

Dementia Among Individuals with Intellectual and Developmental Disabilities: Policies and Practices

By Kate Gordon

Through grants from the Administration on Aging, promising programs are emerging to address the issue of dementia in this cohort.

The onset of dementia causes people with intellectual and developmental disabilities (IDD), their caregivers, and their primary providers to navigate between two service systems developed around each specific population—Aging and

to improve home- and community-based services (HCBS) for people with IDD and dementia and their caregivers. The agencies are focusing on developing a dementia-capable and culturally competent system of care across agencies

a description of a dementia-capable system, dementia-capable policy initiatives, and promising practices that highlight examples of training efforts to build dementia-capability in HCBS serving this population.

Dementia prevalence in people with Down syndrome as they age is higher than in the general population.

IDD Service Networks (see sidebar on page 31 for IDD definition). The Administration on Aging, within the Administration for Community Living (ACL/AOA), is funding efforts

and organizations, primarily through training staff to ensure that formal services and family care supports are prepared for dementia.

This article provides a brief overview of the types of HCBS available to individuals with IDD who develop dementia,

Dementia Prevalence in People with IDD

Research shows that age-related health problems among people with intellectual disabilities are similar to those in the general population, including the development of dementia in later life (Heller et al., 2010; May and Kennedy, 2010; McCallion et al., 2013). However, the

→ABSTRACT Aging and disability service systems must build greater capacity to provide services to an increasing number of aging persons with lifelong disabilities. People living in community who have intellectual and developmental disabilities develop age-related health problems, including dementia. They and their caregivers need access to dementia-capable home- and community-based services. Through the support of public policies and dementia-specific grants from the Administration on Aging, within the Administration for Community Living, promising practices in developing dementia-capable systems of care are emerging nationwide. | **key words:** *intellectual and developmental disabilities, dementia, dementia-capable home- and community-based services, Administration on Aging, Administration for Community Living*

Defining Intellectual and Developmental Disabilities

This article makes frequent use of the term intellectual and developmental disabilities (IDD). Intellectual disability is defined as a disability that originates before age 18 and is characterized by significant limitations in both intellectual functioning and in adaptive behavior, which includes many everyday social and practical skills (American Association on Intellectual and Developmental Disabilities, 2017a). The most common syndromes associated with intellectual disability are autism, Down syndrome, Fragile X syndrome, and Fetal Alcohol Spectrum Disorder (The Arc, 2015).

The term developmental disability means a severe, chronic disability that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual reaches age 22; is likely to continue indefinitely; and results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; and capacity for independent living.

Also, developmental disability reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized supports, or other forms of individually planned and coordinated assistance of lifelong or extended duration (Developmental Disabilities Assistance and Bill of Rights Act of 2000). Developmental disability encompasses intellectual disability but also includes physical disabilities, such as cerebral palsy, traumatic brain injury, and epilepsy (American Association on Intellectual and Developmental Disabilities, 2017b).

prevalence of dementia in people with Down syndrome who are in middle and early older age is higher than in the general population (Ball et al., 2008; McCarron et al., 2014). Individuals with other intellectual disabilities characterized by developmental delays and impairments in social function are also at risk for Alzheimer's disease (Strydom et al., 2009). Although some people with IDD experience neurological symptoms (e.g., seizures) more than the general population, the majority of the dementia symptoms and the stage-based losses in capacity mirror those of the general population (Ball et al., 2008).

The need for enhanced community-based support for persons with IDD and their caregivers will expand as the

overall population ages. With the aging of the population, the number of older people will increase significantly over the next twenty years, a trend that will be consistent among older adults with an intellectual disability (National Task Group on Intellectual Disabilities and Dementia Practice [NTG], 2012)

Access and Use of Home- and Community-Based Services

The services and supports needed by the general population with dementia are the same as those needed by persons with IDD with dementia. However, understanding the nature of the person with IDD's non-dementia-related, lifelong disability is necessary to provide person-centered services and supports.

Though the general population with dementia does not access HCBS until after the onset of dementia, typically in later life, HCBS support is provided within the intellectual disability system to individuals with IDD throughout their life span (Watchman et al., 2017). Individuals with IDD primarily access such HCBS as non-medical in-home support services, non-institutional residential care facilities, and adult day services.

