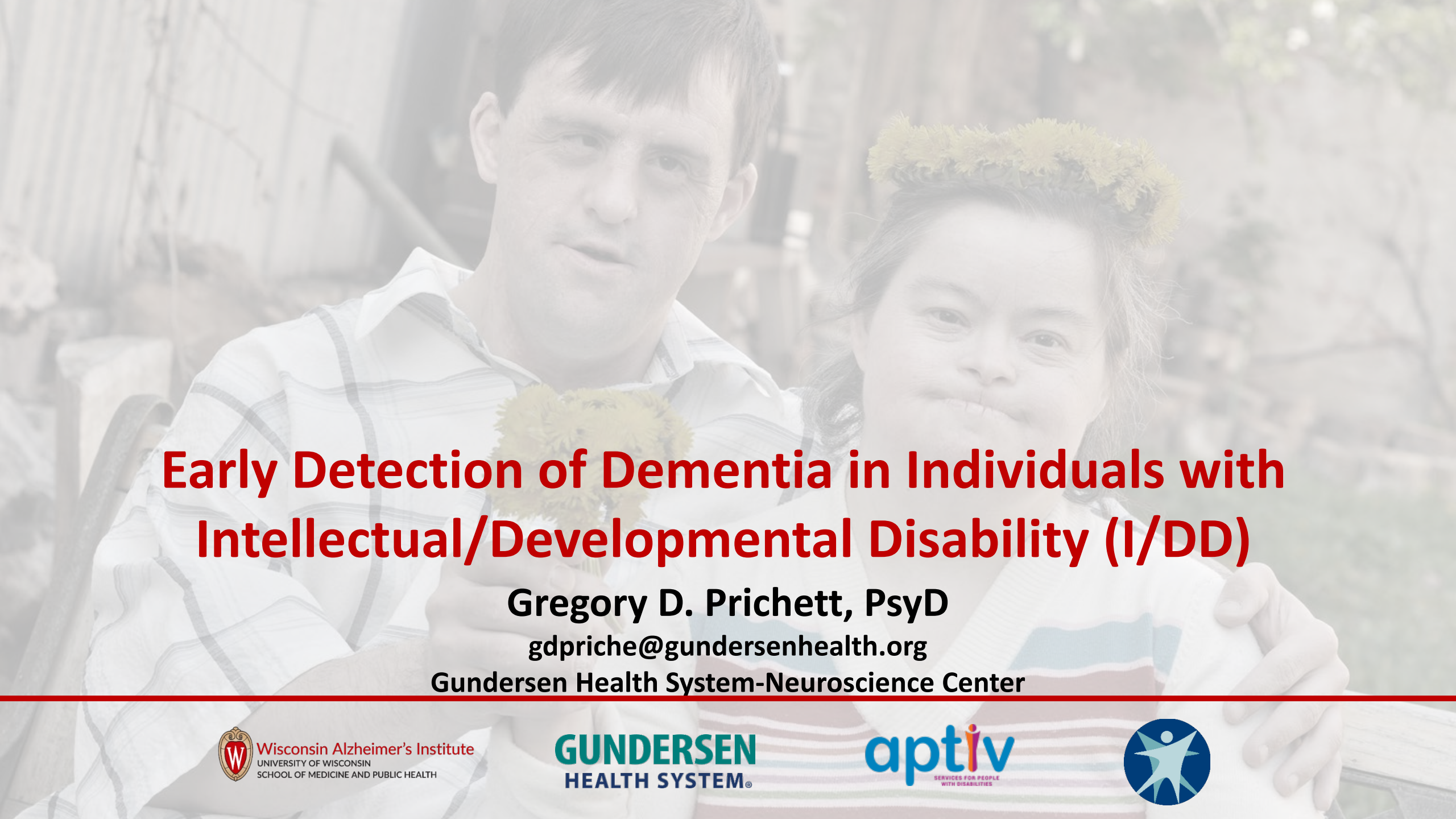

Early Detection of Dementia in Individuals with Intellectual/Developmental Disability (I/DD)

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SERVICES FOR PEOPLE WITH DISABILITIES

Objectives

- Provide an overview of the clinical manifestations, incidence/prevalence, and risk factors for Alzheimer's disease and related dementias (ADRD) in persons with Intellectual Disability (ID) with emphasis on Down syndrome.
- Review assessment challenges encountered in diagnosing dementia in persons with ID.
- Provide an overview and rationale for use of the EDSD-an administrative screen designed to detect dementia-related changes in individuals with ID.

