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## Commentary

# Dimensions of community participation

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Community participation is vital to the wellbeing of human beings. So much so, that lack of social connection affects mental and physical health, and associated rates of morbidity and mortality.<sup>1–6</sup> One only needs to look at the impacts of social distancing due to COVID-19 to witness a precipitous decline in the mental and physical health of the U.S. population.<sup>7,8</sup>

While individuals have varied desires for social connection, everyone deserves the opportunity to participate in ways that align with societal norms and their personal preferences. Unfortunately, many people with disabilities lack opportunities for community connection due to structural, environmental, and sociodemographic barriers.<sup>9</sup> Barriers can take many forms, starting with inaccessible housing,<sup>10</sup> and extending out into the community in terms of limited or non-existent accessible public transportation options,<sup>11–13</sup> inaccessible public spaces and events,<sup>14,15</sup> inaccessible

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businesses and employment settings,<sup>16</sup> and stigmas that prevent full inclusion in public life.<sup>9</sup> Sociodemographic factors, such as low educational and employment rates further limit choice and opportunity due to added financial constraints.<sup>17</sup> And secondary health conditions in combination with limitations in healthcare access and delivery contribute as well.<sup>18</sup>

The impact of these barriers is evident in the social model of disability, which makes a distinction between impairment and disability, and highlights the intersection between person and environmental factors that create the experience of disability.<sup>19</sup> This intersection is manifest in one's ability to contribute and participate in the community. In this way, the outcome of community participation has become the gold standard in disability related research.

In 2016, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) began funding a center focused on interventions to support community living for people with disabilities. Researchers at this center, the Research and Training Center on Promoting Interventions for Community Living (RTC/PICL), focused their efforts on a multi-faceted intervention to improve community participation for adults with mobility disabilities—efforts that were disrupted by the pandemic in 2020. Center researchers contributed papers on their early findings and findings related to the pandemic and also reached out to other researchers addressing community living and participation to generate the articles included in this online supplement. Taken together, these papers provide a good overview of the state of the science in research to improve community living and participation for people with disabilities, particularly for those with mobility disabilities. The papers address factors affecting participation across the lifespan, how the pandemic has affected participation, interventions and technology to improve participation, suggestions for policy makers, and directions for future research.

## Overview of articles

The special supplement opens with a quantitative analysis of data from the National Survey on Health and Disability (NSHD) to explore sociodemographic factors that predict feelings of social disconnectedness among people with mobility impairments. Hall, Kurth, and Goddard explore the constructs of social isolation and loneliness and highlight a distinction between objective and

subjective experiences. Findings reinforce past research, and highlight how sociodemographic factors, such as unemployment and poor health, are associated with lower rates of community connectedness. They also show that facilitators, such as employment and access to personal assistance services, associate with higher levels of social connectedness. Together, these data lay the foundation for later articles, which address several environmental factors in more depth.

Remillard, Campbell, Koon, and Rogers take on one of the most persistent barriers to full participation—transportation. Accessible transportation is vital to independent living, social interaction, and employment for people with disabilities. As such, there are a variety of transportation laws, policies, and guidelines intended to increase access. Unfortunately, many of these do not fully address the transportation barriers experienced by people with disabilities. The authors triangulate transportation policy, feedback from a national stakeholder group of transportation providers and nonprofits, and qualitative interview data with older adults with mobility impairment to explore gaps between transportation policy, implementation, and lived experience. The most apparent gaps relate to individual concerns for safety and societal attitudes. Other areas, such as inaccessible transportation features, were identified across data sources. Together, the data highlight the importance of user input in the design and implementation of transportation initiatives.

In many ways, community participation starts at home. Living in a home that fits individual needs and function can reduce fatigue, pain, and stress, and leave more energy for engagement.<sup>10</sup> Two articles tackle different dimensions of housing. First, Greiman, Koon, Schulz, and Nary explore the relationship between home usability and community participation through qualitative interviews with people who have mobility disability. Central to this exploration is the concept of home usability as opposed to home accessibility. While usability and accessibility both address physical space needs, home usability is broader and includes social and psychological needs as well. Results show how usability is a moving target that shifts in relationship to individual, social, and environmental factors.

Greiman, Ravesloot, Goddard, and Ward build on these qualitative findings by exploring the effects of the Home Usability Program (HUP) on community participation. Essentially, the HUP is a consumer-driven process that includes a home satisfaction assessment, identification of home usability problems, prioritization of needs, and leveraging of personal and community resources (including up to \$350 in grant funds) to make changes. Study participants were recruited through Centers for Independent Living (CILs) and partner agencies, and were randomly assigned to receive the HUP intervention or CIL services as usual. Pre to post-intervention data showed that consumer-directed changes to the home environment increased social and recreational participation relative to study controls.

Like home usability, assistive technology (AT) is another strategy that can improve participation at home and in the community. Assistive technology includes devices, tools, equipment, and software that increase the functional ability and independence of people with disabilities. Rice, Fliflet, Frechette, Brokenshire, Abou, Presti, Mahajan, Sosnoff, and Rogers explore the usability of an automated fall detection device for older adult wheelchair and scooter users using a participatory qualitative approach. Fall detection devices have the capacity to increase participation by reducing fears, building confidence, and better managing fall incidents. Use, however, depends on building products that meet end-user specifications. To this end, Rice et al. interviewed end-users about their preferences ahead of device development. Participants identified several desired features such as stretch bands

that are easy to take on and off, wireless charging, and tailored notification options. Findings reinforce the value of including end-users in the design and development of AT devices.

The final article focuses on the coronavirus pandemic and related impacts on community participation. Although the pandemic has resulted in diminished community participation for most people, impacts may be greater for people with disabilities due to enhanced risk for COVID-19 related complications<sup>20</sup> and compromised access to transportation, health care, and support services.<sup>21</sup> To learn about COVID19 impacts on community participation, Koon, Schulz, Greiman, Nzuki, Goddard, and Hall conducted an analysis of open-ended survey responses with a sample of people with mobility impairments. Study participants indicated that almost every dimension of community participation was compromised, including access to friends and family, groceries, transportation, employment, and independent living. These impacts call for new ways of functioning in an evolving environment, such as enhancing use and availability of technology, and better planning for emergencies.

Together, these articles are threaded around a theme of usability. Usability places participation outcomes at the intersection of evolving person and environmental factors, and must be addressed at both individual and systems levels. Involving end-users is central to the theme of usability, as individuals with disabilities are the best equipped to identify how these intersections occur and to offer realistic and meaningful solutions.

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## Disclaimer

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