

Development of a Community-Based Research Network

In the United States, the best available estimates indicate that 15.4 million people are aging with a disability. People aging with long-term physical disabilities may experience conditions like pain, weakness, and fatigue. They also face the onset of general age-related health problems, often at an earlier age than people without disabilities. These changes in a person's physical health can lead to decreases in function and participation, or involvement in life situations such as work, school, social activities, and religious activities. Declining function and participation can negatively affect a person's quality of life and further impact their health.

People with disabilities and older adults may use services from community-based organizations like Centers for Independent Living (CILs) and Area Agencies on Aging (AAAs) and to remain independent. Traditionally, CILs and AAAs have focused on services for older adults or people with disabilities, but not both. For example, CILs generally focus on independent living issues for people with disabilities, such as information and referral, independent skills training, and peer counseling. AAAs, on the other hand, offer services with a focus on long-term care for older adults, such as home-delivered meals and homemaker assistance, but rarely focus on independent living issues. Together, CILs and AAAs offer a variety of services to people aging with long-term physical disabilities (e.g., personal care attendants, health and wellness classes, support groups, transportation). However, services from these community organizations may not meet the unique needs of people aging with long-term physical disabilities.

CILs and AAAs are encouraged to use evidence-based programming. However, evidence-based programs for older and aging adults are often not tested among people with many health conditions that are associated with disability. Community agencies like CILs and AAAs need tested programs to help promote participation for people aging with long-term physical disabilities.

Formal networks of community-based healthcare providers, called practice-based research networks, have been shown to promote research and improve patients' access to health services. We used the concept of practice-based research networks to create a formal network of researchers, AAAs, and CILs—a community-based research network (CBRN)—to:

- Encourage communication among organizations that provide services to people aging with long-term physical with disabilities
- Conduct research on the best ways to promote participation for people aging with long-term physical disabilities
- Close the gaps in services for people aging with long-term physical disabilities

Formation of the CBRN

We reached out to community-based organizations in Missouri that provide services to older adults and adults with disabilities and had expressed an interest in joining the CBRN. Nine community organizations volunteered to participate:

- Three CILs
- Three AAAs
- One hybrid CIL/AAA
- One non-CIL disability organization
- One non-AAA aging organization

In the first year, we introduced members to one another, defined a name and clear mission for the network, developed the structure of the network, consulted with experts in aging and disability research, and designed the CBRN's first research study. CBRN members were surveyed after one year to see the progress of the network.

The CBRN—deemed the Missouri Aging and Disability Research Network—holds four meetings per year to discuss current research projects, upcoming opportunities for education, upcoming events from member organizations, resources that are available for both the member organizations and their clients, and plans for future meetings.

The network has provided educational opportunities for member organizations and the community, including three webinars: “Aging, Disability, and Depression,” “Technology for Addressing Toileting for People Aging with Disabilities,” and “Fall Prevention.” The network also launched its first research study in 2017, which is surveying people aged 45–65 with long-term physical disabilities once every three years to learn about their health and participation, as well as how their health and participation may be changing over time. Most of the participants in the study were recruited via the CBRN.

One year after the CBRN was formed, member organizations were surveyed for their thoughts on the network, including strengths and weaknesses and benefits and drawbacks of participating in the CBRN. One representative from each organization filled out the survey. All CBRN organizations said that the benefits of the network outweighed the drawbacks. Responses showed that members felt that this new, cross-agency network was already achieving its goals and, at the same time, still had room to grow.

We found that it is possible to use the practice-based research network approach to form a network of community-based organizations that serve people aging with disabilities. This CBRN is the first step in closing the gap between researchers and community agencies that serve people who are aging with long-term physical disabilities. The CBRN is a promising method of creating partnerships to improve health and participation for people aging with long-term physical disabilities.