

Access to Health Care in South Carolina: Impacts on the Employment of Individuals with
Disabilities
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Abstract

In the presence of several work incentives, the rate of SSDI beneficiaries making a successful return to work remains low. Research suggests that health care reform, such as the passing of the Affordable Care Act, should result in a decrease in the SSDI caseload. This study will examine how health care factors into the decision to return to work among SSDI recipients in South Carolina. More specifically, this study aims to determine how low access to healthcare impacts their ability to work, and whether the loss of Medicare acts as a work disincentive. Given the exploratory nature of this research, a convenience sample will be used. For the purposes of this study, working age was defined as individuals between the ages of 18 and 64. Low access to health care was defined as the inability to receive medical attention due to lack of health coverage, inability to pay healthcare expenses, or lack of transportation. A pilot survey was administered prior to finalizing the questions for the large-scale survey. The research instrument was designed to gather information about each respondent's disability, employment history and ability to access healthcare. The survey also gauged their interest in returning to work and participating in work incentive programs. The sample consists of SSDI recipients of working age across the State of South Carolina to allow for comparison between urban and rural areas. Findings show that the majority of respondents are in good health and specify the potential loss of Medicaid or Medicare benefits as a factor hindering their return to work. Lack of transportation, lack of proper accommodations to perform job duties, and potential loss of disability benefits were also among the barriers chosen by respondents. Further research must be conducted at the national level. A cost-benefit analysis examining the costs of continued health coverage for disabled workers compared to the benefit of the potential decrease in SSDI caseload may be beneficial. Extending the period for which SSDI recipients can receive Medicare coverage after a return to work may result in a decrease in caseload for the Social Security Administration. Future policy concerning health care should consider the economic impacts of limiting health care options for disabled workers.

Introduction

“Disability is [not] just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives (World Health Organization, 2017).

Individuals with disabilities are employed at lower rates and have higher rates of health disparities, as well as health care disparities, than individuals without disabilities (Brucker et al 2016; Erickson 2012; Reichard 2011). They face many barriers to employment including the loss of income supports and health insurance benefits (White 2005; MacDonald 2005; Polak 1996). The Social Security Administration (SSA) assists individuals with disabilities through the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. These programs provide monthly payments to individuals who are unable to work because of a medical condition that is expected to last at least 12 months or result in death. One of the Social Security Administration’s goals is to rehabilitate individuals with disabilities so that they can successfully perform substantial gainful activity (SGA). The SGA level is the maximum monthly income one can earn to be deemed eligible for SSI benefits. This level is determined annually by the SSA using federal poverty levels (Substantial Gainful Activity, 2017). There are several work-related incentives to assist in this process.

The 2017 Red Book is a summary guidebook to employment supports for persons with disabilities, explaining how to take advantage of the myriad of supports that are available to SSDI and SSI beneficiaries. The Impairment-Related Work Expenses (IRWE) incentive, for example, is an income deduction, calculated by SSA, for the cost of certain impairment related items and services from gross earnings when the SSA decides if the individual’s work is at the SGA level. The administration also offers help creating a Plan to Achieve Self Support (PASS). With this incentive, individuals can set aside income to support the pursuit of a work goal that will reduce or eliminate their benefits, such as educational or vocational training. Also, the Ticket to Work Program (TTW) increases beneficiaries’ available choices when obtaining specific employment services, vocational rehabilitation (VR) services, and other support services that they may need to get or keep a job (*The 2017 Red Book*, 2017).

Statement of the Problem

These are just a few examples of work incentives provided by the SSA. Despite the administration’s efforts to foster vocational rehabilitation, the percentage of beneficiaries returning to work remains low. In 2016, only 0.54% of disabled workers had their benefits terminated after making a successful return to work (*Annual Statistical Report*, 2016).

Employment as a social determinant of health has been well-documented (Waddell and Burton 2006; Hagler 2016; Ross 1995). Numerous studies have demonstrated the association between employment and improved mental health and quality of life among individuals with disabilities (Marwaha and Johnson 2004; Turner and Turner 2004). Employment incurs both financial benefits, which reduces mental distress due to economic stress and improves the ability to access higher quality food and housing, and psychological benefits, through the concurrence

of social connections, status, and productivity (Montgomery et al 1999; Turner et al 2004; McKee et al 2005). Employment and income subsequently improve access to medical care and health insurance coverage, with most Americans receiving coverage through their employer (Sonier, 2013).

Few studies have examined the health status of people who are employed with disabilities, but several have found that employment is associated with being healthier among the population of individuals with disabilities and employed individuals with disabilities are less likely to utilize high rates of healthcare services (Yelln and Trupin, 2003; Thomas and Ellis, 2013). Individuals with disabilities who are employed are less likely to report mental distress and more likely to report better quality of life than individuals with disabilities who are not employed (Okoro et al 2007; Hall et al 2013).

