Chapter 11
National Task Group Early Detection Screen for Dementia (NTG-EDSD)

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Introduction

Alzheimer's disease, one of the major causes of dementia, is a progressive degenerative disease which causes loss of neurons in the brain and leads to neurocognitive dysfunction. As noted by Alzheimer's Europe [1], the symptoms may eventually manifest as dementia of the Alzheimer's type which impacts cognition, function and behavior, becomes progressively worse over time and cannot be reversed. The World Health Organization (WHO) [2] has noted that the prevalence and incidence projections indicate that the number of people with dementia will continue to grow, particularly among the oldest old and that the total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. Further, dementia has a devastating impact on adults with an intellectual disability (ID) as well as on their families, friends, housemates, and service provider staff who often provide key long-term support and care; and that community services' providers are facing a 'graying' of their service population, many of whom are affected by cognitive decline and dementia, and are challenged to provide the most effective and financially viable daily supports and long-term care [3]. Further, specialized assessment and diagnostic resources are needed to help more effectively identify adults with an ID and dementia and a common screening instrument would be useful for the early detection and follow-through to assessment and diagnosis [3].

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Alzheimer's disease is but one cause of dementia (or neurocognitive disorder), albeit a primary one. One recent study [4] of some 3.1 million health services beneficiaries in the United States found that 43.5% were diagnosed with Alzheimer's dementia, 14.5% with vascular dementia, 5.4% with Lewy body dementia, and 1.0% with frontotemporal dementia. Other types of dementia made up the balance. Studies show that persons with ID are as susceptible to the causes of dementia as are other adults, with the relative distribution of etiologies mirroring those of other adults [5]. One exception is among adults with Down syndrome (DS) who tend to express primarily dementia of the Alzheimer's type. Although these various dementias may have some variations in expression and early phenotypic markers, they all generally result in changes in progressive neurocognitive dysfunction and eventual death. The challenge, as noted by the WHO is to identity early those adults susceptible and affected so that assessment and diagnostic work-ups can be undertaken [2]. When behavioral changes are evident, the next step is to identify whether they are the result of a neurodegenerative disease or condition or whether some other factor (endocrine, psychiatric, pharmacological, neurotoxicity, etc.) is contributing to the decline.

To get to the stage where assessment or diagnostics are warranted, clinical and other services need to implement some form of screening to identify at-risk individuals. These same challenges present among adults with ID. While assessment processes and scales are in place for the general population [6], screening tools generally rely on brief patient assessments and surveys, such as the Mini Mental State Examination [7]. However, most, if not all, are inefficient for persons with ID [8, 9] due to intellectual variations, communication and performance challenges, and discordant context. Thus, the challenge: First, what type of dementia screening instrument might be useful to use with the range of functions expressed by older adults with ID? Second, what benefits may accrue from using a dementia screening instrument?

Screening

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 diseases causing dementia and providing quality care. Family and professional carers should work with the adult's health care provider to share information about observed changes. A screening tool can be used to substantiate changes in adaptive skills, behavior and cognition. In the United States, early detection is one of the aspects stressed by the *National Plan to Address Alzheimer's Disease* [10]. 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. With respect to screening, specialized measures

are needed that help take into account lifelong impairment and assist in picking up on subtleties in dysfunction.

Screening and the accompanying activities are important to effective early detection of cognitive decline and general dysfunction. To effectively address dementia-related decline, there are a number of steps that should be undertaken [5, 11, 12]. First, establish a baseline of 'personal-best' functioning and have staff who are familiar with the individual or family complete a screening tool in order to capture information about change. Second, share information from the tool with all members of the support or care team and with the adult's health care provider, and if the individual has had a rapid change in mental status consider that there may be a medical condition that warrants an immediate medical assessment. If the individual appears to be depressed or disoriented, have the person evaluated for medication interactions and ascertainment of whether depression is present. If there are sensory deficits these maybe contributing to decline in adaptive functioning, and these too require further assessment. Such factors may lead to decline and most likely are not neuropathologies. Thus, screening can help with starting the triage approach process in determining whether seemingly classic symptoms of dementia are potentially something else, or may actually represent the expression of dementia. Re-current screening then may be the first of many steps in determining the cause of functional and behavioral change in adults who are suspected of dementia.

