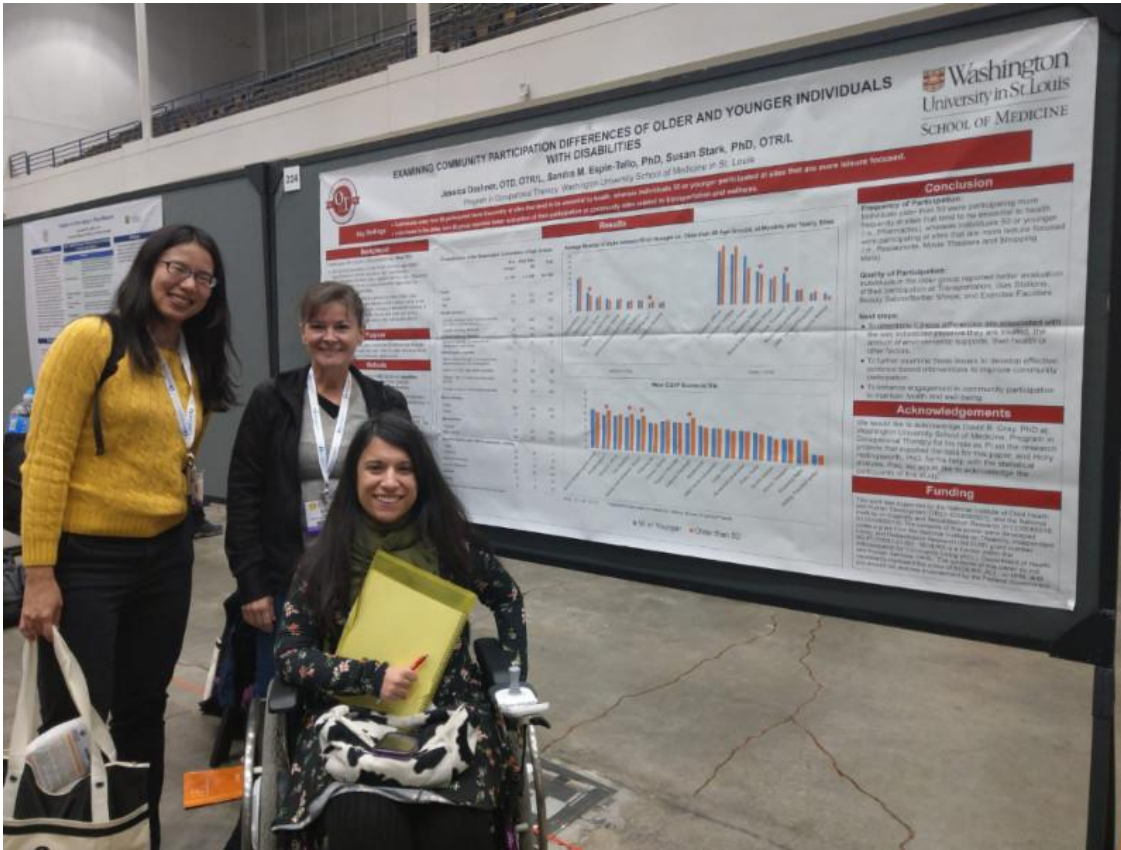


Community Engagement for Disability and Aging Research (CEDAR) Midwest

Issue 2: Fall 2018

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.



CEDAR Midwest researchers Yi-Ling Hu, Susy Stark and Sandra Espin-Tello present a poster about differences in participation patterns between younger and older adults with disabilities at the Gerontological Society of America Conference (read more in *What We've Been up To*).

Current Projects

Cohort Survey

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 change that with a community-based, multi-disciplinary, longitudinal study that will inform community organizations about changing needs, areas for potential intervention and overall participation patterns of people aging with a long-term physical disability. In short, the goal of this study is to investigate how participation changes over time for people aging with a long-

term disability.

For this 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 in our study, please [click here](#).



Volunteers recruit participants for our cohort study in the lobby of the Paraquod Health and Wellness Center

Focus Groups

The next 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) 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.

