

# Work Accommodations and Opportunities for Adults Who Have Developed Severe Physical and/or Communication Impairments and Use Assistive Technologies

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## **Abstract**

Maintaining employment can be extremely challenging for adults who develop or acquire a severe disability, such as a spinal cord injury or Amyotrophic Lateral Sclerosis (ALS). As a result, a severe impairment often involves not only physical and mental trauma to the individual, but loss of identity as an employed person. This research aims to determine the barriers and opportunities to continued employment for adults who develop severe physical and/or communication impairments. Through a qualitative methods approach, seven adults participated in semi-structured, in-depth interviews about their employment experiences before, during, and after their acquired impairment. In addition, an eighth participant responded to a survey based on the initial findings from the in-person interviews. Findings revealed four themes: 1) employee feelings of loss and regret at having to leave work, 2) employer attitudes significantly impact the ability to continue work, 3) employee's changing physical abilities impact both employer and employee attitudes and expectations regarding acceptable work productivity, and 4) requirements for future work are clear, opportunities for work are challenging. We also found that public policies and support systems impact employee and employer actions regarding continued employment. We conclude with a discussion focused on how public policy makers and employers can positively contribute to extending continued employment for adults who acquire severe communication and/or physical impairments.

## **Background**

The ability to speak with your voice is so natural that many of us take this for granted. However, the number of people worldwide who have severe communication impairments is estimated to be in the millions (Beukelman & Mirenda, 1992). These individuals comprise a diverse group of ages and diagnoses. It is not unusual for an individual with a severe and complex communication disorder to also have concomitant restrictions with movement in other parts of the body. For example, an acquired condition such as Amyotrophic Lateral Sclerosis (ALS) will commonly present with limited movement in the extremities along with limited verbal abilities. The combination of severe communication and physical impairments can make employment difficult

(McNaughton, Light, & Arnold, 2002; Odom & Upthegrove, 1997). However, assistive technology systems may provide support to ongoing employment in the form of work accommodations.

The field of assistive technology (AT) encompasses a variety of systems designed to assist individuals with both speech and physical access. Physical access may include wheelchairs, walking supports, joysticks, and head or eye controlled computer interactions. Specific to communication access, the field of augmentative and alternative communication (AAC) can encompass a variety of methods to augment or replace speech. People who use AT and AAC systems vary across all ages, diagnoses, and ability levels.

Existing research has established that people who use AAC and AT want to work, and that being employed, or even volunteering, can have positive impacts on mental health and quality of life (Johnston, Jongbloed, Stainton, & Drynan, 2014; Trembath, Balandin, Stancliffe, & Togher, 2010). However, a number of barriers prevent people who use AAC and/or AT from paid employment. Common barriers to employment for people with disabilities who use AT include transportation, physical accommodations, and discrimination/attitudinal barriers (Johnston et al., 2014; McNaughton et al., 2002). Secondary barriers include policies, both government policies regarding disability benefits, and employer policies regarding purchasing additional technologies/equipment for work (McNaughton et al., 2002; National Academies of Sciences & Medicine, 2017; Yeager, Kaye, Reed, & Doe, 2006). People who use AT can feel anxiety because they have not yet been able to find paid employment (Johnston et al., 2014). Concern over losing government funded benefits and pressure to find paid employment can cause additional anxiety to a population that already has their fair share of health concerns.

Working from home, or telework, is one possible solution to address some of these barriers. Limited research on working from home has shown that adults with a variety of physical impairments are able to work from home. However, while research has shown that telework can help with transportation and physical accommodations, it also can increase feelings of social isolation (Johnston et al., 2014; McNaughton, Rackensperger, Dorn, & Wilson, 2014).

Maintaining social ties through employment is important for adults who have developed or acquired severe physical and/or communication impairments mid-career. One study indicates that adults who developed Amyotrophic Lateral Sclerosis (ALS) and required augmentative-alternative communication systems (AAC) found that social and intellectual stimulation were important benefits of continuing employment during the progression of their disability (McNaughton, Light, & Groszyk, 2001). Research participants also stated that government policies, such as the Americans with Disabilities Act (ADA), can help them advocate for continued employment through provision of accommodations.

With constantly evolving technological advances, accommodations for continued employment for adults who develop severe physical and/or communication impairments might take a variety of forms, however, public policies do not always keep up with the rapid development of new technologies (National Academies of Sciences & Medicine, 2017). Balancing the need for social

and intellectual stimulation with the need for physical accommodations can be challenging for adults who have developed severe physical and/or communication impairments.

