Health and Quality of Life among People with Intellectual and Developmental Disabilities and Direct Support Professionals during the early United States COVID-19 Pandemic

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Plain Language Summary

COVID-19 has harmed people with intellectual and developmental disabilities (IDD). It has also harmed the Direct Support Professionals (DSPs) who support them. We did a study to learn how quality of life changed for people with IDD and DSPs during the pandemic. We did interviews with 18 people with IDD and DSPs. People who did interviews said their quality of life mostly got worse because of isolation and having fewer resources. Some people talked about ways their quality of life got better. We hope this study helps researchers and providers support people with IDD and DSPs during pandemics.

Abstract

People with intellectual and developmental disabilities (IDD) and the direct support professionals (DSPs) who support them have faced unique risks to their health and quality of life (QoL) throughout the COVID-19 pandemic. We sought to understand how COVID-19 has influenced QoL and overall well-being among these populations. We conducted a rapid qualitative inquiry study with a sample of people with IDD and DSPs (n = 18) to gain deeper perspectives about QoL and well-being during the pandemic. Participants described that changes in QoL were typically negative and influenced primarily by reduced socialization and impacts on health and independence; however, participants also described the ways their interactions and mutual support for each other helped to preserve some aspects of QoL. Participants described how racism and publicized acts of racial violence contributed to their COVID-19 experiences, and offered descriptions of

resources they benefited from, and those they lacked, during this time. Study findings have the potential to inform the development of policies and best practices that support people with IDD and DSPs during and following similar infectious disease emergencies.

Introduction

The SARS-CoV-2 (COVID-19) pandemic has affected health and quality of life (QoL) for individuals and families particularly in the United States. As of May 31, 2022, over 83 million U.S. citizens have tested positive, and over 1 million have died of COVID-19 (Centers for Disease Control and Prevention [CDC], 2022). Individuals with intellectual and developmental disabilities (IDD), and particularly those who also represent other marginalized communities, have been disproportionately impacted by COVID-19; 59.1% of adult individuals who identified as having a disability have tested positive for COVID-19 compared to 49.1% without a disability (Ryerson et al., 2021). Between 7 and 8 million people in the U.S. have some type of IDD (Larson et al., 2018). People with IDD face substantial risks during disasters and emergencies (CDC, 2015; Flanagan et al., 2011). Various biomedical, behavioral, social, and environmental factors have contributed to the disproportionate representation of people with disabilities in COVID cases and mortality (Turk et al., 2020). For example, among patients of health care organizations seen during the first 10 months of the pandemic, patients with IDD were more likely to be diagnosed with COVID-19 (OR = 2.59), to be admitted for inpatient services (OR = 2.74), and to die from the virus (OR = 5.91; Gleason et al., 2021).

Increased prevalence of chronic disease and secondary health conditions in people with IDD, along with barriers such as reduced access to health care (Krahn et al., 2015), increase their risk of developing severe complications if they do contract COVID-19 (CDC, 2020; Turk et al, 2020). People with IDD may require support to implement preventive hygiene measures, like handwashing, that are known to reduce illness (Courtenay & Perera, 2020). Receiving such support may increase their risk for exposure by placing them in close proximity to care workers and others who provide support; however, practicing distancing and, therefore, *not* receiving such support, may also increase their risk. Further, ableism may have influenced medical triaging decisions in the early months of the pandemic; people with disabilities and older adults were reported to be less likely than people without disabilities and younger individuals to receive ventilation when staff, hospital beds, and equipment were short (Andrews et al., 2021; Chen & McNamara, 2020; Solomon et al., 2020).

The disproportionate spread of COVID among individuals with IDD has been tied to living and working conditions that place individuals in close proximity and with minimal protections. For example, data from the early stages of the pandemic showed that on average, 43% of states' deaths due to COVID-19 occurred in long-term care facilities where people with disabilities, older adults, and other vulnerable community members are more likely to reside (Lau-Ng et al., 2020). Similarly, individuals with IDD living in other congregate settings such as group homes have had a significantly higher case fatality rate than those with IDD who did not live in congregate settings (Landes et al., 2021).

