

Community Engagement for Disability and Aging Research (CEDAR) Midwest

Spring 2019

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



Makenna Snyder (second from left), a graduate student in Dr. Stark's lab, answers questions following the presentation of her research on race and fear of falling in older adults at the Washington University Program in Occupational Therapy Scholarship Day, a day for students to share their work with faculty, their fellow students and their families.

Current Projects

Cohort Study

We are conducting 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. The goal of the study is to investigate how participation changes over time for people aging with a long-term physical disability.

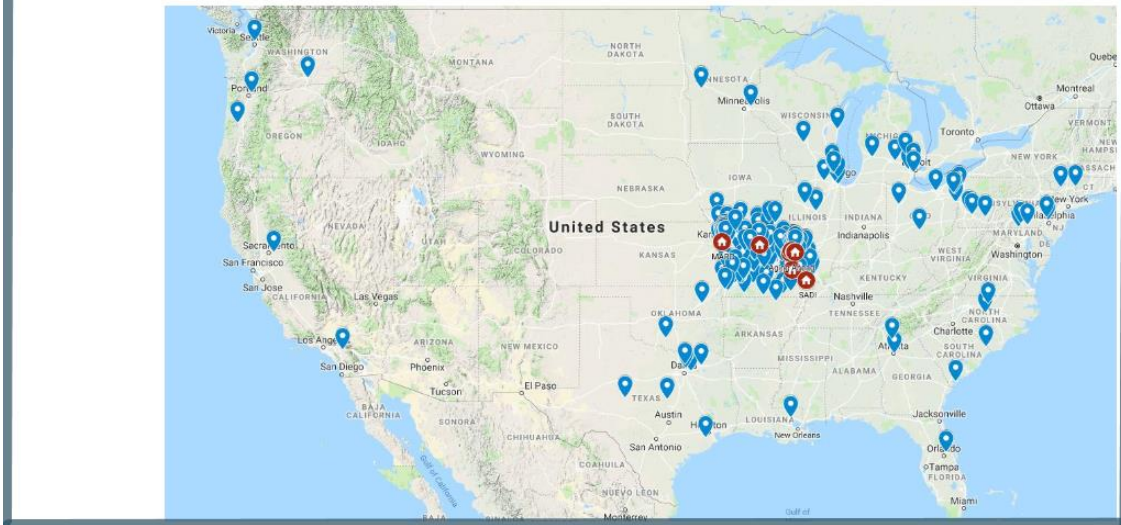
For the study, we are recruiting 360 people aging with a long-term physical disability to fill out surveys about their health and participation patterns once a year for three years to measure changes in their participation, as well as their use of services and supports in the community, over time.

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 email us at cedarmidwest@paraquad.org.

What We've Learned So Far

Cohort Study

LOCATION OF PARTICIPANTS



Although our cohort study recruitment focus has been on Missouri, people across the United States have participated.

So far, 378 people have taken our cohort survey about aging, participation and disability. People all over the country have taken the survey, but participants are primarily concentrated in Missouri. Preliminary data analysis on service use has revealed that 52% of participants feel that they need more help than they are currently receiving, and 60% feel that they need more help than they did one year ago. The most common service used was personal assistance, followed by home health services, home-delivered meals and case management. We look forward to entering our second year of the longitudinal study and further analysis of the data we are collecting.

SERVICE USE



Services used by participants of our longitudinal cohort study

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: Kerri Morgan



Kerri Morgan, PhD OTR/L ATP, is an Assistant Professor in Occupational Therapy and Neurology at Washington University School of Medicine. Kerri earned her master's degree in occupational therapy from Washington University and her doctoral degree in movement science from Washington University. She is the principal investigator of the Enabling Mobility in the Community Laboratory in the Washington University Program in Occupational Therapy, where she conducts research focusing on promoting health and physical fitness for persons with a mobility disability (including but not limited to spinal cord injury, stroke and multiple sclerosis) to enhance participation in meaningful life activities.

Specifically, she is interested in community-based research to bridge the gap between services offered to persons with a disability through rehabilitation and in the community. She has both federal and foundation funding to research exercise, assistive technology and disability. This funded research has helped to develop wheelchair training interventions and exercise education interventions. She has also collaborated with engineering to design a wheelchair roller-based system to be used for exercise and wheelchair training purposes.

