

Factors influencing participation among adults aging with long-term physical disability

People aging with long-term physical disabilities can face barriers to living independently and participating in the activities they want and need to do. In order to address those barriers, researchers and community organizations must first understand them and how they affect the individual. We analyzed answers to open-ended questions from the first year of our three-year survey of people aging with long-term physical disabilities to learn about factors that affect their participation in personal and life activities. Participants in the study answered questions about the barriers they faced and supports they needed to successfully participate in nine activity categories:

Daily Activity	Example
Interior household chores	Cleaning, laundry, running errands, cooking
Exterior household chores	Yard work, taking care of pets, home maintenance, car maintenance
Managing medical conditions	Going to the doctor managing medical bills
Employment	Paid work, full- or part-time
Physical exercise	Working out, playing a sport, going for a walk
Religious and civic activities	Volunteering, going to church, praying or meditating
Personal leisure	Watching movies/videos, TV, reading, playing games, doing puzzles
Social activities/helping others	Visiting friends or family, helping others, communicating,
Community leisure	Going to movies, concerts, restaurants

We then organized these responses by assigning codes and grouping them into themes.

A total of 215 participants took part in the survey. Factors that affected respondents' participation fell under eight themes. These themes, as well as related subthemes, are listed below in order of how often they were described; the number of references to each category is included in parentheses.

Theme	Description	Examples from respondents
Body structure and function (639)	Physical health, including body parts and functions, as well as the physical effects of disability Subthemes: mobility, balance, cognition, strength, sight, sensation, hearing	Discomfort going out due to bowel and bladder issues
Symptoms (493)	Symptoms related to aging and disability Subthemes: fatigue, pain, sleep problems	Pain interfering with ability to socialize with friends
Physical environment (437)	Any aspect of the physical environment	Difficulty making/keeping appointments because of inadequate public transportation

	Subthemes: natural environment, transportation, assistive technology, the built environment (e.g., roads, sidewalks, buildings)	
Social environment (340)	Relationships, behaviors, and social situations Subthemes: social support, social attitudes and accessibility, access to knowledge and information	Losing friends from before diagnosis
Temporal environment (263)	Timing, routines, and sequencing Subthemes: Experiencing changes in function over time, time limitations, time management	Not enough time to exercise
Economic environment (240)	Access to financial resources; financial constraints	All funds go to necessities; no money remaining for social, leisure, or community activities
Mental and emotional state (171)	Mental and emotional health Subthemes: depression, fear of worsening health problems, anxiety, stress, feeling a lack of purpose, substance abuse	Staying at home more due to depression
Policy environment (125)	The systems and policies that can affect the individual and their participation Subthemes: healthcare, insurance, Social Security Insurance (SSI) Social Security Disability Insurance (SSDI), additional policies at the local, state, and national level	Lack of insurance makes it difficult to go to the doctor regularly

Respondents described a combination of factors relating to the person (body structures and function, symptoms, mental and emotional state) and the environment surrounding that person (physical, social, temporal, economic, and policy environments).

While we found eight distinct categories, respondents often described one factor influencing or combining with other factors to affect their participation. For example, respondents described feeling less motivated (mental and emotional state) when they were fatigued (symptom). When faced with transportation barriers (physical environment), respondents were less likely to socialize in the community (social environment). One respondent shared that the stress (mental and emotional state) of 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 multiple sclerosis symptoms. It can be very demoralizing, so I always try to concentrate on all my blessings and keep my gratitude in the center of things.

People aging with long-term physical disabilities experience a range of factors that may affect their ability to remain independent and participate in society. By pinpointing barriers to participation, new programs addressing these barriers can be designed. Our respondents' experiences depended on many factors; these eight categories overlapped and interacted in complex ways to shape the experience of participation. These complexities must be considered when designing programs to promote participation for people aging with physical disabilities.