Numerous factors make South Carolina a representative southern state to examine the prevalence of employment among individuals with disabilities. South Carolina is ranked 40th of 50 states, based on residents with disabilities as a percent of the population (Social Security Administration, 2016). South Carolina has a higher proportion of residents with disabilities than the national average; 7.9% of South Carolina residents live with disabilities versus 6.3% of the United States population (Social Security Administration, 2016). Additionally, South Carolina, and many southern states, have some of the lowest labor force participation rates for individuals with disabilities in the nation (The Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC), 2017). Among the states with the highest percentage of individuals with disabilities, seven are in the southern United States and five of them, like South Carolina, fall into what has been traditionally called the Southern Black Belt (Social Security Administration, 2016). To illustrate this, South Carolina has a larger proportion of African-American residents (27.9% versus 12.6%, $p < 0.01$) and rural residents (33.7% versus 19.3%, $p < 0.01$). Furthermore, South Carolina also has fewer residents with a bachelor's degree or higher (25.8% versus 29.8%, $p < 0.01$) than national averages (U.S. Census Bureau, 2015).

This demography is common among Southern Black Belt and rural states, making South Carolina an excellent case study for generalizability among a broad cross section of U.S. states. This study aims to describe the relationship between employment and health care access using a sample of South Carolina SSDI recipients. Given the effect that health has on one's ability to work, it is imperative that research is performed to determine how health care reform has impacted individuals with disabilities' access to care. The Affordable Care Act (ACA), has allowed an estimated 20 million adults to acquire health insurance, since its passing in 2010 (Uberoi, Finegold, & Gee, 2016). Maestas, Mullen and Strand (2014) conducted a study demonstrating the effect that Massachusetts' health insurance reform has on the SSDI and SSI application rate. Given its similarities to ACA, the Massachusetts reform acted as a test case for it, and the authors predict a decrease in overall SSDI and SSI caseload. Though healthcare access has expanded as a result of reform, it is hypothesized that factors hindering a return to work include the potential loss of Medicaid or Medicare benefits, lack of transportation, lack of proper accommodations to perform job duties, and potential loss of disability benefits.

Purpose of the Study

The purpose of this study is to determine how access to health care affects an individual's decision to return to work post-SSDI enrollment. The following questions define the research objectives of this study:

- How does low access to health care affect a disabled individual's health and thus their ability to return to work?
- How does health care factor into one's decision to return to work?
- Is the loss of Medicare benefits a work disincentive?

Definition of Terms

For the proposed study, the definition of low access to health care is, the inability to receive medical attention due to lack of health coverage, inability to pay healthcare expenses, or lack of transportation.

For the proposed study, working-age refers to individuals ages 18 to 64.

Literature Review

The Social Security Administration has several work incentive programs to encourage SSDI and SSI recipients to work and continue to receive their monthly payments and health benefits. Despite these incentives, many beneficiaries do not obtain employment post-SSDI enrollment. A study of SSDI application behavior showed that “no more than 37% of [SSDI] beneficiaries would return to work if they did not receive [SSDI] benefits” (Lahiri et al 2008). Research shows several reasons for this lack of labor force attachment aside from changes in functional capacity.

The beneficiary's financial outlook is a major influence on their decision to return to work. Many applicants were low wage earners prior to applying for SSDI. According to Lahiri et al (2008) 21.78% accepted SSDI applicants were earning less than \$6,000 annually and were not expected to return to work. Moreover, to be determined eligible for SSDI benefits, one must demonstrate that they are not capable of engaging in substantial gainful activity (SGA). The SGA level is the maximum monthly income one can earn to be deemed eligible for SSDI benefits. The SGA level for 2017 is \$1,170 per month for non-blind individuals which is approximately 116% of the federal poverty level. (“Substantial Gainful Activity, 2017). Consequently, there is a decline in individuals' earnings and employment observed in the year prior to application (von Wachter et al., 2011). Taking a decrease in earnings to apply for SSDI is a huge risk, considering the award rate in 2014 was 29.2% (*Annual Statistical Report, 2016*). Berkowitz and Greene (1989) credit the strict criteria for eligibility, as well as the complex application process, for the low rate of return to work among SSDI beneficiaries (as cited in Kennedy & Tuleu, 2007). The application process may take several years before a determination of eligibility is reached, especially if appeals are involved. After they are deemed eligible for

disability benefits, the applicant must wait an additional 24 months to be eligible to receive Medicare.

Health care costs are often a source of financial burden for disabled persons, especially during the Medicare waiting period. In Riley's (2006) study on access to health care for SSDI beneficiaries in the waiting period, 27% had income below the poverty level. If the applicant was receiving employer-sponsored coverage prior to disability onset, they have the option to maintain their coverage, for 18 months, through COBRA provisions. Individuals selecting this option may pay up to 102% of the premium cost. In 2015, the average monthly COBRA premium for individual coverage was approximately \$536 (Claxton et al. 2016). If an individual qualifies for the 11-month extension available to disabled persons, they would have coverage for the entire waiting period. However, they could be charged up to 150% of the premium for the additional 11 months. This is a large expense, especially considering the average monthly payment for disabled beneficiaries is \$1,165.79 (*Annual Statistical Report*, 2016). Low incomes, coupled with high insurance premiums and prescription costs cause many to remain uninsured during this waiting period. Research reveals that approximately 26% of SSDI beneficiaries did not have health insurance during the waiting period; among that percentage, 78% stated that they were uninsured because health insurance is too expensive or unaffordable (Riley, 2006).