Beyond the immediate risks to their health, people with IDD may also be at risk for worsened social and behavioral outcomes, like diminished QoL, resulting from the pandemic and guidelines in place to help reduce its spread (Andrews et al., 2021; Courtenay & Perera, 2020). QoL is a broad and multidimensional concept that involves the subjective perception of one's satisfaction with their life and living experiences (Karimi & Brazier, 2016). There are numerous models and frameworks for understanding and assessing QoL; generally, the concept is comprised of multiple domains including overall life satisfaction, career and vocational experiences, social experiences, and independence or autonomy (Brown et al., 2013; World Health Organization [WHO], 1997). The ability to be independent, socially interactive, and productive play a major role in QoL for people with IDD (Schalock & Keith, 1993). Having adequate professional support is known to enhance QoL and overall well-being for people with IDD (Friedman, 2018). Direct support professionals (DSPs) take on a range of roles supporting the maintenance of health, well-being, and independence of the people with IDD they support. For example, they support individuals with IDD to engage in self-care; access medical care; engage in social, educational, and vocational endeavors; and live independently or however they choose.

Professional support may be reduced as DSPs contract COVID-19 themselves (National Association of Direct Support Professionals [NADSP], 2020). Indeed, DSPs are another high-risk population due to their "front-lines" contact with others at risk (CDC, 2021). In one study, 41% of DSPs reported that they supported someone who contracted COVID-19 and 47% reported work-related exposure to at least one client or coworker who contracted COVID-19 (Hewitt et al., 2021). In addition, many DSPs receive inadequate pay, lack adequate sick and family leave, and are likely to be un- or under-insured (Houseworth et al., 2020; President's Committee for People with Intellectual Disabilities, 2017). They have increased levels of work-related stress and depression (Gray-Stanley et al., 2010), and during the pandemic, have reported increased fear of contracting COVID-19 at work and transmitting it to their families, resulting in decreased ability to cope with life stressors and increased isolation (Embregts et al., 2021). These factors compounded contribute to high turnover rates in the profession, which have only increased since the pandemic began (Houseworth et al., 2020).

People with disabilities and their DSPs are likely to experience unique QoL risks as a result of the COVID-19 pandemic. Recently published research has explored the effects of COVID-19 on a number of social and health outcomes for people with IDD and DSPs separately (Embregts et al., 2021; Lake et al., 2021); however, qualitative approaches that explore and integrate perspectives from people with IDD *and* their DSPs have not been used. Our study sought perspectives about QoL among people with IDD and DSPs resulting from the COVID-19 pandemic. We aimed to explore how people with IDD and DSPs described the experiences they had during the COVID-19 pandemic that affected their QoL and overall well-being. Schalock and Keith's (1993) QoL framework, initially developed specifically with individuals with IDD, was used as our guiding conceptual framework. This framework is comprised of four domains: Personal Life Satisfaction, Work Competence & Productivity, Empowerment & Independent Living, and Social Belonging & Community Integration.

Methods

This study was an RQI study designed to uncover the perspectives and needs of people with IDD and their DSPs during the COVID-19 pandemic. Qualitative methods, including RQI, are suitable when research questions attempt to (a) understand contextualized processes, relationships, and specific experiences (Morrow, 2007); and (b) develop substantive conceptualizations of specific events or phenomena (Smith et al., 2009). RQI is an applied research method designed to quickly develop, usually in less than several weeks, a preliminary understanding of a complex and often rapidly changing situation (Beebe, 2014) and, as such, was well suited to this study. The goal was for each participant to complete two interviews: one during June or July of 2020 and one during September or October of 2020; this decision was made to attempt to capture qualitative data about changes that occurred over time as the COVID-19 landscape rapidly changed.

