AGING IN ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES; CONCERNS AND HOPE

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Changing US Population Demographics

By 2050, People Age 65 and Older Will Equal 20% of the Population
U.S. Population (and Forecast) by Age Category and Gender

- 1900: U.S. Population: 76 Million
- 1960: U.S. Population: 151 Million
- 2050: Population (forecast): 392 Million

Source: U.S. Census Bureau
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.
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
- **Homeostenosis** – narrowing of reserve capacity
- Seizures
- Osteoporosis
- Falls and fractures
- Behavioral challenges
- Visual and hearing deficits
- Dementia
- Gait dysfunction

- Cardiopulmonary disease
- Strokes
- Cancer
- Spinal disease
- Liver and Kidney disease
- GI disturbances
- Changes in medication metabolism
Diversity of the Aging Process

Cognitive Reserve

- Susceptibility to disease
- Social and cultural factors
- Compensatory behaviors + access to resources

Individual Aging Process

Plasticity

- Individual organ systems age differently
- Genetic predisposition
- Lifestyle

Gender
Aging Persons with Intellectual and Developmental Disabilities (IDD)

- Individuals with IDD are living longer and some experience age-related functional and/or cognitive decline
- Normal aging vs pathologic aging
- Syndrome specific aging concerns
- Change in interests
- Aging support networks; siblings and parents
- Younger support networks not adapted to seniors
- Direct support staff/agencies not trained in recognizing the changes of aging nor trained in most age related conditions including dementia care and support
- Participation in competitive physical activity-based sports may become more difficult as one gets older
- Adults with IDD often drop out of Special Olympics as they get older
- Aging and health promotion is not routinely a part of most programs
AGING AND DECLINE AFFECTS QOL

Small Change in Cognitive Capability could have profound impact on Independence

15%

Dependent Living

Independent Living
SUPPORTING THROUGHOUT THE LIFESPAN

• A balancing act of guiding philosophies

Increasing Age

Autonomy & Self-direction

“Duty of Care”
Functional decline is the decrement in physical and/or cognitive functioning and occurs when a person is unable to engage in activities of daily living.
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 = 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
Cognitive Changes with Aging In those with Down Syndrome

Who I Am: My Stories, My Memory, My Life History

- Regression
- Medical
- Psychological
- Normal Aging
- Mild Cognitive Impairment
- Dementia (Alzheimer’s)
## Diagnosed Disorders for 148 Adults Who Presented with a Decline in Function

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Frequency</th>
<th>Percent of Diagnosed Disorders (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood</td>
<td>76</td>
<td>31</td>
</tr>
<tr>
<td>Anxiety</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>Obsessive-Compulsive Behavior</td>
<td>29</td>
<td>12</td>
</tr>
<tr>
<td>Hypothyroid</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>Adjustment</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>B12 Deficiency</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Menopause</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Attention Deficit / Hyperactive</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Gastrointestinal or Urinary</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Sensory Impairment</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Psychotic</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Psychotic</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Other Medical Conditions*</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Cardiac Conditions</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>247</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>
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
• Early - Young Onset
• Normal Onset

Vascular Dementias (Multi-infarct)

Lewy Body Dementia

Fronto-Temporal Lobe Dementias

Other Dementias
- Genetic syndromes
- Metabolic pxs
- ETOH related
- Drugs/toxin exposure
- White matter diseases
- CTE
- Depression(?) or Other Mental conditions
- Infections – BBB cross
- Parkinson’s
- NPH
ALZHEIMER’S DISEASE IN DOWN SYNDROME

- Women with Down’s syndrome are more at risk of developing Alzheimer’s disease than men in the 40 to 65 age group.
- People with Down’s syndrome who develop Alzheimer’s disease live, on average, 4-10 years from first symptoms; median 7 years.
- Rapid decline can occur.
- Sensory impairments (vision: 93.3%; hearing: 61.3%) were evident in adults with dementia.
- Late onset seizures were evident in 73.9%; with epilepsy dx at mean age of 55.4, and interval of about ½ year following dx of dementia.

