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During the Wait: A Phenomenological Study on Denied Social Security Disability Applicants Awaiting Appeal

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During the Wait: A Phenomenological Study on
Denied Social Security Disability Applicants Awaiting Appeal

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Rehabilitation Education

by

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Abstract

The purpose of the present study is to investigate the essence of the experience of individuals who were denied Social Security Disability benefits and who sought the appeals process. In the first round, five semi-structured face-to-face interviews allow the participants to share their thoughts, feelings, and actions taken and, if any, what life changes occurred during the appeals process. Data analysis using phenomenological methods create textural-structural descriptions from which, in a second interview, applicants choose to confirm, edit, or add to their analyzed interviews. The findings present as seven major themes that describes the phenomenon. They are: (a) procedural unfairness and inefficiencies; (b) losses and changes (c) independence versus dependence; (d) emotional (e) mental effect (f) self-advocacy; and (g) recommendations. These findings describe the experiences of individuals denied social security disability benefits and while seeking appeal. Implications for best practices for rehabilitation counselors and those who provide mental health counseling as well as procedures for the state vocational rehabilitation agencies and the Social Security Administration are presented. Policy and legislative recommendations are outlined as avenues for future research to promote fair disability procedures, financial recovery, independence, and emotional health.

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Dedication

Your lives were spent preparing, guiding, disciplining, supporting, and loving me and I am forever grateful. As you look down on me, I know you are as proud of me as I am thankful of you. You gave so much of yourself. I am so thankful for all of your sacrifices.

This work is dedicated to those that I lost along the way: Mother, Mary L. Clay 1944-2013, Uncle, Elmer Strickland, 1944-2014, Mee-maw, Lillie B. Clay 1922-2015

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Chapter 1: Introduction

Chapter one will present an explanation of the disability determination process and an introduction to the population being studied, followed by the research problem and purpose. A presentation of the theoretical lens through which this project is framed will precede the research questions. The significance of the study and its delimitations will be presented prior to the chapter summarization.

The Disability Determination Process

The Arkansas Disability Determination for Social Security Administration Agency (DDS) has an agreement with the Federal Social Security Administration (SSA) to determine disability status (Arkansas Disability Determination, 2014). Their website reports the application process as having average time constraints. The procedure, like the national process, passes through five phases: the initial phase, the determination phase, the reconsideration phase, the administrative Law Judge (ALJ) phase, and the appeals council. An unfavorable decision at any phase allows the applicant to progress to the next appeals phase. During the initial phase, the applicant submits a disability application to a federal Social Security office where it is reviewed for age- and work-related requirements before submitting it to DDS for disability benefits determination. The initial administrative process should take 5-10 days before submission to the DDS, with DDS making a determination within three months. The reconsideration phase adds an additional four months to the disability process and a request for a hearing before an Administrative Law Judge (ALJ) adds approximately 10-12 months. Another unfavorable decision allows the applicant to request a hearing before the Social Security Appeals Council (AC), which adds approximately one more year before the applicant is either denied or approved for benefits. An applicant's final option is to seek civil litigation in the federal court

system. Civil suits can be appealed up to our nation's highest court, the US Supreme Court (Arkansas Disability Determination, 2014).

Research has shown that, on average, it takes one to one and a half years for a file to move from its initial phase to completion of the ALJ hearing; appeals at each phase can be filed by the applicant, negating the necessity for legal representation to proceed through the Social Security Disability process (Arkansas Disability Determination, 2014). However, bringing a civil suit before the federal district court requires the ability to pay fees (SSA Hearings and Appeals, 2014).

During these lengthy wait times, applicants tend to use other resources, both governmental and non-governmental, to fund their living expenses (Coe, Lindner, Wong, & Wu, 2014). Denied applicants waiting for benefit approval are likely to use governmental assistance programs to fund their wait times (Thompkins, Honeycutt, Gill, Mastrianni, & Bailey, 2014). In essence, denied applicants who spend months to years waiting for disability approval increase governmental rolls by becoming consumers of assistance programs to fund their daily living expenses (Thompkins et al., 2014) and, each time they are denied disability benefits, there is a perception that the applicant is more able to work than those who are approved for benefits (Wachter, Song, & Manchester, 2011). It is these denied applicants moving through the disability process that are the topic of study.

Statement of the Problem

Arkansas has two Offices of Disability and Adjudication and Review (ODAR), located in Fort Smith and Little Rock. These offices have Administrative Law Judges that hear Social Security Disability (SSD) and Supplemental Security Income (SSI) cases. There are seven judges in the Fort Smith office and thirteen judges in the Little Rock office, who have a 47%

combined approval rate for the state (SSA, 2016). That leaves 53% of cases being either dismissed or denied. It is those individuals whose cases make up this 53% that interests this researcher. This group of Arkansas applicants were denied benefits and have been off work for almost a year, as the average claim processing time from hearing request to final disposition is 379 days (SSA, 2015). Unable to work, living without income or with a reduced income, what does a person think about the process? How does one feel? What is a person to do? What changes are endured? What programs and benefits are sought? The answers to these questions are the driving force behind this research.

Purpose of the Study

The purpose of this study is to investigate the lives of those individuals who were denied disability benefits and who participated in the appeals process; it seeks to determine their thoughts, feelings, and courses of action taken while living without SSDI or SSI benefits, and if any, what life changes were made during this wait. An applicant may be denied at the initial level but approved at the ALJ level or never approved. If never approved, what does the applicant do? How does a person provide for their families without disability benefits? Did the applicant turn to other avenues to gain assistance and support? To obtain the thoughts, feelings, and the reasons for specific actions taken by someone, we can simply ask them. A phenomenological qualitative study is in order here. It is through this type of research that applicants will be allowed to fully convey their perceptions of their disability, their financial status, and explain the course of action taken to fund their living expenses while pursuing disability benefits.

Theoretical Framework

The perspective from which research questions are populated, data collected, and research designs developed is the theoretical perspective (Creswell, 2009) or interpretive framework (Creswell, 2013). Some qualitative research is not guided by a theoretical framework; rather, the researcher attempts to set aside theoretical orientations and assumptions to learn from the research participant. An example of this approach is phenomenology research (Creswell, 2009). In phenomenological research, the researcher achieves their goals by bracketing their biases and theoretical assumptions in order to understand the essence of the experiences from the research participants' perspective (Moustakas, 1994).

This study is not oriented via a theoretical framework; it is guided by a transcendental phenomenology approach. According to Moustakas (1994), this approach “focuses on the appearance of things . . . is concerned with wholeness . . . seeks meanings from appearances . . . and is committed to descriptions of experiences, not explanations or analyses” (p. 58).

Research Questions

This research project sets out to describe the experiences of adult applicants who reside in the state of Arkansas and who, within the last five years, were initially denied disability benefits and are appealing those benefits. As part of the data collection process, demographic information such as age, race, gender and classification of disability will be obtained.

The primary research question is: (a) What does it mean to be denied Social Security Disability benefits and appeal the decision? Research questions related to the primary question include: (b) What do Arkansas applicants who have been denied Social Security Disability benefits and are appealing the decision think about the decision? (c) How do they feel about the

experience? (d) What courses of action do they take?; and (e) What changes, if any, do they make in their lives?

Significance of the Study

The information gained from conducting this study will identify how adult Arkansans provide daily necessities for themselves and their families while waiting to be approved for Social Security Disability benefits. This information can be used by policy makers to detect areas of need and aid in the development of interventions that will facilitate return to work for this subpopulation of denied applicants.

Delimitations

All applicants are from Arkansas with an application date within the last five years. Therefore, applicants from other states or whose applications are older than five years will not participate in this study.

Chapter Summary

The purpose of this study is to gain a deeper knowledge of the meaning that individuals who have been denied Social Security Disability benefits make of their experience. To do so, a phenomenological qualitative study is being conducted to better understand the essence of the experience in terms of applicants' thoughts, feelings and courses of action taken while waiting to receive a disability decision.

Research outcomes will describe the experiences of and changes endured for denied applicants who are awaiting a determination of disability benefits. This information will be useful in providing insights into the thoughts, feelings, and course of actions taken while waiting for a disability decision. Rehabilitation professionals may find this information valuable to

providing return to work and independent living services. It may be useful for policymakers and in providing a foundation for further research.

Chapter 2: Literature Review

The primary purpose of the literature review in qualitative research “is to identify the gaps in what is known about the phenomenon” (Koch, Niesz, & McCarthy, 2013, p. 3). Chapter two will provide a condensed history of the Social Security Administration (SSA), and show the inequality between available programs for Social Security beneficiaries and those for Social Security applicants. After presenting characteristics of beneficiaries, this chapter will discuss the staff positions, programs, and national research projects which are presently or have been conducted to support beneficiaries in their return to work. It will then follow the same outline to present information on Social Security applicants and denied applicants, ending with a chapter summary.

Social Security

What, in 1935, was initiated as a retirement program for those who were 65 and older has, through legislation, expanded to include benefits for dependents, survivors and people with disabilities. The Social Security Administration is a federally administered program which provides cash benefits to retired and disabled workers and families based on specific criterion (SSA, 2012).

Between the 1930s and 1950s, through legislation such as the Social Security Act, benefits were paid to retired workers who were 65 years old and older, their spouses, their children, and to family members of deceased workers (SSA, 2012).

The next 20 years of legislation implemented the Social Security Disability Insurance program (SSDI), which provided cash benefits to eligible disabled workers who had completed a six-month waiting period and who were between the ages of 50-64. It also provided benefits for those who were disabled before the age of 18 and were dependents of retired, deceased, or

disabled workers (SSA, 2012). In 1960, the program was expanded to include qualified individuals under the age of 50, and widows and widowers between the ages of 50-64. The amendments passed during the 1970s pushed the age limit for which a childhood disability should have begun from 18 to 22, reduced the waiting period, extended Medicare, and turned the Supplemental Security Insurance (SSI) program into a need-based program for disabled children age 17 and under (SSA, 2012).

From the 1980s to 2000, legislation sought to tighten the growing disability rolls and allow for rehabilitation of disabled workers. Legislation during the 80s was responsible for eliminating benefit payments to imprisoned felons, determining a limit to disability benefits, and establishing reviews through which individuals could continue receiving their benefits. Reviews of disability decisions allowed individuals to keep their cash and Medicare benefits while their review by an administrative law judge (ALJ) was pending. In addition, drug and alcohol abuse/addiction became reasons for denial of benefits if either was found to be a contributor to the impairment (SSA, 2012).

The late 1990s brought legislation specific to returning disabled beneficiaries to work, The Ticket to Work (TTW) program (SSA, 2012). TTW provides for a beneficiary to return to work by seeking employment support services from employment networks. These employment networks are made up of government agencies such as state vocational rehabilitation programs and private organizations that provide job seeking services. The beneficiary is able to choose which employment network is to provide their return to work services and do so without the fear of losing their benefits (SSA, 2012).

Characteristics of Beneficiaries

Over the course of more than 75 years, the Social Security Administration has expanded its services from providing retirement benefits to providing disability benefits for children, disability benefits for adults, return-to-work programs for disability beneficiaries, and the funding of research projects related to disability.

The total number of workers, widows, widowers, adult and minor children and spouses receiving disability benefits for 2012 was a little greater than 10 million people, at a reported \$136 billion cost. (SSA, 2013). In 2012, the three diagnostic groups with the highest numbers of disability beneficiaries aged 18-64 were: musculoskeletal system and connective tissues, mood disorders, and intellectual disability (SSA, 2012). Demographically, the largest group of recipients of those aged 15 and above who reported only one race were white, female, and between the ages of 65-74. Of those reporting more than one race, the largest group of recipients were white, female and between the ages of 15-54 (SSA, 2013). From 2009 to 2010, payments from the Disability Insurance Trust Fund increased by 5% (SSA, 2011), by 3.8% for 2010 -2011 (SSA, 2012) and by 6.2% for 2011-2012 (SSA, 2013), at an annual cost of a billion dollars. Social Security Disability is a billion-dollar industry, which is a good reason for the federal government to develop programs that will aid disability beneficiaries to return to work, engaging in substantial gainful activity (SGA) and thereby reducing government cost.

Substantial gainful activity is defined as a monthly monetary amount that is earned from work that requires activity that is physical, mental, or a combination of both and that is for profit or pay (SSA, 2014). The 2014 SGA levels for blindness is \$1800 and, for people with disabilities excluding blindness, is \$1070 per month (SSA, 2014). If a person is able to earn the SGA level of income, they are not eligible for disability benefits (SSA, 2014).

Programs for and Studies of Beneficiaries

Programs within the social security administration.

The Red Book (2014) is published by the Social Security Administration to provide an overview of its programs and provisions that support beneficiaries' return-to-work (RTW) efforts and states that supporting disability beneficiaries in their RTW efforts is one of the SSA's "highest priorities" (p. 1). The following employment initiatives are introduced to show the extent of SSA's support for beneficiaries to return to gainful employment. The terms *employment supports* and *work incentives* are used interchangeably to define these efforts.

The SSA employs personnel who provide information to individuals, organizations, the public, and the community concerning the different work incentives offered (SSA, 2014). At the Social Security office level, these individuals are called Work Incentive Liaisons (WIL). There is a WIL located in each office with the task of discussing the return-to-work services provided by SSA to beneficiaries. The Area Work Incentives Coordinator (AWIC) is responsible for overseeing the dissemination of information to the public and for training personnel on SSA work incentives. Grant-funded, community-based organizations that provide work incentive information to beneficiaries are called Work Incentives Planning and Assistance Projects (WIPA). WIPAs work in partnership with other governmental community-based, for-profit and non-profit agencies to provide assistance with work incentive planning (SSA, 2014). If the beneficiary is unable to meet with any of the aforementioned individuals, Work Incentives Seminar Events (WISE) provide free webinar training via the Internet to disabled beneficiaries to allow access to information concerning work incentives (SSA, 2014).

In addition to the SSA, American Job Centers, State Vocational Rehabilitation Agencies and Employment Networks all provide an assortment of services and tools to facilitate RTW

(SSA, 2014). Beneficiaries can receive skill assessments, career interests testing, help with resume development, and information on job vacancies. Whether the beneficiary is going to work for the first time or after several years of employment, these agencies can provide tools to prepare them for their journey. Should the beneficiary need accommodations in order to return to work, the Job Accommodation Network (JAN) is an employment resource which provides information on job-related accommodations (SSA, 2014). The federal government has jobs reserved for individuals with certain disabilities; information on these opportunities can be found at the Office of Personnel Management.

The Plan to Achieve Self-Support (PASS) is a way for SSI recipients to set aside monies such as income from SSDI or earned wages in order to achieve a work goal. The monies are set aside for a specified time and the work goal is one that will decrease the amount of or terminate benefits (SSA, 2014). An example would be a person with a disability who is receiving SSI benefits and working part-time who wants to set aside part of their working income to start a business; once this goal is achieved, this business will provide enough income to lower or eliminate their SSI income. The PASS has to meet certain criteria; for example, it must be in writing, show how the plan will meet the work goal, and be approved by the Social Security Administration (SSA, 2014).

Ticket to Work is a national program in all 50 states that seeks to provide people who are disabled a plan to return to work (SSA, 2014). A ticket or voucher is given to the individual with a disability to be assigned to the organization of their choosing which provides employment support services (SSA, 2014). The ticket allows for many free services such as job training and vocational rehabilitation (SSA, 2014). These services are provided by Employment Networks comprised of public and private companies and individuals who have agreed to provide

employment-related services (SSA, 2014). Two major assets are that, while using the ticket, the beneficiary is no longer at risk of disability review, and if benefits are lost based upon wages, if needed, they can request reinstatement of benefits with expedited features (SSA, 2012).

