



Aging with Intellectual and Developmental Disability (IDD)

DID YOU KNOW?

- By age 60, about 1 of every 16 adults with IDD will be affected by some form of dementia. This rate increases as the population ages.
- People with IDD are living longer with an average lifespan of over 60 years.
- Both men and women with IDD tend to experience decreased bone density at younger ages than people without IDD, thereby placing them at increased risk for osteoporosis.
- Adults with IDD have a similar risk for falling as the elderly population, but at much younger ages. Fall risk increases with age.

The average age of people receiving services from the Massachusetts Department of Developmental Services (DDS) is increasing each year, as are the number of adults in older age groups. Nationally, the number of adults with intellectual and developmental disabilities (IDD) aged 60 and older is projected to double from 641,860 in 2000 to 1.2 million people by 2030¹. In Massachusetts, 6,209 people served by DDS, or about 1 out of every 4 adults, is aged 55 and older².

People with IDD age in a similar manner as the general population, but age-related changes may appear at much younger ages. The average onset of age-related changes in the general population is 65-70 years; in people with IDD, age-related changes may be seen as early as 45-55 years. Certain medical conditions such as some types of cancer, diabetes, dementia or Alzheimer's disease, osteoporosis and mobility impairment are more common in people with IDD as they age.

In 2015, DDS convened a workgroup to develop recommendations to address the needs of people with IDD who are aging. The workgroup targeted the following 3 priority areas:

- 1) **Healthy Aging and Clinical Resources:** DDS increased clinical consultation resources, accessed through the Area Offices, and developed training resources on Aging and IDD.
- 2) **End of Life Care:** DDS revised the Life Sustaining Treatment Policy and distributed *Five Wishes* planning documents to Area Offices, as well as created training resources.
- 3) **Support and Planning, Community and Work/Retirement Activities:** Created Memory Cafes and innovative day activities and also increased collaboration with the Executive Office of Elder Affairs.

¹Heller, T. et al (2010). *Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities*, 23(1). U. of Minnesota, Institute on Community Integration.

² Massachusetts Department of Developmental Services 2014 Mortality Report (published 2017). Prepared by the Center for Developmental Disabilities Evaluation and Research (CDDER).

Aging with an Intellectual or Developmental Disability Webinar Series

DDS partnered with the Center for Developmental Disabilities Evaluation and Research (CDDER) at UMass Medical School to produce a series of webinars addressing the challenges of aging with IDD. These webinars are designed for caregivers, families, direct support professionals, residential managers, and service coordinators who support people with IDD entering older adulthood.

Webinar series: Each module includes accessible videos, handouts, and resources: http://shriver.umassmed.edu/cdder/aging_idd_education

The following topics are covered:

General Aging: This series provides a general overview of aging for people with IDD and teaches caregivers and others about what to expect as people with IDD age. Modules include:

- General Aging
- Understanding Age Related Changes
- Identifying and Assessing Pain
- Health Promotion and Aging
- The Role of Polypharmacy
- Mobility and Aging in Adults with IDD
- Behavior Related Changes and Aging
- Aging and Cerebral Palsy
- Aging with Down Syndrome

Considerations for Accessing the Community: This video addresses how to adapt residences, day programs, and community organizations to better meet the needs of aging adults with IDD.

Aging and Disability Resource Consortia (ADRC): This video provides an overview of what ADRCs do, who they help, and how to access ADRC partners and Options Counselors.

End of Life Planning http://shriver.umassmed.edu/cdder/aging_idd_education

- **Five Wishes¹ & End of Life Planning:** Planning before retirement or illness occurs can be an important step for many people. The *Five Wishes* document guides and documents end of life wishes. This webinar addresses the personal, emotional, spiritual and medical aspects of end of life planning and offers an overview of how to have this discussion with adults who have IDD and their caregivers.
- **Medical Orders for Life Sustaining Treatment (MOLST):** The MOLST form ensures that end of life treatment choices are discussed and that a plan is in place. This webinar explains different sections of the MOLST, when it might be used, and who can sign it.
- **DDS Life Sustaining Treatment (LST) Policy:** An overview of the new DDS Life Sustaining Treatment policy including informed consent, authorization for decision making, when it is appropriate to activate a health care proxy, the role of a guardian, and different LST options.
- **Guardianship:** An overview of guardianship including why and when one might be needed and different types of guardianship. Various case examples are also presented.

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Alzheimer's Disease and Dementia

Evidence suggests that the prevalence of Alzheimer's disease in those with IDD, especially Down syndrome, is higher than in those without IDD, and may develop at younger ages. The average age of onset of dementia for adults with IDD is in the late 60's; however, the average age of onset for adults with Down syndrome can be as early as 35. It is estimated that at least half of all people with Down syndrome who live into their sixties will develop Alzheimer's disease. Risk factors for dementia include age, family history, high blood pressure, high cholesterol, diabetes, and multiple medication use.