Why is this important?

- Well recognized association between Down Syndrome (DS) and Alzheimer's Disease
- Strong relationship between reduced brain reserve associated with ID and increased risk for dementia
- Increasing life expectancy of persons with ID
- Population prone to develop age-related d/o such as dementia
- People with ID represent particularly vulnerable segment of our population
- Increasing pressure on caregivers and support system

Down Syndrome

- Most common genetic cause of intellectual disability (ID) resulting in significant limitations in intellectual function and adaptive behavior (ID Definition, AAIDD.org; n.d.) and classic physical stigmata
- 1/691 live births annually or ~6000 born in US each year (CDC, 2012)
- More than 400,000 people are living with Down Syndrome in the US (National Down Syndrome Society, 2012)
- Prevalence of children (5-19) with ID-2.5% (mild); 0.4% (moderate); 0.1% (severe) (Roeleveld, 2008).
- 1.2 million non-institutionalized adults had ID in 2010 (Brault, 2012)

Down Syndrome

- Brought about by a full or partial extra copy of chromosome 21
- Extra genetic material alters course of development producing characteristics associated with DS
- Trisomy accounts for 95% cases; translocation 4%, mosaicism ~1%

Alzheimer's Disease

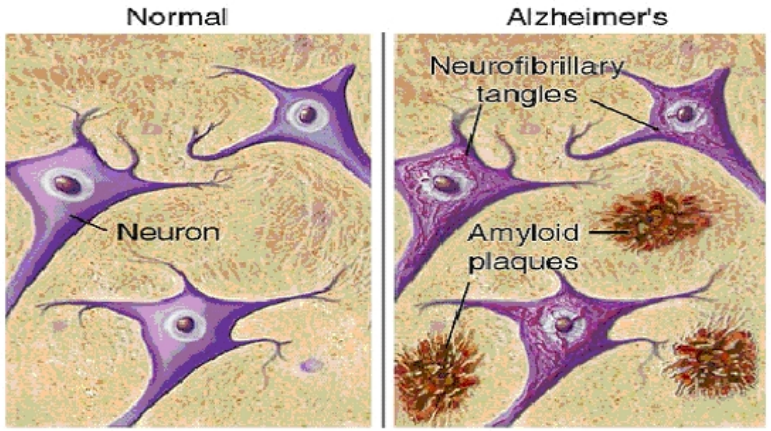
- Most common cause of progressive dementia among older people
- Insidious onset/gradual deterioration is typical but impairments can be abruptly unmasked by significant stressor or inter-current illness or injury
- As disease progresses there is slow erosion of cognition resulting in increased functional dependence and eventual death

Alzheimer's Disease

- 5.4 million Americans; 200,000 early onset (Alzheimer's Association, 2016)
- 2:1 women to men
- Estimated 7.1 million by 2025; 13.8 million by 2050 (Alzheimer's Association, 2016)
- Biggest risk factor for Alzheimer’s disease is age
- Prevalence of Alzheimer’s Disease increases markedly with age

Well Recognized Association Between AD and DS

- Signature brain lesions (amyloid plaques; neurofibrillary tangles) critical to the development of AD
- Characteristic brain changes in AD are found in “virtually all” adults with DS by age 40
- Gene for B-APP linked to region of chromosome 21 which must be trisomic for full expression of Down Syndrome



Other Causes of Developmental Disability/Intellectual Disability

- Cerebral Palsy
- Epilepsy
- Developmental Delay
- Autistic Spectrum Disorder
- Phenylketonuria
- Rett Syndrome
- Prader-Willi Syndrome
- Fetal Alcohol Syndrome

Non-DS ID Dementia and the Brain Reserve Hypothesis

(Strydom et al, 2013; Stern, 2013)

- Refers to structural differences in the brains of persons with ID (smaller brain size, fewer neurons or synapse count) compared to general population
- Also bolstered by protective cognitively stimulating activities (work/play/education) that many persons with ID are not engaged in to the same extent as general population, i.e. more limited range of life experiences
- Reduced brain reserve increases vulnerability to neuropathology later in life

