Alternative Work Opportunities for Adults Who Have Degenerative Conditions, and Implications for Social Security Disability Insurance Policy and Practices

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Abstract

Adults who have degenerative conditions which occur mid-career, such as Amyotrophic Lateral Sclerosis (ALS), face a number of obstacles to continuing their work. While employment accommodations can sustain an individual's employment status for a period of time, adults with degenerative conditions often need to leave their current employment when fatigue and the physical demands of their job compromise their personal health and safety. However, many adults do not want to leave work, and express a desire to continue active engagement and service to their community. Utilizing qualitative methods, this study sought to understand the types of alternative, occasional work available to people with degenerative conditions who use assistive technologies for daily living and the implications those types of work might have on Social Security Disability Insurance benefits. We interviewed professionals who provide education and/or counseling on Social Security Disability Insurance, conducted an internet keyword search on alternative, accessible employment opportunities and we surveyed adults with degenerative conditions. We found two over-arching themes: 1) options for accessible, alternative, occasional work opportunities are not well-known– but wanted, and 2) Social Security Disability Insurance policies regarding alternative and occasional work are not easily accessible or well-understood. As a result, we discuss implications for Social Security Disability Insurance policies and opportunities for improving outreach and education for adults with degenerative conditions who use assistive technologies.

Background

Adults who have degenerative conditions, such as Motor Neuron Diseases like Amyotrophic Lateral Sclerosis (ALS) or Primary Lateral Sclerosis (PLS), lose physical abilities as their condition progresses (ALS Association, 2010; *What Is MND? | MND Association*, n.d.). Adults who are working at the time of their first symptoms can find that balancing the demands of their current work with their healthcare needs and changing physical abilities can be a challenge (Beneteau & Pratt, 2019). Many adults want to continue working (McNaughton et al., 2001) but, over time, may find that they are no longer able to continue the same job they had prior to onset of their illness.

Research has shown that engaging in work or volunteering is beneficial for the mental health and quality of life of people who have severe physical and communication impairments (Johnston et al., 2014; McNaughton et al., 2001; McNaughton & Arnold, 2010). McNaughton, et al. found that social and intellectual stimulation were important benefits for people with ALS who continued to engage in work (McNaughton et al., 2001). However, the degenerative nature of ALS and similar degenerative conditions often require a variety of accommodations and adaptations for individuals to continue to work and interact with the world. Many people with degenerative conditions such as ALS require assistive technologies to help with mobility, communication, and/or computer access for daily living, which can further complicate employment options.

<u>Employment, Assistive Technologies and Benefits</u>
Assistive technologies can include a variety of tools used for daily living, including wheelchairs, hearing aids, voice dictation software, and high-tech voice-output communication systems. The

little research available on employment and people who use assistive technologies tends to include a wide variety of disabilities, as seen in Yeager et al.'s (2006) study of the experiences of Californians who use assistive technologies, which included people with hearing impairments, intellectual disabilities, blind and low-vision, mental health needs, as well as mobility and speech disabilities. Surveying 1,507 people with disabilities who used assistive technologies, Yeager et al. found that the biggest barrier to employment was the disability itself and the second most common barrier was a concern of the potential of losing benefits.

Similarly, prior ARDRAW research shows that people, who acquire impairments mid-career and who use assistive technologies for daily living, want to work but have concerns regarding how part-time work might impact disability benefits and healthcare (Beneteau & Pratt, 2019). These concerns can become barriers to seeking new employment opportunities. People with degenerative conditions who require the use of assistive technologies may experience additional challenges to finding work opportunities. Fatigue can be a significant factor when considering any type of employment, which can make volunteering seem more appealing, as some participants perceive unpaid work as more flexible and less demanding than paid work. Flexible work hours, with the option to work from home, are some of the requirements participants cite when considering potential employment (Beneteau & Pratt, 2019).

The option to work from home has been increasing over the years with telework, and has increased dramatically with recent events related to the COVID-19 pandemic. While some initial research has explored the concept of telework from home for people who use augmentative-alternative communication systems (McNaughton et al., 2014), work opportunities that accommodate adults with degenerative conditions have not yet been fully explored. In addition, a reconciliation between people's concerns about losing benefits with balancing part-time, flexible employment opportunities has not been addressed in the literature. Therefore, we seek to better understand how occasional, flexible, employment options might impact the benefits of people with degenerative conditions who use assistive technologies for daily living.

