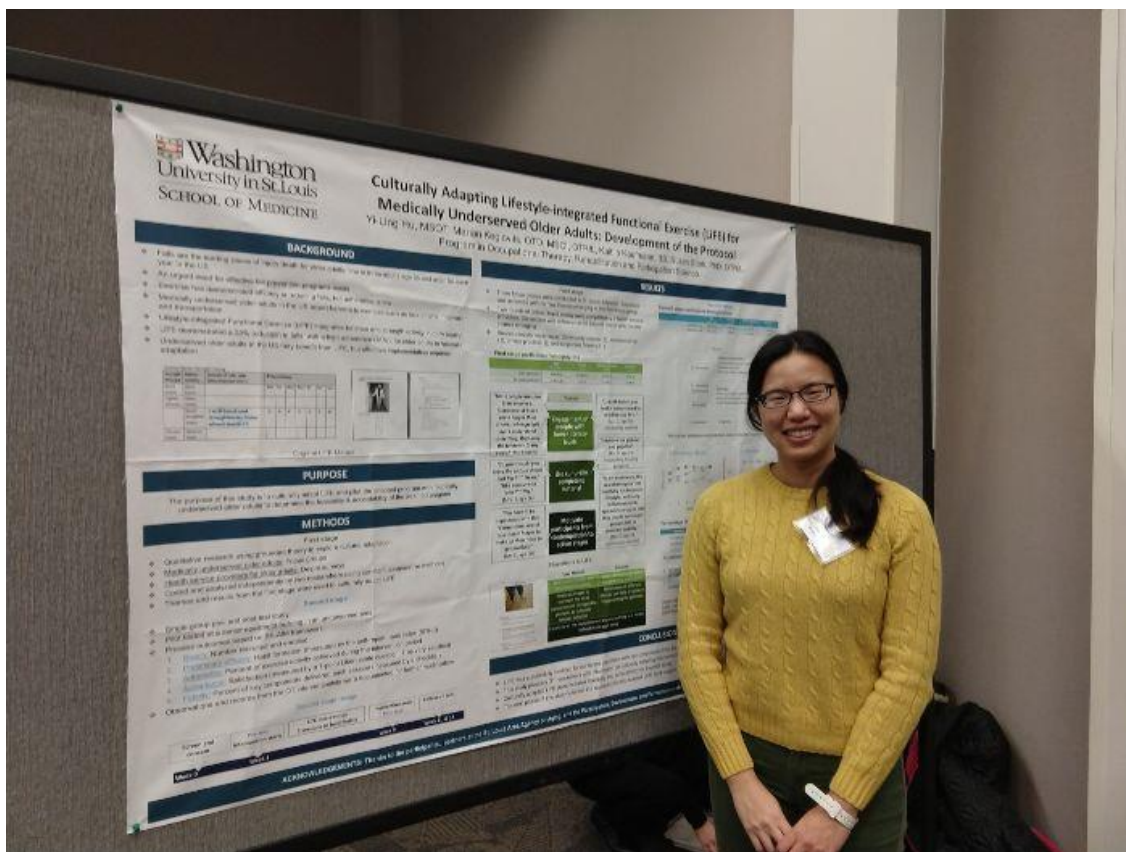


Community Engagement for Disability and Aging Research (CEDAR) Midwest

Winter 2019

CEDAR Midwest is a Disability and Rehabilitation Research project funded by the National Institute of Disability, Independent Living and Rehabilitation Research. This 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.



Washington University PhD student Yi-Ling Hu presents a poster at the Washington University ICTS Symposium on an exercise intervention to reduce falls among community-dwelling older adults

Current Projects

Community-Based Research Network

Our community-based research network, the Missouri Aging and Disability Research Network (MADRN), is a network of community organizations that provide services for older adults and people with disabilities in Missouri. In our first year, we have shared webinars and in-person trainings with MADRN members, who have in turn helped design our longitudinal cohort survey and recruit participants for the study. MADRN member organizations have recently completed a survey about the network's progress so far and what they would like to see going forward. We look forward to sharing the results.

