

Community Engagement for Disability and Aging Research (CEDAR) Midwest

Issue 1: Summer 2018

Welcome to the inaugural quarterly newsletter of CEDAR Midwest. CEDAR Midwest is a Disability and Rehabilitation Research Project funded by the National Institute of Disability, Independent Living and Rehabilitation Research. This research project will explore the participation needs of people aging with a physical disability in the community and how community organizations can best meet those needs.



As people with disabilities age,

barriers to independence and community participation frequently increase. This occurs for a variety of reasons, including, but not limited to, the onset of new health problems and functional limitations, as well as lack of transportation or personal assistance services.

- Long-term support service providers like Centers for Independent Living can help provide assistance (e.g., home modifications, personal care attendant services, assistive technology) to people with disabilities, and
- Area Agencies on Aging can offer assistance (e.g., meal delivery, transportation) to older adults.

People aging with disabilities, however, are a “crossover” population that potentially qualifies for both age- and disability-related services. Improving communication between agencies that provide services for people with disabilities and older adults is vital to increase access to services and, thus, independence for people aging with physical disabilities.

To help improve the programs and services of these community agencies, we have formed a network of providers to:

- improve communication between different types of service providers,
- test the effectiveness of new programs for people aging with disabilities and
- share these evidence-based discoveries so that they can be implemented in other communities.

The overall goal of CEDAR Midwest is to bridge the gap between service providers for this population and advance the understanding of the health and well-being of individuals with long-term disabilities, along with their needs for services and supports and their preferences for community participation.

CEDAR Midwest—Mission and Importance

With the ultimate goal of improving participation for people aging with disabilities in the community, CEDAR Midwest will:

1. Bring together community agencies that serve people with disabilities (i.e., Centers for Independent Living) and older adults (i.e., Area Agencies on Aging) to form a community-based research network
2. Understand how participation changes over time as people with long-term physical disabilities also experience aging-related changes
3. Adapt and test an evidence-based intervention for people aging with disabilities



About the Grant

This project is funded by the National Institute of Disability, Independent Living and Rehabilitation Research's (NIDILRR's) Disability and Rehabilitation Research Projects (DRRP) program. The

DRRP program funds projects that carry out research, development, demonstration, training, dissemination, utilization and/or technical assistance with the goal of increasing the inclusion and integration of people with disabilities in the community. NIDILRR's goals are to:

1. generate new knowledge and promote the effective use of that knowledge to improve the abilities of people with disabilities to perform activities of their choice in the community, and
2. expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

CEDAR Midwest contributes to both of these aims by building innovative new practice networks of Centers for Independent Living and Area Agencies on Aging to bridge a gap in services for people aging with a disability, to work together to address unanswered questions about aging in place with a disability, and to translate our research findings into practice.

Our Team

CEDAR Midwest includes well-established scientists in rehabilitation/participation science and aging research, and community organizations that serve both older adults and people with disabilities. Our team is experienced in community-engaged research approaches. The institutional partners, Washington University, Paraquad and the Simmons School of Social Work, are leaders in participation and aging with disability. Scientific and community advisory boards enhance the team and ensure the scientific rigor and community focus of our projects. To learn more about our team, please visit cedarmidwest.org.

Team Member Spotlight:

Susy Stark, Principal Investigator



Each quarter, we will spotlight one of our research team members. This month, we introduce Dr. Susy Stark, principal investigator of the project.

Susy Stark, PhD, OTR/L, is an Associate Professor of Occupational Therapy, Neurology and Social Work and Co-director of the TL1 Program at Washington University in St. Louis. Susy earned her master's degree in occupational therapy from Washington University and her doctoral degree in environment and behavior science from the University of Missouri. She is currently Principal Investigator of the Participation, Environment and Performance Laboratory in the Washington University Program in Occupational Therapy, where she conducts research focusing on the influence of the environment on the daily activity performance and participation of community-dwelling older adults with chronic conditions. The goal of her work is to support aging in place at home and to prevent falls via clinical trials and implementation studies with community-dwelling older adults. She promotes the participation of older adults with functional limitations through the provision of intensive, tailored environmental interventions that are designed to enhance daily activity performance.