Accessible Work Options

For people with degenerative conditions, a key component to exploring potential work opportunities is how accessible the work itself is to the person who is using assistive technology. For example, a person who cannot use a traditional keyboard and mouse will need to ensure that any computer work is accessible via their alternative access method (such as eye control, switch scanning, or voice dictation). In 2017, the National Academy of Sciences called for additional research to better understand the use of assistive technologies for employment and inclusion in society (National Academies of Sciences & Medicine, 2017). In their report, the National Academy of Sciences proposed a framework in which health condition, body functions, activities, personal factors, environmental factors and physical environmental factors are considered when addressing employment needs of people who use assistive technologies. The report details a variety of assistive technology options in depth, including wheelchairs, prostheses, telecommunications and hearing technologies, augmentative and alternative communication devices and more. As a result, a wide variety of potential assistive technologies

that can aid employment are well documented. However, specific work options that might address the needs of people with degenerative conditions are not covered in this report.

Prior ARDRAW research indicates that adults who acquire mobility and/or communication impairments mid-career want to continue to work or contribute to society in some form, but do not have definite ideas of what types of future work would meet their needs (Beneteau & Pratt, 2019). Alternative, occasional, part-time work options, such as crowdsourcing (Brabham, 2008; Howe, 2006; Kittur et al., 2008) might be possible employment opportunities which meet both accessibility needs as well as health-related needs of people with degenerative conditions. Crowdsourcing work is typically computer-based, requires an internet connection, and can be done from home, generally at times that are convenient for the worker. Crowdsourcing can include micro-tasks, such small tasks that can be completed in minutes, or online freelancing services, which typically involve professional skills for a designated project (Kuek et al., 2015). Crowdsource workers' pay varies widely, depending on the type of work performed. In 2016, approximately half of workers on the crowdsourcing platform, Mechanical Turk, earned less than $5.00/hour (Pew Research Center et al., 2016).

When asked about crowdsourcing, adults who acquired disabilities mid-career were generally unfamiliar with the concept, or had minimal and unsatisfactory experiences (Beneteau & Pratt, 2019). However, many of the employment criteria voiced by participants with degenerative conditions match the opportunities provided by crowdsourcing platforms: flexible hours, the ability to work from home, accessible work compatible with their physical abilities and assistive technologies, and low-stress work. As a result, we seek to understand how crowdsourcing might be accessible to people who use assistive technologies and how receptive people with degenerative conditions are to specific crowdsourcing employment opportunities.

Building on prior work, our research study examines two aspects of employment that have been identified as important areas of concern by people who use assistive technologies: 1) how part-time employment impacts their current benefits and 2) what options for accessible, flexible part-time employment are available. Our research focuses on adults who acquired degenerative conditions mid-life, as this population has particularly difficult challenges in finding work which can accommodate their changing needs.

Our research questions are:

1) What types of alternative, occasional, part-time employment opportunities are available for adults with degenerative conditions that meet their accessibility needs?

2) How do Social Security Disability Insurance policies impact the pursuit of alternative, occasional part-time employment by people with degenerative conditions?

3) What interest do people with degenerative conditions have in pursuing accessible, occasional work opportunities that meet their stated needs?

We investigate these areas by including participants who represent different perspectives regarding employment and disability: professionals who provide education and/or counseling on

Social Security Disability Insurance (SSDI) benefits and people who have degenerative conditions who use assistive technologies.

Methods

This research study uses an inductive, qualitative research approach to address our research questions (Bryant & Charmaz, 2007; Creswell & Poth, 2018; Patton, 2015). The specific research methods used include semi-structured interviews, an online survey using Qualtrics, and reviews of existing data and resources. A combination of these methods were used to answer the research questions. Details of the methods used for each research question are listed below.

Research Question 1: What types of alternative, occasional part-time employment opportunities are available for adults with degenerative conditions that meet their accessibility needs?

We used three main methods to investigate Research Question 1. Based on prior ARDRAW work, we identified the parameters of any future type of employment, as expressed by adults who acquired significant disabilities mid-career (Beneteau & Pratt, 2019). We then contacted the participants from the ARDRAW study who had indicated an interest in participating in future research work, and asked them if they had pursued any type of employment since their interview or if they had learned of any employment opportunities which might be appropriate for people who used assistive technologies. We also conducted semi-structured interviews with social workers and other professionals who provided education and/or counseling on Social Security Disability Insurance and related benefits. During the semi-structured interviews, we asked what types of employment opportunities they were aware of for people who use assistive technologies. Finally, we conducted an internet-based search, which lead to a number of resources detailing potential alternative employment options.

