

## Participation over time for people aging with disability as measured by a tool designed for use by community-based organizations

People aging with disability can experience changes in their health and function as well as symptoms like pain, depression, and fatigue. This may have a negative effect on their participation in everyday activities. Understanding changes in participation over time could help community-based organizations (CBOs) like Centers for Independent Living and Area Agencies on Aging support participation for their clients who are aging with disability.

To learn about participation in a variety of everyday activities, we developed a set of activity domain questions, the Participation in Activity Domains Screening Tool (PADS). CBOs can use the PADS to assess how a client's participation changes over time, the client's satisfaction with their participation, and how to support participation in activities the client wants to do. We included these questions in our three-year survey of the health and participation of people aging with long-term physical disability.

### PADS Items

The PADS includes questions about participation in nine activities. For each activity, the participant is asked: (1) whether they do the activity, (2) if they would like to do more or less of the activity, and (3) what help they need to improve their satisfaction with the activity.

The activity domains included in the PADS are:

- Chores inside of the house (cleaning, laundry, cooking)
- Chores outside of the house (yardwork, pet care, home maintenance)
- Managing medical conditions (going to the doctor, paying medical bills)
- Employment (full- or part-time paid work)
- Physical exercise (working out, playing sports, walking)
- Home leisure (watching movies or TV, reading, playing games)
- Community leisure (going to movies, concerts, restaurants)
- Social activities (visiting friends and family, helping others, talking on the phone/video chat)
- Civic/religious activities (volunteering, going to community meetings, going to church, praying, meditating)

### The Study

A total of 323 people aging with a long-term physical disability responded to the survey, including the PADS questions, every year for three years. Generally, our sample had high levels of participation. The activities they did the most were managing medical conditions, leisure activities, chores inside the house, and social activities. The activity with the lowest level of participation was employment.

Although participation levels were high overall, many people said that they were not satisfied with the amount of time they spent doing several activities. Specifically, participants said they

wanted to spend more time in exercise, employment, community leisure, social activities, civic/religious activities, and chores (inside and outside). Some participants, on the other hand, said they wanted to spend less time on chores inside the house. Other activities participants wanted to spend less time on were managing medical conditions and home leisure.

There was not much change in participation over the three years of the study. Most change that did take place was people reducing their participation. Specific areas where participation declined were community leisure, civic/religious activities, and social activities. The most common reasons given for reduced participation were aging/health and the COVID-19 pandemic. Things participants thought would help improve their participation were personal assistance, transportation, changes to the environment, and better health.

### Conclusions and Implications

We designed the PADS, a set of activity domain questions for CBOs to use to assess participation for clients who are aging with physical disability. We used these items in a study of people aging with disability to learn about their participation patterns and needs. Study participants said they participated in most of the nine activity domains; however, many were not satisfied with the amount of time they spent on some of the activities. CBOs can use the PADS to understand participation over time, identify participation challenges, and find ways to improve satisfaction with participation for clients who are aging with disability.

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