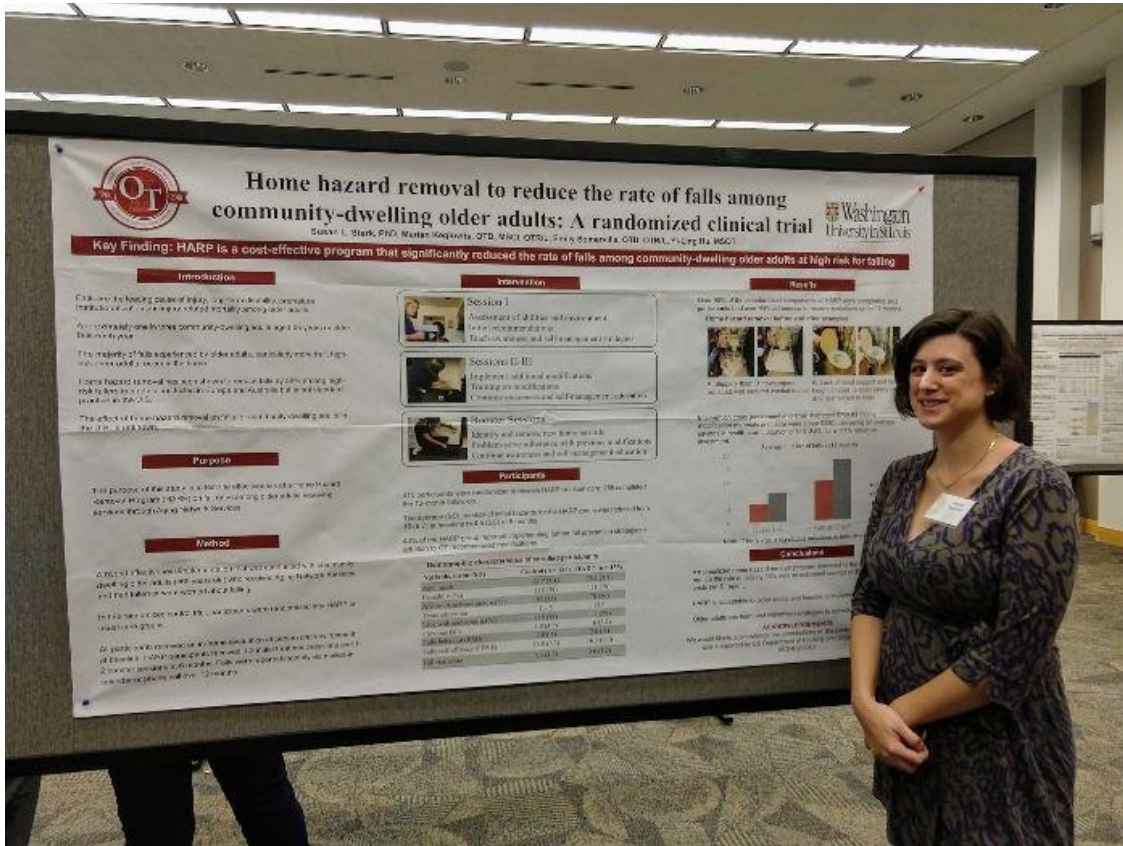
Cohort Study

Current research on participation among people with disabilities 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 answer some of these questions with a longitudinal study to inform community-based organizations about changing needs, areas of potential intervention and overall participation patterns of people aging with long-term physical disability. In short, the goal of the cohort study is to investigate how participation changes over time for people aging with a long-term physical disability.

For the study, we are recruiting 360 people aging with a long-term physical disability to 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 between the ages of 45 and 65, have had a disability for 5 or more

years and would like to participate, please [click here](#). We are particularly looking to increase the representation of men in our study. Please share with anyone you know who may be interested!



CEDAR Midwest researcher Marian Keglovits presents a poster at the Washington University ICTS Symposium on a home hazard removal program to reduce falls among older adults

Focus Groups

The community Participation after Stroke (COMPASS) program is a complex intervention that combines two evidence-based treatment strategies: home modifications and self-management. A home modification intervention will help remove barriers in the home, and self-management education teaches participants problem-solving skills to manage their health conditions. Building self-management skills enables people with disabilities to successfully identify

and resolve barriers to participation.

