

EARLY RECOGNITION OF DEMENTIA AND IDD

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Objectives for Today's Webinar

- ▣ Make the case for early detection of changes that may be associated with dementia
- ▣ Provide current thinking on differential diagnosis of depression, delirium and dementia among persons with IDD
- ▣ Review the use of the **NTG-EDSD** to capture information about early change
- ▣ Consider next steps...

What is Neurocognitive Disorder a.k.a. dementia?

- ▣ Neurocognitive disorder is brain disease that affects all domains of functioning:
- ▣ **Cognitive skills** like memory, attention, problem solving, perception and language
- ▣ **Social skills** such as understanding behavior and emotional and behavioral self-control appropriate to setting and situation
- ▣ **Adaptive Skills** like the ability to walk, dress, toilet and feed oneself

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.
- ▣ Greater opportunity to impact quality of life and quality of care

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 should work with the consumer's health care provider to share information about observed changes
- ▣ NTG is promoting a screening tool the **National Task Group Early Detection Screen for Dementia (NTG-EDSD)** to substantiate changes in adaptive skills, behavior and cognition

What is the Value of Early Recognition?

- Early recognition provides a larger window to intervene: we may **slow the progression** of symptoms; early treatment can help maintain a person's current level of functioning.
- An early differential diagnosis can also help to **identify reversible conditions** that may mimic dementia such as depression, medication side effects, substance abuse, vitamin deficiencies, dehydration, bladder infections or thyroid problems.
- Accurate and timely assessment can avoid the trauma of a diagnosis of dementia where it does not exist. It also prevents unnecessary and possibly harmful treatment resulting from misdiagnosis

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
- ▣ The quality of life for both the person with dementia and the family can be maximized

How does one establish baseline?

- ▣ Obtain direct measures, rating scales and collateral information regarding the person's typical and characteristic functioning
- ▣ Adult functioning tends to be fairly stable unless there are problems that result in departure from baseline characteristic
- ▣ Share with healthcare provider observations of changes in sleep, appetite and food consumption, mood, behavior and energy level that persist for longer than 2 weeks

What do we do with information about change

- ▣ Changes from characteristic patterns may serve as red flags for further investigation:
 - ❖ Establish baseline in cognition, adaptive behavior and emotional/social functioning
 - ❖ Monitor changes and confer with individual's health care provider
 - ❖ Watchful waiting with continued monitoring until changes in functioning require modifications in services and supports

What complicates early recognition and diagnosis of dementia?

- ▣ Lack of standardized assessments for persons with IDD that can reliably be used to confirm/disconfirm *significant* changes in cognition and adaptive functioning
- ▣ Debate about what constitutes *significant change* among persons with pre-existing memory and other cognitive impairments
- ▣ Diagnostic overshadowing...everything is attributed to IDD

The 3D's

- ▣ 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
- ▣ In particular we want to differentiate among the 3 D's: **dementia, delirium and depression** (previously called “pseudodementia”)
- ▣ Other conditions may alter mental status including psychiatric illness, sensory impairment, and exposure to stressors

What causes Dementia?

- ▣ Dementia is an umbrella term that refers to a set of conditions resulting in a progressive and unremitting course of cognitive and functional decline associated with aging brain changes:
- ▣ Alzheimer's disease
- ▣ Multi-infarct dementia (strokes)
- ▣ Korsakoff's syndrome (alcoholism)
- ▣ Parkinson's Disease
- ▣ Lewy body and frontal lobe dementias

Recognizing Delirium

- ▣ Delirium is a serious medical emergency that can be mistaken for dementia or psychiatric problems among persons with IDD. It is characterized by:
 1. Acute onset and fluctuating course
 2. Inattention
 3. Disorganized thinking
 4. Altered Level of Consciousness
- ▣ The diagnosis of delirium requires the presence of features 1 and 2 and either 3 or 4

Acute Onset and Fluctuating Course

Acute Onset and Fluctuating Course

- ▣ Information about this is usually obtained from a family member or staff and is illustrated by positive responses to the following questions: Is there evidence of an acute change in mental status from the individual's baseline? Did the (abnormal) behavior fluctuate during the day, that is, tend to come and go, or increase and decrease in severity?

Inattention

Inattention

- ❑ This feature is shown by a positive response to the following question: Did the person have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?

