Living longer, living better: Improving service quality and supports for persons with ID/DD and dementia
An environmental scan of ID/DD and dementia

Alzheimer's disease and related dementias (ADRD) are debilitating conditions that impair memory, thought processes, and functioning, primarily among middle-aged and older adults. The effects of these conditions can be devastating for individuals afflicted with ADRD and for their loved ones.

The Alzheimer's Foundation of America identifies Alzheimer's disease as the most common cause of dementia or loss of intellectual function among people aged 65 or older. The Alzheimer's Association estimates that more than five million Americans are living with Alzheimer's disease, and it is the fifth leading cause of death for persons aged 65 and older.

With advances in medicine and assistive technology, persons with intellectual disabilities or developmental disabilities (ID/DD) are living more productive and longer lives. This extended life expectancy also means that these individuals experience an increased risk for ADRD as they age.

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) cites research confirming that, although dementia as experienced by adults with ID/DD “is generally similar to that as experienced by other persons, there are exceptions. Some individuals with select conditions (Down syndrome, in particular) are more at risk for dementia, experience earlier age of onset, more rapid decline, and a briefer duration between diagnosis and death.”

The National Alzheimer’s Project Act and the NTG

The National Alzheimer's Project Act (NAPA), which was passed unanimously by the U.S. Congress in 2010, called for a national action plan to address issues related to ADRD and to produce annual plan updates through 2025. Passage of the NAPA prompted a multiagency response within the federal government to address research, care practices, and public education. The NAPA also created a federal advisory council responsible for overseeing the activities of the national plan, among them a special focus on persons with ID/DD and ADRD. Concomitant with this federal effort, the intellectual disabilities sector created the NTG—which was charged with ensuring that the nation would address the needs of adults with ID/DD and their families affected by dementia. The NTG now corresponds with the NAPA federal advisory council and through its efforts promotes a greater involvement of people with ID/DD within the national plan. A member of the CARF Board of Directors, Thomas J. Buckley, Ed.D., of Lucanus Developmental Center in Hollywood, Florida, serves as a member of the NTG.

The NTG envisions that careful planning would enable adults with intellectual disabilities affected by dementia to remain in community care settings. The group produced a landmark publication in 2012, ‘My Thinker's Not Working’: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports.

The report identified five major goals in a National Dementia and Intellectual Disabilities Action Plan:

- To better understand dementia and how it affects adults with an intellectual disability and their caregivers.

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**Abbreviations**

AADMD: American Academy of Developmental Medicine and Dentistry

ADRD: Alzheimer's disease and related dementias

AMDA: formerly American Medical Directors Association

CARF: Commission on Accreditation of Rehabilitation Facilities

CCRC: continuing care retirement community

ID/DD: intellectual disability or developmental disability

ISAC: International Standards Advisory Committee

LEAD: Leaders Engaged on Alzheimer's Disease

NAPA: National Alzheimer's Project Act

NTG: National Task Group on Intellectual Disabilities and Dementia Practices
To institute effective screening and assessment of adults with an intellectual disability who are at risk or showing the early effects of dementia.

To promote health and function among adults with an intellectual disability.

To produce appropriate community and social supports and care for adults with an intellectual disability who are affected by dementia.

To produce a capable workforce and produce education and training materials.

In 2013, the NTG produced *Guidelines for Structuring Community Care and Support for People with Intellectual Disabilities Affected by Dementia*, which provides detailed information and guidelines related to:

- Community care that addresses the physical, cognitive, emotional, and behavioral symptoms of ADRD and is tailored to the stages of disease/condition progression.
- Program and support options provided in various settings, including adult day services and programs or services for persons who are living in private homes with a caregiver, alone or with a housemate, in a group residence, or a specialized “dementia capable” residence.
- Ancillary issues such as funding and financial considerations, managing choice and liability, abuse prevention, medications, and nutrition.

The NTG has joined Leaders Engaged on Alzheimer’s Disease (LEAD), a national coalition of 59 foundations, associations, organizations, and providers working collaboratively to focus national strategic attention on ADRD.

**Governmental supports work in tandem with dementia care enhancements**

The NTG’s *Guidelines* publication notes:

- The Olmstead Decision (1999), related to Department of Justice settlements with states and a class action lawsuit, makes it easier for many adults, including those with ID/DD who are affected by dementia, to receive services in their communities and have Medicare pay for qualified home-based care.
- The Patient Protection and Affordable Care Act (2010) emphasizes seamless chronic care management that will benefit families providing in-home care for adults with ID/DD affected by dementia.

