

National Task Group Early Detection Screen for Dementia NTG-EDSD

Background for NTG-EDSD

- ▶ The NTG-EDSD considered an administrative, and not a clinical assessment, tool.
- ▶ The NTG-EDSD was not designed to diagnose dementia, but to be a help in the early identification and screening process, as well as to provide information to begin the dialogue with health care professionals.

Why do we need early detection of Alzheimer's or other dementias?

- ▶ With early detection, assessment and diagnosis can be carried out to determine whether cognitive changes are the result of a neuropathological process related to disease or trauma to the brain, or attributable to other causes, often treatable and reversible.

Early detection in persons with Intellectual Disabilities

- ▶ Early detection among persons with lifelong cognitive impairments can often be difficult and problematic. Specialized measures are needed that help take in account lifelong impairment and assist in picking up on subtleties in dysfunction.
- ▶ The NTG-EDSD was developed to address these issues, capturing early changes in function and specializing in accounting for subtleties in these changes.

- ▶ NTG wanted to make a tool available that was accessible to caregivers who were not necessarily trained to do assessment, but had valuable information regarding day-to-day changes in functioning. The tool needed to be easy to administer, cannot be time consuming, and should be sufficiently robust to yield information that could be used as an aid in shared decision making.
- ▶ The items that make up the NTG-EDSD are associated with the changes typically observed in dementia. Via the use of this screening tool caregivers or staff can substantiate if a person with an intellectual disability manifests these changes and can then share the information with health care providers.

Uses of the EDSD

- ▶ The NTG-EDSD can be completed at any point in time on an adult with an intellectual disability. Minimally it can 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 initial review using the NTG-EDSD can be accompanied by notes indicating onset of conditions. Following the initial review which would serve as a baseline, the caregiver completing the form can indicate whether there has been a change within the last year since the last review.

Who can complete the NTG-EDSD?

- ▶ 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 and 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

Useful information to have available to complete the EDSD

- ▶ Sources such as the individual's medical record, information on living arrangement and personal functioning, as well as consensus information on functioning from other staff or family members would be highly beneficial to have on hand. A list of laboratory tests that can be useful in determining if there are medical conditions that may contribute to cognitive or adaptive changes are found in Appendix B.

How to complete the EDSD

APPENDIX A: Instructions for the completion of the NTG-EDSD:

Item #	Item Title	Comments
1	Form	For agency use
2	Date	Date form completed
3/4	Name of person	Fill in first and last name of person being assessed
5	Date of birth	Provide day, month, year
6	Age	Age when form was completed
7	Sex	Indicate male or female
8	Best description of level of intellectual disability	Draw from any previously completed assessments or estimate if none ever done
9	Diagnosed condition	Draw from any previously completed assessments or estimate if none ever done
10	Current living arrangement of person	Pick most appropriate item
11	General characterization of current physical health	Pick most appropriate item
12	Compared to one year ago, current physical health	Pick most appropriate item
13	Compared to one year ago, current mental health	Pick most appropriate item
14	Current prison	Indicate those diagnosed or used or allowed
15	Significant recent (in past year) life event	Indicate those that occurred
16	Delirium	Pick most appropriate item
17	Diagnostic history	Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic reports
18	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms were noticed
19	Comments/Explanation about dementia diagnosis	Indicate any behaviors that triggered suspicion or referral for assessment
20	Activities of daily living	Pick most appropriate item for each category based on the data; rates the need, problem, or behavior has been present for a given living time "Always but worse" means the existing need, problem or behavior has further declined, requiring more personal assistance "New emphasis in past year" means this need,

How do we use the information completing the NTG-EDSD gives us?

1. If no "signal items" pop up as warranting further attention, then the form should be retained for comparison against any future administrations
2. If select signal items begin to show, then the form can be used to begin a conversation with available clinicians to determine their relevance and immediacy for concern
3. The information on the form can be shared with the examining physician during any health visit, and in particular during the annual wellness visit

"Signal items" are those items throughout the NTG-EDSD that are linked to the general warning signs of early dementia, and include:

- Unexpected memory problems
- Getting lost or misdirected
- Problems with gait or walking
- New seizures
- Confusion in familiar situations
- Changes in personality

Languages available

▶ The NTG-EDSD form is available in:

- ▶ English
- ▶ Dutch
- ▶ German
- ▶ Greek
- ▶ Italian
- ▶ Japanese
- ▶ Scottish
- ▶ French
- ▶ Spanish - North American

▶ The NTG-EDSD Manual is available in:

- ▶ English
- ▶ French
- ▶ Italian

Other languages may become available - see www.aadmd.org/ntg/screening for copies of available language versions for the tool and manual

Example of ESD format

NTS-ESD - page 3

[check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
III Activities of Daily Living				
Needs help with washing and/or bathing				
Needs help with dressing and/or undressing				
Needs help with eating and/or drinking				
Needs help with walking and/or balance				
Needs help with transferring (e.g., back to back, wheelchair, independently for wheelchair)				
Needs help with grooming (e.g., in shower)				
Needs help with lifting and/or moving objects, checking				
Needs help using the telephone (e.g., writing, dialing)				
Needs help with driving (e.g., occasional accidents)				
IV Language & Communication				
Does not follow conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including getting lost in writing)				
V Sleep-Wake Change Pattern				
Excessive sleep (during usual wakefulness and during bed)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
VI Incontinence				
Has accidents (urine or stool) inside or on the ground				
Has accidents (urine or stool) on the ground				
Has accidents (urine or stool) on the ground				
Has accidents (urine or stool) on the ground				
Has accidents (urine or stool) on the ground				

ANY QUESTIONS?
