Aging, Dementia, and Developmental Disabilities

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Co-Chair National Task Group on ID and Dementia Practices

Nothing to Disclose

Changing US Population Demographics
Aging and Intellectual and Developmental Disabilities

- In 2002, an estimated 641,000 adults with IDD were older than 60.
- In 2002 about 75% of all older adults with IDD were in the 40-60 year old age range.
- The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 due to increasing life expectancy and the aging of the baby boomer generation.


- Currently estimated life expectancy of a 1-year-old child with DS is between 43 and 55 years.
- 25% of persons with Down syndrome are still alive at 65 years.


Expected Physical Changes of Aging

- Osteopenia/Osteoporosis - normal aging-related bone loss
- Sarcopenia - progressive loss of muscle mass
- Presbyopia: the lens of the eye becomes stiffer and less flexible – affecting the ability to focus on close objects (accommodation)
- Presbycusis – aging related change in the ability to detect higher pitches – more noticeable in those age 50+
- Gustation (i.e. the sense of taste) decrements become more noticeable beyond 60+
- Olfaction (i.e. the sense of smell), decrements become more noticeable after age 70+
- Somatosensory System - Reduction in sensitivity to pain, touch, temperature, proprioception
- Vestibular – Reduction in balance and coordination
- Cognitive – Reduction in short term memory loss, attention, and retrieval
**Diversity of the Aging Process**

<table>
<thead>
<tr>
<th>Cognitive Reserve</th>
<th>Plasticity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susceptibility to disease</td>
<td>Individual organ systems age differently</td>
</tr>
<tr>
<td>Social and cultural factors</td>
<td>Genetic predisposition</td>
</tr>
<tr>
<td>Compensatory behaviors + access to resources</td>
<td>Lifestyle</td>
</tr>
</tbody>
</table>

**Successful Aging**

**Optimal Aging**

“A kind of utopia, namely, aging under development enhancing and age-friendly environmental conditions”


**Successful Aging**

- Avoidance of disease and (additional) disability
- Maintaining mental and physical function
- Sustained engagement in social and productive activities


**Modifiable versus Unmodifiable Factors for Successful Aging**

**Unmodifiable**

- Age
- Gender
- Genetics
- Ethnicity
Modifiable Factors for Successful Aging

- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Don’t smoke (and avoid secondary smoking!)
- Education (promote lifelong learning)
- Occupation (esp. promotes curiosity, or working with people)
- Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment

Optimizing Successful Aging for Older Adults with IDD

- Health promotion/health prevention - Wellness screenings (e.g. vision/hearing, dental checkups, cancer screenings, mammograms).
- Psychological well-being - advocate to ensure availability of optimal treatments/medications for those with dual diagnosis (e.g. anxiety, depression).
- Important to offer a range of new activities, that may result in continuing personal development and compensatory skill building.
- Effective epilepsy management.
- Avoiding Polypharmacy
- Involve families and support team

Life Course Health Promotion

- A balancing act of guiding philosophies.

Increasing Age

Autonomy & Self-direction

"Duty of Care"
### Leading Causes of Death, Adults 65+ Years, 2010

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Heart disease</td>
</tr>
<tr>
<td>2</td>
<td>Cancer</td>
</tr>
<tr>
<td>3</td>
<td>Chronic lower respiratory diseases</td>
</tr>
<tr>
<td>4</td>
<td>Stroke</td>
</tr>
<tr>
<td>5</td>
<td>Alzheimer’s disease</td>
</tr>
<tr>
<td>6</td>
<td>Diabetic</td>
</tr>
<tr>
<td>7</td>
<td>Influenza and pneumonia</td>
</tr>
<tr>
<td>8</td>
<td>Kidney disease</td>
</tr>
<tr>
<td>9</td>
<td>Accidents (unintentional injuries)</td>
</tr>
<tr>
<td>10</td>
<td>Septicemia</td>
</tr>
</tbody>
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### Cognitive Changes with Aging

- **Normal changes** = more forgetful & slower to learn
- **MCI – Mild Cognitive Impairment** =
  - Immediate recall, word finding, or complex problem solving problems (½ of these folks will develop dementia in 5 yrs)
- **Dementia** = Acquired chronic thinking problems in > 2 areas
- **Delirium** = Rapid changes in thinking & alertness
  (seek medical help immediately)
- **Depression** = chronic unless treated, poor quality, I “don’t know”, “I just can’t” responses, no pleasure
  can look like agitation & confusion
The Diagnosis of Dementia

