The NTG-EDSD as a Team Decision-making Tool

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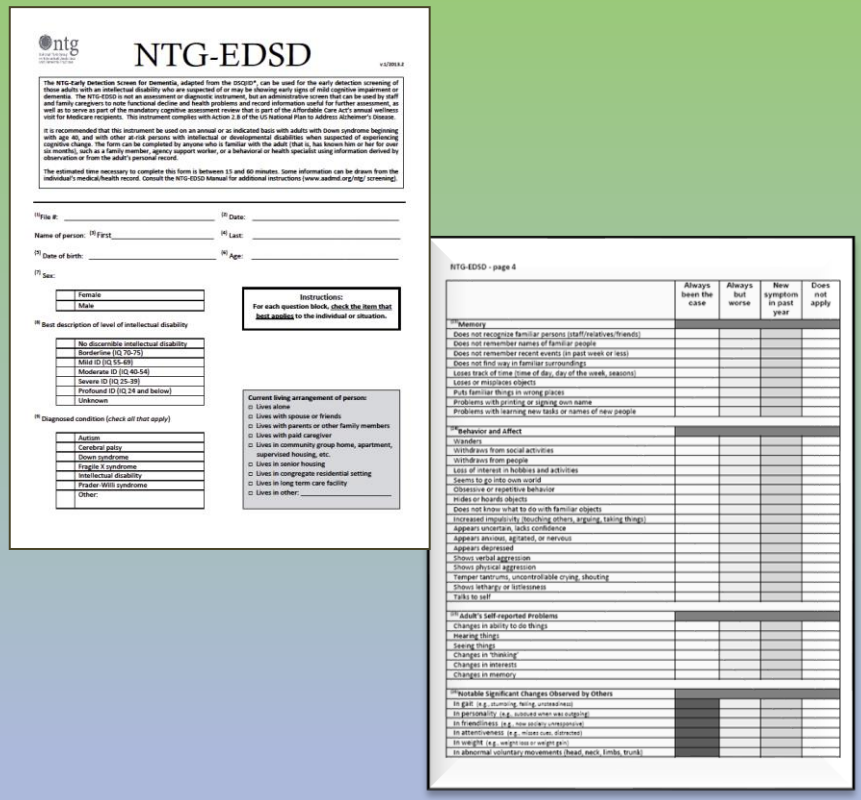
Objectives

- Introduce the use of the ***NTG-EDSD*** as a tool to aid team decision-making
- Provide considerations of the use of findings from the ***EDSD*** advance conversation about planning services, supports and seeking healthcare for individuals served with suspected dementia

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

- Completed by support staff, family and other stakeholders 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



NTG-EDSD

The NTG-Early Detection Screen for Dementia, adapted from the DSQ/ID*, 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

[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:

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

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: _____

NTG-EDSD - page 4

	Always been the case	Always but worse	New symptom in past year	Does not apply
[10] Memory				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
[11] Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
[12] Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
[13] Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, feeling, unsteadiness)				
In personality (e.g., outbursts when asks outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

www.the-ntg.org

Completing the NTG-EDSD

- **Who**: The **NTG-EDSD** should be completed by someone who is familiar with the consumer. This is an ***administrative tool*** and not a clinical screen. It is best completed by whomever has everyday knowledge of the individual whose functioning is being rated
- **Where**: 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 by providing input to family or residential support staff completing a form
- **What**: Gather medical and other chart materials in order to fill out some of the questions pertinent to medical and mental health status changes

Capturing Observations of Change

- The assessment of dementia depends upon **observation**
- For neurotypically developing older adults, there are tests that can yield information about change (particularly decline) from age-relevant behaviors and thinking skills which may signal dementia
- There are very few assessments that provide similar **information about change** pertinent to detection of dementia for individuals with IDD, and little consensus about use of those tests that do exist
- Health care practitioners depend upon collateral information from family members and staff who know the individual and can recognize changes from **baseline functioning**

Baseline is what is typical, usual, and characteristic

- When we consider someone's baseline, we are talking about what is ***typical*** or ***usual*** for the person in terms of memory, thinking, behavior and ADLs

- David ***usually*** remembers staff names and is good about following up on his work routine, can follow two-step instructions, is mild mannered and polite and is independent in his ADLs

- If David cannot learn the names of new staff members and refers to them by names of staff who have long-ago left the workplace, has difficulty following through on instructions, is frequently irritable and rude and needs supervision in showering and toileting, we would say he is displaying a ***departure or change from baseline***

Identifying meaningful change in functioning

- Not all change from baseline is meaningful for our purposes
- The ***NTG-EDSD*** identifies domains important to the recognition of meaningful change in functioning that alerts caregivers about the need to follow-up.
- Let's consider how we can follow-up by sharing findings from the ***NTG-EDSD***:
  - A) by bringing up to the IDT/MDT the topic of the client's changes from usual functioning for further investigation
  - B) by bringing up to the client's Health Care Provider (HPC) observed changes from usual (baseline) functioning
  - C) by recognizing that more information is needed, and identifying additional, useful tracking or data collection
  - D) by considering changes in how staff and families support the individual with suspected dementia on a daily basis

What are we interested in tracking?