The majority of research in the field of employment and assistive technology includes a variety of disability populations, including congenital conditions, cognitive, vision, and hearing impairments. Workplace accommodations for one population are not necessarily the same accommodations needed for another population. In addition, the employment experiences may be different for different disability populations. There is very little research about the specific needs for adults who have developed severe physical and/or communication impairments while already employed, and who ultimately require assistive technologies. The motivation for this current research study is to have recent work which explores barriers and opportunities to a specific population: adults who acquired severe communication and/or physical impairments mid-career. This work is also motivated with the understanding that policy decisions and accommodations need to be informed based on research regarding the specific needs of specific populations.

This research paper is scoped to explore the experiences of adults who acquired severe communication and/or physical impairments mid-career, particularly those adults who require the use of assistive technologies. The aim of this paper is to provide employers and public policymakers with a better understanding of the employment barriers and opportunities available for adults who acquire a severe impairment mid-career.

## **Methods**

This study uses a qualitative, inductive methodology in order to achieve an emic perspective, in which the research reveals an insider's view of the phenomenon being researched. Qualitative, inductive research methods are well suited for emerging research topics (Bryant & Charmaz, 2007; Creswell & Poth, 2018; Glaser & Strauss, 2006; Patton, 2015). Patton describes qualitative, inductive analysis as: "generating new concepts, explanations, results, and/or theories from the specific data of a qualitative study" (p. 541). Inductive, qualitative research methods sample data until data saturation is reached. Qualitative research studies which include participants with severe communication and/or physical impairments typically use small sample populations. For example, saturation ranged from 5 participants to 16 participants in studies which utilized interviews or focus groups with adults who use assistive technologies for communication and/or mobility impairments. (Cooper, Balandin, & Trembath, 2009; Fresher-Samways, Roush, Choi, Desrosiers, & Steel, 2003; Johnston et al., 2014; McNaughton et al., 2002, 2001, 2014; Murphy, 2004).

The research study described in this paper utilized semi-structured, one-on-one interviews with participants to generate data related to opportunities and barriers for employment after acquiring severe impairments. All interviews took place at a time and place of the participants' choosing. Four interviews were held over Skype, in which one of those interviews was conducted primarily with the participant responding via writing in the chat window, due to speech impairment. Two interviews were conducted with caregivers present in the room for a portion of the interview.

Interviews were audio recorded (when applicable) and the researcher also took notes during the interviews. Data analysis occurred iteratively, utilizing a series of coding practices: open codes which lead to axial codes, which broaden to themes derived from the data analysis (Bryant & Charmaz, 2007; Creswell & Poth, 2018; Heath & Cowley, 2004; Kenny & Fourie, 2015; Olson & Kellogg, 2014; Patton, 2015; Tan, 2010). Using a coding approach to generate themes is used in a variety of research disciplines, including psychology, the social sciences and human computer-interaction (Braun & Clarke, 2006; Guest, MacQueen, & Namey, 2012; Paay, Kjeldskov, Howard, & Dave, 2009; Urquhart, Lehmann, & Myers, 2010; Wyche & Grinter, 2009). The iterative coding approach allowed the researcher to refine emerging codes and categories by using a method of constant comparison of data as it was generated, incorporating a process of reflection, refinement, and action during analysis and data generation (Glaser & Strauss, 2006; Markham & Dean, 2006).

To ensure that the researcher accurately captured data from participants, member-checking was conducted in two forms (Birt, Scott, Cavers, Campbell, & Walter, 2016; Cooper et al., 2009; Creswell & Poth, 2018). Emails were sent directly to the two participants who had caregivers present during the interview, to confirm the researcher's interpretation of their answers to specific questions. In both cases, the participants confirmed and/or added to the data collected during the interviews. The second form of member checking took place after initial analysis, in which the researcher had developed axial codes (Bryant & Charmaz, 2007; Creswell & Poth, 2018; Kenny & Fourie, 2015), abstracting the specific data from individual participants into broader categories. The axial codes were put in the form of statements in a survey, and participants were asked to rate their level of agreement with the statements. Three interview participants completed the member-checking survey.

Finally, to determine saturation and generalization of the findings, the survey was given to an additional participant who was not involved in the original interviews. In total, eight participants were involved in the research study, and data obtained from both the interviews and the surveys were analyzed using an iterative approach to develop the findings.

A second researcher contributed to the generation of broader themes, by reviewing axial codes and discussing open codes and axial codes with the primary researcher. These themes represent the findings of the research.