Attorneys and advocates work for the Protection and Advocacy for Beneficiaries of Social Security (PABSS) program to provide services to assist in removal of return-to-work barriers (SSA, 2014). PABSS also informs beneficiaries of return-to-work programs and investigates complaints against providers or return-to-work services (SSA, 2014). Each state has at least one PABSS office, with a total of 57 nationwide (SSA, 2014)

Other features that allow SSDI beneficiaries to return to work without losing their disability benefits are the Trial Work Period (TWP) and the Extended Period of Eligibility (EPE) (SSA, 2014). The TWP allows a beneficiary to receive full SSDI benefits for a minimum of nine months of work with no wage limits (SSA, 2014). The nine months of work do not have to be consecutive but they must be within a 60-month period (SSA, 2014). If a person is successful in working those nine months, they will undergo a review and SSA will decide if they are able to earn SGA. The Extended Period of Eligibility (EPE), also called the re-entitlement period, begins one month after the TWP ends. It is a three-year period during which SSDI benefits can automatically be reinstated without restarting the disability process any time earnings fall below SGA (SSA, 2014). If at any time SGA is earned, the individual is no longer considered disabled and will receive benefits for that month and two following months. These two months are known as the grace period (SSA, 2014). If the beneficiary's income falls below SGA and he or she has passed the 36-month re-entitlement period, she or he may still be able to restart benefits under the Expedited Reinstatement (EXR) provision. Along with other criteria, EXR allows for reinstatement as long as application is made within 5 years of benefit cessation. A beneficiary

who is working and has completed their TWP without medical improvement is also allowed continued Medicare health coverage for 93 consecutive months (SSA, 2014).

The Trial Work Period, EPE and continued Medicare coverage are employment supports that are only available to SSDI beneficiaries. Earned Income Exclusion (EIE), Student Earned Income Exclusion (SEIE), Property Essential to Self-Support (PESS), Section 1619(a) and continued Medicaid are supports limited to those benefitting from SSI.

When calculating SSI payments, EIE disallows the first \$65 of monthly earnings for those SSI recipients who work (SSA, 2014). SEIE disallowances are also applied to the payment of working SSI beneficiaries who are under the age of 22 and who regularly attend school based on the SSA attendance standards. Under SEIE, this group is allowed to earn \$1,750 a month – a maximum of \$7,060 a year – that will not be counted towards calculating their SSI payments (SSA, 2014). PESS allows for up to \$6,000 of resources that are essential for self-support to be disallowed when SSA is making a decision concerning continuing SSI disability payments (SSA, 2014). There is also a re-instatement provision for SSI beneficiaries; it allows reinstatement without filing a new application if benefits were suspended due to work (SSA, 2014). Under section 1619(a), when certain basic income and resource criteria are met, SSI recipients are allowed their cash payments while working at SGA (SSA, 2014). Finally, there is also a health care coverage provision 1619(b) which, based on eligibility criteria, allows SSI recipients to maintain their Medicaid even if their SSI benefits are terminated due to earnings (SSA, 2014).

These employment supports have been discussed in order to show the abundance and type of work incentives established by the Social Security Administration to facilitate return to work of those already receiving benefits and to spotlight the lack of programs for denied applicants.

National Demonstrations.

Work incentives have a primary goal of providing services for returning disability beneficiaries to work that will allow earnings at or above substantial gainful activity (SGA). This level of earnings will remove them from the disability rolls and thereby reduce government costs. These work incentives are part of the Social Security framework (SSA, 2014). Intervention projects are another avenue by which SSA provides for the return-to-work of beneficiaries. These interventions or research projects are called national demonstrations and are funded by the SSA to study ways to improve services they provide to beneficiaries (SSA, 2016). The following paragraphs will discuss previous and current national demonstrations designed and funded by the Social Security Administration with the purpose of returning to work those who receive SSDI or SSI or who are beneficiaries of both.

Transitional employment (TE) describes a situation in which an individual trains on a job to acquire skills that will transition into competitive work within the labor market (Prero & Thornton, 1991). TE services have the following characteristics:

Training services available for a limited time, and placement in a potentially permanent competitive-level job is an integral part of program services. Training takes place on a real job, that is, a paid job that consists of tasks that another worker would otherwise perform for the employer and in which the worker has an opportunity to interact with non-handicapped coworkers or the public. Special training is provided by job coaches. Training support is reduced over time to promote independence. (Prero & Thornton, 1991, p. 4)

For one national demonstration, eight organizations were chosen to promote TE services such as job coaching, job development, and job placement to half of the 745 participants who were assigned to the treatment group. The other half, assigned to a control group, were left to seek services provided within their communities. Participants were granted waivers that protected their disability status, but not the possibility of a payment reduction based on earnings

(Prero & Thornton, 1991). Thirty-four percent of participants held a permanent position at project end and their average month earnings were enough to reduce SSI payments, should job retention prevail (Prero & Thornton, 1991). However, that information was only part of the program and it alone did not determine program success. There were other issues such as the diverse needs of clients; they learned at different levels and some had behavior problems. This created a challenge as to how to allocate time and resources (Prero & Thornton, 1991).

Transportation and the challenge in gaining employer participation were other issues that were noted from the demonstration (Prero & Thornton, 1991). Overall, Prero and Thornton (1991) summarized the demonstration by stating that “. . . despite these difficulties, transitional employment in its various forms is a highly promising means to help persons with mental retardation become more self-sufficient, achieve greater community respect and self-respect, and lead generally more productive lives” (p. 23).

The Transitional Employment Training Demonstration used TE services as the tool to increase employability among a specific group of SSI recipients. Another SSA demonstration which took place in the early 1990's, Project Network (PN), used case management as the tool to promote return to work for individuals with severe disabilities (Kornfeld & Rupp, 2000). The goal was to “test case management as a means of promoting employment among persons with disabilities” (Kornfeld & Rupp, 2000, p.12). Incentives to participate were waivers which suspended continued disability review and the disallowance of up to 12 months of earnings in regard to SGA and TWP; participants who were beneficiaries of SSDI or SSI were randomly assigned to either the treatment or control group. Treatment group participants received one-on-one case management services such as assessment of work potential and job search assistance; these services led to customized return-to-work plans. Control group participants received

community-provided services. Overall, project cost outweighed government savings (Kornfeld & Rupp, 2000), disproving the idea that case management was a successful tool to use to facilitate return-to-work services for beneficiaries.

In 2006, SSA sought to make health benefits for newly awarded SSDI recipients available sooner than the 24-month waiting period. The Accelerated Benefits (AB) Demonstration had a goal of improving recipients' health, thereby increasing return to work and decreasing SSDI payments, and was intended for those who were "recently awarded SSDI benefits, had at least 18 months before they became eligible for Medicare, were between the ages of 18-54" (Wittenburg, Warren, Peikes, & Freedman 2010, p. 2) and who lived within one of the 53 metropolitan areas where the project would take place (Michalopoulos et al., 2011). Similar to previous studies, participants who met the eligibility criteria were randomly assigned to one of two treatment groups or the control group. There were two health care plans, AB and AB Plus (Wittenburg et al., 2010). Upon assignment, participants in the first group received healthcare from a private health plan while the second treatment group participants received the same health plan as the first but with additional employment, functioning, and medical case management (Wittenburg et al., 2010). The additional services were delivered telephonically and were aimed at preparing participants for return to work by addressing medical concerns, increasing physical functions, and providing employment tools that would enhance their chances of obtaining gainful employment. In contrast, the control group would remain under the SSA policy guidelines and wait for 24 months before becoming eligible for healthcare services (Wittenburg et al., 2010).

The Accelerated Benefits Demonstration had the following outcomes in relation to health; both the AB and AB Plus groups had an increase in health care usage, and overall health status over the control group. They also had a decrease in unmet needs over that of the control

group (Michalopoulos et al., 2011). In terms of employment, all three groups had low percentages, but the AB Plus group had a greater number of participants preparing and looking for jobs than did the other two groups (Michalopoulos et al., 2011).

In summary, the groups that received health-related services increased in those areas when compared to the control group and the group that received employment-related services increased in employment areas compared to the other two groups. However, overall, no group experienced a statistical significant impact on current employment, all groups having low percentages. It is logical to draw from these outcomes that accelerated benefits do allow for an increase in health care usage, which in turn improved health status but did not increase return-to-work numbers.

The Benefit Offset National Demonstration (BOND) (Werner, Wood, Percari, & Libman, 2008) sponsored by the Social Security Administration seeks to offer SSDI-only and SSDI/SSI dual beneficiaries the chance to return to work without an immediate loss of all benefits. The \$1 for \$2 initiative allows for the gradual decrease of benefits, with the beneficiary having a \$1 reduction for every \$2 earned (Werner et al., 2008). Previous research has not shown a significant impact on employment due to financial incentives, with studies revealing that this is due to a lack of understanding of the participants. Therefore, intensive benefits counseling has been included in the program with the belief that it will improve return-to-work efforts (Werner et al., 2008).

This gradual decrease serves as a support in that it alleviates the sudden loss of benefits when a SSDI beneficiary has employment earnings at the SGA level (Gubits, Cook, & Bell, 2013). If the TWP has ended, the BOND offset will begin 30 days after recipients are randomly

assigned into a group. If it has not ended, it will begin one month after the 9th month of their trial work period. BOND participants have 60 months to benefit from the offset (Gubits et al., 2013).

The BOND enrollment period was from April 2011 to September 2012. There are 12 states represented in the 10 demonstration site areas (Gubits et al., 2013). These areas were randomly selected from one of the 53 Social Security area offices (Stapleton, Wittenburg, Mann, Hoffman, & McGurik, 2014).

BOND has two stages; at stage 1, the sample of participants comprised all current SSDI recipients aged 20-59 who were located within the 10 demonstration sites with the focus on the entire SSDI population and how BOND would affect their earnings and project outcomes (Stapleton et al., 2014). For 2012, there was no impact on earnings; both the treatment and control groups had low earnings (Stapleton et al., 2014).

From that sample, volunteers were identified and randomly assigned to two treatment groups and one control group (Gubits et al., 2013). The focus for stage 2 was how the offset would affect those participants who volunteered and the impact of enhanced benefit counseling (Stapleton et al., 2014). As of December 2012, 2% of stage 2 treatment group had used BOND to offset their benefits. BOND is still an active national demonstration project and should produce additional data in the coming years.

Olney and Lyle (2011) proposed that the Social Security Administration has been sending mixed messages to both applicants and beneficiaries. They have to be unable to work and making less than SGA to qualify for benefits and must remain below SGA to keep benefits, yet they offer incentives to return to work. The authors also discussed the many disincentives of the system. Before eligibility, there is an arduous journey to qualify for benefits, starting with proving an inability to work, and no return-to-work incentives for applicants. After approval of

disability benefits, there is a twenty-four-month waiting period before receiving health care benefits. There are limits as to how much can be earned; continued reviews of disability with the understanding that benefits can be reduced or terminated; and fear of overpayments that must be repaid. Olney and Lyle (2011) held 60-90 minute qualitative interviews with twelve SSDI beneficiaries who had a desire to return to work. Two years later, eight of the twelve participated in follow-up interviews. The outcome was that only one person succeeded in getting totally off the disability rolls. Some were afraid of losing their benefits and therefore worked low paying jobs to maintain benefits rather than pursuing full time work. Others did not have a full understanding of SSA's work incentive programs and therefore were apprehensive about participating in them. However, there was an overall improvement in satisfaction and finances in the lives of those who worked during the two-year period (Olney & Lyle, 2011). Future studies and demonstrations will need to market how the benefits of obtaining earnings at or above SGA will outweigh working lower paying positions and continuing to receive disability benefits.

Characteristics of Applicants

Although much of the Social Security Administration's focus and studies have been on returning Social Security beneficiaries to work, there has been a switch in attention to returning Social Security applicants to work.

Each year, thousands of people apply for disability benefits through the Social Security Administration. In a study to discover how SSDI applicants pay their living expenses while waiting for disability benefits, Coe et al. (2014) gave a description of applicants during the month that they applied for benefits. On average, they were 45 years old; more than half were male; and more than 75% of applicants were white. Thirty to thirty-seven percent of applicants' educational levels were categorized into three groups: high school graduate, high school drop-

out, or a person with some college. A quarter of applicants were divorced and over half were married. The average family and household size was three, with average monthly earnings ranging from \$1,000 for the individual to \$3,000 for the household.

The same study sought to determine how specific supports were used to pay for applicants' expenses while waiting for SSDI benefits (Coe et al., 2014). These supports were governmental programs such as unemployment benefits, workers' compensation, and benefits from the supplemental nutrition assistance program (SNAP). Non-governmental supports were using credit cards, liquidation of housing assets, benefitting from spouses' income, and making a change in their living arrangements (Coe et al., 2014). The researchers observed that just because there were longer wait times for approval of benefits did not mean that spouses increased their workload to provide more support for their family; however, it was noted that a working spouse did provide support for expenses, thereby allowing for longer wait times. As for the government programs, the longer a person waited for benefit approval, the more likely they were to benefit from SNAP (Coe et al., 2014).

A similar study by Thompkins et al. (2014) matched Social Security Administrative files with results of the Survey of Income and Program Participation (SIPP) to determine characteristics of beneficiaries before they applied for disability insurance. SIPP files from 1996, 2001 and 2004 were used for that study. When compared to the general population, applicants for disability benefits tended to receive more assistance from poverty-related benefits programs such as SNAP, and those that provided energy and housing assistance. They were black, were older than 25-55, had less education, and were either divorced or separated; their earning trends decreased prior to application and continued to decrease up to six months after application (Thompkins et al., 2014). The largest employment decline and the largest increase in

receipt of poverty-related benefits were within 6 months prior to application; as the application date grew closer, the number of those with private health insurance decreased and those reporting Medicaid benefits increased (Thompkins et al., 2014). This study also identified groups at risk of applying for Social Security Disability benefits and analyzed applicants for disability benefits and non-applicants within these groups. The seven at-risk groups were:

1) Unemployment Insurance (UI) recipients with a disability, 2) workers with disabilities at risk of applying for UI, 3) individuals with high health expenditures, 4) workers' compensation recipients, 5) private short- and long-term disability insurance (PDI) beneficiaries, 6) military veterans with a disability, and 7) individuals with disabilities who received job training or education services within the past year. (p. 9)

Of the seven at-risk groups, four had high application rates for disability benefits; they were those newly receiving workers' compensation short-term/long-term disability, unemployment insurance, and those with a disability at risk of applying for unemployment insurance (Thompkins et al., 2014).

By matching administrative files with SIPP files, researchers from both studies were able to extract data to identify characteristics of those applying for disability insurance before and during the application process. These studies were helpful in providing information concerning groups at risk of applying for disability benefits and by identifying supports used to offset long wait times for determination of benefits. This information is available for usage in policy development and modification. One area would be in services that seek to return applicants to work prior to attaining disability payments. Success in providing early intervention services would benefit the government by returning applicants to work, thereby offsetting the rise in disability rolls and governmental cost.

Programs for and Studies of Applicants

The Disability Research Institute (2006) summarized the Early Intervention Project as a four-year project that would design service models to provide return-to-work services for SSDI applicants. The first two years focused on the development of service models, procedures, selection process, and evaluation design, while years three and four centered on implementation and evaluation. Details are discussed in the following paragraphs.