Research Question 2: How do Social Security Disability Insurance (SSDI) policies impact the pursuit of alternative, occasional part-time employment by people with degenerative conditions?

We used two research methods to investigate Research Question 2. First, we conducted semi-structured interviews with social workers and related professionals about common questions and concerns that arise regarding SSDI when they are working with their clients. We also asked them about SSDI policies that they felt could support alternative and occasional paid work for people with degenerative conditions who use assistive technologies. Second, we conducted a survey in which we asked people with degenerative conditions who use assistive technologies about what types of concerns they had (if any) regarding their benefits and pursuing occasional, part-time employment and how they felt about paid employment vs. volunteering.

Research Question 3: What interest do people with degenerative conditions have in pursuing accessible, occasional work opportunities that meet their stated needs?

We conducted a Qualtrics online survey of the target population in which we provided examples of four different online-based work opportunities and asked participants to rate their interest in

those work opportunities.[1] The four types of online work opportunities were a selection of crowdsourcing platforms: UpWork[2], TranscribeMe![3], Appen[4], and Mechanical Turk[5,6]. The survey included a screenshot from each platform, with basic information regarding the types of employment available for each platform (and the reimbursement rates, when available). For an example, see Appendix A.

Research Participants

This research study included two groups of participants: 1) social workers or related professionals who provided counseling and/or education regarding Social Security Disability Insurance and 2) adults with degenerative conditions who use assistive technologies for daily living. Due to the small participant population size of this study, additional participant details are summarized and described to protect participants' privacy. Participants resided in a variety of states, including: Washington, Oregon, Idaho, California, Minnesota, and Virginia. All participants consented to participate in this study and this research study was reviewed and approved by our Institutional Review Board.

Professionals worked at non-profits, government agencies, universities and at medical clinics. Many of the professional participants held a Master's of Social Work. Two participants specialized in working with people with degenerative conditions, while other participants provided support to clients with a range of disabilities. The majority of participants' job titles/departments included terms such as Care Services and/or Rehabilitation.

Participants with degenerative conditions included diagnoses such as: Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Primary Lateral Sclerosis, and Friedreich's Ataxia. Three participants reported they were currently engaged in part-time or occasional work and three participants reported that they were currently not working. Survey participants used a variety of assistive technologies, including: text to voice output apps on phones or tablets, walkers, wheelchairs, voice dictation software, alternative mice, and voice amplification.

Analysis

Interview data was coded using open codes and through affinity diagraming. Open codes from each interview were grouped together around emerging categories and themes. Categories were broadened by involving a second researcher to review the open codes and early emerging categories. Through a process of constant comparison, the researchers broadened the categories into larger themes (Bryant & Charmaz, 2007; Creswell & Poth, 2018; Patton, 2015).

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[1] Note that this survey was conducted after COVID-19 had spread throughout the United States. As a result, many individuals and agencies who the researcher had planned to assist with recruitment were unavailable.
[2] https://www.upwork.com/i/how-it-works/freelancer/
[3] https://www.transcribeme.com/transcription-jobs#monetize-downtime
[4] https://connect.appen.com/qrp/public/faq;jsessionid=37CF286663444D3DF408976DD0A47AD4
[5] https://www.mturk.com/worker/help
[6] Disclaimer: The researchers are not affiliated with or have any interest in these crowdsourcing platforms. They were chosen because they offered a wide range of employment options which appeared to be accessible and flexible.

Survey data was collated and analyzed by the primary researcher. The survey data was compared and synthesized with the data from the interviews of professionals to inform the findings for research questions two and three.

Findings

Overall, the findings from this research highlight a need for targeted education and outreach to adults with degenerative conditions who use assistive technologies. Education is needed on specific SSDI policies and benefits targeted to the special circumstances of adults with degenerative conditions. Education is also needed on available, accessible, occasional work options. Our findings indicate that people who use assistive technologies and acquire significant disabilities mid-life are often unaware of many SSDI policies until they receive advising and counseling on the topic, often from a professional. In addition, we find that both professional counselors and individuals with degenerative disabilities have little knowledge of available crowdsourcing work options.

