

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

What Can the Fields of Aging and Intellectual/Developmental Disabilities Learn from Each Other to Support Family Caregivers?

More than 65 million people in the US serve as caregivers to family members who have a disability or are seniors in need of assistance, according to the Family Caregiver Alliance, and the number of caregivers is expected to grow in the coming years. These caregivers include families of adults with intellectual and developmental disabilities (IDD), many of whom are also experiencing age-related disabilities. For adults with IDD, families are the single largest provider of care with more than half of adults with IDD living at home with family. Family caregivers face many challenges including stress, depression, poor health, and financial hardship as the burden of caregiving increases demands on time away from work. Programs and services are available to help families cope with these challenges, but they usually focus on either caregivers for older adults or caregivers for adults with IDD, but not both. A recent NIDILRR-funded study looked at some of the differences and similarities between these programs and what the aging and IDD fields can learn from each other as they develop new interventions to support family caregivers.

Researchers from the [Rehabilitation Research and Training Center on Health and Developmental Disabilities](#) reviewed nearly 70 studies of interventions developed to help family members who provide care and support to adults who have IDD or to those who are aging. In reviewing the research in these two fields, the authors noted a difference in the way each community talked about providing care for a family member.

Among the differences, they found that, while the aging field referred to providing care as “caregiving,” the IDD field more often referred to it as “family support.” Caregiving programs tended to focus on the person providing care, while family support programs were often directed to the entire family. The authors found similarities in the types of caregiving and family support programs as well. For both groups, most of the programs fell into two broad categories: government programs and small-group interventions that addressed psychological and social issues. Government programs tended to focus on either care coordination and support services or financial and home supports. These included, but were not limited to, case management programs, respite care, consumer-directed services, and in-home medical supports. The psychosocial programs tended to focus on either support and counseling or education and training for the caregivers. Examples of these interventions included future planning programs, support groups, disease-specific education, and counseling sessions, among others.

The authors found that, overall, both caregiving and family support programs benefited those who participated. Government care coordination and respite programs gave caregivers more access to services and satisfaction with the caregiving role while psychosocial support programs improved participants’ mental health and reduced caregiver burden. Some programs also benefitted participants’ physical health, employment, productivity, future planning, and access to supports, and resulted in delayed institutional placement for the care recipient.

In their search of the literature in caregiving and family support, the authors found little or no cross-over discussion between aging and IDD. Only a few articles in the family

support literature recognized the intersection of aging and IDD, and no articles in the caregiving literature included people aging with lifelong disabilities like IDD. The authors stressed the importance of bridging this gap, as many families are caring for both adults who are aging with lifelong disabilities and adults aging into disability. They made the following observations regarding how these two fields may benefit from each other's research to improve outcomes for families:

- IDD family support literature had more emphasis on future planning, which, the authors noted, could benefit older adults with and without disabilities as well as caregivers. IDD literature also emphasized self-direction and person-centered planning. Similar interventions may be useful to older adults and their caregivers, as these interventions were found to empower the person receiving care and often had positive impacts on the caregivers as well.
- Many of the IDD interventions featured family peer support and peer leaders as another way to empower and support the independence of people with disabilities. Older adults and their caregivers may also benefit from group interaction when the groups are led by their peers with similar lived experience.
- While both fields were concerned with reducing negative outcomes of caring for a family member, the authors found the IDD family support research was more likely to also examine positive outcomes such as evaluating future planning or caregivers' abilities to maintain employment. Researchers in caregiving may want to seek a similar balance when evaluating the outcomes of their interventions.

- Caregiving interventions in the aging literature employed some innovative and creative strategies, such as arts and movement programs, which were found to improve caregivers' quality of life. Some studies also demonstrated the benefits of alternative therapies. Several caregiving interventions used non-traditional modes of delivery such as phone, video, or Internet. These non-traditional modes increased access for caregivers who could not leave home or who lived in rural areas. Adding these delivery modes to family support interventions may improve quality of life for families in these areas.
- Some of the aging literature focused on providing culturally-appropriate interventions, recognizing that cultural beliefs may shape caregiver needs. The authors noted that cultural competence was rarely addressed in the IDD literature they reviewed.

As more people are aging with and into disability, the authors noted, collaboration between the aging and IDD fields will be increasingly important. As new programs are developed, these two fields may benefit from each other's efforts. Researchers working on family support interventions for people with IDD may want to incorporate ideas from the aging literature, with its broader history and variety of interventions. Researchers developing programs in caregiving for aging individuals may want to incorporate concepts from the field of IDD on person-centered planning for families and broaden their focus to include both negative and positive aspects in caring for a family member with a disability.

To learn more:

The Rehabilitation Research and Training Center on Family Supports conducts research and develops products and publications for families who support members with disabilities: <http://fsrtc.ahslabs.uic.edu/>

Issue Brief: Supporting Families of People with IDD describes the important role families play in supporting family members with IDD and the goals of family support research: <https://aaidd.org/docs/default-source/National-Goals/supporting-families-of-people-with-idd.pdf>

The Family Caregiver Alliance supports people who provide long-term care at home for family or friends: <http://www.caregiver.org>

The National Council on Aging has a collection of resources for older adults and caregivers: <https://www.ncoa.org/for-older-adults-caregivers/>

To learn more about this project:

Heller, T., Gibbons, H.M., and Fisher, D. (2015) [Caregiving and family support interventions: Crossing networks of aging and developmental disabilities](#). *Intellectual and Developmental Disabilities*, 53(5), 329-345. This article is available from the NARIC collection under Accession Number J72665.

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NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.