Disorganized Thinking

Disorganized thinking

This feature is shown by a positive response to the following question: Was the individual's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

Altered Level of Consciousness

Altered Level of consciousness

- ▣ This feature is shown by any answer other than “alert” to the following question: Overall, how would you rate this person’s level of consciousness?: alert [normal]), vigilant [hyperalert], lethargic [drowsy, easily aroused], stupor [difficult to arouse], or coma [unarousable]

Delirium

- ▣ Rapid changes in behavior or thinking due to an untreated medical problem:
 - ✓ Urinary tract or upper respiratory infection
 - ✓ Illness
 - ✓ Pain
 - ✓ Trauma/surgery
 - ✓ Pneumonia
 - ✓ dehydration
 - ✓ Vitamin B deficiency
 - ✓ Adverse effects of medication/polypharmacy

Depression

- ▣ Severe depression can cause changes in thinking, concentration, decision making, judgement and behavior
- ✓ Severe depression can affect appetite and sleep
- ✓ Severe depression can affect motivation and interest in people and activities
- ✓ The person who is very depressed may appear listless, lethargic, “out of it, “ slow to respond or unresponsive, inactive

What signs might alert you to someone who is depressed?

- ▣ Depression can be characterized by:
 - ✓ Mood (crying, looking sad or unhappy, lack of emotional response)
 - ✓ Depressed thinking (talking about sad things, death, dying, self-harm, saying people don't like them)
 - ✓ Loss of interest or enjoyment in usual activities
 - ✓ Irritability
 - ✓ Anxiety
 - ✓ Changes in appetite, weight, sleep
 - ✓ Withdrawal from people, self-isolation

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

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

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 language use compared with baseline (e.g. *a person who was talkative no longer says anything*)
- ▣ Emotional lability, heightened irritability, apathy, “coarsened” social behavior

Physical Changes

- ▣ First onset of seizures in adulthood may be marker of neurocognitive disorder, particularly in individuals with DS
- ▣ Incontinence
- ▣ Gait problems

Cognitive Changes

- ▣ Memory
- ▣ Short term/working memory
- ▣ Episodic/semantic memory
- ▣ Autobiographical memory
- ▣ Attention
- ▣ Selective and sustained
- ▣ Spatial orientation
- ▣ Getting lost in one's familiar environment
- ▣ Executive functioning

Non-cognitive changes

- ▣ Personality change
- ▣ Social skills erosion
- ▣ Behavioral problems
- ✓ Behavioral excesses
- ✓ Behavioral skills deficits
- ✓ Increase in impulsivity (e.g. hitting, stripping, stealing) and compulsivity (e.g. hoarding)

Down Syndrome vs. Non-DS IDD

- ▣ Most of what we know about dementia among persons with IDD comes from the study of probable Alzheimer's and Down syndrome
- ▣ To what extent do other subtypes of developmental disorder (Autism, Williams Syndrome, Prader-Willi etc.) increase the likelihood of neurocognitive changes?
- ▣ To what extent does level of intellectual disability affect the recognition and dx of dementia?

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

Lack of reliable way to diagnose dementia...

- ▣ How do we diagnose dementia for a person who is non-verbal and/or profoundly intellectually disabled?
- ▣ Need caregivers (family and staff) who have worked with the individual long enough to pick up changes in functioning among lower functioning individuals
- ▣ Whereas diagnosis within general population is based on normative comparisons, diagnosis among persons with IDD is based on comparing the individual to his/her own performance over time

A few words about diagnosis...

- ▣ Proceed with caution: a confirmatory diagnosis may take time
- ▣ Probable AD – no definitive means of diagnosis at this time
- ▣ Diagnosis involves rule out of other conditions that may alter cognitive functioning, and involves both **direct and indirect assessment**
- ▣ Rule out delirium, treat underlying medical problems and treat depression (remember the 3D's!)
- ▣ MCI and the progression to dementia(?)
- ▣ What is the value of a diagnosis in terms of services, treatment and supports?

What can we do to advance best practice in dementia care?

