Why Dementia in Persons with Intellectual and Developmental Disabilities is an Important Topic!

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Facts about Dementia

- Loss of cognitive function, serious enough to affect daily life. Symptoms vary widely

- Differential diagnosis; R/O treatable

- Types of dementia—why does it matter?
Intellectual & Developmental Disability (IDD)

- Developmental Disability: severe, chronic disability, onset before age 22

- Intellectual Disability (ID): subset of DD-limits in intellectual function and adaptive behavior; 2% of US population

- IDD & Dementia: Triple Whammy (aging, IDD, Dementia). 6% of adults with IDD affected
What Does IDD with Dementia Look Like?

- Course of disease is different (onset, duration)
- Changes more sensory, behavioral vs. memory
- Concept of cognitive reserve
- Usual diagnostic tests, treatments not effective
Down Syndrome & Dementia

- 260,000 in US with DS; life expect now 60; experience “accelerated aging”

- DS represent largest group of persons with dementia under age 50. Alz most prevalent

- Chromo. 21 key role in relationship between DS and Alzheimer’s Disease. 21 produces key protein involved with brain changes caused by Alz.
Possible Symptoms of Dementia in Persons with Down Syndrome

■ May show signs of pre-clinical dementia

■ Memory decline, judgment, language, emotional control, stubbornness, ADLS

■ Increased risk of seizures (first onset)
IDD Screening & Assessment

- Standard dementia diagnostic tools not useful—cognitive baseline not appropriate

- EARLY screening/diagnosing important. Get baseline assessment age 50 (40 for DS); repeat annually

- Value of observer assessment. Document changes, not losses
Early detection/screening

‘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

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‘NTG-Early Detection Screen for Dementia’ (NTG-EDSD)

Pages ①② Basic information

Pages ③④ Information about function and indicators of problem areas associated with dementia

Page ⑤ Coincident conditions

Page ⑥ Medications & Comments

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## What Should be Ruled Out?

- Thyroid abnormality
- Depression
- Vision & hearing loss
- Medication reactions
- Urinary tract disturbance
- Gastro-intestinal disturbance
- NPH
- Nutritional deficiency
- Vitamin deficiency
- Head trauma
- Brain tumor
- Folic acid abnormalities in people taking anti-convulsants

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Neurocognitive Assessments

Informant-report and objective measures for clinical assessment of dementia in people with intellectual disabilities

- 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)
Care & Treatment

■ Triggers for suspecting dementia (Keller)

■ Know the patient! Must have some understanding of person’s non-dementia lifelong disability and health co-morbidities

■ Use Staging Model (pre-diagnosis, post-diagnosis (early, mid, late stage))
Care & Treatment

- Prepare for office visits (Keller)

- Use multi-disciplinary team (include family)

- Examine functional decline: small change can have profound effect on independence

- Medication use complicated, needs monitoring!
Care & Treatment

■ Goals of Care

■ Use non-pharm strategies. The 4 S approach

■ Determine long and short-term goals

■ Anticipate & problem-solve; disease process means many transitions
Key to Care is Relationships

- **Alzheimer’s Association Approach:** “Culture of Gentleness”

- Connectedness & companionship; emotional memory

- Person-centered
Caregiving in IDD/Dementia

- Caregiving issues are different; experienced, advocates but are also at-risk

- IDD require lifelong services and supports; person-centered, focus on future

- Caregiving is lifelong vs. late-life, challenges differ

- Need appropriate caregiver (family) support
What is Needed In America

- Collaboration among aging, dementia care and IDD. Gaps & unmet needs in rural areas

- Need nexus. (Ex: group homes for both); EQUITY IN SERVICES

- Need Dementia Capable Communities (DFW)

- Goals of the NTG
Closing Comments

■ Little cross-over between fields of aging and disability.

■ Must bridge 2 service networks. Need ed; community-based wrap-around supports

■ Need integration of 2 networks for quality continuous care, equity
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References & Resources


References & Resources


Useful Websites

- “Introduction to Dementia in People with Developmental Disabilities. Alzheimer’s Association.” Alzheimer’s Association. 800.272.3900 Alz.org

- McCallion, Phillip. “Understanding Dementia in Persons with Intellectual Disability: Causes, Prevalence and Assessment Changes.” Center for Excellence in Aging and Community Wellness. mcclion@albany.org


Useful Websites


- “Aiding Older Caregivers of Persons with Intellectual and Developmental Disability: A Toolkit for State and Local Agencies.” Contact dbaxley@albany.edu; 518-442-3791