Dr. Morgan serves on many organizational and state boards including Paraquad Independent Living Center, St. Louis City Office for the Disabled, Lakeshore Foundation Advisory Council, and Permobil Foundation. She is also an avid wheelchair athlete and three-time Paralympian.

Emerging Topics of Interest

Social Isolation

Social isolation is an emerging topic of interest for organizations that provide services to aging adults and people with disabilities. Social isolation can be

defined as the absence of relationships with family and friends on the individual level, and also with society on a broader level. The concept of social isolation is different from loneliness (a subjective feeling of isolation), but the two are often interconnected (Alspach, 2013). If social interactions occur but are not of the quality that the individual needs or expects, feelings of loneliness may arise (Hand et al., 2017)

Hand and colleagues (2017) conducted a survey of aging adults in an economically diverse urban area to better understand the concepts of social isolation and loneliness. Their survey revealed that individuals between the ages of 50 and 64 reported the highest levels of social isolation (higher, even, than participants in the 65+ age group), contrary to some previous research. They also found a connection to socioeconomic status, with a greater proportion of socially isolated participants reporting that their income met their needs poorly compared to non-isolated counterparts. Researchers hypothesized that low income may be a primary barrier to engaging in social activities. Additionally, a connection between social isolation and health was established, with socially isolated individuals reporting poorer health than non-isolated participants.

To further explore the issue of health and social isolation, MacDonald and colleagues (2018) surveyed individuals with and without disabilities and found that people with disabilities were likelier to report both the experience of social isolation and feelings of loneliness than their non-disabled peers. Participants reporting social isolation and loneliness also reported environmental barriers in their communities and leisure activities, indicating that the physical environment is a component of social isolation, and could be an area for intervention to reduce social isolation and loneliness.

Social isolation and feelings of loneliness are topics of critical importance within both the aging population and people with disabilities and, thus, are important subjects for research and resource provision for people aging with disabilities. More information is needed to better support individuals who may be experiencing social isolation. We hope findings from our cohort study can provide more data to continue to explore this issue.

References

Alspach, J. G. (2013). Loneliness and social isolation: risk factors long overdue for surveillance. *Critical Care Nurse*, 33(6), 8-13.

Hand, C., Retrum, J., Ware, G., Iwasaki, P., Moaalii, G., Main, D. S. (2017). Understanding social isolation among urban aging adults: informing occupation-based approaches. *OTJR: Occupation, Participation and Health*, 37(4), 188-198.

MacDonald, S. J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J. ... Highmore, L. (2018). 'The invisible enemy': disability, loneliness, and isolation. *Disability & Society*, 33(7), 1138-1159.

What We've Been Up To...

WHY TOILETING & TRANSFERRING?

