

Research Brief



Lessons Learned from COVID-19: Spinal Cord Injury and Employment

A Human Development Institute Research Brief

Research Brief
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Introduction

The early months of the COVID-19 pandemic exposed virtually every aspect of our lives to rapid and unexpected change. Such major shocks to our systems were most acutely felt among populations that had already experienced vulnerabilities during so-called “normal times.” While exploring the impact of those shocks on distinct sub-populations is illuminating in its own right, it can also allow us to examine with greater precision the overall relationships among factors that may not be as static or as well-defined as we previously thought. In this study, we examined the case of Spinal Cord Injury (SCI) and employment and the early lessons that the COVID-19 pandemic (and the isolation it precipitated) had on shaping our understanding of work among people with SCI.

Introduction & Rationale

The early months of the COVID-19 pandemic exposed virtually every aspect of our lives to rapid and unexpected change. Such major shocks to our systems were most acutely felt among populations that had already experienced vulnerabilities during so-called “normal times.” While exploring the impact of those shocks on distinct sub-populations is illuminating in its own right, it can also allow us to examine with greater precision the overall relationships among factors that may not be as static or as well-defined as we previously thought. In this study, we examined the case of Spinal Cord Injury (SCI) and employment and the early lessons that the COVID-19 pandemic (and the isolation it precipitated) had on shaping our understanding of work among people with SCI.

Current estimates indicate that 288,000 persons in the United States are living with SCIs, and that there are 17,700 new cases of SCI per year (National SCI Statistical Center, 2018). Pre-COVID-19, approximately one-third of persons with SCI reported engaging in some form of employment, which is far below the labor force participation rate in the general American population of 63% (Bureau of Labor Statistics 2020).

Several researchers have identified factors predictive of employment for the SCI population. These include but are not limited to gender (males do better), race (whites fare better), education, self-advocacy, pre-injury employment history, networking, physical health, level of injury, and time since injury (Ottomanelli & Lind, 2009, Inge et al., 2018). Other factors have been shown to have negative consequences for employment, including: disincentives related to the receipt of public benefits; lack of accommodations; discrimination; and lack of motivation, often in response to the previous three factors (Inge et al., 2018, Marini et al., 2008). While many of these factors are static, others may be fluid and impacted by external conditions. The novel coronavirus, or COVID-19, drastically changed nearly every aspect of normal life beginning in early 2020. In the general population, we know that employment among women was impacted more harshly than it was for men, that African-Americans were disproportionately affected, that feelings of isolation and depression dramatically increased, that routine healthcare was delayed, that disincentives toward employment grew due to both business closures and relief programs, and that our education system was disrupted at all levels. Nearly all of these factors aligned with the reasons listed above for lower employment for persons with SCI.

Other factors may offset some of these challenges for persons with SCI. The ability to work remotely and/or virtually is something that persons with SCI may have been more familiar with than the general population, which is now often forced to adapt to this work model. So too are persons with SCI likely to be used to rapid changes in life situations and to more readily adapt to shocks to the system, so to speak.

Study & Method

During the late spring and early summer of 2020, we sought to discover how persons with SCI had their employment experiences impacted by the onset of the global pandemic. This method has been successfully utilized in previous research (Adams et al., 2021). The exploratory nature of the research question required a qualitative approach. A qualitative approach lends itself to understanding how the various contextual factors shape and influence a phenomenon (Conger, 1998).

A series of focus groups were conducted to explore this phenomenon. Focus groups allow for group interaction to explore insights collectively (Ho, 2006). The group interaction also allows for the generation and sharing of perspectives that might not be shared in one-on-one interviews (Stewart & Shamdasani, 1990). Three focus groups were conducted over a period of two weeks. The groups were conducted in late June 2020, almost three months after the start of the COVID-19 pandemic. On March 26, 2020, a 'Healthy at Home' executive order was put in place in the Commonwealth of Kentucky, which asked people to stay at home and limit in-person contact. By the end of June 2020, the order was concluded. At the time of the focus groups, participants had been at home for almost three months but also were aware that the re-opening was imminent.

The focus groups were conducted over Zoom, an online videoconference platform. Sessions were moderated by the research principal investigator (PI), who brought nearly 30 years of lived experience as a person with quadriplegia and made this known to participants at the start of each focus group. The PI is trained in both qualitative analysis and moderating group discussions. The focus groups also had two facilitators for monitoring the video conference platform chat feature and troubleshooting technology issues.

Participants

Participant recruitment was conducted through listservs. A message about the research study was sent to the Kentucky Congress for Spinal Cord Injury and the Kentucky Pilot State Paralysis Resource Center listservs. Participants who expressed interest were asked to complete a short screening questionnaire. The screening questionnaire described the purpose of the study; declared the study's risks; and ensured that participants met the study criteria (i.e., 18 years of age or older, had a spinal cord injury, resided in Kentucky, had internet access and were capable and willing to use it to participate in a virtual focus group, and gave consent to their participation being recorded). The first focus group session had five participants, the second had six participants, and the third had three participants. A total of 14 people participated in the research study.

