

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

Understanding participation in everyday life activities, including how it may change over time, for people aging with long-term physical disability may help community-based organizations (CBOs) support their clients' participation goals.

We held a longitudinal study with a cohort of people aged 45-65 who reported a disability of 5 or more years to learn more about:

- How their participation in a variety of everyday activities changed over time
- Their satisfaction with the amount of time they spent doing the activities
- Things that could help promote participation in desired activities



Study participants took a survey once a year for three years. The survey included the Participation in Activity Domains Screening Tool (PADS), a set of questions to examine participation in nine activity domains. We developed this tool for use by CBOs to better understand their clients' participation levels, interests, and needs.

PADS items ask participants: **(1) if they do the activity, (2) if they want to do more or less of the activity, and (3) what they need to improve their satisfaction with the activity.** The questions are modeled after a natural conversation CBO staff would have with clients when assessing service needs. The nine activity domains are:

## Interior Household Chores

*Cleaning, laundry, cooking, errands*

## Exterior Household Chores

*Yardwork, pet care, home maintenance*

## Managing Medical Conditions

*Going to the doctor, managing medical bills*

## Employment

*Full- and part-time work*

## Physical Exercise

*Working out, playing sports, walking*

## Home Leisure Activities

*Watching TV/movies, reading*

## Community Leisure Activities

*Going to movies, concerts, restaurants*

## Social Activities

*Visiting friends/family, helping others, talking on the phone*

## Civic/Religious Activities

*Volunteering, attending community meetings, attending religious services, praying/meditating*



# Findings

We analyzed data from 323 participants who completed all three surveys.

**Generally, respondents had high levels of participation across all activity domains.**

Domains with highest participation:

- Managing medical conditions
- Home leisure
- Interior household chores
- Social activities

Domains with lowest participation:

- Employment
- Exercise
- Exterior household chores

**For all domains, many participants said that they were unsatisfied with the amount of time they spent participating.**

Wanted to spend more time in:

- Exercise
- Employment
- Household chores
- Community leisure
- Social activities
- Civic & religious activities

Wanted to spend less time in:

- Managing medical conditions
- Home leisure
- Interior household chores

Things respondents said that would help improve their participation were **improved health, transportation, environmental modifications, and assistive technology.**



**Overall, participation did not change much over the 3 years of the study**

Most change that did happen was reduced participation. Areas of participation decline were in **community-based leisure, civic & religious activities, and social activities.**

The most common reasons given for reduced participation were declining ability/overall health and the COVID-19 pandemic.

## Conclusions and Implications

The PADS is a set of questions about participation in nine everyday activities. It was designed to be easy for CBOs to use when assessing service needs for clients who are aging with disability.

This tool can be used to help identify participation challenges, changes in participation over time, and how to improve satisfaction with participation for people aging with physical disability.