accommodation? – How to deal with workplace leprosy because of workers' comp.	No, because she does not have the income she needs and is not working and growing in the field she would like to be in (computers/accounting).	– Work incentives are not enough to really encourage work. – Respectful communication is important. – Not being accommodated after maternity leave. – Disability organizations and information are so helpful. – Stigma is finally being addressed.	Her dream job would incorporate accounting, computers and research without heavy lifting of boxes or other items. Other characteristics include working for an enlightened employer that is looking after the well being of his/her employees by offering ergonomically designed furniture, accommodate disability and provide exercise in the workplace.

(*table continues*)

Table 2 (*continued*)

Outside influences	See self as person with disability	Thoughts/fears about work	Quality of life	Other themes	Dream job
Bob					
– As a child learned: “People with disabilities can’t take care of themselves; what happened to them was sad, they are different and not like us” – Doctor didn’t really say you should never work or you should work. – His friends range from sympathy to anger over his not working and may not really understand the impact of his hidden disability. – Society doesn’t want to think about people with disabilities or accommodate their needs.	He sees himself as a “person with an injury that is not going to go away.”	– Deep concerns around what he can do given this functional limitation. – Struggling with how to explain his disability and what accommodations he might need. – Fear of being pre-judged as incompetent because of a disability. – Fears of re-injury. – Loss of time and age. – Not up-to-date in electronic communication skills. – Complexity of disability insurance when you return to work is frightening. – Trapped by his social isolation and lack of financial resources.	– No, missing a purpose in life and a way to connect with others. – Does not have enough income to meet his needs.	– Disability diminishes options. – Invisible disabilities may be harder to deal with.	Self-employed as a music teacher whose instrument instrument is guitar and produce instructional books for teaching music. Sees himself teaching at a community college or similar type of environment.

Analysis of Themes

Alice. Alice's disability (bipolar disease and substance abuse) was hidden until the physical limitations (skin staph infection, loss of weight, loss of concentration, and physical and mental fatigue) forced her to seek an explanation. Once she was clear about the bipolar disease and her need to self-medicate through drugs, she was relieved to have a diagnosis. Outside influences seem not to have played a big role in Alice's thinking about disability. While she acknowledges that society views disability negatively, she views her disability as having improved her as a person. Wright (1983) might say that Alice is not allowing her functional limitations spread to the rest of her skills and abilities.

Alice has made the judgment (Bandura's, 1986, social cognitive theory) that she can work and has a reasonable plan with the education and drive to accomplish it. However, her fear is around whether she will be accepted in the work place and how to accommodate her disability. She prefers to consider self-employment rather than work in an overly structured employment environment. Those appear to be the only two options she has knowledge of. She may be telling herself that she is too different to work for someone else and making judgments about work environments that could be countered in a rational way with new information (the Ellis & Grieger, 1977, rational emotional behavioral therapy). Her current QOL appears to be very low given her complete impoverishment and impending homelessness while she waits for her benefits to start. Currently, her health is a barrier to work but she is determined to consider work after a year of recuperation and rehabilitation

Joan. Joan's outside influences maybe a bigger disability than her physical limitation. Her parents have repeatedly told her that she is disabled and cannot work. It appears that given their lowered expectations of their daughter, they did not encourage the usual steps to independence that most kids go through as they grow up. Joan sees herself as a person with a disability but does not have a real connection to the term. Her life is very sheltered and she does not have a lot of outside expectations. Joan directly expressed her need to deal with her mental mindset over her ability to work (Ellis & Grieger, 1977). Somehow in the face of all the negative messages from her parents, she has formed a tiny flame of judgment that she can get out there and work (Bandura, 1986) but has no idea how to get there. Without someone to believe and support her—a mentor or counselor—the odds do not seem to favor her achieving her goal. At this point in time, her QOL suffers because she is not independent and does not have her own income.

Molly. Molly has a strong desire to work. For her, work is validation and provides independence in the form of respect and income. Because she does not have respect and income she does not feel she has any QOL. She expresses her frustration with having skills and abilities (a master's degree in fine arts) but no way to put them to use. Her judgment is that she can work given the right circumstances (Bandura, 1986) but what those circumstances are, is unclear to her. She avoids considering herself as a person with a disability as it further demonstrates her deficits as she sees disability. Molly acknowledges a critical committee in her head who tell her she cannot succeed. Then she speaks of the resistance she feels toward looking for work.

Her preference is to eject the tape in her head altogether, but I believe that confronting those tapes using the Ellis and Grieger (1977) rational emotional behavior therapy may help lessen the resistance she is experiencing.

Sam. Sam is the outlier in this cohort. He is happy not to work and has redefined himself in other ways; he does not miss his worker identity. While Sam does see himself as a person with a disability, he has adapted to that view. He seems to have incorporated his limitations proportionately as Wright (1983) suggests. They are a part of him but not the sum of his self-image. Tellingly, Sam expresses a high QOL as his income meets his needs, he has responsibilities within his relationship and household that give him value and he enjoys the freedom that comes from not working. He has adapted his needs to his income. If he were to consider working, his major fear would be re-injury through contact with sick people. However, given his background in gardening and nursing, he could easily provide information and support services to individuals via telephone or online. In my journal, I reflected, this is my bias toward work showing. As Kaye pointed out (personal communication, April 26, 2011), this is a fine option, but Sam is really happy not working and it is acceptable in his community.

Suzanne. Suzanne has positive and negative views of disability from her childhood but does not want to consider herself as a person with a disability. She sees herself as a person with an injury and has had to claim the disability label to get the medical and income services she needed. Make no mistake, she has a disability—a hidden one. She has also been through the workers' compensation system which has clearly been a liability in terms of getting other jobs. She believes she can work (Bandura, 1986) and is working part time as an elder care provider to her physical detriment. Her QOL low as she does not have the income she needs and is not doing the work she wants to do. Her fears center on being too old, not technically up-to-date, re-injuring herself, and not finding an enlightened employer who will respect her skills enough to give her the accommodations she needs. I am not sure that Suzanne knows what accommodations she needs and she does not know how to present them.

Part of the Ellis and Grieger (1977) rational emotive behavior theory is the introduction of new information (new to the individual needing to hear it) as an important component of combating negative self-talk. Counseling to address her fears, updating her technical skills as well as identifying her workplace accommodations and coaching on how to approach the right employers, could lead to a successful placement in a job that may allow her to leave public benefits.