The National Task Group

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) is a collective composed of over 300 agency personnel, academics, government officials, family members, and persons affiliated with various associations and organizations—most of whom are resident in the United States. The members are from medical and non-medical disciplines. The NTG is associated with several organizations in the United States (the American Academy of Developmental Medicine and Dentistry, the American Association on Intellectual and Developmental Disabilities, and the University of Illinois at Chicago's RRTC on Developmental Disabilities and Health) as well as numerous other university centers and national organizations (see www.aadmd.org/ntg). When the NTG was formed in 2010, its members recognized that no systemic and cross-cutting national-level plan existed in the United States that addressed the needs of adults with ID affected by dementia, and that these needs warranted systemic advocacy and attention. Its initial role was to address this issue and the growing requests for information and policy direction. Serendipitously, a new federal law that called for a 'national action plan' was enacted in 2011 and the NTG's role was expanded to advocate for the inclusion of ID in this national plan [3, 10].

The National Alzheimer's Project Act required the creation of a national strategic plan to address the rapidly escalating Alzheimer's disease crisis and called for coordination of Alzheimer's disease research and carer support efforts by the federal government. One of the considerations in this national plan was the promotion of an

assessment tool for detection of cognitive impairment as part of the annual wellness visit under the U.S. Patient's Bill of Rights and Affordable Care Act (PL. 111–148). As a result, the NTG undertook to develop an administrative screening and early detection instrument for dementia among adults with ID that could be easily used by family carers and service provision staff. This chapter describes the development and use of the National Task Group Early Detection Screen for Dementia (NTG-EDSD) screening instrument, and explores factors associated with and benefitting from screening.

The benefits of differentiating types of dementia as part of the assessment and diagnostic process, include diagnostic precision; pharmacological treatment applications; projections of residual life years; assemblage of care management plans to address expected behavioral presentations and progression, communication and interaction variations and projecting expectations for change in care needs; and referrals for diagnosis and introducing post-diagnostic measures.

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

The NTG-EDSD is an informant-based rating tool for use with adults with intellectual and developmental disabilities who are suspected of experiencing changes in thinking, behavior, and adaptive skills suggestive of mild cognitive impairment or dementia [11, 13]. The form is a compilation of general information about the adult, health status information, pharmacological usage, and a variant of the DSQIID [14, 15]. It is considered an administrative, and not a clinical assessment, tool. The NTG-EDSD was developed to collate behavior and health information, capture early changes in function, and specialize in accounting for subtleties in these changes [11, 13].

The Historical Basis for the NTG-EDSD The NTG-EDSD has its roots in a meeting held in the mid-1990s, which was the first time a collective of international researchers interested in dementia and ID came together. In 1994, a conference grant from the National Institute for Health helped support a meeting held in Minneapolis, Minnesota, held in association with the Fourth International Conference on Alzheimer's Disease and Related Disorders, which was one of the early iterations of the international conference on Alzheimer's disease now known as the AAIC (Alzheimer's Association International Conference—see https://www.alz.org/aaic/) [16]. 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 ID 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 [17]. While the work of this group was useful to researchers and professionals conducting dementia assessments, it left open what might be applicable for use by lay

workers and family carers. 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 carers. 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 and informant-report assessments requiring professional level administration or interpretation. Many agency staff and families did not have access to psychologists and other practitioners who had the expertise to conduct such extensive assessments and noted the need for something that could serve as a less complex early detection measure. Furthermore, there was increasing demand within the field in general for a rating instrument that could help capture information about changes that could then be shared with clinical teams and health care practitioners to advance services. Subsequently, a number of short form symptom identification measures of varying complexities were developed and introduced into the field [4, 12, 18].

When the NTG was organized in late 2010, among its first tasks was to identify a basic user-friendly screening tool that could be widely used as a first pass screen for early detection of changes and which would identify individuals who needed an additional and more comprehensive assessment. Consequently, the NTG charged a working group to undertake a process to recommend such a screening tool. During this process the working group sought input and involvement from some of the original members of the 1994 workgroup on diagnosis and assessment and others regarding tools that were in current use and which had proved helpful in identification of individuals who might have dementia. The outcome, following a review of various extant instruments, was the endorsement of the use of a tertiary modification of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) [14], as well as inclusion of other information pertinent to screening (such as demographic information, health and function status, co-incident conditions, living arrangement, and medication usage). The original work in adapting the DSQIID in the United States was done by a group in Philadelphia, Pennsylvania, with the help of Carl Tyler of the Cleveland Clinic [3]. The instrument was also field tested at various sites in the USA and Canada [16], and was the subject of an efficacy study in Austria and Germany [19].