As a result of this research study, we find two over-arching themes: 1) options for accessible, alternative, occasional work opportunities are not well-known- but wanted, and 2) Social Security Disability Insurance policies regarding alternative and occasional work are not easily accessible or well-understood. We discuss these two themes in more detail below.

Options for Accessible, Alternative Work Opportunities are Not Well-Known– But Wanted
We studied alternative work opportunities in three ways. We asked prior ARDRAW research participants about work opportunities, we asked professionals who provide education and/or counseling on SSDI about work opportunities, and we conducted an internet search on accessible work opportunities. The findings in this theme answer two research questions—

> Research Question 1: What types of alternative, occasional part-time employment opportunities are available for adults with degenerative conditions that meet their accessibility needs?

> Research Question 3: What interest do people with degenerative conditions have in pursuing accessible, occasional work opportunities that meet their stated needs?

First, we reached out to previous ARDRAW research participants who had indicated an interest in continuing to participate in research (Beneteau & Pratt, 2019). We asked those participants if they had engaged in any paid work since their last contact with the researcher, or if they were aware of any paid work opportunities that could be done from home that other people in similar circumstances might be interested in. We had three former participants respond. One participant responded by asking the researcher if there were any jobs that they could do (indicating that they were looking for work themselves). One participant indicated that they had not yet found any alternative work options since having to leave their career. The other respondent listed possible occasional employment opportunities that could be done from home, such as data entry, accounting, and research work.

During our semi-structured interviews with professionals who provide counseling and/or education about SSDI benefits, we asked if they were aware of any paid work opportunities for

adults who acquired disabilities mid-life who used assistive technologies. In keeping with results from prior work (Beneteau & Pratt, 2019), interview participants indicated that most of their clients tried to keep working with accommodations as long as possible, until they are unable to work anymore. Once their clients stopped working, they usually do not return to work, often due to fatigue. Interview participants report that many clients, particularly older clients, feel devastated about not being able to continue to work. Clients who want to continue to work or stay engaged with their community often express an interest in continuing to do something that is meaningful and makes a difference.

While many of our professional participants provided guidance and education regarding SSDI, suggestions for specific paid alternative work opportunities for their clients who had to stop working were less common. Three participants referred to the Department of Vocational Rehabilitation (DVR) as a possible resource for learning about alternative employment. One participant also provided a number of website resources, both from Social Security and from volunteer organizations, which they provide to interested clients who are looking for other forms of employment after having to leave their career. Another participant shared a handout listing 30 alternative work options gathered by a statewide organization dedicated to disability resources. The list of 30 types of work options included work options such as: in-home transcription, testing websites, selling personal possessions, freelance taxi driving, renting out property, tutoring/teaching, house-sitting, and more. While the list did not provide many details for getting started with these types of alternative work options, it did provide a wide range of options for a range of abilities.

Professionals indicated that volunteering, rather than paid work, was generally more appealing to people who use assistive technologies and in particular, people who have degenerative conditions. Volunteering is often seen as more flexible than paid work and volunteering is seen as a way to do something meaningful. A list of examples of the types of employment resources shared by professionals during their interviews is available in Appendix B.

In addition to interviewing professionals who provide education and/or counseling on SSDI benefits, we conducted an internet search on alternative employment options for people who use assistive technologies. We used key words in various combinations, using words such as "employment," "jobs," "accessible work," "accessibility," "assistive technologies," and "disabilities." We then reviewed search results, specifically looking for paid employment options in which the employee could work from home, at their own pace, and in which the work was likely accessible via assistive technologies. A list of resources from this search are in Appendix B.

We then chose four options of crowdsourcing work from the internet search and created a survey to better understand how people with degenerative conditions might feel about engaging in crowdsource work as a form of alternative, occasional paid employment. We deployed the survey using Qualtrics, an online survey platform, and we used a format that was accessible via alternative computer access.

Six adults with degenerative conditions who use assistive technologies completed the survey. Three participants indicated that they were currently engaged in part-time or occasional paid employment, including social work, public speaking, writing, bookkeeping, and advisory board work.[7]

Survey participants were provided with a short description and screenshot of four crowdsourcing platforms which offer paid, occasional employment: Upwork, TranscribeMe!, Appen, and Mechanical Turk. One participant reported having known about online transcription work (such as TranscribeMe!) as a work option prior to taking the survey. Prior to the survey, none of the participants had heard of Upwork, Appen, or Mechanical Turk. When participants were asked if they might look at a crowsdsourcing platform's website for more information, respondents were most favorable to Upwork, with four participants indicating that they would "probably" check out the website and two participants indicating that they "might or might not."