Increasing Life Expectancy of Adults with ID

Penrose, 1949; Janicki et al. 1999

- Persons with DS ID:
  - 1920s – 9 years; 1990's – 56 years
  - 21st century- 60+ years (Fortea, et al, 2020)
- Persons with Non-DS ID:
  - 1930s – 19 years; 1990s – 66 years

Presence of Multiple Disabilities and Level of ID Influence Life Expectancy

Bittles et al. 2002; Coppus, 2013

- Median Life Expectancy
  - Mild ID – 74.0 years
  - Moderate ID – 67.6 years
  - Severe ID – 58.6 years
- Increased survival not only associated with a longer period of care but also related to a longer period of more specialized needs (Bittles and Glasson, 2004)

Population Prone to Develop Age-related Disorders

- Middle-aged persons with DS show many age related changes in health and functional status that suggest premature aging
  - Skin changes
  - Osteoporosis
  - Obesity
  - Early onset visual/hearing impairments
  - Brain atrophy and white matter lesions
  - Increased risk of dementia
  - --Early menopause
  - --Osteoarthritis
  - --Immunological changes
  - --hypogonadism
- Biomarker changes can be seen 20 years prior to the “onset” of dementia (Fortea, et al, 2020)

Vulnerability/Caregiver Pressure

(Heller & Factor, 2004)

- As of the year 2000, ~640,000 adults with ID/DD >59 years of age in the U.S.
- Projected to nearly double to 1.2 million by 2030 when last of baby boomers reach 60
- Majority of adults with ID (60%) live with family;
- In a sizeable number of households the primary caregiver is >59 yoa

Vulnerability/Caregiver Pressure

- By 2030 will see significant increase in #s of 2 generation elderly families living together whose parents 80+ yoa (possibly developing dementia) caring for older son/daughter with ID who may be developing age-related conditions and dementia
- Most families stay together due to lack of options or choice even though care will likely be compromised by parents health problems

Dementia Rates in General Population

Brookmeyer et al. (2011)

Age	All Dementia	AD
71-79	4.97	2.32
80-89	24.19	18.10
90+	37.20	29.60
Total	13.67	9.51
Average Age Onset: 75 years		
Average Duration: 8-10 years (3-20+)		
Mixed pathologies are more common		

Median Life Span Following Diagnosis

Brookmeyer et al (2002)
Fortea et al (2020)

- Depends on age and presence of comorbid medical conditions
- Age 60s-70s: 7-10 years
- Age 90s: 3 years or less
- Mean duration between onset of symptoms and diagnosis: 2.8 years

In a more recent study by Fortea and colleagues, the average age of a diagnosis is 53.7, with the mean duration between onset of symptoms and diagnosis of 3.5 years.

Risk Factors for AD in the General Population

- **Age**-risk doubles every five years for individuals greater than 65; ~37% after 85
- **Family History**-first degree relatives; risk increases if more than one immediate family member has the disease
- **Genetic Risk Factors**-**APOE-e4**; familial (autosomal dominant) AD caused by variances in APP, PS-1, PS-2
- **Traumatic brain injury**- more severe or frequent linked to > risk; also reduces time of onset of AD
- **Modifiable risk factors- <u>What is good for the heart is good for the head (brain)!</u>**

Dementia Rates in Adults with Down Syndrome

Ball et al. 2006

Age	%
30-39	<3%
40-49	10-25%
50-59	20-50%
>59	30-75%
Average Age Onset: 50.2 yrs *	
Average Duration: 3.5 – 10.5 yrs**	

*Fortea et al (2020)

**Dalton & Wisniewski, (1990)

Dementia Rates in Adults with Non-Down Syndrome ID

Strydom et al. 2007

Age	All Dementia	AD
>59	13.1	8.6
>64	18.3	12.0
Average Age Onset: 67 years		

Risk Factors for ADRD in People with ID

- Persons over the age of 40 who have Down syndrome
- If the person is over the age of 59 and has an intellectual disability of another cause
- if the individual has some form of head injury, especially severe or multiple head injuries
- if the individual has a family history of Alzheimer's disease

Summary: Dementia Rates and Risk Factors

- Adults with DS have highest rates of AD and the prevalence increases substantially after age 40.
- **It's possible for these individuals to remain dementia free between the ages of 55-70 yrs, however most do not live to age 70.**
- Onset of AD in DS is earlier than the general population likely due to a combination of factors-genetic predisposition, tendency toward premature aging, more aggressive form of the disease versus delay in diagnosis