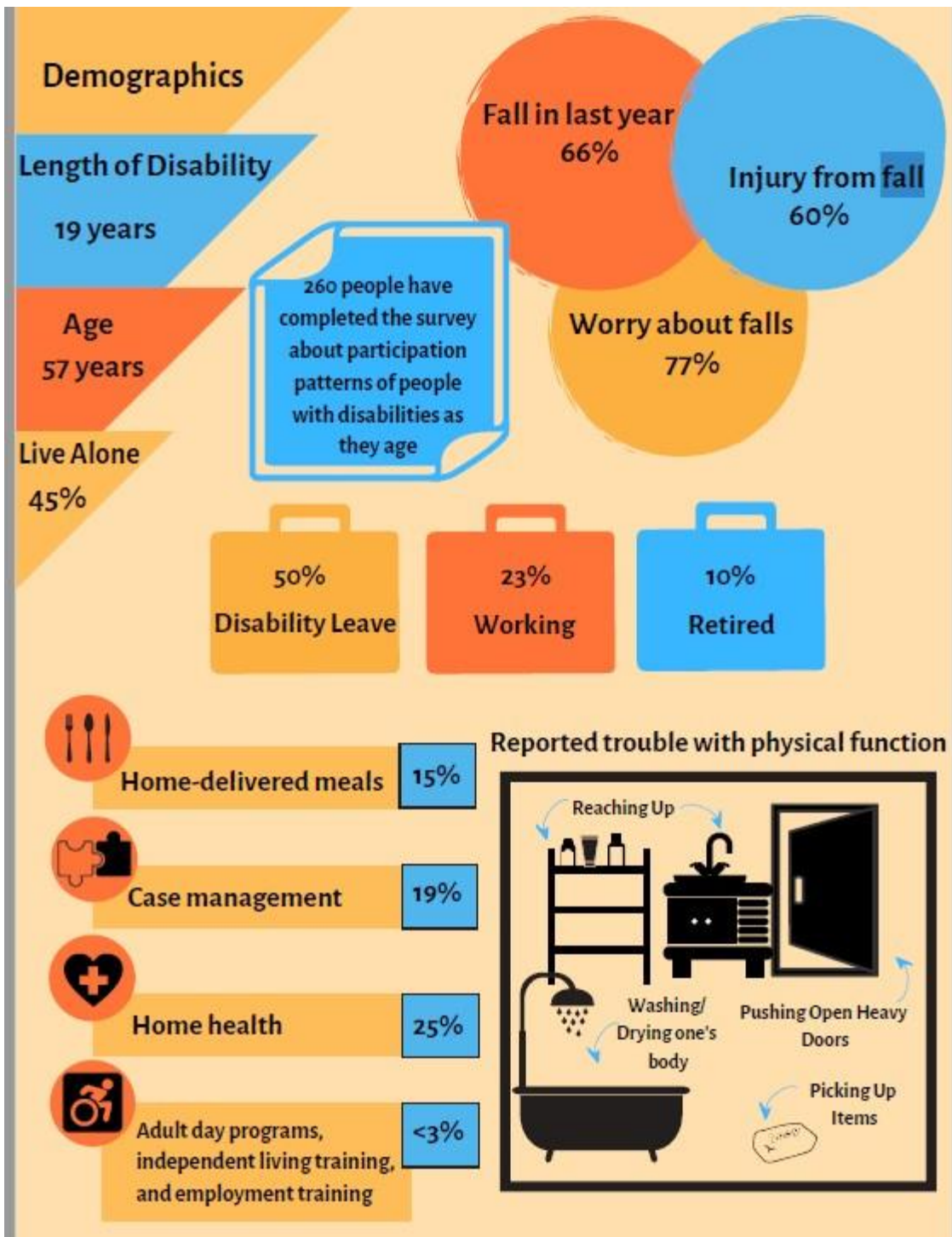
The COMPASS intervention was developed to help promote community participation following stroke. We will adapt this program for people aging with long-term physical disabilities. In order to adapt the COMPASS, we are conducting focus groups and key informant interviews to learn how the program can be tailored to best work for people aging with disabilities.

We are currently recruiting people aging with disabilities and service providers for focus groups and key informant interviews for this project. If you are interested in participating, please email us at cedarmidwest@paraquad.org.