Bob. Bob struggles against having a disability but knows that his hidden limitations are real. The messages he received as a child about people with disabilities as being sad, unable to care for themselves, and different from others could be unconsciously affecting his thinking about his own disability. He believes that society does not want to see or deal with disability, which seems to echo his own state of mind about disability. Bob states that he thinks about what he was before and the limitations he now has just stop him from thinking of alternatives. This is a person whose thoughts about his functional limitations have spread inappropriately across his self-image (Wright, 1983). He has made a judgment (Bandura, 1986) that he cannot work if he cannot use his hands. But his QOL suffers from social isolation, lack of enough income, and lack of life purpose. He believes he can and should make a contribution to the world through work but does not have a way to explain or talk about his disability. He cannot articulate the accommodations he needs. Bob’s fears about work include being too old and out of touch with technology, re-injuring himself, and dealing with the complexity of disability insurance regulations around work. Gaining information and insight about his disability and his beliefs (Ellis & Grieger, 1977) about his disability and work, including new information about assistive technology, could unlock the door to employment options that could supplement his social security benefits and improve his QOL.

Cross Participant Analysis

It is striking to note that not only did all of the participants have a hidden disability but five of them acquired their disability as an adult. I believe this is a significant characteristic. The fact that these are hidden disabilities often makes it easier for someone to pass as an able-bodied person. However, such passing does not encourage one to actively and appropriately incorporate functional limitations into one’s self-esteem.

It is important to say at the outset that five of the six participants strongly want to work. They see work as a way of validating their worth, providing a social connection, and providing contributions to others. Most importantly, all five did not receive enough income to meet their needs. They believe that working would improve their QOL. One person spoke about the responsibility of an adult to financially support herself, and I believe the other four would agree with that statement. However, one person did not miss his identity as a worker. He was content to construct his identity around other life activities, he played a valued role in his significant relationships, and, most importantly, he had enough income to cover his needs.

The discussion about dream jobs was revelatory. At the beginning of the interview, two people could not picture a job, because their physical limitations were seen as being too difficult to overcome in their minds. What could they do and who would accommodate them? Another person had a vision but wondered if there were any employers who would accommodate her and how might they do that. Another individual had a very small view of what she could do, given the lack of expectations from her parents. Another individual had a clear idea of what she could and would do once her disability stabilized. Self-employment was mentioned by two individuals as an alternative to working for an organization that might not accommodate them.

Significant outside influences on thoughts about disability and work came from families and friends either directly or indirectly. Two individuals had significant negative family messages around not being able to work or being very critical and dismissive about the individual's ability to do anything. Another two participants had either experiences in childhood with others' disability and/or received negative and disrespectful messages about people with disabilities as children. Two more participants had not much negative influence from families and friends and for the most part their families were accepting of the situation. One person lost friends who felt he should just get over his disability and go to work.

Doctors seemed to play a very small role with regard to the long term prospects of being able to work. Of course, all of the participants' doctors signed their federal benefits application as not being able to work at their current occupations or in specific situations. However, for all but one participant, doctors offered no information on the ability to work in fields other than the occupation in which the injury occurred. On the other hand, Joan did have a doctor refer her to an employment program for people with epilepsy.

Teasing out society's influences was much more difficult. While all the participants were aware of their belief that society views people with disabilities in a negative light, only one could articulate specific messages from society. Childhood messages may have come from their teachers and neighbors as well as parents and other children, but there is not enough information in the transcripts to determine which came from society and which came from family.

One of the most surprising findings of this study was the lack of a disability identity. All of the participants have hidden disabilities, which may account for this theme. None have role models for working or living with their disability. Two people spoke about either incorporating the disability into their self-esteem appropriately or that the disability experience had deepened or improved various aspects of their personality. One person has not had enough life experiences to think much about her disability identity other than to say it is a negative thing to have. However, three people did not want to accept the label of disability; they felt humiliated, devalued, and wondered how they could participate in society with a disability. Two of those individuals referred to themselves as persons with injuries that will not go away. Those who were having the most trouble accepting the idea of having a disability could be seen as having the most difficult time thinking about work (Bob) or appropriate work (Suzanne)

Thoughts and fears about working ranged from a lack of concrete information about their disability and their rights, to fears about being able to actually work, and managing or losing benefits while working. The five who want to work all spoke about concerns around being able to do a job, being a different person now that they had a disability, and what specific accommodations would they need and how does one ask for those accommodations. Three people directly or indirectly wondered what they could do given their functional limitations. Several participants who are over the age of 50 shared the concern of loss of time and their age. Is it too late for them to get a job? They rate their technology and other skills as deficient in the face of younger competition. These findings support the Livermore et al. (2007) work, which captured factors such as (a) discouragement in search efforts, (b) being over the age of 55, (c) lacking in technology skills, (d) perception of others that they cannot work, and (e) not having a way to get back into the employment community in their research on barriers that keep people on benefits from working.

For two people who have been on workers’ compensation, an additional fear centers on whether and how to tell employers about that stigmatizing event. Three individuals spoke about the fear of re-injuring themselves. For one person, fear and rejection after trying to get work was paralyzing. Interestingly, another individual who did try to work with an untreated mental health disability and failed did not see that as paralyzing; she saw it as one more piece of evidence that she needed to get help and look at her employment goals differently. Three people talked about the complexity of disability insurance rules that must be followed so as not to lose health benefits as a barrier to work.

Before getting into the details of my conclusions, I want to update my role in this research project. While my role has always been one of researcher, that is, asking questions, gathering information, and reformulating my questions, during the course of these interviews, my role changed. Faced with the enormous lack of information about their disability and work, the resources out there that could assist, and the pain that was evident as each struggled to talk about their disability experiences; I became an information and referral specialist, and counselor for a brief period after each interview. I referred participants to the California Department of Rehabilitation, to websites about their disability, and back to the local ILC for different services. I explained what reasonable accommodations were and briefly talked about their rights under the ADA. Finally, I listened and reflected back what I heard them saying about their disability and gently pushed them to refute what they were telling themselves about their functional limitations. While I will never know whether this helped, at least I had the opportunity to offer information and support around a painful part of their lives.