### **Research Participants**

Participants recruited for this research were specific to the scope of the project- adults who acquired or developed severe communication and/or physical impairments mid-career. For the purposes of this research, severe communication impairments are specific to speech and voice, in which the individual is unable to communicate verbally and be understood by others. Severe physical impairments are defined in this study as an impairment which limits an individual's mobility so that they are unable to independently walk and/or move their upper extremities without the use of assistive technologies. All participants had some form of assistive technology for daily living, including apps on tablets and smartphones, as well as dedicated forms of assistive technology.

Due to the sensitive topic of research, and the relative ease of identifying participants based on their impairment and employment, we protect participants' privacy by reporting gender, age, and diagnoses generally and not by individual participant. In total, seven participants were recruited to participate in semi-structured interviews. Two participants were males and five were females. Participant ages ranged from their 40's to 60's. Diagnoses ranged from progressive, adult-onset conditions such as Amyotrophic Lateral Sclerosis (ALS) or Primary Lateral Sclerosis (PLS) to injuries resulting from a car accident. Participants' specific demographic information related to inclusion criteria are listed in Table 1. Six interview participants were located in the Western United States, one interview participant was located in an English-speaking country outside of the United States.

**Table 1. Interview Participant Information**

Participant ID	Employment Type at Time of Impairment	Assistive Technologies Used	Ethnicity	Impairment(s)
P1	Legal	Alternative Computer Access; Wheelchair	White	Speech; Upper and Lower Limb
P2	Insurance	Alternative Communication Technologies; Walker; Scooter	White	Speech
P3	Engineering	Alternative Computer Access; Wheelchair	White	Upper and Lower Limb
P4	Engineering	Alternative Computer Access; Alternative Communication Technologies; Mechanical Ventilation	White	Full body, Speech
P5	Service	Wheelchair; Scooter; Alternative Communication Technology; Ventilation	Hispanic	Lower Limb; Speech
P6	Insurance	Walker; Alternative Communication Technology	White	Lower Limb; Speech
P7	Construction	Alternative Computer Access; Alternative Communication Technologies; Wheelchair	White	Full body; Speech

One additional participant (P8), located in the Eastern United States, completed a survey which was created based on the data obtained from the first seven participants. The purpose of the survey was to determine if the themes found in the interviews were applicable to people with severe physical and/or communication impairments in other geographic areas, and to determine if data saturation was reached. The survey participant was female, and her age fell into the same

age range of the interview participants. The survey participant also used a similar form of assistive technology and had similar impairments as the interview participants.

This research study was approved by the institution's Internal Review Board, and all participants provided consent to participate in the study.

## **Findings**

Our research is specific to participants who developed or acquired severe impairments mid-career. As a result, the majority of our findings reflect the experiences of participants with their employment at the time of the onset of their impairment. Only one interview participant was in-between jobs at the time of onset. All other interview participants were employed at the time of the onset of their impairment. The majority of interview participants attempted to maintain their original employment after the onset of their impairment. Two participants ended up switching to part-time work, primarily unpaid, (and continued to be engaged in those careers at the time of the interview). One participant decided to discontinue their job search as a result of onset of their impairment.

Despite a small participant population of eight total participants, data quickly revealed common themes between all participants' experiences. Four key themes regarding barriers and opportunities to employment emerged from analysis that are relevant to all participants' experiences. The four themes are described in detail, below. To protect participant privacy, we do not associate quotes or individual participant stories with specific participant identifiers.

### **Employer Attitudes Shape the Employee's Ability and Willingness to Continue Working**

Our findings revealed two distinct themes regarding employers' attitudes: supportive employers and unsupportive employers. The majority of our participants experienced supportive employers. However, in one instance the employer was initially unsupportive but became supportive with increased understanding of the employee's condition. In another instance, the employer continued to be unsupportive throughout the participant's employment experience.

Employer attitudes generally manifested through their engagement in providing accommodations to their employee. For example, one participant explained that initially, their direct manager did not approve an accommodation request when the participant was no longer able to easily walk up and down stairs. When discussing their request for work accommodations, the participant said:

*"That was kind of a rigmarole actually. My manager...became a real stickler about what technically my job entailed, which of course, there's that tricky catch-all 'other duties as assigned' ...so that's when I had to officially get HR involved and start documenting my conditions with them."*

In this participant's case, the Human Resources team assigned an internal case worker to the participant, and the case worker worked with the participant and manager to clarify why accommodations were needed. Over the years, the participant needed additional accommodations, including changes to the physical accessibility of their workspace as well as assistive technologies for computer access. Aside from the initial resistance for the initial

accommodation, the participant reports that additional accommodations were provided without any resistance or questioning by management.

