

Quality Is No Accident

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DID YOU KNOW?

By age 60, about 6% of adults with ID will be affected by some form of dementia. This rate increases as the population ages.

In July 2012, about 5% of adults with DDS Health Care Records had a diagnosis of Alzheimer's disease or dementia listed in their records.

The number of deaths from Alzheimer's Disease (AD) in the DDS adult population has been increasing each year. In 2009, 15.2% of deaths were attributed to AD.

Alzheimer's & Dementia

The average age of people who receive services from the Massachusetts DDS is increasing each year, as are the number of adults in the older age groups. While many adults are living long, happy lives in their communities, DDS and community providers are facing an increasing number of older people who are showing signs of dementia and Alzheimer's disease. This is a challenging issue for providers because it can be difficult to recognize and diagnose dementia, and dementia can cause many problematic changes in behavior for individuals. This brief discusses the Massachusetts DDS effort to help identify and support people affected with Alzheimer's disease and other dementias.

Dementia and Intellectual Disabilities (ID)

One of the most significant risk factors for developing Alzheimer's disease is having Down syndrome. Dementia may develop at an earlier age in people with Down syndrome and may lead to more significant decline. People with ID who do not have Down syndrome may also be at greater risk of developing dementia than people in the general population. Dementia was noted in about 1.5% of adults surveyed through the National Core Indicators Project, a survey of individuals with ID receiving services in 20 states. Of this 1.5%, some 35% were adults with Down syndrome and about 70% lived in some type of formal residential setting (primarily group homes)

Early identification of dementia is crucial, as are educational and support services. DDS established a clinic on aging and ID that provides educational and diagnostic support to providers, as well as ongoing clinical monitoring of the individual. Providers are encouraged to use tools recommended by the National Task Group on ID and Dementia to screen individuals for early signs of dementia.

Dementia is a general term for progressive decline in mental ability severe enough to interfere with daily life. Alzheimer's disease is the most common type of dementia, accounting for about 2/3 of dementia cases. Alzheimer's causes problems with memory, thinking, and behavior. It gets worse over time. Approximately 5.2 million Americans are affected by dementia. –*Alzheimer's Association*



Assess & Manage Risk

Dementia Screening

Early warning signs of dementia may be missed or attributed to other conditions, like depression. A screening tool can help identify early signs and symptoms of dementia.

The National Task Group (NTG) on Intellectual Disabilities and Dementia Practices recommends that individuals be screened for dementia beginning at age 50 for adults with ID and at age 40 for adults with Down syndrome. This is consistent with the DDS Preventive Screening recommendations.

The NTG recently developed a dementia screening tool for use with people who have ID. This tool was developed so it could be easily completed by informal caregivers or paid staff with minimal training. The information can be shared with health care providers and others who aid in caring for the individual.

Other conditions that may cause behavior changes or functional decline should be ruled out before diagnosing age-related dementia. It may be especially difficult to diagnose dementia in people with communication difficulties.

*Tool adapted from the Dementia Screening Questionnaire for Individuals with ID (DSQIID; Deb et al., 2007) and the Dementia Screening tool (2010; Philadelphia Coordinated Health Care Group)

The NTG Dementia Screening Tool* is a resource for documenting and reporting changes in individuals over time in areas associated with dementia, including:

- Language & Communication skills
- Independence in daily living skills
- Sleep and wake patterns
- Memory and recall
- Behavior, function and affect
- Ambulation

This tool was piloted in the summer of 2012 and is planned for release on October 15, 2012. For more information or to see a field test version of the tool, please visit:

<http://aadmd.org/ntg/screening>

Risk Factors for Alzheimer's disease and Dementia

- Down syndrome (DS): Adults with DS are at high risk for developing dementia. At least 25% of people with DS will be affected with dementia after age 40; up to 75% by age 60. Personality changes may also appear more prominently in persons with Down syndrome.
- Age: The risk of Alzheimer's disease and dementias increases significantly with age. The average age of onset of dementia for adults with ID is in the late 60's; the average age of onset for adults with Down syndrome is 52.
- Family history: People with a family history of Alzheimer's disease or dementia may be a greater risk for developing the condition themselves.
- Other health conditions: Such as high blood pressure, high LDL cholesterol levels, atherosclerosis, Parkinson's disease, multiple sclerosis and diabetes all increase the risk of developing Alzheimer's disease and dementia.