In 2002, Berkowitz proposed a design of an early intervention project for Social Security applicants. Initial screening was conducted if the applicants had an impairment that would last continuously for not less than 12 months and if the person was earning less than the SGA level. If so, they underwent two additional screenings to determine which applicants would end up on the Social Security rolls if it were not for the intervention, as all other applicants could use the services of the general vocational rehabilitation program. And lastly, they were assessed on their probability of returning to work. If they passed the two screenings, they were allowed to choose whether to pursue their SSDI benefits or to participate in the return-to-work program. To encourage participation, applicants would receive cash stipends in the amount of disability payments received had the applicant been approved, health care coverage, and a \$1 for \$2 offset of earnings. Choosing to participate in the return-to-work program did not guarantee an applicant would be chosen to participate in the study. However, if they were, they would be assigned to either the treatment or control groups.

Three models were designed to provide return-to-work services for those assigned to the treatment group: The Maximum Return Model, the Innovative Model and the Contingent Fee Model (Berkowitz, 2002). The Maximum Return Model was so named because it required the least amount of change by using already existing return-to-work offices and personnel and was

therefore expected to have the greater return. Participants under this model would utilize the local vocational rehabilitation agencies.

The Innovative Model looked for entities that used innovative ways to provide return-to-work services for the participants and, under the Contingent Fee Model, providers of return-to-work services would be paid a fee contingent upon the participants' returning to work and maintaining employment for specified time (Berkowitz, 2002).

These three models were part of a design for an early intervention project for Social Security applicants. In essence, applicants traded disability benefits for return-to-work services augmented by incentives (Berkowitz, 2002). Design implementation was set to be tested in the fall of 2002 in three states. Each state would test a model; Maryland would test the Maximum Return Model, Vermont, the Innovative Model and Wisconsin, the Contingent Fee Model (Berkowitz, 2002).

Mitra and Dean (2002) discussed the evaluation of the Early Intervention Pilot phase and with a start date of 2003 for the pilot and 2004 for the national demonstration. At that point, the return-to-work models were renamed as "The Integrative Community Support Model, the Intensive Service Barrier and Removal Model, and the Employment Service System Model" (Mitra & Dean, 2002, p. 4). Although their names changed, their provisions did not and were comparable to The Maximum Return Model, The Innovative Model and The Contingent Fee Model, respectively; however, the pilots would take place in four states instead of three, with New Mexico and Oregon taking the place of Maryland (Mitra & Dean, 2002). The pilot project was expected to address the design and implementation procedures so that any issues and concerns could be worked out before the implementation of the national demonstration. The outcomes of the national demonstration would be evaluated for program savings, suitable

employment and SGA earnings for applicants as well as whether or not early intervention prevented reliance on disability benefits (Mitra & Dean, 2002).

In 2004, Debra Bruckers, who worked on the project to design an early intervention program (Berkowitz, 2002) co-authored *The Early Intervention Project* with Sophia Mitra (2004), who wrote articles concerning the project evaluation (Mitra & Dean, 2002) which presented a project that appeared to be a follow-up of their previous work. While the Berkowitz (2002) article presented the design, Mitra and Bruckers (2004) were slated to test the project with a pilot phase that began in 2003 and a national demonstration in 2005. After applicants were determined, they were to maintain the two-part selection process, screening for the likelihood of receiving SSDI benefits and being successful return-to-work candidates. Inducements were more specifically outlined to include cash stipends for one year in the amount of disability payments they would have received had they been approved for benefits, immediate Medicare coverage for three years, access to Medicaid buy-in programs, and consumer-directed employment services, with the benefit packages to be processed and maintained by an agency specifically hired for this task (Mitra & Bruckers, 2004).

Two of the original three return-to-work models (Berowitz, 2002) were maintained. The Intensive Service and Barrier Removal model is a fee-for-service model that allows providers to address and use funds to remove barriers. The second model, the Employment Services Model, paid providers based on the employment outcome of the participant. Both models allowed the participants to use any provider of choice, whether public or private (Mitra & Bruckers, 2004). The authors noted four factors for pilot success: adequate prescreening of participants, effectiveness of the prescreening tools, the adequacy of the incentives to remove barriers, and the accuracy of the theory that there is a demand for return-to-work services for applicants. Those

questions could only be answered once the project's implementation and evaluation had been completed.

Mitra and Bruckers (2004) supported intervening as early as possible to increase return-to-work possibilities as “the likelihood of a labor force reentry declines as the length of absenteeism due to a disability or sickness increases” (p. 161). Early intervention was a major change in disability policy as it placed rehabilitation before receipt of benefits rather than afterwards (Mitra & Bruckers, 2004). This project was set to take place over a two-year period in New Mexico, Vermont, and Wisconsin and was to be used to identify and develop guidelines for the national demonstration (Mitra & Bruckers, 2004)

Current research has not shown the Early Intervention Project ever becoming a national demonstration as it was discontinued by the SSA administration (S. Mitra, personal communication, July 21, 2014). However, in the 2015 Budget Overview, the Social Security Administration reported that, “In addition to our extramural research budget, we also have a \$400 million legislative proposal to provide mandatory funding for early intervention demonstrations intended to build the evidence base for policy innovation,” further noting that “while many demonstrations for existing DI beneficiaries have shown positive results, they have not identified interventions that would return beneficiaries to substantial and sustained employment” and “services or programs provided earlier in the disability process would prove cost effective if they arrested sharp declines in health (leading to lower medical expenses) or prevented the loss of earnings capacity that can result from job separations or long periods out of the labor force (leading to fewer DI claims or other public expenditures)” (pp. 10-11). This indicates that SSA has clear support and future intentions for early interventions demonstrations.

Under the Ticket to Work and Work Incentive Act of 1999, the Demonstration to Maintain Independence and Employment (DMIE) was approved by Congress and funded by the Centers for Medicare and Medicaid Services (CMS) to provide Medicaid services to individuals to delay their entry onto the disability rolls (Whalen, Gimm, Ireys, Gilman, & Croake, 2012). DMIE operated from 2007-2009 with the goal of providing working individuals with impairments extensive health services that would preclude their impairment from worsening to the point of preventing work and landing them on the federal disability roster (Whalen et al., 2012). Grants were provided to four states, Hawaii, Kansas, Minnesota, and Texas, which were hence responsible for defining their targeted audience and designing their own intervention and methodology.

For all states, participants were not applicants or recipients of disability benefits, working at least 40 hours per month and between the ages of 18-62. “All states provided medical benefits and financial assistance for health care” (Whalen et al., 2012, p. 3) and used the same design. They randomly chose their participants and then assigned them to either the treatment group or the control group. The treatment group received the intervention while the control groups did not.

The states differed in their chosen participants and provision of other services. Hawaii targeted individuals with diabetes and, in addition to their medical service, provided diabetes education, nutrition counseling and medical therapy management (Whalen et al., 2012). Kansas provided physical therapy and home health services to those recruits with physical and mental conditions (Whalen et al., 2012). Minnesota and Texas recruited individuals with behavioral issues; Minnesota’s other services included medical transportation and a health club membership while Texas provided mental health services (Whalen et al., 2012).

DMIE results showed a positive impact on health outcomes, with Minnesota having a positive outcome in mental health with significance at the 3% level based on the mental SPF-12 scores. Hawaii had insignificant improvements in both mental and physical health. Kansas had higher limitations pertaining to activities of daily living. Texas had lower physical health scores for 2007 enrollees and higher scores for those enrolled in 2008 (Whalen et al., 2012).

Employment outcomes showed no significant impacts on employment or earnings based upon the calendar year; however, some states showed an increase in work hours for specific enrollees of their treatment groups while Hawaii showed an increase for the control group (Whalen et al., 2012). Outcomes pertaining to disability benefits found treatment groups in Texas and Minnesota having a lower percentage of participants applying for disability benefits than the control group. No impact was detected in Kansas and none of Hawaii's participants received disability benefits (Whalen et al., 2012).

In summary, DMIE had the following policy implications: "Targeting early interventions in vulnerable, at-risk populations can be effective in successfully preventing or forestalling dependence on federal disability benefits" (Whalen et al., 2012, p. 47). Further, "early intervention services that build upon or wraparound existing programs to address the problem of underinsurance can be a cost-effective strategy to help participants maintain independence." (Whalen et al., 2012, p. 49).

Thus far, the literature has discussed previous and current national demonstrations to aid beneficiaries of disability insurance in returning to work. There are several programs within the day-to-day operations of the SSA whose sole purpose is to assist those who are willing to return to work to do so. We have discussed national demonstrations that sought to analyze specific tools that may facilitate return to work for specific sub-populations of benefit recipients.

Research did not stop with beneficiaries but led to interventions for Social Security applicants. SSA supported the development of a research design to intervene early with SSDI applicants prior to benefit approval and addition to the Social Security rolls. The Center for Medicare and Medicaid Services funded the DMIE early intervention research for impaired workers in order to limit dependency on disability benefits provided by SSA.

I propose that there is a subgroup of applicants who could benefit from the same type of services that have been previously outlined for both beneficiaries and applicants. This group would include applicants that have been denied benefits from SSDI, SSI or both. Throughout the disability process, which will be discussed in detail, there are stages of denial and at each stage, there is an opportunity to intervene and provide return-to-work information and services to the applicant.

Studies of Denied Applicants

In 1972, SSA administered the Survey of Disabled and Non-Disabled Adults (SDNA) and, in 1978, SSA administered the Survey of Disability and Work (SDW). Survey answers were matched with earning histories and then used in research on the earnings of denied male applicants aged 45-64. This study found that among rejected applicants, the employment rate one year prior to taking the survey was less than 50%; 90% cited health as a limiting factor to the type and amount work they were able to perform; and 50% provided health as the reason they could not work (Bound, 1989). Less than 50% of men in their prime age who did not pass the medical assessment to receive disability insurance returned to sustained employment. Those who returned to work did so with earnings at 30% less than their pre-disability level and 50% less than non-applicants (Bound, 1989). From that study, we can ascertain that, in the 1970's,

the employment rate and return to work for denied male applicants of disability benefits were low, both being less than 50%.

As part of their study to compare employment and earnings information between beneficiaries of disability insurance and rejected applicants, Wachter et al. (2011) merged databases with DDS initial application information and beneficiary final receipt information to define their groups of allowed applicants, rejected applicants, and applicants who were rejected at DDS level and later allowed. Their one percent sample was made up of all initial applicants who applied for SSDI and SSI benefits between the years 1981-1999. Rejected applicants were those who were disallowed disability benefits at the DDS level and did not receive benefits within ten years (Wachter et al., 2011). If approved for benefits, they were defined as a ‘new beneficiary.’ Beneficiaries who were allowed in the later stages of disability process, which they termed ‘hearing level allowed,’ were, among new beneficiaries, the group deemed “ more likely to be able to engage in gainful activity” (Wachter et al., 2011 p. 18). This implies that as a person moves along the spectrum of disability denials, they are increasing the perception of being more able to work than those approved for disability benefits in the earlier stages.

The Disability Determination Process

The disability determination process takes place at the state and the federal levels. The initial application is turned in to the Social Security Administration, which determines if the applicant has worked enough quarters to be covered under disability insurance and other work-related requirements (SSA, 2014). The application is then sent to the disability determination agency within the applicant’s state. This state agency will look at all available medical information from the applicant’s doctor(s) and they may require the applicant to undergo a medical evaluation. This medical information, along with work and earning information, is

reviewed and the state will then make the first decision on disability (SSA, 2014). The applicant will receive a letter that will inform them of either an approval or denial of benefits. If approved, the letter will include information on benefit amounts; if denied, it will inform the applicant about the appeals process (SSA, 2014). If the applicant decides to appeal, then all original information and any newly submitted information will be reviewed by an individual who did not take part in the initial decision. A second disability decision is granted, which is called the reconsideration level of appeals. If disability is denied at this level, the applicant can request a hearing before a federal Administrative Law Judge (ALJ); thus, the hearing level of appeals. Representation is not required in order to have a hearing before the ALJ. The judge will take all past medical and vocational information, any new information, the testimony of the applicant, and any witness testimonies into consideration (SSA, 2014). The judge will render yet a third decision determining disability. A denial at this stage allows for a fourth level of appeal, which is made to the Appeals Council, which can render one of three decisions: it will uphold the ALJ decision and deny the applicant's request for review; approve the applicant's request for review and decide the case; or return the case to the ALJ for another hearing. If this level ends in denial and the applicant would like to proceed, their last chance is to file a lawsuit before the federal district court (SSA, 2014).

Chapter Summary

The disability determination process allows the applicant four opportunities to present evidence of medical impairments and their inability to work. Each appeal stage takes place under the auspices of someone who was not a part of the previous stage and allows the applicant to present additional information. At each stage and with each denial, the applicant is faced with a major decision pertaining to continuing with the disability process and making a work-related

decision. From the date of the hearing request, the average wait time for a hearing ranges from 7 to 22 months (SSA, 2014). This range does not include wait time from the initial referral to the ALJ hearing or the time spent waiting to hear from the appeals council. The appeals council received over 40,000 new requests from April-June 2014. Although they had over 44,000 dispositions, by the end of the quarter, they still had over 156,000 pending review requests (SSA, 2014). During the same quarter, 4600 new court cases were received; 2700 were sent back to the court on remand, meaning they were returned to the ALJ level for another hearing. Twenty-nine hundred were disposed and over 1300 were pending (SSA, 2014). As we can see from these numbers, the wait time to receive a response from the appeals council would be over three months. If we add 3 months to hear back from the appeals council and 3 months for the time from initial application to the hearing request, there is a wait time range of 13-28 months, during which a person is out of work and waiting for disability income. This phenomenological study seeks to better understand how denied applicants requesting disability income think, feel, and act, and in what ways were their lives affected by this experience? Their experiences are examined further to identify areas in need of interventions and policy changes. The interventions and policy changes should address the long wait times and its' ramification to the applicants, as well as, seeking to educate and provide referrals to programs and resources that can aide the applicant in their area of need.

Chapter 3: Methodology

Chapter 3 provides a rationale for using qualitative research and how its philosophical assumptions cohere to the research process. I also provide a justification for using the phenomenological design. Finally, I describe the researcher's role, site and participant selections, steps to data collection and analysis, trustworthiness and ethics.

Qualitative Rationale

The purpose of this study is to gain a deeper understanding of the experiences of Social Security Disability applicants who were denied at their initial stage of application and who requested a hearing before an administrative law judge. In order to obtain this information, a qualitative phenomenological study was conducted to add to the rehabilitation counseling knowledge base new information about the thoughts, feelings, and actions of denied Social Security Disability applicants seeking appeal.

There are four philosophical assumptions made in qualitative studies: ontological, epistemological, axiological and methodological; respectively, they relate to the reality, knowledge, values, and process of research (Creswell, 2013). An ontological assumption is that the research will embody multiple realities as seen by the different researchers and the different participants (Creswell, 2013). The epistemological assumption is that qualitative research requires as close of a relationship as possible between the researcher and the participants so that a deeper knowledge of the subject can be gained from those participants, while an axiological assumption is one by which researchers place value on the information being gained and present that value along with any bias associated with the research (Creswell, 2013). Although the methodology for a qualitative study is not as concrete as for a quantitative study, there is a certain methodological assumed process, e.g., it is assumed the research process will utilize

inductive procedures from which the emerging data will provide detailed knowledge about the phenomenon (Creswell, 2013).

Phenomenology is a type of qualitative research design that seeks to ascribe meaning to the commonalities of the lived experiences of several individuals (Creswell, 2013). Creswell (2013, p.77) presented commonalities of philosophical assumptions of phenomenology research as follows, “the study of the lived experiences of persons, the view that these experiences are conscious one (as cited in van Manen, 1990), and the development of descriptions of the essences of these experiences, not explanations or analyses” (as cited in Moustakas, 1994).

