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“It’s an Opportunity to get Opportunities”: A Brief Report on the Working Lives of Individuals with Intellectual and Developmental Disabilities During the Covid-19 Pandemic

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Plain Language Summary

The global pandemic has changed the lives of many people. It has also changed the lives of people with IDD. For many people, working is an important part of their life. Working provides the chance to achieve a desired quality of life. Currently, there is little known about the working lives of people with IDD. There is less known about how a pandemic impacts work. We used the psychology of working theory to frame our brief report. We conducted six interviews with adults with IDD across the United States. We used the theory to understand how participants make meaning of work. We used content analysis to examine our data. We looked for themes across participant responses. Results show the pandemic changed people’s work lives. Changes in work included reduced hours and loss of jobs. The pandemic also changed people’s personal lives. People had less access to social contact with family and friends. Results also showed participants wanted to work. At the end of the brief, we talk about what it means to make decisions based on risk. We also talk about ways to support people with IDD as they continue to work.

Individuals with intellectual and developmental disabilities (IDD) strive for similar life outcomes as those that do not experience a disability, such as active community participation, postsecondary education, and integrated employment (Shogren & Plotner, 2012). While in school, transition-age students with IDD often work with teachers to make person-centered, self-determined goals for the future (Claes et al., 2010; Park & Bouck, 2018). For many students with disabilities, including students with IDD, these goals often are focused on gaining employment (Sinclair & Poteat, 2020). Having opportunities to work provide a number of social benefits as well, including personal connection, economic benefits, self-pride and satisfaction, and an opportunity to learn (Lysaght et al., 2009). Ultimately, planning for adulthood helps an individual start preparing for the quality of life they desire (Cobb & Alwell, 2009; Morningstar & Clavenna-Deane, 2018).

Although young adults with IDD share the same employment aspirations as their peers without disabilities, the opportunities available to them are not equitable. Young adults with IDD continue to experience poorer post-school outcomes compared to peers with other disabilities.
or without disabilities (Lipscomb et al., 2017; Liu et al., 2018). There are multiple systemic factors (e.g., ableism, prejudice, ignorance) causing inequitable outcomes (Kocman et al., 2018). For example, current estimates report approximately 19% of all people with a disability were employed in 2019 in contrast to 66% of individuals without a disability (Bureau of Labor Statistics [BLS], 2020). These discrepant outcomes persist as new initiatives such as Employment First (i.e., laws and policies supporting competitive and integrated employment for individuals with IDD) are starting to make an impact on state and federal levels (Klayman & Coughlin, 2017). In addition, individuals with IDD continue to experience chronic rates of underemployment or unemployment (Kraus, 2017).

Furthermore, amid times of economic hardship and a global pandemic, individuals with IDD are likely to experience even more challenges attaining and retaining integrated employment. Within the emergent research about the employment experiences of individuals with IDD (e.g., McMahon & Cuskelly, 2020), there is no research available specifically about the working lives of individuals with IDD during times of a global pandemic. The present study sought to explore this novel situation by capturing the working experiences and perspectives of people with IDD during the COVID-19 pandemic in 2020.

Theoretical Framework

This qualitative study was guided by the Psychology of Working Theory (PWT; Blustein, 2006; Duffy et al., 2016), which considers the importance of work through an equity-based social justice lens, contextualizing work within systems of power for certain populations. The theory also centralizes human behavior and the life experience to an individual’s relationship with work. The PWT proposes three major functions of working: (a) social connection, (b) self-determination, and (c) power and survival (Blustein, 2006). Social connection encapsulates how individuals build community through networks and interpersonal relationships at work. Self-determination captures the motivating functions of work through extrinsic or intrinsic means. Last, power and survival convey the idea that work is a function of obtaining money in exchange for goods or services and provides individual status and power. While the PWT has a strong foundation in understanding the employment lives of individuals, it has limited research in its application to individuals with disabilities.

Method

This research brief includes data from a larger qualitative study using the PWT lens to describe how individuals with IDD make meaning of work (see Gilson et al., under review) and explores the extent to which the global pandemic has impacted their working experiences. The current paper provides follow-up data gathered approximately 1 year after initial data collection through the member-checking process (Lincoln & Guba, 1985; Creswell & Poth, 2018), which has not been included in any previous analysis or publication. Approval for this study was granted by the Institutional Review Board of Texas A&M University (protocol number IRB2019-0018D).
Setting and Participants

A total of 18 participants were recruited to participate in semistructured interviews for the original study. Participants were recruited through national disability organizations (e.g., University Centers of Excellence of Developmental Disabilities, Autism Society, National Down Syndrome Society) and convenience sampling. Inclusion criteria for the study consisted of (a) participants must have self-identified as someone with an intellectual or developmental disability, (b) had current or previous working experiences (i.e., within the last 6 months), and (c) were between the ages of 18-40.