Sampling and Recruitment

This study was approved by the university IRB prior to participant recruitment. A purposively selected sample of people with IDD and DSPs who participated in a previous survey study were invited to participate in this qualitative study. We purposively sampled participants to represent the heterogeneity of the population of individuals with disabilities and DSPs and allow us to access "information-rich cases" (Patton, 2002, p. 230). Specifically, interviewees from historically marginalized and underrepresented racial and ethnic communities were contacted first to join the interview study given the ways that COVID-19 has disproportionately impacted these communities. Participants with disabilities were encouraged to have a support person attend the interview with them if they chose.

Research Team

The research implementation team was comprised of four individuals. The lead researcher was a White female UCEDD faculty member in public health with training and experience in qualitative research and working with individuals with disabilities and their families and caregivers. The other three researchers were graduate students: one Black female master's student in public health with a focus in epidemiology; one Asian female master's student in public health and social work with a focus in community-engaged research and services; and one White female doctoral student and former LEND trainee in public health with a background in kinesiology and adapted physical activity.

Participants

We conducted initial interviews with 18 individuals in June and July of 2020, and conducted second interviews with 16 of these participants (2 participants were lost to follow-up, representing an 88.9% retention rate) in September and October of 2020. One audio file (second interview with Participant 008) was corrupted and could not be transcribed; therefore, it was

removed from the analytic sample. The final analytic sample included 33 interviews (18 Time 1, 15 Time 2) with 18 individuals (9 identified as people with IDD and 9 identified as DSPs). Demographic information for the qualitative study participants is found in Table 1.

Table 1

Demographic Data for Qualitative Interview Participants

Participant ID	Gender	Age	Race/ ethnicity	DSP or person with IDD	Interview 1 length (M:s)	Interview 2 length (M:s)
001	Female	34	Black	DSP	18:57	12:09
002	Male	24	Asian	DSP	34:55	40:04
003	Female	60	White	DSP	34:15	36:51
004	Male	24	White	IDD	34:15	36:51
005	Male	39	Black	DSP	33:28	19:14
006	Male	38	White	DSP	34:24	35:34
007	Female	48	Black	DSP	25:06	24:17
008	Female	23	Latinx	IDD	27:19	--
009	Male	25	White	DSP	26:28	20:13
010	Female	24	White	IDD	36:38	--
011	Female	28	Latinx	IDD	31:58	20:23
012	Female	29	White	DSP	23:58	13:47
013	Female	25	Black	DSP	19:20	19:56
014	Male	33	White	IDD	46:01	32:18
015	Male	28	White	IDD	23:21	14:11
016	Male	25	White	IDD	29:02	32:06
017	Male	60	White	IDD	44:18	43:06
018	Female	26	White	IDD	36:36	--

Data Collection

The research team conducted rapid semistructured interviews to gather participants' perspectives. The study design was conceptualized to maximize access and safety; therefore, interviews were conducted using video conferencing so that the people with IDDs, DSPs, and interviewers did not need to be in the same physical location to engage with each other. Processes recommended for RQI studies, such as team immersion, team-based interviewing, and regular peer debriefing were integrated at all phases (Beebe, 2014).

Two interviewers were present for each interview. The majority of interviews were conducted with individual participants; however, two participants, a young man with an intellectual or developmental disorder (IDD) and his mother who works professionally as a DSP and also supports him, opted to interview as a dyad. Initial interviews lasted on average 31

minutes and 7 seconds, and second interviews lasted on average 26 minutes and 44 seconds (see Table 1 for interview lengths). The initial interview guide is provided in Table 2. Second interviews asked for updates on the same concepts as the initial interview, as 2 months had passed. The interview guide for second interviews is available from the authors upon request.