Percent persons with Down syndrome showing evidence of neurofibrillary tangles (NFT) and senile plaques (SP) at autopsy


Representative Amyloid Scans in DS and AD
‘NTG-Early Detection Screen for Dementia’ (NTG-EDSD)

• Usable by support staff and caregivers to note presence of key behaviors associated with dementia
• Picks up on health status, ADLs, behavior and function, memory, self-reported problems
• Available in multiple languages

Use: to provide information to physician or diagnostician on function and to begin the conversation leading to possible assessment/diagnosis

http://aadmd.org/ntg/screening
• Adaptive Behaviour Dementia Questionnaire (ABDQ), Prasher et al. (2004)

• Assessment for Adults with Developmental Disabilities (AADS), Kalsy et al. (2000); Oliver et al. (2011)

• Dementia Questionnaire for People with Learning Disabilities (DLD)*, Evenhuis (1992); Evenhuis (1996); Eurlings, Evenhuis & Kengen (2006); Evenhuis et al. (2007)

  *Originally named the Dementia Questionnaire for Mentally Retarded

• Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), Deb et al. (2007)

• Prudhoe Cognitive Function Test (shorter versions), Kay et al. (2003)

• Test for Severe Impairment (Modified), Albert & Cohen (1992)

• Dementia Scale for Down Syndrome (DSDS), Gedye (1995)
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/support families
- Palliative Care
- End of Life Care
- Determining and measuring outcomes
# Behavioral and Psychological Symptoms of Dementia (BPSD)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>40%</td>
</tr>
<tr>
<td>Delusions</td>
<td>63%</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>4-41%</td>
</tr>
<tr>
<td>Aggression</td>
<td>31-42%</td>
</tr>
<tr>
<td>Apathy</td>
<td></td>
</tr>
<tr>
<td>Pseudobulbar Affect</td>
<td></td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td></td>
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<tr>
<td>(day/night reversal)</td>
<td></td>
</tr>
<tr>
<td>Hoarding</td>
<td></td>
</tr>
<tr>
<td>Shadowing</td>
<td></td>
</tr>
<tr>
<td>Disinhibition (stripping)</td>
<td></td>
</tr>
<tr>
<td>Sexually inappropriate</td>
<td></td>
</tr>
<tr>
<td>behavior</td>
<td></td>
</tr>
<tr>
<td>Sundowning</td>
<td></td>
</tr>
<tr>
<td>Wandering</td>
<td></td>
</tr>
</tbody>
</table>

- Associated with worse prognosis
- More rapid cognitive decline
- Increased caregiver burden
- Leads to earlier admission to institutional care
- Increased healthcare costs
COMMON TRIGGERS

• Physical
  • Acute illness/infection, medications, pain, poor vision, hearing, poor sleep

• Cognitive
  • Inability to understand, express oneself, lack of insight, misinterpretation of environment, difficult to problem solve

• Emotional
  • Fear, anxiety, depression, frustration, apathy, boredom

• Environmental
  • Changes in caregiver, confrontational approach, tasks that exceed abilities, change in routine, over/understimulation, lack of visual cues
NONPHARMACOLOGICAL APPROACHES

- Familiar environment—avoid frequent moves
- Soft lighting
- Calm colors
- Places to walk
- Access to outdoor spaces
- Home-like environment
- Low stimuli—minimize background noise
- Time out space
- Reminiscing

- Individualized Care Planning
- Careful analysis of care interactions
- Meaningful activity
- Art/Music Therapy
- Exercise/Movement
- Snoezelen (multisensory stimulation program)
- Aromatherapy
- Yoga

- Yoga
QUESTIONS TO BE ANSWERED IN EVALUATING MEDICATION USE

• What is the target problem being treated?
• Is the drug necessary?
• Are nonpharmacologic therapies available?
• Is this the lowest practical dose?
• Does this drug have adverse effects that are more likely to occur in an older patient?
• By what criteria, and at what time, will the effects of therapy be assessed?
• Safety of the medication