**AMDA Clinical Practice Guidelines seek to improve services and reduce risk**

AMDA, a professional association of medical directors, attending physicians, and others practicing in the long-term care continuum, has crafted a series of *Clinical Practices Guidelines (CPGs) in the Long Term Care Setting*. CPGs are designed to improve patient outcomes and the safety of staff, the organization, and patients. They also are meant to reduce costs, avoidable transfers, and risks of penalties and litigation. The association’s CPGs for dementia were revised in 2012.

**CARF International’s commitment to quality care**

Since its founding in 1966, CARF has developed and refined standards for programs that serve persons with disabilities. CARF’s standards have always been rooted in a strong tradition of focusing on a tailored, individualized service model that:

- Is inclusive.
- Engages the persons served and their families.
- Protects the rights and dignity of those served.
- Optimizes the life experiences of those served.
In 1995, CARF reorganized its structure to emphasize three distinct rehabilitation fields: Medical Rehabilitation; Behavioral Health; and Employment and Community Services, which includes vocational/employment and developmental disability programs and services.

Four years later, CARF published its first set of standards for Aging Services. In the same year, CARF’s Employment and Community Services accreditation area introduced standards for the Older Adults Specific Population Designation, which may be applied in conjunction with an accreditation survey of community or employment services. The standards are published in CARF’s annual Employment and Community Services standards manual.

In 2006, CARF introduced standards for Dementia Care for application in many settings, including adult day services, assisted living residences, person-centered long-term care communities (nursing homes), and continuing care retirement communities (CCRCs). CARF’s Dementia Care standards are published annually in the CARF–CCAC standards manual and the CARF Aging Services standards manual.

CARF ISAC recommends nine key areas for action

In January 2013, CARF convened an International Standards Advisory Committee (ISAC) in collaboration with the NTG to address needs related to standards for individuals with ID/DD and co-occurring dementia. Meeting in Baltimore, Maryland, the ISAC included diverse service providers in the aging services and employment and community services fields as well as persons served and family caregivers. Prior to the ISAC, a CARF webinar briefed participants on issues and standards that would be addressed.

ISAC participants identified practices that can be implemented by service providers to promote quality of care for individuals with ID/DD and dementia. Mindful of dementia’s accelerated impact on individuals with ID/DD as they age, the ISAC participants’ recommendations focused on the following nine key areas for action:

- **Support for caregivers using information, methods, and resources that are understandable to them.**
- **Education for direct care personnel on dementia-specific care.**
- **Information for families about dementia’s aspects and progression.**
- **Community living environments that support individuals’ rights and promote safety and security.**
- **Personnel support systems to reduce worker stress and to manage grief.**
- **Appropriate screening, assessment, diagnoses, and monitoring of individuals with ID/DD and dementia.**

### Resources for dementia care for individuals with ID/DD

- Alzheimer’s Association®
  www.alz.org
- Alzheimer’s Foundation of America
  www.alzfdn.org
- AMDA™
  www.amda.com
- CARF International
  www.carf.org
- *Guidelines for Structuring Community Care and Support for People with Intellectual Disabilities Affected by Dementia*
- ‘My Thinker’s Not Working’: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports
  http://aadmd.org/sites/default/files/NTG_Thinker_Reportv6-edit%20version-e.pdf

- LEAD
  www.leadcoalition.org
- NAPA
  http://aspe.hhs.gov/daltcp/napa
- NTG, hosted by the American Academy of Developmental Medicine and Dentistry (AADMD)
  http://aadmd.org/ntg
- Effective communication between care team members to support ethical practices and decision making.
- Person-centered care planning that considers disease progression and anticipates the needs of the individual.
- Funding, regulatory, and licensing systems for congregate residential settings as well as for individuals living independently or with family or participating in adult day services.

CARF will submit the revised set of Dementia Care standards to a field review in the summer of 2013, inviting comments from consumers, professionals, regulators, payers, and other stakeholders. The revised standards will be published in the 2014 CARF Employment and Community Services Standards Manual, 2014 CARF–CCAC Standards Manual, and 2014 CARF Aging Services Standards Manual.

CARF plans to provide educational opportunities for consumers and providers of care for individuals with ADRD and ID/DD. Information and education will be provided in various formats and may include webinars as well as electronic and printed materials. Specialized education for CARF surveyors will help hone their abilities to apply CARF’s Dementia Care standards during on-site surveys of residential and community-based organizations.

**Participants in the 2013 CARF ISAC**

CARF acknowledges with gratitude the participants who served on the ISAC in January 2013:

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Accreditation Matters

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