Susy conducts community-based clinical trials, focusing on the implementation of evidence into practice. These nationally recognized interventions, including home modification and fall-prevention programs, have been adopted by multiple organizations where she has held voluntary leadership positions, including the St. Louis Area Agency on Aging, the St. Louis Naturally Occurring Retirement Community, and Home Services, Inc., a local organization that provides free assessments, home modifications and repairs for aging adults wishing to remain in their own homes. With her extensive

community collaborations, she has been able to offer outstanding opportunities for her students, regularly instilling in them her own passion for community service. Her students and staff offer hundreds of free fall-prevention workshops and home assessments to older adults each year. For more information on Susy's research, please visit her [lab website](#).

Project 1: Development of a Community Network

About the network

The first component of CEDAR Midwest was to develop a strong regional network of service providers who do not typically work together. Our network has linked aging and disability service providers with researchers in rural and urban Missouri.

Our network is poised to generate new research questions, explore readiness to change, disseminate new interventions and determine client knowledge and preferences.

What does this network look like?

Six community organizations that serve people with disabilities and/or older adults were originally recruited to participate in the network, the Missouri Aging and Disability Research Network (MADRN). The six original community members include three Centers for Independent Living, two Area Agencies on Aging and one Center for Independent Living/Area Agency on Aging hybrid organization. After presenting on previous successful community partnerships at the annual Missouri Aging Summit, we recruited three additional aging organizations, two of which have joined MADRN.



For more information about the members of MADRN, please visit our website, cedarmidwest.org.

MADRN Mission Statement:

MADRN members came together to create the following mission statement:

The mission of the Missouri Aging and Disability Research Network is to accelerate the translation, adaptation, evaluation *and* availability of evidence-based interventions designed to improve independence and community participation for people aging with long-term physical disabilities.

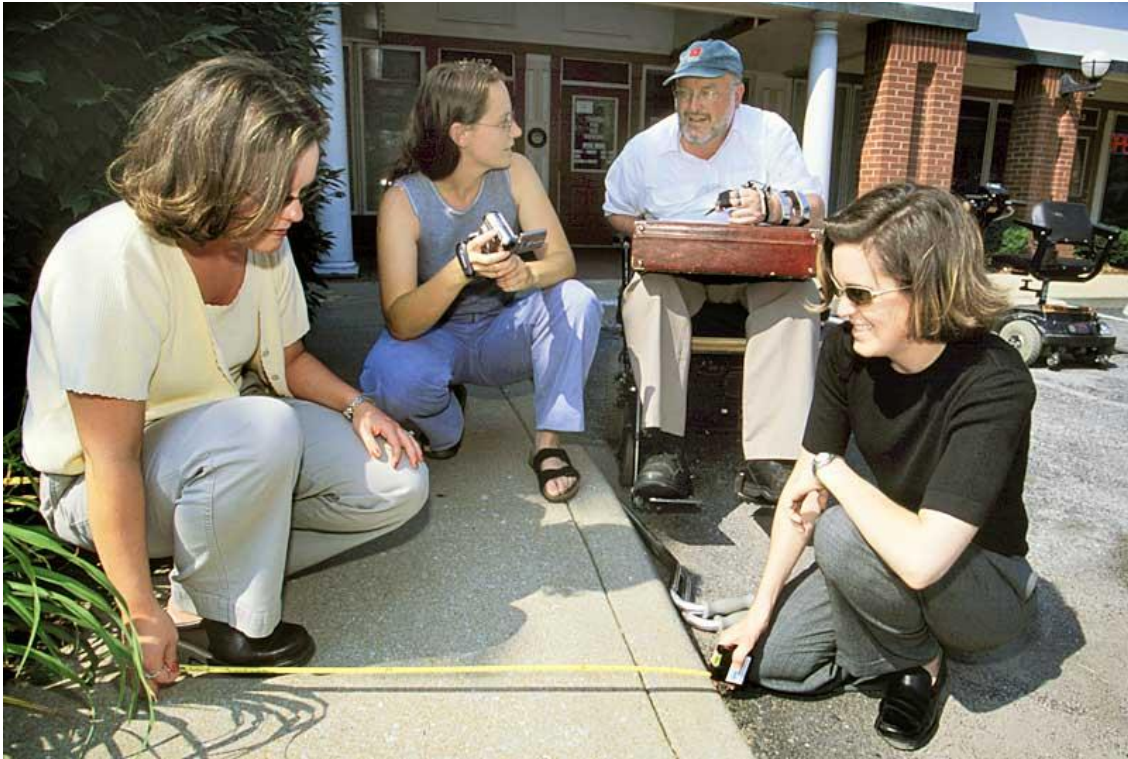
Project 2: Conduct a Longitudinal Cohort Study

Current research on participation among people with disabilities in general is limited in how it explores the ways participation changes over time, how those changes relate to growing older, and the effects of personal and environmental factors on community participation. We hope to change that with the second CEDAR Midwest project: a community-based, multi-disciplinary, longitudinal study that will inform community-based organizations about changing needs, areas for potential intervention and overall participation patterns for people aging with a long-term physical disability.