What We're Learning So Far

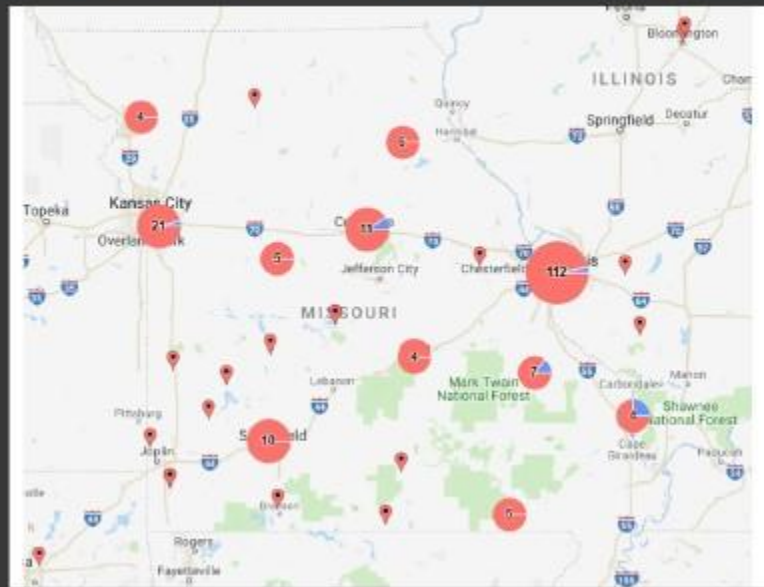
Cohort Study

As of January 25, 260 people have completed the cohort survey to help us learn about the demographics, health conditions, participation patterns and use of community services of people with disabilities as they age. Some of our findings thus far are highlighted below.



Preliminary data from our longitudinal cohort survey on demographics, falls, service use and activities that participants reported having the most trouble with.

Although our primary recruitment focus is on Missouri, people from all over the country have taken the survey.



A look at where our survey respondents are located across the United States (top) and Missouri.

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. Our 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: Sarah Coyle, Information and Referral Specialist

Sarah Coyle, BA, CIRS, is an Information and Referral Specialist at Paraquad Center for Independent Living in St. Louis. Sarah earned her bachelor's degree at Southern Illinois University at Carbondale. She has been with Paraquad for 23 years and is a Certified Information and Referral Specialist through the Alliance of Information and Referral Systems, a national professional organization.



In her supporting role for the CEDAR Midwest technical assistance line, she handles phone and email queries directed to the project. Typically, those topics include information about the project and its goals, how to begin the process of participating in the project, and other wide-ranging community resource information.

Sarah is currently a member of the St. Louis County Commission on Disabilities. She is a past president of the Gateway Chapter of Little People of America and was a member of the Bi-State ADA Committee that assisted in bringing local public transportation into compliance with federal disability law requirements. She also served on the St. Louis Cardinals' Access Advisory Committee for the current stadium.

Sarah's community outreach, in addition to her Information and Referral experience at Paraquad, has furnished her with an extensive background in resources for people living with disabilities and a keen understanding of the independent living philosophy.

What We've Been Up To...