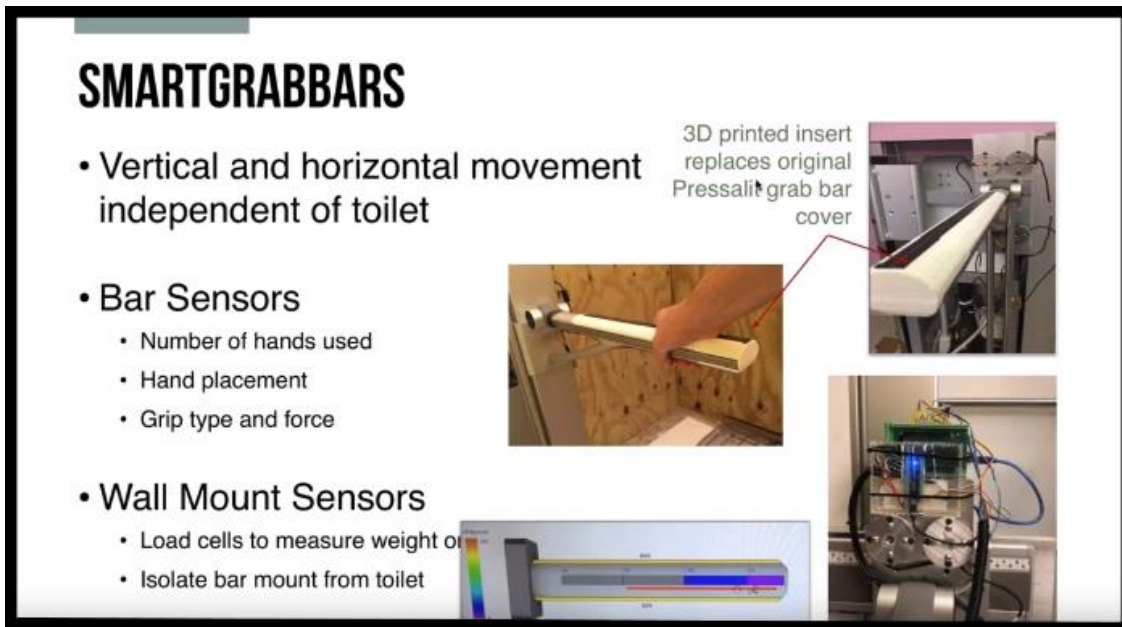
- One of the most physically demanding ADLs, requiring constellation of functional abilities
- Prevalence of toileting/transfer difficulty
 - 6% in general population of community older adults 65+ ([Lee, Lindquist, Segal, & Covinsky, 2006](#)).
 - 45% among frail community-dwelling older adults ([Carey et al., 2008](#)).
 - More than 60% of older nursing home residents ([Jones, Sonnenfeld, & Harris-Kojetin, 2009](#))
- Toileting & Transfer disability as predictors of
 - subsequent disability in other areas of life, institutionalization
 - decreased community mobility/participation
 - increased caregiver burden

Dr. Lee of Georgia Tech highlighted the importance of safe toilet transferring in CEDAR Midwest's second webinar

Webinar with Dr. Lee: Technology to Address Toileting Needs

On April 1, CEDAR Midwest hosted its second webinar; Su Jin Lee from Georgia Tech University's Center for [Assistive Technology and Environmental Access](#) joined us to present information on technologies to assist with toileting and transfers for people with disabilities as they age. Ms. Lee discussed the importance of safe toilet transfers, ADA standards, and her lab's surveys of community-dwelling individuals with disabilities and their perspectives and

preferences, as well as emerging digital technologies. Watch the full webinar [here](#).



SMARTGRABBARS

- Vertical and horizontal movement independent of toilet
- Bar Sensors
 - Number of hands used
 - Hand placement
 - Grip type and force
- Wall Mount Sensors
 - Load cells to measure weight of
 - Isolate bar mount from toilet

3D printed insert replaces original Pressalit grab bar cover

The slide features four images: a hand holding a white 3D printed bar, a close-up of the bar's sensor mechanism, a hand holding a bar with a sensor, and a close-up of the bar's internal wiring and sensors.

Dr. Lee shared her team's research on technology for toilet transferring, including the development of smart grab bars that automatically adjust for the individual using them

Washington University Grand Rounds: Community-based Exercise Intervention for Persons with a Mobility Disability

On April 17, CEDAR Midwest researcher Kerri Morgan presented her research on exercise and disability at the Washington University Department of Neurology's Grand Rounds, a weekly, one-hour lecture series in which Washington University rehabilitation scientists and guest lecturers share their research with colleagues. Kerri discussed the importance of habitual exercise for people with mobility disabilities and her research on the implementation of effective community-based exercise programs for this population.

NAARTC Annual Meeting

On April 23 and 24, CEDAR Midwest researcher Brittany Minor attended the NAARTC Annual Meeting in Arlington, VA, where she presented a poster on our

progress in the adaptation of the Community Participation after Stroke (COMPASS) program for people aging with disabilities. The NAARTC Annual Meeting provides grantees of the National Institute of Disability, Independent Living and Rehabilitation an opportunity to share their research with fellow grantees.



CEDAR Midwest researcher Brittany Minor presented a poster on the development of a community-based research network at the NAARTC Annual Meeting

What's Coming

ACRM Conference

CEDAR Midwest researchers will discuss our projects at the 96th annual American Congress of Rehabilitation Medicine (ACRM) [Conference](#) 10/5-10/8 in Chicago, Illinois. The goal of the [ACRM](#) is to improve "lives through interdisciplinary rehabilitation research." The ACRM conference invites

researchers in a variety of fields related to rehabilitation to share their research with an interdisciplinary audience.

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**.