This intervention will study the factors that affect participation (e.g., physical, behavioral, environmental), ultimately promoting sustained participation for individuals aging with a long-term physical disability. In short, the goal of this study is to investigate changes in participation over time among people aging with a long-term disability.

For this study, 360 people aging with a long-term physical disability will fill out surveys about their health and participation patterns once a year for three years to measure changes in their participation, as well as their use of services and supports in the community, over time.

If you are aging with a long-term physical disability and would like to participate in our study, please email us at cedardmidwest@paraquad.org.



Projects 3 and 4: Adapt and Test an Evidence-Based Intervention for People Aging with Disabilities in the Community

The third project CEDAR Midwest will undertake is to adapt a home modification and self-management intervention for people aging with disabilities. The Community Participation after Stroke (COMPASS) intervention is a complex intervention that combines two evidence-based treatment strategies: home modifications and self-management. A tailored home modification intervention will help remove barriers in the home. Self-management incorporates the ability to use problem-solving skills to manage a health condition. Building self-management skills enables people with disabilities to successfully identify and resolve barriers to participation. Key components include education about the influence of the environment on function, instruction in problem solving to modify the

home and community environment, and generalization of strategies for emerging problems.

The COMPASS intervention was developed to help facilitate community participation following stroke. For Project 3, we will conduct focus groups and key informant interviews in order to adapt the intervention for people aging with disabilities. Based on this feedback and the results of our longitudinal cohort study (Project 2), we will adapt COMPASS for use with people aging with disabilities in the community. Project 4 will consist of implementing the adapted intervention to test its preliminary efficacy for removing barriers and encouraging participation for people aging with disabilities.

We are currently recruiting participants for focus groups and key informant interviews for Project 3. If you are interested in participating, please email us at cedarmidwest@paraquad.org.

What We've Been Up To...

NAARTC Conference

On March 26, Washington University researcher and CEDAR Midwest team member Brittany Minor attended the NARRTC 2018 Conference in Washington, D.C. NARRTC is an organization that promotes research and training with the goal of the full inclusion of persons with disabilities in American society. NARRTC “values excellence in the quality of the research process and product, relevance of research efforts to solving issues of disability and service delivery, and products which are disseminated, used and evaluated in such a manner as to make a difference in the lives of persons with disabilities.” Minor presented a poster describing the development and goals of the community network (MADRN), which was met with interest and enthusiasm by other conference attendees.

American Occupational Therapy Association (AOTA) Conference

On April 20, Susy Stark shared information about CEDAR Midwest at a round table discussion at the AOTA Conference and Expo in Salt Lake City, UT. AOTA is the official national professional association for occupational therapy practitioners and students in the United States. The ATOA Conference and Expo is the largest annual occupational therapy gathering in the world.

Help Us Design Our Logo!

Do you have an eye for design? Help us design our CEDAR Midwest logo by entering the Logo Contest [here!](#)

Things to keep in mind:

- The goal of CEDAR Midwest is to study the participation needs of people aging with a disability in the community and how community organizations can best meet those needs.
 - Our target audience is people aging with disabilities, caregivers/family of people aging with disabilities, community organizations that serve older adults and/or people with disabilities, and researchers in the field of aging and/or disability.
 - Logo resolution should be at least 72 pixels per inch.
 - Please note that if we choose to use your logo, any copyright will be given to CEDAR Midwest.
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What's Coming

- Recruitment for cohort study and focus groups

- Presentation at Show Me Summit on Aging

Technical Assistance

For technical assistance with any part of this project including information, resources and data, please call **314-289-4270** or email us at **cedarmidwest@paraquad.org**. Find out more at cedarmidwest.org.

Do you know someone who is aging with a disability, a caregiver or relative of someone aging with a disability, or a service provider who may be interested in any part of our project? Please feel free to share our newsletter!

[Click here to subscribe to our mailing list.](#)