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Original Article

# Examining the effects of the COVID-19 pandemic on community engagement for people with mobility disabilities

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## ABSTRACT

*Background:* The COVID-19 pandemic and subsequent mandates upended community participation in the United States. People with disabilities were often more vulnerable to the adverse effects of the pandemic. Some areas of community participation affected for this population include employment, access to transportation, and social engagement and connection to others.

*Objectives:* The purpose of this study was to explore the effects of the COVID-19 pandemic for people with mobility disabilities across a variety of topics related to community engagement including social interactions with family and friends, and access to caregivers, groceries, transportation, and employment.

*Methods:* A survey was administered to participants with mobility disabilities ($N = 39$). Participants were asked to elaborate on topic areas that they identified as being affected by the COVID-19 pandemic. Data analysis included descriptive statistics and a content analysis in search of themes from open-ended responses.

*Results:* Results indicate that access to family and friends was the most negatively affected topic related to participation, followed by access to food and groceries, transportation, employment, living independently, caring for others, and participating in the community in general. In response to these pandemic-related challenges, participants reported utilizing technology to connect with others and to get essential items delivered.

*Conclusions:* Findings from this rapid research emphasize the need for emergency preparedness strategies, accessible and reliable resources related to technology use (e.g., Internet), and continued access to services for people with disabilities to maintain various aspects of community participation throughout the COVID-19 pandemic and in the future.

The COVID-19 pandemic and subsequent social distancing mandates have severely and disproportionately affected the lives of people with disabilities compared to those without disabilities.[1] Although these mandates were enlisted to prevent the spread of the virus and protect individuals from infection, many people with disabilities have been unable to adhere to social distancing mandates for a number of reasons including (a) residential situations (e.g., group homes, institutions), (b) the need for outside services and supports (e.g., personal care assistants), (c) being employed as an essential worker, or (d) the need for accommodations that conflict with health mandates such as wearing a mask.[2] The

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disproportionate impact that these mandates have on people with disabilities illustrates the social and environmental barriers that are the foundation of the social model of disability.[3–8] The social model of disability states that the experience of disability is not rooted in an individual but rather in interactions between a person and their physical and social environments. It is the continued existence of these disabling environments (shaped by social conventions, political policies, and built environments) that keep people with disabilities marginalized.[7,8]

The emerging inequalities for people with disabilities in relation to the continuation of the COVID-19 pandemic are not unprecedented. For example, research exploring the effects of Hurricane Katrina indicates that approximately 38% of the people who were unable to evacuate safely were either people with disabilities or those taking care of someone with a disability.[9,10] Although limited data have been collected specifically on the impact of pandemics for people with disabilities, previous research indicates services such as access to caregivers, service providers, and accessible communication have been disrupted.[11,12] Overall, limited research has been conducted on the experiences of community-dwelling people with disabilities, and virtually no research has been conducted that focuses on emergency preparedness for those receiving home- and community-based services.[13]

There is an immediate priority to implement high-quality, rapid research efforts to explore the ways in which people with disability are affected by COVID-19.[13–15] Among those in the public health field, concerns are shared over the social distancing mandates in place given that social isolation and loneliness are strongly associated with anxiety, depression, and suicide attempts.[14,16,17] Identifying the socioeconomic and psychosocial effects of the pandemic allows researchers, service providers, policy makers and health care professionals to develop strategies for continued support for the duration of the pandemic for people with disabilities. Such efforts also serve to prepare and mitigate the effects of future emergency situations for people with disabilities.[14] Therefore, the goal of this research study was to implement rapid research to document the effects of the COVID-19 pandemic on people with mobility disability across a variety of topics, including access to family and friends, access to essential items (e.g., groceries), employment, and access to transportation.

