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

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?

<table>
<thead>
<tr>
<th>Changes in ADLs: Activities that supports daily living</th>
<th>Changes in IADLs: Activities that support independent living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incontinence</td>
<td>Difficulty handling money (if this was previously a skill)</td>
</tr>
<tr>
<td>Balance and gait problems</td>
<td>Difficulty maintaining one’s own space</td>
</tr>
<tr>
<td>Apraxia- dressing, feeding, speaking</td>
<td>Difficulty shopping or cleaning (if these have been skills within the person’s repertoire)</td>
</tr>
<tr>
<td>Increased dependence upon assistance for bathing and grooming</td>
<td>Difficulty using the phone or other devices</td>
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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...

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…

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.
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.
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.