Table 2

Interview Guide: Initial Interview

Question	Prompts
1. Can you talk me through what a day in your life looks like now, during the pandemic?	
2. Overall, how are you doing right now, during the pandemic?	• What has been going on where you live- in your town or neighborhood? • How do you think your racial and/or ethnic identity has influenced your experiences during the pandemic?[a] • What have been some of the major effects of COVID-19 for you? Tell me briefly, then we can explore each area.
3. When I say, "quality of life," what does that mean to you?	• Where does that definition come from? • What helps you think about how you define quality of life?
4. How has the COVID-19 pandemic affected your quality of life?	• How has it affected your independence? Your employment? Your productivity? Your life satisfaction?
5. How do you think the COVID-19 pandemic has affected *the people with disabilities that you work with* -OR- *the professionals that support you*?	• What changes have you noticed? • What do you think causes these changes?
6. How has your relationship with *your clients with intellectual or developmental disabilities* -OR- *with the professionals that support you* changed as a result of COVID-19?	• Do you see each other more? Less? • What has been hard about your relationship right now? • Do you find yourself providing/needing support in new ways? • Do your clients/professional supports have the same or different racial/ethnic identity as you? Do you notice changes in your relationship based on race/ethnicity?[a] • Describe ways that you and your supports have helped <u>each other</u>. How has that made your life better?
7. What resources have you been using to navigate the pandemic? What resources are you missing?	• How do you access these resources? • What resources do you think people with IDD need to prepare better if something like this happens again? • What resources do you think DSPs need to prepare better if something like this happens again?
8. Is there anything else you would like to talk about that you think is important for me to know?	

[a] Questions that were added after the initial interview with Participant 002.

As is required for RQI studies, all team members met weekly throughout the data collection process to debrief interviews and discuss any changes to the interview guide based on data collected. Following the first interview with Participant 002, during which the participant discussed at length the challenges he faced as an Asian American during COVID-19, the research team collaboratively decided to add two interview questions specifically related to race and racism to the interview guide.

Coding and Analysis

Qualitative interviews were analyzed using a qualitative content analysis approach consistent with RQI guidelines (Beebe, 2014; Mayring, 2000). The two members of the research team each independently open coded the first five interview transcripts. These two study team members engaged in peer debriefing (Lincoln & Guba, 1985) to determine a final set of codes and develop the study codebook; all members of the research team reviewed the codebook before moving forward. One team member then coded all interviews based on the codebook. Once all data were coded using the codebook, one team member engaged in a final round of coding and theming using focused and descriptive coding (Saldaña, 2016), and engaged in a diagramming process (Buckley & Waring, 2013) to condense and combine codes that linked with each other across interviews, and to eliminate codes that faded out (Charmaz, 2008).

Qualitative Rigor

We applied a number of techniques to enhance the study's methodological and interpretive rigor (Lincoln & Guba, 1985). We used a member checking process to improve the study's credibility; within 1 week following each interview, a study team member emailed a two- to three-paragraph summary of the interview to each participant and asked the participant to confirm or correct it to ensure it accurately reflected the perspectives they shared during the interview. Summaries were generated from interview transcripts and the interview team's detailed field notes. All summaries were verified by participants without revision. We also enhanced the study's credibility by engaging multiple coders who represented different disciplines and theoretical orientations, which is a form of data triangulation (Beebe, 2014).

Results

Five major emergent themes were found in the data, including: (1) *Impacts of COVID-19 on QoL,* (2) *Relationships and Mutual Support,* (3) *A Dual Pandemic, (4) Resources and Supports,* and (5) *Change Over Time.* Each major theme also included subthemes, italicized and described below. Illustrative participant quotes support each theme or subtheme.

Theme 1: Impacts of COVID-19 on QoL

Participants described a number of ways they felt COVID-19 impacted their QoL and that of others with whom they live and work. Participants with disabilities and DSPs alike described

the general impacts on their *overall wellbeing*. Nearly all participants expressed feeling *uncertainty*, which was a major contributor to their increased stress and frustration, particularly among people with IDD. One DSP commented:

> *I think there's just a lot of confusion. I feel confused and don't really know the right answers, um, and the right things to do. We don't know when this is gonna be over, and I think that's amplified for some of the folks that I work with that process things differently. (Participant 012, DSP)*

Similarly, a participant with IDD expressed needing to "know how long it is, or something. 'Cause I'm very picky about that lasting forever" (Participant 004, person with IDD).

