

## Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

### Study Highlights the Impact of COVID-19 on the Delivery of Personal Assistance Services for People with Disabilities

*A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).*

The ongoing COVID-19 pandemic has impacted marginalized communities in many ways, especially those with disabilities and their access to health care. Approximately eight million people in the US have disabilities that make it difficult to carry out everyday activities such as bathing and dressing. Recent studies have shown that around 2.3 million people with disabilities in the US access paid personal assistance services (PAS) to help them with these daily activities. Some of the most common services provided include meal assistance, housecleaning, and partaking in social activities. However, with the pandemic and subsequent safety restrictions, many of the people receiving PAS saw their services canceled or delayed.

In a recent NIDILRR funded study, researchers sought to understand the consequences of the COVID-19 pandemic on the delivery of PAS and its impact on the lives of people with disabilities who were relying on these services.

Researchers at the [Rehabilitation Research and Training Center for Place-Based Solutions for Rural Community Participation, Health and Employment](#) analyzed data from 1,683 responses to the National Survey on Health and Disability (NSHD) gathered between January and May 2021. Participants were over 18, living in the US, and had a disability or chronic health condition that affected their daily activities or necessitated the use of special equipment like a mobility or communication device. As part of the survey, participants answered questions about their health and access to services, including whether they needed or used PAS since pandemic restrictions began in March 2020. Participants were asked: “Since the pandemic began, when you needed help at home from a paid or unpaid helper, did you ever NOT GET IT because of the COVID-19 pandemic?” Participants who answered “yes” were invited to provide a written answer to a follow-up question: “How did you manage without the help you needed in your home? How long did you not have the help you needed?”

The researchers found that 283 participants responded that they needed or used PAS since the start of the pandemic. All of these participants indicated that COVID-19 led to a delay or cancellation in their services at some point, and more than half had to either postpone or cancel their PAS between March 2020 and the time of answering the survey. When the researchers looked at the responses to the open question about managing without help, they found there were three overarching themes: causes of unmet needs, consequences of unmet needs, and adaptations. These themes and subthemes were as follows:

- Causes of unmet needs: Participants described systemic problems, worker shortages, and issues of personal choice and trust as causes of unmet needs and delays in accessing care. The pandemic exacerbated existing problems in a system that was already experiencing delayed access to care. Even before the pandemic, PAS workers were hard to come by due to poor working conditions and pay inequities. During the pandemic, the access to care was further reduced because many PAS workers left the field during the pandemic rather than risk infection. Agencies that provided PAS were also delayed in hiring replacements. Finally, some participants chose to limit or forgo their use of PAS rather than risk exposure or because they did not trust that workers would follow health protocols.
- Consequences of unmet needs: In general, participants reported a significant drop in their quality of life and well-being due to their needs not being met. They reported not having help with housekeeping and food preparation, leading to unsafe or unhealthy conditions and added expenses for ordering out or hiring cleaners. Participants reported forgoing personal care such as bathing or bowel and bladder care, or reducing their eating and drinking, all of which had health consequences. Disruptions in PAS led to delays in health management activities, like physical therapy sessions, assistance with medical equipment, and transportation to medical appointments. Participants reported that these delays and unmet needs took a toll on their mental health and that of the PAS workers who did stay on the job.
- Adaptations: Participants reported adaptations to cope with changes as PAS disruptions continued for short or long periods. Some participants reported paying out of pocket for services like transportation to appointments or meal preparation or cleaning. Others turned to family or friends to fill in when services were delayed or canceled. Some participants moved in with family or friends to receive care in the home.

The authors noted that, while adaptations may have helped participants cope, they sometimes had their own consequences. Participants reported that relying on friends or family created an unwanted dynamic and led to challenges in relationships. Help from friends was not as consistent as from family members. Limiting access to the home to close family meant PAS workers could not enter and provide services. Some respondents were hopeful for the future, with increased vaccination rates offering the promise of a return to pre-pandemic days. However, many of the respondents noted that the COVID-19 pandemic was not the only reason for the unmet needs they identified. As noted earlier, some issues, such as worker shortages, existed within the healthcare and PAS system before the pandemic.

The authors noted that PAS workers provide people with disabilities the assistance they need to lead independent, healthy lives in the community. However, the workforce is shrinking just as the need is growing. The authors offered some possible solutions that

could help alleviate some of the problems identified in this survey. Giving individuals with disabilities more control over hiring and managing PAS workers, rather than relying on an agency, may offer more autonomy, flexibility, and consistency of care. However, during an extended, challenging time like the pandemic, the extra work of interviewing, hiring, and managing a PAS worker might be an added burden. Unionization in the PAS industry might help address issues of low wages, poor benefits, worker safety, and lack of career advancement opportunities, which caused many to leave their jobs since the start of the pandemic. Researchers may want to identify effective policies and practices that support a robust PAS workforce, and work with policymakers and advocates to improve conditions and attract and retain PAS workers,

To learn more:

The [Community Living Policy Center](#) offers several resources for consumers and providers of home and community-based services such as PAS. A recent study from this center highlighted the link between unmet needs and health and community participation outcomes. This center also collected [resources on self-directing services and supports during the COVID-19 pandemic](#).

Previous issues in this Research In Focus series focused on the impact of the COVID-19 pandemic on different aspects of participation:

[Both Employers and Workers with Disabilities Are Feeling the Effects of COVID-19 on Employment and Earnings](#)

[Survey Offers Insight into Impact of COVID-19 on Community Living and Travel Behavior of People with Disabilities](#)

To learn more about this study:

Sage, R., Standley, K., Ipsen, C. (2022). [Everything is a mess. I'm just trying to survive it: Impacts of COVID-19 on personal assistance services](#). Journal of Health Care for the Poor and Underserved. This article is available from the NARIC collection.

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