Early Detection of Changes Associated with Cognitive Decline in Adults with IDD

An EDSD ECHO presentation

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National Task Group for Intellectual Disabilities and Dementia Practices

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The 3Ds: Delirium, Depression and Dementia

- Several conditions other than dementia are associated with cognitive decline; they may mimic dementia
- It is important , when possible, to rule out other sources of cognitive and functional decline
- We want to differentiate among the **3 D's: delirium, depression** (previously called "pseudodementia") and ***dementia***
- Other conditions may alter mental status including psychiatric illness, sensory impairment, and exposure to stressors

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Cognitive changes of Aging with Disabilities which deserve attention

- Memory problems that interfere with everyday functioning
- Problems in orientation to time, place or person (presuming that the person was previously oriented in these spheres)
- Slowing down in movement, thinking and processing information
- A coarsening of social behavior
- Increased impulsivity
- Difficulty with new learning
- Change in ability to communicate (impoverishment of communication)
- Problem pursuing well-learned routines and activities
- Confusion in familiar places

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Dementia and IDD vs. dementia in the general population?

- Neurocognitive disorder is brain disease that affects all domains of functioning cognitive, social, behavioral and adaptive regardless of whether the person is classified as intellectually disabled or has been neurotypical:
- **Cognitive skills** like memory, attention, problem solving, perception and language
- **Social skills** such as understanding behavior and emotional and
- **Behavioral skills** such as self-control appropriate to setting and situation
- **Adaptive Skills** like the ability to walk, dress, toilet and feed oneself
- Individuals with pre-existing cognitive deficits (IDD) are more likely to display early onset dementia
- Individuals with Down Syndrome are at particular risk

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Brain changes occur before signs of dementia

Brain changes are likely to precede functional signs of probable Alzheimer's dementia by more than a decade

- If dementia can be identified earlier, there is the potential to proactively address signs and symptoms.
- Interventions, services or supports may be more effective if offered prior to significant cognitive and/or functional change.

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Early Identification

- Early identification of signs and symptoms of cognitive and functional decline associated with dementia is an important first step in managing the course of the disease and providing quality care
- Family and professional caregivers can work with the consumer's health care provider to share information about observed changes
- NTG promotes a rating tool the **National Task Group Early Detection Screen for Dementia (NTG-EDSD)** to substantiate changes in adaptive skills, behavior and cognition

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Benefits of Early Identification of Change

- Identifying the cause of decline can lead to proper, targeted care and affords a greater chance of benefiting from existing treatments
- Early diagnosis can help ease the anxiety that may accompany unexplainable changes in behavior
- Educating persons with dementia and their caregivers gives them time for advanced care planning
- Quality of life for persons with dementia and their family can be maximized

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I/DD may complicate early recognition

- Pre-existing cognitive impairment, behavioral disorders and poor emotional control may complicate recognizing the early signs of dementia
- Early cognitive and functional changes may be subtle or intermittent
- Pre-existing level of intellectual ability, sensory impairment, and health status may all impact upon cognitive and functional status

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Things to Know about Dementia

- Dementia is not a diagnosis or disease, it is an umbrella term for changes (from characteristic baseline) in behavior, cognition, emotional control, and functioning
- Alzheimer's Disease is the most common form of dementia
- The average age of onset of dementia in a person with Down syndrome is about age 52; actual brain changes may begin as early as 20 years prior to "onset"
- Changes in personality and behavior often predate changes in memory among individuals with DS and dementia
- Progressive decline can last from 1-7+ years for persons with DS
- As the disease progresses, so do the care needs of the individual as memory, self-care, communication and walking become more difficult

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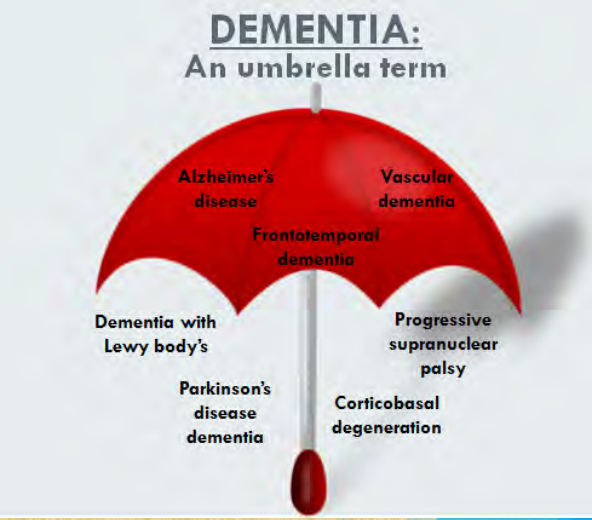
Neurocognitive Disorders

- What will you observe?
- What will you do?
- How can you best advocate?