Two participants with IDD described experiencing reduced wellbeing, and that they found themselves spending time primarily on "video games" and "sleeping" because there is "nothing else to do" (Participant 004, person with IDD). DSPs described feeling stressed and "very tired" (Participant 001, DSP). Interestingly, many participants also expressed a *common humanity* and sharing that even though they were feeling negative impacts, they recognized their privilege compared to many other people. For example, one participant described, "Physically and mentally, I'm in a better place than a lot of people" (Participant, 002, DSP). A DSP who manages other DSPs mentioned:

> *I feel guilty at times because of what [other] DSPs are doing day to day. They're doing much more work than I am and carrying much more stress than I am… it's been a guilty time and a lot of that guilt is rooted in maleness, and cisgender, and Whiteness—all of those things. (Participant 006, DSP)*

Other common subthemes associated with Theme 1 included *impacts on socialization and recreation* and *impacts on health and independence*. Every participant described not having access to the same level of socialization (e.g., "missing friends" [Participant 011, person with IDD], "not being able to visit my family" [Participant 007, DSP]), and recreation (e.g., "I miss going out to dinner" [Participant 003, DSP]). All participants also described effects on their mental health, and many mentioned the need for emotional support resources (described further under Theme 5).

Theme 2: Relationships and Mutual Support

Participants were asked about how their relationships with each other had changed during the pandemic, and how they found themselves providing and receiving mutual support. Many participants described that they felt their relationships had not changed. Some reported *positive changes*, such as deepening relationships with the families they work with. One DSP described:

> *Talking to this other person about their loved one's health complications has just gotten me more involved in the families in a way I had not been in the past. Even though some of those things have been frustrating, the experiences have*

all been positive relationship-building experiences. (Participant 006, DSP)

Other participants talked about changes in their relationships they found to be *challenges*. For example, one participant with IDD described that because of the nature of moving to virtual supports and meetings, he felt like his "case manager's barely there" and that his "mom helps a lot more than [his] case manager" (Participant 004, person with IDD). This participant also mentioned that he feels like his mom is around more because she is working from home, but she's "always working all the time and [he feels] more lonely."

Participants described how they have found *mutual support* with each other (i.e., between people with IDD and DSPs). The DSP, who is also a parent of an individual with IDD, described how technology has been a barrier for her during the pandemic, but that her son with autism has been able to help her navigate technology while she has been helping him to keep a schedule and a positive mood.

> **Participant 004 (IDD):**   *[Participant 003] tells me to get up sometimes…
> when it's like something important.*
>
> **Participant 003 (DSP):**   *And [Participant 004] helps me tremendously with
> the technology.*

Many participants explained that at the foundation of this, mutual support has been "working together and learning together" (Participant 001, DSP). As Participant 007 (DSP) described, "You're probably gonna hear this a million times…. We are all in this together."

Theme 3: A Dual Pandemic

One of the most profound findings from the study was that most participants openly engaged in discussions about, in the words of one participant, the "two pandemics" of COVID-19 and racial injustice co-occurring in the U.S. (Participant 005, DSP). This discussion emerged unprompted by researchers during the initial interview with Participant 002; the team later added two questions to the interview guide to ask participants explicitly about how they perceived *race and racism* to play into their pandemic experiences. One participant, an Asian-American man working as a DSP, described how the pandemic has been racialized publicly and at the national level as a "Chinese and Asian virus," and, after hearing "stories and concerns of his Chinese and Asian-American friends," being in a constant state of "fear for [his] physical safety…fear of being attacked, of being called racialized, disease-related slurs" (Participant 002, DSP). This DSP described a time when one of the individuals he supports (a White male with IDD) asked him questions about whether he has ever traveled to China and commenting that he loves to eat Chinese food, which he perceived as a *racial microaggression* and felt detracted from his professional relationship with that particular individual.

