

## **Survey of People Aging with Long-Term Physical Disability: Year 1 Demographic, Health and Participation Summary**

People with long-term physical disabilities can go through aging-related changes in their health and function earlier in life than people without disabilities. These changes can also happen at a faster rate. Participation, or involvement in life situations like work, school, social or religious activities, also declines for many people with disability as they age. However, few studies have looked at health and participation—and how they change over time—for people aging with long-term physical disability.

We held a three-year cohort study to learn more about these issues. The ultimate goal of this study is to gather the information needed to create programs that promote engagement in important life activities for people aging with disability.

Here, we describe demographic, health and participation information from Year 1 of the study. We also look at how our cohort compares to both the general U.S. population and participants in other studies of people aging with disability. Future reports will look at relationships among these demographic, health and participation factors, as well as how they may have changed over the three years of the study.

### **The Study**

We invited people aged 45–65 with disability for at least five years to take part in the study. People who agreed to be in the study filled out the survey once a year for three years.

We analyzed the answers to questions about their demographics, finances and living situations. These questions included:

- Age
- Race and ethnicity
- Gender
- Marital status
- Years of education
- Living arrangement (living alone vs. living with others)
- Employment
- Food security
- Sources of income
- Health insurance

We asked participants about the main health problem causing their disability. We also asked how many years they have had that health problem. Other health questions were about overall health status, physical function, and common symptoms related to both disability and aging: fatigue, pain and depression.

Finally, we looked at social participation. We asked participants how they would rate their **ability** to participate in their social roles and activities. We also asked how they would rate their **satisfaction** with that participation.

## Year 1 Findings

### Demographics and Finances

The average age was 56.8 years old. Participants had lived with their disability for an average of 19 years. Sixty-four percent reported their race or ethnicity as White.

The majority of participants had social security disability insurance (SSDI), with other sources of income including paid work, social security retirement insurance (SSI, and personal retirement savings. For employment status, most participants said that they were on disability leave. About 35% had an income below the state's poverty level.

### Health and Function

The most common health problems causing disability were:

- Musculoskeletal disorders
  - e.g., osteoarthritis, spinal stenosis, amputation
- Neurological conditions
  - e.g., cerebral palsy, multiple sclerosis, spinal cord disorders, traumatic brain injury
- Immunological problems
  - e.g., rheumatoid arthritis, connective tissue disorders

About 46% said that their health status had declined in the past 12 months, and 54% said that their ability to do the things they want to do in their daily lives had decreased. Participants had higher rates of pain, fatigue and depression than the general U.S. population.

### Participation

Participants in our study reported lower ability to participate in their social roles and activities than the general population. They also had lower satisfaction with their ability to participate in social roles and activities.

## How Do Our Participants Compare to Those of Other Studies?

Overall, our participants have fewer social, financial and physical resources than those in other studies of people aging with disability. Looking at race, our cohort is made up of more than 36% non-White participants, which is higher than the only other cohort study of persons aging with disability that we know of. This diversity is a strength of our study; results will be relevant to a wider array of people aging with long-term physical disability.

Our participants' primary health problems were similar to those in other studies of people aging with disability. Their symptoms (pain, fatigue and depression) were also similar. While our cohort's social participation scores were lower than in the general population, they were similar to other studies of people aging with disability.

Based on these comparisons, we are confident that this cohort can represent people aging with disability in the U.S.

## Next Steps

Future reports on this study will look at relationships among health conditions, falls, the physical environment, use of community services, and participation. We will also explore how these factors may have changed over three years. We believe that this study will lead to programs that support people aging with disability to engage in their communities.

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