## Method

This study was implemented amidst an on-going intervention by the Research and Training Center on Promoting Interventions for Community Living (RTC/PICL). The PICL project is a multi-faceted intervention aimed at improving home usability and community participation for people with mobility disability in conjunction with Centers for Independent Living (CILs). CILs are community-based nonresidential agencies that provide advocacy and independent living services for people with disability. The PICL study was underway when the COVID-19 pandemic began in the US in March of 2020. Thus, interventions efforts were temporarily delayed, and the research team obtained approval by the University of Kansas Institutional Review Board to recruit and administer a survey to identify the effects of the pandemic and subsequent social distancing mandates for current PICL participants. Recruitment for this COVID specific survey was limited to individuals already enrolled in the PICL intervention, which included participants with mobility disability, the most prevalent disability among all disability groups in the U.S.[18] Participants met the inclusion criteria for the study if they indicated any difficulty with one of three upper and lower body mobility items from the Washington Group Extended Set on Functioning.[19] While all participants experienced mobility disability many participants also experienced co-occurring disabilities (e.g., blind/low vision). Three partnering CILs that recruited a sub-sample of current participants were located within three communities located in the Midwest and Northeast regions of the U.S. Participants were compensated $25.

### Measures

The goal of the survey was to document the effects of the COVID-19 pandemic and social-distancing mandates for people with mobility disabilities. Participants responded to items inquiring about the effects of the pandemic on their ability to engage in their community, including (a) employment/education; (b) access to transportation; (c) access to family and friends; (d) access to groceries and food; (e) access to personal assistance services; and (f) their ability to live independently. Participants were also queried about their access to health care, with those responses reported elsewhere (Goddard et al., 2021). The survey items asked how the COVID-19 pandemic had affected participants' employment/education; access to medications, medical supplies, and medical providers; food/groceries; personal assistance services; friends/family; and transportation, and responses included "*not changed,*" "*become worse,*" "*improved*", or not applicable. If participants responded with worsening or improved conditions, they were prompted to elaborate on their conditions with open-ended responses.

### Data collection

Participants were given the choice of completing the surveys online (n = 23) or receiving a telephone call from a researcher for phone administration (n = 16). The online surveys were provided via email with a link, and the participants were prompted to provide electronic consent before completing the survey. For the surveys administered over the phone, the researchers obtained verbal consent and entered the participant responses in the online survey form. The open-ended responses were transcribed in real-time and read back to the participant to confirm accuracy.

### Data analysis

Descriptive statistics were calculated for the demographic responses and initial survey responses to the community engagement items. Survey responses to the open-ended questions were tabulated and are presented below in order of topic areas which were most negatively affected by COVID-19 pandemic to least negatively affected regarding participation in the community. Four members of the research team identified and cross validated key illustrative quotations. In addition, the research team conducted a content analysis in search of any additional themes beyond the survey's topical areas, with technology as a response strategy emerging as a separate theme.

## Results

### Participants

CIL staff recruited participants (N = 39) to complete surveys inquiring about the effects of the COVID-19 pandemic. Participants ranged in age from 24 to 92 years, with a mean age of 53 years (*SD* = 16.4) and were predominately women (61.5%). Table 1 shows complete participant demographics and descriptive statistics.

### Access to family and friends

When asked about the effects of the COVID-19 pandemic on their ability to access family and friends, ten participants reported that their situation had not changed, while others ($n = 28$) reported worsening conditions, and one participant reported improvement. Among those whose access had worsened, many expressed limited to no contact with family and friends since the start of the pandemic, resulting in frustration, fear, and sadness. Several participants expressed concerns about losing the ability to care for family or friends – a role that they previously held. Others acknowledged that the social distancing efforts kept them and their friends and family safe from the virus. Table 2 provides example quotes. The participant who reported improved access to family and friends reported that “they're checking in virtually more than ever before,” despite not having physical contact with significant others. Interestingly, several participants reported that they were currently serving as primary caregivers to others (e.g., older relatives) at the onset of the pandemic. There was concern expressed about losing that role and fear of what might happen to the person for whom they were actively caring. To combat this concern, some participants described using delivery services to maintain their support and provide the necessary items to their family members.

### *Access to food and groceries*

Many participants reported negative effects of the COVID-19 pandemic on their ability to access food and groceries. Among those who reported worsened conditions ($n = 22$), many noted challenges based on scarcity of items or an increased risk of exposure associated with physically going to the store. Participants also reported using delivery services, but this strategy was met with challenges such as financial strains or inconvenient delivery times. Table 3 displays example quotes. Other participants ($n = 17$) reported no change, stating that their grocery stores had begun “sanitizing all the carts” and that they felt safe going to the store. No participants reported improved access to food and groceries.