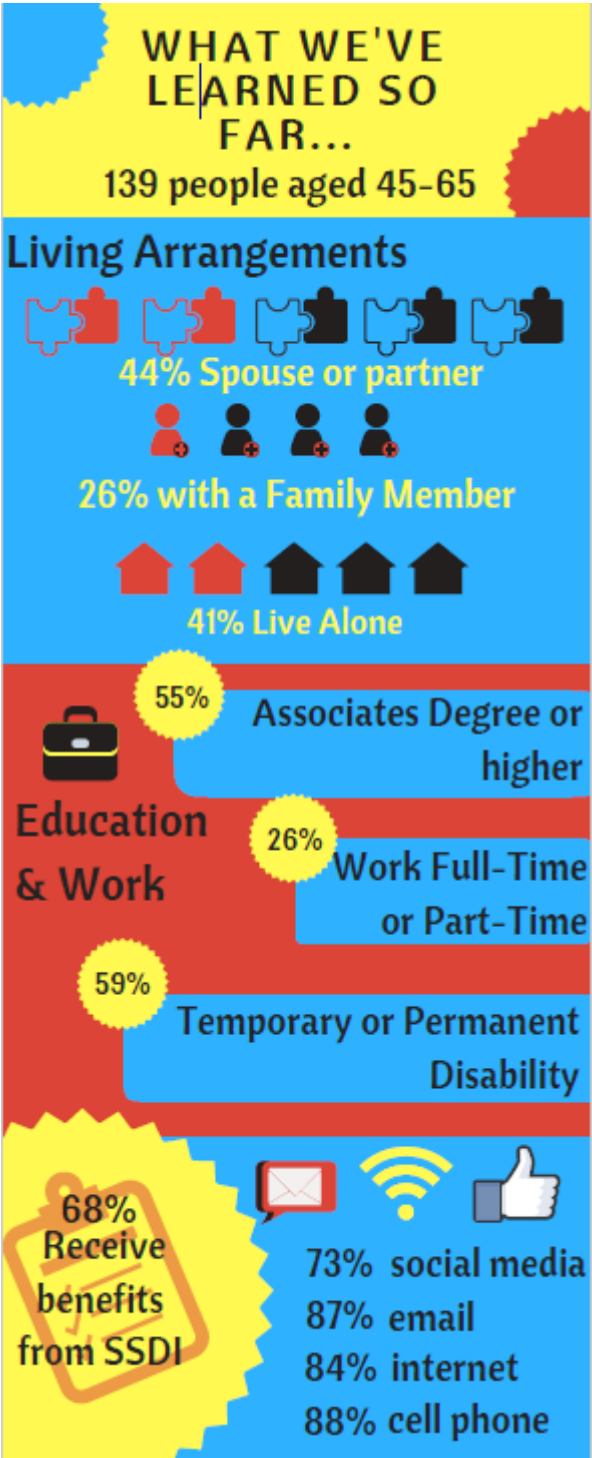
The COMPASS intervention was developed to help facilitate community participation following stroke. We will adapt this program for people aging with long-term physical disabilities. In order to adapt the program, we are conducting focus groups and key informant interviews to learn how the program can 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've Learned So Far

Cohort Survey

As of November 6, 139 people with disabilities between the ages of 45 and 65 have completed our cohort survey. A preliminary analysis of the demographic data shows that a majority of participants are single (51%). The majority of participants have completed an associate's degree or higher, but only 26% indicated that they work full- or part-time. A large number of respondents reported that they use a mobile phone or smartphone, the Internet, email and social media.



This is a small and early snapshot of our demographic data so far, with much more to come regarding health, disability, participation and use of community services.



Although we are particularly interested in ways we can help organizations within our regional community-based research network provide services to their clients, people from across the United States have taken part in our longitudinal participation study.

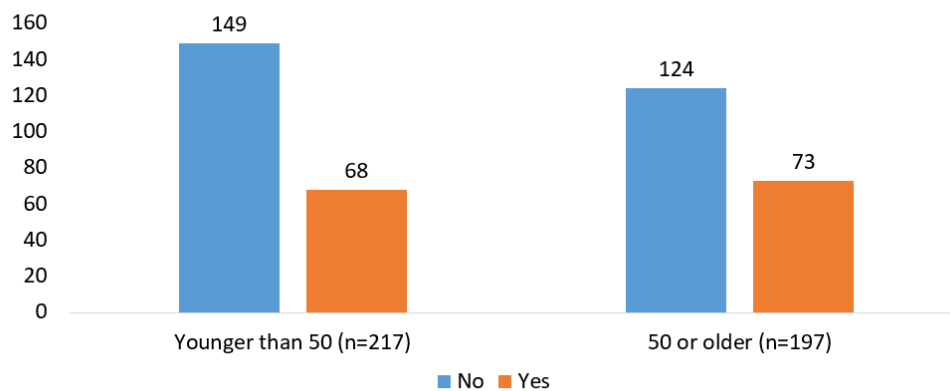
Focus Groups

So far, we have held two focus groups with 10 total participants to learn how to adapt the COMPASS home modification and self-management intervention for people aging with disabilities. We are continuing to recruit participants, and data from the focus groups that we have held thus far are being transcribed and analyzed for trends. One topic that was discussed by many participants regarding how they find information is the importance of social media, particularly Facebook, with some respondents wishing that they had familiarized themselves with social media platforms earlier.

