National Task Group Early Detection Screen for Dementia (NTG-EDSD) Manual

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[Editor's note: The National Task Group for Intellectual Disabilities and Dementia Practices was formed in 2010. This voluntary coalition of stakeholders consists of over a hundred agencies, professionals, families, and other interested individuals both within the United States and abroad. The purpose of the NTG is to raise public awareness about the unique challenges and needs of individuals with IDD and dementia and to serve as a representative voice for the disabilities community within forums advancing dementia research and practice. To date, the NTG has developed and disseminated the *Thinker Document*, *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia*, and an administrative tool, the *NTG-Early Detection Screen for Dementia* (*NTG-EDSD*). This administrative tool has been available online since earlier this year. The publication of the manual within this issue of the *NADD Bulletin* marks its inaugural presentation to the public. The manual was developed in order to provide guidelines to family and professional caregivers for completion of the *NTG-EDSD*. Additionally, it provides information that might support the use of this tool for shared decision making among family, professional caregivers and health practitioners on behalf of individuals with IDD who are suspected to have mild cognitive impairment or dementia. All of the documents developed by the NTG, including the *NTG-Early Detection Screen for Dementia*, can be found on the American Academy of Developmental Medicine and Dentistry website: http://aadmd.org/ntg.]

Background

The National Task Group Early Detection Screen for Dementia (NTG-EDSD) is an informant-based rating tool for use with adults with intellectual and developmental disability who are suspected of having changes in thinking, behavior, and adaptive skills suggestive of mild cognitive impairment or dementia. It is considered an administrative, and not a clinical assessment, tool. The use of the NTG-EDSD provides an opportunity to review relevant information that can be used by the team and healthcare practitioner to aid in shared decision-making and planning training, services, and supports. 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. Persons who complete this instrument are asked to indicate whether they have observed the occurrence of new problems or a worsening of problems that have previously been observed. The items are associated with changes in cognition, behavior, mood, and activities of daily living.

Why Early Detection?

Early detection is one of the aspects stressed by the *National Plan to Address Alzheimer's Disease*. 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. However, early detection among persons with lifelong cognitive impairments can often be difficult and problematic. Specialized measures are needed that help take into 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.

In general, dementia is not a condition that can be solely determined on the basis of one laboratory or medical test. The diagnosis of dementia is based on a combination of data, including the confirmed observations of changes in cognition, mood, behavior, and adaptive functioning with a rule-out of other known conditions and factors that might mimic dementia, but which are not related to dementia (such as sensory loss, delirium, depression, or environmental stressors). Recent evidence indicates that signal biological markers may be present some twenty years prior to the observation of behavioral changes. However, by the time these observable changes occur, significant neurological changes have already begun to occur. Therefore, the earlier that change in cognition, behavior, and functioning is recognized in adults with intellectual disabilities, the greater the opportunity for families and staff to allocate

necessary resources, access available treatment, and plan for future programming, services and supports.

Early detection is necessary in cases where functional changes are suspected or observed so as to pick up areas of concern that may require immediate or prolonged attention. The early detection of functional change can signal the need for a more comprehensive evaluation and help in identifying the cause of the functional decline. Early detection can result in treatments or interventions that reverse functional change or introduce a period of greater surveillance to check for other areas of decline or change. For instance, early recognition of change in cognition might lead to recognition of unaddressed sensory impairments, untreated depression or difficulties adjusting to a new life situation (such as a new roommate or new living arrangement).

Early detection can be an outcome of individual screening. There is an important distinction between *screening*, involving the use of the NTG-EDSD, and *evaluation or assessment* which is conducted using formal instruments designed to diagnose dementia. The function of screening is the identification of current atypical functioning indicative of decline or cognitive impairment. A screening tool does not help establish the origins of change; but, it is useful in substantiating change. On the basis of this observation, the person with suspected dementia can be referred for an assessment using a standard dementia assessment instrument and other medical measures. Screening tools generally are quick, easy to administer, can be completed by a family member or staff caregiver, and can be used at intervals to ascertain changes. Such screening results in a determination that the adult meets a clinical, behavioral, or functional threshold to be referred for assessment and / or to initiate dementia-related services and supports.