The recommended age to begin dementia screening is 50 in adults with IDD and age 40 for adults with Down syndrome. A baseline of current functioning is usually completed and then compared with assessments of functioning, memory, and behavior change over time.

Dementia and IDD Webinars

The Dementia and IDD Webinar series includes:

- Introduction to Dementia and IDD
- Stages of Alzheimer's Disease
- Early Evaluation of Dementia and Alzheimer's Disease
- Launching a Memory Cafe
- Caregiving in Action: Case Studies and Practical Tips
- Applying the Knowledge to Dementia Caregiving and Caregiver Support

http://shriver.umassmed.edu/cdder/aging_idd_education/dementia-and-idd

Memory Cafés

Memory Cafés are meetings where people with dementia, either with or without IDD, and their care partners join together to enjoy a variety of activities. They are regularly-scheduled meetings providing social activities and support. In 2016, DDS funded 13 organizations across Massachusetts to pilot Memory Cafés that included people with and without IDD and their care partners. Cafés are held in senior centers, community centers, museums, libraries, and even gardens. Activities range from sharing music such as singing or drum circles, to art projects like creating memory collages and coloring, to petting zoos. Participants report that the memory café is a place where people with dementia and their care partners can still participate and find enjoyment in an activity. Find inclusive cafés here:

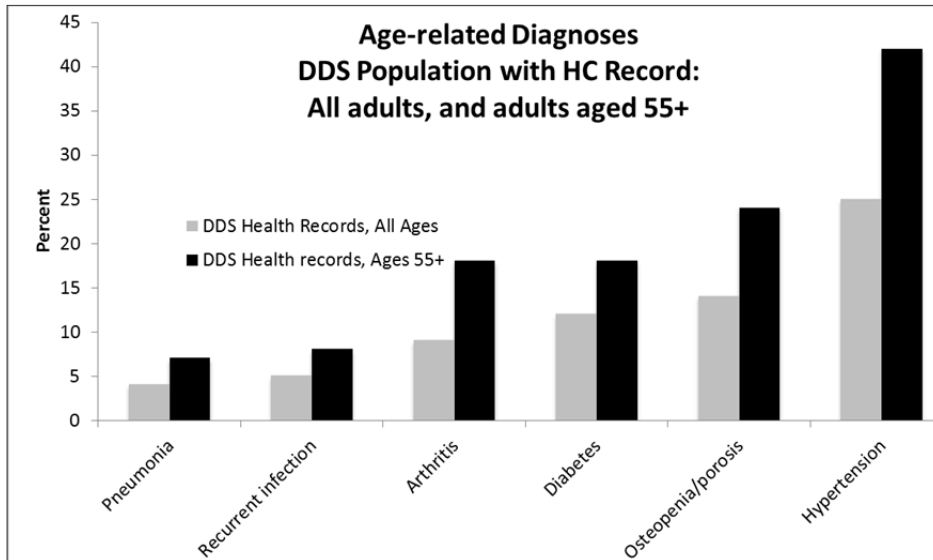
<http://www.mass.gov/eohhs/docs/dds/aging-memory-cafes.pdf>

Launching a Memory Café: This webinar focuses on how to launch a Memory Café, and provides resources across Massachusetts.

http://shriver.umassmed.edu/cdder/aging_idd_education/launching-a-memory-cafe

DDS Population and Age-related Diagnoses

About 25% of adults served by the Massachusetts DDS are over the age of 55 (*DDS 2014 Mortality Report*). These adults may have additional support needs as they age.



An examination of Health Care Records for adults aged 55 and older served by DDS shows that these adults are **more likely** to experience chronic health conditions than younger adults with IDD. As shown in the graph on the left, hypertension is the most frequent condition experienced by older adults with IDD, followed by osteopenia or osteoporosis, and diabetes.

Future DDS Initiative: Models of Innovative Day Programs

As people with IDD age, they may want to retire from their jobs or do something different with their days. DDS recently funded a pilot for innovative service models as an alternative to traditional day, work or community-based activities for the DDS population that is aging. The program chosen is the Cooperative for Human Services, which is implementing a program that includes 1) site and community activities in shorter time increments than a traditional day program; and 2) a mobile “pop-up” approach for individuals who can’t get to the program for a variety of reasons. Technology will also play a role with CHS using Ipads, Nintendo Wii and Facetime for multi-generational interactions, staying connected, exercise and entertainment. DDS hopes to learn from this program in order to determine if similar programs would be appropriate to support in the future.

Aging with IDD Resources

[QINA Brief: Age-related Health Issues in People with IDD](#), October 2014

[QINA Brief: Alzheimer's & Dementia](#), September 2012

DDS Aging with IDD Site, including DDS resources to access expanded clinical consultations:

<http://www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html>

DDS Life Sustaining Treatment Policy:

<http://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/developmental-services-policy-2017-1.pdf>

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