CHAPTER V

CONCLUSIONS

> The more they believed they would be devalued and discriminated against, the less likely they were to accept disability. (Li & Moore, 1998, p. 22)
>
> We are all influenced by the values, beliefs and attitudes that condition us from birth. Often these are subconscious and we have little awareness of them, but most often our response to impairment and disability is negative. It is not just non disabled people who exhibit dysfunctionphobia—many people who are impaired either fear or dislike their own functional deficit and/or the possibility of further loss of function. (Patston, 2007, p. 1627)

The six participants in this qualitative study demonstrated a range of responses about outside influences regarding their disability, their acceptance of their disability, as well as thoughts and fears about work. Their assessment of their QOL fell into two categories and was primarily based on having enough income and satisfaction with life. The fact that all of the participants had hidden disabilities and five of the six acquired their disability as an adult makes this cohort a unique group. Examining the issue of adjustment to disability along with using Anthony's (1994) suggested framework of self-efficacy, self-awareness, and satisfaction with one's life situation or QOL issues, will help to bring all of these statements together to identify the internal barriers that kept this cohort from working.

Adjustment to Disability

As discussed in the literature review, there is a large body of research on adjustment to disability including various models that attempt to map out the process. Livneh and Antonak (1997) ask the question, how does a change in function affect individuals' " physical, psychological, social, vocational and economic lives" (p. 26)? Putnam and Adams (1992) showed that one of the most significant barriers to successful rehabilitation is poor adaptation or adjustment to the functional limitation.

Four of the six participants did not see themselves as persons with disabilities. Several indicated they were people with injuries that would not go away. This is a major barrier for how does one incorporate one's disability into one's self-image if there is no acceptance of this change? How does one even find the right services to help? This lack of disability identity will be further discussed under the section, Self Awareness.

Five of the six participants acquired their disability as adults, that is, after forming their self-image as an able-bodied person. Livneh and Antonak (1997) acknowledge that there are differences between those who have a congenital disability, those who have sudden or traumatic disability but stabilize, and those for whom the disability is chronic and fluctuating. For the five adult onset participants, it can be difficult to digest the changes in their self-image as they are not only dealing with loss of function but stigma and lowered expectations from society (Li & Moore, 1998; Livneh & Antonak, 1997; Smart, 2001; Wright, 1983). This coupled with the hidden nature of the functional limitations of this group really amplify the barriers that adults with hidden disabilities face.

Self-Efficacy

Bandura (1986) wrote and talked extensively about self-efficacy as the capacity for people to set goals and execute them successfully. Bandura made a point of stressing that it is one's judgment of one's skills, not the actual skill that one possesses, that determines the self-efficacy of an individual. If the individual does not think he can do it, he probably will not even try (Bandura, 1986). In general, people are not self-efficacious in all areas of their lives (Bandura, 2003). Rather, they excel in some areas and are less successful in others. Self-doubt can occur when exposed to circumstances that undermine their beliefs about their abilities (Bandura, 1997).

Joan, Molly, Suzanne, and Bob all formed judgments about their abilities that lowered their expectations of what they can do given their disability. Joan explicitly indicated that she could not see any higher than working in a plant store ringing up purchases and talking to people. Joan's comments also vividly demonstrated what Saunders et al. (2000) found about the negative effect lowered aspiration levels have on vocational choices for children and youth. Such lowered aspirations occur when one is continually exposed to negative beliefs from parents and other adults as well as other children. Joan's negative experience working for her aunt combined with her parents' strong negative messages make it difficult for her to decide she can work and follow through.

Molly, struggling with the unpredictable nature of fibromyalgia, originally confined her dream job to teaching an art class for children. Her experience with her disability was that she could not keep regular hours and lost jobs; thus, her experiences have reduced her belief in herself, even though she has considerable talent as an artist. It is difficult for her to go out and try for a job given the experience of rejection due to her disability in the past. Bob, having lost the use of his hands (with computers) felt that his career choices were severely limited. He knows he has skills as a music teacher and is vaguely aware of assistive technology that could help him with computer access. However, he has deep concerns as to what he really can do and whether he could work successfully, in spite of acknowledging that his disability is not as severe as others. He is still comparing his current limitations with how he used to be and (perhaps unconsciously) deciding he cannot work, given his beliefs about disability.

Suzanne, on the other hand, knows she can work as she is working now (albeit in a part-time job that aggravates her functional limitations), but she has made the judgment that she is untouchable as a person who went through the workers' compensation program. Her experience has been that no one wants to hire her given that she was on workers' compensation. Her ability to set a goal and follow through has been hampered because of family obligations and educational rules that required full time course work when her functional limitations would not support full time study. She is unaware of what accommodations she needs in the workplace and is technologically out of date. She has settled for work that is not using the skills she has or pays enough to improve her QOL. Suzanne does not believe she deserves help as a person with a disability as she still sees herself as someone with an injury. She does not have role models to talk to about coping with her physical limitations and workers' compensation label. While she is working some hours in a field that can make her disability worse, she does not see what other options could be open to her.

Alice has had extremely positive experiences in setting big goals and achieving them. While her ability and perseverance to push through and achieve contributed to her body's ultimate collapse, she knows that she is smart, has skills, and can work. Alice seems to have the self-efficacy to put her disability into perspective and plan around it. While she recognizes there are barriers and has some fears around her ability to work, she does not seem to see these as insurmountable.

Marinelli and Dell Orto (1984) indicated that "the individual's self concept and perceived ability to perform an occupation are critical" (p. 25) to the successful career development of persons with disabilities. Four of the five participants above have a compromised self-esteem due to their lack of acceptance of their disability, which has lowered their perceptions of their ability to work. Only Alice, who is just getting on benefits, still has her self-concept intact for now. She has a plan and the education to make it work; it remains to be seen if her drive to succeed will power her through the isolation that often accompanies getting on benefits. A good rehabilitation counselor and peer support counselor from the ILC could be very helpful, especially during the initial disability treatment and recovery.

In summary, SCCT indicates that people make career choices based on what they think they can do, their expectations for success, and the goals they set for themselves (Lent et al., 1996). Four of the five individuals are either unsure of what they can do or have a diminished view of what they can do. These four have lowered expectations and have set small or no goals for going to work. The fifth, Alice, seems to have the self-efficacy to not devalue herself because of a disability and has a chance of getting back to work if she can get support that keeps her from being isolated. Sam, the sixth participant, has constructed value and meaning to his life without work.

Self-Awareness

Wright's (1983) theory of values shift rests on the idea that one must accept the functional limitation as non-devaluing in order for rehabilitation to be successful. That is to say that the individual realizes that he/she has other talents and skills besides what was lost, the individual's self-esteem encompasses more than the body function that was lost, and he/she views the disability as a realistic part of life and focuses on other personal assets rather than comparing self to others (Wright, 1983).