Concerns regarding online, paid, occasional work
When asked if participants would be more interested in part-time, alternative work that is NOT computer based, three participants responded "no" and three respondents indicated "maybe- I'm not sure." Participants indicated that physical abilities made computer-based work "most realistic," because "physical disability makes going out into the world an ordeal." However, two participants indicated that they'd like to learn of other options with the potential for being around people.

When asked if they had a preference between volunteering and paid work, one participant indicated that they preferred volunteering, two participants indicated they preferred paid work, and three indicated no preference. Reasons for preferring paid work included: "I need an income," "the amount of energy needed would require paid work." Responses also indicated that the type of work/volunteering was important: "If the cause is legit, I'm happy to help. If it's just making money for someone else, no thank you," and "[volunteering] is more in line with my personal philosophies."

The survey concluded asking the participants if their feelings regarding occasional, part-time work had changed after taking the survey from when they first began the survey. Four respondents indicated that their feelings had changed, one indicated that their feelings had not changed, and one indicated that their feeling might have changed. Participants who indicated that their feelings had changed stated that there were more opportunities than they had been aware of: "I didn't realize that there are so many opportunities to work from home," and "There are more opportunities than I realized, and more variety."

Social Security Disability Insurance Policies Regarding Alternative and Occasional Work are Not Easily Accessible or Well-Understood
The findings in this section are in response to Research Question 2.

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[7] It is possible that at least one participant misread this survey questions, as they indicated at another time that they engaged in work but it was not paid work.

Research Question 2: How do Social Security Disability Insurance policies impact the pursuit of alternative, occasional part-time employment by people with degenerative conditions?

In this section, our findings expand upon this research question to address not only how policies impact pursuit of employment but how individuals learn about SSDI policies.

In our survey, we asked participants if they were concerned about part-time, occasional paid work negatively impacting their current benefits. Three people indicated "yes," two people indicated "no" and one person indicated that the question was not applicable, because they did not currently receive benefits. In our interviews with professionals who provided education and counseling regarding Social Security Disability Insurance, participants indicated that people with degenerative conditions had to weigh the pros and cons of disability benefits with paid work and personal values and priorities. Professionals indicated that understanding and navigating SSDI regarding occasional, part-time employment could be complex and confusing.

Our interview participants explained how Social Security Administration oversees a wide variety of populations and programs, and how Supplemental Security Income (SSI) is different from Social Security Disability Insurance (SSDI), but that many people do not understand these differences. For example, P3 explained that SSI and SSDI are both very different and both are complex and P2 described how sometimes people fill in the SSI paperwork and then they need to start over when they realize that they actually need to apply for SSDI, and that often they need to have the difference between SSI and SSDI explained to them. P4 reports that people usually have family or friends help them find information about SSDI benefits because it can be difficult to understand and navigate the system. As a result of the complexity and confusion of the programs, there can be a great deal of misinformation and distrust of the Social Security Administration system, and about SSDI benefits in particular.

People who have acquired disabilities, and specifically people with degenerative conditions, have additional concerns regarding benefits beyond SSDI benefits, such as concerns regarding their ongoing healthcare and how their condition will impact family members' benefits and income. For example, interview participants discussed the Medicare wait period, which is dependent on receiving SSDI, and can impact people's timing and decisions regarding registering for SSDI. Similarly, long-term disability insurance and extended health insurance plans, such as COBRA, are also factors that individuals with acquired disabilities need to consider while learning about SSDI. P6 explains that individuals with degenerative conditions also need to consider the implications for any current or future home health care that they may need, which then has the potential to impact their caregivers' considerations about their own work and health benefits.

We see from the interview data that adults with degenerative disabilities not only need to navigate Social Security, but also healthcare systems and possibly private health insurance and/or private disability insurance systems. Understanding how these systems interrelate is imperative to individuals with degenerative conditions, but educational resources which explain how these systems relate to each other are scarce.