Summary: Dementia Rates and Risk Factors

- Rates of dementia in Non-DS ID adults are at least equal to and probably higher than the general population
- Biomarker change in people with DS can be seen 20 years prior to diagnosis, but the onset and course of dementia approximate that of the general population

Clinical Manifestations of Dementia in Adults with ID

- The course of decline of dementia in persons with ID is the **same** as that for the general population…only it's **different**.
- Core sxs of dementia involve progressive loss of function in memory and multiple cognitive domains **similar** to the general population
- Presentation of dementia in adults with ID is **different** (especially in DS) as personality and behavior change mark the early stages

Clinical Manifestations-Personality and Behavior Change

- Emotional lability
- Irritability
- Apathy/inactivity
- Stubbornness and coarsening of social behavior

Clinical Manifestations of Dementia in Adults with ID

- While the course of memory and cognitive decline is similar to Non-ID adults, its presentation will differ according to
  - Severity of ID
  - Level of education
  - Life experience
  - Ability to compensate for newly acquired deficits
  - Demands of everyday life/culture of care

Clinical Manifestations-Memory Loss

- Memory loss in Mild-moderate ID (IQ 40-70) similar to that seen in adults without ID (excepting those tasks too complex or difficult to begin with)
- In Severe-Profound ID, (IQ < 40) ability to detect will depend on baseline verbal skills and ability to meet task demands
- Profound ID (Mental Age <2) may preclude detection; need to rely on neuro signs

Clinical Manifestations-Cognitive Loss

- Mild-moderate ID (IQ 40-70)
  - If verbal skills well-developed will see typical word-finding difficulty and dysnomia
  - If verbal skills poor will see decreased use of language progressing to total loss of verbal expression
- Severe to Profound ID (IQ <40)
  - General slowing in all areas
  - Greater impairments to attention
  - Decreased temporal/spatial orientation

Common Physical Signs

Lai & Williams, (1989)

- Myoclonic jerks
- Late onset Sz or new type of seizure
- Postural abnormalities
- Limb rigidity
- Slowness, shuffling of gait
- Urinary incontinence
- Pathological reflexes

Everyday Functioning

(Zigman et al. 2002)

Functional declines are first evident in more complex skills with progression to more fundamental skills later on

Everyday functioning-early changes

- Decline in work productivity
- Household chores skills-table setting, washing dishes, making meals, making bed, use of appliances
- $ handling, banking and budgeting, ability to shop
- Sense of direction, use public transportation
- Dependability with assigned activities

Everyday functioning-later changes

- Initiative, persistence and perseverance in activities to structure and pass time
- Basic arithmetic, counting and time telling
- Toileting, Bathing and personal hygiene
- Ability to eat, understand spoken language and ambulate last to be affected

Sequence of Decline In ID Adults

Strydom et al. (2010)

	ADULTS WITH DS	NON-DSID
Trigger Symptoms	• Memory loss and disorientation • Deterioration in speech • Personality and behavior change • Functional deterioration • Neurologic symptoms – seizures, incontinence • Frontal lobe-related symptoms	• General deterioration in function • Behavioral and emotional change
Sequence of Memory and Cognitive Changes – Early and Middle Stage Dementia (in order of typical progression)	• Memory loss • Deficits in executive function • Complex cognitive functions • Visual organization • Verbal memory • Semantic and short-term memory • Dyspraxia	• Memory/cognitive decline less prominent early on
Sequence of Functional Decline, Personality and Behavior Change	• Decline in ADLs –successive deterioration in ○ Personal hygiene ○ Housekeeping skills ○ Dressing ○ Spatial orientation ○ Eating	• Signs of depression – ○ Lack of energy ○ Low mood ○ Disturbed sleep • Psychosis – persecutory delusions; auditory hallucinations
	• Increasing number and more severe maladaptive behaviors ○ Irritability ○ Aggression ○ Self-injurious behavior ○ General slowness ○ Apathy ○ Loss of interest ○ Decreased social engagement	• More aggressive than DS counterparts (but higher prevalence of other behavioral change in DS)

Sequence of Decline In ID Adults

	ADULTS WITH DS	NON-DSID

Neurological and Physical Changes	• Epilepsy
	• Myoclonus
	• Pathologic reflexes
	• Brain atrophy associated with frontal lobe dysfunction
	• Rigidity
	• Postural abnormalities
		• Late stage symptoms –
		  ○ Urinary/fecal incontinence
		  ○ Difficulty walking

End-Stage Symptoms	• Unresponsive to environment • Loss of ability to speak • Total dependence • Unable to walk • Incontinent • Parkinsonian features • Almost all have seizures	

Pre-Clinical Stage

Jokinen et al. (2013) Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia.

