

## 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 important everyday activities. To address those barriers, researchers and community organizations first need to understand them and how they affect participation. We analyzed the answers to open-ended questions from the first year of our 3-year survey of people aging 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 as well as supports they use to participate in nine activity categories:

Daily Activity	Example
Interior household chores	Cleaning, laundry, errands, cooking
Exterior household chores	Yard work, taking care of pets, home maintenance, car maintenance
Managing medical conditions	Going to the doctor, managing doctors' 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, or TV; reading; playing games; doing puzzles
Social activities/helping others	Visiting friends or family, helping others, communicating
Community leisure	Going to movies, concerts, restaurants

Factors that affected participation fell under eight themes. These themes, as well as related subthemes, are listed below in order of how often they were mentioned.

Theme	Description	Examples from respondents
Body structure and function	Physical health, including body parts and functions and the physical effects of disability  Subthemes: mobility, balance, cognition, strength, sight, sensation, hearing	Not comfortable going out because of bowel and bladder issues
Symptoms	Symptoms related to aging and disability  Subthemes: fatigue, pain, sleep problems	Not going out with friends as often due to pain
Physical environment	Any aspect of the physical environment  Subthemes: natural environment, transportation, assistive technology, the built environment (e.g., roads, sidewalks,	Trouble making/keeping appointments because of poor public transportation

	buildings)	
Social environment	Relationships, behaviors, and social situations  Subthemes: social support, social attitudes and accessibility, access to knowledge and information	Losing friends from before diagnosis
Temporal environment	Timing, routines  Subthemes: Experiencing changes in function over time, time limitations, time management	Not enough time to exercise
Economic environment	Access to financial resources; financial limitations	All funds go to necessities; no money left for social, leisure, or community activities
Mental and emotional state	Mental and emotional health  Subthemes: depression, fear of health problems getting worse, anxiety, stress, drug or alcohol abuse	Staying home more due to depression
Policy environment	The systems and policies that can affect the individual and/or their participation  Subthemes: healthcare, insurance, Social Security Insurance (SSI) Social Security Disability Insurance (SSDI), other policies at the local, state, and national level	Lack of insurance makes it hard to go to the doctor regularly

Respondents described a variety of factors relating to both the person (body structures and function, symptoms, mental and emotional state) and the environment around the person (physical, social, temporal, economic, and policy environments) that influence their participation. One factor often influenced or combined with other factors to affect participation for the people in our study. For example, respondents described feeling less motivated (mental and emotional state) when they were fatigued (symptom). When faced with transportation barriers (physical environment), they were less likely to socialize in the community (social environment). One respondent shared that the stress (mental and emotional state) of managing her symptoms got in the way of 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 wide range of factors that may affect their ability to remain independent and participate in important everyday activities. Our respondents' experiences depended on many factors; the eight categories we found overlapped and interacted to shape the experience of participation for them. These complexities should be considered when designing programs to promote participation for people aging with long-term physical disabilities.

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