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
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
  - www.aadmd.org/ntg
  - NDSS (National Down Syndrome Society) Booklet
  - International Summit 2016 Glasgow

kathyservice@gmail.com

With warm appreciation to:

Robin, John, Bobby, Fred, Tony, Bobbi, Kathleen, Nancy, Kirk, James, Tony, + +++ and their families and staff~

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