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Research Report: Social isolation and loneliness experiences among people with disabilities before and during COVID-19

University of Montana Rural Institute

RTC:Rural
Research & Training Center
on Disability in Rural Communities

RESEARCH REPORT

SOCIAL ISOLATION AND LONELINESS EXPERIENCES AMONG PEOPLE WITH DISABILITIES BEFORE AND DURING COVID-19

December 2021

INTRODUCTION

In 2017, the U.S. Surgeon General, Dr. Vivek Murthy, declared the rising prevalence of social isolation and loneliness a public health epidemic.[1] Since that time, COVID-related lockdowns and social distancing have increased rates of social isolation and loneliness. In fact, the impacts of COVID-19 have been described as a double pandemic, where both social isolation and the virus have negatively impacted health and wellbeing.[2]

We know that COVID-19 has disproportionately affected vulnerable populations, where existing health disparities place them at higher risk of COVID-19 complications. These vulnerable populations include older adults, people with disabilities, people with pre-existing health conditions, and certain racial and ethnic groups.[3] Increased risk and fear of exposure may also impact social isolation and loneliness among these populations.

- People with disabilities reported more social isolation but lower rates of loneliness pre- to post-COVID-19.
- Opportunities to engage online may protect against loneliness.
- Centers for Independent Living (CILs) have played a significant role in addressing social isolation during COVID-19.

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SOCIAL ISOLATION AND LONELINESS

Social isolation refers to having few or limited social connections, and is generally measured in objective terms. Loneliness, on the other hand, refers to a dissatisfaction with level of social connection and is based on subjective experience. While social isolation and loneliness are similar, sometimes they diverge. For instance, people who enjoy spending time alone may not feel lonely but may be socially isolated. Both social isolation and loneliness are associated with worse mental and physical health.

In an earlier research report we reported findings from the 2016 Health and Retirement Survey that people with disabilities experienced more than double the rates of social isolation and loneliness compared to those without disabilities for adults aged 50-65. More recent data indicates that rates of social isolation and loneliness have climbed for the general population due to COVID-19.[4] There is less information, however, on how rates of social isolation and loneliness have shifted for people with disabilities.

METHODS

We used longitudinal data from the National Survey on Health and Disability (NSHD) to determine if rates of social isolation and loneliness have changed since the start of COVID-19. The NSHD is a national convenience survey focused entirely on people with disabilities. To date, the NSHD has been administered three times, including in 2018, 2019/20, and 2021. Data collected from 2019/20 (pre-COVID) occurred prior to COVID-19 lockdown and social distancing measures. Data collected in 2021 (post-COVID) occurred approximately one year into the COVID-19 pandemic, but prior to vaccine roll-out.

A subset of NSHD respondents (n = 566) provided data in both the 2019/20 and 2021 NSHD surveys. Using these data, we explored how experiences of social isolation and loneliness shifted over time.

DATA ANALYSES AND MEASURES

We used paired samples t-tests to compare responses pre- to post-COVID on several measures of social connectedness, social isolation, and loneliness. Table 1 lists these measures and response options.

Table 1: Social Isolation and Loneliness Measures

Measure	Survey Item or Question	Response Options
Leisure	I am satisfied with my current level of leisure activity.	Scale of agreement from 0 = not at all to 4 = very much
Social activity	I am satisfied with my current level of social activity.	Scale of agreement from 0 = not at all to 4 = very much
Social network quantity	How many family members or close friends do you see or hear from at least once a month?	0 to 9, where 9 includes 9 or more
Social network quality	When you have an important decision to make do you have someone you can talk to about it?	Scale from 0 = never to 5 = always
Social Isolation	I am isolated from others in the community.	Scale of agreement from 0 = not at all to 4 = very much
UCLA Loneliness Scale	1. How often do you feel you lack companionship? 2. How often do you feel left out? 3. How often do you feel isolated from others?	Scale from 1 = hardly ever to 3 = often, where responses to the three questions are added together to create a loneliness score from 3 to 9.

FINDINGS

Table 2 shows ratings of social connectedness including satisfaction with leisure activity, satisfaction with social activity, social network quantity, and social network quality pre- to post-COVID. Notably, ratings of social connectedness were largely stable over time. The exception was leisure activity, where respondents reported significantly higher satisfaction during the post-COVID period.