Conversely, the function of an assessment is to comprehensively evaluate the health and functioning of the person when changes are suspected. The assessment is conducted by a qualified individual with the appropriate credentials; the focus is on those areas of functioning that are most relevant in confirming a diagnosis of dementia. In the case of individuals with intellectual disabilities, instruments must be selected that are appropriate to the level of the individual's known cognitive abilities. Assessment instruments that have been developed for the non-IDD population will not be informative. Usually assessments result in a preliminary diagnosis of possible or probable dementia or determination of underlying causes of atypical functioning or progressive cognitive impairment. Assessment may also be used to determine that the individual does not meet criteria for dementia and observed functional changes may be attributed to other, potentially reversible, causes (e.g., medication interaction, depression, ornutrition or hydration problems, etc.)

The NTG recommends conducting a screening either on a prophylactic basis or when caregiver suspicions are raised. The early identification of signs and symptoms of cognitive impairment and dementia is an important first step in managing the course of the disease and providing quality care.

Why the Need for an Administrative Tool?

The NTG-EDSD is considered an administrative tool. Such a tool is meant as a first pass screening to identify individuals who might need more comprehensive assessment. Each service setting may develop its own protocol regarding how information from this assessment can best be utilized on behalf of the consumer. However, it is conceivable that care paths might include sharing the information with the consumer's physician, deciding if there needs to be a change in programmatic or personal care supports, a reallocation of resources, or recognizing the implication for the residential setting. The team may want to adopt a "watchful waiting" approach in which certain areas of identified change are further monitored through additional data collection. As many agencies indicated that they did not have access to professionals who could provide a cognitive screening, the 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, could not 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.

The NTG-EDSD can also be helpful in training caregivers or staff in being good observers and reporters of information which will be valuable

in making decisions to advance the care, supports, and services of persons with intellectual disability. This can provide an opportunity for family and provider data to support initial suspicions, to provide preliminary data for an initial assessment interview, and to provide longitudinal information. The tool can be used by caregivers to record observed behavior and can be used by providers to have a running record of health and function that can complement any in-depth personal and clinical records. An administrative tool can also serve as an addition to the permanent record and augment any other periodic assessment information kept on the individual.

Development of the NTG-EDSD

Historical Basis

The NTG-EDSD has its roots in a meeting held in the mid-1990s, which was the first time a collection of researchers interested in dementia and intellectual disabilities came together. In 1994, a conference support grant from the National Institute for Health helped support a meeting held in Minneapolis, Minnesota, held in association with an international Alzheimer's conference, which was one of the early iterations of the international Alzheimer's conference now known as the ICAD (International Conference on Alzheimer's disease). The outcomes and products of this meeting included a number of reports and publications as well as the formation of an informal network of the researchers in the field of intellectual disabilities and dementia. One of the papers that resulted from the meeting was co-authored by a team led by Drs. Elizabeth Aylward and Diana Burt (see Aylward, Burt, Thorpe, & Lai, 1996) and published in the *Journal of Intellectual Disability Research*. The paper addressed the rationale for and reviewed assessment and diagnostic tools relevant to conducting research on individuals with intellectual disabilities affected by dementia. These tools were for direct assessment of adults with intellectual disabilities suspected as having cognitive changes associated with dementia and were in use for various purposes (some purely clinical and some research based). The interested reader is directed to the work of Alyward and Burt (Alyward et al., 1996; Burt & Alyward, 2000). See also Jokinen, Janicki, Keller, McCallon, and Force (2013) for a listing of prevalent assessment instruments currently in use and their applications.

The work accomplished by these reviewers put in play an analysis of the utility of the various instruments for both research and clinical purposes but also spoke to their limitations with respect to how to best assess cognitive change associated with dementia in persons with diverse intellectual capacities. While the work of this group was useful to researchers, it left open what might be applicable for use by lay workers and family caregivers. Over the years, there evolved a growing interest in the early recognition of cognitive, behavior, and adaptive changes that could be substantiated by family and staff caregivers. Provider agency staff indicated that they needed an instrument for early detection and initial screening that could be used by direct support workers and families. The original instruments cited in the 1996 effort were direct assessments requiring professional level administration and were tied to full diagnostic workups. Many agency staff and families did not have access to psychologists and other practitioners who had the expertise to conduct such assessments; however, there was a need for something that could serve as an early detection measure. Furthermore, there was increasing demand for a rating instrument that could help capture information about changes that could then be shared with health care practitioners to advance service planning, supports, and decision-making.