This first participant story is an example of an initially unsupportive employer attitude becoming supportive based on an educational intervention. As a result, the employee continued to remain employed and happy with their employer and said the employer “*made sure I knew I had a job until I wanted to leave.*” The participant’s employer also provided flexible accommodations as the participant’s abilities changed, including the ability to work from home. The participant said:

*“That is absolutely the number one reason that I could work as long as I did... [to]conserve energy. Getting dressed is a whole thing, and then getting in a chair, and then getting to work...if they hadn’t done that [allowed work from home] I wouldn’t have been able to work as long as I did.”*

Other participants experienced supportive attitudes and accommodations from their employers from the beginning. One participant saying: “*My company was great about it. They were so awesome....anything I wanted, they were behind me 100%!*” In this participant’s case, their employer was supportive both in attitude and in accommodations. The employer provided continued accommodations as the participant’s physical abilities changed, including an internal job transfer to a less stressful position which also required less walking and was in a location that did not have stairs. In recognition of the participant’s skills, the employer continued to give the participant special projects to keep their new job challenging, as long as the participant wanted them. In addition, the employer provided accommodations to the participant’s work hours, which allowed the participant extra time to get ready for work and limited physical fatigue and stress.

In contrast, another participant experienced unsupportive employer attitudes which did not change. This participant had experienced significant impairments and had taken some time off as a result, after returning to work, the participant said:

*“My employer was not very encouraging to me. I guess they wanted to get rid of me. I was getting episodes of illness....and they just got tired of people having to substitute my position....I wasn’t secure. They weren’t warm and sympathetic....They weren’t encouraging and I needed a lot of encouragement to stay in my same field, just a lot of encouragement. It was too daunting to pretend like I could do everything like before.”*

In this instance, lack of support manifested in both attitudes towards the participant’s work and in their needs for accommodation. The participant felt that their employer’s attitude was a barrier to continuing work. The participant attributed some of their employer’s attitudes to inexperience in working with people with disabilities or significant illnesses. Regardless of the cause of the employer’s inflexible and unaccommodating attitudes, the result was an uncomfortable workplace environment for the participant. The participant stated “*If your office didn’t want to hire you or you were a pain in the butt, it’s not very pleasant.*” As a result of the lack of understanding, and lack of willingness to provide job accommodations and encouragement, the participant ended up leaving their employment. Another participant had a similar experience regarding employer expectations and lack of accommodations, saying, “*they didn’t offer anything and I didn’t have the resources [knowledge of assistive technologies and community*

supports] yet...I was specialized [in career choice] and realized that I couldn't continue, so I left with grace." In both of these cases, both participants explained that their job duties were specialized, and were heavily dependent on specific communication skills, which were affected by their impairments. As a result, both employer and employee attitudes highlighted significant barriers regarding job expectations and the participants' abilities to execute those job expectations. Neither of these participants reported that they were offered alternative career options or work duties, such as the internal transfer option that another participant was offered (as described earlier).

Overall, participants found that their employer's attitude impacted their ability to work. Employer attitudes are reflected both at the front-line managerial level as well as at the structural/organizational level. Employer attitudes manifest primarily in the form of offering work accommodations to the employee. Participants felt that if an employer was unclear or did not offer work accommodations, the results would be that they were uncomfortable continuing their employment.

### **Physical Abilities Affect Employee Attitudes and Expectations Regarding their Own Work**

Not only do employer attitudes directly impact employees' interest in and ability to continue work, but findings reveal that both employer and employee attitudes played a part in expectations regarding work productivity and competence. In fact, some participants judged their work productivity as harshly or more harshly than their employers.

One participant discussed how their own expectations of themselves significantly impacted their feelings of obligation to their employer. As the participant's physical abilities changed, they found that they progressively lost efficiency and productivity in doing their work tasks. Eventually, even assistive technologies were unable to compensate for the participants' expectations of their own work productivity. The participant explained, "*It was becoming harder. My hands don't work well anymore. I had Dragon [for alternative computer access] but Dragon doesn't work very well with spreadsheets, which was a huge part of my job.*" Despite being provided with accommodations, the participant felt dissatisfied with their competence when comparing their current productivity to productivity prior to onset of their impairment. Ultimately, the participant left employment because of their own expectations. The participant stated:

*"I feel like the only limitations and expectations were self-imposed, absolutely. They [employer] were happy to keep me in a limited capacity. It was my own work ethic that made me feel like it was time to leave. I wasn't as productive. They weren't getting their money's worth, as it were. It was never really any pressure I felt from them [employer]."*

Another participant also left work after acquiring their impairment, based on their own judgement of their abilities, stating: "*I gave up work because of safety concerns for myself and others I work with.*" In this case, the participant's job duties required physical demands that the participant felt they were no longer able to execute safely. Therefore, the participant discontinued their current job because of concerns not only for themselves but for the impact they might have on others' safety.