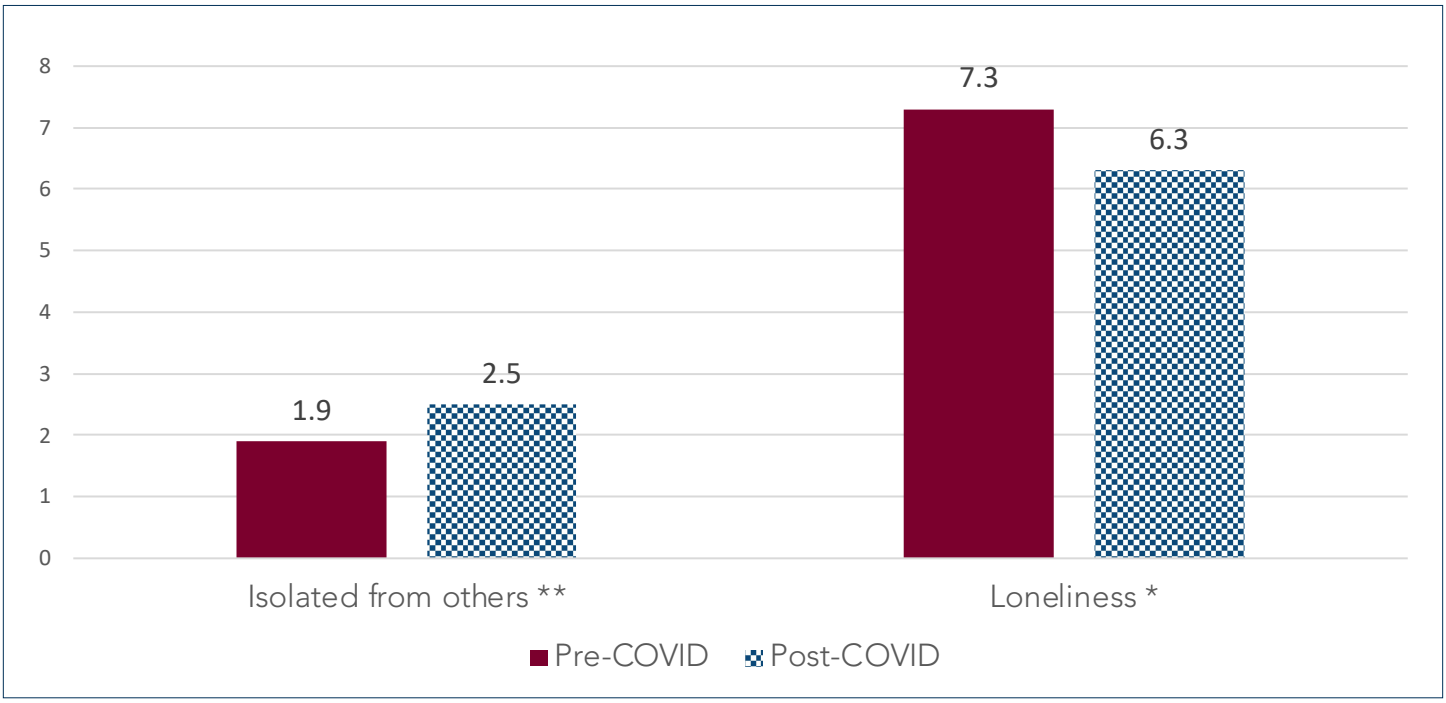
Table 2: Social Connectedness Ratings Pre- to Post-COVID

Item	Pre-COVID	Post-COVID	p-value
Satisfaction with leisure activity	1.94	2.41	.039 *
Satisfaction with social activity	1.90	1.81	.734
Social network quantity	4.47	4.55	.459
Social network quality	3.80	3.85	.351

* $p \leq .05$

Figure 1 compares ratings of social isolation and loneliness pre- to post-COVID. While respondents indicated that they were more isolated from others in the community, they reported lower ratings of loneliness pre- to post-COVID. Both of these ratings were significantly different.

Figure 1: Comparing Change in Social Isolation and Loneliness Pre- to Post-COVID



* p ≤ .05; ** p ≤ .01

EXPLAINING LOWER RATES OF LONELINESS

Usually, the experiences of social isolation and loneliness move together. This was not the case, however, for our sample of people with disabilities when comparing rates before and during the COVID-19 pandemic. One explanation relates to the subjective nature of loneliness. Because COVID-19 broadly reduced opportunities for in-person community engagement, it is possible that subjective experiences of being left out were reduced.

Another explanation stems from a shift in how people connected with one another. Online opportunities for remote work and socialization replaced many in-person activities. Virtual groups and classes ranged from at-home exercise to painting to playing cards to professional development. While digital literacy barriers may have delayed opportunities early in the pandemic, the duration of social distancing in combination with growing opportunities for online participation may have resulted in new digital competencies and confidence among many people with disabilities.

CENTERS FOR INDEPENDENT LIVING (CILS)

CILs provide independent living skills training to people with disabilities, and is one example of how service agencies may have increased online opportunities. For instance, CILs have translated core programs for online delivery, supported development of digital literacy skills, and provided virtual opportunities for sharing experiences and support. The Living Well in the Community (LWC) workshop provides one such example. Prior to COVID, several CILs were delivering LWC in an in-person group format. Once social distancing measures were in place, CILs supported one another in transitioning to online delivery. One CIL developed and shared video instructions for how to run a virtual meeting, including how to join, use the chat feature, raise hand, turn on captioning, and established a process for how members share comments. Participants supported their peers to overcome digital hesitancy and continue engagement in the group. Online participation provided additional benefits such as removing access barriers associated with traveling to an in-person group, and expanded networks through newly acquired digital skills. For instance, participants joined other online groups, held virtual meetings outside the workshop with friends and family, and did online searches. In this way, CILs played a role in building community and online skills to address social isolation.

CONCLUSION

There is no question the pandemic has had disparate and negative impacts on people with disabilities, including high rates of COVID-related deaths, disrupted personal assistance services, inaccessible health messaging, and postponed medical treatment.[5] Despite these, some COVID-related changes have led to new opportunities. In particular, remote work and online engagement may reduce structural barriers to participation, including limited transportation options, inaccessible physical environments, and stigmas that further limit confidence, choice, and control.[6] To expand upon these opportunities, however, it is important to recognize and address existing digital barriers through improved online accessibility, digital skills development, and strategies to address the persistent digital divide experienced by vulnerable populations.

Paying attention to these new ways of connecting and ensuring that people with disabilities are fully included is imperative to reducing their social isolation and loneliness. Although our data suggest the pandemic did not significantly increase feelings of loneliness among people with disabilities, let us remember that it has not repaired it either. People with disabilities remain substantially more isolated and lonely than people without disabilities, undermining both their health and quality of life.

RECOMMENDED CITATION

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