People with dementia are at greater risk for these conditions:

- Depression
- Confusion/frustration
- Agitation
- Wandering
- Sleep patterns
- Anxiety

Resources for Diagnosis and Support

Providers can best support adults with dementia by:

- Keeping the person as active as possible.
- Engage in activities that draw on past interests and skills and utilize their existing physical skills. Keep activities short.
- Think of activities that stimulate all senses find what soothes them. Is it music? A walk? The smell of lavender? Identify a place to enjoy these activities.
- Create routine in the day. Routine is comforting and reassuring. Activities may be short but try not to rush through them.
- Try not to criticize or correct. Look for the feelings behind the words and respond accordingly.
- Smile. Your demeanor, approach and tone of voice is as important as what you say.
- Use short, simple sentences. Give one step instructions. Identify objects by name. Instead of saying "Here it is" you might say, "Here is the book".
- Call the person by their name.
- Help the person make choices by being careful how you ask questions. Offer a selection between two things, or ask a yes/no question. Try to avoid open-ended questions.
- The person may now prefer baths over showers or vice versa. Experiment.
- Be vigilant about the risks in the environment as the person loses their ability to assure their own safety.
- Remember that other issues like aspiration or swallowing disorders, incontinence, and inability to communicate may emerge as the Alzheimer's disease progresses.

A NEW DDS Dementia Clinic

Dr. Julie Moran is a geriatrician and director of the Aging and Developmental Disabilities Clinic at Beth Israel Deaconess Medical Center (BIDMC). She has recently teamed up with DDS to develop a clinic for individuals who are experiencing issues related to aging including dementia. The clinic is held at the Glavin Regional Center and serves the western region of Massachusetts, while the BIDMC clinic is available to people in the eastern portion of Massachusetts. Since April 2012, over 19 people have been diagnosed with dementia through her clinic, and she's received over 60 referrals for consults state-wide.

A DVD resource for caregivers on supporting people with Down syndrome and Alzheimer's disease is available for individuals diagnosed through the clinics entitled, "***Adults with Down Syndrome And Alzheimer's Disease: A Practical Guide For Caregivers***".

[For more information on the clinic or to purchase a copy of the DVD](#) for your organization, contact Jane McCue Magner at Jane.MCCueMagner@state.ma.us.

Additional Information

Rehabilitation Research and Training Center on Aging with Developmental Disabilities
<http://www.rrtcadd.org/>

Alzheimer's Association <http://www.alz.org>

National Task Group on ID and Dementia
<http://aadmd.org/ntg>

Report, 'My Thinker's Not Working' A National Strategy for Enabling Adults with ID Affected by Dementia to Remain in the Community and receive Quality Supports.'

<http://aadmd.org/ntg/thinker>

Data on Dementia and Alzheimer's Disease in Adults Served by MA DDS

Alzheimer's Disease and Dementia in DDS Health Care Records

In July of 2012, about 13,800 adults had a health care record in DDS's electronic HCSIS system. This represents almost all adults that receive 24 residential supports, and a subset of people receiving individual supports, residential support from other agencies, and those living at home independently or with their family.

About **5% or 669 adults had a diagnosis of dementia or Alzheimer's disease** listed in their record. This may be an underestimate of the number of people served by DDS with these diseases, as the person's record may be incomplete.

Link with Down Syndrome

Among people who have a DDS health care record, 11% were reported to have Down syndrome. **Of those with Down syndrome, 14% were reported to have dementia or Alzheimer's disease.**

Alzheimer's Disease and Mortality

Alzheimer's Disease as a cause of death

Alzheimer's disease was the second leading cause of death in 2009 among adults who are eligible for services from DDS and was responsible for 15.2% of deaths in 2009, with a mortality rate of 2.6 per thousand people. In 2009, this cause was responsible for more deaths than in any previous year since 2000 (the first year of this report). The increasing impact of Alzheimer's disease on mortality is a trend that is mirrored in both the Massachusetts and U.S. adult populations.

Palliative end-of-life care for people with Alzheimer's disease

As dementia and Alzheimer's disease are degenerative diseases, people with these conditions may reach a point where they and their health care provider decide to focus on their comfort and quality of life. A variety of resources are available for end of life care. The most common is hospice, which is available for people with a life expectancy of six months or less, though this can be difficult to predict in people with dementia. Other services may also be available at earlier stages.

The availability of hospice services has increased in recent years across the various residential service settings in the network of MA DDS. Second to cancer, terminal dementia or Alzheimer's disease continued to be the most common reason for hospice services use by adults served by DDS who died in 2009. These conditions are a more frequent reason for hospice use in DDS hospice users than in hospice users across the nation.

Analyses conducted by:
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For more information on assessment and treatment options for
people with signs of dementia contact:
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