Of the 14 participants, 11 were employed at the time of the focus groups. Of the three participants who

were not employed, one participant was unemployed and actively looking for work, one was a student, and another was retired. The participant who was unemployed lost her job because of the pandemic. Years since injury ranged from two years to 44 years. Of the 14 participants, four identified as male and 10 as female.

Data Collection and Analysis

The focus groups were guided by a series of questions related to the COVID-19 pandemic. The question most relevant to this manuscript was, “How has COVID-19 impacted employment for Kentuckians with spinal cord injuries?”

Focus group sessions were digitally recorded, transcribed verbatim, and saved as a Microsoft Word file. Participants were given pseudonyms in the transcripts to reduce bias. These pseudonyms are used in the results and discussion sections of this research brief. An open coding process was done as a part of the initial coding. The open coding process allows the researcher(s) to keep an open mind and approach the data without predetermined categories and themes (Ezzy, 2002). The textual data were read multiple times independently by each researcher. As a part of the initial reading, the researcher wrote headings within the textual data to describe and broadly sort the responses. After each review, the researchers convened to review the coding of the textual data and to collectively identify categories which were labeled with identified properties and finally merged to create broader themes.

Study & Method

Three major themes emerged from our analysis of the data. For ease of interpretation, we will refer to these themes as: Physical and Mental Health, Accommodations for Working Remotely, and Sustainability of Employment.

Theme 1: Physical and Mental Health

Participants discussed how normal routines that came with going to work every day were necessary to keep them in good health. Addison used a manual chair with e-motion wheels, and she was pushing it a lot when working at her office downtown. Because of remote work, Addison did not use her manual chair as much. River talked about how not going out and into a car impacted his physical health. He said:

My physical health has suffered a little bit from not getting out and getting into a car, going places...it's messed with my sleeping routine. I'm really lucky that I've been able to work from home. But it's kind of caused a lot of, I just feel a little more pain and things like that that I just noticed more, and I think it's... strictly because I'm not in a regular routine of just kind of going out into the community and doing things which kind of help to keep me moving.

Prior to the pandemic, Addison had a routine that involved getting up early. She not only went to work but also had to go to a rehabilitation center. With the pandemic, her routine was disrupted, and her health was impacted. Addison said, *“But now it’s all sort of gone and I sleep really late, and I stay up really late and don’t have anything I have to do at a particular time of any day. I’m eating fewer meals, I realized, because my sleep schedule is changed.”* Addison sustained a skin breakdown because her job required her to be in front of the computer in stationary fashion for extended periods of time.

As would be expected, participants talked about how remote work required them to pivot from in-person activities to virtual offerings, which presented mental health challenges. Participants mentioned how they were experiencing “Zoom fatigue”. While technology allowed participants to continue to do their work during the stay-at-home order, it also created an environment wherein people worked on their computers for extended periods. For example, Vinnie said *“I just stayed at the computer too much. You know, I’m sitting here eating my lunch, sitting here taking a break, sitting here constantly focused on this.”* Odell mentioned, *“In fact, there was almost more communication and more Zoom fatigue as a result of all of this.”* Coby, who has an outgoing personality, missed interacting with his co-workers and talking to people to help deal with the issues he was facing. Addison, who also has an outgoing personality and is a public speaker, also missed interacting with people and felt unmotivated to work.

Theme 2: Accommodations for Working Remotely

Being able to ask for and receive appropriate accommodations for working remotely took on added importance during this phase of COVID-19. For example, Lavern mentioned how she loved working from home because it completely fit her needs. Lindsey’s employer delivered a table that positively changed her experience working from home. Before the pandemic, she did not have a customized table, and working from home caused pain in her upper extremities. Lindsey’s employer also gave her a cell phone to make necessary client calls.

Working from home was often cited as an important accommodation as it allowed people to remain working safely. However, asking for this accommodation presented its own barriers. River worried about how long his employer might continue to accommodate him working from home. Lindsey was already working on paperwork asking to work from home as a reasonable accommodation; she could not risk working at an office building with many people. Lavern asked her employer for a modified work schedule, but she also noted that she felt uncomfortable asking for a special accommodation:

I did ask if I could come in on Tuesdays and Thursdays...work at home the rest of the days of the week...

It's really annoying because I want to feel normal and be treated normally and not feel like my injury really controls my life or my ability to control my life but then when it comes to circumstances like this, they do. I have to speak up. I have to...protect my immune system and because if I did get it, God forbid, you know, it could be pretty detrimental for my abilities. So that was really annoying, but I knew it was the right thing to do, to ask for those [accommodations].

Addison felt guilty that she would need to rely on her co-workers to provide personal support to her clients when her workplace was re-opened to a regular working mode. For Addison to continue to work from home in the long run, she would need to re-arrange the services she provided for her clients. She said, *"I don't feel like it's safe for me to be going into a big, crowded building...I know that it's going to impact my clients and that makes me feel kind of guilty."*

Theme 3: Sustainability of Employment

Several employed participants mentioned how they were not sure if they would still have a job in the future. Much of this stemmed from changes in the types of work being done and the disparate impacts of a changing work force. Some quotes are provided below.