Given the increasing number of adults with intellectual disabilities who were growing older and the uptick in the prevalence of adults affected by age-related cognitive and functional decline, there was a general call for some type of screening or instrumentation that could help families and agencies better prepare and become aware when changes were occurring. For this and for other reasons, there was a need for some type of national conversation on ways to identify early and address suspected dementia among adults with such lifelong disabilities.

When the National Task Group on Intellectual Disabilities and Dementia Practices was organized in late 2010, among its first tasks was to identify a screening tool that could be widely used as a first pass screen for early detection of changes that would identify individuals who needed additional, more comprehensive assessment. Group S (for 'screening'), one of the NTG's three original working groups, was tasked to look at extant instruments and see which, based upon the literature and professional judgment, would be best suited to be adapted for more general usage as a screen. During this process Group S had input and involvement from some of the original members of the 1994 workgroup on diagnosis and assessment.

Group S members elicited feedback from the other NTG members regarding tools that were in current use and which have proved helpful in identification of individuals who might have dementia.

Development Process

In preparation for the inaugural June 2011 NTG meeting in St. Paul, Minnesota, Group S had been charged with determining whether individuals could be identified for possible or probable signs of dementia. Members of Group S submitted 11 screens for review. Most of the respondents favored an informant based instrument. The instruments reviewed represented a delimited sample of instruments in use in the US and elsewhere. Criteria were that a first instance instrument should be tied to behavioral indicators of dementia or warning signs and still capture newly presented and successive changes in function. It should also be constructed in a manner so it could be completed by direct support staff or family caregivers with minimal training or orientation. Further, the screen could be used to confirm suspicions or changes in function to support decisions to refer individuals for further assessment. One of the instruments that was favorably rated by Group S was an adaptation of the Dementia Screening Questionnaire and Interview for Intellectual Disabilities (DSQIID), originally developed in the United Kingdom by Professor Shoumitro Deb of the University of Birmingham in the United Kingdom, and adapted for use by the Philadelphia PMHCC (Philadelphia Mental Health Care Corporation) for use with the Pennhurst class. The resulting adaptation was an easily administered screen that could help family and direct care providers open up a dialogue around declining function.

The members of Group S then reviewed the instruments on a variety of indicators. On the basis of this review, the members endorsed the use of the DSQIID (Deb, Hare, Prior, & Bhaumik, 2007). This recommendation was reviewed when the full NTG convened at its June 2011 meeting in St. Paul in conjunction with the AAIDD's annual conference. At this meeting, Group S was further tasked to come up with an early detection screen that included an augmentation and adaptation of the DSQIID and which could be used by family and staff caregivers. It was decided also to include ancillary information so as to broaden its content and usefulness for clinicians. Thus, items gathering information on individual demographics, co-incident medical conditions and impairments, and significant life factors were added. Coincident, with the working group's efforts, the Philadelphia PMHCC also undertook a secondary adaptation of the DSQIID with the assistance of Dr. Karl Tyler of the Cleveland Clinic (Philadelphia Coordinated Health Care Group, 2011). This version was further adapted by the working group to include items felt to be pertinent to early detection. The draft composite instrument went through several revisions and then was field tested over the summer of 2012 in eight sites, including agencies in the continental U.S., Canada, and Austria. The Austrian field test used a German language translation.

Field Testing of the NTG-EDSD

The field test was designed to elicit feedback on items and the process of completing the instrument. Each participating site was asked to rate at least five adults suspected of having dementia using the instrument and to provide feedback on the utility of the tool. The feedback provided included comments on wording of items, formatting, content, and utility. The eight field test sites all indicated that the NTG-EDSD was helpful in relevant data collection and was user friendly. Comments were also received from agency reviewers who, while not 'officially' applying the draft instrument, scrutinized it and offered suggestions. Specific comments and suggestions on wording and structure were assessed and final changes were made to the instrument at a working group meeting in December 2012.