The NTG-EDSD was designed as a way of collecting key information and enabling the recording of indicators and signal behavioral markers of significant change [13]. The purpose was to give family and professional carers 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. In the United States, the NTG-EDSD could also present helpful data which can be shared during the annual wellness visit under the U.S. Patients' Bill of Rights and Affordable Care Act, as many service agencies were looking forward to that process to help them with identifying any significant potentially neuropathologic functional and cognitive changes among the individuals whom they support.

The Uses of the NTG-EDSD When applied, 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 clinical teams and 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.

The NTG-EDSD is considered an 'administrative' tool as it is not a clinical determination instrument—it doesn't result in a validation of a clinical impression or a diagnosis. It, however, permits the user to note dysfunction in key areas generally associated with the expression of dementia, helps confirm suspicions of change in behavior by concordance with key marker items, and helps with statistical reporting of functional areas of concern. It also enables carers to have a means of creating a summary of behavioral changes and events and health shifts that can help form a basis of discussion among carers and between carers and clinicians. The completed form can also be entered into the adult's medical record or program plans and successive iterations compared for variations from the baseline. Specific information on the interpretation of items and processes to use to collect the data for the NTG-EDSD are found in the instrument's manual [13].

A tool, such as the NTG-EDSD, is meant as a first-pass screening to identify individuals who might need more comprehensive assessment. Each service setting can 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 adult'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 adult's team may want to adopt a "watchful waiting" approach in which certain areas of identified change are further monitored through additional data collection via the use of the NTG-ESDS or other means. As many service agencies indicated that they did not have access to professionals who could provide a cognitive screening, the NTG wanted to the tool to be accessible to carers who were not necessarily trained to do assessment, but had valuable information regarding day-to-day changes in functioning—or experience or observed telling behavior (see Table 11.1). 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 [14] (see Table 11.2). Via the use of this screening tool caregivers or staff can substantiate if a person with ID manifests these changes and can then share the information with health care providers.

Components of the NTG-EDSD The NTG-EDSD is composed of four primary sections containing some 40 questions or question groupings about relevant subject

Table 11.1 Noted symptoms and notable incidents that lead to suspicions of dementia

Common symptoms	Notable incidents reported by group home staff	Notable incidents reported by family carers
Memory loss	Wandering	Falling
Difficulty performing familiar tasks	Falling	Difficulty eating
Problems with language	Decline in general abilities	No longer talking
Disorientation to time and place	Short term memory loss	Increased aggression
Poor or decreased judgment	Increased aggression	Short-term memory loss
Problems with keeping track of things	Increased conflicts with peers	Throwing self on the floor
Misplacing things	Called fire department instead of taxi for outing	Decline in general abilities
Changes in mood or behavior	Safety issues	Undressing inappropriately
Changes in personality	Stealing others possessions	Difficulty getting out of bed
Loss of initiative	Medical problems	Increased conflict with peers
	Uncommon behaviors (stuck head in toilet to wash hair)	Becoming disinterested in activities
		Medical problems (e.g., seizures, incontinence)
		Other problems (such as 'trying to make guests leave house')

characteristics, ratings of health, mental health and life stressors, a review of multiple domains associated with adult functioning, and a review of chronic medical conditions (see Appendix I for the original American English language version[1]). 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 DSQIID (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 includes a listing of chronic illnesses from the University of Illinois at Chicago Longitudinal Survey [20], which can be 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 co-occurrence of chronic illness and neurocognitive disorder, for instance, cardiovascular issues and diabetes are among highly co-incident conditions for dementia of the Alzheimer's type in the general population. These data are

[1] Other language versions of the NTG-EDSD can be found at www.aadmd.org/ntg/screening.

