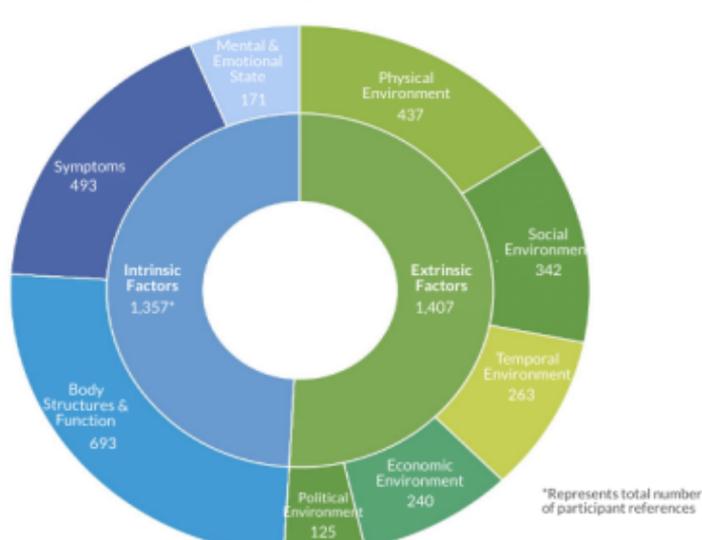


Longitudinal Study of People Aging with Long-Term Physical Disabilities: Health & Participation

We surveyed 475 people with disabilities between the ages of 45 and 65 on their health and participation in order to learn more about the needs of people aging with disabilities. We used qualitative analysis to explore the themes participants expressed in open-ended questions about their health and participation

Themes

Analysis uncovered 8 themes comprising both intrinsic factors (relating to the individual) and extrinsic factors (relating to the individual's environment).



"At restaurants and friends' houses, there are often steps and bathrooms that are not accessible for wheelchairs. Even movie theaters don't have electric doors. My 'unpaid help' is always my husband, friend or family member. My husband will lift me up steps, hold the door, and even help with the restroom, if necessary. Friends are always willing to help hold the door, give me a push, cut my food, etc., but I try to do as much as possible."

Common Barriers

Body Structures & Function

This theme relates to a person's physical health, including anatomy, physiology and the physical effects of one's disability.

"Sometimes I feel isolated. I know that all I have to do...is pick up the phone and ask someone, but I am uncomfortable going out much of the time due to mobility and bladder/bowel issues."

Symptoms

Symptoms related to both aging and disability were described as barriers. We further categorized symptoms as fatigue, pain and sleep problems.

"I used to love going out with my friends and socializing, but now it is too difficult to even show basic affection like hugging. Even petting my cat can be too difficult because of the pain."

Transportation

Participants frequently mentioned transportation, falling under the Environmental Factors theme, as a barrier to their participation in the community.

"Waiting for buses is an all-day job. It can sometimes take 6 hours round-trip to go 7 miles to and from a doctor's appointment, plus the time for the appointment."

But Themes Were Not Discrete

Participants often reported that one factor influenced or combined with other factors to affect their participation. For example, one participant shared that the stress (mental and emotional states) resulting from managing her symptoms interfered with her ability to work and volunteer:

"I've tried to work since my diagnosis, but the stress was unmanageable. I completely stopped taking care of myself and was always utterly overwhelmed. I wish I was able to earn a little extra income or be able to volunteer in my community. I'm unable to keep a regular schedule due to my illness and managing my multiple sclerosis symptoms. It can be very demoralizing, so I always try to concentrate on all my blessings and keep my gratitude at the center of my thoughts."

The diverse needs of people aging with physical disabilities must be considered in order to improve the effectiveness of services and interventions. Each of the 8 themes we found could be a target for intervention.