- Sporadic memory lapses
- Getting lost/misdirected
- Gait and walking difficulties
- Confusion with familiar tasks or familiar situations
- Increased frustration, lack of patience
- Personality change

Early Stage Changes

- Loss of memory that further affects performance in daily activities and social interactions
- Increased confusion with anxiety
- Communication difficulties
- Decreased zest for living

Mid-stage Changes

- STM loss/difficulty recognizing family, friends and staff
- LTM of people and events confused with the present
- Disengagement from family activities
- Restlessness, pacing, agitation
- Hoarding, wandering and shadowing
- Difficulty understanding and being understood
- Repetitive statements
- Challenging behaviors

Late/End Stage Changes

- Severe intellectual deterioration
- Immobility
- Falls
- Seizures
- Difficulty swallowing
- Respiratory/breathing problems
- Complete loss of self-care skills
- Conditions leading to death

Staging Model of Decline

Jokinen et al. (2013)

- **Pre-clinical Stage**-sporadic changes; 33% conversion rate to dementia in 18 months; conduct assessment when suspicions present.
- **Early Stage**-Sxs more pronounced/constant; last on average 5-8 years; increased supervision and supports needed.
- **Mid-Stage**-increased loss of abilities; greater likelihood of emergence of challenging bxr; 2-10 years; move to prevention of antecedents.
- **Late/End Stage**-Severe cognitive/functional deterioration; 1-3 years; 24/7 care needs.

Diagnosis of Dementia in Persons with Intellectual Disability

- The diagnosis of dementia requires documentation of changes in personality and social behavior and declines in cognitive function and daily living skills from a prior level of function
- In the general population this is a relatively straightforward process
- In adults with ID documentation of declines is complex and poses significant challenges

Diagnostic Challenges

- Susceptibility to Other Causes of Decline
- Premorbid Cognitive Deficits
- Heterogeneity of skills
- Diagnostic Overshadowing
- Atypical Presentation
- Lack of knowledge and training
- Access to services

Conditions That Produce a (Potentially) Reversible Dementia

- Hypothyroidism-50% prevalence
- B12/folate deficiency-due to long-term use of anti-seizure meds; oral contraceptives
- Depression/psychiatric impairment/life stress-common in people with ID, often co-exists
- Medication effects-narcotic analgesics, sedative hypnotics, anxiolytics, tricyclic anti-depressants, anti-psychotics

Conditions that Mimic Dementia

NIH (2011)

- Sleep Apnea-> chronic sleep deprivation; EDS
- Cardiovascular & circulatory defects- common cause of death in people with ID
- Infection (usually respiratory)- common cause of death
- Osteoporosis/osteoarthritis-->Pain/Joint Problems-> activity/functional decline
- Sensory Impairments-40-77% hearing loss, 46% cataracts in DS individuals

Susceptibilities/Conditions that Mimic

- All conditions can have effects on memory, cognition, mood and behavior and lead to deterioration in function
- Frequent source of misdiagnosis
- Effects often assumed to be due to Alzheimer disease
- Comprehensive and systematic medical evaluation needed to rule out reversible causes

Premorbid Cognitive-Intellectual Impairments

- Adults with ID often lack the skills to perform standardized diagnostic tests of mental status
  - 77% false+ rate using MMSE (Deb & Braganza, 1999).
  - Informant reports far superior in detecting dementia
- Compounded by limited ability to self-report, lack of consistent and reliable documentation of premorbid functioning; high staff turnover.
- Makes it difficult to detect declines unless marked.