Table 11.2 Correspondence with prevalent markers/indicator of dementia and the NTG-EDSD

Feature	Descriptors	Applicable NTG-EDSD area
Behavioral and psychological symptoms of dementia (BPSD)	Behavioral symptoms include physical, social inappropriateness, hitting, pushing, scratching, kicking and biting, throwing things, wandering/pacing, hoarding, verbal screaming, cursing, temper outburst, complaining or whining, repetitive sentences, verbal sexual advances, constant request for attention, rummaging, and nighttime wandering. Psychological/psychiatric symptoms can include anxiety, depression, hallucinations or delusions.	[24] Behavior and affect (p. 4)
Memory	Decline in memory. Memory changes and increased confusion resulting in problems with accepting personal assistance;	[23] Memory (p. 4)
Sensory impairment	Changes in vision and hearing and loss of sensory acuity can be related to increased confusion and agitation. The inability to process information about the environment through our senses can either increase agitation or present as increased lethargy and disengagement.	Conditions present (p. 2) Items 30–32 sensory (p. 5)
Psychosocial stressors	May be evident via significant losses and significant changes. Occur when situations exceed the person's ability to adaptive or effectively respond and may be expressed by agitation, confusion, or being overwhelmed to the point of being less functional.	[14] Significant recent (in past year) life event (p. 2)
Seizures	May be evident among adults with a history of seizures, but after a long period of seizure inactivity, may show breakthrough seizures. Also, may occur in new late-onset seizures in someone who never previously had seizures (particularly in adults with Down syndrome).	Seizures (p. 2)
Gait and balance	Neurological changes may be evident in an increase in gait and balance problems.	[26] Notable significant changes observed by others (p. 4)
Changes in Activities in Daily Living (ADLs)	Individuals with neurocognitive disorder may show difficulties in sequencing (affects dressing, eating, and toileting independently), visual spatial (safe ambulation and finding way within environment); Language and communication; verbal memory problems lead to loss of words; impoverished speech; lack of spontaneous speech; receptive language issues. Sleep-wake pattern changes due to changes in circadian rhythm.	[19] Activities of daily living (p. 3)

important as effective treatment of chronic medical conditions can increase quality of life for the person who does have a neurocognitive disorder. Also, the data create an opportunity to see the patterns of co-occurring medical problems with dementia. The last section of the NTG-EDSD also contains an item on current medications; a place to note comments related to other notable changes or concerns, as well as

next steps and recommendations. Lastly, there is an area for notations on form completion.

Completion and Use of the NTG-EDSD The NTG-EDSD can be completed at any point in time on an adult with ID. The NTG recommends that the instrument be used with adults with DS beginning with age 40 (or earlier—age 35—if functional decline is suspected), and with other at-risk persons with intellectual or other developmental disabilities when they are 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 6 months), such as a family member, agency support worker, or a behavioral or health specialist, using information derived by observation or from informants, as well as the adult's personal and medical record. Carers and staff with close knowledge and familiarity are more likely to be aware of subtle changes in behavior and functioning that may signal important information for health care providers. What should carers or staff observe? First, they should look for changes from characteristic baseline behaviors in cognition (memory, attention, problem solving), behavior (social and control of impulses), and emotion (mood, emotional regulation). Secondly, they should look for changes in expected function in activities of daily living. The estimated time necessary to complete this form is between 15 and 60 min. Minimally, it can be used on an annual or on an "as-indicated" basis when there is a suspicion of cognitive change.

Use with Medical Visits The NTG-EDSD can also be used in preparation for medical visits. Having concise information available for the examining physician can help instigate queries and any follow-up assessments. Moran and colleagues [21] and Prasher [22] covered the manner of examining for potential dementia; the NTG-EDSD can be instrumental for conveying key health and dysfunction information by informants as a preliminary during such an assessment visit [13].

In situations where the healthcare provider may not know the individual, especially if a new practitioner or specialist is being consulted, data aggregated from the NTG-EDSD can be most useful to complement any interview data. This will be particularly helpful with practitioners who do not have experience in the care of individuals with ID and may not be able to discern functional decline associated with normative aging from that of an underlying pathology, such as that seen in early onset Alzheimer's disease. Also, when a practitioner may have unintended biases and stereotypes and apply "diagnostic overshadowing," the data can be used to offset this when the adult with ID is brought into the office or clinic for evaluation. Carers also may also be susceptible to "diagnostic overshadowing"—that is, they may have observed change but interpret such to be in line with aging. Such diagnostic overshadowing can occur when there is an automatic tendency to attribute all changes to the adult's primary ID and thereby overlook other medical and psychiatric issues that may need attention.