A different participant felt that their physical impairments affected their employer's attitudes regarding their competency, and as a result, the participant also judged themselves harshly based on the change in their abilities, stating *"my skills weren't what they used to be. I didn't feel as competent....I guess I was kind of ashamed, and...embarrassed."*

Yet another participant felt that they had no choice but to leave work, due to the nature of their job duties. This participant said:

*"I was forced to leave this very lucrative and intellectually challenging career because my speech was deteriorating...without an intelligible voice, I could not do my job. The frustration with not being able to talk is indescribable!"*

All participants had some form of assistive technology to help with their impairments. However, findings show that despite having assistive technologies, many participants felt that assistive technologies did not bridge the gap between their job performance pre-onset vs post-onset of their impairment. As a result, assistive technologies helped to get by with daily living and basic job duties, but the perceived deterioration in job performance negatively impacted participants' willingness to stay in the same career. In these cases, the employer's willingness to provide accommodations helped participants continue working only up to a point.

In this study, the majority of participants were as critical of their work abilities after onset of their impairment as their employers, and perhaps even more so. Participants put pressure on themselves by comparing their performance as an employee post-impairment with their performance prior-impairment. Even participants who were provided with work accommodations continued to feel dissatisfied with their work performance, particularly for those participants with degenerative conditions or impairments which impacted speech production. Ultimately, for the majority of participants, their change in physical abilities became the major reason they discontinued with the employment they had prior to acquiring their impairment.

### **Employees Have Feelings of Loss at Having to Leave Work**

All interview participants indicated that they stopped work (or stopped looking for work) as their choice, not being forced by anyone to make the decision. However, the majority of participants spoke of leaving their employment with a sense of significant loss. One participant explained:

*"I really didn't want to [leave work] because in society, so much of your identity is tied to what you do. How you justify your existence is with a paycheck...part of me still wants to have an answer to 'what do you do?'"*

The choice to give up working was not taken lightly by the participants. After exhausting a variety of work accommodations, including an internal job transfer, one participant finally ended work due to the significant impacts work had on their physical health, saying *"It was bittersweet. I knew that it would be better for me to quit [because of health]. But it was so hard to give up my career. But I knew that I could never continue."* Another participant also felt that the stress of work aggravated their physical symptoms which negatively affected their health, which contributing to their decision to leave their employment.

Despite choosing to leave work, participants continue to want to work and contribute to society in some way. All participants indicated they wanted to (or were continuing) to work in some form. A common expression was for a participant to say that they “*loved work*” and “*missed working*.” Many participants expressed a feeling of loss at having to end their careers earlier than intended. One participant explained, “*it’s not really regret, but I miss work. And I wish I was still there. I love what I did.*” Another participant explained that they were depressed after having to resign from work, particularly because they felt “*it wasn’t my choice.*” Participants did not choose to acquire their impairments, yet they did choose to leave their employment based on their physical condition and their perceptions of their job performance. Another participant explained they did not want to be a “*burden*” on society by relying on Social Security Disability. However, that participant was concerned at pursuing part-time employment because of concerns regarding maintaining consistent health insurance.

Findings revealed an underlying theme related to participants’ awareness of public policies and concerns regarding how public policies impacted employment and benefits. The majority of participants had assistance in learning about benefits, healthcare options, and public policies related to their acquired impairment and employment. Only one interview participant reported that they found out about Social Security Disability policies without the assistance of others. Most participants learned about disability benefits with the help of non-profits, medical staff, friends, or support groups. Some participants also felt that they had to make a choice regarding working full time or disability benefits- they were concerned that part-time paid work might negatively affect their ability to access benefits and healthcare. Consistent health care coverage was a particular concern for some participants who had degenerative conditions, in which consistent access to health insurance was viewed as critical, and prevented them from pursuing part-time work.