- ▣ Raise awareness of symptoms
- ▣ Request/provide assessments
- ▣ Monitor health and medications
- ▣ Keep a record of changes
- ▣ Plan ahead for eventual decline
- ▣ Design residences that are “dementia capable”
- ▣ Encourage state and local officials to budget for community care resources for those adults affected by dementia and their caregivers
- ▣ Support local Alzheimer’s/dementia events

A First Pass Screen

- ▣ The information collected from the **NTG-EDSD** can be shared with the consumer's primary care physician and then a determination of need for further testing or a referral to a specialist can be made at that time.

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

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


Piloting the NTG-EDSD

- ▣ Tool based on the DSQIID (Deb, 2007)
- ▣ Unlike the original instrument, the NTG does not purport that the **NTG-EDSD** should be used for the purpose of diagnosis or comprehensive assessment
- ▣ Items from the Longitudinal Health Inventory have been added to provide information about chronic health conditions
- ▣ The **NTG-EDSD** can be downloaded from the **AADMD website**

NTG -EDSD

- Early Detection Screen for Dementia
 - an instrument 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 age 40 then annually, non-DS begin when changes are noted
- Piloted in 8 sites during the Fall of 2012

v.1/2013.2



NTG
National Task Group
on Intellectual Disabilities
and Neurological Conditions

NTG-EDSD

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID[®], can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

Female
Male

Instructions:

For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

(9) Diagnosed condition (check all that apply)

Autism
Cerebral palsy
Down syndrome
Fragile X syndrome
Intellectual disability
Prader-Willi syndrome
Other: _____

Current living arrangement of person:

☐ Lives alone

☐ Lives with spouse or friends

☐ Lives with parents or other family members

☐ Lives with paid caregiver

☐ Lives in community group home, apartment, supervised housing, etc.

☐ Lives in senior housing

☐ Lives in congregate residential setting

☐ Lives in long term care facility

☐ Lives in other: _____

<http://aadmd.org/ntg/screening>

Role of Staff

- ▣ Staff 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
- ▣ Staff are more likely to be aware of subtle changes in behavior and functioning that may signal important information for health care providers

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

Ratings on the Early Detection Screen for Dementia

- ▣ The outside two columns are the least informative: they refer either no observed change in the particular behavior being rated or if the consumer has never had a problem in this particular area (*does not apply*)
- ▣ The central two columns are the most informative: it is the opportunity to indicate a new symptom since last assessment or that a particular problem has worsened over time
- ▣ If this is the first time the **EDSD** is being completed, staff may want to indicate an approximate date during which they first observed the onset of a particular problem

Additional Comments

- ▣ The **NTG-EDSD** is an evolving instrument. Since it is a “work in progress,” we appreciate your comments and questions which can help guide further development of the tool
- ▣ There is no “score” that is currently obtained on the basis of the rating. Currently DSM-5 and DM-ID criteria for dementia will be used to determine if there has been “significant change” to warrant recommendation for further evaluation or if other recommendations are indicated to address issues that affect cognitive and adaptive functioning that may not be related to dementia

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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The Role of Environment

- ▣ Catastrophic reactions in response to noise, sensory overload and task demands that overtax a confused individual
- ▣ Clutter free, stress free
- ▣ Sensory stimulation for individuals who are lethargic and under-activated; sensory decompression for individuals who are overstimulated and over-activated

The Role of Hospitalization

- ▣ Medication is not usually effective and is potentially harmful to individuals whose behavioral presentation is due to dementia
- ▣ Occasionally an individual needs medication to calm down or remain safe because of the severity of their aggression or self-injury
- ▣ Wandering is not a reason to hospitalize
- ▣ Hoarding is not a reason to hospitalize
- ▣ Being a pain-in-the-neck is not a reason to hospitalize

Summary

- ▣ Establish baseline
- ▣ Have staff who are familiar with the individual or family complete the **NTG-EDSD** in order to capture information about change
- ▣ Share information with the consumer's health care provider
- ▣ If the individual has had a rapid change in mental status consider that there is a medical condition and this is acute confusion and not dementia
- ▣ If the individual appears to be depressed, have person evaluated for medication and psychosocial approaches to depression management

Additional Resources

- ▣ <http://www.cddh.monash.org/research/depression/>
- ▣ <http://www.knowledge.scot.nhs.uk/improvingcareforolderpeople/think-delirium.aspx>
- ▣ http://consultgerirn.org/uploads/File/trythis/try_this_13.pdf

Any Questions?

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