- An acquired syndrome consisting of a decline in memory and other realms of cognitive functioning
- At least one of the following deficits
  - Language difficulties (aphasia)
  - Difficulty with common tasks (apraxia)
  - Unable to identify common objects (agnosia)
  - Disturbance in executive functioning
    - Planning, judgment, decision making

Source: Diagnostic and Statistical Manual of Mental Disorders. DSM-IV
Alzheimer’s Disease

- First described by Alois Alzheimer in 1906
- Described pathologic changes
- Emil Kraepelin coined the term Alzheimer's disease

(1864-1915) Auguste Deter

Alzheimer’s Disease Pathology

Amyloid plaques and neurofibrillary tangles (NFT).

Natural history of Alzheimer’s Disease

- Early diagnosis
- Mild-to-moderate
- Severe

Mini-Mental State Examination (MMSE)

Alzheimer’s Disease in Down Syndrome

- “In not a few instances, however death was attributed to nothing more than general decay-sort of precipitated senility”. Fraser and Mitchell (1876)
- Senile plaques seen in brains of those with DS. Jervis (1948)
- Uncommonly can have rapid progression and death.
- Late onset seizures were evident in 73.9%, with epilepsy dx at mean age of 55.4, and interval of about 1/2 year following dx of dementia.

<table>
<thead>
<tr>
<th>Age percentage with clinical signs of dementia</th>
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<tbody>
<tr>
<td>30's</td>
</tr>
<tr>
<td>40's</td>
</tr>
<tr>
<td>50's</td>
</tr>
<tr>
<td>60's</td>
</tr>
</tbody>
</table>


Diagnosis of I/DD and Dementia

- Suspection that pathologic decline in cognitive function is occurring; must be aware of prior baseline level of functioning
- Avoid Diagnostic Overshadowing
- Use of early warning screening and Early Stage Detection and Diagnosis (EDSD)
- Neurocognitive assessments
- Workup and rule out/definition in accurate diagnosis
- Empiric diagnosis; Possible, Probable, Definite
- Usage of Biomarkers
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Alzheimer’s Disease Biomarkers

**AD Progression**

- Pre-Symptomatic
- eMCI
- uMCI
- Dementia

- Biomarkers:
  - CSF Aβ42
  - CSF tau
  - FDG-PET
  - MRI hippocampus
  - Amyloid imaging

- Diagnostic Criteria:
  - CSF Yes
  - CSF No
  - Amyloid-positive
  - Amyloid-negative
Challenges to diagnosis and care

- Individuals with I/DD may not be able to report signs and symptoms
- Subtle changes may not be observed
- Commonly used dementia assessment tools are not relevant for people with I/DD
- Difficulty of measuring change from previous level of functioning
- Conditions associated with I/DD may be mistaken for symptoms of dementia - Diagnostic overshadowing
- Aging parents and siblings
- Lack of research, education, and training

Realistic Goals of Dementia Treatment

- Attenuate cognitive and functional decline
- Prevent / decrease behavioral and psychiatric symptoms
- Delay nursing home placement
- Lengthen period of self-sufficiency
- Reduce caregiver burden
Community Care Needs of Adults with ID and Dementia

- Dementia is a condition that lessens an individual's ability to self-direct and be left alone—thus long-term living on one's own may not be an option as the disease progresses.
- Aging in Place/In Place Progression/Aging Out
- What are the needs?
  - In home supports (to family caregivers and the person)
  - Advanced planning for alternative care
  - Diagnostic, medical and behavioral health care
  - Support groups for caregivers (family or staff)
  - Dementia capable community housing
  - Day care programs and respite for family caregivers
  - Usage of technology/telehealth

Change in Focus of Supports Provided

- Maintaining skills
- Stabilizing the environment
- Minimizing choices
- Giving reassurance
- Personal care
- Assessing and meeting medical needs
- Meaningful activities

Staff Levels and Training

- Appropriate levels of staffing
- Dementia specific training
- Maintaining and preserving skills vs. learning new skill
- Pain recognition and management
- Addressing concerns about reactions and actions related to the disease
- End of life care, the dying process and grieving for themselves and roommates
Support for Grieving and End of Life Care

- Support teams for staff and roommates
- Pastoral care for families, staff and roommates
- Staff discussions around their beliefs and concerns
- Families values and beliefs around death and dying
- Utilizing hospice and palliative care
- Arrangements for final farewells

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Thank You!!