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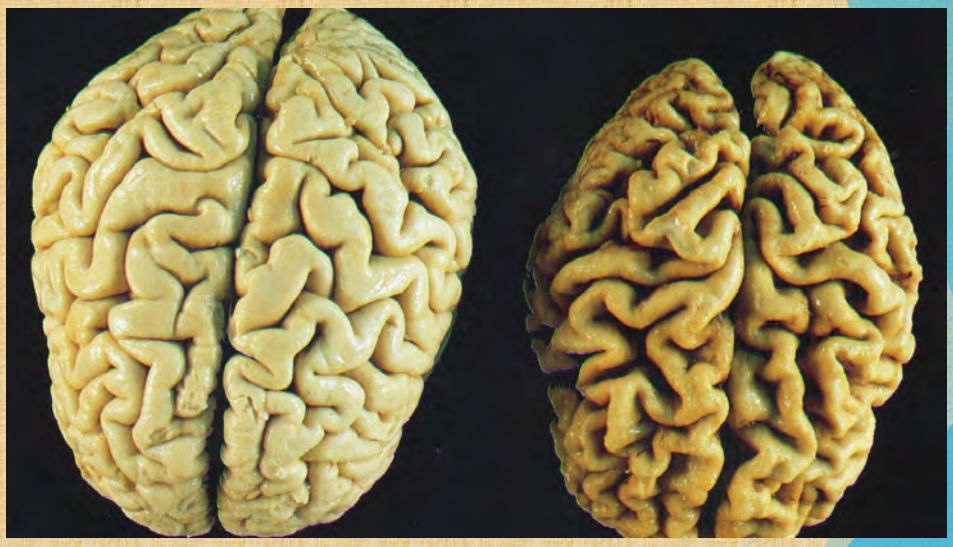

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Know the Warning Signs of Dementia

- Unexpected memory problems
- Getting lost or misdirected in a familiar setting
- Problems with gait or walking
- New seizures
- Confusion in familiar situations or with customary tasks at home or at work
- Changes in personality
- Difficulty maintaining social connections with family and friends

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Variety of Early Indicators

- Reduced work performance
- Difficulties with recent memory and new learning (e.g. *can't remember the names of new staff*)
- Changes in communication skills including impoverishment in expressive language compared with baseline (e.g. *a person who was talkative no longer says anything*)
- Emotional lability, heightened irritability, apathy, "coarsened" social behavior

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First steps…

- When you observe a change in thinking, mood or behavior that is significantly different than what is typical and characteristic for the person whom you support:
- ✓ Collect information for a period of 2 weeks
- ✓ Make an appointment for the consumer to see his/her PCP
- ✓ Advocate for assessment if the consumer demonstrates changes in behavior at work and within his/her residence/familiar setting

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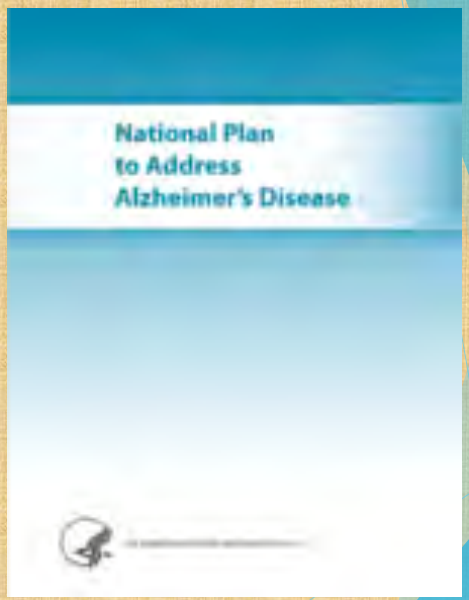
National Plan to Address Alzheimer's Disease

Five goals of The Plan required by the National Alzheimer's Project Act (2011) :

1. Prevent and effectively treat Alzheimer's disease by 2025
2. Optimize care quality and efficiency
3. Expand supports for people with Alzheimer's disease and their families
4. Enhance public awareness and engagement
5. Track progress and drive improvement



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Rationale for development of the NTG-EDSD

- Need to equip family and professional caregivers with a tool to capture information about changes in cognition and function
- Provide caregivers with a format to share important information with the consumer's health care practitioner
- Tool trains caregivers to be better observers and reporters of relevant signs and symptoms of change

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Need for an administrative tool

- Clinicians report that individuals are not brought to attention until well advanced in the dementing process
- Need for an administrative tool that will help link individuals who exhibit change to relevant health care options
- Cognitive and functional status are not usually included in annual health screenings
- For those eligible, the **NTG-EDSD** could be used as part of the Annual Wellness Visit