Moustakas (1994) presented two types of phenomenological research, empirical and heuristics. Empirical research is a type of phenomenological study in which the researcher describes the phenomenon with an interpretation of the lived experience (Moustakas, 1994). “Giorgi (1985) outlines two descriptive levels of empirical phenomenological approach: Level I, the original data is comprised of naïve descriptions obtained through open-ended questions and dialogue. On Level II, the researcher describes the structure of the experience based on reflective analysis and interpretation of the research participant’s account or story (p. 69)” (as cited in Moustakas, 1994, p. 13). Moustakas (1994) explained the heuristics approach as “a process that begins with a question or problem which the researcher seeks to illuminate or answer . . . it is autobiographic . . . the deepest currents of meaning and knowledge take place within the individual through one’s senses, perceptions, beliefs, and judgments . . . it is not text to be read or interpreted but a comprehensive story that is portrayed in vivid . . . meaningful language” (pp. 17-19).

Through these approaches, along with commonalities of quality research and a great deal of influence from Edmund Husserl, a distinguished phenomenological researcher, Moustakas

(1994) presented a phenomenological research approach comprising the following data analysis steps: epoche, phenomenological reductions, imaginative variation, and synthesis.

Moustakas (1994) described the steps of a transcendental phenomenological study as follows: To achieve epoche, the researcher must first eliminate their own bias and feelings by setting aside or “bracketing “(p. 85) all worldly knowledge, self-experiences, and approaching the research with a mind that is void and cleared of any prejudices, biases, or pre-conceived notions about the phenomenon. The phenomenological reduction phase is exercised during data analysis. All data are given equal weight with a reduction of redundant and repetitive statements. Textural themes are built from these smaller common threads of data. A textural description of the lived experiences is written. In the imaginative variation phase, “the structures of the experience are revealed; these are the conditions that must exist for something to appear” (p. 98). This phase seeks to identify variables that account for what is experienced. These themes are then used to write a structural description of the lived experiences of the participants. The final step is a synthesis of both textural and structural descriptions that relate to the overall phenomenon.

Denied Social Security applicants are an under-researched population. The first step to understanding what denied applicants experience while waiting for their appeal hearing and a disability decision is to learn firsthand from their lived experiences with the phenomenon. This can only be accomplished by using qualitative methods. The transcendental approach is chosen because it utilizes structured steps to data analysis. Current research was conducted as a transcendental phenomenological study by asking open-ended questions of participants to better understand the essence of their experience. It was assumed that each participant would share

their lived experiences; their stories would be conscious accounts of their lives and what they experienced while waiting for a decision on disability (Creswell, 2013).

The primary research question guiding this study is: (a) What does it mean to be denied Social Security Disability benefits and appeal the decision? Secondary questions include: (b) What do Arkansas applicants who have been denied Social Security Disability benefits and are appealing the decision think about the decision? (c) How do they feel about the experience? (d) What courses of action do they take? and (e) What changes, if any, do they make in their lives? By gaining a better understanding of the essence of the experience, rehabilitation researchers, educators, and counselors will be more knowledgeable about the circumstances involving and the decisions made by denied Social Security Disability applicants who sought appeal. The information gained allows access into their lives and identifies areas of need, weaknesses, and variables to be addressed by provision of services, interventions, education and further research.

Researcher's Role

I am a certified vocational rehabilitation counselor who owns her own business providing vocational services to individuals with a disability for private entities. I became interested in this sub-population of Social Security applicants as potential consumers of vocational services and set out to develop a return-to-work intervention for this group. However, I realized that I first needed to identify their needs in terms of work, training, and disability issues. Prior literature presented several programs aimed at facilitating return to work for those receiving disability incomes but little information is available concerning those who have made application and await a decision. This lack of information sparked my interest in discovering what a person endures while waiting for a decision on disability income.

I am not an individual with a disability and I have not been a participant in the Social Security Disability application process; however, I do value work and believe that individuals with a disability can work with the appropriate accommodations. The participants with whom I spoke believe that they cannot work, which is made evident by their applications for disability. During my interaction with the participants, there was potential for me to influence the data collection and data analyses based upon my biases, assumptions, and experiences (Creswell, 2013). My profession as a rehabilitation counselor who places value on working was a bias that needed to be bracketed. Also, during this research process, I have found myself thinking about the answers that I would hear during data collection and possible themes that would arise from data analysis. I had to stop my thought process and tell myself that I had yet to interview the first participant and that I needed to clear my mind. Therefore, when necessary, I practiced bracketing prior to the interview by meditating and clearing my mind of answers and feelings from previous interviews (Moustakas, 1994). My meditation consisted of listening to music and allowing the melody and the words of songs to flow through my thoughts. This method allowed me to approach the interviews without assumptions about what to expect. After each interview, I reflected and made a conscious effort to become aware of any biases, assumptions, or feelings that arose. They were then recorded in my reflective field notes (Creswell, 2008) to be bracketed before the next interview. By doing this, I practiced reflexivity, which is “critically self-reflecting on one’s biases, theoretical predispositions, and professional and personal orientations to the phenomenon one is studying and how these may influence data collection and analyses” (Koch et al., 2013, p. 7).

Site and Participant Selections

Upon approval from IRB (Appendix A), I began to contact sites for participants that matched my criteria of being a Social Security Disability applicant between the ages of 18-64 who, within the last five years, were initially denied benefits but appealed for an ALJ hearing. By intentionally contacting sites that appear to have a better chance of obtaining samples that would provide rich data for this study, I conducted a purposeful sample (Creswell, 2008). I developed an invitational letter with an attached flyer and emailed them to those who were affiliated with agencies that were more likely to be in contact with individuals who met the eligibility criteria. Making purposeful contacts that had a higher probability of access to people who have applied for disability and are currently waiting or had to wait for a decision (Creswell, 2013) was implemented in four phases. The first list was made up of the Directors of Student Disability Centers from ten major universities and colleges in Arkansas. I gathered their contact information from the school websites and emailed them a letter asking for their participation in posting the attached flyer, which was a solicitation for participants. In the second phase, the letter and flyer were emailed to rehabilitation professionals. In the third phase, the letter with attached flyer was emailed to family and friends. Finally, I made paper copies of the letter and flyer and put them in a folder in my car to be given out to whomever I missed electronically or new people that I met. Through family and friends, five participants contacted me and agreed to participate in the study, but only four actually followed through. Those who responded by contacting me were questioned to confirm they met the criteria to become eligible for participation; this is referred to as criterion sampling, which Patton (2002) described as “picking all cases that meet some criterion . . .” (p. 243). After we completed their interview, I asked each of the four to recommend other participants. This is known as snowball sampling, defined as

when “the researcher asks participants to identify others to become members of the sample” (Creswell, 2008, p. 155). Through this method, Applicant 5 was referred by Applicant 4.

Creswell (2013) cited phenomenological studies with sample sizes varying from 1-325 participants. The goal for the current research was to obtain a sample of 5 to 10 participants who meet the eligibility criteria. Because this is an exploratory study, I believed 5 to 10 participants to be a sufficient number to provide a basic foundation of information that could be utilized in future studies. It is the period in which they are not working and are waiting to have their hearing or to receive a decision after they have had their hearing that is relevant to this study, and five applicants shared their experience.

Demographic data were gathered secondary to eligibility confirmation. The initial interview questions were asked to confirm that each applicant met the eligibility criteria; secondarily, they presented demographic data. Disability is defined as either physical, mental or both. Total time passed represents the number of years and months from the date of initial interview to our second interview. ALJ hearing presents whether or not they have had a hearing at the ALJ level. Race and marital status were identified from observation or information shared during the interview.

There were five applicants who participated in the study. They ranged in age from 20 to 57. All applicants are African Americans, three are female and two are male. Two are married, one is single, one engaged, and one has a significant other. They all are within the disability appeals process. Two applicants had their cases heard before an Administrative Law Judge and is appealing that decision. Their wait time between their initial denial and the date they interviewed for this project ranged from one year to three years and seven months.

Data Collection

Data collection was initiated by my efforts to purposefully recruit (Creswell, 2008) participants. I disseminated via email an attached invitational flyer (Appendix B) to the directors of disability centers for ten college and universities throughout Arkansas, other rehabilitation professionals, family, and friends. During initial telephone contact with participants, I explained the study's purpose, risks, and benefits (Creswell, 2013). If the caller was still willing to participate, I determined eligibility by asking questions pertaining to their age, disability status, and application status. If they were deemed eligible, I asked them to bring me a copy of their denial letter. I then set up an initial meeting with a date, time and location that was suitable to the participant (Creswell, 2013). Applicants 1, 4, and 5 met me at their local library. Applicant 2 invited me to her home. I interviewed Applicant 3 in a classroom at her church prior to services.

When discussing phenomenological research methods, Moustakas (1994) told the reader to “set aside our prejudgments, biases, and preconceived ideas about things” (p. 85). They are to be “bracketed” (p. 85) outside of the mind and are not to enter the research process. In order to accomplish the first stage, epoche, I had to approach each interview with a mind that had identified and deleted any identified preconceptions (Moustakas, 1994). To do this, I listened to music prior to interviewing and allowed it to take my mind elsewhere.

Ethical considerations were covered during my initial meeting with each participant; they were given a consent form stating the purpose, risk and benefits of the study (Appendix C). I answered any questions from the participant and then obtained written consent (Creswell, 2013). I confirmed current contact information and assigned the term ‘applicant’ with a number by which participant information would be identified. I explained that I would refer to them

throughout the process as Applicant #. They were assigned numbers based on the order that I interviewed. The long interview with open-ended questions is the customary method for data collection in a phenomenological study (Moustakas, 1994). I conducted a semi-structured interview (Creswell, 2008) to allow each participant to share his or her lived experiences. Each interview was tape recorded. I used a semi-structured open-ended interview guide (Appendix D) with the same open-ended questions being asked of each participant, which allowed each applicant to answer the same questions, and increase the chances of responding on topic (Patton, 2001). To further the chances of the applicant responding on topic, interview question 2 was changed. It was originally stated as, “what is your disability or disabilities?” I changed it and asked, “Is your disability physical, mental, or both?” This change eliminated the chance for the applicant to render a deeper discussion of the medical aspects of their disability. The purpose of the questions was to confirm eligibility of having a disability and to categorize disabilities for demographic purposes.

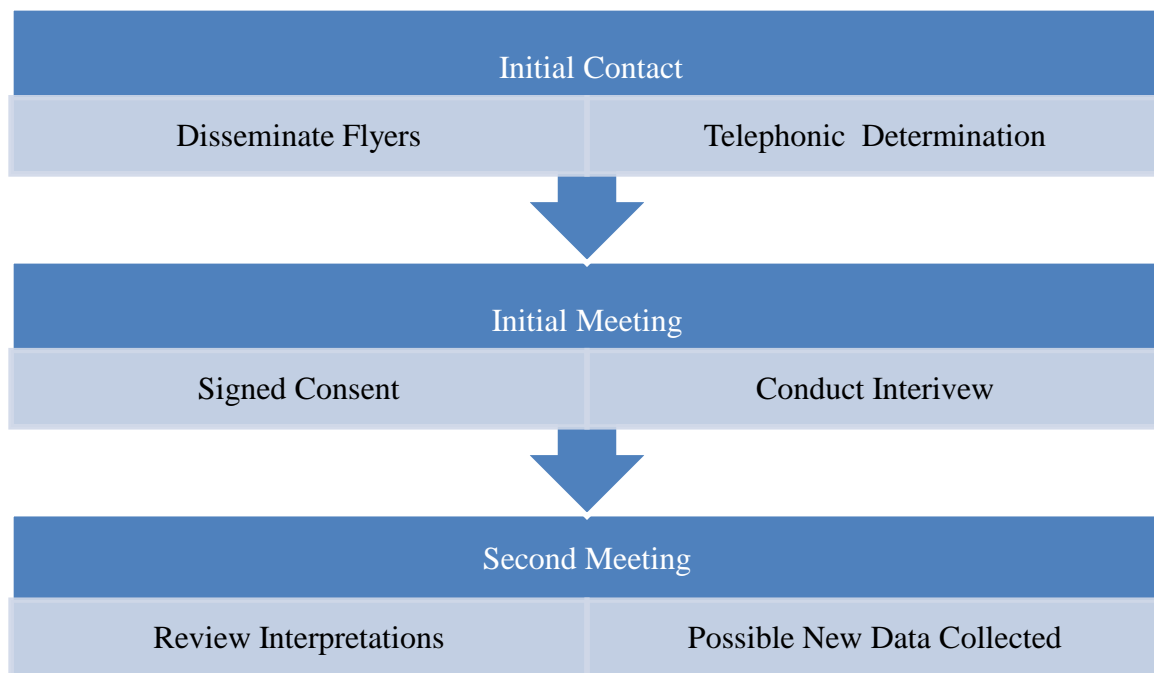
I began the interview confirming eligibility by repeating the previous questions concerning age, disability, and application status. I stopped and checked the recording device to confirm its operation and volume. The semi-structured interview continued with my asking a series of open-ended questions as outlined in the interview guide (Appendix D). Immediately after each interview, I recorded field notes. Descriptive field notes were made to describe what was observed and reflective field notes recorded my personal thoughts and reflections concerning what I observed during the interview as well as how my role as researcher shaped that interview (Creswell, 2008). Data collected from secondary resources were copies of the letters from Social Security documenting their denial and the status of their application

(Creswell, 2013). These letters were filed with the signed consent. Each interview was copied from the recorder to a file on my PC and a USB drive.

There was a second interview with each applicant after analysis of the initial data to check for accuracy of my interpretations and understandings (figure 1). An interview guide was used to conduct second interviews (Appendix E). All applicants confirmed my interpretations and none changed or deleted information. Three applicants presented additional information, which went through the same stages of analysis as the original data. Methods of analysis will be discussed in detail in the next section.

Figure 1.

The Steps to Data Collection



Managing and Recording Data

A new interview protocol sheet was used for each applicant. Audio recordings and transcriptions were maintained on my personal computer in a file labeled “interviews and transcriptions,” with a second copy saved on a USB drive with the same label. A third copy of

each transcript was printed out for use in data analysis. The recorder, transcribed interviews, descriptive notes, and field notes were kept in my home office in a locked file cabinet.

Data Analysis Procedure

According to Moustakas (1994), the steps in data analysis are epoche, phenomenological reduction, imaginative variation, and synthesis. As previously stated, epoche is the first step in data analysis and requires the researcher to make the research topic the sole focus of the analysis by bracketing out everything else. Epoche was achieved by using meditation techniques. I chose to manually analyze the data. Phenomenological reduction started with my transcribing the audio tapes verbatim. All statements on the transcript were treated as equal in value. Horizontalizing occurred when I deleted statements that were irrelevant and duplicating. The information that was left are the horizons (Moustakas, 1994). Horizons were defined by Moustakas (1994) as “the textural meanings and invariant constituents of the phenomenon” (p. 97). Textural meanings are defined as:

. . . describing in textural language just what one sees, not only in terms of external object but also the internal act of consciousness, the experience as such . . . the task requires that I look and describe, look again and describe, look again and describe; always with reference to textual qualities-rough and smooth; small and large; quiet and noisy; colorful and bland; hot and cold; stationary and moving; high and low; squeezed in and expansive; fearful and courageous; angry and calm-descriptions that present varying intensities; ranges of shapes, sizes, and special qualities; time references; and colors all within an experiential context. (pp. 90-91)

Textural meanings for each applicant were grouped into themes and then organized into a description of the phenomenon (Moustakas, 1994). This textural analysis sought to discover the “what” of the phenomenon (Moustakas, 1994, p.78). From the transcriptions, I analyzed the statements made by the applicants concerning the experienced phenomenon. I then looked for the commonality between those statements and grouped them together into themes by

eliminating irrelevant and repetitive data. These themes were used to write a summary description of the shared lived experiences for each applicant (Creswell, 2013).