Unlike the DSQIID, the tool upon which the NTG-EDSD was based, the instrument was not intended to provide a definitive diagnosis of dementia. The instrument was designed as a way of collecting seminal information and recording indicators and signal behavioral markers of significant change. The purpose was to give family and professional caregivers a tool that would enable them to capture objective data on changes in function when suspicions arose and prior to making a referral for a comprehensive assessment. As such, the NTG-EDSD is regarded as an administrative rating tool and not an assessment instrument. The NTG-EDSD can also present helpful data which can be shared during the annual wellness visit under the Affordable Care Act as many agencies are looking forward to that process to help them with identifying any significant potentially neuropathologic functional and cognitive changes among the individuals whom they support. See Cordell et al. (2013) for a discussion of instruments in use with the general population for this function.

The NTG-EDSD

Description of the NTG-EDSD

The NTG-EDSD is composed of four primary sections containing some 40 questions or question groupings about relevant demographics, ratings of health, mental health and life stressors, a review of multiple domains associated with adult functioning, and a review of chronic medical conditions. It also provides for a notation on the number and nature of medications being taken, and permits comments on observations to be entered. Specifically, the NTG-EDSD contains ten basic demographic items (such as identification data, personal characteristics, diagnostic, and residential setting information, eight health and function items, and the adaptation of the DSQ-IID (including queries as to Activities of Daily Living, Language and Communication, Sleep-Wake Change Patterns, Ambulation, Memory, Behavior and Affect, the Adult's Self-Reported Problems, and Notable Significant Changes Observed by Others). The NTG-EDSD also contains an adapted form of the University of Illinois at Chicago's Longitudinal Health and Intellectual Disability Survey (Rimmer & Hsieh, 2010) and used to note co-incident conditions (these include the following categories: Bone, Joint and Muscle; Heart and Circulation; Hormonal; Mental Health; Pain-Discomfort; Sensory; and Other). The last section of the NTG-EDSD contains an item on current medications; a place to note comments related to other notable changes or concerns and next steps and recommendations, as well information on the form completion.

Uses of the Instrument

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 NTG-EDSD can also be used in preparation for the annual wellness visit under the Affordable Care Act. Having concise information available for the examining physician can help instigate queries and any follow-up assessments. For recommendations on it use as part of any physician visit, see Moran et al. (in press).

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. At the point that the individual is determined to need more comprehensive assessment, a referral should be made for more comprehensive work-up that would include medical and psychological testing.

The interdisciplinary team can share ratings of "new symptoms" or "always but worse" with the health practitioner and discuss among members of the team implications for programming, personal assistance, residential placement, services, and supports. With the advent of the Diagnostic Statistical Manual-5th edition (DSM-V), the health care practitioner can link documentation of change with updated criteria for the diagnosis of dementia.

Who can Complete the NTG-EDSD?

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.

Useful Information to Have Available to Aid Completion

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 Form

See Appendix A for a 'pull-out sheet' on how to respond to the items on the NTG-EDSD.

How to Use the Information Obtained from this Review

The information may be used in various ways: (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 as provided for under the Affordable Care Act); and (4) the form may be shared with the agency's consulting psychologist as part of any follow-up procedures put in place specific observations for noted change areas

What Are Some Signal Items?

Signal items are those items throughout the *NTG-EDSD* that are linked to the general warning signs of MCI or 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

Limitations

It is important to understand that the *NTG-EDSD* is NOT a diagnostic instrument and should not be solely used to determine the presence of dementia.

Areas for Further Development

There is no scoring system currently associated with the use of the NTG-EDSD. This instrument provides the opportunity for a qualitative, not a quantitative review of changes that may be associated with the types of changes in cognition and adaptive functioning observed in dementia. As the instrument gains more widespread use there would be value in collecting data linking confirmed diagnoses with results of screening. This may result in a scoring system or allow for identification of signal items most likely indicative of dementia.