Falls

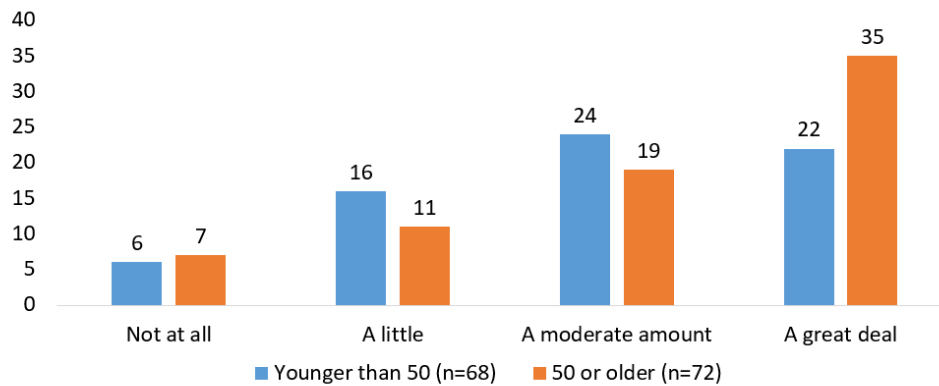
One of the greatest concerns for people aging in the community is falls. In order to learn about falls and fall risks among people aging with long-term disabilities, we analyzed data from a large, nationwide sample of people 18-75 years of age with physical disabilities, comparing those younger than 50 to those aged 50 and older. Of 414 people in the data set, 141 reported poor balance/falls in the past 30 days, with older adults more frequently reporting poor balance/falls.

Question: Have you experienced Poor balance (falls) within the past 30 days?



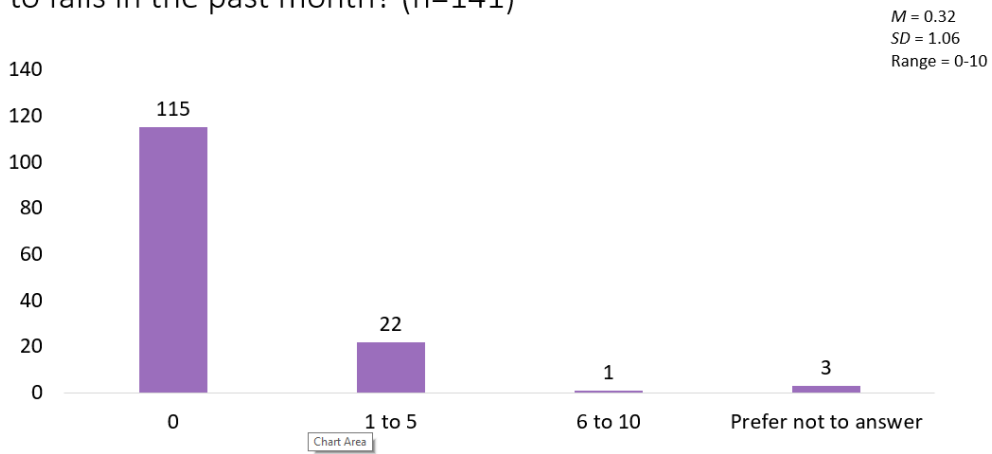
Of the 141 individuals who reported poor balance/falls, younger adults were likelier to report that loss of balance limited their participation in daily activities "a little" or "a moderate amount," and older adults more frequently reported loss of balance limiting their participation "A great deal."

Question: How much has the **loss of balance** limited your participation in daily activities in the past month? (n=141)



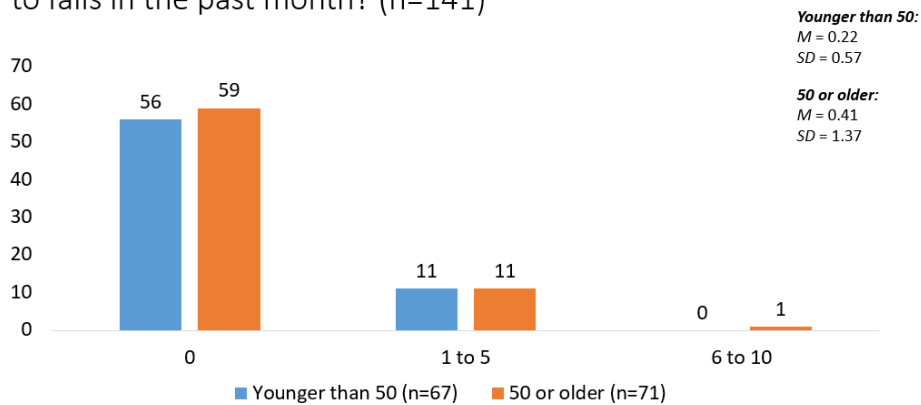
Of the 141 total participants who reported poor balance or a fall in the past month, 115 did not seek medical attention after a fall.