### *Access to transportation*

While most of the participants indicated there had been no change to their access to transportation ($n = 21$), others reported worsened transportation conditions ($n = 16$). The reluctance to use public transportation due to fear of exposure to the virus emerged as a common challenge, as did reductions in availability of public transit or paratransit services. See Table 4 for example quotes regarding difficulty accessing transportation due to the pandemic. One participant mentioned an improvement in their access to transportation, stating that, “Fewer people are riding paratransit, so they are more able to accommodate my schedule. Rides are free until the coronavirus threat subsides.”

### *Employment and education*

Participants also reported adverse effects ($n = 7$) due to the COVID-19 pandemic and social-distancing to their employment or education. These effects included job loss, challenges transitioning to remote work, changes to hours allotted or pay, lack of public transportation during regular working hours, and unfavorable working conditions. Table 5 displays example quotes. One participant reported improved conditions in that they were able to start a new job.

### *Additional findings*

The following additional findings were drawn from a small subset of our sample, and included changes in access to personal assistance services (PAS) and impact on overall ability to live independently and participate in the community. Among those who were previously utilizing PAS at home, the COVID-19

**Table 1**
Participant characteristics.

| Characteristic | *n* (%) |
|---|---|
| Age | |
| 18-34 | 7 (17.9) |
| 35-64 | 23 (59.0) |
| 65+ | 9 (23.1) |
| Gender | |
| Men | 15 (38.5) |
| Women | 24 (61.5) |
| Race[a] | |
| American Indian/Alaskan Native | 1 (2.6) |
| Black/African American | 5 (12.8) |
| White | 31 (79.5) |
| Other | 3 (7.7) |
| Hispanic/Latino | 1 (3) |
| Missing | 1 (2.6) |
| Marital Status | |
| Married | 8 (20.5) |
| Separated, Divorced, Widowed | 14 (35.9) |
| Never been married | 13 (33.3) |
| Unmarried couple | 4 (10.3) |
| Education | |
| Less than high school diploma | 2 (5.3) |
| High school graduate | 9 (23.7) |
| Less than bachelor's degree | 13 (34.2) |
| Bachelor's degree | 10 (26.3) |
| Master's degree or higher | 4 (10.5) |
| Missing | 1 (2.6) |
| Household Income | |
| $10,000 or less | 11 (28.2) |
| $10,001 to $20,000 | 12 (30.8) |
| $20,001 to $40,000 | 10 (25.6) |
| More than $40,000 | 6 (15.4) |
| Employment Status | |
| Employed | 12 (30.8) |
| Not employed | 27 (69.2) |
| Benefits | |
| Supplemental Security Income | 10 (25.6) |
| Social Security Disability Insurance | 17 (43.6) |
| Social Security Retirement | 6 (15.4) |
| None | 5 (12.8) |
| Other | 9 (23.1) |
| Self-rated Health Status | |
| Excellent | 3 (7.7) |
| Very good | 4 (10.3) |
| Good | 18 (46.2) |
| Fair | 11 (28.2) |
| Poor | 3 (7.7) |
| Housing Tenure | |
| Own | 15 (38.5) |
| Rent | 18 (46.2) |
| Other | 6 (15.4) |
| Personal Assistance | |
| Any | 25 (64.1) |
| None | 14 (35.9) |
| Access to Transportation[b] | |
| Sometimes | 9 (23.1) |
| Often | 8 (20.5) |
| Routinely | 22 (56.4) |
| Transportation Mode[c] | |
| Personal vehicle | 11 (28.2) |
| Bus | 2 (5.1) |
| Family/friends/coworker | 8 (20.5) |
| Paratransit | 8 (20.5) |
| Ridesharing | 1 (2.6) |
| Walk or wheelchair | 2 (5.1) |
| Other | 7 (17.9) |

[a] No participants identified as Asian or Native Hawaiian/Pacific Islander.
[b] No participant indicated they never have access to transportation.
[c] No participants indicated use of a bike.