One Black participant described how the "dual pandemic" impacted him personally and professionally; he expressed wishing he could "go out there and protest," but did not feel comfortable doing so knowing that Black individuals experienced higher risk for the virus

(Participant 005, DSP). He also expressed that he informed his supervisor he could not perform a job task (i.e., conducting face-to-face visits) because he knew his risk was heightened and he did "not want to put the other person at risk."

A participant who identified as Puerto Rican described that she had thought about the stress of navigating the "dual pandemics" of COVID-19 and police brutality. She expressed knowing that "half of police killings are people with disabilities," and that "it's different for Black people, you know, because they have to worry about police brutality and worry about the police" (Participant 008, person with IDD). Last, several White participants expressed that this has been a time of *learning and education about Whiteness, privilege, and racism* for them: "I am slowly learning about White privilege" (Participant 010, person with IDD).

Theme 4: Resources and Supports

Participants identified a number of resources they used, and a number they needed, during the first 4 months of the COVID-19 pandemic. *Technology* was the most frequently mentioned resource that almost all participants found helpful toward maintaining their work, social life, and "sense of normalcy" (Participant 011, person with IDD). Technology, though, was also perceived as a challenge, in that it was "a big learning curve" for people who were not frequent users and some individuals with IDD (Participant 003, DSP). It was also mentioned that many people lacked access to technology, which could exacerbate issues in communities that were already experiencing increased risk during the pandemic. Another resource that was considered both a benefit and a challenge for participants (particularly DSPs) was *personal protective equipment* (PPE). Participants 002 and 006 mentioned how important it was to have access to adequate PPE; however, these participants as well as Participants 009 and 011, mentioned that there were shortages of PPE in their areas and that this situation was really stressful for them to navigate both as care workers and people receiving support.

Resources that participants *frequently used* included the Centers for Disease Control and Prevention/World Health Organization COVID safety guidelines (Participants 001, 003, 006, and 012); informational webinars for DSPs and people with IDD (Participants 005, 008, and 010); financial assistance through government and other formal supports (002 and 008); relying on other people, including friends, family, coworkers, and counselors for emotional support (Participants 002, 005, 006, 008, 009, and 011); social media (003 and 004); and food and hygiene supply delivery services (Participants 007 and 009). Resources that participants mentioned they *needed or wished they could access* included a "well-funded federal pandemic response team" (Participant 002), and relatedly, better preparedness services, warnings, and procedures to help ease uncertainty (Participants 001, 002, 004 and 008); and additional supports/hotlines for mental health and emotional support (Participants 002, 005 and 008). Two DSPs specifically mentioned needing more staff at all times: "We were just underprepared when it came to staff" (Participant 013). Last, participants were asked to identify resources they thought might be specifically beneficial for people with IDD. Responses included access to financial support (including federal pandemic unemployment and webinars about savings accounts to prepare for emergencies in the future; Participants 005, 008, and 011); access to safe and reliable

transportation (Participant 003); and news and other information presented in more accessible or universally designed ways so that it is easier for people with IDD to understand (Participant 012).

Theme 5: Change Over Time

Interviewing most participants twice—once in summer and once in fall 2020—allowed us to ask participants about changes that occurred over at least 2 months of the pandemic. Participants shared different perspectives about how their QoL had changed, or not, over these months. Several participants reported *positive changes:*

> *I guess they've gotten better in the sense that we're just kind of settling into, we've just kind of adapted to, to this being the normal for now. Um, it's not easy and some days, you know, are harder than others, but I think overall, like I said, we're just kind of adapting to the fact that this is what life is gonna be like. (Participant 011)*

Interestingly, several participants (especially DSPs) reported *changes in employment* that impacted QoL changes over time. Participant 013 (DSP) was "working 12-hour shifts," supporting individuals with IDD who were not able to leave their homes, which caused significant behavior issues among residents, when we first interviewed her. She reported that she left that job and moved to a new state, closer to her family, which immediately improved her QoL. The previous position was more stressful than being temporarily unemployed for this individual.