The financial repercussions of disability onset have the potential to cause major health issues for these individuals. At least 75% of beneficiaries reported lack of insurance or high cost as the reason for not receiving needed medical care (Livermore, 2010). Almost one quarter of beneficiaries reported that they needed care but were unable to get it, and 46.5% delayed seeking care because of cost (Riley, 2006). Disabled Medicare beneficiaries often fail to fill prescriptions if they perceive the cost to be too high (Kennedy et al., 2007). These effects appear to be more prevalent among working age beneficiaries. The scope of these prescription costs can be substantive. Six percent of disabled workers incurred medical costs of \$50,000 or higher, as opposed to 4% of seniors. Moreover, younger beneficiaries receive more prescriptions per year and spend more on drugs than the elderly. As a result, these beneficiaries report higher rates of cost-associated prescription non-adherence which can have major consequences for those with chronic conditions or disabilities (Kennedy et al., 2007).

The 2017 Red Book, states that, in the absence of medical improvement, persons with disabilities will be able to maintain Medicare coverage for 93 months, after completing the 9-month Trial Work Period (TWP). After the 93-month period, these individuals can purchase Medicare coverage. The monthly premium for Medicare Part A in 2017 was \$413 for individuals with less than 30 quarters of coverage. Individuals with more than 30 quarters of coverage, or a spouse (former or deceased) with this amount of coverage, qualify for a reduced Part A premium of \$227. The Part B premium was \$134 in 2017 (2017). Although, these are designed to be incentives, these premiums may not be affordable despite gaining earnings above SGA level.

Literature highlights that Medicare is of great value to applicants and beneficiaries. The prospect of receiving Medicare benefits results in an increase in the average probability of application for SSDI benefits by approximately 12%. Of the 9.5% of growth in applications, 2.8% can be explained by Medicare alone (Lahiri et al., 2008). Bailey and Weathers (2014) note

that access to health insurance during the waiting period prevents significant declines in health, which in turn could lead to a decrease in future Medicare costs.

Research has addressed, to some extent, how low access to health care can affect employment among disabled beneficiaries. According to Livermore et al (2010) health insurance is likely to factor into decisions concerning employment among people with disabilities. These authors also suggest that de-linking eligibility for public health insurance from federal disability programs would reduce labor force withdrawal and encourage disabled persons to find employment (2010). This study builds upon this existing knowledge and provide programmatic and policy implications concerning employment supports and health care for disabled persons. Improving the health of disabled persons is necessary for their return to work and could result in decreased caseloads and expenditures for state and federal disability programs.

Methodology

Research Design

This analysis utilizes a survey instrument as the primary methodological tool to analyze underlying research questions. A pilot survey was administered in September 2017 prior to finalizing the questions for the large-scale survey. The initial survey was external; thus, participants' responses were not included in the results of the main survey. The procedure for the pilot survey was followed as outlined in *Health Science Research: A Handbook of Qualitative Methods* (Peat, Mellis, Williams, & Xuan, 2002). The survey was administered to pilot subjects in the same manner as it was administered for the main survey. The time necessary to complete the questionnaire was monitored so that a decision could be reached regarding whether the timing and demands on participants was reasonable. Any unnecessary, difficult or ambiguous questions were discarded. Each question was assessed for the variety of responses it elicited and whether those responses contain the required information. The surveys were also reviewed to confirm that all questions were answered. Any questions that did not elicit the expected response were re-worded or re-scaled. Lastly, the effectiveness of the survey distribution and recruitment methods were also considered and changed, as appropriate. Once all revisions were complete, the large-scale survey was administered in February and March 2018.

The survey was conducted utilizing the SurveyMonkey® survey building and data analytics system. A hard copy of the survey was also available, upon request, to provide equity of access to the survey. The survey was designed to be completed in one sitting and required approximately 15 minutes of the participant's time. There was no follow up data collection. Each participant accessed the survey link by contacting the principal and/or co-investigator or by contacting one of the partnering agencies. Once the link was accessed, the participant was presented with information about being in a research study, how much time it required, compensation for their time, protective measures to protect confidentiality, and possible risks, comforts, or benefits. Upon completion of the survey, participants were redirected to a separate form to fill out their contact information in order to receive their incentives, and the results of the study. The incentives were delivered via email or SMS with the information provided by the participant.