As part of this interview and assessment visit, to complement the data shown on the NTG-EDSD, it is helpful for the carer or family member also to provide a general life synopsis or life story that includes some details about the adult and his or her history, which should include information on dietary patterns, language skills,

family history, social history, psychiatric history, medications, substance abuse, and past medical history [21]. The NTG-EDSD data can then be presented as current information about issues or problems noted, with any changes noted. This collection of information can then be put into a fuller context with respect to whether the change(s) noted is a natural sequalae of the ID, a function of aging, an effect of a comorbidity, or the result of possibly emerging neurocognitive disorder. Thus, the findings from the NTG-EDSD can be contextualized within the person's life story and information regarding changes from his/her previous highest baseline. The importance of this process is key since it will now be up to the practitioner to decide what the next steps should be [23].

Consequently, the practitioner may decide to track the individual's behavior and function to ensure that decline is indeed occurring, but not rush to any immediate conclusion and wait for a subsequent assessment visit. However, if it has been made clear via the NTG-EDSD and other data that decline has absolutely taken place, then it is up to the practitioner to institute a work-up and evaluation appropriate for adults with ID looking for possible explanations for these changes. In this context, the carer and family can add their voice as advocates and supporters and speak up on behalf of the adult as they helped to provide baseline information and other facts, including the NTG-EDSD.

How to Use Observations Captured by NTG-EDSD? Suspicions of cognitive and functional changes are often aroused by everyday events (see Table 11.1). Families and staff may perceive select behaviors that are out of norm or context and question them. There might be a need to reflect on antecedent event(s) which may have triggered the behavior. Observing to see if the behavior repeats or whether it is triggered by something unrelated is important and should lead to a discussion with persons providing supports to the adult. If warranted, this may call for further tracking of changes on the NTG-EDSD in key areas of functioning and using the information gleaned for advanced planning regarding staffing, residential, and programmatic decisions. It can be helpful if 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 carer or staff person completing the form can indicate whether there has been a change since the last review. If concerns are raised and the individual is determined to need a specialized assessment, a referral should be made for more comprehensive work-up that would include medical and psychological testing. The team can share ratings of "new symptoms" or "always but worse" with the examiner and discuss among members of the team implications for programming, personal assistance, residential placement, services, and supports. With the issuance of the APA's Diagnostic and Statistical Manual of Mental Disorders -5th edition (DSM-5) [24] and the Diagnostic Manual for Intellectual Disability (DM-ID-2) [25], the health care practitioner can link documentation of change with updated criteria for the diagnosis of dementia. The DM-ID-2 is the preferred manual to consult regarding neurocognitive disorders in adults with ID.

Case Studies

The following case scenarios are offered as illustrations of how the findings from the NTG-EDSD can be used to guide the decision-making activities by members of the adults' support teams.

Example	Back story related to ratings on the NTG-EDSD	Screening/Impressions
Case presentation #1: Laura	Laura is a 55-year-old woman with a history of mild ID and DS who had been living with her mother in their family home until that parent needed placement in a nursing home… and then Laura went to live with her older sister Mary and Mary's family. Mary has noticed that Laura is not attentive to her hygiene and appears to take showers irregularly. Mary reports that Laura often seems "…out of it" and spends most of her time while at home in her room. Laura works at Tesco. Laura's work supervisor called with concerns that Laura has gotten into a few arguments with customers, recently, one of whom filed a complaint. Although Laura has several friends with whom she had been socializing or with whom she had maintained phone contact, she has not kept up with social dates for several months.	Further investigate the impact of psychosocial stressors. Track changes with more frequent use of NTG-EDSD and look for signal changes that may warrant assessment Ask to what extent might she have displayed earlier decline in adaptive skills that were either compensated for by the mother or unobserved and unaddressed? Investigate extent to which this is an adjustment reaction to changes in her living situation with accompanying depression
Case presentation #2: James	James is a 67-year-old male with a history of moderate ID who lives in a group home. He has worked at a production center for 18 years and has always had the reputation of being a quick, productive and efficient worker. Over the past 6 months he has been slowing down and earning less on his paycheck; he has been displaying difficulty learning the names of new staff at his program and residence; he has been forgetful with regards to doing routine chores in the group home. He wears hearing aids and glasses; he has lost both these devices and both are in the process of being replaced. He has a history of diabetes and arthritis.	Further investigate the role of sensory deficits in his performance. Develop a routine for storage of hearing aids. Use NTG-EDSD to coalesce data from the work and home sites – To review for disparities Work supervisor might assess to see if there are any modifications in work task demands or opportunities for a change in day activities that may be beneficial. Consideration given to possible shift to 'retiree' status