Four of the participants seem to have made a poor adjustment to their disability. Joan, Molly, Suzanne, and Bob all devalue themselves because of their functional limitations. Failure to see themselves as more than their disability, that they have worth regardless of functional limitations and the inability to focus on their assets, are major internal barriers. If one is stuck comparing one's current self to the self of the past or others who are able-bodied, it is very difficult to integrate back into society. If a person does not acknowledge having a disability, how does he or she connect with disability services that can help?

Conversely, two of the participants had a very different view of disability. Alice viewed her functional limitations as an experience to learn from and made her a better person. She explicitly said that fundamentally she is still the same person inside albeit that she may have to do things very differently in the future. Sam viewed his disability in the context of a productive life already lived; this part of his life would be focused on finding value and meaning through his family and friends.

Both Alice and Sam exhibit all four of Wright's (1983) value shifts, and as a result each saw the functional limitations as having or adding value to their lives. Alice has the most concrete plans and enthusiasm for how she will find meaning and work in her life after her health improves. She is still involved with friends and is forging a new relationship with her family. Sam is content with his life and finds meaning outside of work. He has a circle of friends who care about him and with whom he connects. While Alice and Sam both fit Wright's successful value shift, the other four are in various stages of denial of their disability, which impacts their ability to move beyond the limitation and succeed in reaching their goals.

DeLoach and Greer (1981) indicate it is hard to develop a positive view of disability when family, medical providers, and society all devalue the individual. These cohorts all have hidden disabilities that often makes it difficult to find others who could serve as role models to counteract stereotypical thinking absorbed from family, medical personnel, and/or society.

While medical providers did not play much of a role with any of these participants, family played an important role for Joan and society's views played a big role in Bob, Suzanne, and Molly's maladjustment to disability. Statements like "They are different . . . sad . . . unable to take care of themselves" (Bob) or "A label I don't want to think about or accept as it is devaluing" (Molly) make it difficult to do the work to appropriately incorporate a functional limitation into one's self-image. Vash (1981), Wright (1983), and Weinberg (1988) all speak to the acceptance or embracing (Weinberg, 1988) of one's disability as the solution (Vash, 1981) to the struggle of fitting into a world that devalues disability. Once acceptance has been achieved, the individual can move forward in using other talents and skills to construct an enjoyable and productive life.

Clearly, four of the participants could benefit from counseling around the issue of disability acceptance as well as meeting and getting to know role models who have hidden disabilities. In addition to forming a self-concept that incorporates their functional limitations appropriately, they could benefit from counseling around what careers are suitable given their interests, abilities, and skills. The participants could also receive information on their rights and what reasonable accommodations they need. They could watch role models interacting with others, interviewing for jobs, and asking for accommodations. They could also receive support around coping with stereotypes and stigma. Even Alice, who has a strong sense of self-efficacy, could benefit greatly from counseling and role modeling services.

As one starts to accept the functional limitations, the process of change begins (Charmaz, 1995). This is where REBT (David et al., 2010) becomes useful. REBT works to uncover the individual’s beliefs (as evidenced by his/her self-talk) so that he/she can examine and replace them. Is it true that people with disabilities are sad or cannot take care of themselves as Bob grew up believing? Refuting that belief with better information and creating positive self-talk in place of the negative can lead to behavior change. Developing a more realistic view of receiving workers’ compensation services may help both Suzanne and Bob to present that experience in a way that does not scare employers away is another example of REBT in action. Using REBT to impart new information about disability, one’s rights, and how to cope with negative stereotypes can provide a strong basis for psychological change that leads to a realistic acceptance of disability.

Quality of Life

The third factor that Anthony (1994) suggested be examined as it relates to the decision to work was satisfaction with current situation. This topic was discussed in the Chapter II literature review. Halpern (1993) suggests asking the basic question: Am I satisfied with my life? Among the six participants, five people answered no and one answered yes. Four of the five who answered no indicated a strong need to share their talents or make a contribution to others; they also wanted a higher QOL than what they were currently experiencing. One, the youngest, is struggling to keep alive her drive to be self-sufficient, a normal developmental task for her stage in life. The sixth participant, who is happy with his life, had shared his talents and contributed to others throughout his career. He is very satisfied to redefine his role in life as one that does not include work.

Brown et al. (1988) suggested another definition of QOL that centers on the differences between an individual's met and unmet needs; the larger the gap the poorer the QOL. For the five who indicated that they had a poor QOL, one of the major reasons was lack of income to cover their needs. While they had some income from benefits, it was not enough. Joan reported having no access to her benefit income as her parents controlled her funds. Molly indicated that the benefit income she received was enough to just keep one alive. Alice spent her entire life's savings while trying to find a job and health care, but in the end became destitute to get access to health care and a small monthly income. She hopes that by receiving these benefits she will regain her health and stability in order to rejoin the labor force in the future. Sam, the individual who felt he did have a good QOL had income support from both federal disability benefits and city disability retirement, which gave him more financial support than the others. In addition, he was part of a family unit that presumably had more income sources. Sam indicated that he had adapted his needs to his income and did not feel he lacked for what he needed to live comfortably.

Goode (1990) described QOL as being able to satisfy one's own goals in important life areas such as employment, education, community, and home. For Joan, the 24-year-old woman seeking autonomy through employment after living a very sheltered life, she has a role in the home but no where else. Her basic living needs (food, shelter, and family) are being met but not her need for independence. Alice, the former MBA/CPA, has experienced success in the employment, education, and community arenas, but her disability has shut down her ability to work for now. However, she is very determined to support herself, so getting back to employment will be very important to increase her QOL. Interestingly, she described herself as extremely self-reliant in the past but now must rely on her father for support while she recuperates. Perhaps she will have an opportunity to be nurtured by her family in ways that she missed as a child. For Molly, Suzanne, and Bob, working and making a contribution with their education and/or skills is a very important secondary reason they seek to work. Each spoke about how work helps to define themselves, their value to the community, and decrease isolation. Sam, on the other hand, feels that after a bachelor of arts degree and two associate degrees as well as 30 years of productive work, it is acceptable for him to construct a different QOL, one that is centered on his role at home and in the community. While he is still relatively young (54) and could work, he is quite happy not to work.