- Changes in adaptive behaviors that:

  a) Interfere with independent functioning

  b) Diminish quality of life and gets in the way of individual's valued goals (independent living, work, relationships)

  c) May put the individual or others at risk (safety, loss of placements)

- Response to interventions put in place

What changes might we observe in adaptive skills?

Changes in ADLs: Activities that supports daily living

Incontinence

Balance and gait problems

Apraxia- dressing, feeding, speaking

Increased dependence upon assistance for bathing and grooming

Changes in IADLs: Activities that support independent living

Difficulty handling money (if this was previously a skill)

Difficulty maintaining one's own space

Difficulty shopping or cleaning (if these have been skills within the person's repertoire)

Difficulty using the phone or other devices

What changes might we observe in behavior?

- Increased impulsivity: hoarding, verbal and physical aggression
- Increased reactivity to others
- Social behavior not matched to social situation
- Increased restlessness and agitation

What changes might you observe in cognition?

- Memory changes that interfere with productivity at work or chores at home
- Problems maintaining focused attention, highly distractible
- Difficulty adapting to change (learning new information)
- Difficulty in everyday problem solving
- Language skills may become impoverished

The NTG-EDSD utilizes Likert Ratings

- A Likert rating is composed of a series of four or more items that represent a range of choices for the same question
- You are probably most familiar with Likert Scales that ask you to rate something with number from 1-5, or ask you to indicate agree, somewhat agree, neutral, disagree, strongly disagree
- For the ***EDSD*** on pages 3-4, you are asked to indicate if something has always been the case, has always been the case but is worse, is a new symptom or does not apply
- ***Let's consider what each of these tells us as a way of capturing observations of change…***

Always been the case…

Pages 3-4

What do we mean by "*always been the case*"?

- Kenan has always needed help bathing
- It has always been the case that he does not initiate conversations
- He always sleeps excessive amounts

By choosing "always been the case," you are indicating this is usual for the person and there has been no change

Always the Case but worse…

Pages 3-4

What do we mean by “always the case but worse”?

- Rose has previously needed verbal prompts to complete showering and now she needs hand-over-hand assistance
- Rose has mobility problems—she previously used a walker --and now needs a wheelchair for anything further than short distances
- She previously needed her food cut up for her, but now she can only eat finger food

***By choosing “always been the case but worse” you are indicating the person has lost more skills and is less independent with an activity of daily living for which she has already had problems—the situation has gotten worse*.**

New symptom

Pages 3-4

What do we mean by choosing “new symptom”?

- Walt has episodes of incontinence which began 3 months ago.
- Walt has become lost while walking home from his program twice within the past 6 months
- He cannot remember the name of his new staff and began calling the new staff by the name of a worker who has not been at the home for several years.

By choosing “new symptom” you are indicating that this was not a problem observed during last assessment but is a problem now and is a new sign of change

Does not Apply

Pages 3-4

What do we mean when we choose the rating “does not apply”?

- Joy does not need assistance in showering
- She does not need assistance in dressing
- Joy may have episodes of mild forgetfulness, but this does not interfere with her work or daily activities

By choosing “does not apply” we are indicating that this is an area in which Joy does not have a problem

Sharing Findings with Members of the IDT

- Discuss observations captured through ***EDSD*** ratings within the IDT/MDT
- Reconcile any discrepancies across settings
- Request additional information, if necessary
- Brainstorm possible approaches
- Operationalize a plan of action
- Is it time to refer to the HealthCare Provider or other professionals?
- Evaluate the effectiveness of the plan

How can we utilize 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 identified issues?

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
  - Psychosocial stressors

Types of Decisions that May Follow from Use of the EDSD

- Modify residence
- Change in residence
- Change in staffing support
- Change in program
- Positive daily routine
- Activities

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, you can still use the rating form to baseline observations of change but do not need to continue using if the person has been formally diagnosed with neurocognitive disorder

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

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

Findings from further evaluation may confirm the likelihood of dementia or uncover treatable conditions

Take Home Messages

- Family and staff are in the best position to recognize everyday changes in memory, thinking, behavior skills and ADLs for the people whom they know and support
- The ***NTG-EDSD*** is an administrative screening tool that can be used to capture information about observed changes in functioning of individuals with IDD
- Findings from the ***EDSD*** can aid and promote healthcare advocacy
- Findings can be shared with members of the Interdisciplinary Team and with Health Care Providers to make decisions about services, supports and treatments