Participant 009 (DSP) stayed at the same job but shifted from a live-in position to a non-live-in position; as a result, this participant reported, "I feel like I've been able to engage more when I go to work." Participant 002 experienced the opposite change—he moved from a non-live-in position to a live-in position. He reported that

> *Living where I work have decreases the everyday risk of exposure in my opinion. Um, because I'm not living with others, I'm living with adults with developmental and intellectual disabilities and with other DSPs.*

Participant 003 (DSP) reported that her caseload had quadrupled: "They got rid of all the DSPs. Um, and now I have close to 40 people by myself." Last, Participant 016 (IDD) got a new job that was more flexible, which made his QoL "definitely better."

Discussion

Our study used a rapid qualitative inquiry approach to investigate the impact of COVID-19 on QoL for people with IDD and DSPs, and the specific factors contributing to QoL changes during the pandemic. We conducted qualitative interviews to gain more information about factors contributing to QoL and overall health and well-being during the pandemic among people with IDD and DSPs. We used Schalock and Keith's (1993) QoL framework to guide interpretation of findings across the following domains: Personal Life Satisfaction, Work Competence &

Productivity, Empowerment & Independent Living, and Belonging & Community Integration. Findings are contextualized below.

Effects on Individuals with Intellectual and Developmental Disabilities

QoL is largely influenced by an individual's interactions with systems of support including their families, health and educational institutions, and communities. Given the disruptions to everyday life caused by COVID-19, it was no surprise that participants described declines in each of the four domains of QoL present in Schalock and Keith's (1993) framework. For example, individuals with IDD described effects on their *overall wellbeing* and overwhelming feelings of *uncertainty* that contributed to their decreased Personal Life Satisfaction. This finding aligns with findings from prior qualitative research suggesting that COVID-19 overwhelmed the daily lives of individuals with IDD, which led to feelings of stress and frustration that would affect overall life satisfaction (Lake et al., 2021).

For individuals with IDD, one of the domains of QoL that was described at length by all participants was Work Competence & Productivity. Individuals with IDD who discussed changes in their employment, education, and productivity reported that when they were unable to work or attend school, or had reductions in hours, they were spending their time sleeping and playing video games, which contributed to their decreased QoL and overall well-being. Interestingly, this finding seems to be unique to our study as it was not described in other scholarship describing the impacts of COVID-19 on individuals with IDD (e.g., Courtenay & Perera, 2020; Lake et al., 2021).

A reduced sense of Belonging & Community Integration was attributed by participants to *impacts on socialization and recreation*—participants with IDD felt isolated during both interview timepoints and described missing their friends, family, and typical activities. Feeling detached from community life and subsequently experiencing reduced mental health was a theme found in prior research in this population (Embregts et al., 2021; Tromans et al., 2020). Social isolation during the pandemic was certainly not unique to individuals with disabilities but may be more pronounced in this community in part due to their increased risk for isolation and limited social support structures even pre-pandemic (Lippold & Burns, 2009).

Effects on the Direct Care Workforce

Although there has been substantive research exploring the effects of the pandemic on individuals with IDD, less research has focused on understanding how the pandemic affected the individuals who support them. The DSP workforce is largely comprised of women who were underpaid, isolated, may be working multiple jobs, may have lacked family and sick leave, and who worked with multiple members of health-vulnerable populations (e.g., people with disabilities, older adults) each day (Hewitt et al., 2021). Our study concludes that because of these factors and others, DSPs also experienced declines in the four domains of QoL represented in the study's conceptual framework. Some of the more notable emergent findings in our study were the factors that DSPs described as impacting their Belonging & Community Integration. The

impacts of COVID-19 and the simultaneous widely publicized acts of violence against Black and Asian Americans, in particular, was salient for several DSPs. Concerns for personal safety for DSPs of color affected opportunities for socialization, recreation, relationships, health, and independence beyond the effects experienced by those of the general population, leading to decreased feelings of belonging and community integration and overall decreased QoL.