**Table 2**
Participant responses (n = 28; 72%) to the adverse effects of COVID-19 pandemic on their access to family and friends.

| Example Quotes for Access to Family/Friends |
|---|
| *"Everyone is afraid of it. Like my sister, I am ten years older than her, and her health isn't good, so she is afraid to come over here. And my other sister goes to Florida every winter hasn't been able to come back either. I miss my two sisters."* |
| *"Nobody wants to come over; nor do I really want anybody over."* |
| *"It's completely ended my access to friends, it's basically just ended social contact."* |
| *"My son moved back to his father's on February 21st before we were told as a country how serious COVID-19 was. I have not seen my son for visitation, spring break or Easter. I probably will not see him for Mother's Day either. These are all first times being apart from him like this. I also have not been able to go visit friends."* |
| *"I am unable to spend time with my grandmother. She started hospice right before the pandemic was thought to arrive in the US and I have been unable to spend her remaining days by her side. I have been able to bring her groceries and prescriptions, which I am grateful to be able to do, but she's beginning decline in health and is alone in her assisted living facility."* |
| *"[We are] on stay-at-home order so we haven't seen anyone in person. My mom lives in a nursing home and has tested positive and we can't see her."* |
| *"This has been the biggest struggle for me. I have not seen anyone in the flesh in a month. Living alone, this really stinks!"* |

pandemic put an abrupt stop to many of those services. At the time of the survey administration, many of these services were reported to be "on hold," and several participants reported attempting to perform activities of daily living (e.g., bathing) on their own. As one participant stated,

> I have been pushing myself on a few occasions to handle things physically that I normally would have gotten help with and ended up with [injuries] … because of either pushing myself too hard or becoming accident prone due to fatigue after doing too much by myself.

Participants also reflected on the ways in which the COVID-19 pandemic affected their general ability to live independently and to participate in their community. The act of participating in the community was not defined specifically, which allowed participants to interpret the concept as it best resonated with them. The majority of participants ($n = 26$) reported a complete disconnect with the community. One participant explained, "There is no community right now!" and another reported, "No one is allowed to do anything." One participant stated that their community engagement now involved other means (e.g., telecommunication) to connect with others. Many expressed concerns regarding health risks to themselves or others, and thus opted to refrain from any sort of community participation for the time being.

*Technology as a Response Strategy*. Adverse conditions resulting from the COVID-19 pandemic resulted in the use of technology to maintain some level of community participation, social engagement, or even employment or school. As one participant expressed, "Any participation with the community is limited to telephone, texts, Zoom, and my front porch." Another participant reported, "Even though I do keep in touch [with family] via phone and social media, it's not the same." Others reported using technology to obtain goods (e.g., groceries, prescriptions) and using technology to work remotely. However, they also reported numerous problems, such as "my internet is not secure and it drops" and "videos go in and out due to poor internet service." Nevertheless, using technology as a way to maintain social engagement, employment, or accessing necessities emerged as a common response strategy for this sample.

## Discussion

The adverse effects of this COVID-19 pandemic on the ability of people with disabilities to engage in their community is currently unknown. Thus, it was our goal to implement a high-quality, rapid research study to better understand the socioeconomic and psychological effects of the COVID-19 pandemic.[13–15] The results will provide data to inform strategies for service providers, policy makers, and others who work with people with disability to prepare and mitigate the effects of this ongoing pandemic and future emergency circumstances.[14]

Our results indicate that many participants reported adverse effects of the COVID-19 pandemic on their ability to engage in their community. These adverse effects included difficulty connecting with family and friends, accessing essential items and using public transportation. Limited engagement with family and friends emerged as the community aspect most negatively affected by the pandemic. For people with and without disability, this is a huge concern as the psychological impact of social isolation can be devastating for mental health.[14,16,17] Thus, strategies to maintain community involvement for people with disability should be a high priority for health care and service providers. In response to this challenge, many participants reported the utilization of technology to connect with others, a result that has been identified in recent research efforts.[1,20–23] Using various telecommunication (e.g., Zoom, Skype) platforms, people with disability are able to continue to meet with friends or family in a remote format through virtual get-togethers. However, with the ongoing social distancing mandates, additional data are needed to identify the needs of those who have been exposed to long-term social isolation or who lack access to technology. The results here underscore the need to ensure effective strategies for people with disabilities to maintain connections with others.

