



# CEDAR Midwest

## Project Summary

# Introduction

The aging of a population with disabilities poses challenges for community agencies that have traditionally addressed either aging or disability services but not both. To close this gap in services, we completed a series of projects bringing together researchers, organizations that serve people with disabilities, and organizations that serve older adults to better understand participation for people aging with long-term physical disabilities who are living in the community.

CEDAR Midwest is a Disability and Rehabilitation Research Project (DRRP) funded by the National Institute on Disability, Independent Living, and Rehabilitation Research that consists of four research projects. The goal of CEDAR Midwest is to translate, adapt and evaluate evidence-based interventions that community-based organizations can use to improve independence and participation for people aging with long-term physical disabilities.

**Project 1** saw the creation of a community-based research network, a group of researchers and organizations that provide services to people with disabilities and/or older adults. **Project 2** was a three-year longitudinal cohort study on the health and participation of people aging with long-term physical disabilities. In **Project 3**, we developed an intervention to promote participation that can be delivered by community organizations, and in **Project 4**, we tested the intervention through the community-based research network. More details on each of the projects are included in this report, and further information can be found at [cedarmidwest.org](https://cedarmidwest.org).

## Project 1

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# Build a Community-Based Research Network

We formed a **community-based research network (CBRN)** to link researchers and community organizations that serve people with disabilities and older adults across Missouri. The goal of the CBRN was to develop programs that can be delivered through community agencies for people aging with long-term physical disabilities.

## CBRN Activities To Date

01

### Form the Network

Representatives of organizations serving urban and rural communities joined researchers in occupational therapy, gerontology and social work to collaborate on ways to best serve people aging with long-term physical disabilities.

02

### Work Together on a Longitudinal Cohort Study

CBRN members helped researchers recruit participants for a longitudinal cohort study of people aging with long-term physical disabilities (Project 2).

03

### Adapt and Test an Evidence-Based Intervention

CBRN members informed the development of a program to promote participation in home and community activities (Project 3) and helped recruit participants to test the program (Project 4).

04

### Generate New Ideas

CBRN members held a focus group to discuss delivering an evidence-based fall prevention program through community organizations. The program is now being pilot tested through several CBRN member organizations. The network is continuing to develop this project.

# Project 2

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## Conduct a Longitudinal Cohort Study

We held a longitudinal cohort study of 474 people aging (45–65) with long-term physical disabilities. Participants took one survey every year for three years.

Participants answered questions about their health; symptoms (pain, fatigue and depression); and participation in home, community and social activities.



## Cohort Study: Baseline Findings

Compared to the general U.S. population, our 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

The health conditions and symptoms participants reported were similar to those seen in other studies of people aging with disabilities.

While lower than general population averages, social participation scores were also similar to those in other studies of people aging with disabilities.

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# Cohort Study: Activity Participation

We created the **Participation in Activity Domains Screening Tool (PADS)** for community-based organizations to assess participation in everyday activities (e.g., household chores, employment, leisure) for people aging with disabilities. We used the PADS in the longitudinal cohort study to see what activities participants were doing, what they wanted to do more or less of, and what supports could facilitate their participation in the activities they want to do more.

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

Participants said the following would facilitate their participation: **improved health, transportation, environmental modifications** and **assistive technology**.



## Activity Participation Over Time

Activity participation remained relatively stable over three years. Most of the changes that did happen were decreased participation in community leisure, civic and religious activities, and social activities.

Individuals whose participation declined attributed it to disability- or aging-related changes and the COVID-19 pandemic.

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## Using the PADS to Look at Exercise

We compared participants who reported exercising with those who didn't. Participants who exercised had **lower pain, fatigue and depression; greater self-efficacy; 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 enable their participation in exercise:



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

## Cohort Study: Social Participation



A person's ability to participate in social roles and activities is important for their health and wellbeing. We looked at factors that affect social participation, as well as how social participation changed over time, for study participants.

Greater **pain, fatigue and depression** were associated with lower social participation scores. Personal factors including age, gender, race, income and living situation (alone or with others) were also associated with social participation.

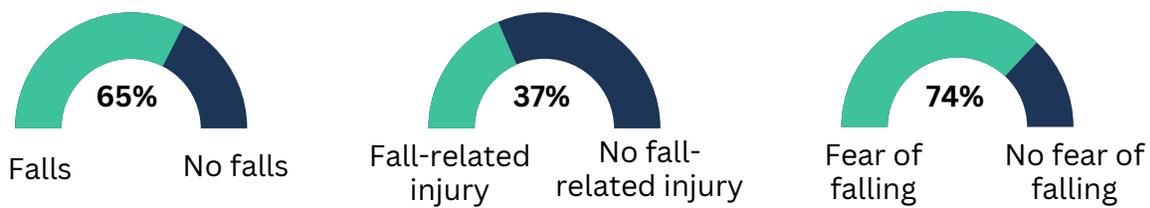
Social participation ratings did not change much over the course of the study. The impacts of pain, fatigue and depression were also consistent over time. Strategies and treatments to reduce these symptoms can support social participation for people aging with long-term physical disabilities.