Limitations

The present study was not without limitations. We did not collect socioeconomic status data from participants; such data may have helped to tease out important demographic differences that may impact QoL. All of the interview participants lived in Georgia, likely due to the location of our UCEDD and our sampling and recruitment strategies. Because of the lack of statewide safety measures implemented in Georgia throughout the pandemic, findings from our study are likely to be context-dependent and may differ from similar research conducted in other states. Despite these limitations, the study makes a novel contribution to the burgeoning literature addressing the impacts of COVID-19 among members of the disability community and the individuals who support them. Our study design allowed for us to explore changes in QoL among both populations. We used several approaches to strengthen the study's methodological and interpretive rigor (Onwuegbuzie & Johnson, 2006, p. 57).

Implications for DD Network Members and Member Organizations

Our study findings have the potential to broadly impact policies at the local, state, and federal levels that determine how resources and supports are allocated during emergencies to vulnerable populations, including people with IDD and DSPs. For example, ensuring that accurate and balanced information about the pandemic, including community transmission rates, testing and vaccination sites, vaccine consent forms, safety guidelines and recommendations, and other critical information, is consistently provided in plain language and easy-to-read versions across multiple modalities (e.g., web, print, radio, TV, etc.) is a health equity issue, and a legal and ethical requirement that has not been fully met during the COVID-19 pandemic (Courtenay & Perera, 2020). Initiatives such as the Georgia Institute of Technology Center for Inclusive Design and Innovation's *Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities* project (https://cidi.gatech.edu/covid) worked to translate medically accurate and non-partisan COVID-19 information into plain language and other accessible formats. However, such material needs to be *originally released* in these formats, rather than being translated after their initial release, so that people with disabilities have access to the same information at the same time as individuals who do not have disabilities. DD Network member organizations, and UCEDDs in particular, should work to ensure that local information dissemination activities around COVID-19 are accessible to the disability community.

Increased efforts to ensure the safety and ability to maintain health and well-being for people with disabilities and their caregivers by the government and companies that employ DSPs are also needed now, and in the future. Although hazard pay and access to sufficient PPE were provided by some employers, these resources were not mandated and were not provided equally

for all essential patient care workers (Hewitt et al., 2021). Participants in our study—particularly those who identified as members of racial and ethnic minority groups—described how lack of access to these resources affected not only their physical health (i.e., risk for contracting COVID from, or transmitting COVID to, vulnerable patients), but also the emotional and psychological consequences associated with consistent feelings of vulnerability at work. Although FEMA and the CDC provided *recommendations* to provide these resources for protection, U.S. systems of care lacked sufficient measures to ensure that the guidelines were being adequately followed (Hewitt et al., 2021). This is a policy issue that DD councils and protection and advocacy organizations should consider working to address.

Relatedly, additional efforts to ensure the safety and well-being particularly of Black, Asian, and other minoritized care workers are overdue. National Alliance for Direct Support Professionals (NADSP) has hosted a series of "Black DSPs Matter" webinars throughout the pandemic that have highlighted the issues that DSPs of color working in IDD service systems have faced throughout the COVID-19 pandemic, and practical solutions that can be implemented by organizations that employ DSPs (https://nadsp.org/tag/black-dsps-matter/). State DD Networks might consider amplifying this work within their states and using evidence-based strategies (e.g., collective impact) to push research, practice, and policy forward in this area.

Conclusion

At the current stage of the pandemic during which the Delta and Omicron variants have been rampant in several U.S. regions, and as we continue to experience surges nationwide, we encourage researchers to continue exploring how COVID-19 has affected health and QoL among people with IDD and DSPs. Collecting similar data now, nearly 2 years since the second timepoint in our study, would illuminate changes over a longer period of time and inform researchers, practitioners, and policymakers of resources needed by individuals with IDD and DSPs over the long-term.

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