Follow-up interviews related to the global pandemic were not part of the original study. After an IRB amendment was approved, the authors reached out to the original study participants for follow-up interviews. Six of the 18 participants agreed to participate in follow-up interviews; 4 identified as male and 2 identified as female. They ranged in age from 22 to 32 years ($M = 25$ years). Participants were from a diverse subset of the U.S. (Wisconsin, North Carolina, Wyoming, Nebraska, and Texas). Participants reported having intellectual disability ($n = 3$) or autism spectrum disorder ($n = 3$). One participant identified as Native American, and five participants identified as White. Four participants were working at the time of follow-up; two participants lost their jobs due to the COVID-19 pandemic. These interviews were conducted in June 2020, about 3 months after the start of the pandemic in the U.S.

Research Team and Positionality

The first author identifies as a White male with over 10 years of experience working with youth and young adults with disabilities in clinical and applied settings and holds a doctoral degree in special education. The second author identifies as a White female with prior experience as a secondary special education teacher and job coach for individuals with IDD and holds a doctoral degree in special education. The third author is a doctoral candidate in special education who identifies as a White female. The final author identifies as an Asian woman, a doctoral candidate in special education, and former special education teacher.

Procedures

A semi-structured interview protocol was developed to address two research foci (contact corresponding author for interview protocol). First, participants were asked to share how the COVID-19 pandemic impacted their work and life. Specifically, participants were asked (a) how the pandemic impacted what they do at work, (b) if they are still employed, and (c) if they view work differently because of the pandemic. Second, as part of the member checking process, participants were asked to confirm or expand upon how the authors defined the three major functions of working based on their initial interviews 1 year prior. Confirming the findings with participants allowed the researchers to validate the PWT for individuals with IDD. Follow-up interviews lasted between 11 and 39 minutes ($M = 20.2$ minutes).
Data Analysis

All interviews were conducted via phone, recorded, and transcribed through automated transcription software (Rev, 2020; Trint, 2020) with manual refinement. We analyzed the deidentified data using Dedoose (2020), a web-based qualitative data analysis software. All participants were given pseudonyms, which are presented in the current paper. Utilizing a qualitative content analysis framework, data were analyzed for deductive and inductive codes. Deductive coding allowed for the authors to review the data that aligned with the three major functions of work within PWT. Inductive coding allowed for the lived experience of individuals with IDD to emerge through the data as the participants navigated work through the COVID-19 pandemic. Coding procedures followed Saldaña (2016), including individual coding of participant interviews, in-depth consensus meetings and reconciliation of differences, and reflexive memoing. The first two authors coded all the transcripts and met to establish consensus and develop themes.

Results

Impact of the Pandemic

The pandemic altered participants’ experiences in numerous ways—some more drastically than others. Regarding the act of working, there was no one common experience held by all participants. The COVID-19 pandemic impacted each participant’s work experience uniquely—with participants reflecting on a loss of job, loss of hours, and even loss of community at work. Two participants, Nicholas and John, lost their jobs indefinitely. Two other participants were able to keep their jobs, but only after losing their jobs for a couple months at the beginning of the pandemic. Another participant, Shelley, had her work reduced from 5 days a week to 3. Last, for Michael, circumstances beyond his control, including a move across country, resulted in his loss of job.

Nicholas discussed the hardships and challenges of unemployment. He stated “something I’ve been suffering from recently is a lack of opportunities. And that’s because I don’t really have a job. I’m not coming into contact with people. I’m not going to training. I’m not at a workplace.” Michael discussed what his state of mind was being a job seeker during the pandemic. In his follow-up interview, Michael reported looking for jobs was difficult and that he was unsure if he wanted to obtain a job or wait until after COVID-19 was under control, stating “I’m still looking. I’m not dropping my stuff down. I’m looking and it’s going to work out. It’s just going to be... I may wait until after the whole corona thing is over to look for more jobs.”

