

ECHO IDAHO

Alzheimer's Disease and
Related Dementias

Improving Dementia Care in Individuals with Intellectual / Developmental Disabilities

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Learning Objectives

- Evaluate early behavioral, emotional, neurological, and functional changes to differentiate dementia in adults with intellectual and developmental disabilities—particularly Down syndrome—from normal aging and psychiatric conditions.
- Integrate longitudinal, baseline-referenced assessments and ICD-10–aligned diagnostic criteria to formulate accurate differential diagnoses and guide person-centered dementia care planning for individuals with intellectual disability.

Intellectual / Developmental Disabilities

- Intellectual developmental disorders
- Developmental Disabilities including Cerebral Palsy
- Autism spectrum disorder

Increased Longevity and Risk

- Individuals with intellectual and developmental disabilities (I/DD) and autism are living longer
- Increased lifespan is associated with a higher risk of developing dementia

Annual Wellness Visit

Detection of any cognitive impairment as part of the Affordable Care Act's annual wellness visit in primary or other health care settings for adults with pre-existing neuroatypical or neurodivergent conditions (NACs) is challenging

Down Syndrome and Alzheimer's Disease

- Individuals with Down syndrome commonly develop Alzheimer's dementia if they live beyond age 50
- Average age of dementia onset: 54.5 years
- Average life expectancy: approximately 60 years

Comprehensive Approach to Diagnosis

- A multidisciplinary framework that incorporates insights from diverse sources, including family members, caregivers, and, when possible, the individuals themselves.
- Longitudinal assessments and regular monitoring are essential for detecting subtle changes that may signal the onset or progression of dementia.

Diagnostic Challenge

- No dementia diagnostic criteria are specifically designed for individuals with intellectual disability
- Standard diagnostic approaches may not be appropriate for this population

Use of ICD-10 Criteria

- ICD-10 criteria are considered most appropriate for individuals with I/DD
- Greater emphasis on non-cognitive symptoms
- Two-step differential diagnostic process is recommended

Early Clinical Presentation

- Dementia may present differently in individuals with intellectual disability
- Personality and behavior changes may be early indicators
- Emotional lability, irritability, apathy, stubbornness, and social behavior changes are common

Neurological and Physical Features

- 50–80% develop late-onset seizures or a new seizure type after dementia diagnosis
- ~20% show Parkinsonian features (slowness, shuffling gait, rigidity, posture changes)
- Other features may include pathological reflexes, urinary incontinence, and myoclonic jerks

Depression vs Dementia

- Depression often shows an up-and-down (fluctuating) course
- Dementia is characterized by progressive and irreversible decline

Assessment Considerations

- Single-point-in-time standard assessments assume normal premorbid functioning
- Often inappropriate for individuals with intellectual disability
- Longitudinal assessment is required, based on a personal baseline or “best” level of function

Behavioral and Emotional Changes

- Emotional lability with crying spells and rapid mood changes
- Increased irritability, low frustration tolerance, and anger
- Apathy, inactivity, withdrawal, and slowing of movement and speech
- Loss of interest in previously enjoyed activities

Executive and Adaptive Function Decline

- Decline in frontal/executive functioning may occur before memory impairment
- Impacts judgment, planning, organization, and adaptive skills

Cognitive Changes by Level of ID

- Mild ID: difficulty with planning, judgment, and non-routine tasks (e.g., shopping, cooking)
- More significant ID: loss of routine skills such as dressing or toileting
- May show apraxia, aphasia, alexia, and agraphia

NTG-EDSD

- The National Task Group – Early Detection Screen for Dementia
- Primary care providers may ask families or other caregivers to complete the NTG-EDSD prior to visits

DSQIID

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities
- Level of “best” ability

Cognitive Scale for Down Syndrome

- Informant rated questionnaire
- Suitable for all adults regardless of cognitive ability

Diagnostic Work Up

- History and physical exam (including neurological exam)
- Review of NTG-EDSD
- Laboratory tests: CBC, CMP, TSH, B12
- Neuroimaging: MRI of the brain without contrast
- Neuropsychological testing
- Biomarker testing

Treatment of Dementias in I/DD populations

- Extrapolated from general population guidelines
- Foundation: Individualized, predominantly nonpharmacological approach
- Occupational and physical therapy
- Family and staff education, training and support

Treatment of Dementias in I/DD populations

- Deprescribing anticholinergics and problematic medications
- Addressing treatable comorbidities (e.g., nutritional deficiencies)
- Brain healthy lifestyle (six domains): exercise, sleep, nutrition, relaxation exercises, social activities and cognitive stimulation
- Structure and routine (consistency, predictability)

Diagnostic Overshadowing

- Cognitive, behavioral, or functional decline may be incorrectly attributed to lifelong intellectual/developmental disability
- New symptoms are sometimes dismissed as:
 - “Baseline behavior”
 - Psychiatric illness alone
 - Autism-related traits
 - Normal aging
- Behavioral changes may actually reflect:
 - Pain
 - Delirium
 - Depression
 - Medication adverse effects
 - Emerging neurodegenerative disease
- Diagnosis should focus on change from the individual’s established baseline
- Longitudinal caregiver observations are often critical

Caregiver and System Challenges

- Many adults with intellectual/developmental disabilities depend on aging caregivers
- Dementia-related decline may lead to:
 - Increased supervision needs
 - Behavioral dysregulation
 - Caregiver burnout
 - Placement instability
- Consistency, routine, and familiar environments become increasingly important
- Staff education and caregiver support are essential components of care
- Future planning may need to address:
 - Residential needs
 - Decision-making support
 - Guardianship (or power of attorney if appropriate) considerations
 - Long-term care coordination

Limitations of Traditional Neuropsychological Testing

- Most neuropsychological tests were normed on neurotypical populations
- Standard scores may be difficult or impossible to meaningfully interpret in individuals with pre-existing intellectual impairment
- “Floor effects” are common:
 - Extremely low scores may occur despite meaningful retained abilities
 - Quantitative scores alone may underestimate real-world functioning
- Single-point-in-time testing may fail to detect meaningful decline
- Baseline (“best level”) functioning is often more clinically informative than comparison to population norms
- Testing frequently requires adaptation – thus breaking standardization:
 - Simplified instructions
 - Modified pacing
 - Increased behavioral support
 - Integration of collateral/informant data
- Adaptive and functional decline may be more diagnostically meaningful than isolated cognitive test scores

When Neuropsychological Evaluation Can Be Helpful

- Establishing or clarifying longitudinal cognitive and functional change
- Assessing strengths and preserved abilities to guide care planning
- Evaluating executive, behavioral, and adaptive functioning
- Supporting recommendations regarding:
 - Supervision needs
 - Safety
 - Vocational/day programming
 - Caregiver supports
- Assisting with complex or atypical diagnostic presentations
- Providing education and counseling to families and interdisciplinary teams
- Neuropsychological evaluation is most valuable when integrated with longitudinal history, caregiver observations, adaptive functioning, and medical assessment

References

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- Janicki et al., and Neuroatypical Conditions Expert Consultative Panel. (2022). Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments – Report of the Neuroatypical Conditions Expert Consultative Panel. The National Task Group on Intellectual Disabilities and Dementia Practices and the LuMind IDSC Foundation

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Resources

- [Down Syndrome and Alzheimer's Disease \(Alzheimer Society of Canada\)](#)
- [Cognitive Scale for Down syndrome \(CS-DS\)](#)
- [Dementia Screening Questionnaire for Individuals with Intellectual Disabilities \(DSQIID\)](#)
- [National Task Group on Intellectual Disabilities and Dementia Practices](#)