All data was stored in a password protected electronic file in a locked room. Phone numbers and e-mail addresses were collected for dissemination of the survey results. This contact information was also used to distribute the incentive payments. All identifiable data was captured in a form separate from the participants' survey responses, utilizing the JotForm platform. Identifiers were kept until all incentives were distributed to the participants. All results are reported in the aggregate with no identifying information.

Sampling

The survey was open to South Carolina residents, ages 18 to 64, who are beneficiaries of the SSDI program. Participants for the large-scale survey were recruited through the following agencies that offer services and resources to disabled persons: South Carolina Vocational Rehabilitation, SC Spinal Cord Injury Association, Able South Carolina, Center for Community Services, and Greer Relief.

Given the exploratory nature of this research, a convenience sample was used. There is a disadvantage to using this method, as it does not prove causality (Emerson 2015). However, there are some advantages as well. There is a potential risk associated with the disclosure of the participants' health care status due to the laws governing the mandate for minimum essential coverage. If an individual can afford health insurance but chooses not to buy it, they must pay a fee called the individual shared responsibility payment. As a result, participants may be reluctant to share this information. Self-selecting into the study helps ensure that the participants are committed to taking part in the study. Participants were presented with an informed consent form prior to beginning the survey and protective measures were also put in place to ensure that participants' responses are confidential and that they cannot be identified by their responses.

Instrumentation

The survey examined the relationship between access to health care and the decision to return to work among individuals with disabilities. The instrument contained a combination of categorical and ordinal questions (See Appendix A for questions). All ordinal questions contained an odd number of values to establish a midpoint. Demographic information was also collected to establish sub-groups of the population for analysis. The survey also included the six-item set of questions which are the data standard for determining disability status set by the Secretary of the U.S. Department of Health and Human Services (HHS) in accordance with the 2010 Affordable Care Act, Section 4302 (*Disability Data*, 2016). The rationale for the disability data standard is as follows:

The six-item set of questions used on the ACS and other major surveys to measure disability was developed by a federal interagency committee and reflects the change in how disability is conceptualized consistent with the International Classification of Functioning, Disability, and Health. The question set defines disability from a functional perspective and was developed so that disparities between the 'disabled' and 'nondisabled' population can be monitored. The question set went through several rounds of cognitive and field testing and has been adopted in many federal data collection systems. OMB has encouraged the use of this question set by other federal agencies conducting similar

population studies due to the extensive testing used in the development of these measures, including the findings that alternative measures did not test as well. Cognitive testing of these questions revealed that the six questions must be used as a set to assure a meaningful measure of disability. (Brault, Stern, and Raglin, 2007)

The survey sample was restricted to SSDI recipients, so it is assumed that the participant already meets the Social Security Administration's definition of disability. The inclusion of these questions allows the researcher to view the participant's disability from a functional perspective. Given the research focus on employment, this is critical information because one's degree of functionality will impact their ability to work. The researcher consulted with the Assistant Commissioner and Benefit Specialist at the South Carolina Vocational Rehabilitation department to approve all survey questions.

Findings

The majority of the respondents were male (66.7%), Hispanic (51.0%), less than forty-two years of age (78.3%, Table 1). The majority of respondents were also currently employed (92.2%). There were 28 South Carolina counties represented in this sample with 39.2% of the sample residing in rural areas. In regard to family composition, 94.1% of respondents were married or had a live-in partner and 94.1% had children under 18 living in their household. Financially, the average respondent was receiving a monthly SSDI benefit in the amount of \$1,295.

Less than twenty percent (15.7%) of respondents experienced disability onset prior to reaching 18 years of age (Table 2). The most common impairments amongst this group are: amputated limb (21.6%), anxiety (21.6%), skin disorders (17.6%), trauma/stress related disorders (15.7%) and depressive/bipolar disorders (11.8%). From a functional perspective, respondents experience significant impairments; 47.0% of respondents experienced difficulty walking or climbing stairs, 35.3% suffer from a hearing difficulty or deafness, 33.3% have serious difficulty concentrating, remembering things, or making decisions, and 31.4% have a vision impairment. A smaller portion of the participants experience difficulty dressing and/or bathing (11.8%) or difficulty running errands alone (17.6%).

Despite these impairments, respondents self-report being in good health. On a scale ranging from "poor" to "excellent", 62.3% believe they are in "very good" health (Table 3). All respondents were insured at the time of survey completion. Respondents possessed a variety of health coverage types such as Medicaid (96.1%), Medicare (94.1%), employer-sponsored coverage (92.2%), coverage provided through the Healthcare Marketplace (74.5%), private insurance (37.3%), and COBRA (2.0%). Moreover, 60.8% of respondents report that they are "always" able to access medical care. Others reported they can "frequently" or "sometimes" access healthcare (35.3%; 21.6% respectively). Of those that cannot always access medical care, the survey results show that healthcare costs are the most common barrier (68.2%). Over half (54.6%) of respondents report they lack enough health coverage to cover needed services and 40.9% lack the transportation to access care when needed.