**Table 3**
Adverse participant responses (n = 22; 56.4%) to the effects of the COVID-19 pandemic on access to food and groceries.

| Example Quotes for Access to Food/Groceries |
|---|
| *"It's been almost impossible [to get food], my daughter and my aide have gone out a few times and there is almost nothing. So far somehow, I have food, using food banks and food stamps right before this all hit. Otherwise, I would have nothing."* |
| *"I've been using Kroger's Instacart [app]. I have had to spend money I don't have on delivery service. There are fees, and markups on food that I would not normally spend."* |
| *"The availability of time slots for delivery are scarce. The availability of specified foods is less. Delivery is non-contact, so I have to be able to lift, carry, and put away what the store packed without my direction. There's little social distancing in store."* |
| *"Grocery store is out of a lot of things, and there's this social distancing but then you walk into the grocery store, and it's like a concert. You can't move."* |
| *"Although I am able to drive myself to the grocery store, I do so at a health risk. I was recently diagnosed with asthma (which makes me a higher risk person for contracting the virus). Getting groceries has become a calculated procedure for when I estimate there won't be as much traffic and as many shoppers."* |

**Table 4**
Adverse participant responses (n = 16; 41%) on the effects of the COVID-19 pandemic on access to and use of transportation.

| Example Quotes for Transportation |
|---|
| *"I am working on a paratransit application. However, [the] applications can take 2-*3 months *to get approved during non-COVID-19 times. I am hesitant to use paratransit as they have dumped me out of my wheelchair before and with the risk of COVID-19."* |
| *"Because I am immunocompromised, I am choosing not to be in public transit vehicles at this time."* |
| *"I wouldn't get on [paratransit] … I do still have my own car but it's just too hard to get in and out and it's a lot for my attendant, too. And I can't ride in anyone else's car, that's just out of the question."* |
| *"I could go to the grocery store by the transportation afforded by the Senior Center, but I chose not to because I was afraid. They only had a limited number of drivers who were willing to drive. When I heard that I became anxious about it."* |
| *"Public transports go less places, and my job does not change to what is available for the bus route"* |

Assessing changes in access to food and groceries resulted in novel findings, as participants reported items of need being scarce and expressed reluctance to be in public places due to exposure. Responses to this challenge included utilizing delivery or curb-side pick-up services, however this strategy was often met with additional financial barriers for participants. Given that these services may be the only access people with disability have to essential items and groceries, changes may be needed to eligibility for food assistance programs or to allowances for delivery costs during periods of lockdowns or social distancing mandates to offset the added financial burden.

Results from the current study also indicate adverse effects on participants' ability to access and utilize transportation, specifically public transportation. Aligned with previous research findings,[24] many expressed fear of exposure to the virus when taking public transportation, which prevented many participants from using these services as they normally would. Others reported their usual public transportation, particularly paratransit services, had shut down completely or reduced their hours of service. For people with disability, public transportation is most frequently utilized to access their community, including getting to and from work or the grocery store.[25] Disruption to these essential services not only results in barriers to accessing necessary goods and services, but also accessing places of employment.[26,27] Therefore, it is important that some level of accessible public transportation services for people with disability remain available at all times, and that efforts are made to assure the safety of riders and drivers.

Another area of concern for participants in this study were the effects of the COVID-19 pandemic on employment. However, our results may be reflective of the experience of others with disability, particularly for those who work in the service industry. Participants described decreased hours and concern regarding exposure to others through their work, which often required in-person contact. Other participants reported an ability to work from home yet continued to express concerns about technology and the devices used to maintain remote employment. Policies that provide employers with opportunities to support employees with disabilities by maintaining social distancing protocols (e.g., wearing masks, gloves, maintaining distance from others, use of physical barriers) and supporting remote work (e.g., facilitating at-home technology use, supporting reliable at-home Internet access) would help address the barriers our participants reported. Based on our findings, these challenges are evident for people with mobility disabilities and support the concerns expressed by other researchers examining the effects of the COVID-19 pandemic.[28] Technology may serve as a viable source of maintained employment as well. As a result of the pandemic, many businesses have opted to permanently offer remote work options for employees[29,30]; however, such work generally requires a reliable internet connection, as well as functional and appropriate technology devices. While there are efforts in place to endorse and update guidance on remote work for people with disabilities, particularly during the pandemic,[2,31] improved internet and technological infrastructure, as well as policies that support affordable access to both the internet and accessible communication devices, are critical components to addressing disparate effects of disasters on people with disabilities.