The second step in data analysis is imaginative variation. This step builds structural themes from the previously identified textural descriptions. These structures are “the conditions that must exist for something to appear”; the structures answer the question, “How did the experience of the phenomenon come to be what it is?” (Moustakas, 1994, p. 98).

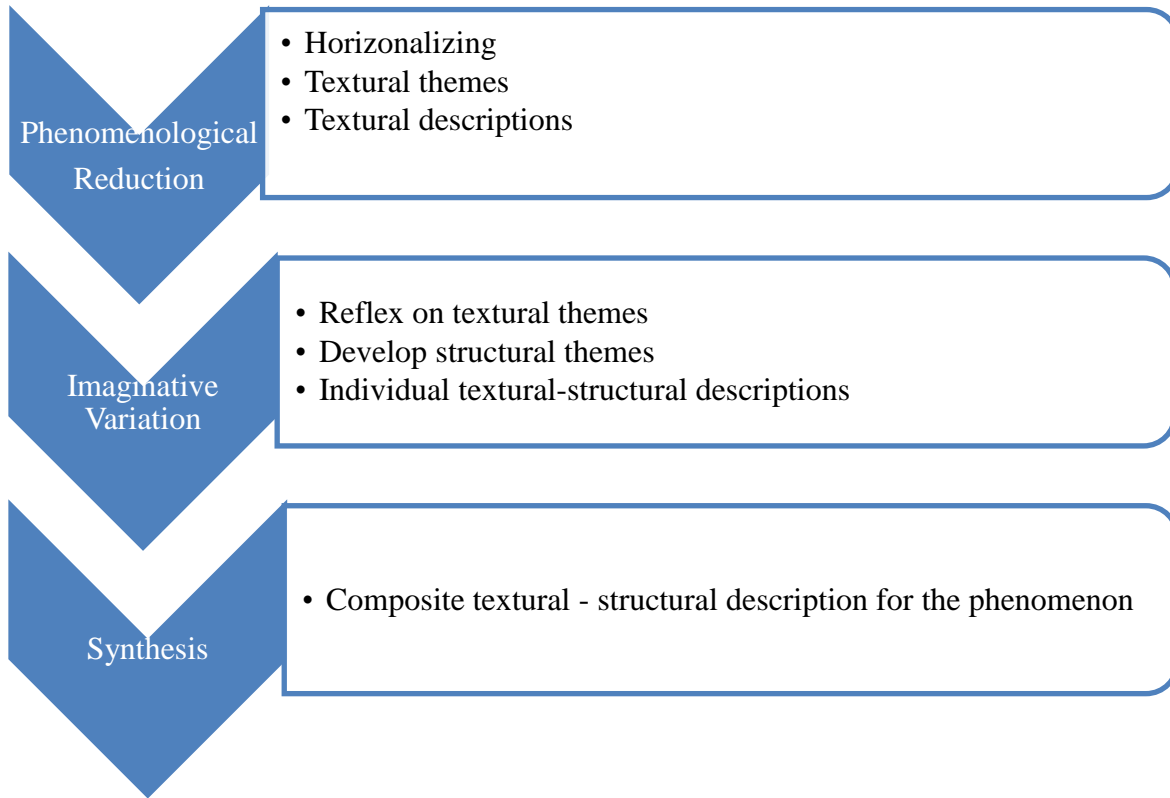
I used the steps described by Moustakas (1994) as necessary for completion of imaginative variation. First, I made a list of the various possible structural meanings by approaching the data “from different vantage points, such as opposite meanings and various roles” (Moustakas, 1994, p. 180) and considering the “dynamics that evoke the textural qualities (Moustakas, 1994, p. 181). From the list, I developed structural themes considering “time, space, relationship to self, to others, bodily concerns, and casual or intentional structures” (Moustakas, 1994, p. 181). Finally, I used those themes to develop a structural description of the experienced phenomenon. The third step combined the textural and structural descriptions for each individual applicant’s experience (Moustakas, 1994). These descriptions were given to each applicant during a second interview. They were asked if the description was accurately captured their experiences. They were then asked if anything needed to be changed, deleted or added. All agreed to the accuracy of their combined description. Two had additional information which was processed through the same steps of data analysis before being added to the original individual textural-structural description.

A textural and structural description for each individual participant’s experience was developed from the previous steps and then used to present a composite textural and structural description of all of the experiences and develop a synthesized description of the phenomenon.

The final step, synthesis, involves the integration of the combined textural and combined structural descriptions into one unified discussion of the meanings of the experienced phenomenon (Moustakas, 1994) and those findings are discussed in chapter 4. A flow chart showing the steps to data analysis is presented in figure 2.

Figure 2.

Workflow of Data Analysis



Trustworthiness

Trustworthiness in qualitative studies “. . . suggests that researchers employ accepted strategies to document the ‘accuracy’ of their studies” (Creswell, 2013, p. 250). To ensure trustworthiness of the collected data, I utilized triangulation, member checking, and intercoder agreement.

Triangulation involves using multiple methods and sources to confirm collected data (Creswell, 2013). I triangulated data by collecting paperwork from the Social Security Administration documenting participants' denial and the status of their application process. Before the interview, I checked identification for each applicant to confirm that they were the person to whom the denied Social Security letter was addressed and whose name was referenced in the letter. I read the letter to confirm its' content included denial of benefits. These steps confirmed that the applicant was denied benefits, and thereby added trustworthiness in their report as being within the appeal process and meeting the eligibility criteria.

Member checking takes place when the participants review the analyzed data for accuracy (Creswell, 2008). Moustakas (1994) gave the example of sending the synthesized description of each participant's experience to them for review. I set up a second interview with each applicant to allow them to review my combined textural and structural description of their experience for accuracy and invite them to contribute additional data and analysis that I may have missed. All applicants confirmed that their textural -structural description accurately represented their experience of the phenomenon. Two applicants shared additional information which was analyzed and added to their individual descriptions.

When multiple researchers analyze or code qualitative data to confirm agreement this is called intercoder agreement (Creswell, 2014). I emailed the first two transcripts to a peer who completed her PhD requirements by conducting qualitative research. I asked her to analyze and code those transcripts and return to me for a comparison of results. This would confirm whether my analysis was proceeding in the right direction. She identified three categories, all of which were similar to my analysis results and two of the three were an exact match. These results gave me confidence in the direction and quality of my analysis.

Ethics

This study began after I received approval from the University of Arkansas IRB review board. I adhered to ethical guidelines by ensuring that each applicant understood the purpose of the study, the research process, their right to anonymity, potential risks and benefits of the study, their right to withdraw from the study at any time, and gives their informed consent (Creswell, 2013). The applicant chose the interview site to allow them to feel comfortable (Creswell, 2013). During the data collection phase, I worked to build a relationship of trust with each applicant and they were treated with respect and sensitivity (Creswell, 2013). During member checking, each applicant was allowed to alter the data to attain a more accurate description of their perceived experience of the phenomenon (Moustakas, 1994). I closed the study by notifying each participant of the completion of my research and presented each with my verbal appreciation.

Chapter Summary

In order to identify and understand the essence of the experiences of individuals waiting for an eligibility determination decision in their application for Social Security Disability benefits, a phenomenological research study has been conducted. Phenomenological research allows firsthand accounts of the perceived experiences from the participants who experience the phenomenon (Moustakas, 1994). Before our initial meeting, a brief telephonic interview was conducted to determine eligibility for the study, explain the purpose and process of the study, and to outline any risks and benefits (Creswell, 2013). The applicants chose our meeting sites, which were mutually agreed upon and permitted close interaction and allowed the applicants to be comfortable, confidential, and compliant (Creswell, 2013). During our first meeting, we discussed the study's purpose, benefits, and risk as well as their anonymity; then I obtained their

informed written consent (Creswell, 2013). During analysis, the data were grouped into textural and structural themes, from which a description of the shared phenomenon was developed (Moustakas, 1994). Member checking and triangulation allowed for confirmation of data accuracy (Creswell, 2008). These themes were the building blocks for a composite textural and structural description of the phenomenon and descriptions were integrated into one unified discussion of the experiences of the phenomenon (Moustakas, 1994).

These personal testimonies will add to the knowledge base of the rehabilitation counseling profession by allowing us to understand the applicants' life changes as they wait for a disability decision.

Chapter 4: Research Findings

This phenomenological study sought to gain a deeper understanding of the experience of Social Security Disability applicants who have been denied at their initial stage and have undertaken the appeal process. Its findings will add new information concerning the thoughts, feelings, life changes, and actions of the applicants to the knowledge base of rehabilitation counselors.

Synthesis of Findings

Using Moustakas (1994) Transcendental Phenomenological method of analysis, I conducted phenomenological reduction to develop textural themes and imaginative variation to develop structural themes before synthesizing both to develop a composite textural and structural description of the phenomenon.

During the phenomenological reduction phase, audiotaped face-to-face interviews were transcribed verbatim. For each individual transcript, I deleted redundant and unrelated information, leaving the horizons. Moustakas (1994) call them “invariant horizons or meaning units of the experience” (p.122). The horizons were reviewed several times to extract statements and quotes that described the phenomenon. These meaning units were reduced into descriptions and placed under the heading (process, changes, feelings, thoughts, actions) which they were describing. They were then clustered into themes from which a textural description was written.

From the shared experiences of all applicants, the following are the reduced descriptions from their horizon. The process was described as: biased, unjust, unfair, multiple applications, lengthy, painful, hard, lack of fluidity, quick answers, long process, and disappointing. Changes were described as: financial instability, spousal support, effecting others, guilty feelings, medical setbacks, mentally stressed, emotional destruction, transportation, living arrangements, medical

benefits, budget, borrowing, Medicaid, foods eaten, reliance on others, uncertain future, and recreation. Thoughts were described as: unrealistic expectations, unhelpful system, irrelevant factors, crisis state, disorienting, misunderstood. Feelings are described as: drained, frustrated, angry, unfair, worn, unassured, undependable, and useless. Actions are described as: continuing through the process, hiring an attorney, researcher and becoming a self-advocate. These descriptions were grouped into individual themes and used to write the textural description. Theme examples are: ineffective process, inaccurate process, monetary loss, family dynamic, and medical changes, reliance on others, effect on relationship, worsening of anxiety, worsening of depression, and researcher.

Moustakas (1994) states, "Describing the essential structures of a phenomenon is the major task of Imaginative Variation. In this there is a free play of fancy; any perspective is a possibility and is permitted to enter into consciousness...he further adds "structures are the conditions that must exist for something to appear" (p.98). For all applicants, I identified the same structural themes of being denied benefits, experiencing wait times and traveling through the disability journey. No textural theme would exist if these structures were not present. The journey is everything they are going through. Their structural description captures and summarizes their experiences, with the emotions in which they were shared to me in the most descriptive manner. A combined textural and structural description was written and presented to each applicant for confirmation of the interpretation of their experience. The individual descriptions were reviewed by each applicant for accuracy and all descriptions were said to be accurate and were approved as written. Two applicants had additional information, which was taken through the same steps of analysis and then added to the description.

The final step is to “develop a synthesis of the meanings and essences of the phenomenon (Moustakas, 1994 p.181). I reviewed each textural-structural description and pulled out common threads to identify seven major themes that emerged. These themes were used to develop a compilation of the experience of being denied Social Security benefits and seeking to appeal.

The themes are: (a) unfair system with procedural inefficiencies; (b) losses and changes (c) shift in balance between independence and dependence; (d) emotional (e) mental effect (f) self-advocacy; and (g) recommendations. Figure 3 presents applicants and themes.

Figure 3.

Applicants and Themes

	Procedural Unfairness & Inefficient	Losses and Changes	Independence Dependence	Emotional	Mental Effect	Self-Advocacy	Recommendations
Applicant 1	x	x	x	x	x	x	x
Applicant 2	x	x	x	x	x	x	x
Applicant 3	x	x	x	x	----	x	----
Applicant 4	x	x	x	x	x	x	x
Applicant 5	x	x	x	x	x		x

Note. X represents applicable areas; ----- represents non-applicable areas.

Composite Textural -Structural Descriptions

Theme One: Procedural Unfairness and Inefficiencies

This theme includes the applicant's perspectives towards the disability process. The process is viewed as being unfair and having a biased point-of-view. It is difficult and lengthy, requiring multiple paper submissions that should be carefully reviewed for accuracy. It has inefficiencies in the administrative staff and a Godlike persona that often leaves the applicant not fully aware of the reasons for denial.

The biased point-of-view is an unreasoned viewpoint that renders a decision that is unjust and leaves the applicant viewing the whole system as unfair.

They're pushing personal judgments and biases instead of using the medical documented information that is already there. Looking at the narratives as to why I am being denied, the personal and judgmental comments that their reviewers make in the narrative I think is really condescending and wrong. I think it [the whole process] is unjust and unfair, very unfair.

Another applicant viewed the experience of being in the appeal process of a denied Social Security Disability claim as a difficult and lengthy process that requires multiple paper submissions that should be carefully reviewed for accuracy. Specific things need to be addressed and, oftentimes, the applicant does not know what to say. As this applicant stated,

Applying is hard because, a lot of times, you don't know what to say and they are looking for you to say certain things and for your doctor to say certain things . . . read over your own medical records because the doctor's notations will put in there what they are thinking and feeling which isn't necessarily aligned with what's going on with you.

Another participant experienced a speedier decision than expected, inefficiencies in the administrative staff and a Godlike persona. The initial decision can be quick, leaving the claimant to wonder if their application was ever reviewed.

It was a quick turnaround of denial, you know, it was almost like they didn't even look at it; and they did not even send it to DDS they denied me at the very first level. Most of the time, they will send it to at least DDS because they have medical people that understand those things.

The experience includes inefficiencies in the administrative staff such as loss of paperwork, issues with communication between offices and the unwillingness to take the extra step to ascertain the necessary information. The offices do not work together for a continuum of services.

We have nothing to do with each other. The regular Social Security office and the hearing office. We don't know how each other work. Sometimes it's only, let me see, 9 steps away or 9 keystrokes. I had to count my Social Security number. Because we all share the same information, the only thing they have to do is go in there and look it up. There is a lack of communication that causes loss of information and the necessity to keep your own copies of submitted documents; I had to make sure I kept a copy of everything because when I did my reconsideration, they told me I did not have a reconsideration in. I said, oh yes, I do have one; it had been sitting on someone's desk for two months and this is what happens to a lot of people. When they find it, they just go ahead and deny it right then because they know they have had it for such a long time. And the saying is, that nobody gets their Social Security the first time. You know, one day, I went in to drop off some paperwork and they had lost my paperwork before then, so I had to say, "Oh no, I can't just give this to you. Can you date stamp it and stamp my copy? I have to have a copy."

As to submitting paperwork, the participant added:

It's like you have never done anything before and you have to go back. I have had to go to the doctor's office and get them to fill our paperwork . . . it's easy for them [SSA] to get the information for you but they won't do that.

When discussing how the administration looks at the applicant's time frame as part of determining eligibility, the applicant said, "But they have this system where they do funny math you know." The Social Security Administration misrepresents itself; it is viewed as a system that is there for a person if and when they become disabled. However, going through the process, one's perception is that it is not for those that work and pay into the system.