Most respondents experienced job loss after becoming disabled (88.2%), yet the majority of respondents also returned to work after becoming disabled (84.3%, Table 4). Among those that returned to work, all respondents cited a need for more income to cover their expenses and nearly all (97.7%) selected a desire to keep health coverage through their employer. Most respondents (88.4%) returned due to their enjoyment of the work. Among unemployed respondents, half had been unemployed for 1-3 years. Two-thirds of unemployed respondents found it “extremely important” to return to work, while 33.33% reported no desire to return to work. Factors that hinder returning to work include the potential loss of Medicaid/Medicare benefits (83.3%), potential loss of disability benefits (66.7%), lack of proper accommodations to perform their job duties (50%), and lack of transportation (16.7%). Respondents were familiar with the Plan to Achieve Self-Support (PASS) program (86.2%) and the Ticket to Work program (80.4%), but most were unlikely to utilize either program (Table 5).

Other findings of interest include a respondent citing issues finding providers that accept Medicaid and/or those with adequate experience as it relates to their disability. These barriers highlight opportunities for further research relating to access to health care and how it may vary by an individual’s specific disability. Moreover, one could explore the quality of care individuals with disabilities can access in the network of providers available with public health insurance.

Discussion

Employment and healthcare status were examined among individuals with disabilities who were currently receiving SSDI benefits. Findings from this survey highlight many themes discussed in previous literature. Healthcare costs continue to be a barrier for individuals with disabilities (Neri 2003). Reduced access to health care may affect health outcomes and an individual’s decision to return to work (Hwang 2009; Cook 2002). The results also mirror those of previous studies showing that Medicare is highly valued by SSDI applicants and beneficiaries (Iezzoni 2002; Riley 2004). Though the majority of respondents have some form of health insurance, it appears that the perception of losing health coverage inhibits a return to work.

However, national surveys report that Americans with disabilities want to work and are striving to do so (Kessler Foundation, 2015). At the same time, there is a growing movement focused on the idea of Employment First; “the vision of making employment the first and preferred outcome of people with disabilities (Minnesota Association of People Supporting Employment First, <https://www.mnapse.org/action>).” Increasingly state policymakers across the country support employment first efforts as a way to grow the workforce and enhance economic development. However, research also illustrates that states must look beyond a few targeted workforce development programs to more substantive coordination with social service agencies and the federal programs that may alter the incentive structures to work (Quinton, 2015). Today, there are over 45 states with some type of employment first conversation occurring at the state level. However, South Carolina and several of the states with the highest disability rates and lowest labor force participation rates for individuals with disabilities, have few, if any, policy measures reported (University of Minnesota, 2014, <https://rtc.umn.edu/prb/214/>).

South Carolina remains a rural, lower income state with less educational attainment than the nation overall. These variables all influence the relationship between disability and

employment. Rural and low-income states have an additional added burden of potential transportation barriers for individuals with disabilities to receive health care and gain full employment. The results illustrate this challenge for South Carolina and highlight the value of innovative policy measures beyond traditional vocational rehabilitation.

North and South Dakota, very rural states, have been leaders in helping individuals with disabilities to gain employment. Over 50% of individuals with disabilities are employed in these states, compared to 34% or less in the 15 states with the fewest individuals with disabilities employed (The Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC), 2017). Iowa, another leader in this area, provides evidence of the value of strong leadership, collaborative public-private partnerships and long term thinking (Mizrahi, J.L., 2016). This study helps to characterize ongoing challenges in states that may lag behind leaders in this area. Investing in employment programs for individuals with disabilities stands to benefit individuals, families, communities and firms and characterization of these issues is valuable in stimulating policy innovation across all states.

A strength of this study is the use of survey methods to investigate potential issues with employment and health access for individuals with disabilities. There were limitations to this survey, particularly with recruitment. Several methods of recruitment were implemented over a period of approximately four months. A number of local nonprofits and government agencies recruited participants with flyers and through various mediums such as email and social media. Information was also disseminated to student disabilities offices at public and private institutions of higher education. Though these are appropriate methods given that the survey was delivered online, the number of respondents remained relatively low.

This rate of response may be attributed to a number of factors. Delivering a survey online helps to reach a larger area; however, it may not provide equity of access to the survey, especially for persons with disabilities. This delivery method also reduces the ability to provide the adaptations a specific respondent may need to participate in the study. Moreover, one must consider the private nature of healthcare information in response to sensitive questions of disability and employment. Given the laws surrounding healthcare and mandated coverage, respondents may have been reluctant to participate. However, these results are important in that they illustrate results specific to South Carolina and confirm the need for additional research and policy work in this area.