### **Requirements for Future Work are Clear, Finding Work which Meets those Requirements is Challenging**

With the loss of a career, participants explained that they wanted to fill that space with purpose. Many participants voiced a desire to work or volunteer in order to remain socially engaged in society, but simultaneously voiced concerns about their physical abilities to do so. One participant explained, “*I want to be helpful to someone for a little while...I’m just worried about what I can commit to.*”

Requirements for future work clearly emerged from participant interviews as well as survey data. All participants strongly spoke of the need for computer access for any future type of work they engaged in. One participant stating, “*paraplegics who want to be employed use the computer.*” Participants also indicated that future work would need to be flexible and relatively stress free, to accommodate their health needs and fatigue. Work requirements included work that was computer based, work that did not have hard deadlines or specific time dependencies, and work that could be done at home if needed. These requirements accommodate many participants’ physical needs and also alleviate the pressure and stress of performing at a level they might not be able to consistently achieve.

In addition, participants voiced a motivation for future work was to remain socially and intellectually engaged. One participant explained *“I want something to do. There’s nothing wrong with my faculties.”* Another participant stated, *“being of some intelligence, you get bored quickly. There’s only so much TV you can watch really.”* However, the majority of participants who are currently not working only had vague ideas of what type of future work they might engage in.

Two interview participants were able to find part-time, primarily unpaid, work as an alternative to their previous careers. In both cases, the part-time work was occasional and involved the support of family members and/or friends. Many other participants expressed interest in volunteering as an alternative to continuing with paid work. When asked why volunteering was more appealing than seeking out paid work, participants indicated that volunteering seemed more flexible and less stressful than paid work, thus they would feel more capable and their health was less likely to be impacted.

Overall, participants indicated a desire to continue engagement with society through some form of work, however, most participants did not have a specific work or volunteer opportunity in mind. When asked about online work opportunities, only one participant had engaged in taking surveys through a research service, in which they were paid very small amounts of money (less than \$1.00). However, that participant discontinued the survey work after one week because the surveys were designed to be completed by able-bodied, employed people, with questions regarding driving and employment. Other participants spoke of potential volunteering within their community or with organizations they had previously volunteered with, however, few participants had explored novel work opportunities which might be better suited to their changed abilities. Findings indicated that few participants had specific ideas of where to begin looking for alternative employment or volunteering opportunities.

## **Discussion**

While the participant population for this data set is small, and findings cannot yet be generalized to a broader population without additional research, such as a large-scale survey, the findings from this study reveal clear themes that indicate how employers and public policy makers can assist in removing barriers to continued employment for adults who acquire severe impairments mid-career. As a result, the discussion section is divided into two sections: 1) what employers can do, and 2) what public policymakers should consider. The purpose of this section is to place the research findings into actionable steps that can help reduce the barriers and increase the opportunities of employment for a population that wants to work: adults who acquire severe communication and/or physical impairments mid-career.

### **Employers Can Remove Barriers and Promote Employee Confidence**

Based on the findings, employers’ attitudes regarding employees who acquire severe impairments play a significant role in continued employment. Employers who provide a variety of work accommodations positively promote longer periods of employment for their workers. In addition, employers who provide assurances regarding the employee’s value as a contributor can also positively promote longer periods of employment. As a result, the following suggestions to employers are intended to promote these concepts within the workplace.

### Increase Education of Staff Regarding Disabilities and Accommodations

The participant sample in this study clearly demonstrates how employer attitudes significantly affect ongoing employment for adults who acquire impairments mid-career. Participants' experiences showcase the continuum of employer attitudes and the impacts that those attitudes had on participants' continued employment. In the case of one participant, the employer's lack of support, understanding, and empathy resulted in an uncomfortable work environment, in which the participant's own self-critique of work skills were exacerbated by the employer's expectations, resulting in the participant leaving employment. The participant speculated that the employer's lack of understanding was in part, due to "*no one had ever known anyone with a disability- they were all young and healthy.*" In this case, the employer's lack of education and knowledge regarding disabilities and workplace accommodations might have been a barrier to providing a more appropriate work environment for the participant.

Lack of education and understanding is also an issue for the participant whose requested accommodations were initially denied by their front-line manager. Unlike the previous participant's story, in this instance, the workplace human resources team provided education to the manager regarding accommodations. Educating the front-line manager not only resulted in providing the initial accommodation the participant asked for, but ongoing, continued support and additional accommodations as the participant's physical impairment progressed. These ongoing accommodations included both physical space accommodations as well as technology accommodations and resulted in the participant continuing employment. This example shows how education at the front-line managerial level can remove employment barriers.

