People with Intellectual Disabilities and Dementia
Considerations for a Dementia Friendly Community
Description

**Intellectual Disability (ID)**
- Below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy (NB: Before age 18)
- Not a mental illness or psychiatric impairment
- Varies in degree and co-impairment
- Compensated by training, education, remediation, habilitation, supports for life activities

**Developmental Disability (DD)**
- Manifests before age 22,
- Is attributed to a mental and/or physical impairment,
- Results in *substantial functional limitations* in 3 or more major life activities including:
  - self-care,
  - receptive and expressive language,
  - learning,
  - mobility,
  - self-direction,
  - capacity for independent living, and
  - economic self-sufficiency,
- And requires special & individualized services over the lifespan
Dementia in adults with ID

• People with ID are growing older
• ‘Early onset’ dementia in Down syndrome (DS)
• Challenges to diagnosis and care (DDS)
  – Key: loss/change from previous level of function
• Assessments
• Care guidelines- Shift Philosophy
• Life Story-Importance
The link between Alzheimer’s Disease and Down syndrome

- 3 copies of chromosome 21 in DS (trisomy)
- Amyloid precursor protein (APP) is coded on 21, and is associated with a protein that leads to senile plaques
- Other genes on chromosome 21 may contribute to increased genetic risk of AD
Epidemiology of Alzheimer’s Disease in Down Syndrome

- Alzheimer’s disease is NOT inevitable in adults with DS
- Estimates have historically fluctuated and research has been flawed by variability in diagnostic methods, characteristics of patients studied, etc.
- Average age of onset: between 50-55 y.o.
- Incidentally...older adults with non-DS ID are not felt to be at higher risk of developing AD (risk is same as general population)
- Majority of adults with Down syndrome who develop Alzheimer’s disease (on average) have a life expectancy between 4 - 7.5 years.
- Life expectancy is fairly similar to the general population with AD, although adults with DS may be diagnosed later in the course of their disease and falsely appear to have a short life expectancy after diagnosis.
Important Care Perspectives

• Change of care focus
  Going from making gains to that of maintaining function and dealing with eventual loss and decline (Philosophy of skills acquisition)

• Supporting family caregivers
  Recognize the challenges faced by the aging caregiver
  Support sibling and parent care providers

• Diagnostic challenges
• Subtle changes, along with staff changes
• Culmination of lifelong struggle
• Lifelong Stigma
Department of Developmental Services (DDS)

Education and Training **PARTNERSHIPS**

Collaboration with NTG Dementia Capable Training (not just for people ‘connected’ w/ID)

**Inclusive Memory Cafés** **Local partnerships**

Eleven providers across Massachusetts have launched memory cafés specifically designed to include the growing population of people with ID with dementia (not just DDS $)
About these Cafés

• “Neutral” places
• Bring people with and without ID together
• Socialization activities
  – Animals
  – Music
  – Gardening
  – Bird watching
Some Resources...

• Webinar series DDS and CDDR
  – [http://shriver.umassmed.edu/cdder/aging_idd_education](http://shriver.umassmed.edu/cdder/aging_idd_education)

• National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
  – [www.aadmd.org/ntg](http://www.aadmd.org/ntg)
  – NDSS (National Down Syndrome Society) Booklet
  – International Summit 2016 Glasgow

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My Greatest Teachers
What the heart has known, it will never forget