Policy changes such as extending the period for which SSDI recipients can receive Medicare coverage after a return to work may result in a decrease in the long-term caseload for the Social Security Administration. Research surrounding delinking eligibility for Medicare from SSDI, for persons under the age of 65, may also yield useful programmatic implications. Future policy concerning health care should consider the impacts of limiting health care options for disabled workers. Health insurance is likely to factor into decisions concerning employment among people with disabilities. These authors also suggest that de-linking eligibility for public health insurance from federal disability programs would reduce labor force withdrawal and encourage disabled persons to find employment (Livermore 2010).

Further research at the national level with a larger sample size could be beneficial for elucidating enhanced understanding of factors inhibiting return to work for individuals with disabilities. Policy programs should be developed to educate individuals with disabilities on health care access, by residence and impairment type. This could be accomplished through case management, transportation services for beneficiaries, or a healthcare provider directory. Supportive services such as these could be especially for beneficiaries in rural areas. Additionally, robust partnerships that target the multi-faceted challenges of poverty, rurality, and health care access for individuals with disabilities are likely to make the biggest impact for communities.

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Figures

Table 1. Demographics of Survey Respondents (N=51)

Characteristics	Percent	N
Age		
26-33	35.2	18
34-41	43.1	22
42-49	1.6	8
50-57	3.9	2
58-64	1.9	1
Gender		
Male	66.7	34
Female	33.3	17
Race/Ethnicity		
White	41.2	21
African-American	7.8	4
Hispanic	51.0	26
Spouse or Partner	94.1	48
Children under 18 in household	94.1	48
Rural County	39.2	20
Currently Employed	92.2	47

Table 2. Disability Characteristics of the Sample (n=51)

Characteristics	Percent	N
Deaf or serious difficulty hearing	35.3	18
Blind or serious difficulty seeing	31.4	16
Trouble concentrating, remembering, or making decisions due to a physical, mental, or emotional condition	33.3	17
Serious difficulty walking or climbing stairs	47.0	24
Difficulty dressing or bathing	11.8	6
Difficulty doing errands alone such as visiting a doctor's office or shopping due to a physical, mental, or emotional condition	17.6	9
Disability prior to age 18	15.7	8
<i>Impairment(s) that best describe your disability:</i>		
Amputated Limb	21.6	11
Anxiety	21.6	11
Skin Disorders	17.6	9
Trauma/Stress Related Disorders	15.7	8
Depressive or bipolar Disorders	11.8	6
Loss of joint function	7.8	4
Cystic Fibrosis	7.8	4

Autism Spectrum Disorder	5.9	3
Immune System Disorders	5.9	3
Asthma and other respiratory disorders	5.9	3
Bone Fracture	5.9	3
Disorders of the spine	5.9	3
Kidney Disease	3.9	2
Diabetes	3.9	2
Irritable Bowel Syndrome	3.9	2
Personality/Impulse control disorders	3.9	2
Burns	3.9	2
Soft tissue injury	3.9	2
Short Bowel Syndrome	3.9	2
Cancer	3.9	2
Other	3.9	2
Endocrine Disorders	2.0	1
Brain injury/tumors	2.0	1
Bone marrow failure	2.0	1
Schizophrenia	2.0	1
Lung Transplantation	2.0	1
Liver disease	2.0	1
OCD	2.0	1
Eating Disorder	2.0	1
Chronic Pulmonary Hypertension	2.0	1

Table 3 Healthcare and Access to Healthcare (n=51)

Characteristics	Percent	N
<i>Self-reported health status:</i>		
Excellent	5.7	3
Very Good	62.3	33
Good	21.6	11
Fair	5.7	3
Poor	1.9	1
<i>Healthcare Coverage</i>		
Medicaid	96.1	49
Medicare	94.1	48
Employee-sponsored health insurance	92.2	47
Marketplace insurance	74.5	38
Private insurance	37.3	19
COBRA	2.0	1
<i>Able to access medical care when needed</i>		
Always	60.8	31
Frequently	35.3	18
Sometimes	21.6	11

Rarely	2.0	1
Never	0	0
<i>Factors that prevent access to medical care (n=22)</i>		
Cost	68.2	15
Lack of transportation	40.9	9
Lack of healthcare coverage	54.6	12
Other	4.6	1

Table 4. Employment Characteristics of the Sample (n=51)

Employment Characteristics among those who were employed prior to becoming disabled	Percent	N
Experienced job loss after becoming disabled	88.2	45
Began working after becoming disabled	84.3	43
Among those that returned to work (n=43), factors that led to return to work:		
More income to cover expenses	100	43
Healthcare coverage through employer	97.7	42
Enjoy working	88.4	8
Among those unemployed, (n=6):		
<i>Length of unemployment</i>		
Less than a year	16.7	1
1-3 years	50.0	3
4-6 years	16.7	1
7-10 years	0	0
11 years or more	16.7	1
<i>Importance of finding employment</i>		
Extremely Important	66.7	4
Did not want to return to work	33.3	2
<i>Factors that hindered return to work</i>		
Lack of transportation	16.7	1
Potential loss of Medicaid or Medicare	83.3	5
Lack of proper accommodations to perform job duties	50	3
Potential loss of disability benefits (SSDI, SSI, etc.)	66.7	4
No desire to return to work	0	0
Other	16.7	1