Including regular, mandatory training for employees and front-line managers regarding disabilities and accommodations could help increase overall awareness and understanding within the workplace. These trainings should also highlight the potential for employees to acquire impairments, resulting in a need for accommodations even though no accommodations had been previously provided. By specifically calling out the special population of adults who acquire impairments, employees will be better prepared to understand that an individual's needs may change over time in the workplace. As a result, employers and employees may be more understanding and accommodating- ultimately resulting in longer periods of retention of employees.

### Provide a Variety of Accommodations for Improved Work Performance, Including Opportunities for Internal Job Transfers

While computer access was rated as an extremely high priority by all participants, technology accommodations for work were not the most prominent factors related to work performance, as revealed in the findings. Employer attitudes and accommodations related to employee fatigue as well as physical space and transportation needs were much more prominent indicators of continued employment. The variety of accommodations related to fatigue and physical space appear to address both physical and mental health needs, promoting overall employee health and well-being.

Two participants in this study were provided with a variety of accommodations throughout their employment, resulting in positive employee-employer relationships and extended employment

post-onset of impairment. In both cases, accommodations included physical space changes and flexible work hours. In one case, an internal job transfer to a less stressful job provided a much needed accommodation for the participant's health. In addition, the added accommodation of providing the participant with additional "*interesting*" projects served to recognize the participant's experienced skill set and demonstrated ongoing appreciation and value of the participant's contributions to the workplace. In the other case, the participant's ability to work from home when needed allowed the participant to conserve energy, which was put towards productive work time from home, rather than expending energy in transportation to and from the workplace. In both of these cases, the participants' employers demonstrated care, concern, and appreciation for the participants as employees. As a result, both participants spoke extremely highly of their employers during the research interviews, and both participants continued to work for as long as they felt they could physically continue working.

#### Provide Education to Employees Regarding Transition from Work to Social Security Disability

All interview participants who were on Social Security Disability, or were applying for Social Security Disability, had assistance in learning about their options for transitioning from work to Social Security Disability benefits. Participants who worked in larger organizations had specialists from their Human Resources department assist them by discussing benefits, health insurance, and the process of leaving work. Participants cited these specialized resources as extremely helpful. These participants also did not feel a rush or pressure to leave their employment, and expressed comfort and confidence in knowing that there were dedicated resources available to help them when needed. As a result, establishing an internal resource that employees can turn to for information about benefits and the transition to Social Security Disability can reduce anxiety, provide increased trust, and encourage a planned and thoughtful transition from employment for adults who acquire impairments mid-career.

#### **Policy Makers Can Remove Barriers Regarding Benefits and Alternative Work Opportunities**

While this study is small, saturation was easily achieved on themes regarding participants' attitudes towards work. This study highlights that adults who acquire severe physical and/or communication impairments mid-career, who also require assistive technologies for daily living, have common general attitudes towards employment. These findings indicate that it is possible, and probably very likely, that Social Security Disability policies should consider the different types of populations who require Social Security Disability. Many of the participants of this study acquired degenerative conditions, such as ALS and PLS, mid-career. Their attitudes towards employment and their needs regarding accommodations and benefits may be different from other populations. The following are suggestions for how policy makers can remove barriers to employment and benefits for the specific population of adults who acquired severe impairments mid-career.

#### People Want to Work- Help Them Work Without Losing Health Care and Benefits

Findings from this study resoundingly revealed that adults who acquire severe physical and/or communication impairments mid-career want to work in some capacity. All participants indicated a desire to continue work, although many participants opted for volunteering as a less

stressful and more flexible form of employment. Part-time work, or occasional work was less appealing to participants for a variety of reasons, one of which was concern regarding health care. Participants who require continuous, uninterrupted medical insurance were concerned about the idea of moving to part-time work, for fear of disruption to their health care benefits. One participant, who has a degenerative condition, indicated that they might feel healthier and be able to work part-time at some point in the future, but were concerned that if their health should suddenly fail again, the wait time to get back on Social Security benefits and Medicare might result in serious, or even fatal, consequences. The purpose of this research study was not to specifically investigate health care benefits for individuals on Social Security Disability, however, the topic of health care was brought up by the majority of participants. Reliable, consistent health coverage was clearly a concern for participants, and was a major element of concern in their transitions from employment to Social Security Disability.

Participants who acquire severe physical and/or communication impairments, and who require assistive technologies for daily living have a number of obstacles to overcome in order to work. Many of these obstacles are related to work tasks, work timing, and work location. Those obstacles can be addressed by employers. The obstacle of how part time or occasional work might impact health insurance and health care coverage can be addressed by policy makers.