Drug use in the nursing home
<table>
<thead>
<tr>
<th>Drug class</th>
<th>Chemical name</th>
<th>Dosage range (mg)</th>
<th>Side effects of class</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotics</td>
<td>Aripiprazole*</td>
<td>2.5-15</td>
<td>Sedation, EPS, NMS, metabolic syndrome, QTc prolongations, increased risk of CVE and mortality</td>
</tr>
<tr>
<td></td>
<td>Haloperidol</td>
<td>0.5-5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Risperidone*</td>
<td>0.25-2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quetiapine*</td>
<td>25-200</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Olanzapine*</td>
<td>2.5-15</td>
<td></td>
</tr>
<tr>
<td>Antidepressants</td>
<td>Fluoxetine</td>
<td>10-80</td>
<td>Anxiety, headaches, sedation, GI symptoms, sexual dysfunction</td>
</tr>
<tr>
<td></td>
<td>Citalopram</td>
<td>10-60</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Paroxetine</td>
<td>10-50</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sertraline</td>
<td>25-200</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Trazadone</td>
<td>25-200</td>
<td></td>
</tr>
<tr>
<td>Mood stabilizers</td>
<td>Carbamazepine</td>
<td>100-400</td>
<td>Sedation, gait and balance issues, falls, liver dysfunction, hyperammonemia, thrombocytopenia</td>
</tr>
<tr>
<td></td>
<td>Divalproex sodium</td>
<td>250-1000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Oxcarbazepine</td>
<td>300-600</td>
<td></td>
</tr>
</tbody>
</table>


PBA: Dextromethorphan/Quidine (Nuedexta ) 20/10 mg
Hepatotoxicity, QTc prolongation, thrombocytopenia
COGNITIVE ENHANCERS

- Cholinesterase Inhibitors; Aricept, Exelon, Razadyne

- NMDA (N-methyl-D-aspartate) receptor antagonist; Namenda

- Herbal Supplements/Vitamins; Vit E, Gingo Biloba
  - Sano, M et al. (1997) A controlled trial of selegiline, alphatocopherol, or both as treatment for Alzheimer's disease. NEJM 336: 1216-22
Possible preventive strategies against dementia

- Promoting healthy lifestyles
  - non-smoking
  - moderate alcohol intake
  - physical activity

- Decreasing vascular burden
  - hypertension
  - heart failure
  - diabetes
  - stroke

- Increasing brain reserve
CHANGE IN FOCUS OF SUPPORTS PROVIDED

- Maintaining skills
- Stabilizing the environment
- Minimizing choices
- Giving reassurance
- Personal care
- Assessing and meetings medical needs
- Meaningful activities
PROGRESSION OF DISEASE; ANTICIPATORY GUIDANCE

- Cognitive Skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections
- Seizures
- Watch for signs of abuse and neglect
- Watch for signs of caregiver burn out
- End of Life care; Palliative and Hospice
IMPACT ON FAMILIES AND CAREGIVERS

- Frequent issues experienced by families and caregivers include:
  - Denial
  - Anger / Frustration
  - Guilt
  - Loss and Grief
  - Letting Go
  - Financial Stress
  - Role Reversals
  - Social Isolation
  - Becoming patients themselves
COMMUNITY, STATE AND NATIONAL SUPPORTS

- Community support provider agencies
  - Private
  - Public – state/local government entities
- Area Agencies on Aging (AAA)
  - Aging and Disability Resource Centers (ADRC)
- State and local Alzheimer's Association chapters
  - As well as other local dementia care groups
- State and local Protection and Advocacy Networks
- AADMD-NTG
- Special Olympics
- Faith-based organizations
PERSON/FAMILY CENTERED RESOURCES

- Aging and Down Syndrome: A HEALTH & WELL-BEING GUIDEBOOK

- Alzheimer’s Disease & Down Syndrome: A Practical Guidebook for Caregivers

- Intellectual Disability and Dementia: A Caregiver’s Resource Guide for Rhode Islanders

- www.learningdisabilityanddementia.org/jennys-diary.html

Recruitment

The NiAD sites will recruit 180 adults with DS (10% with dementia) and 40 sibling controls, age 25 years and older.

The ADDS sites will recruit 225-300 adults with DS, 40 years and older.
Thank You!!

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At every age a happy life is made up of little things