

DEMENTIA AND INTELLECTUAL DISABILITIES

SOME FACTS :

- Most adults with intellectual disabilities are generally affected by forms of dementia at the same rate as other adults (about 6% after the age of 60 – with the percentage increasing with age).
- Some adults with intellectual disabilities are at high risk for dementia – adults with Down syndrome are particularly susceptible – and may show early onset.
- Early identification of signs and symptoms of cognitive impairment and dementia is an important first step in managing the course of the disease and providing quality care.
- A large number of older-aged adults with intellectual disabilities live with their families and their age-associated impairments, including dementia, increase the challenges for older caregivers.
- An emerging model of ‘dementia-capable’ out-of-home care is the use of small community-based group homes.
- Supportive education, training, and services can help caregivers minimize fatigue and prevent burnout.
- Collaborative efforts at the local level, among disability, aging, and health providers can be effective in adapting services and supports to aid adults affected by dementia, and their caregivers.
- With appropriate services, adults with intellectual disabilities affected by dementia can continue to live quality lives in community settings.

KNOW THE WARNING SIGNS

- unexpected memory problems
- getting lost or misdirected
- problems with gait or walking
- new seizures
- confusion in familiar situations
- changes in personality

WHAT CAN YOU DO?

- raise awareness of symptoms
- request/provide assessments
- monitor health and medications
- make residences ‘dementia-capable’
- get help from clinicians
- keep record of changes
- plan ahead for eventual decline
- support local Alzheimer’s events



The NTG is a 501(3)c non-profit corporation chartered in the State of Maine and a member of several dementia-focused organizations.

The NTG welcomes both individual and organizational/providers members.
FOR INFORMATION ON MEMBERSHIP
www.the-ntg.org/membership

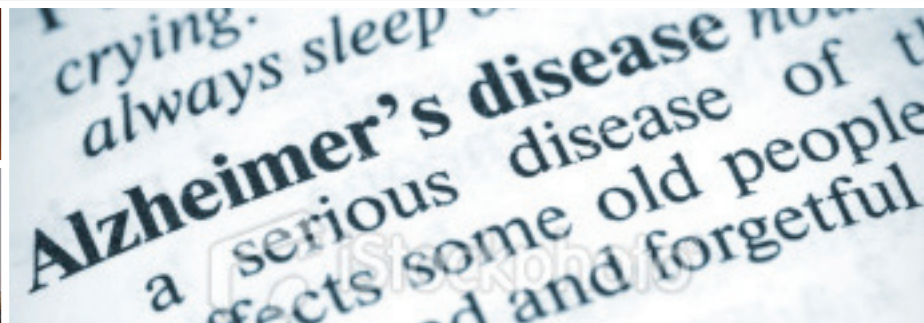
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National Task Group
on Intellectual Disabilities
and Dementia Practices





HISTORY

The National Task Group on Intellectual Disabilities and Dementia Practices was created to bring attention to the growing needs of aging individuals with intellectual disabilities. Its efforts have resulted in the development of a coherent and coordinated national strategy aimed at addressing Alzheimer's disease among adults with intellectual and developmental disabilities and their families. This strategy complements the functions of the National Alzheimer's Project Act (NAPA) and goals of the National Plan to Address Alzheimer's Disease.

MISSION

The National Task Group is an advocacy and education non-profit organized to provide activities that contribute to the NAPA effort and ensures that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are considered and are an integral part of national strategy on dealing with Alzheimer's disease and dementias



OVERALL GOAL

Evaluate and recommend actions directed at improving the nature and quality of community services for people with intellectual and developmental disabilities affected by dementia, as well as their families; and promote greater cooperation among various sectors responsible for providing community supports, health and social care, and public education.

ACTIVITIES

- Promote adoption of a specialized screening instrument and assessment process.
- Define ways to assess 'cognitive impairment' as part of the annual wellness visit requirement under the Affordable Care Act.
- Develop practice guidelines for health and social care practitioners and quality programs.
- Promote 'best practice' service models and systems of care that meet the unique needs of individuals with disabilities and their caregivers.
- Aid families by providing information and aids for coping with dementia and its challenges.
- Assist in adoptions of standards of care.
- Institute public education and training programs.
- Collaborate with national and regional organizations in public education, legislation, and services development campaigns.
- Promote equity for access to screening and diagnostic resources and services.

PUBLICATIONS, EDUCATION, AND WORKSHOPS

“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 summative report issued by the NTG. It contains the National Intellectual Disabilities and Dementia Action Plan, which includes 20 recommendations for creating a system of quality 'dementia capable' services in the United States. The report is available at www.the-ntg.org

The NTG was a core supporter of the 2016 Glasgow Summit on Intellectual Disabilities and Dementia. Reports from the Summit are available at www.the-ntg.org/glasgow-summit-on-id-dementia

The NTG provides a comprehensive program of workshops and webinars across the United States and internationally. The schedule of the workshops and webinars is available at www.the-ntg.org/training-education

For other NTG reports and materials, as well as extensive information on intellectual disability and dementia, see www.the-ntg.org