#### Understanding and Accessing Public Benefits and Policies is Challenging- Help Make Accessing Information Easier

Only one interview participant who accessed Social Security Disability benefits did not have outside assistance in finding information about benefits and applying for benefits. All other participants had assistance from friends, non-profit organizations, or health care providers. One participant stated that finding information was “*not easy.*” Even the participant who was able to find out about and register for benefits on their own suggested that public offices should “*advertise availability of local SSD offices*” more widely, indicating that knowledge of locations and hours of local field offices and the resources that they offer is not well understood by the public.

Policy makers can encourage public programs to engage in broader education and outreach, by educating employers, human resources professionals, and increasing visibility and education via websites. Improved education and outreach will not only assist with increasing individual’s independence in accessing benefits, but will also help to educate beneficiaries on confusing issues, such as how part-time or occasional work might affect benefits and health coverage. Additional research regarding the website infrastructure and potential beneficiaries search patterns would be a stepping stone to improving education and outreach.

#### Policy Makers Can Support Employers to Provide Work Accommodations

This study shows how employers’ attitudes significantly affected an employee’s ability and willingness to continue employment after onset of their impairment. Policy makers have an opportunity to support employers who have employees who acquire severe physical and/or communication impairments mid-career. Policy makers can provide assistance to employers in the form of public policies and education about the variety of work accommodations employers

can, and should, provide to their employees. Existing public programs for employers can be made more visible and accessible to employers, with specific outreach catered towards both large corporations as well as small businesses. In addition, educating employers on the importance of creating an inclusive and accommodating environment towards disabilities, even when an employer does not knowingly have any employees who have disabilities, can help employees who acquire disabilities mid-career. Policy makers can also encourage employers to be creative in their accommodations, and highlight innovative forms of employment which accommodate employees with a range of abilities.

### **Limitations**

This study has a small number of participants. While it is common for interview studies and focus groups involving participants with severe physical and communication impairments to have small participant sizes, care should be taken in generalizing findings. In addition, the majority of our participants were located in the Western United States. However, one participant was located outside of the United States and the survey participant was located in the Eastern United States. Many of the themes listed in the findings applied to participants in all locations. The primary variations in findings were more likely to occur based on if a participant were still employed vs. not working or if a participant had a supportive vs. unsupportive employer. Therefore, this study provides a foundation of findings in which a larger study, such as a larger scale survey, could be deployed to confirm findings with a larger participant population. It is important to note that the findings of this study are limited to adults who have severe physical and/or communication impairments that were acquired mid-career, and that the participants all currently had some form of assistive technology available for daily living. The findings in this report are specific to that population, and findings cannot be generalized to other populations at this time. Additional research would be needed to compare and contrast these findings with a similar study which includes other populations of people with disabilities. The author also acknowledges that the discussion related to healthcare and public policy is entirely informed by information shared from the participants, and only reflects participants' impressions of public policy and benefits, rather than an analysis of the actual policies and benefits themselves. Investigation into specific public policies regarding benefits was beyond the scope of this study. The purpose of this study was to highlight barriers and opportunities perceived by the participants, and the findings and discussion reflect their attitudes and experiences.

### **Summary and Conclusion**

This qualitative research study explores employment opportunities and barriers of adults who acquire severe physical and/or communication impairments mid-career, and who use assistive technologies for daily living. Seven adults participated in semi-structured interviews and one adult, from a different area of the US, took an online survey. Using an inductive, thematic approach, findings reveal that participants want to stay mentally engaged and contribute to society through some form of ongoing work. However, employers significantly impact participants' abilities and willingness to continue with the careers they had prior to onset of their impairments. Employers who provide ongoing accommodations, including accommodations of technology, physical work space, flexible work hours, and internal job transfers are more likely to have positive relationships with their employees, and to have employees continue working as

long as they can. Employers who do not offer accommodations or provide internal job transfers are more likely to have employees leave work. While these findings regarding employer attitudes might not be surprising, they do highlight the need for ongoing education of employers on the types of accommodations that can be offered and the need for creative thinking around alternative work options for adults who acquire severe physical and/or communication impairments mid-career.

Findings from this study highlight the emotional toll leaving work has on individuals who acquire severe impairments mid-career. Future work should explore alternative employment options that meet the needs of these workers, who want to work, but currently do not have clear options that accommodate their physical and health needs.

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