Versions of the NTG-EDSD

The NTG-EDSD is currently available in English, German, Greek, Dutch, and Italian language versions See www.aadmd.org/ntg/screening.

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work of that team in monitoring health status is still on-going and has resulted in three years of data collection. Special appreciation is extended to members of the NTG who offered input into the process and the NTG steering committee who provided input, suggestions and encouragement.

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

How to Complete the NTG-EDSD

Item #	Item Title	Comment
1	File#	For agency use
2	Date	Date form completed
3/4	Name of person	Fill in first and last name of person being screened
5	Date of birth	
6	Age	Age when form was completed
7	Sex	
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
-	Current living arrangement of person	Pick most appropriate item
10	General characterization of current physical health	Pick most appropriate item
11	Compared to one year ago, current physical health is:	Pick most appropriate item
12	Compared to one year ago, current mental health is:	Pick most appropriate item
13	Conditions present	Indicate those diagnosed as well as observed
14	Significant recent [in past year[life event	Indicate those that occurred
15	Seizures	Pick most appropriate item
16	Diagnostic history	Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic report
17	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms were noticed
18	Comments/explanation about dementia suspicions	Indicate any behaviors that triggered suspicions or referral for assessment
19	Activities of daily living	Pick most appropriate column item for each **'Always been the case'** means the need, problem or behavior has been present for a very long time ***'Always but worse'*** means the existing need, problem or behavior has further declined requiring more personal assistance ***'New symptom in past year'*** means this need, problem or behavior was not present until recently *'**Does not apply**'* means these needs, problems or behaviors are not present
20	Language & communication	Pick most appropriate column item for each
21	Sleep-wake change patterns	Pick most appropriate column item for each
22	Ambulation	Pick most appropriate column item for each
23	Memory	Pick most appropriate column item for each
24	Behavior and affect	Pick most appropriate column item for each
25	Adult's self-reported problems	Pick most appropriate column item for each 'Self-reported' means the adult has expressed one or more of these things
26	Notable significant changes observed by others	Pick most appropriate column item for each Assume that these are new behaviors

27	Chronic health conditions	Pick most appropriate column item for each Draw from any previously completed medical evaluations or current health notes in record
28	Current medications	This item is to help the physician or other clinician assess whether current medications may be the cause of behavioral or functional changes. Best to include a listing of current medication, with dosages, when sending or bringing form to assessment.
29	Comments related to other notable changes or concerns	Use this item to make comments of use related to behavior, function, or any events that may influence behavior
30	Next steps/recommendations	Check most relevant item
31	Date completed	Date form completed
32	Organization/agency	Name of organization providing services to the adult
-	Name of person completing form	Indicate your name
-	Relationship to individual	Indicate whether you are staff, a relative or someone else
-	Date(s) form previously completed	If the ***NTG-EDSD*** has been completed before, indicate when

http://aadmd.org/ntg/screening

Appendix B

These are among the laboratory and medical tests that might be used to rule out other sources of cognitive change among persons with IDD

1. Recent Primary Care Physician appointment/review
   - o Review of existing lab results and follow up on out of range values
   - o DD Diagnosis

     Recent blood work (within 3 months) that includes
     - Liver panel (especially if on psychotropic medications
     - Kidney function (GFR)
     - Complete Blood Count (CBC)- to account for some causes of potential delirium)
     - Comprehensive Metabolic Panel
     - Hepatic testing
     - Renal Function Test
     - Thyroid Studies(including TSH)
     - Vitamin B 12
     - Folic Acid
     - Hormone levels in women over 30
   - o Sleep Apnea ruled out
     - If sleep apnea then investigate possibility of vascular dementia
   - o Specifically for people with Down Syndrome, celiac screening (total serum IgA if not done previously, and tTg)
2. Hearing/Audiology Testing
3. Electroencephalogram
4. Urinalysis
5. Chest X-Ray
6. Computerized Tomographic Scan
7. Magnetic Resonance Imaging
8. Vision Testing

   Explore conditions which are likely to involve pain/discomfort (including dental pain) and put in place a pain management protocol

   Explore medication side effects or interactions (pharmacist and or PCP are most likely resources)

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