Question: How many times did you seek medical attention due to falls in the past month? (n=141)



Results for this question were similar for both age groups, with the majority of both older and younger adults reporting that they did not seek medical attention at all after a fall.

Question: How many times did you seek medical attention due to falls in the past month? (n=141)



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:

Sandra Espin Tello

We are excited to welcome Sandra M. Espin Tello to our team for her postdoctoral experience. Dr. Espin Tello was born in Crivillen (Teruel), Spain. She earned her bachelor's degree in occupational therapy in 2009, her master's degree in social gerontology in 2010, and her PhD in health sciences in 2016 from Universidad de Zaragoza in Zaragoza, Spain.



The topic of her doctoral thesis was the influence of functional capacity on self-esteem in adults and young people with cerebral palsy. This study showed that higher self-esteem was weakly associated with greater functional capacity.

She spent three months in 2015 as a visiting researcher at Newcastle University in the United Kingdom, working with Professor Allan Colver, where her duties included analyzing data from the SPARCLE (Study of Participation of Children with Cerebral Palsy Living in Europe) and reviewing the adaptation of the European Child Environment Questionnaire (ECEQ) for adults, as proposed for the SPARCLE 3. As a result of this research, together with Professor Allan Colver, she published a paper (Espín-Tello & Colver, 2017), the aims of which were to examine the availability of environmental features that enable optimal participation for children with cerebral palsy, and whether the availability of these features changed for participants from age 8–12 to age 13–17 years. The study showed that many children and young people with cerebral palsy do not have available to them the environmental features they need to participate fully; this was true both at ages 8–12 and 13–17. Additionally, they found striking differences between European regions in the availability of needed environmental features, that these differences persist into adolescence, and that the relative rankings of the better and less good regions were very similar for both age groups.

In 2017, Espin Tello began work as a Clinical Trial Assistant in a Contract Research Organization in Madrid, Spain, and she has begun working as a Postdoctoral Research Associate in the Participation, Environment and Performance Laboratory (PEPL) in the Washington University Program in Occupational Therapy in St. Louis, MO, USA. Her research interests include promoting community participation for people with disabilities.

Espín-Tello, S. M. and A. Colver (2017). "How available to European children and young people with cerebral palsy are features of their environment that they need?" *Research in Developmental Disabilities* 71: 1-10.

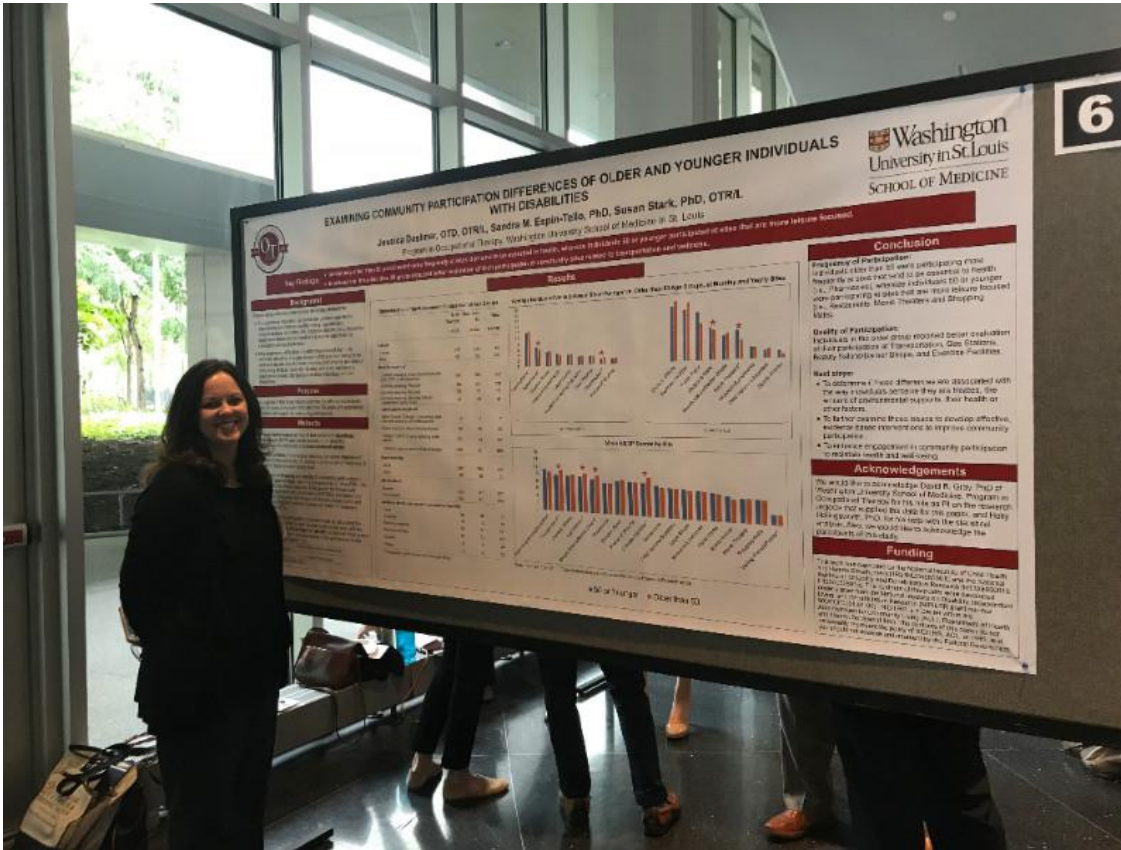
What We've Been Up To...