The lack of enough income clearly plays a role in whether someone considers working. But being open to work and actually acquiring the skills, combating both personal and society negativity to actually work, is a daunting task without proper support from others.

Summary of Internal Barriers

What are these participants telling us they need in order to work? They need a way and a place to talk about their feelings and fears around their disability. They need counseling to help them successfully work through integrating their functional limitations into their self image. Most of this group is hungry for information on what kind of work they can do given their disability, skills, and interests. They need training to upgrade their skills, particularly with technology. They need to become aware of learned oppression and how to combat society's and, more specifically, employers' lowered expectations. They need information on their rights and the accommodations they need to live, work, and play in the community. Finally, they need role models to see how to be with their disability and practice talking about their disability and their accommodation needs.

It is important to state that I believe each of these participants can work. While none of them can afford to lose their health care, all are good candidates for the Medicaid Buy-In program if it were not for other barriers. However, changing this paradigm is complex. This group of participants shares two major characteristics that make it more difficult to change; all have hidden disabilities and five of the six acquired their disabilities as adults. Thus, the barriers are complex and not easy to solve, particularly for those who have been on benefits for years. For the remainder of this discussion, I am going to focus on five participants, taking Sam out of the mix since he is happy not working and seems to have adjusted well to his disability.

People with hidden disabilities sometimes do not see themselves as having a real disability or believe it is not so severe as to warrant rehabilitation services such as someone in a wheelchair or blind might require. So the first internal barrier begins. Failure to acknowledge that a functional limitation is more than an injury and deserves services severely limits access to the critical counseling and other services that are needed. In addition, it is more difficult to find role models with hidden disabilities to learn from and talk with. Thus, begins the second barrier: Who do I talk to and where do I get services? Stumped by this question, the third barrier sets in. Bob was very articulate about the isolation that sets in especially after an intense physical (or emotional) rehabilitation phase. By the time he was ready to take up the thought of work, his employment connections were lost and he was left behind regarding the technology used in most workplaces today. At this point, information about dealing with society's lowered expectations, civil rights, and talking about one's disability or asking for accommodations becomes irrelevant without basic counseling and role modeling to address the earlier barriers.

The second characteristic is that four of the five participants in this discussion acquired their disabilities as adults. As discussed earlier in the literature review and this chapter, adult onset of a disability complicates the process of changing one's self-image. It is tempting to get stuck in thoughts of how one used to be without counseling and role models to help construct a new way of being and doing. Adult onset of disability can lead to needing to use one's skills and abilities in new ways or acquiring new skills altogether. It certainly means confronting society's and possibly family's lowered expectations as well as one's own lowered expectations of life with a disability. These are complex issues to work on and they become very difficult in the absence of anyone to talk to or learn from.

I would be remiss if I did not address the issues of the one young person in the cohort. She has issues in terms of not receiving information about her disability. She has not had an opportunity to receive counseling around self-image or find out about her interests and possible work options. Her access to education has been limited, apparently by her parents. While she has support from her family, she is isolated from others who have successfully integrated their disability into their self-concept and created a viable life. Her parents have placed her squarely on the path of dependency from an early age through their repeated messages that she cannot work. One wonders if the Social Security check for this individual is supporting the family at the cost of this young woman's independence. That is a complex issue to open up and resolve. But without intervention and the services described above, this participant may never achieve her goal of working and becoming independent.

Each of these five participants wants to work. Each wants to raise the quality of their lives for independence, financial stability, and self-worth or contributing-to-society reasons. Thus, they have motivations to seek to work, but the barriers above can keep them locked into a life of poverty on government benefits.

Implications of the Research

One way of organizing the implications of research is to look at the various levels upon which it could have an impact. To that end, I want to focus on three arenas: the system, professionals and workers in the field, and individuals with disabilities. Since my research is directed toward helping people with disabilities, I will start there.

People with Disabilities

People with disabilities, regardless of when acquired or whether it is hidden or visible, need to understand that the task at hand is to appropriately integrate that functional limitation into their self-concept. Acceptance is the way to a successful rehabilitation experience and a successful life (Vash, 1981). Through counseling, seeking out role models and receiving information about the options available to them regarding living independently, receiving an education, and working, it is imperative to not let the disability overshadow the value that individual has to his or her self, family, and community.

If the individual is successful in the first task, he or she will be better equipped to deal with learned oppression or society's lowered expectations. When someone has completely accepted his or her disability and sees the value he or she brings to the world, a funny thing happens. The world seems to forget the disability and see the person instead.

People with hidden disabilities need to come out of the closet, to borrow a metaphor from another minority group that faces stigma and stereotypes. Those whose disability remains hidden must take the first step to acknowledge the disability and seek out counseling, role models, and services. Without talking about the disability and feelings it produces, it can be very difficult to move toward creating a satisfying life.

Once the individual with a disability, regardless of visibility or when acquired, can accept or even value the disability experience, then it becomes easier to learn about one’s civil rights, accommodations and equipment needed to construct a positive life. The late Laura Hershey, disability poet and activist, spoke about how to begin to value the disability experience in her poem, “You Get Proud by Practicing” (1992):

> If you are not proud
> For who you are, for what you say, for how you look:
> If every time you stop
> To think of yourself, you do not see your self glowing
> With golden light; do not, therefore, give up on yourself.
> You can
> Get proud.
>
> You do not need
> A better body, a purer spirit, a Ph.D
> To be proud…
> You do not need
> To be able to walk, see or hear,
> Or use complicated words,
> Or do any of the things you just can’t do.
> To be proud
> You only need more practice,
> You get proud by practicing.
>
> There are many, many ways to get proud.
> You can try riding a horse or skiing on one leg,
> or playing a guitar,
> and do well or not so well,
> and be glad you tried
> either way.
> You can show something you've made
> to someone you respect
> and be happy with it no matter
> what they say.
> You can say
> what you think, though you know
> other people do not think the same way, and you can
> keep saying it, even if they tell you
> you are crazy.
>
> You can add your voice
> all night to the voices
> of a hundred and fifty others

in a circle
around a jailhouse
where your brothers and sisters are being held
for blocking buses with no lift,
or you can be one of the ones
inside the jailhouse,
knowing of the circle outside.
you can speak your love
to a friend
without fear.
You can find someone
who will listen to you
without judging you or doubting you or being
afraid of you
and let your hear yourself perhaps
for the first time.
These are all ways
of getting proud.
None of them
are easy, but all of them
are possible. You can do all of these things,
or just one of them again and again.
You get proud
by practicing. (p. 28)

Professionals and Workers in the Field

For this cohort of persons with hidden disabilities and adult onset of disability, it would have been important to have access to counseling and support around building a self-esteem that puts the functional limitation into perspective. Receiving information about their specific limitations, discussing their thoughts that lead to fears and feelings, and understanding their work and living options early on in the disability experience could have helped to prevent the time each has spent in the poverty trap of government benefits.