"And I don't know if I can continue to work from home, we've been accommodated up to this point." (River)

"My place of employment, we are federally funded through grants...this continued downturn and lack of tax revenue will potentially impact my employment status." (Coby)

Sandy, a self-employed public speaker, mentioned how social distancing requirements had decreased her speaking opportunities. She said, *"... I do a lot of public speaking and that is primarily in high schools, middle schools, churches, and all of those have been closed. So, it's just pretty much been nonexistent for that period of time."*

Sage, who was actively looking for work, had lost her temporary job because it shut down due to COVID-19. She commented not only on how jobs were hard to find but also that the job opportunities in her community were not suitable. Sage said:

So right now, the only thing hiring is like production and maintenance and stuff like that. So obviously being in a wheelchair, I can't do production or stuff like that, but I did have the temp agency called me for one job to be the temperature taker. And I was all lined up to do that. And then they realized that I would be going up and down steps so that ruled that out.

Discussion & Conclusion

Undoubtedly, the global pandemic related to COVID-19 has had a major impact on virtually all members of society and in virtually every domain of people's lives. One of those domains is employment. It should be noted that our target population, persons with SCI, encounter all of the same issues that the general population does in relation to employment due to the pandemic. People with SCI also confront disability-specific issues related to mobility, access to technology, and health maintenance that need to be better understood by vocational rehabilitation professionals and employers.

The major themes of our qualitative findings included: the impact of disruption in a routine on physical and mental health, the importance of having the right accommodations including the ability to work from home, and the sustainability or uncertainty of work. As with many qualitative studies, there are limits to the generalizability of the findings due to the non-random sampling procedure, which in this case favored the experiences of those who were already employed.

Obtaining and retaining employment for persons with SCI is frequently a greater challenge than it is for the non-SCI population, even in normal times (Ottomanelli and Lind 2009). Our employed participants' desire to keep their jobs and the fear of losing their jobs cannot be overstated. Many spoke to the need for accommodations such as working from home during this time and the need to work from home even after their workplaces re-opened to on-site work. The Job Accommodation Network is an excellent resource for individuals to identify what kinds of accommodations are necessary within the realm of applicable laws and provides advice on how to ask for reasonable accommodations (www.askjan.org, Job Accommodation Network website). Now two years into the pandemic, these issues may have changed somewhat, but they also remain highly important as we reconfigure our work and personal lives to the "new normal."

Another major issue raised by several of our participants involved feelings of guilt over asking for accommodations. During a period of heightened unemployment, it may be the case that individuals think of their jobs as more expendable and thus do not want to be seen as someone who needs "one more accommodation." Most respondents spoke highly of their employer's willingness to provide accommodations, so a larger issue may be psychological in nature rather than pragmatic or legal. Similarly, respondents noted feelings of guilt related to requesting assistance from fellow employees as well as the ability to remain flexible for clients. This speaks to the mental and emotional toll of living through a pandemic with a SCI and the need for a more holistic approach to ongoing rehabilitation that addresses not only the physical needs but the psychosocial well-being of individuals with SCI.

Even when accommodations were available (as they almost always were) for individuals to work remotely, many participants indicated the negative consequences of changing their routines in this way. Things as simple as not pushing one's manual wheelchair further within the office and getting to one's place of business caused muscle weakness among some respondents. Others noted that the lack of regular movement caused skin breakdown. Respondents noted disruptions in sleep patterns leading to the inability to concentrate.

Respondents noted the need to move into different areas of employment. Abrupt changes in the labor market disadvantaged those with less diverse skill sets. The presence of SCI makes the acquisition of many jobs nearly impossible. Some respondents noted that they currently work in the public sector, and as public revenue decreases over time, they may have limited opportunities for the type of employment for which they have been trained. Even without a global pandemic, it will always be the case that workforce needs change over time. We must prepare people with SCI for a multitude of diverse employment outcomes (Cooney, 2016; Lindstrom et al., 2013).

Of course, one of the biggest fears during the time of this study for everyone was contracting COVID-19. As individuals return to on-site work, greater risks of COVID-19 exposure are the reality for everyone. However, reduced lung function, compromised immunity, and the inability to detect subtle changes in much of one's body all create a greater risk of a severe response to COVID-19 for people with SCI (Lopez-Dolado & Gil-Agudo, 2020). When faced with the risk of fully engaging with others in a workplace setting or elsewhere, persons with SCI, including those in our sample, have expressed reluctance to do so. Finally, the emergence of "long COVID," "post-COVID," and other more chronic factors remain largely unknown but will undoubtedly have long-lasting effects not only on individuals but also for employment norms and policies.

HDI Research Briefs highlight the research activities at the Human Development Institute. Projects at HDI focus on building inclusive communities, addressing inequities, and improving the lives of all people who experience disability across the lifespan. Research priority areas include: early childhood and education, leadership and self advocacy, employment, health, universal design and assistive technology. With each issue of HDI Research Briefs, we will provide a cross-section of HDI's research activities. The brief reports are intended to give an overview of the research and emphasize the implications of the studies.

You can find more examples of our research at www.hdi.uky.edu

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