Last, those who were currently working discussed other changes at work including having to use safety precautions (e.g., wearing a mask) while at work, which they all disliked. Beth responded to the question, “do you like wearing the mask,” by saying “I have to. But do I like it? No.” In addition, Shelley remarked how she lost connections with co-workers because they quit, “They actually quit the job. I lost three of my coworkers that worked hard...It’s just too much for them, and because of the virus.”
The pandemic altered the participants’ lives in other ways as well. Participants discussed how their personal lives were impacted by not having access to important social activities, including seeing friends, going shopping, participating in Special Olympics, and attending church. John was reflecting on his lack of access to friends, and how that has impacted him, mentioning “I mean, it’s been hard just because I’m usually a very social guy and like to hang out with people in person.” John also reflected on the work life dichotomy. “It’s just honestly been kind of crazy with the whole pandemic. Just not able to hang out with people...still being able to actually work, but not able to just hang out with people.” Furthermore, participants were impacted close to home, with some participants, including Beth and John, reporting being unable to see their family members.

**Psychology of Working Theory**

Participants reflected on the meaning of work when prompted to discuss the three major functions of PWT (a) social connection, (b) self-determination, and (c) power and survival. Within the construct of social connection, participants reflected on a shift in their abilities to develop strong relationships while working during the pandemic. Reflecting on his experiences of having a disability and the impact the pandemic had on his social connection, Nicholas shared, “…especially for us, if we have more limited opportunities elsewhere, our best friends that we have, might be at work since that’s where we go every day.” Nicholas, articulated how working provided a critical space for relationship building, Shelley suggested that work provided an opportunity to connect and engage with others—creating strong relationships, stating “Probably, like, get to know people better.” Seamus’ remarks also encapsulated the meaning of social connection because through his work he could create relational networks. Seamus enjoyed work because he got to “help other workers” and because of “teamwork.”

Within the self-determination construct, participants found that working provides strong intrinsic rewards and is a motivating driver for their life. Sam was passionate about how he envisioned his future and was motivated to take advantage of upcoming opportunities if his job ended for some reason. “You're almost enabled or empowered to do something else, to go somewhere else or try something new. I think that work is an amazing opportunity. It's an opportunity to get opportunities.” Shelley mentioned why she was so motivated to work: “[It is] real helpful in my life. And it makes me happy.” Beth mentioned her drive for work was due to the people she worked with. “I have the best job coach. And that drives me to go to work.... Best people at work, too.” Michael, who had moved and lost his job was motivated to find a job and expressed not wanting to “look lazy” because he was not working.

Last, within the power and survival construct, participants discussed how jobs were critical to their independence and continued way of life. John talked about how getting two jobs after being let go of his previous job allowed him to keep making car payments. Michael also reflected on the importance of having a job even though he currently did not have one, stating bluntly, “Honestly. Because you’re going to have to have money” [referring to the need of a paycheck]. Seamus aligned with Michael, mentioning how his paycheck from work allowed him to send birthday cards to people.
Discussion

The pandemic’s impact on participants’ employment experiences consisted of hour reductions, loss of jobs, and other minor changes to working life. In addition, a theme found across discussing the pandemic and PWT with participants was a desire for social connection. Participants’ social interactions were negatively impacted not only by their own personal employment changes but the loss of social connection because of coworker changes as well. Another important finding was, even during a pandemic, participants affirmed that employment was a motivating factor in their lives. Participants were self-determined to engage in work and look for work.

Supporting Individuals’ Rights to Work During a Pandemic

Employment provides opportunities for social connection, self-determination, and power and survival. Therefore, if an individual strives to work, even amid a pandemic, it is suggested to provide them the dignity to take the risk of working if they are determined to do so. Dignity of risk refers to the need to provide opportunities for individuals to take risk that may provide subsequent enhancement of quality of life (Marsh & Kelly, 2018; Perske, 1972). For example, although individuals with IDD are at an increased risk of dying from COVID-19 compared to individuals without disabilities (FAIR Health, West Health Institute, & Makary, 2020), yet higher risk individuals, including those with IDD, may be among the first to receive the vaccine (Rabin, 2020). When supporting the right to work, individuals with IDD should be presented with risks and given agency to make informed decisions.

Implications for Developmental Disability Organizations

Evolution of job preparation will be critical to meet the changes in expectations set by employers to function within a new era during and post-pandemic. First, educators and service providers will have to find ways to support individuals with IDD during the pandemic through tailored supports and services. This may include social stories for mask wearing, video modeling for handwashing, and practicing job preparation skills through alternative means (e.g., video interviews). Future research can investigate the feasibility and application of research-based employment skill strategies using virtual modalities. In addition, the pandemic presents issues and barriers to traditional information sharing, building strong interdisciplinary partnerships with other community agencies can expand access to information and support the dissemination of employment and COVID-19 related information. Last, it is strongly recommended that developmental disability organizations disseminate information to their communities in a culturally responsive and timely manner because of the ever-changing nature of the pandemic.

References