Interview participants referenced educational materials from Social Security as possible resources for their clients, such as the Adults Disability Starter Kit (*Adult Disability Starter Kit*, n.d.). Some participants used materials adapted for specialized groups, such as from the ALS Association, which combines information regarding health benefits with Social Security benefits and programs (*The ALS Association- Guide to Assisting Families with Obtaining Government Benefits*, n.d.). Interview participants also mentioned the Trial Work Period (TWP) as a possible option for adults who acquired disabilities mid-career, if they are seeking occasional, part-time paid employment. Three participants shared a Social Security publication regarding TWP as a potential resource to share with clients who were interested in learning about possible part-time employment and how part-time paid employment might impact their SSDI benefits (Social Security, n.d.).

However, for the most part, interview participants indicated that individualized counseling and education was needed for many clients to best explain the interactions between the benefit programs unique to each individual client.

When discussing accessibility of obtaining SSDI benefits, interview participants indicated that once an individual is aware that they need to register for SSDI, the registration process is relatively accessible and user friendly (available online, in person at an office, or via phone). Ongoing reporting is less accessible. If an individual wants to explore occasional paid employment through a program such as TWP, income reporting must be conducted via phone, in-person, or via postal mail. These reporting methods can be especially challenging for individuals with degenerative conditions who use assistive technologies for daily living.

Interview participants identified a need for more customized educational resources as well as more streamlined reporting. For example, one participant indicated that there currently is not any reliable way to calculate estimated benefits online. Another participant indicated that there is a lag between reporting income and receiving benefits, so that when an individual qualifies for and receives SSDI benefits, they may need to reimburse Social Security at a later date if they earned income during a reporting period but the extra income was not processed until months after it was reported. This time delay between reporting income and the processing of reported income can create additional hurdles for individuals tracking their benefits, particularly those who are engaging in occasional, part-time paid work.

Discussion

Our study sought out and analyzed data from multiple sources to provide holistic answers to our research questions. We have the perspectives from professionals who provide education and/or counseling to adults with acquired and degenerative conditions as well as the perspectives of people with degenerative conditions themselves. In addition, we draw on an internet-based search and literature from Human-Computer Interaction research to find possible employment opportunities and resources that neither of our participant populations had familiarity with. Based on our findings, we identify opportunities for possible actions by the Social Security Administration and possible opportunities for crowdsourcing platforms. We discuss these findings and their implications in the following sections: 1) Increase Online Education and

Outreach Regarding SSDI and Related Benefits, 2) Increase Education and Outreach Regarding Crowdsourcing Opportunities, and 3) Increase Accessible Wage Reporting Options.

Increase Education and Outreach Regarding SSDI and Related Benefits
Our findings from interviews with professionals who provide education and/or counseling on Social Security Disability Insurance benefits clearly show that they feel that the various policies regarding SSI and SSDI are complex and challenging to navigate and understand. The Social Security Administration (SSA) is a large organization, with nearly 60,000 employees and 1,230 field offices (*SSA Org Charts & Manuals*, n.d.). Within that structure lies Social Security Disability Insurance (SSDI), just one of several benefit programs administered by SSA. Individuals with a wide range of circumstances and disabilities access SSDI, and some of the complexity and confusion around SSDI benefits may be due, in part, to the wide scope of clients the program serves.

Adults who acquire disabilities mid-career, and in particular, adults with degenerative conditions who use assistive technologies, have unique needs and concerns and they may not easily identify or relate to some of the broader educational materials produced for the wide spectrum of potential SSDI recipients. For example, SSA has a starter kit available for adults to get started with Social Security disability benefits (*Adult Disability Starter Kit*, n.d.). While this starter kit can be valuable, it is, by necessity, generic and discusses the broad Social Security disability benefits appointment and determination process. The start of the kit explains "we sent you this disability starter kit because you requested an appointment to file for disability benefits" which implies that the individual has already known to apply directly for SSDI (rather than SSI) benefits. However our interview data indicates that people need guidance first in understanding the difference between SSI and SSDI to ensure that they apply to the correct program. Therefore this starter kit might not reach some of the people who need the most guidance (such as those individuals who applied to the wrong program).

The ALS Association has created their own starter kit to help assist families with obtaining government benefits which includes more targeted information relevant to the needs expressed in our interview data (*The ALS Association- Guide to Assisting Families with Obtaining Government Benefits*, n.d.). For example, the guide explains the difference between SSDI and SSI and provides basic information about Medicare. As described in our findings, adults with degenerative conditions seek out information regarding both health benefits as well as disability income benefits.