I have worked all my life. I was in the military. I served my country and I paid in my Social Security and to be disabled. I am a disabled veteran and the military tries to take care of me . . . and Social Security should take care of me the same because I have paid [into] my Social Security. If you pay into your Social Security, why can't you get your Social Security when you need it? You know fair is for children so to speak, but I think that it misrepresents what it is really all about. I feel that Social Security does not stand for what they say. I feel they should do what is right by the citizens that is paying into their Social Security.

The experience with the benefit approval process left the applicant personifying the Social Security system as one who thinks and is all powerful. "They get to choose whether or not I am disabled . . . to me, it's as though it's their money, and it's not . . . they think they're God."

Another applicant addresses the lengthy process which left them desiring a quicker decision. The wait time is perceived as a game and a tool to facilitate a reason for denial and the process has no guarantee as to when a decision will be given.

I am going to say that it's a lot of B.S. to me because it shouldn't take this long to see if a person has a problem. [They] should be able to look at the medicine that I'm on and be like, well, we know for sure he can't work on this medicine so it shouldn't be all these months . . . this waiting game ain't no fun; it's like they [are] giving me a chance to mess up somewhere so I won't have to get it (disability benefits) or something . . . waiting around on these people, ain't no telling how long it's going to take.

Another applicant saw age, not as a determining factor for disability, but as the 'tool' which was used to deny him.

I feel if I would have been older and they would of seen the medicine that I have, I would of got it with no problem. But, since I'm young and I didn't have that much work experience and stuff like that, well, we gonna deny him; maybe he will go get a job or we gonna make him do this. It's like they basically trying to make me get a job even though they know with the medication I'm on, I can't get one. They using my age to affect the decision.

This applicant also noted inefficiencies in processing of applications:

When you fill out for disability, instead of having a person look at it and sit it down and then somebody else pick it up three weeks down the line, it [would] be cool if a person go ahead and pass it down the line and you make your answer and

it speeds up some. Instead of, I am going to sit it over here on this desk and it sits there a couple of weeks.

The experience of being in the appeal process of a denied Social Security Disability claim involves patience as it is a long process which, for this applicant, did not render explicit reasons for the denial as an adult when children's benefits were received.

It was pretty long . . . I feel like I really don't understand how I got denied . . . they didn't tell me no specific reason . . . If you gone take something that somebody needs then you need to tell them why . . . I think they took it because they didn't want to pay. They didn't want to help me out.

Theme Two: Losses and Changes

In this theme, losses and changes in the applicants' lives are discussed. The primary loss which every applicant experiences was that of income. Three applicants lost their jobs due to their disabilities and prior to filing for disability. One applicant was incarcerated and did not work in between being released and filing for disability benefits. The last applicant lost his disability benefits under the children guidelines and had to reapply under the adult criteria.

This income loss was sustained with the denial of disability benefits and led to other losses or changes. There were changes in living arrangements, transportation, medical benefits, financial status, in the type of food eaten, and in recreation.

One participant explains "I had to take a leave from my job due to my health issues in 2012 and then it was a requirement from my long-term disability with my job that I had to apply for disability." Battling through the system and waiting for a decision for the last three years has brought about changes. Some losses were immediate: "I had to file another claim because after the judge denied me, my attorney dropped me, as soon as that was over"; and some losses developed over time. The drop to one income is a shake-up in the household but to sustain that level of loss for years leads to a fall. "We went through a lot of financial issues, eventually

having to file for bankruptcy, because my husband was the only one that was working and I was no longer able to get disability from my job.” This participant also experienced changes in medical treatment and medical benefits.

I am just really frustrated with the whole thing and having to deal with my health and stuff. The doctors trying to find out the best way to help me with my pain and stuff like that. [They are] trying me on different medicine that’s not working. Me dealing with my insurance denying me for services and medications that I need. Then I don’t have any additional resources to be able to pay for the stuff that my insurance doesn’t cover or that my doctor wants me to have.

Going from earning income to not working and having less or no money brings about changes in a person’s life. “I had a two-bedroom townhouse in the suburbs, a car, a full-time job with benefits and private insurance.” Unearned income such as insurance disability benefits allows for a person to maintain a certain quality of life but, oftentimes, downsizing is required and insurance disability benefits last for a specific time frame, thus requiring change.

Changes in my home, changes in transportation, changes in medical benefits, right down to the food that I eat. I eat a lot cheaper than I used to. I had to downsize. Most people aren’t as fortunate as me; [they] don’t work in insurance and know to have policies in place just in case. I am one of the lucky ones and I have that, but my policy is almost up, which is scary and hard to explain.

Changes in medical benefits were experienced.

As for Medicaid, Arkansas is one of the nicer states where, if you are disabled, no income or whatever, they at least give you Medicaid. I have been able to get medical needs taken care of; however, it is not the same as when I had private insurance. You don’t get the same drugs; they don’t pay the same price. I don’t have the same waiting time. I don’t have the same doctors.

Prior to filing for Social Security Disability benefits, one participant stopped working. She has spousal support and VA benefits. A reduction or total loss of income can bring about life changes for many but for some, due to spousal support and other benefits, a hardship is not experienced.

I have to say that it's been pretty much the same, because I do have my husband and everything . . . I can pretty much live good because I am a veteran, so I can always go to the VA for my medical problems; that's a plus for me.

Another applicant has lost the ability to contribute monetarily to the household and the lack of funds has affected his relationship, his manhood, and his recreation.

You know, at first, it wasn't like this; we still had a little pinching . . . but as time go[es], that little bank roll gets littler. I have support (from fiancée) but, at the same time, I would like to help out, being the man; I hate putting all this extra pressure on my fiancée. I can see the extra pressure on her because she has kids and then she got me now because I can't work. I can't do nothing, like say, she come home and the light bill is a hundred and something dollars; I'm sitting here. I suppose to be a man and I can't do nothing. It's not just financial; it affects other things. It affects everything, my relationship, my friends and stuff, because like I said, I can't do a lot of things that I used to do, therefore, I don't. I ain't got no money to do things so I don't go certain places to mess with certain friends. We used to take trips every week; now that I ain't working, we had to halt that . . . I was used to getting up on Friday, pack my bags and we [were] gone until Sunday night when we were back. Our family outing consists of fishing now. That's cheap; I can get a cup of worms, get my Mama and sister and we can go fishing instead of us going out to eat.

Another applicant was receiving benefits as a child and had to reapply under the adult guidelines. Upon losing those benefits, he has problems with paying bills and worries concerning the loss of health insurance.

The benefits were kind of helping me out like [paying the] car note and getting through school, buying books and stuff like that. They sent me another letter in the mail about my insurance, Medicare, I think. If they don't decide to take me back to Social Security, then I have to get insurance over again.

Theme Three: Shifting in Balance between Independence and Dependence

This theme comprises the applicants' alternative support, i.e., applicants depending on spouses, parents, and significant others for financial and emotional support. Other support was that of public resources such as Medicaid, food stamps, and Arkansas Rehabilitation Services.

One participant experienced a change in roles. The spouse became caretaker and sole provider while interaction with children lessens. The family balance of responsibility changes;

one takes on more to keep the family together and the other gives up some things to keep themselves together.

. . . the toll it took on my younger son with his mom not being able to do much or get out much, do my part and helping with the family as a wife and mother . . . I went through a real deep depression about that part from feeling guilty and helpless because I wasn't able to [do] . . . things falling on my husband to take up the slack and having to deal with the denial from Social Security.

The monetary loss has had the applicant seeking additional resources. Becoming a recipient of Medicaid still has its challenges. There are services and medications that will not be accepted: "They won't pay for occupational therapy . . . and I am limited to the amount of medications that I can have each month." Without additional resources to pay for the services or medicine that the doctor has prescribed, the applicant can become discouraged, hindering healing.

. . . it's about my provider wants me to have certain services and medication and my insurance doesn't pay it so how else am I going to pay for it? I don't have anything else, at least to try and get me to feel better where I can go back to work.

Another additional resource for applicants is Arkansas Rehabilitation Services, an agency that aids individuals with disabilities in their pursuit to return to work.

I have an appointment with the state rehab this month on the 19th to see what type of services I could qualify for and to see if there are any jobs or anything that I would be able to do with my health issues.

How the applicant maintains medical appointments and medication changes to the use of public aid, specifically, Medicaid.

Arkansas is one of the nicer states where if you are disabled, no income or whatever they at least give you Medicaid. I have been able to get medical needs taken care of . . . without a ride going through Medicaid, you know they will transport you, that takes a great deal of time. That may be an all-day event just trying to go to the doctor.

The changes in income includes a need to borrow from others.

Borrowing money from people and sometimes not being able to pay it back and sometimes not having any money at all. This gets very depressing and it never lets up because there is never any money really coming in because you are not approved yet.

There are budgetary changes but spousal support and veterans' benefits has allowed one participant to avoid any hardships.

Financially, when I was working, of course, I made more money and I could do more things as far as my budget, [it] has really changed. If I wasn't a disabled veteran and had my husband, I would really be on hard times.

Participants increased their dependency on others, one relied on his fiancée and states that without her help, the possibility of homelessness would increase. "If it wasn't for my fiancée, I probably wouldn't have nowhere to go . . . I probably [would] be somewhere under a bridge."

Another lives with his mother, who has taken on a greater percentage of his financial support.

I stay with my mother and we were using that [benefits] to live on and then like I said insurance all of that. Co-pays on medicine . . . I feel like I am just staying at my momma's house for free. I don't really like that; I want to help out with something.

Theme Four: Emotional

This theme discusses applicants' feelings about the experience of being denied Social Security Disability benefits and going through the appeal process. Participants explain,

I am very . . . um . . . emotionally drained. I am frustrated. I am angry and it's really not good to have those kinds of feelings, because I am already dealing with that side, with my own personal life.

Another participant adds,

I was really upset when I got the letter [denial letter]. It wasn't saying that I am not disabled, but that I am too smart to be disabled. I am too educated. I am too young and educated to be disabled, and to me, that is discrimination. I don't think it's quite fair to turn around and tell somebody go take that job at Wal-Mart for \$7 an hour when you are used to \$15, knowing you can't live off \$7 an hour and you can barely work and you're still making pennies and they still won't turn around and give you disability.

One participant felt deserving of the benefits.

I don't think that's fair; I have paid into the system. Whether or not I am 65 or not, I have paid in. I have worked three jobs since I was fifteen and half. Not only do I not want to flip fries or be a greeter at McDonalds, I shouldn't have to be. Like you [SSA] said my level of education has surpassed that I don't want to say it's demeaning because I don't look down on those people who have those jobs. But for me, that's not me. I am not going to do that, I refuse. I have paid my dues.

Another shared their feeling of entitlement.

I have worked all my life. I was in the military. I served my country and I paid in[to] my Social Security and to be disabled. I am a disabled veteran and the military tries to take care of me . . . and Social Security should take care of me the same because I have paid [into] my Social Security.

Emotionally, participants shared feelings of unsureness and uselessness.

The disability part, ah, it makes me feel unassured, 'cause like when you on disability, you kind of getting old, I kind of think about that and when I think about that, it send[s] me into a darker depression-type stage. It makes me feel useless and stuff like that you got to depend on someone to take care of you.

With the loss of income and becoming more dependent on his mother, another participant stated that he felt “irresponsible, undependable, and like a burden.”

Theme Five: Mental Effect

This theme discusses applicants' mental state; most applicants labeled it as stress or depression and categorized it as getting worse. The following participant expressed her mental effect as depression.

I went through a real deep depression about that part from feeling guilty and helpless because I wasn't able to [do] . . . Day-to-day stressors really took a toll on our marriage. A really big toll, especially emotionally, mentally as well as financially. The bigger part is mentally. They are saying, given my age compared to someone else, I should be able to do this, which is I think outrageous. It should not depend on how old I am; I have limitations and I should not be compared to someone else my own age and what they are able to do. That took a toll on mentally because it has me feeling guilty because I am not able to do what someone my age should be able to do.

The stress from all the changes causes a worsening of present anxieties.

I have anxiety disorder so I don't deal with the stress of everything well, even talking about it and all the stuff that goes with it is just overwhelming . . . 'cause that's why I have got a dog and go online; it helps with the loneliness, heart pains, and depression.

The wait time is an added stress for the participant.

Steady waiting and stressing. The stress about it . . . maybe if it do[es] come through, everything gets better. I get to sitting around thinking too much and stressing about things I can't change right now because the ball [is] in somebody else hands. The disability part . . . ah . . . it makes me feel unassured, 'cause like when you on disability, you kind of getting old. I kind of think about that and when I think about that, it send[s] me into a darker depression-type stage because I feel like, why is this happening to me? I am so young and its extra stress going through the process.

When discussing his recreational limitations from not having income, a participant stated “it sends you almost into a depression.” When asked if this process was making his depression worse, he responded:

I think it do[es] have something to do with my depression because once I get to thinking about it and how I can't help the household and things like that kind of makes me get in my feelings. Financially, that's the real problem right there . . . if it were coming in, maybe I wouldn't be so depressed and I would still be able to go about and live life like a regular person.

Yet the overall mental affect experienced by another participant was described as follows.

It kind of make[s] me depressed. [It] add[s] a little depression to my problem, because I will just worry and I'll be thinking about how I'm [going to] do certain stuff. Like right now, I be worried about how I'm [going to] pay my car note and my insurance and all I got is like 5 hours a week of work. You know what I'm saying? And is my credit going down, which I have been trying to build up for so long, so everything I worked for just wiped away like that.

Theme Six: Promotes Self-Advocacy

This theme discusses applicants' actions, anything that was done to better their application status, or their physical or mental states.

The process of disability application is a complicated procedural task, one that is based upon facts and the interpretation of these fact by others. Its results are both just and unjust, depending on the perspective from which it is viewed. For the applicant who chooses to seek justice, concerning procedural inefficiencies, there is no formal complaint process.

I made several complaints, with the local DDS office . . . the ethics department of Social Security . . . and the DDS regional director. Because it's got to be somebody that we can contact when we have issues like that. If we can look on their website that they publish for the public to see and look at their guidelines and stuff like that and if they can't follow those simple guidelines, then what are we to do?

Along with filing complaints, another action taken is to hire an attorney. Although the applicant was not pleased to do so, it was a necessity.

I had to hire an attorney because they said that going before a judge by yourself is not a good thing . . . I just don't want to go through the same thing that I did last time with my attorney. Last time, my attorney and his team did not go through the medical information to see what's in there and what needs to be corrected . . . it said that I denied depression and anxiety and I never did that. That is something that should have been caught by my attorney and his team because we only get one time to go before the judge. If everything isn't tight, we get denied like I did.

One applicant demonstrated an interest in returning to work, setting up an appointment to meet with Arkansas Rehabilitation Services, which is a state agency that aids individuals with disabilities in their pursuit to return to work.

I have an appointment with the state rehab this month on the 19th to see what type of services I could qualify for and to see if there are any jobs or anything that I would be able to do with my health issues.

When asked about action, an applicant stated, "outside of getting an attorney, that's about it, just scaling things back to where I can live, if need be, on my own and carry the bills." To deal with the daily stress, another applicant utilized an online support group and her significant other, as well as getting a dog.

I realize that by being online, we help each other so much. There are so many people who need to apply and don't know that they can. They don't know about FMLA. They don't know about ADA; they don't know about insurance and short-term and long-term [insurance]. As for her pet, she states, "it helps with the loneliness, heart pains, and depression . . . it works a little bit, when I get upset like this and what not just petting him I can calm myself down and not go into panic attack mode and stuff like that.