It is important for rehabilitation counselors and peer support counselors to really focus on surfacing thoughts that lead to the negative feelings and hopelessness that comes from believing society's lowered expectations. These professionals should look to working with family members as well as helping them understand the self-esteem task at hand and how they can be a positive influence. Giving the individual a place and support to practice talking about and living with their disability could be so helpful.

Reaching out to those with hidden disabilities will be critical as it is so easy as a person with a disability to try to pass as an able-bodied person and put off dealing with the acceptance of that disability. In order to facilitate a successful rehabilitation, it will be necessary to take the time to provide information, counseling, and role models to those with hidden disabilities in the hopes of raising the individual's awareness of their disability and possible lack of acceptance.

Rehabilitation counselors are trained as counselors who have medical and disability related information. Using those skills to help individuals with disabilities not only integrate their disability into their self-concept but help them figure out what careers are open to them; help create a path for financially sustaining themselves; and provide access to training, assistive technology, and knowledge about their rights and need for accommodations could improve the rehabilitation outcome.

It is critical that those who are training to be rehabilitation counselors or other direct services positions in the field get solid training on counseling techniques and really understand disability adjustment theory and practice. I would argue this is the heart of rehabilitation; it is where the change starts for people with disabilities. For those counselors already in the field, it is critical to have good counseling skills, an understanding of the disability adjustment process and use them. Helping people make a successful adjustment to their disability can lead to an improvement of the counselor’s closure rate but more importantly, it helps the individual with a disability change their life for the better.

The “System”

First, Social Security’s requirement that individuals be completely unable to work before qualifying for health care and a benefit check forces people with disabilities to see themselves as unable to work. Social Security becomes an early retirement program even for children with significant disabilities. Stapleton et al. (2006) called for a rethinking of that requirement as work incentives in the form of the Medicaid Buy-In program became available. While one can appreciate that there must be strict guidelines as to who receives government benefits, it is still very detrimental to children and adults with disabilities to be labeled as unable to work—ever. Individuals take this label in order to get the health care they need to stabilize and consider work. It would be much better to start with the premise that every one can work unless they prove otherwise and provide them with the supports they need to go to work (Stapleton et al., 2006).

Second, Rehabilitation Services Administration, as prompted by the Federal Government has moved the field toward outcomes evaluation. That is, there must be a concrete outcome from dollars spent. It is easier to show an outcome from vocational evaluation, a job club, acquisition of equipment, or case management. It is not so easy to quantify or touch a counseling outcome. Yet, this is fundamental to a successful rehabilitation outcome (Putnam & Adams, 1992). Counseling, finding role models, and providing information about disability, rights, and accommodations are not expensive but without it, the rest of the interventions in a rehabilitation counselor's tool box have a very good chance of failing. Yet, Herbert (2004) shows that counseling is not valued by vocational rehabilitation agency supervisors. This needs to change.

Third, the disability movement has gotten away from peer support, a major key to personal barrier removal. While the ILCs have often focused on people with visible disabilities, it is time to make role models with hidden disabilities available. It is time to go back to our roots as one of the four core services that all ILCs must provide is peer support. But, as such, service must focus on thoughts and feelings about disabilities. It should focus on getting proud by practicing and discussing the success or lack of success with our practice. The centers need to be more explicit in giving people with disabilities a place and a chance to practice talking about their disability and learning about their options for creating a life they want to live.

Finally, parents, family, and teachers have a role to play here as well. Children need to have positive messages of hope, and they need dreams for the future beyond living on Social Security. Children and young adults need to have their disability acknowledged and know they are loved and accepted regardless. Transition programs need to help their students practice talking about their disabilities and the accommodations they need to live and work in the community. The notion that it is not okay to talk about the young person's disability in school slows down the successful transition process (M. Donnelly, personal communication, April 27, 2011).

Future Directions for Research

Future research should focus on interviewing people with visible disabilities as well as young people (18 to 30) on their thoughts and fears about work. Are there similarities across the groups? While this project used individual interviews, focus groups are another method that lends itself to this research question. Once qualitative data has been collected and analyzed across the three groups, a survey should be launched with a much larger representative sample in order to determine if the experiences here are shared by the larger population of people with disabilities on benefits.

Summary

The research question I sought to answer through this qualitative research was:

Q What internal barriers impact the decision not to work for people with disabilities?

Using the lens of Anthony's (1994) work, I examined the self-efficacy, self-awareness and QOL of six individuals with disabilities. This cohort shared two unintended but important characteristics: their disability was hidden, and for the majority their disability was acquired as an adult. Through in-depth interviews, a demographic survey and my observations, I sought to understand the outside influences, whether they saw themselves as a person with a disability, their thoughts and fears about work, and their QOL, in order to answer the research question. Because the group all had hidden disabilities and most were adult onset disabilities, these findings should be limited to those with similar characteristics.

However, it is clear that all the job clubs and equipment in the world will not help people who have experienced a disability to go to work if the foundational work of rehabilitation and independent living fundamentals has not been addressed. If individuals with disabilities believe they cannot work, they will not. Helping people with disabilities successfully incorporate their functional limitations into their self-esteem and understand what their vocational options are given their functional limitations is critical. Helping people with disabilities to see that a disability does not cancel out all the positive skills and abilities they possess (they are more than their disability) is a fundamental goal of rehabilitation. Finding role models with hidden disabilities could provide much needed support and information on how to be with a disability. Finally providing information and education about their disabilities, their civil rights, disability disclosure and appropriate accommodations, and practice in discussing their disability and negotiating their accommodations will serve them well over the course of their life with a disability. These are the foundations for living and working with a disability successfully; they are the tools for removing internal barriers to work.