We realize that creating customized educational resources for people with different disabilities can be a challenge because SSDI beneficiaries include individuals with a wide range of ages, disabilities and needs. However, our findings indicate that the generalized educational materials are not meeting the needs of the population targeted in our study, which suggests that it is possible that the generalized resources may not be meeting the needs of other disability populations as well.

Therefore, we suggest that SSA consider contracting or partnering with national disability organizations to create targeted educational materials which can provide greater understanding of

SSDI policies and processes to potential beneficiaries. For example, SSA might hold an annual conference in which different disability groups are invited to attend. During the conference, SSA can provide educational outreach to the disability groups about new, existing, and updated Social Security disability policies and practices. In return, attendees could be chartered with crafting educational materials tailored to their representative populations about SSDI. A centralized website from SSA could include links to the various groups which in turn, directs people to resources that are tailored more specifically to their needs.

In this way, professionals who provide education and counseling regarding SSDI are able to stay current with SSDI policies and are empowered to create online educational materials tailored to the clients who they work with, better meeting the needs of their clients.

Increase Education and Outreach of Crowdsourcing Opportunities
Within the technology community, and specifically the Human-Computer Interaction research community, crowdsourcing platforms are relatively well-known and used (Howe, 2006; Kuek et al., 2015; Schmidt & Jettinghoff, 2016). However, emerging research has indicated that outside of the tech-community, crowdsourcing is not well known or well understood. A survey of 505 older adults (Brewer et al., 2016) found that the majority of participants had not heard of crowdsourcing or crowdwork, but expressed interest if the work was easily accessible and aligned with their personal motivations. The research from our study of adults with degenerative disabilities who use assistive technologies show similar results as those in Brewer et al.'s study. Work which aligns with personal motivations and values, as well as the accessibility of the work, are key factors for adults with degenerative conditions when deciding if they might pursue crowdsourced work opportunities.

Crowdsourcing platforms must assure that their work is accessible. Prior work has also called out a need for crowdsourcing platforms to assess and improve their accessibility to individuals with disabilities (Swaminathan et al., 2017). If crowdsourcing platforms are accessible to individuals using assistive technologies, crowdsourcing platforms can potentially benefit from a diverse population of workers who have a variety of skills.

Crowdsourcing platforms need to make the motivation for the work tasks transparent. Our research indicates that adults with degenerative conditions want to do things that are meaningful to them. If a work task provides information on the purpose of the task, a potential worker may be more likely to engage in the work if it is for a purpose or a cause that they believe in.

Our research suggests that crowdsourcing platforms should engage in outreach to broaden awareness of their employment opportunities. Our participants had little knowledge of crowdsourcing employment opportunities and may not have learned of those opportunities if it had not been for participating in this research study. Once crowdsourcing platforms have ensured that they are accessible to people with disabilities, we suggest targeted outreach to disability groups, disability employment resource centers, and to professionals who provide education and counseling regarding employment and disabilities.

Increase Accessible Wage Reporting Options

Our research indicated that the initial application for SSDI is available in a variety of formats: online, going to a Social Security office, or via phone. However, ongoing reporting of income is limited to phone, in-person, or via postal mail. Individuals who are unable to speak and/or independently move their arms or legs are restricted by these limited forms of reporting. We suggest implementing an online income reporting system to increase accessible reporting options, particularly for individuals who use assistive technologies. We understand that there are likely to be significant infrastructure costs for implementing such a system. However, we propose that ultimately, using an online income reporting system would not only assist SSDI beneficiaries but also improve the accuracy and turnaround time of processing benefits. Our research indicated that there is a lag time between reporting income and having that reported income processed, during which time a recipient might receive SSDI overpayments and then be required to pay back the overpayment after their reported income has been duly processed. It is possible that online reporting may cut down that lag time, improving overall efficiency and reducing time spent in reconciling overpayments.

We also suggest that it might be possible to combine online reporting options with online employment. A purpose-built crowdsourcing platform might include online income reporting to SSA via the same portal in which employees are paid for their crowdsource work.

Overall, our findings indicate that crowdsource work is of interest to adults who use assistive technologies and have degenerative conditions. We imagine that this type of work might appeal to many other adults who use assistive technologies and are unable to be engaged in full time employment, or who must work from home due to health reasons. In addition, with the onset of the COVID-19 pandemic, it seems clear that employment options for working from home are becoming increasingly important options to consider. Social Security Disability Insurance policies and educational materials will likely need to explicitly address these types of employment options in the future.