(continued)

Example	Back story related to ratings on the NTG-EDSD	Screening/Impressions
Case presentation #3: Stephanie	Stephanie is a 70-year-old woman with a history of bipolar disorder and mild intellectual impairment and spectrum disorder. Although maintained on medication, she is displaying more rapid cycling including periods when she appears to experience psychotic features while manic. She has become verbally aggressive, property destructive and combative with staff–all of which had been noticed during manic episodes but are now occurring on a regular basis despite apparent mood stability. She has displayed episodes of disruptive and impulsive behaviors leading members of her team to believe that she can no longer safely remain in a supervised living situation.	Further investigate medication management of bipolar disorder. Look for collateral signal data on NTG-EDSD beyond psychiatric symptoms Has she become a "rapid cycler" which may render current regimen insufficient. Investigate how can the support team provide positive routine and realistic limits to behavior that promote safety.

A number of questions and queries for follow-up can surface following use of the NTG-EDSD (see case studies). For example, the user and the team can ask whether the adult has displayed new symptoms in at least two domains on the NTG-EDSD. Alternatively, it may be noted whether the adult has gotten worse for symptoms already noted in the two areas. Other factors to consider is whether delirium and/or depression have been ruled out? Delirium would be notable if the confusion and other disruptions in thinking have had an abrupt onset. Depression typically would involve lack of affect ('down mood') and a lack of interest in what is going on around the person. At times, hallucinations may be a factor. Hallucinations would be evident if the adult sees or hears someone speaking who is not there. Often hallucinations may occur in more severe forms of dementia and are generally indicative of Lewy body or Parkinson's disease dementia. Individuals with dementia of the Alzheimer's type can also experience hallucinations and paranoia that appear psychiatric in presentation; however, these symptoms are related to the brain changes associated with dementia. Another rule-out is the adverse effects of medications. Some medications may interact and create adverse interactions or have side effects that may mute or alter behavior. Also, there may be circumstance in the adult's life or environment or in relationships that may adversely affect behavior in some of the domains. All of these considerations should be factored in when discussing the information obtained by the NTG-EDSD.

Usage to Date The NTG-EDSD has been adopted for screening by various services agencies and organizations across the world [26, 27]. The form is available in multiple language translations (all forms are available at www.aadmd.org/ntg/screening) and organizations are welcome to translate or adapt the form into their language

as long as the core items are not changed and due credit—is given to the NTG. As an example of use for broad screening, NHS Health Scotland [26] has recommended that local screening efforts using the Scottish adaptation of the NTG-EDSD be undertaken as follows (a) establish a baseline assessment of functioning against which to compare future suspected changes and that this should begin at age 30 with adults who have DS; (b) screen adults with DS over the age of 40 every 2 years and annually after the age of 50 (as recommended by the British Psychological Society because of the increased risk of dementia and the prevalence of undetected but treatable illnesses) and that this screening be linked to the person's overall health action plan; and (c) for individuals with ID other than DS, a baseline assessment should be conducted at age 50 with no further action or screening until concerns are raised.

Applications have also included inclusion in research where the NTG-EDSD is used as one of the instruments in both small and large population studies. Small, such as the Wichita Project study of small group homes for community-based dementia care being undertaken by the University of Illinois at Chicago [28, 29] and large, as the US National Institute on Health's US$37 million dollar multisite 'Biomarkers of Alzheimer's Disease in Adults with Down Syndrome' study [30]. Further, as a screening tool, it has been recognized as having utility among other tools generally used to identify early signs of dementia [9, 31, 32].