Having a significant other has also helped with the loneliness and support.

About six months out of the whole thing I was by myself and I think it's really scary. Going through this process is really different if you're alone. If you don't have nobody to bounce ideas off or talk through, it is really rough. Just trying to muddle through all of the red tape and what needs to be done' everybody's situation is different and everybody has to do something different. But it's just going through it with somebody is a lot easier than being alone.

One participant shared the following about hiring an attorney.

I am in a position where I did not think I needed a lawyer because I understand how it works. If I win my Social Security case, I am going to have to pay someone to do something; no one should have to pay someone to do this for them.

To enhance future outcomes, another participant researched why he was denied and contacted attorneys, although he did not hire one.

I looked it up and tried to do a little research as to why I got denied. That's how I know about my age. I was trying to find one [an attorney] but all of them kept telling me 'naw' because I had got the denial letter. I got a letter from one a couple of weeks ago saying that he would take my case, but I had already put my appeal form in so I was going to wait and see. I don't want to go and get him and he don't got to do nothing since I done already put the appeal form in.

Another participant continues to work part-time and is actively looking for a job that will provide insurance since he is at risk of losing his Medicaid.

They sent me another letter in the mail about my insurance . . . Medicare, I think. If they don't decide to take me back to Social Security, then I have to get insurance over again. I am having to find a job that can insure me which is hard because interviews and stuff I don't do well in. The only reason I got my job now is because I know my boss. We had a prior relationship.

Theme Seven: Recommendations

This theme encompasses the changes and advice applicants provide for others and the disability process.

Administratively, Social Security should look at how they request medical information.

They requested medical records from my providers. The problem I have with that is that they send the medical records template to the medical records department and not to the specific physician. The medical records department will just send medical records that they are requesting from a date span. They put on there they want specific information but they do not have that information. And they do not follow up with the specific physician to get those exact information that they need. If you need something specific, you need to specifically talk to that doctor or contact us to contact that doctor to get the specific information that they need.

Secondly, all information submitted since the last decision should be reviewed and addressed in the final decision.

The guidelines are for reconsiderations they can only confirm what the previous reviewer said if there is no new information or if I had not updated records. They did a copy and paste of what their [reviewer from previous decision] notes were . . . the same exact wording and everything. That means to me that they didn't even take a look at the records that were on file.

Thirdly, for review of medical information, they should use a specialist that treats the type of disability the applicants have and not one from another field. "On my physical part, they had a gynecologist to review the previous doctors' notes. There is no way that a gynecologist can tell me that I am not disabled."

Recommendations to other applicants is to review their medical records for accuracy.

If you are applying for Social Security Disability, then read over your own medical records because the doctor's notations will put in there what they are thinking and feeling which isn't necessarily aligned with what's going on with you.

Recommendation for the Social Security process including partial payments prior to determination.

They should do like unemployment and give us something so we can live until you make your decision. Maybe they should have a maybe thing. Maybe we gone give it to you so we gone give you this amount of money so you can live with it until the final decision comes out.

Based on his experience, one participant offered the recommended modifications to the Social Security process: an attorney provided by the Social Security Administration, partial payments, and for determination purpose, get testimony from ‘important’ people in their lives.

I feel like since it’s like a court thing, I should have an attorney present already to help me out. If you go to court in Faulkner County, they are going to ask you if you want an attorney or if you want to represent yourself. I kind of want a lawyer or attorney or something. Instead of just taking people completely off something they been depending on, they could like lower the amount that you give them where they can slightly adjust their life to being independent, you know. And contact important people in their life, like my work, they could of contact my coach, my boss, ask them how I been doing, do he notice any symptoms of the disease that I have?

Essence of the Experience

The experience of going through the disability determination and appeal process is viewed as being unfair and having a biased point of view. It is difficult and lengthy, requiring multiple paper submissions that should be carefully reviewed for accuracy. It has inefficiencies in the administrative staff and a Godlike persona that often leaves the applicant not fully aware of the reasons for denial. The primary loss which every applicant experienced was that of income; 80% lost their job prior to making application for disability benefits. The other 20% was due to termination of disability benefits received based on the eligibility criteria for children. This lost income led to other losses or changes. There was downsizing from a two-bedroom townhouse to living with a significant other, the loss of a private vehicle and having to use Medicaid transportation to doctor’s appointments. Applicants transferred from being recipients of private insurance to using state-approved Medicaid. Becoming a beneficiary of the Medicaid system required some applicants to change doctors and medications that are approved under that

plan. Bankruptcy became a financial status for one applicant, while terminating weekend trips, eating cheaper types of food, and not eating out at all became a reality for others. The experience involves a greater percentage of dependency on other people and other things than on oneself. This alternative financial support was acquired from spouses, parents and significant others. They took up the slack from their loved one's loss of income. Necessities such as medical benefits were provided by Medicaid for all but one applicant, who utilized their veteran's benefits. Food stamps provided food for some and Arkansas Rehabilitation Services was utilized for return-to-work options. Emotionally, involves receiving an initial denial, which is upsetting, disappointing, and bewildering. The process is long, taking months to years for a decision. The experience is exhausting and frustrating and, at times, it angers the applicant. Feelings of entitlement and unfairness are experienced, as well as perseverance and diligence, both of which are demonstrated by the applicants' pursuit through the appeal process. The mental state of the applicants was labeled as stress, worry or depression. Those applicants who have a mental disability discussed their depression worsening due to the losses, changes, and feelings experienced during the wait. Applicants advocated for self, doing whatever was needed to enhance their chances for approval during appeal, and to better their physical or mental status. They sought to better understand why they were denied in the first place by reading the disability guidelines posted on the Internet and speaking with others in an online group. The most frequently acquired resource was that of an attorney. Eighty percent either researched for, contacted for future use, or hired an attorney. Their experiences elicited recommendations; recommendations to other Social Security applicants are to review medical records for accuracy, to request information from treating physicians rather than broad information from the medical records department and, when possible, the applicant should not go through the process alone.

For the Social Security Administration, partial payments, providing an attorney for the applicant, and speaking with others that may have insight into the applicant's life before making a determination have been recommended, as well as making sure there is continuity between offices and levels in the flow of the determination process.

Finally, the essence of the experience of traveling through the disability process is an arduous journey. The denial is like a slap in the face; it startles the applicant and has them wondering why and what's next. Moving through the appeals process is the like sailing through rough waters. The applicant moves forward, pushed by the forces of necessity and entitlement. Document resubmissions toss the boat to the left, reconsiderations hinder its stability, while denials almost anchor it, causing an abrupt stop to the journey. A filed appeal keeps the boat afloat. Some hire an attorney as captain to guide the boat through the legal muddy waters. There is a wait for a hearing before an administrative law judge. The experience of the wait is like a destructive force putting the applicant in a state of crisis. Finance is a major foundation to the quality of life. Lack of income and lack of inadequate savings to sustain them through the waiting period leads to financial difficulty and, for some, bankruptcy. It is like a crack in the foundation of a structure. A crack that spreads through the walls of relationships and the back spaces of the mind. Stress is increased due to the changes, thoughts, and feelings that are being dealt with on a daily basis, pounding at the applicant's mental state like a roaring wind. Mental and medical declines are additional weights on top of a fragile family structure, every member dealing with their own personal effects from the fallout called time. The waiting period, that time is like traveling down a long dark road, and at each mile marker, looking for an exit, a decision of approval that renders a turn.

Chapter 5: Discussion of Findings

The purpose of this study was to investigate the lives of those individuals who applied for Social Security Disability benefits, were denied, and sought the appeals process. Research has shown that, on average, it takes one to one and a half years for a file to move from its initial phase to completion of the ALJ hearing (Arkansas Disability Determination, 2014). Unable to work, living without income or with a reduced income, what does a person think about the process? How does one feel? What is a person to do? What changes are endured? The answers to these questions are the driving force behind this research.

I thought it best to use qualitative methods, which allow face-to-face interviews to obtain rich and raw data of this experience. My research goal was not to develop or add to theory but to describe the experience of those waiting for a decision on disability benefits. Therefore, phenomenological methods were used to analyze data. This resulted in seven themes which described what an applicant experienced during the wait for a decision. They were: unfairness and inefficiencies with the process; losses; a shift from independency to dependency; emotional experiences; changes in mental state; a rise in self-advocacy; and recommendations for system changes.

Strengths of the Study

The strengths of this study are obtained from its methodological components. Its first strength is that it was a qualitative study, which allowed us to learn, about the phenomenon, firsthand from the applicants lived experiences. The experience was presented by the one who experienced it, giving me pure, straightforward data.

The second strength is the use of a peer for intercoder agreement (Creswell, 2014). This person reviewed the first two transcripts and identified three category codes. All three were

similar to my analysis and two of three were an exact match. This match gave me confirmation the direction and quality of my analysis.

The third strength lay in conducting a second interview with each participant, known as member checking (Creswell, 2008). They were given the textural-structural description from the analysis of their transcript interview and asked if it was an accurate description of their experience. They were also allowed to add or delete any information they deemed necessary. All five said the description was accurate and recommended no changes. Two applicants gave additional information about the overall experience, which was analyzed and added to the description.

The fourth strength was the use of different sources to determine and confirm eligibility, known as triangulation (Creswell, 2013). I obtained a copy of each applicants' denial letter from the Social Security Administration to confirm that they were denied applicants. Before the interview, I checked identification for each applicant to confirm that they were the person to which the denied Social Security letter was addressed or whose name was referenced in the letter.

The above measures —intercoder agreement, member checking, and triangulation — are traditional research methods used to promote trustworthiness in the research process. I believe their use in this study has added strength to the overall process and the research outcomes.

Limitation of the Study

The limitation in this study falls within the area of data collection. There are two limitations, one in number of participants and the other in the diversity of participants. My goal for this study was 5-10 participants. I reached that goal with the least amount. There is no known database with public access to Social Security applicants from which a random sample

could be drawn and there is no available avenue to reach the type of participants that was needed for this study. Therefore, I contacted people that I knew professionally and personally and asked for them to participate if they were eligible or recommend someone who was eligible. I received six referrals, five of whom were willing to participate in this study. The participants reached were based on who I knew and how many of them were willing to go the extra mile and refer others. Many contacts responded that they did not know of anyone that fit the criteria.

The second limitation was in the diversity of participants. There were three women and two men, all of whom were African American. I am an African American woman with mostly African American contacts and because I recruited participants via contacts my sample had a greater percentage of being African American.

Relationship to the Literature

In a study to discover how SSDI applicants pay their living expenses while waiting for disability benefits, Coe et al. (2014) found that both governmental and non-governmental supports were used. Governmental supports were programs such as unemployment benefits, workers' compensation, and benefits from the supplemental nutrition assistance program (SNAP). Non-governmental supports were using credit cards, liquidation of housing assets, benefitting from spouses' income and making a change in their living arrangements. Similar to Coe et al. (2014), this study found that denied applicants utilize governmental and non-governmental support. Governmental supports consist of Medicaid and VA benefits, and the state bankruptcy court. Non-governmental supports were spousal income, living with a fiancée, living with their mother, living with a significant other, and private disability insurance policies.

Current research demonstrates that denied applicants spend several months to years, going through the disability process. Establishing these long wait times, support the opportunity

for early interventions that facilitate return to work and independence. Mitra and Bruckers (2004) supported intervening as early as possible to increase return-to-work possibilities as “the likelihood of a labor force reentry declines as the length of absenteeism due to a disability or sickness increases” (p. 161). Early intervention was a major change in disability policy as it placed rehabilitation before receipt of benefits rather than afterwards (Mitra & Bruckers, 2004). The Disability Research Institute (2006) summarized the Early Intervention Project as a four-year project that would design service models to provide return-to-work services for SSDI applicants. Service models were designed; however, the Early Intervention Project did not become a national demonstration (S. Mitra, personal communication, July 21, 2014). This study supports the idea that projects for early interventions are still viable options for servicing applicants who have been denied social security benefits.

The literature further demonstrates the inequality of available return to work supports for social security beneficiaries and social security applicants. It presents and discusses 12 supports for beneficiaries versus none for applicants. It also discusses the benefit of intervening early on behalf of denied applicants. This study establishes that there are stages in the disability process and that at each stage there is opportunity and time for an intervention. Secondly, there are long wait times before the applicant receives a disability decision. During these long periods of waiting financial struggles arise and are followed with mental and emotional conflicts. The current study presents areas of need and recommends interventions of support.

Using a qualitative approach, this current study was able to discover the thoughts, feelings, and emotions that an applicant for Social Security Disability benefits experiences while traveling through the appeal process and waiting for a decision. This information is useful for

professionals and policymakers who service, approve funding, develop, and implement policy and programs to advance individuals with disabilities.

Recommendations for Professionals and Policy Makers

The current research provides areas for intervention and policy change. This section seeks to relate the research outcomes to implications for policy intervention and change within the rehabilitation and counseling professions, the state vocational rehabilitation agencies, and the Social Security Administration. Specifically, it addresses the roles of the vocational rehabilitation counselor in providing work related and independent living services to individuals with disabilities and those professionals that provide mental health counseling with no regard to their title, ex: social worker, therapist, or counselor. The state vocational rehabilitation agencies employ vocational rehabilitation counselors and the 2017 Code of Professional Ethics for Rehabilitation Counselors (2017) states,

Rehabilitation counseling is a systematic process which assists persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals in the most integrated setting possible through the application of the counseling process. The counseling process involves communication, goal setting, and beneficial growth or change through self-advocacy, psychological, vocational, social, and behavioral interventions (p.1). It further adds, “ Rehabilitation counselors understand that trust is the cornerstone of the counseling relationship, and they have the responsibility to respect and safeguard the client’s right to privacy and confidentiality (p. 4)

Vocational rehabilitation counselors and those in the mental health counseling fields will find this information useful while gaining an understanding of, and being empathic to clients’ experiences and using that knowledge to build trust and rapport.

The Social Security Administration is the agency that decides federal disability claims. The role of both agencies and their relationship to individuals with disabilities determined their inclusion in the discussion.

Theme One: Procedural Unfairness and Inefficiencies

This study identified inefficiencies in the administrative staff to move the paperwork along a continuum and communicate with each other as well as with the applicant. Three of the five applicants in this study addressed loss and resubmission of paperwork. Another observed the breakdown in communication between offices while all reported lengthy wait times.

Best Practices for Claimant's Representative (SSA, 2016) explains the best methods and actions to be taken throughout the disability process. When discussing document submission, it states that representatives can access the claimant's electronic folders, that all data related to their disability claim must be submitted, and documents should be submitted as early as possible. It further states that the file is reviewed by staff for accuracy and duplication of documents and they are to ensure the claimant's copy of the file has all of the evidence. Social Security has an eFolder system that allows for electronic submission of documents and review by the representative. Representatives should ensure that applicants understand this process and work with them in the submission of paperwork. It is also noted that untimely and incorrect submissions require additional time for corrections and delay case file processing (SSA, 2016).

It behooves representatives, applicants, and especially those applicants that are representing themselves to have an understanding of document submission and how untimely and erroneous submissions can lead to delays in file development while an undeveloped file can cause longer wait times for the applicant or disability denial. Knowing this, the applicant could work with their representative in obtaining documents needed for file submission. The information on document submission is listed on the Social Security website in the article cited above and is available for review by all parties. The responsibility falls to the representative to notify the applicant and if the applicant is representing themselves then they should educate

themselves on the role of the representative. This information allows the applicant to become an active team player in the development of their file and supports the need for the applicant to have access to review their disability electronic folder for accuracy.