Limitations

This research study is exploratory and has a small participant population, therefore we caution that the findings and discussion in this report might not reflect the experiences and attitudes of a larger population. While the geographic distribution of participants is somewhat diverse, the majority of participants reside and/or work in the Western region of the United States. Different states have different incentives and programs regarding employment and disability, and we encourage future research to expand to participants from a greater number of states.

An additional limitation to this study was that the survey of participants with degenerative conditions was launched after COVID-19 was present in the United States. As a result, we were unable to recruit participants in the manner originally planned, because many individuals and organizations were occupied with COVID-19 related work. Therefore, our survey sample is primarily from the Western region of the United States and is a small sample size. We recommend redeployment of the survey to other regions of the United States after the COVID-19 pandemic is over or stabilizes.

Summary and Conclusion

We sought to understand the work opportunities available to adults with degenerative conditions who use assistive technologies and the implications those work opportunities may have for Social Security Disability Insurance policies. We had three specific research questions: 1) What types of alternative, occasional part-time employment opportunities are available for adults with degenerative conditions that meet their accessibility needs?, 2) How do Social Security Disability Insurance policies impact the pursuit of alternative, occasional part-time employment by people with degenerative conditions? and 3) What interest do people with degenerative conditions have in pursuing accessible, occasional work opportunities that meet their stated needs? Using an inductive approach, we collected primary data from three sources: 1) semi-structured interviews with professionals who provide education and/or counselling regarding Social Security disability benefits, 2) an internet-search of accessible employment opportunities, and 3) survey responses from adults with degenerative conditions who use assistive technologies for daily living.

Our findings revealed two primary themes: 1) options for accessible, alternative, occasional work opportunities are not well-known– but wanted, and 2) Social Security Disability Insurance policies regarding alternative and occasional work are not easily accessible or well-understood. As a result of these findings, we suggest that online education and outreach regarding SSDI and related benefits is increased and targeted to specific disability populations. We recommend that crowdsourcing opportunities are made more accessible to people who use assistive technologies and that education and outreach regarding crowdsourcing opportunities are targeted to disability groups. We also suggest that SSDI income reporting be made available online to increase the accessibility of reporting income and also to potentially increase the efficiency of processing reported income.

While this research study has a small sample size, many of our findings resonate with prior work. We hope that our research study provides additional insights into the perspectives of adults with degenerative conditions regarding employment. We also hope that SSA, disability groups, and crowdsourcing platforms are able to use this research to improve work opportunities and education regarding SSDI policies.

Acknowledgements

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Appendix A

Example of Survey Question Listing a Crowdsourcing Platform

Example 1: Upwork

One example of an online workplace is Upwork. Upwork allows freelancers to post their skills on their website and bid for projects. The work can be occasional and part time. Freelancers represent a variety of skills including: administration support, marketing, copywriting, engineering and more. More information about being a freelancer at Upwork can be found at their website (clicking on this link opens a new tab).

Appendix B

Lists of Alternative, Occasional Employment Options

Possible Alternative Work/Employment Resources Provided by Interview Participants

State Vocational Rehabilitation Agencies: https://askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm

Volunteer Match: https://www.volunteermatch.org/

United Way: https://www.unitedway.org/get-involved/volunteer

501 Commons (professional volunteering opportunities): https://www.501commons.org/

Social Security Redbook: https://www.ssa.gov/redbook/

Possible Alternative Paid Work Opportunities Based on Internet Search

Opportunity	Resource
Mechanical Turk	https://www.mturk.com/worker
Zooniverse	https://www.zooniverse.org/
Flexjobs	https://www.flexjobs.com/jobs/writing-editing-journalism
ProBlogger Jobs	https://problogger.com/jobs/
Website evaluation jobs	https://connect.appen.com/qrp/public/jobs/list
Website evaluation jobs	https://www.dreamhomebasedwork.com/lionbridge-work-from-home/
Work from home w/disability options	https://www.disabled-world.com/disability/employment/home/
Tutoring	https://www.thepennyhoarder.com/make-money/side-gigs/online-tutoring-jobs/
Transcription- Transcribe Me!	https://workhub.transcribeme.com/Account/Register
Transcription- Rev	https://www.rev.com/freelancers/transcription
Transcription- CrowdSurf	http://crowdsurfwork.com/get-started-on-work-market/
UpWork	https://www.upwork.com/i/how-it-works/freelancer/