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

People Aging with Mobility Disabilities Share Common Challenges and Strategies for Success

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

An estimated 15% of U.S. adults aged 65 and older have a mobility disability, defined as serious difficulty walking or climbing stairs, according to the 2016 American Community Survey. While some people may develop mobility disabilities as a part of aging, a growing number of people are aging with mobility disabilities acquired earlier in their lives, such as cerebral palsy, spinal cord injuries, multiple sclerosis, or polio/post-polio syndrome. As people with long-term mobility disabilities get older, they may experience new challenges related to the aging process. However, people aging with mobility disabilities may use a variety of resources to remain actively involved in community life. In a recent NIDILRR-funded study, researchers asked people aging with mobility disabilities to describe the challenges they encountered most often in everyday life and the strategies that they used to overcome these challenges.

Researchers at the <u>Rehabilitation Engineering Research Center on Technologies</u> to Support Aging-in-Place for People with Long-Term Disabilities (TechSAge RERC) interviewed 60 adults ages 60-79 with long-term mobility disabilities. The participants had been living with a mobility disability since before the age of 50, with some of the participants having had a mobility disability since childhood. The causes of disability included polio, neurological conditions such as cerebral palsy, congenital conditions such as spina bifida, and injuries such as spinal cord injuries, among others. During the interviews, the participants were asked to rate the level of difficulty they experienced in performing specific activities of daily living, including basic activities (e.g., bathing, toileting); activities outside the home; health management; shopping and managing finances; activities around the home; and transportation. The participants were then asked to describe in more depth what challenges they encountered in performing the most-difficult activities and what strategies they used to mitigate those challenges.

The researchers found that the participants described a variety of challenges. The most commonly mentioned types of challenges included:

 Personal physical challenges: The most frequently mentioned specific challenges across activity types were physical in nature, including limited strength or range of motion in particular parts of the body, limited balance or stamina, or health challenges in general. For example, several of the participants expressed that transferring from a chair to a wheelchair (or vice versa) had become more difficult due to decreased balance or a loss of arm strength. Fatigue and decreased stamina also limited the types of community activities in which the participants were able to engage.

- Physical inaccessibility: Other challenges commonly mentioned were related to inaccessibility of public or private spaces. For example, many of the participants described not being able to visit friends or relatives in their homes with steps. Other accessibility limitations included difficulties reaching items in stores while shopping, a lack of accessible restroom facilities in some public buildings, or home appliances that were not fully accessible (such as a top-loading washing machine). Transportation, in particular, presented a variety of accessibility limitations; for example, some of the participants described difficulties with air travel or with the limited number of wheelchair spaces on public buses. Due to lack of transportation options, many of the participants were limited in their ability to travel far from home.
- Lack of assistance: Some of the participants mentioned needing assistance from others with tasks and being unable to obtain it, either because assistance from family or friends was unavailable or there was a lack of affordable paid help. Some of the participants also expressed hesitancy to ask for assistance with tasks because of safety or privacy concerns.

The researchers also took a more detailed look at the basic activities of daily living that the participants rated as most challenging. These included transferring, toileting, and bathing. When asked about how they addressed these challenges, the participants discussed a variety of strategies. The most commonly mentioned strategy types included:

- Assistive tools and technologies: Many of the participants mentioned using a variety of low-tech and high-tech tools to aid them in overcoming physical limitations. For example, they reported using tools such as transfer boards, shower chairs, or portable lifts to aid them in basic activities of daily living, or a portable ramp to facilitate access in a building with stairs. However, respondents frequently reported cost as a barrier to utilizing many of the currently available technologies.
- Assistance from others: Another commonly reported strategy was to utilize physical assistance from family, friends, hired professionals, or service animals to aid in completing challenging tasks.
- Strategic planning and adaptation: Many of the participants described planning ahead and adapting familiar routines to make things easier, for example, organizing the kitchen so that most-needed items were always in easy reach, researching restaurants ahead of time to find the ones that were most accessible, or redesigning their homes to optimize accessibility.
- Opting out: Less commonly, some of the participants reported that they became unemployed or disengaged from community activities because the physical, access, transportation, or other challenges were too great. Others reported that they stopped doing tasks such as housekeeping on their own, preferring to outsource these tasks to professionals or other assistants.

 Other strategies: A variety of other strategies were mentioned by the participants. Some of the participants had ideas for new accessibility workarounds that have not yet been adopted. For example, one person suggested designing an airplane chair which could be unhooked from the plane cabin and rolled to the passenger in the lounge area, then rolled back into the cabin, eliminating the need to transfer after boarding. Some of the participants also mentioned using adaptations that they had learned from other people with similar disabilities in order to best overcome specific challenges.

The authors noted that the population of people aging with long-term mobility disabilities is likely to continue growing. As these individuals age, they may need to adapt the strategies that they previously used to effectively engage in desired activities. Aging may present additional physical challenges that may require new strategies in order to overcome. The results of this study emphasize the important role of accessible spaces and transportation in order to optimize participation. Rehabilitation providers serving older adults with mobility disabilities, assistive technology developers, and building designers may wish to collaborate together with adults with mobility disabilities. In addition, people aging with mobility disabilities may benefit from networking with each other to exchange strategies and solutions to commonly encountered challenges.

To Learn More

Researchers from the TechSAge RERC recorded <u>several episodes of the Assistive</u> <u>Technology Update podcast</u>, discussing smart home technologies for independence, home renovations and the importance of voice and touch controls in smart home devices, and the Internet of Things in the home.

For designers and developers, the TechSAge RERC has developed a set of <u>Personas</u> for <u>Designing for Individuals Aging with Mobility Impairment</u> to aid in the design of technology and environments that support independence. The 10 personas represent themes of real-life, everyday activity challenges among individuals with these disabilities that emerged from in-home studies.

Each state has an Assistive Technology Project, funded to help people with disabilities access assistive technology and modifications for independence at home, school, work, and in the community. <u>Find your state's Assistive Technology Project</u>.

To Learn More About this Study

Koon LM, Remillard ET, Mitzner TL, Rogers WA, (2020) <u>Aging concerns, challenges,</u> and everyday solution strategies (ACCESS) for adults aging with a long-term mobility <u>disability</u>. Disability and Health Journal. This article is available from the NARIC Collection under Accession Number J85154 and 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 <u>www.naric.com</u> or call 800/346-2742 to speak to an information specialist.

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