Table 5. Work Incentives

Characteristics	Percent	N
Familiarity with Plan to Achieve Self-Support (PASS)	86.2	44
<i>Likelihood to create a PASS</i>		
Very Likely	3.9	2

Somewhat Likely	9.8	5
Neither Likely or Unlikely	5.9	3
Somewhat Unlikely	47.1	24
Very Unlikely	33.3	17
Familiarity with Ticket to Work (TTW)	80.4	41
<i>Likelihood to use Ticket to Work (TTW)</i>		
Very Likely	5.9	3
Somewhat Likely	33.3	17
Neither Likely or Unlikely	2.0	1
Somewhat Unlikely	33.3	17
Very Unlikely	25.5	13

Appendix A

Information about Being in a Research Study Clemson University

Access to Health Care & Employment

Description of the Study and Your Part in It

Dr. Lori Dickes and Ashley Jamison are inviting you to take part in a research study. Dr. Dickes is an assistant professor at Clemson University. Ashley is a student at Clemson University, running this study with the help of Dr. Dickes. The purpose of this research is to examine how access to health care affects the employment of SSDI recipients in South Carolina.

Your part in the study will be to complete the following survey. It will take you approximately 15 minutes to answer all the questions.

Risks and Discomforts

There is the possibility for loss of confidential information, but we have minimized this risk by capturing all identifiable data separate from the participants' survey responses.

Possible Benefits

We do not know of any way you would benefit directly from taking part in this study. However, this research may help us understand how to support SSDI recipients' return to work.

Incentives

All participants will receive a \$10 gift card upon completion of the survey. You may also enter a drawing for a chance to win an iPad mini. The drawing for the iPad mini will be conducted upon collection of all survey responses.

Protection of Privacy and Confidentiality

We will do everything we can to protect the confidentiality of the data. Identifiers will be kept until all incentives have been distributed to the participants. Responses will not be identified by individual. All responses will be compiled together and analyzed as a group.

We might be required to share the information we collect from you with the Clemson University Office of Research Compliance, the Social Security Association (SSA) and the federal Office for Human Research Protections. If this happens, the information would only be used to find out if we ran this study properly and protected your rights in the study.

Choosing to Be in the Study

You do not have to be in this study. You may choose not to take part and you may choose to stop taking part at any time. You will not lose any of your benefits if you decide not to be in the study or to stop taking part in the study.

If you choose to stop taking part in this study, the information you have already provided will be used in a confidential manner.

Contact Information

If you have any questions or concerns about this study or if any problems arise, please contact Dr. Lori Dickes at Clemson University at 864-656-7831. If you have any questions or concerns about your rights in this research study, please contact the Clemson University Office of Research Compliance (ORC) toll-free at 866-297-3071 or irb@clemson.edu.

Clicking on the "agree" button indicates that:

- You have read the above information
- You voluntarily agree to participate
- You are at least 18 years of age

You may print a copy of this informational letter for your files.

Survey Questions

Disability

1. Are you deaf, or do you have serious difficulty hearing?¹
 Yes No
2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses?¹
 Yes No
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?¹
 Yes No
4. Do you have serious difficulty walking or climbing stairs?¹
 Yes No
5. Do you have difficulty dressing or bathing?¹
 Yes No
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?¹
 Yes No
7. Please select the impairment(s) that best describe your disability:

<input type="checkbox"/> Autism spectrum disorder <input type="checkbox"/> Loss of speech <input type="checkbox"/> Kidney disease <input type="checkbox"/> Diabetes <input type="checkbox"/> Endocrine disorders <input type="checkbox"/> Amputated limb <input type="checkbox"/> Bone marrow failure <input type="checkbox"/> Schizophrenia <input type="checkbox"/> Immune system disorders <input type="checkbox"/> Asthma and other respiratory disorders <input type="checkbox"/> Irritable Bowel Syndrome (IBS) <input type="checkbox"/> Trauma/stress related disorders <input type="checkbox"/> Heart failure/heart disease <input type="checkbox"/> Liver transplant <input type="checkbox"/> Epilepsy <input type="checkbox"/> OCD <input type="checkbox"/> Eating disorder <input type="checkbox"/> Other	<input type="checkbox"/> Loss of joint function <input type="checkbox"/> Cystic Fibrosis <input type="checkbox"/> Sickle Cell Disease <input type="checkbox"/> Skin disorders <input type="checkbox"/> Brain injury/tumors <input type="checkbox"/> Bone Fracture <input type="checkbox"/> Lung transplantation <input type="checkbox"/> Personality/impulse control disorders <input type="checkbox"/> Liver disease <input type="checkbox"/> Burns <input type="checkbox"/> Anxiety <input type="checkbox"/> Disorders of the spine <input type="checkbox"/> Soft tissue injury <input type="checkbox"/> Chronic pulmonary hypertension <input type="checkbox"/> Depressive or bipolar disorders <input type="checkbox"/> Short Bowel Syndrome (SBS) <input type="checkbox"/> Cerebral palsy <input type="checkbox"/> Cancer
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¹ Questions from the disability data standard set by the Secretary of the U.S. Department of Health and Human Services. <https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>