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APPENDIX A

REVISED INFORMED CONSENT

UNIVERSITY of
NORTHERN COLORADO

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH

Project Title: A qualitative study: People with disabilities and Internal Barriers to Work
Lead Researcher: Patricia Yeager, 999-999-9999
Yeag0386@bears.unco.edu
Research Advisor: Dr. Juliet Fried, Human Services, Department of Human Rehabilitation Services, 999-999-9999
Juliet.Fried@unco.edu

This letter is being given to you so that you have the information you need to decide if you want to participate in this study. I am a student with a disability at the University of Northern Colorado conducting research for my dissertation on Human Rehabilitation. I am interested in talking to a small group of persons with disabilities, who are not working about their thoughts, feelings and experiences regarding disability and work. I would like to see if any of those thoughts, feelings or experiences get in the way of deciding to go to work.

I plan to conduct several in-depth telephone interviews with 6 to 8 people, who have disabilities about their disability along with thoughts, feelings and experiences that may have kept them from going to work. If you agree to participate, I will ask you to fill out a demographic survey. The survey asks about age, type of disability, source of income, how long you have been on benefits, and any interviewing accommodations you might need. We will talk first by telephone or Skype, if you have access to that Internet service. I will share a little information about myself and this study and ask you some informal questions about yourself. If you would like to see me in person before interviewing, then Skype will make that possible.

_____ Initial here to indicate you have read each page

After we are comfortable talking by phone or Skype, I will set up a telephone interview on a toll-free conference line that is secure and allows for digital audio recordings of our conversations. We may have two or more conversations over the course of the 4 to 6 weeks I will be conducting these interviews. A transcriptionist will transcribe our conversations into print for research analysis purposes. The transcriptionist will only have a subject number for each conversation. She will not have access to any identifying information about you. After our conversations, I will email you a transcript and ask you to review it for correctness to make sure that we captured what you meant to say.

No one but me will know your complete name or any other identifying information. During the study all papers, tapes and transcriptions will be kept in a locked file in my office. Once the project is completed, your audio tape and demographic survey will be destroyed. When I am finished, I will write my dissertation, and may write a brochure about the findings geared toward persons with disabilities who may be struggling about whether or not to work. I may write a professional journal article on the results. I will report the findings as a group. Any specific examples mentioned will be disguised so that no one can guess who said it. Your participation may help others with disabilities that are thinking about going to work but may be fearful or unsure. As a token of my appreciation for your time and participation, you will receive a Visa Gift card in the amount of $50 after the last interview and review of transcript(s).

The risk to you is minimal, no greater than what you would ordinarily encounter in daily life. Your government benefits or your relationship with your benefits counselor or vocational rehabilitation counselor will not be harmed by participating. If, after we meet, you feel that you would like counseling to re-examine your decision to work, I will provide contact information for Vocational Rehabilitation counselors and the local Independent Living Center if one is nearby. Or your Benefits counselor will be happy to discuss this with you. Your responses are welcome and your participation is completely voluntary and confidential. You may stop participation at any time. If you have questions about this project you can call or email Dr. Juliet Fried, whose contact information is at the top of this letter. She is the supervisor for this project.

If you want to participate in this study, please sign below. If you have a guardian, he or she must sign this form also. If you do not want to participate just return the form to the Benefits Counselor who gave it to you. Thank you.

Patricia Yeager, M.S. Lead Researcher

_____ Initial here to indicate you have read each page

Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado, Greeley, CO 80639, 970-351-2161.

_______________________________________ _____________
Signature of Participant Date

_______________________________________ _____________
Signature of Guardian, if needed Date

____
Telephone or email so that I may contact you

If you decide to participate, please sign and date, then either fax to me or hand back to your counselor who will fax it to me. Or you may send this back by US Mail to:

Patricia Yeager
UNC Dept of Human Services
Campus Box 132
Gunter 1250
Greeley, CO 80639

Or Fax to: 970-352-1298
Attn: Patricia Yeager

_____ Initial here to indicate you have read each page

APPENDIX B

DEMOGRAPHIC SURVEY

DEMOGRAPHIC SURVEY

Name:________________________ Zip code:________

Best way to contact you:

2. Race & Ethnicity: (Select as many as apply)
   - ☐ White
   - ☐ Hawaiian/Pacific Islander
   - ☐ Black/African American
   - ☐ Asian
   - ☐ American Indian/Alaska Native
   - ☐ Hispanic/Latino/a
   - ☐ Other, please specify ____________________
   - ☐ Decline to State

3. Disability: Which of the following statements apply to you? (Check all that apply)
   - ☐ I am blind
   - ☐ I have low vision
   - ☐ I am Deaf
   - ☐ I am hard of hearing
   - ☐ I don’t speak
   - ☐ People have trouble understanding me when I speak
   - ☐ I can’t get around without help or equipment
   - ☐ I have trouble walking or am limited in mobility
   - ☐ I have a learning disability
   - ☐ I have a cognitive disability
   - ☐ I have a developmental disability
   - ☐ I have a mental health or psychiatric disability
   - ☐ I have some other type of disability Specify:

____

Are there any disability accommodations you need to participate in the focus group or individual interviews?

☐ Sign Language Interpreting
☐ Personal Assistance during the focus group
☐ Print information in alternate format
    What format:__________________________________

How old are you today?

☐ 18 - 21 ☐ 22 - 26 ☐ 27 - 30 ☐ 31 - 35

How old were you when you acquired your disability? ____

Source of Income:

☐ SSI ☐ SSDI ☐ Other (please specify):_____________

Have you received information about Utah's (California's) Medicaid Buy-In Program?

☐ Yes ☐ No

Did you decide not to go to work for reasons other than poor health?

☐ Yes ☐ No

If you would like to see the results of the focus group and give me feedback, please check here: ☐

I will need your email address and a telephone number to communicate with you?

Email: _________________________________

Phone number: _________________________

Mailing address:

____

____

(Either I will take this information over the phone or send by email or fax/mail and ask for it to be faxed back to me)

APPENDIX C

E-MAIL RECRUITMENT MESSAGE

Dear :

I am emailing you for assistance with a research project I am working on for my dissertation in Human Rehabilitation at the University of Northern Colorado. I am looking to interview folks over the phone who meet a very specific criteria and will send them a $50 Visa gift card for their time. I am hoping you could help identify one or two people from the consumers you serve.

My topic is examining the internal barriers that some people with disabilities may have toward work. This is a specific sub group- here are the criteria

1. have a disability and on federal benefits less than 10 years
2. health status is such that they could consider working some
3. are not currently working
4. Understand that there is a work incentives program in place that allows them to work and keep their benefits up to a point.
5. Still reluctant to try work.

