

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

Adults with Physical Disabilities from Marginalized Communities Describe Feelings of Fear, Isolation, and Invisibility During the COVID-19 Pandemic

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

In March 2020, Wayne County in southeast Michigan reported among the highest rates of COVID-19 infections in the US. People from low-income households and marginalized communities in cities such as Detroit and Flint in Wayne County were particularly hard hit. Health experts warned that those with pre-existing health conditions were at risk for experiencing severe illness from coronavirus, including people with physical disabilities. Studies have shown that other factors such as income level, age, and racial identities were also associated with a higher risk of severe cases of COVID-19 for people with and without physical disabilities. People with physical disabilities were also at risk of being negatively impacted by pandemic control measures such as lockdowns which reduced access to services such as personal assistance services, transportation, and health care.

In a recent NIDILRR funded study, researchers explored the experiences of people with physical disabilities from marginalized communities during the period when lockdown measures were put in place beginning in March 2020. Researchers wanted to hear from these individuals about the feelings and concerns they had and the pandemic's impact, if any, on their health services, daily life needs, and access to accommodations.

Researchers at the Rehabilitation Research and Training Center on Promoting Healthy Aging for People with Long-term Physical Disabilities conducted a series of remote interviews with 15 individuals with physical disabilities from the Metro Flint and Detroit areas during April and May 2020. The participants were from low-income communities, over 18 years of age, living with a moderate to severe physical disability for at least five years, and reported a high level of engagement with their families and community. During the interviews, the participants engaged in guided conversations with researchers and answered open-ended questions regarding their feelings and fears during the pandemic, the context in which they experienced these feelings, and whether or not their healthcare and resource needs were being met.

The participants included five women and ten men, ranging in age from early 20s to mid-70s. They reflected the demographics of the general population of southeast Michigan: 9 participants were African-American, 4 were white, 1 was Middle-Eastern-American, and 1 was Native American. Eight of the participants were activists or involved in disability organizations. More than half of the participants were considered to be living in low-income households.

From the interviews, the researchers identified three overarching themes:

- Participants described feelings of fear and isolation, and a sense of being invisible. Some expressed extreme fear of leaving the house, taking public transportation, or shopping. More than half of the participants expressed feeling isolated and that the pandemic exacerbated existing feelings of loneliness and isolation.
- Participants described barriers to health and healthcare, home care assistance, and access to resources. Cancelled checkups and reduced access to therapies and medical services led some to experience pain and discomfort, as well as loss of social connections with medical staff. Participants described personal care attendants and household help as essential, but presented an added layer of concern due to exposure risk.
- Participants reported different strategies to access limited services and supports to accommodate their needs such as moving into the home of a personal care assistant. One participant launched a mutual aid organization for adults with physical disabilities in their community, offering delivery services and virtual group sessions to combat feelings of isolation and share important information.

The authors noted that some participants expressed concerns that pandemic protocols, such as lockdowns, overlooked people with disabilities, limited their access to essential services, and made them feel unseen. For example, when local grocers shut down, there was little thought to accommodations for customers with physical disabilities. While some people could access online grocery services, some participants in this study reported they lacked the money and technology to have groceries delivered to them. A few participants said they were not concerned about the virus and reported no change or disruption in their life due to the pandemic.

According to the authors, this study highlighted some of the challenges faced by adults with physical disabilities from marginalized communities during the early days of the pandemic safety measures. The authors noted that the pandemic protocols may have exacerbated existing feelings of fear, isolation, and invisibility experienced by this community. They also noted that marginalized communities were already facing barriers to accessing health care services as well as higher risk of contracting COVID-19. For people with physical disabilities in these marginalized communities, the pandemic restrictions created another layer of challenges. These included having to balance risk and need, the lack of accommodations, and the negative impact on physical and mental health. Most of the participants faced a dilemma between engaging in risky behavior to have their needs met or avoiding risk and not having those needs met. Having accommodations in place could help resolve that dilemma and reduce the impact of an event like the pandemic on physical and mental health. The authors suggested that policy makers may wish to include people with physical disabilities when making public health decisions and emergency response policies.

To Learn More:

The continuing COVID-19 pandemic is impacting the lives of people with disabilities in many ways. The Research In Focus series has previously examined research in employment, health, and community 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](#)
- [Survey Examines the Pandemic's Impact on the Health of People with Mobility Disabilities](#)
- [Study Highlights the Impact of COVID-19 on the Delivery of Personal Assistance Services for People with Disabilities](#)
- [Caregivers of People with Chronic Illness and Disability Reported Increased Health Care Roles During the Pandemic](#)

The Administration for Community Living offers a range of services and supports through its programs including:

- The Disability Information and Access Line (DIAL 888-677-1199), a no-cost hotline that helps people with disabilities access information about COVID-19 vaccines and tests and connect to community resources and programs that support independence and participation.
- [Centers for Independent Living](#) are county-level organizations run by and for people with disabilities.

[The Centers for Disease Control and Prevention \(CDC\)](#) offer health information on living with disabilities and share resources and support networks for people with disabilities.

To Learn More about this Study:

Reber, L., Kreschmer, J., DesShong, G., (2022). [Fear, Isolation, and Invisibility during the COVID-19 Pandemic: A Qualitative Study of Adults with Physical Disabilities in Marginalized Communities in Southeastern Michigan in the United States](#). *Disabilities*. (2) 119-130. This article is available from the NARIC collection under Accession Number J88520 and free in full text from the publisher.

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study

and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

The contents of this publication were developed under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (140D0421C0021). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.