Publications

The first manuscript based on our research for this project has been accepted by *The Journal of Aging and Health*. We analyzed data from a large, nationwide data set of people with disabilities to determine whether there were differences in where/how younger and older people with disabilities participate. The sample included 692 adults between 18 and 75 years of age with self-reported limitations in mobility, hearing and/or vision; all participants lived in the community. We compared demographic and self-reported participation data between individuals under age 50 and those aged 50 and older. We also looked at the impact of disability onset by comparing participants who acquired their disability at or before age 40 with those who acquired their disability over age 40.

Analysis revealed that older adults visit pharmacies more frequently, while younger participants reported visiting restaurants, shopping malls and movie theaters more frequently. Participants over age 50 had the most difficulty participating without assistance at grocery stores and gas stations. The early-onset group reported the highest evaluative quality of participation at places of work/volunteer/education and the homes of family and friends. The late-onset group reported a higher evaluative quality of participation at exercise facilities.

Dashner, J., Espin-Tello, S. M., Snyder, M., Hollingsworth, H., Keglovits, M., Campbell, M. L., Putnam, M., & Stark, S. [In Press]. Examination of community participation of adults with disabilities: Comparing age and disability onset. *Journal of Aging and Health*.



Jessica Dashner presents a poster comparing community participation patterns among younger and older adults with disabilities at the Washington University Centennial faculty poster session

Centennial Presentation

The Washington University Program in Occupational Therapy celebrated its Centennial on October 6, 2018. Faculty shared their current research with colleagues and Program alumni, where CEDAR Midwest researcher Jessica Dashner presented a poster based on our in-press manuscript comparing community participation patterns between older and younger adults with disabilities.

Show Me Summit on Aging

On September 10-12, CEDAR Midwest researchers Brittany Minor and Marian Keglovits attended the Missouri Association of Area Agencies on Aging's 15th annual Show Me Summit on Aging and Health, where they presented a poster about the development of our community-based research network, the Missouri Aging and Disability Research Network.

Click [here](#) for more about the Show Me Summit on Aging and Health

GSA Conference

CEDAR Midwest researchers Susy Stark, Sandra Espin-Tello and PhD student Yi-Ling Hu attended the Gerontological Society of America (GSA) conference held in Boston, MA, from November 14-18. There, they presented posters based on our first manuscript and a home hazard removal program to prevent falls among community-dwelling older adults.

Click [here](#) for more information about the GSA conference.



Washington University PhD student Yi-Ling Hu presents a poster about home hazard removal at the Gerontological Society of America conference

Webinar

On November 30 at 12:30 p.m., we hosted a webinar on Depression and Aging and Disabilities with presenter Dr. Eric Lenze, Professor of Psychiatry and director of the Healthy Mind Lab at Washington University. Dr. Lenze's research focuses on anxiety disorders, depression and brain health in older adults. The webinar will be uploaded to our [website](#), so be sure to check back!

What's Coming

Road Trip!

CEDAR Midwest researchers Jessica Dashner and Brittany Minor are getting ready to hit the road to visit Independent Living Centers in our community-based research network to help them disseminate the cohort survey among their clients.

Follow Us on Social Media!

Follow us on [Twitter](#), [Facebook](#) or [Instagram](#) for updates on our work and information relevant to community-dwelling adults with disabilities!

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.