Employment

1. Did you become disabled prior to turning 18 years of age?
 Yes No
If YES, skip to #6
2. Were you employed prior to becoming disabled?
 Yes No
If NO, skip to #6
3. Did you experience job loss after becoming disabled?
 Yes No
If NO, skip to #6
4. Did you begin working for any amount of time after losing your job?
 Yes No
If NO, skip to #7
5. Please select the factors that led you to return to work
 - I needed more income to cover my expenses
 - I did not want to lose health coverage through my employer
 - I enjoy the work that I do
 - Other _____
6. Are you currently employed?
 Yes No
If YES, skip to Access to Health Care
7. How long have you been unemployed?
 - Less than a year
 - 1-3 years
 - 4-6 years
 - 7-10 years
 - 11 years or more
8. Please select the option that BEST describes how important it is for you find employment:
 - Extremely important
 - Somewhat important
 - Neither important nor unimportant
 - Somewhat unimportant
 - I do not want to return to work
9. Please select ALL factors that hindered you from returning to work:
 - Lack of transportation
 - Potential loss of Medicaid or Medicare
 - Lack of proper accommodations to perform job duties
 - Potential loss of disability benefits (SSDI, SSI, etc.)
 - No desire to return to work
 - Other _____

Access to Health Care

1. How would you rate your health right now?

- Excellent
- Very Good
- Good
- Fair
- Poor

2. Do you have health coverage?

- Yes No

If NO, skip to #4

3. Please select the option below that best describes your health coverage:

- Medicaid
- Medicare
- Private Insurance
- Marketplace Insurance, commonly known as “Obamacare”
- Employer- sponsored health insurance
- COBRA
- Other _____

4. Are you able to access medical care when needed?

- Always
- Frequently
- Sometimes
- Rarely
- Never

5. Please select the factor(s) that prevent you from accessing medical care:

- Cost
- Lack of transportation
- Lack of health coverage
- Other _____
- I am always able to access medical care

Work Incentives

1. Are you familiar with the Plan to Achieve Self-Support (PASS)? Yes No
2. The following scenario is an example of a PASS. Please read and respond to the following questions²:
 - Maria wants to go to school and would like to create a PASS.
 - Anyone can help Maria with creating a PASS; for example, a PASS specialist, social worker, or vocational rehabilitation counselor.
 - Maria receives \$800 in SSDI benefits.
 - Maria determines she needs \$780 per month for tuition, books, and school supplies and lists these expenses in her plan. The Social Security Administration could **possibly** exclude up to \$780 per month in SSDI income. This will **possibly** make Maria eligible for up to the full SSI payment (\$735 for 2017).
 - Maria is now able to use the SSI payment of \$735 for living expenses and use the PASS funds of \$780 to go to school.

After reading this scenario, how likely are you to create a PASS?

- Very likely
 - Somewhat likely
 - Neither
 - Somewhat unlikely
 - Very unlikely
3. Are you familiar with Ticket to Work (TTW)? Yes No
 4. The following scenario is an example of how someone could use a TTW. Please read and respond to the following questions³:
 - Steven began receiving SSDI benefits after becoming injured in a car accident.
 - He did not want to rely on this fixed income and desired to return to work.
 - Steven's local SSA office informed him that he was eligible for TTW, which helps people prepare for work.
 - Steven selected an employment network (EN) that suited his needs and met with a career counselor to build a resume, practice interview skills, and look for work.
 - With these supports, Steven was able to find employment and become more financially stable.

² This scenario was adapted from the Social Security Administration's Red Book (2017 English version). <https://www.ssa.gov/redbook/>

³ This scenario was adapted from a success story provided by the Social Security Administration's Ticket to Work program. <https://www.choosework.net/library/rae-anna-success-story>

After reading this scenario, how likely are you to use TTW?

- Very likely
- Somewhat likely
- Neither
- Somewhat unlikely
- Very unlikely

Demographic Information

1. What is your Date of Birth? _____
2. Please select your gender: Male Female
3. Please select the racial/ethnic group you most identify with:
 - White
 - Black or African American
 - Hispanic or Latino origin
 - Asian
 - American Indian or Alaska Native
 - Native Hawaiian or Other Pacific Islander
 - Other _____
4. In what county, do you reside? _____
5. Do you have a spouse or other live in partner? Yes No
6. How many children (under the age of 18) live in your household? _____
7. Do you receive a monthly Social Security Benefit? Yes No
8. Approximately, how much is your monthly Social Security benefit? _____

Contact Information

Please provide your contact info, if you would like the results of this survey.

Phone #: _____
Email: _____