Existing IDD services, financing, and the settings in which they are delivered, may differ from the services that older adults with dementia tend to access. IDD services for adults without dementia emphasize supporting client employment and education. When individuals with IDD



develop dementia, their caregivers and their primary service providers must learn to navigate between the two systems developed around each population. However, similar to aging services programs, many of the services available to individuals with IDD also focus on maintaining or improving functioning, such as providing assistance with basic tasks of everyday life.

Nearly a quarter of all persons with IDD live with family caregivers who are ages 60 or older (Braddock et al., 2014). Because of the stress of long-term caregiving, by the time people with IDD who are living at home reach early old age, their caregivers tend to experience adverse health impacts, such as obesity, poorer self-rated health, limitations in

their own activities of daily living (ADL), and poor health-related quality of life (Seltzer et al., 2011). Family caregivers of adults with IDD may have additional challenges in continuing to provide care at home compared to solely caring for individuals with intellectual disabilities or individuals with dementia.

Such challenges may include meeting the need for certain home modifications or caring for individuals who require assistance with a greater number of ADLs (McCallion, McCarron, and Force, 2005).

Research points to Medicaid as being the key to financing the services and supports provided to individuals with

IDD. In-home services and other community-based supports that states offer through their Medicaid program or state-only funding (through publicly funded state IDD agencies) to families of adults with IDD include: adult day services; respite services; financial services such as cash

People with IDD and dementia, and their caregivers, need access to dementia-capable HCBS in community.

subsidies, vouchers, and in-home supports such as personal assistance or homemaker services; assistive technology and environmental modifications; adaptive medical equipment; health and professional services; family counseling or training; parent support

groups; transportation and recreation activities; specialized clothing; and dietary services (NTG, 2012).

In addition, all persons with dementia who are older have the same rights to access publicly funded HCBS for which they are age-eligible, such as Older Americans Act-funded programs. For example, all caregivers of persons with dementia, regardless of co-occurring disabilities in these care recipients, are eligible to access services funded by the National Family Caregiver Support Program.

Improving the Dementia-Capability of HCBS

A dementia-capable system meets the unique needs of persons living with dementia by identifying those with a possible dementia and recommending a subsequent visit with a physician; ensuring that the staff clients encounter have appropriate training, an understanding of clients' needs and the services available; knowing how to communicate with clients; and providing quality, person-centered services that help clients remain independent and safe in their communities.

To support adults with IDD who are affected by dementia and help them to remain in their homes and communities, some parts of the aging services and IDD networks are developing a dementia-capable system

of care that is bolstered by community care programs. The focus of current efforts includes training staff in aging and dementia care about issues specific to people with intellectual disabilities, and ensuring that formal services and family care supports for individuals with IDD are prepared for dementia (Jokinen et al., 2013).

Forging Collaborative Policy Initiatives

In recent years, policy initiatives have sought to formalize dementia-focused cross-network collaboration, such as the 2017 National Plan to Address Alzheimer's Disease (2017) and the state dementia plans of Alaska, Arizona, Delaware, Georgia, Massachusetts, New Jersey, New York, Oregon, Tennessee, and Washington. The National Plan includes the development of standardized interprofessional education to address the unique needs of individuals with intellectual disabilities through cross-network collaboration (Opachan Gardner, 2016). *The Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias* (New York State Coordinating Council for Services Related to Alzheimer's Disease and other Dementias, 2013), recommends that the Department of Health and its partners train professionals and paraprofessionals who work with individuals with develop-

mental disabilities to be aware of the connection between Down syndrome and Alzheimer's disease, and to identify indicators of dementia.

Funding for Promising Practices

Since 2014, the ACL/AOA has sponsored projects to ensure that people with dementia of all ages and their family caregivers have access to a sustainable HCBS system that is dementia-capable. The ACL/AOA's Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) provides grants to states in their efforts to expand the availability of community-level supportive services for persons with dementia and their caregivers. In addition, the ADI-SSS program is designed to fill gaps in dementia-capable long-term services and supports for persons with dementia and their caregivers.

More than twenty-five grantees of these programs are working on improving the quality and effectiveness of services dedicated to individuals with IDD and dementia, or those who are at high risk of developing dementia. Through the support of these dementia-specific grants, new and emerging practices in dementia-capable HCBS for persons with IDD and dementia are being implemented and evaluated.

