

Three-Year Study of Health and Participation for People Aging with Disabilities: Project Summary

You took part in a study on your health and participation in home, community and social activities. We held this study because people with disabilities can face changes in their health and function as they age, but not much is known about how those changes can affect their participation in everyday life activities.



The ultimate goal of this project was to gather information that community-based organizations (e.g., Area Agencies on Aging and Centers for Independent Living) can use to support people aging with disabilities.

Specifically, we wanted to find out about:

1. How health factors relate to participation
2. Changes in participation over time
3. How community organizations can support participation for people aging with disabilities

The Study

Thank you for participating in this study! Every year for three years, you and other study participants took a survey on your health and participation in different kinds of activities.

Survey Questions

You answered questions about:

- Social and demographic factors (*race, gender, marital status, education*)
- Health and function (*number of years with disability, other health conditions, physical function, falls*)
- Symptoms (*pain, fatigue, depression*)
- Participation in home and community activities
- Ability to participate in social roles & activities
- Satisfaction with participation in social roles & activities

Results

You were one of **474** people who took part in this study!

Baseline Findings

Compared to the general U.S. population, participants had:

- Higher fall rates
- More pain, fatigue and depression
- Lower ability to participate in social roles & activities
- Less satisfaction with their participation in social roles & activities

Social Participation



A person's ability to participate in social roles & activities, like visiting with family or talking to a friend on the phone, is important for their overall well-being and health.

In our study, people with more **pain, fatigue** and **depression** had lower scores for both their ability to participate in social roles & activities and their satisfaction with their social participation.

Social participation did not change much over the course of the study. The negative effects of pain, fatigue and depression were also consistent over three years.

Home and Community Activity Participation

We created a questionnaire called the **Participation in Activity Domains Screening Tool (PADS)** to look at everyday activities like chores, employment and leisure. We included PADS questions in the survey to find out what activities study participants were doing and how they felt about the amount of time they spent doing them.

Participants **wanted to spend more time** in:



- Exercise
- Employment
- Exterior and interior household chores
- Community leisure
- Social activities
- Civic/religious activities

Participants **wanted to spend less time** in:



- Managing medical conditions
- Interior household chores
- Home leisure



People said **improved health, transportation, changes to the environment,** and **assistive technology** would help them to do more of the activities they want to do.

Using the PADS to Look at Exercise

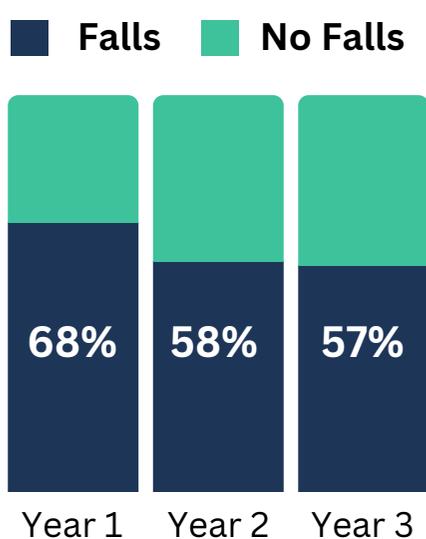
We used the PADS exercise questions to compare participants who said they did and didn't exercise. People who exercised had less pain, fatigue and depression and higher social participation scores (both for ability and satisfaction) than participants who didn't exercise. Participants in both groups listed things that would help them participate in exercise:



- Better health
- Personal assistance
- Environmental modifications
- Assistive technology
- Knowledgeable instructors
- Facilities (e.g., accessible gyms)

Falls

Falls can cause serious injuries, but they can also be prevented. Most programs to prevent falls focus on older adults, but people aged 45-64 who have disabilities are also at risk. We asked study participants about falls, fall-related injuries, and if they worried about falling.



Participants had **high fall rates**: every year, more than half of participants reported falling. There were also high rates of fall-related injuries, and many people were worried about falling.

Participants who fell had higher rates of **pain, fatigue** and **depression** than participants who didn't fall.

Falls also affected social participation: people who fell had lower scores for both ability to participate in social roles & activities and satisfaction with participation in social roles & activities.

Conclusions

Some of the most important findings from this study were the high fall rates and the need to address symptoms of depression, pain and fatigue in people aging with physical disabilities. This study provides community-based organizations with data and tools to understand and support people aging with disabilities to participate in home, social and community activities. It also lays a foundation for future studies to support health and participation for people aging with disabilities.

**Thank you so much for your participation!
This study would not have been possible
without you!**

Papers from This Study

Chen, S.-W., Keglovits, M., Devine, M., Stark, S. (2022). Sociodemographic differences in respondent preferences for survey formats: Sampling bias and potential threats to external validity. *Archives of Rehabilitation Research and Clinical Translation*, 4(1), 1001.

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