Heterogeneity of Skills

- Often wide-ranging skills between individuals of the same level of ID
- Different “starting points” makes it difficult to detect change without a baseline for comparison

Diagnostic Overshadowing

- High prevalence of emotional, social and behavioral problems in individuals with ID at baseline, e.g. **soliloquy (self-talk); self-stimulatory or self-injurious behavior; verbal or physical aggression; depression/anxiety; OCD; psychosis**
- Behaviors have a strong "**perceptual pull**" that may overshadow the emergence of dementia
- Run the **risk of misdiagnosis** if unfamiliar with the adult or behavioral problems common to individuals with ID

Atypical Presentation

- Persons with ID experience the full range of psychiatric impairments
- **Psychiatric disorders are 2-4x more common compared to the general population** (Eaton & Menolascino, 1982; Cooper & Bailey, 2001; Clay & Thomas, 2005)
- Changes in adaptive skills or behavior may predate early impairments in memory in adults with ID making it difficult to differentiate changes related to dementia versus new onset behavioral/psychiatric impairment (or exaggeration of baseline behavioral problem).

Lack of Knowledge and Professional Training

- Many physicians and healthcare professionals lack training in the needs of individuals with intellectual disability across the life span (US Public Health Service, 2002)
- Many clinicians and caseworkers are inadequately prepared to recognize symptoms or conduct diagnostic assessments of adults with ID who may be affected by dementia (Perkins & Moran, 2010).
- Few specialists in this area

Need for Coordinated Screening Process Tailored to Adults with ID

- Conduct baseline assessments
- Follow longitudinally
- Monitor for signs and symptoms of decline
- Document declines from “best level of performance”
- Screen on annual basis or as indicated beginning age 40 for DS; 50 for Non-DSID
- Refer for formal eval when suspicions arise

But How? And With What?

- National Task Group Early Detection Screen for Dementia (NTG-EDSD)
- Offers carers and staff a resource to record changes in cognitive and adaptive function known to be associated with dementia
- Not an assessment/diagnostic instrument but an “administrative screen” that provides info to begin conversations with providers about next steps; plan and prepare

National Task Group (NTG) on Intellectual Disabilities and Dementia Practices

- Formed in response to National Alzheimer's Project Act (NAPA) signed into law by President Barack Obama
- Comprised of American Academy of Developmental Medicine and Dentistry (AADMD), Rehabilitation Research and Training Center on Aging and Developmental Disabilities-Lifespan Health and Function at the University of Illinois at Chicago, American Association on Intellectual and Developmental Disabilities (AAIDD).

NTG-Historical Perspective

- Primary goal to ensure that the concerns and needs of people with ID and their families, when affected by dementia, were and continue to be considered as part of the National Plan to Address Alzheimer's Disease issued to address the requirements of NAPA (Moran et al. 2013).

NTG- 3 Primary Objectives

- Creation of an early detection screen to help document suspicions of dementia-related decline among adults with ID
- Practice guidelines for healthcare and supports related to dementia among adults with ID
- Identification of models of community-based supports and long-term care of persons with ID

NTG-EDSD

- Gathers information on
  - Relevant Demographics
  - Ratings of Health, MH and life Stressors
  - Review multiple domains of function
  - Survey of chronic health conditions
  - Signal items that reflect early signs of dementia

NTG-EDSD

- Can be helpful in training caregivers and staff to become good observers and reporters of pertinent information
- Serves as a running record of health and function to be reviewed annually
- Serves as a tool accessible to caregivers who are not trained to do assessment but have valuable info about change in daily function

Summary

- Individuals with ID are living longer and as such at increased risk for age-related conditions such as ADRD, especially in the DS population.
- Diagnosis of dementia in persons with ID is challenging due to their baseline intellectual limitations and atypical presentation.

Summary

- Documentation of declines necessary for diagnosis of dementia is further hampered by a lack of consistent and reliable documentation of premorbid function, as well as lack of knowledge and training of physicians and healthcare professionals in the needs of individuals with ID as they age.
- Standard assessment measures are inappropriate for use with ID adults as many persons lack the skills to perform these tasks at baseline.

Summary

- There is a need for an early detection screening tool to be used to establish both a baseline level of function and one that can be used to obtain longitudinal measures that indicate change
- With early detection further diagnostic assessment can be carried out to differentiate dementia from other causes
- Prompt and appropriate treatment can then be initiated at a time when it is likely to be most helpful

Summary

- The NTG-EDSD is an informant-based rating tool (administrative screen) that can be of help in the early identification and screening process.
- It is an easy to use instrument that offers carers and staff a resource to record changes in function known to be associated with dementia, and provides information to begin conversations with healthcare providers about next steps.

To Learn More

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Thank You!

- Next Steps
- Questions/Comments