Activities supported by ADI-SSS include the following:

- Training providers of services for individuals with IDD about dementia;
- Developing State Board for People with Developmental Disabilities dementia specialist positions to provide outreach, training, and other support for families of individuals with IDD who are at risk for dementia; and
- Conducting legal and financial planning workshops to assist adults with IDD and their caregivers with money management and future planning.

Examples of these promising practices from Rhode Island and Wisconsin are described below.

Rhode Island

A social services organization in Woonsocket, Rhode Island, called Seven Hills Rhode Island is working with several stakeholders (including the National Task Group on Intellectual Disabilities and Dementia Practice [NTG], the Alzheimer’s Association of Rhode Island, a Medicare Quality Innovation Network-Quality Improvement Organization, and a Medicaid managed care organization). It provided a statewide two-day training to advance knowledge and skills among fifty clinical leadership staff at IDD and Alzheimer’s provider organizations and the Rhode Island Developmental Disabilities Nurses Association.

Seven Hills expanded its adult day health program to include a dementia-specific special care license through the state of Rhode Island to support more than thirty-five adults with IDD and dementia with the long-term goal of incorporating older adults from the general public to lessen the segregation of the IDD population.

They developed a resource guide for 4,000 adults with IDD and their caregivers, supported by the Community Provider Network of Rhode Island (CPNRI). CPNRI represents twenty-three private providers of services and supports to people with developmental disabilities in Rhode Island; the network’s mission is to improve understanding of dementia and lead to earlier identification and acquisition of timely supportive services.

Seven Hills, a CPNRI member, designed a legal and financial planning workshop to assist 100 adults with IDD and their caregivers with money management and future care planning. It is working toward the adoption of a standardized tool to be used by organizations supporting individuals with IDD and dementia for early detection of dementia.

Wisconsin

The State of Wisconsin Department of Health Services, which houses the state unit on aging, partnered through an ADI-SSS project with the Wisconsin

Board for People with Developmental Disabilities to certify its staff as trainers through the NTG. The curriculum covers the following components: an introduction to aging with IDD; early detection of dementia; diagnosis; stages of dementia; nonpharmacologic management of difficult behaviors; how to support both professional and family caregivers; and bridging the aging and IDD networks (personal communication with Kathleen M. Bishop and Kathryn Pears, lead trainers for the NTG Education and Training Curriculum on Dementia and Intellectual & Developmental Disabilities, January 7, 2015). Trained staff provides training and outreach for individuals with IDD, families, and professional caregivers at a variety of health, aging, and IDD service provider organizations.

The project has given training to staff at Aging and Disability Resource Centers, managed care organizations, and consultant agencies that help manage an IDD Waiver program. The training covered dementia and IDD, Down syndrome and Alzheimer’s disease, early detection for dementia, differential diagnosis, healthcare advocacy, and caregiving needs. The grantee also developed an IDD and dementia toolkit for the medical community that includes diagnostic protocol guidelines and best practices,


as well as recommended diagnostic tests.

Lastly, the State of Wisconsin Department of Health Services and the Wisconsin Board for People with Developmental Disabilities have partnered with Special Olympics to

system, policy, and practice levels. Nationwide, models are emerging for developing dementia-capable and culturally competent care across agencies and organizations.

Such models include training designed by the NTG,

public through the AOA on the National Alzheimer's and Dementia Resource Center (NADRC) website (nadrc.acl.gov/) beginning in October 2017. The website includes the IDD and dementia toolkit for the medical community created and tested in Wisconsin, and the Rhode Island resource guide.

ACL/AOA also has a report and a webinar on IDD and dementia available on the NADRC website. With the support of ACL/AOA's dementia-specific grants, these resources are available to help systems address the needs of persons with IDD and dementia and their caregivers, using new and emerging practices. 

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promote dementia awareness, via family health forums, which serve to educate families and share families' stories of how they are caring for aging family members with IDD.

Conclusion

People who live in the community with IDD and dementia, and their caregivers, need access to dementia-capable HCBS. This can only be accomplished by improving the dementia-capability at the

which offers a national series of workshops on dementia and intellectual disability for staff of provider agencies, program personnel, administrators, and caregivers. The NTG is creating a network of regional trainers on dementia and intellectual disability to make this training more accessible nationwide. The resources created through the ACL/AOA programs, mentioned in the Promising Practices section above, will be available to the

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