My goal is to identify the things that we tell ourselves about work or the judgments we make about our ability to work. If I can identify statements of this self talk, then we can begin to address them with consumers. But I need people to talk to! I have three interviews so far and it is very interesting! Do you know of individuals who, after hearing about the work incentives program came away saying... "I don't know...let me think about it." Those are the people I am looking for.

I have attached my consent form so that you could share that with anyone that you can think of that meets my criteria. If he/she would contact me then I can begin the process. Do not share the consumer contact information with me but have the consumer contact me directly to protect their choice and privacy. Alternatively, if the consumer is willing to sign the consent form and allow you to fax it to me, that would work as well. My University contact is on the consent form and my personal phone and email is on this message.

I really appreciate any assistance you can give me. I am looking to do these interviews over the next several weeks.

Patricia Yeager
UNC Doctoral Student

APPENDIX D

LETTER FORM OF THE INVITATION

On agency letterhead

Date here

Dear Benefits Recipient,

Our agency will be participating in a research study to explore the internal barriers to work that some people with disabilities may have. Please consider this invitation to participate. Participating in this research will not harm your benefits or the services that you receive from ________. All information will be held strictly confidential and even we here at the agency will not know who participated or what was said.

As a participant in the study, you will be invited to participate in one on one interview(s) with a Human Rehabilitation doctoral student from the University of Northern Colorado. Patricia Yeager is working on her dissertation and would like to interview, by telephone, people with disabilities who:

- have been on social security for less than 10 years
- are currently not working
- are relatively healthy (that is, they could work a few hours a week or more)
- have received information about work incentives programs
- are reluctant to try work.

During the interview you will be asked about your thoughts and feelings about disability, work and what might keep you from working. The interview, will be digitally audio taped for the researcher to transcribe. Afterwards, you will be asked to review a typed copy of the transcript to make sure it accurately captured what you said.

If you choose to participate, you will be asked to fill out a Demographic information form that includes questions about your age, race or ethnicity and disability, age of onset of disability and what type of Social Security benefits you receive. It will also ask for contact information so that the Researcher can contact you to arrange the interview and make sure any disability accommodations are addressed.

As a token of appreciation, all interviewees will receive a $35 Visa gift card. If you would like to see a copy of the results of the research, let the researcher know and she will share that with you.

All personal information will be held confidential and any statements you make will not be attributed to you. If you are interested but have questions, please feel free to contact Patricia at yeag0386@bears.unco.edu or call 999-999-9999. If you want to participate please sign and date the consent form and fax or mail it to the contact information on the form. Patricia will call you as soon as she gets the form.

Thank you for your response to this invitation.

Sincerely,

Benefits counselor at agency

APPENDIX E

REVISED QUESTIONING GUIDE FOR INDIVIDUAL INTERVIEWS

REVISED QUESTIONING GUIDE FOR INDIVIDUAL INTERVIEWS

Initial conversation that is not recorded:

This conversation will be conducted via telephone or Skype. The purpose of this call is to allow the participant to get to know me a bit and understand the research topic and process. I will also ask a few questions about his/her interests, family, and other details to begin to establish a rapport or relationship prior to the interviews. If the participant has access to Skype and would like to see me in person, then we will use Skype for that purpose. While Skype has several recording options I cannot determine how secure and safe they are. The interviews will be conducted through a web-based telephone conference system that is secure and provides digital audio recordings.

Recorded Interview (may be conducted over multiple calls):

1. Tell me a little about you. Family status, education level, where you live, interests etc.

2. Tell me about your past work experience. What did you think about those past jobs? Why did you stop working? Have you thought about going back to work in the past 5 years?

3. If you haven't worked, tell me about your dream job. What would it be like to work and how would you feel about working?

4. Tell me about your disability? When you acquired your disability? How does it impact your daily life? How does it impact work for you?

5. What does your family say about your disabilities? What expectations do they have for you? How about friends? Your Doctor?

6. What does "society" tell you about working as a person with a disability?

7. Do you see your self as a person with a disability?

8. What keeps you from working? (anticipate answers such as my disability, education, employers won't hire me, lose my benefits, etc). This may elicit some discussion around external barriers.

9. What do you think about your ability to work?

    a. If you have been thinking about going to work, tell me what you hear yourself saying inside about working.

   b. Think of your dream job and tell me what you hear yourself saying about pursuing that dream.

   c. What if any fears do you have about going to work?

10. Are you satisfied with your life as it is right now? Does that influence your decision to work or not?

APPENDIX F

PEER REVIEW COMMENTS

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Dr. H. Stephen Kaye's peer reviewer response (e-mail communication, April 26, 2011)

I think you've captured some really good stuff, and you've done a fine job of distilling it. I don't really have any reactions to the themes you selected or your interpretation of them (everything seems fine to me), but there were a few things that struck me:

– I was glad that you had the one "outlier" who is happy not working. I think it's important to acknowledge that not everyone needs or wants to work, and that using one's disability benefits as a way to stay home and tend the garden (even though you thought of a perfectly fine career option for him) can be a good outcome for some people. I mean, if the point is social participation and integration, rather than simply economic participation, then he's got things covered pretty well--plus, he's part of a community that has gotten used to and accepts working-age people who aren't working and doesn't necessarily pass judgment. (And, you know, he seems pretty happy.)

– Boy do most of the rest of these interviews demonstrate the importance of early intervention to either keep people working or get them to return quickly following onset of a disability. Once they've gotten detached from the labor force for a while, there's really no going back, or at least no clear path back in. Especially for those who are somewhat older, because they've got to face the additional source of discrimination based on age, plus they probably haven't mastered or kept up with technology. Where's the person to tell them, early on, that there are accommodations and laws and other ways of contributing without doing exactly the same work they've always done? Where's the person to give them that opportunity, or help them find it? VR is probably too far down the road to help keep someone from losing their connection to the world of work. It's bothering me that the doctor tells them only that they can't work in their former occupation (really? ever heard of accommodations?), but can offer nothing in the way of guidance or referral to an alternative.

– Again, most of them have no role models.

– Observation: Researchers who are embedded in the social model often do research on people with disabilities who are also embedded in the social/IL model, the natural result of recruiting through ILCs and other disability organizations. Which is of limited utility, I think, because most people with disabilities are more like the people you interviewed. We need to find better ways of getting PWD who don't think of themselves as PWDs to participate in studies (other than representative surveys).