Technology use was the common theme for participants to maintain access and engagement in their community during the COVID-19 pandemic. However, people with disabilities have less access to telecommunication services, such as such as reliable internet (54% with disability compared to 85% without); and this disparity is even larger for those living in rural communities.[32–34] Given that remote access via technology may be the only option for those concerned about exposing themselves to health risks, access to telecommunication technology is a critical emergency preparedness aspect to consider in maintaining community participation (for health care support, employment, or interpersonal connection).

Overall, our findings align with the social model of disability in that many of the barriers to community engagement experienced by participants were tied directly to public policies that disproportionately affected people with disabilities. For example, in many instances, public transportation kept running, but paratransit services were canceled or reduced. Similarly, structural inequities that result in lower income for many people with disabilities made it more difficult for participants to access grocery deliveries and adequate internet services. At the same time, many people with disabilities were more susceptible to contracting COVID-19, and thus had an especially strong need for these services to avoid public exposure. Disability advocates, service providers, and public health

**Table 5**
Adverse participant responses (n = 7; 33.3%) on the effects of the COVID-19 pandemic on employment or education.

| Example Quotes for Effects on Employment and Education |
|---|
| *"I work 4 different jobs and 3 of them are non-essential and have shut down!"* |
| *"My education status has gotten worse as there's only so much that can be taught from home. Especially in the organic chemistry lab course. The experience is not as fulfilling, and I don't feel as motivated to watch lectures and retain the material."* |
| *"We got a pay increase of $2 an hour, but our hours are cut to 15 per week, I've been given 8–10. I have a weak immune system … I'm trying hard not to quit and be sensible. This job accommodates my disability, so I'd like to keep it."* |
| *"I work for a radio station. I have not been able to do my on-air weekend shifts in a month. A lot of my day to day I can do from home, but I don't have my work computer here, and I am having to use my personal computer, and it is taxing the system."* |

officials must continue to advocate for policies and supports that create equitable access to goods and services for people with disabilities.

### *Limitations and future research*

Several limitations should be noted for the current study. First, despite a wide range of recruitment strategies to include a diverse sample, the participants in this study were predominately female, and identified as Caucasian, reducing the generalizability of the findings to others with a mobility disability. Second, the sample was small and represented only two geographic regions of the country. We echo the suggestions of previous researchers[13,14] on the need to continue research efforts to identify the effects of the ongoing COVID-19 pandemic and social-distancing mandates for people with disability. Areas for needed research include assessing the long-term changes to community participation such as effects on employment and finances, perceived social isolation, or transportation access due to the pandemic. Mental health concerns should also be addressed in future research efforts, as social distancing mandates are likely to have had a negative and cumulative effect on people with disability who need to maintain isolation to avoid the virus and maintain their health.

## Conclusions

The purpose of this study was to explore the effects of the COVID-19 pandemic on community participation for people with mobility disability. The research efforts here meet the need for rapid research by exploring the ways in the people with disability are affected by the COVID-19 pandemic and subsequent social-distancing mandates.[13,14] Results indicate that social distancing mandates and health concerns resulted in abrupt changes to their community engagement, affecting access to friends and family, shopping for essential items such as groceries or prescriptions, transportation use and access, sustained employment, or ability to live independently. Additionally, participants described the shared response strategies employed, including attempting to engage in daily living activities independently or using technology to maintain social engagement and participation. To better prepare for future pandemics or emergency situations, policies and supports must be developed that allow people with mobility disabilities to meet their needs for living independently in the community, including access to adequate personal protective equipment for personal assistants, access to ongoing safe transportation, access to appropriate technology and affordable and reliable internet service, receipt of reasonable accommodations in employment, and the continuation of community services such as grocery delivery services that are affordable and accessible.

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