Specifically, Best Practices for Claimant's Representative states: "Please submit evidence via the ERE more than 15 working days before the hearing, as this practice allows hearing office personnel to exhibit the evidence and ensures that the claimant's copy of the file includes a copy of all the evidence that has been received" (SSA, 2016).

Examination of Proposed Exhibits and Other Claim(s) File Material notes that ". . . When a claimant is unrepresented or when the instructions in HALLEX I-5-1-22 do not apply to a representative, HO staff will burn an encrypted compact disc (CD) of an electronic claim(s) file" (SSA, 2016). These articles provide evidence that, upon request, the claimant will receive a CD of their file and does not have access to their electronic folder in real time. That access is for the representative. The ability of applicants to access their eFolder's for review only could be an advantageous intervention. Applicants would be able to go into the database and retrieve their files to confirm receipt and inclusion of records. They would be able to read those records to determine the accuracy of what is written by medical professionals or their staff, keeping in mind that the applicant knows their information better than the judge or their attorney. This database would allow the applicant to see the continuous building of their file, permit checks and balances in the development of disability files, and inform the applicant as to what information the judge has available for his review. Files would be more accurate and the time spent requesting information could be reduced, which, in turn, could reduce applicants' wait times.

Theme Two: Losses and Changes

The primary loss that every applicant experienced was that of income. Out of the five applicants interviewed, only one had an interest in seeking vocational services. The rare mention of return-to-work and the use of vocational services in this research supports the idea that referrals to and recruitment for vocational rehabilitation services are indicated.

The Social Security Administration could refer applicants to return-to-work services. When a person is denied Social Security Disability benefits, they are notified in writing. That letter could include an introduction to the services supplied by the state's vocational rehabilitation agencies, along with their contact information. This would be no more than an extra one to two pages of information or the inclusion of a pamphlet. There is opportunity for it to be supplied with every denial at every stage of the process.

The Commission on Rehabilitation Counselor Certification defines their scope of practice for Rehabilitation Counselors as,

[a] systematic process which assists persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals in the most integrated setting possible through the application of the counseling process. The counseling process involves communication, goal setting, and beneficial growth or change through self-advocacy, psychological, vocational, social, and behavioral interventions. (SSA, 2016)

Current research identifies denied social security applicants as prospective consumers who could benefit from vocational rehabilitation services. From an agency perspective, a possible intervention is the development and implementation of methods for recruitment. Possible marketing strategies include sending pamphlets to disability attorneys which can then be forwarded to their denied clients and those whose cases they have rejected. Brochures introducing and explaining rehabilitation services can be placed within the hearing sites and a radio advertisement could be utilized to reach this group. While they are waiting months to

years for a disability decision, they could be seeking rehabilitation services, possibly providing a means to return to work and recover lost wages, lost homes, lost cars, and lost mental stability.

Chapter 2 identified SSA programs that have been established to facilitate the return to work of beneficiaries. The Work Incentive Liaisons (WIL) is located in each office and has the responsibility of discussing the return-to-work services provided by SSA to beneficiaries.

WIPAs work in partnership with other governmental community-based, for-profit and non-profit agencies to provide assistance with work incentive planning (SSA, 2014). If the beneficiary is unable to meet with any of the aforementioned individuals, Work Incentives Seminar Events (WISE) provide free webinar training via the Internet to disabled beneficiaries to allow access to information concerning work incentives (SSA, 2014). Denied applicants are not beneficiaries of disability income and therefore are not a financial responsibility of SSA. Therefore, there are not incentives for them to participate in these programs. However, the information provided through these resources could benefit denied applicants. This identifies an area in which SSA could possibly provide an intervention for denied applicants by adding them as a targeted audience for these services.

To combat income loss, denied applicants should receive contact information for agencies that provide return to work services in their written denial letter from SSA, be targeted as a consumer and recruited by vocational rehabilitation agencies, and be included in the dissemination of return to work services provided by SSA.

Themes Three to Five: Shift in Balance between Independence and Dependence, Emotional and Mental Effect

Themes three through five are combined in this discussion because they build on one another and lead to the implications. Theme three comprises the applicants' alternative support.

It demonstrates how they moved from a level of independence to a level of dependence by depending on spouses, parents, and significant others for financial and emotional support as well as public resources such as Medicaid, food stamps, and Arkansas Rehabilitation Services.

Rehabilitation counselors should seek to provide services that promote independence such as job attainment.

Current research shows the move towards dependence on others can affect applicants emotionally. Theme four discusses applicants' feelings about the experience of being denied Social Security Disability benefits and going through the appeal process. Current research has established that an individual moving through the disability process may be experiencing feelings of uselessness, frustration, anger, and irresponsibility.

Rehabilitation and counseling professionals should be aware that denied applicants are experiencing life changes; hence, they may be emotional. Rehabilitation counselors should keep in mind that these emotions, if not adequately regulated, may become barriers to job attainment and retention or lead to mental disorder. The World Health Organization (2017) has stated that "there are many different mental disorders, with different presentations. They are generally characterized by a combination of abnormal thoughts, perceptions, emotions, behavior and relationships with others." Using the feelings of the applicants as examples and starting with anger, if a person consistently becomes angry, leading to inappropriate workplace behaviors, then that is a barrier to job attainment and retention. Feelings of uselessness or low self-worth can lead to the mental state of depression; both of these require a referral to a more specialized professional, someone who can help to regulate an applicant's emotions or address their mental state.

Theme five discusses applicants' mental state; most applicants labeled it as stress or depression and discussed it as getting worse. The World Health Organization has observed the following about depression:

Depression is characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, tiredness, and poor concentration. Sufferers may also have multiple physical complaints with no apparent physical cause. Depression can be long-lasting or recurrent, substantially impairing people's ability to function at work or school and to cope with daily life. At its most severe, depression can lead to suicide. (2017)

Emotions rising to a level at which they start to resemble signs of depression would be an example of a time in which rehabilitation counselors would need to refer the applicant to another professional, such as a mental health counselor. If the depression worsens, the mental health counselor may need to refer the applicant to a psychiatrist. The goal for both professionals is the same, to refer the applicant to someone who is better able to address applicants' mental concerns and promote emotional and mental health. Emotional and mental stability is necessary for individuals with disabilities to reach their personal and career goals; attainment of these goals can move applicants along the spectrum from dependence towards independence.

Theme Six: Promotes Self-Advocacy

This theme discusses applicants' actions, anything that was done to better their application status, or their physical or mental states. Current research identifies a gap in the complaint process. When discussing the requisition and submission of medical records and how they related to her disability decision, Applicant 1 stated,

I made several complaints. I made a complaint with the local DDS office and I had delivered my complaint to the supervisor. I never received a response back. I have submitted complaints to the ethics department of social security disability. They said that it is like an administrative issue and they don't deal with that. They only deal with things that have to deal with discrimination and stuff like that.

This statement exemplifies a possible problem within the Social Security Administration. SSA does provide information for filing a claim for unfair treatment concerning an administrative law judge and for filing a discrimination complaint (SSA, 2015); it appears that there is not a formal process to receive complaints on procedural inefficiencies. This issue relates back to theme one and could be addressed with the applicant having real time access to their eFolder. Access would allow the applicant to review medical records and correct them prior to their hearing before an Administrative Law Judge, thereby easing concern that their decision was based upon erroneous information in their files.

Theme Seven: Recommendations

This theme encompasses the changes and advice applicants provide for others and the disability process. Surveys are highly effective instruments for obtaining feedback. The Social Security Administration should seek feedback from applicants concerning the disability process and their research instrument should allow applicants the ability to enter recommendations. The state vocational rehabilitation agencies should seek feedback on the services provided by the RC's and their research method should also allow for the applicant's input. This information can be utilized for growth in the provision of and the quality of services.

Recommendations for Future Research

For future research, I recommend additions to the methods for data collection, and additional research areas. As stated in the limitations, I would have liked to have other ethnicities and races as part of this study and feel that data collection methods should be expanded to allow for such diversity. Using my current research methods will probably identify a group of participants that are a direct representation of the researcher and their contacts. If funding permits, radio advertisement on channels that reach different groups such as hip hop,

country, and gospel stations would allow for a more diverse group of participants.

Dissemination of flyers in areas beyond those of the researcher may increase the number of participants from other cultures. This study focused on the thoughts, feelings about the disability process and changes and actions during the process. Duplication of this study with efforts to identify a more diverse group of participants is recommended.

Future research should also include direct questions relating to return-to-work. I asked broad questions about changes endured and actions taken during the process. I believe the rehabilitation profession could benefit from more direct questions aimed at ascertaining the mindset of the individual towards returning to work. Questions should be asked as to the knowledge of the existence of the state VR agency and the role of rehabilitation counselors. We should seek to discover whether applicants have knowledge that there is a state VR agency and then what is its' function.

This research involved the use of open-ended questions about the changes endured while going through the disability process. Future research should include direct questions pertaining to public services and governmental support that are sought after and utilized while journeying through the disability process.

Finally, in this study, 'recommendations' was identified as a theme that addressed the advice and recommendations given by applicants both to other applicants and the Social Security Administration itself. Future research could be designed using qualitative methods to address these two questions to many applicants, specifically, what would they recommend to others going through the disability process and what recommendations would they make to SSA?

Chapter Summary

This study has allowed us a glimpse into the lives of a few applicants. Some have waited months, others, years; however, together, they identified seven themes that described their combined experiences. These themes have been presented and detailed, along with supporting data. These outcomes have been discussed as to their implications for rehabilitation counselors, those who provide mental health counseling, the state vocational rehabilitation agencies, and the Social Security Administration.

This study is important because it has allowed us to obtain a baseline of information as to the experiences of denied Social Security applicants. We need to better understand what denied applicants experience and utilize that information to design and build supports and interventions that promote fair disability procedures, financial recovery, independence, emotional health, mental stability, and to allow feedback.

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MEMORANDUM

June 14, 2016

Office of Research Compliance
Institutional Review Board

TO: Steafnie Ford
Brent Williams

FROM: Ro Windwalker
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 16-05-764

Protocol Title: *During the Wait: A Phenomenological Study on Denied Social Security Disability Applicants*

Review Type: EXEMPT EXPEDITED FULL IRB

Approved Project Period: Start Date: 06/14/2016 Expiration Date: 06/07/2017

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<https://vpred.uark.edu/units/rscp/index.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 20 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or irb@uark.edu.

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The University of Arkansas is an equal opportunity/affirmative action institution.

Appendix B

Research on Denied Social Security Applicants

If you are:

- Between the ages of 18-64 and live in Arkansas
- Have a disability and have applied for Social Security Disability benefits
- If you were denied and have made appeal to have a hearing before an Administrative Law Judge and you are
- Willing to share your experiences for a research project

Then you qualify to participant to the following research study.

I am Stefanie Ford, a doctoral student with the University of Arkansas at Fayetteville.

You are invited to participate in a research study under my direction. Taking part in this research is entirely voluntary. The status of your disability claim will not be effected should you choose to participate or if you decide to withdraw from the study at any time.

The purpose of this study is to investigate the lives of those individuals who were denied disability benefits and who participated in the appeals process; it seeks to determine their thoughts, feelings, and courses of action taken while living without SSDI or SSI benefits, and if any, what life changes were made during this wait

If you are eligible and interested, then please contact me at 501-590-0327 or email sanelson@uark.edu; leave a message with your contact information stating that you are interested in participating in the study. If you are not eligible or interested but know of someone who is eligible or may be interested, then please recommend this study and encourage their participation.

Thank You

Appendix C

Consent to Participate Form

Dear Participant,

You are invited to participate in a research study under the direction of myself, Stefanie Ford, a doctoral student with the University of Arkansas at Fayetteville. Taking part in this research is entirely voluntary. The status of your disability claim will not be effected should you choose to participate or if you decide to withdraw from the study at any time.

The purpose of this study is to investigate the lives of those individuals who were denied disability benefits and who participated in the appeals process; it seeks to determine their thoughts, feelings, and courses of action taken while living without SSDI or SSI benefits, and if any, what life changes were made during this wait

Data will be collected using two face to face interviews. The first interview should last approximately 1 to 1.5 hours. The second interview should last approximately one hour. During the first interview, I will meet with you to determine eligibility, to collect demographic information, to obtain consent to participate and to conduct an interview. Our second meeting will consist of you reading over my analysis of data for confirmation of the accuracy of the information you have given. All interviews will be audio recorded and transcribed verbatim for analysis. Your name will not be used, instead your data will be assigned a number and referred to throughout the publication as Applicant 1, Applicant 2, and so on. Verbal transcriptions from the recordings will be maintained on my personal computer in a dissertation file, with a second copy saved on a USB drive. I am the only person who has access to my personal computer. All data collected (audio recordings, transcribed notes) will be kept locked in my home office in a locked file cabinet with one key; which is only in my possession. All information collected will be kept confidential to the extent allowed by law and University policy. There are no known risks and/or discomforts associated with this study. As a benefit, the process of interviewing will allow you to reflect on your current situations and increase your insight and awareness of these situations. This additional information may promote change in your thoughts and feelings and thereby facilitate the desire for new actions.

If you have any questions or concerns about this study you may contact, faculty advisor, Dr. Brent Williams at (479) 575-8696 or by email at btwilli@uark.edu. For questions or concerns about your rights as a research participant, please contact Ro Windwalker, The university's IRB Coordinator, at (479) 575-2208 or by email at irb@uark.edu.

Please sign your consent with full knowledge of the nature and purpose of the procedure. A copy of this consent form will be given to you to keep. Thank you for your participation.

Stefanie Ford, Researcher

Signature: _____ Date: _____

IRB #16-05-764 Approved: 06/14/2016 Expires: 06/07/2017

Appendix D

Interview Protocol for the First Interview

Date:

Place:

Time:

Interviewer: Stefanie Ford

Interviewee:

Applicant # assigned to Interviewee:

Position of Interviewee:

Introduction:

Mr. or Mrs. _____. I want to thank you for agreeing to participate in this study. I would like to first inform you that although I am using your name, you assigned # ____ and will be referred to as Applicant #__ in this study. Secondly, I would like to remind you that this interview is being recorded. And lastly, I am going to ask you a series of questions, they are not yes or no questions so feel free to speak as long as you need and to say whatever you need to say to answer the questions. If you do not understand a question, then please let me know.

Preliminary Questions:

1. How old are you?
2. What is your disability or disabilities?
3. When did you apply for SSA benefits?
4. When did you receive notification that you were denied?
5. When did you request a hearing before an ALJ?
6. Have you had your hearing before the ALJ? If so, when

7. What was the outcome of your hearing?
8. How much time has passed since between when you requested a hearing and actually received a decision about benefits?

Primary Questions

9. Describe the process of applying for and being denied social security benefits.
10. What changes, if any, did you experience between requesting a hearing and obtaining a decision?
11. What are your thoughts about being denied?
12. What are your feelings about being denied?
13. What actions have you taken since being denied?

Probes for expanding responses:

1. Can you elaborate on what you mean by...?
2. Tell me more about...?
3. Can you give me examples...?
4. What else did you experience...?
5. What other feelings, if any, did you have about...?
6. What other thoughts, if any, did you have about...?
7. What other actions, if any, did you take...?

Appendix E

Interview Protocol for the Second Interview

Date:

Place:

Time:

Interviewer: Stefanie Ford

Interviewee:

Applicant # assigned to Interviewee:

1. What are your thoughts about the accuracy of the interpretations of your experiences?
2. Is there anything you think I need to change?
3. Is there anything I missed that you would like me to include in the analysis?