Webinar with Dr. Eric Lenze: Depression

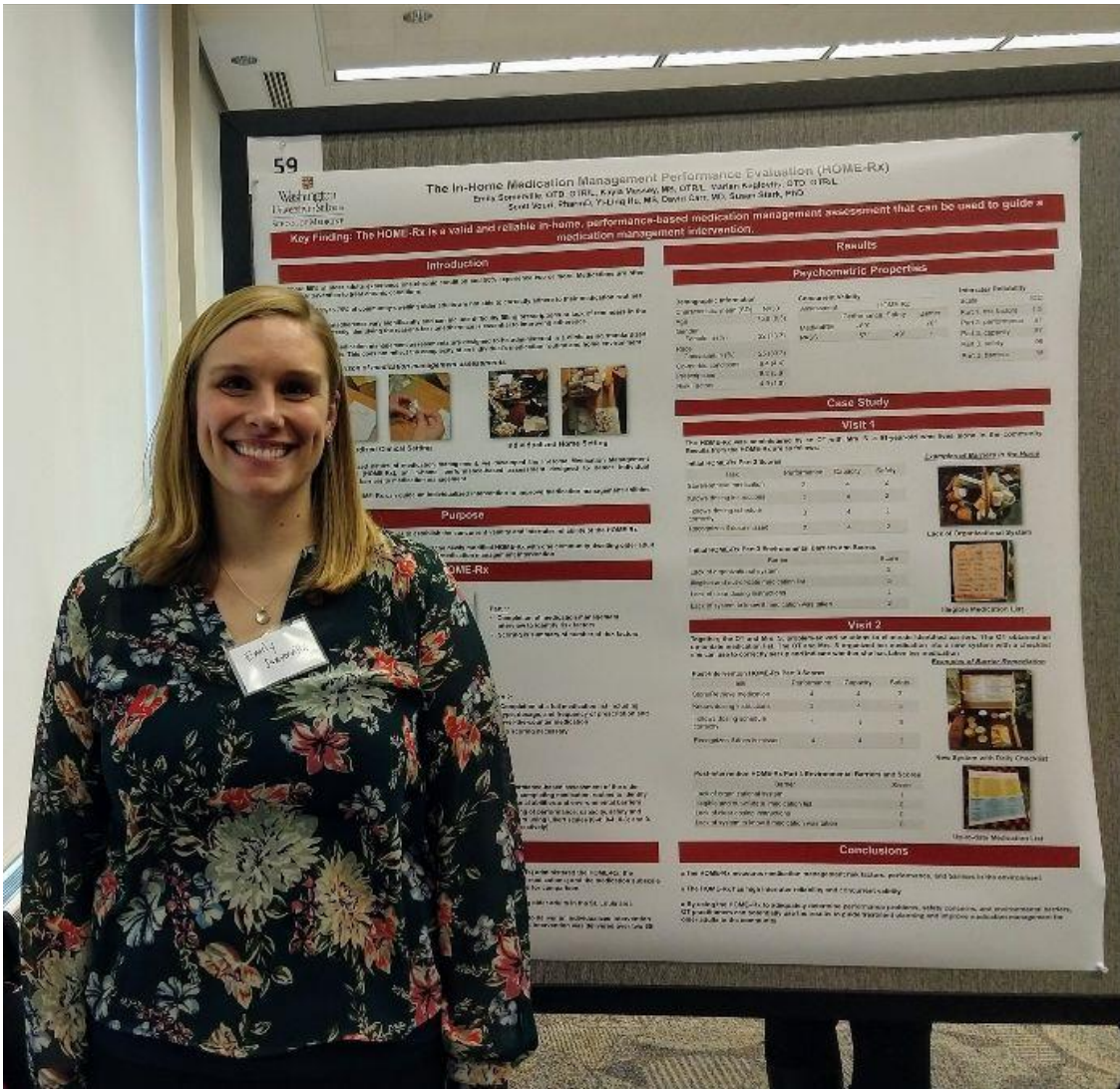
On November 30, 2018, we hosted our first webinar. **Dr. Eric Lenze**, Professor of Psychiatry at Washington University School of Medicine, presented information about the important issue of depression among older adults and people aging with disability. Watch the webinar [here](#).



ICTS Symposium

On 1/15, CEDAR Midwest researchers joined over 170 students, faculty scholars and community partners at Washington University's second annual **Institute of Clinical and Translational Sciences (ICTS)** Symposium. The theme of this year's symposium was From Clinical Discovery to Community Impact. CEDAR Midwest researchers presented posters on a

medication management intervention, a home hazard removal program and a fall-prevention exercise program for older adults living in the community.



CEDAR Midwest researcher Emily Somerville presents a poster on a medication management intervention for older adults at the Washington University ICTS Symposium poster session

What's Coming

Webinar with Dr. Jon Sanford: Technology for Toileting

We will host our next webinar on 3/11 at 12:00 p.m. **Dr. Jon Sanford** from the Center for Assistive Technology and Environmental Access at Georgia Tech

University will join us to discuss assistive technology to help with toileting. Dr. Sanford is a professor in the School of Industrial Design at Georgia Tech and is recognized for his expertise in universal design, accessible design and design for aging. If you are interested in joining the webinar, please email us at cedarmidwest@paraquad.org.

NAARTC Conference

CEDAR Midwest researcher Brittany Minor will present on our adaptation of the COMPASS program at the NARRTC Conference 4/23-4/24 in Arlington, Virginia. The goal of **NARRTC** is "to improve the quality of life, choices and the inclusion of individuals with disabilities and their families through relevant research, training, technical assistance, knowledge translation, development and demonstration activities." The annual NARRTC conference provides an opportunity for National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) grantees to share their research. The theme of this year's conference is Inclusive Disability Research and Practice: Building on Our History.

Help Us Design Our Logo!

Do you have an eye for design? We are still accepting submissions for the CEDAR Midwest logo! Enter 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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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**.