# Cohort Study: Falls

Falls can cause serious injury, institutionalization and even death, but they are preventable. Most fall prevention research and programs concentrate on older adults, but people who are aging with disabilities are also at risk of falls. We asked participants about their falls, fall-related injuries and fear of falling.

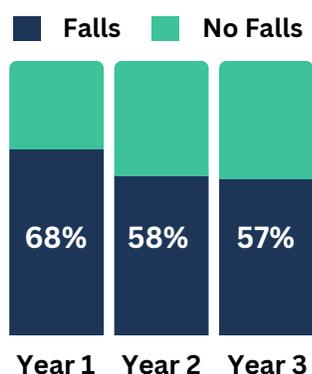
## Baseline Findings

We looked data from the first year of the study and found high rates of falls, fall-related injuries and fear of falling.



We also found a **relationship between falls and social participation**: people who fell had lower scores for both ability to participate in social roles & activities and satisfaction with their participation in social roles & activities.

## Falls over Time



We analyzed data from all three years of the study to look at trends over time and found associations between falls and symptoms of **pain, fatigue** and **depression**.

The severity of fall outcomes changed significantly over three years, with the greatest change occurring after the first fall. **Tailored interventions to prevent falls are needed to support health and participation** for people aging with long-term physical disabilities.

## Project 3

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# Adapt an Evidence-based Intervention

We developed an intervention to promote participation in home and community activities for people aging with long-term physical disabilities: Removing Environmental Barriers to Independent Living (REBIL). REBIL was informed by:

### **COMPASS**

Community Participation Transition After Stroke, a program to support activity participation for people returning home from rehabilitation after a stroke

### **HARP**

The Home Hazard Removal Program, an intervention to prevent falls by removing hazards from the home

### **Interviews and Focus Groups**

Input from people aging with long-term physical disabilities and service providers

### **Longitudinal Cohort Study**

Data from our longitudinal cohort study (Project 2)

### **Community-Based Research Network**

Feedback from our community-based research network (Project 1)

## **REBIL Process**

- 1.** Participant demonstrates activities that they have difficulty with for the occupational therapist (OT).
- 2.** Participant and OT identify barriers that make the activities difficult, as well as fall hazards in the home.
- 3.** Participant and OT work together to resolve barriers and remove fall hazards.
- 4.** OT trains the participant to safely use new equipment and/or strategies to complete daily activities.



## Project 4

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# Test an Evidence-Based Intervention

Fifty people aging with long-term physical disabilities participated in a pilot study to test the efficacy and feasibility of REBIL.

Twenty-four people received the REBIL intervention, and 24 people in the control group participated in life interview sessions. We compared the REBIL and control groups to see what impact REBIL had on:

- Activity performance
- Environmental barriers to activity performance
- Community participation
- Fall hazards in the environment
- Fall prevention behaviors

## Results



The most common hazards were lack of bath/shower rails, seating surfaces, lawn/garden grounds, shower recesses, and lack of toilet grab rails.

On average, there were 11.3 modifications per participant. Six months after the intervention, 94.5% of implemented modifications were still in use. We found that it was feasible to deliver REBIL to individuals aging with long-term physical disabilities through community-based organizations.

The REBIL group had trends toward improved activity performance, reduced activity limitations, and reduced falls.

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# Conclusion

The goal of this project was to build capacity for community-based organizations to support community participation for people aging with long-term physical disabilities. We brought together organizations that serve older adults and people with disabilities, held a three-year study on health and participation, and adapted and tested an evidence-based program.

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## Highlight 1

This population has high rates of pain, fatigue and depression, which impact social participation

- Community organizations and health-care providers should screen for these symptoms and provide strategies and treatments to manage them.
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## Highlight 2

People aging with long-term physical disabilities have high rates of falls, fall-related injuries and fear of falling

- Fall-prevention interventions are needed to promote health and participation for people aging with long-term physical disabilities.
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# Future Directions

Discussions with our CBRN and findings from our longitudinal cohort study revealed the need for evidence-based fall prevention programming for people aging with long-term physical disabilities. We have partnered with some CBRN member organizations to pilot test the Home Hazard Removal Program in this population.

# Papers

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Morgan, K. A., Putnam, M., Espin-Tello, S. M., Keglovits, M., Campbell, M., Yan, Y., Wehmeier, A., & Stark, S. (2023). Aging with long-term physical disability: Cohort analysis of survey sample in the U.S. [version 2; peer review: 1 approved, 1 approved with reservations]. *F1000Research*, 11, 68.

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