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NTG -EDSD

Early Detection Screen for Dementia

- adapted from ***the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities*** (Deb et al., 2007) and ***the Dementia Screening Tool*** (adapted by Philadelphia Coordinated Health Care Group from the ***DSQIID***, 2010)
- Down Syndrome: begin as early as age 35 but not later than age 40, then annually; non-DS: begin when changes noted or ≥ 50
- Piloted in 2012; now used internationally

http://aadmd.org/ntg/screening

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NTG-EDSD use considerations…

- This tool is not used for the diagnosis of dementia
- This is an administrative and not a clinical rating instrument
- The diagnosis of a neurocognitive disorder involves medical exam and direct cognitive and adaptive testing of the individuals in question
- If the consumer is already known to have a neurocognitive disorder, use the rating form to baseline observation
- Since this is an early screening tool, it is not necessary to continue using if the person has been formally diagnosed with neurocognitive disorder

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Role of Families and Professional Caregivers

- Caregivers are raters for the **NTG-EDSD**
- Staff need to have worked with the individual for at least 6 months in order to serve as a rater on this instrument
- Families and Staff who are familiar with the person, are more likely to be aware of subtle changes in behavior and functioning that may signal important changes for the individual, constitute important information for health care providers

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How to complete the form

- The **NTG-EDSD** should be completed by someone who is familiar with the consumer
- Gather medical and other chart materials in order to fill out some of the questions pertinent to medical and mental health status changes
- If the consumer attends day program, it may be helpful for the staff at day program to complete a separate record form or the day program's staff can be included in the completion of one rating instrument

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Utilizing findings from EDSD

- Has the individual displayed new symptoms in at least 2 domains on the ***EDSD***?
- Alternatively, is the individual rated as having gotten worse for symptoms already noted in 2 areas?
- Has delirium been ruled out?
- Has depression been ruled out?
- What is the healthcare provider suggesting with regard to medication, monitoring, non-pharmacological interventions?

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How Does the EDSD help capture information about change?

- Domains correspond to areas in which you may see a decline in functioning (from baseline) related to dementia:
- *Behavior*
- *Personality*
- *Memory*
- *Activities of Daily Living*
- *Sleep*

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How do you establish baseline?

- Baseline is what is characteristic and usual for the person
- Observation
- Data collection
- Self-report

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What do you do with the Ratings from the EDSD?

- Look for patterns
- What are areas in which change has been noted?
- What is the extent of change?
- Is something being done to currently address issue?
- Bring to team to brainstorm an options
- Develop an Action Plan
- Share with everyone
- Evaluate the effectives of the plan

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Sharing Findings with Members of the IDT

- Discuss observations captured through EDSD ratings
- Reconcile any discrepancies across settings
- Request additional information, if necessary
- Brainstorm possible approaches
- Operationalize a plan of action

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Sharing findings from EDSD can advance important conversations

- Raise neurocognitive disorder or competing problems for exploration as possible explanation for change. In addition to dementia, the following can be contributing to observed changes:
- Depression
- Delirium
- Sensory loss
- Unaddressed pain

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Types of Decisions that May Follow from Use of the EDSD

- Modification of residence
- Change in residence
- Changing staffing support
- Changing programming
- Developing a positive daily routine
- Identifying items and activities for stimulation

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Promote time-sensitive interventions and support

Findings:

- The consumer has declined in ADLs requiring additional support with personal care and other activities
- This may affect level of care supports, deployment of staff, staffing arrangements, physical or modifications to the setting in which the individual is supported

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Share ratings from NTG-EDSD with the healthcare provider

- Use: to provide information to physician or diagnostician on the consumer's daily functioning
- Advance the conversation leading to possible assessment/diagnosis
- Get the most out of visits with the healthcare provider

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Utilize to determine care and support needs of the individual

- What types of visual and verbal cuing, role modeling or other supports help the individual remain as independent as possible?
- What does the person need in order to be safe?
- What does the person need in order to be comfortable?
- What does the person need in order to have the best Quality of Life (QoL)

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How might the use of the EDSD lead to a diagnosis of neurocognitive disorder?

By ruling out other factors, the health care provider may recommend further testing and evaluation

Although the ***NTG-EDSD*** is not a diagnostic tool, the review of the findings may result in a referral for further diagnostic work-up that can confirm/disconfirm the likelihood of dementia

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To Educate is to Empower

- https://www.nia.nih.gov/health/alzheimers
- adear@nia.nih.gov
- www.aadmd.org/ntg
- https://www.cdc.gov/aging/healthybrain/index.htm

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Thank you for attending this presentation!

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