People with Long-Term Physical Disability Have a Lot to Share About Successful Aging

As people age, they may experience new and chronic health conditions that make it difficult to participate in activities at home, at work, and in the community. For many people, successful aging means avoiding preventable conditions which may lead to disability, maintaining physical and social activity, and interacting with the community in meaningful ways. People who were born with disabilities or developed them early in life may experience aging differently from people who first develop disabilities as older adults. Due in part to improved medical care, more and more people with physical disabilities are living into their 50s, 60s, and beyond, and they have their own perspective on successful aging. In addition to health conditions associated with aging in general, they may face unique challenges, such as secondary conditions related to their disabilities, or financial challenges from needing to retire early due to their disability. They may also have important resources and knowledge to share from living with their disability for a long time, which may benefit those who are aging into disability.

In a recent NIDILRR-funded study, researchers identified a group of middle-aged and older adults who reported disability due to a medical condition they had since birth, or acquired early in life. The researchers asked these participants what successful aging means to them, and what qualities and resources they think are most important for successful aging.

Researchers at the Rehabilitation Research and Training Center on Healthy Aging with Physical Disabilities (Healthy Aging RRTC) held focus groups with 49 adults with physical disabilities. The participants were 45-80 years old, and had muscular dystrophy (MD), multiple sclerosis (MS), post-polio syndrome (PPS), or spinal cord injury (SCI). The focus groups were held either in-person or over the phone. During each focus group, the researchers asked the participants to explain what “successful aging” meant to them, as well as the resources they had in their lives that helped them to age successfully.

When the researchers looked at ideas that came up most during the focus group discussions, they found that the participants mentioned four areas that they felt were important for successful aging with a physical disability. These were:

1. Resilience and adaptability: The participants described having a positive outlook and adapting to changes in their lives as being important for successful aging.
   One participant said, “Life is what you make it, and it can be a very beautiful thing if you just look for the beauty that is in your life, present every day, as opposed to looking for the problems.”
2. Autonomy and choice: The participants felt it was important to have control over life decisions, such as choosing where to live and what adaptive equipment to use.

3. Social connectedness: The participants described having strong relationships with others, such as spouses and friends. They also found it helpful to meet others with the same disability, through support groups or community programs, to share experiences and advice.

4. Physical health and access to healthcare: The participants described the importance of maintaining their physical wellness so they could keep participating in valued life activities, like working or pursuing hobbies. They felt it was important to minimize bothersome symptoms, such as pain, fatigue, and sleep problems. Along with this, the participants valued access to doctors, rehabilitation therapists, and community wellness programs. The participants stated the importance of having access to reliable healthcare, including doctors and specialists who know about their disability or are willing to learn, and medical offices that are wheelchair-accessible.

The authors noted that successful aging is possible for people with long-term physical disability, and can be enhanced by social and community resources. Some of the resources mentioned by the participants in this study included support groups for people to meet others with their same medical condition, community wellness programs for older adults, and in-home supports enabling people to “age in place” and take charge of their living situation. Rehabilitation providers working with people aging with physical disability may want to emphasize home and community supports that enable these individuals to keep participating in activities they find meaningful. In addition, researchers and policymakers who focus on aging can learn a great deal from the collective wisdom of middle-aged and older adults with long-term disability, as this group of people has much experience in managing their lives and symptoms, and maintaining important goals despite barriers.

To Learn More

The Healthy Aging RRTC has many factsheets and research briefs on aging with physical disabilities, including information on resilience, pain management, and the importance of being physically and socially active. [http://agerrtc.washington.edu/](http://agerrtc.washington.edu/)

Living Well and Working Well with a Disability are two peer-led health promotion workshops that help people with disabilities to set and reach quality of life goals by developing a healthy lifestyle. Workshops are offered at independent living centers and aging resource centers across the US. [http://livingandworkingwell.ruralinstitute.umt.edu/](http://livingandworkingwell.ruralinstitute.umt.edu/)

The NIDILRR-funded RRTC on Disability in Rural Communities is currently adapting the Living Well with a Disability Program, originally funded by the Centers for Disease Control and Prevention, into an online multimedia program. [http://healthycommunityliving.com/living-well-in-the-community.html](http://healthycommunityliving.com/living-well-in-the-community.html)
The National Center for Health, Physical Activity, and Disability offers a wealth of information and resources to help people with disabilities maintain a healthy, active lifestyle, including examples of adaptive exercise and recreation and resources for fitness professionals. https://www.nchpad.org/

EnhanceWellness is another evidence-based wellness program targeting chronic conditions that encourages older adults to take on health challenges and maintain control of their lives. This program is also available through senior centers across the US. http://projectenhance.org/AboutUs.aspx

To Learn More About this Study

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.

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