Applications

Staging and Etiology Data drawn for one or more successive administrations of the NTG-EDSD can help with framing suppositions about possible type of dementia and about staging. Why is it important to know about etiology (type of dementia) and staging of dementia with respect to planning care? Both can provide insights into the nature of the behavior and losses of function that the adult may experience and consequently impact staffing, programming, interventions, and adaptation in the living environment. Although the NTG-EDSD should not be used for diagnostics, preliminary assumptions about the type of dementia might be drawn from the nature of the domains that show particular changes. For example, data showing progressively declining sharpness in memory, sleep impairments, and other adverse functional changes might suggest the presence of Alzheimer's disease, whereas, memory consistency, but marked changes in performance, may suggest frontotemporal dementia.

As the NTG-EDSD is not a diagnostic tool, but a screen, any suppositions should only be used to help to stimulate discussion within the team and for framing the referral to a clinician for an assessment or diagnostic work-up. Particularly for individuals with no known psychiatric history, the onset of paranoia, hallucinations or behavioral aberrations from known characteristic baseline should alert the team to the need for further assessment and diagnostic clarification. The same comment applies to staging. At times, the adult may present for screening whilst already showing clinical features of progressive or mid-stage dementia (as opposed to mild cognitive impairment [MCI] or early stage dementia). In such cases, experienced

clinicians and team members may be able to make some assumptions about staging, particularly if there is a strong presence of hits on markers on the NTG-EDSD and other clinical indicators (and there is evidence of changes from pre-morbid functioning). Thus, getting validation of the potential etiology and confirmation of staging can be beneficial to planning the interventions to be developed, for estimating duration of being affected by dementia, and planning staffing and environmental modifications. Research is needed that would substantiate that general ratings on the NTG-EDSD align with different stages of neurocognitive disorder.

To offer some context, these features warrant consideration. Dementia is a description of a clinical phenomenon of significant decline from pre-existing baseline functioning in cognitive, behavioral or social skills that interferes with daily functioning. By capturing information on changes in behavior, emotional and social functioning and everyday behavior, the NTG-EDSD can be used to identify items that lead to suspicions of dementia for a particular person.

Dementia is not a clinical diagnosis; it is a clinical description of observed change in functioning. Dementia does not indicate etiology of decline, it denotes a state of significant changes in cognition, function, and/or behavior that interfere with the individual's independence and pursuit of daily routine and relationships. Dementia describes the effects of neurocognitive disorder such as probable Alzheimer's disease, cerebrovascular dementia, frontotemporal dementia, and other dementias [33].

As the NTG-EDSD includes a listing of chronic conditions and illnesses from the University of Illinois at Chicago's Longitudinal Health in Intellectual Disability Survey (LHIDS) [20], the notation of the co-occurrence of chronic conditions and illnesses may signal some aspects associated with neurocognitive disorder. For instance, cardiovascular problems and diabetes are among highly co-prevalent conditions for dementia of the Alzheimer's type. The presence of such conditions may be telling, as studies have shown that adults with ID and dementia tend to have about twice as many comorbidities as those age- and function-matched adults absent dementia [34, 35]. Tracking such chronic medical conditions and providing effective treatment can increase quality of life for adults with a neurocognitive disorder.

Neurocognitive disorders are progressive and deteriorative. As the adult moves through stages of dementia regardless of the etiology, the adult will need increased personal assistance and supervision. Thus, offering training toward competency in provision of dementia-capable services is warranted. Staff working with adults with dementia should have a grounding in facets of normal vs. pathological aging, neurocognitive disorders, variations of dementia and staging, health and social care practices, as well as day-to-day care management of people with dementia.

Commentary

A few closing comments. Screening and the accompanying activities are important to effective early detection of cognitive decline and general dysfunction. To effectively address dementia-related decline, there are a number of steps that should be

undertaken. First, establish a baseline of 'personal-best' functioning and have staff who are familiar with the individual or family complete the NTG-EDSD in order to capture information about change. Second, share information from the rating scale with all members of the care team and with the adult's health care provider, and if the individual has had a rapid change in mental status consider that there is a medical condition or cerebrovascular accident present and not necessarily dementia. If psychiatric symptoms are evident, such as depression, have the person evaluated for medication and psychosocial approaches to depression management and eliminate any factors that may be leading to decline that are not neuropathologies.

Findings from the NTG-EDSD should be reviewed by a health care practitioner who knows something about the profile of change for dementias and about appropriate assessment/evaluation methods in adults with ID. He or she can therefore steer further inquiry and assessment in thoughtful ways. The Diagnostic Manual for Intellectual Disability-second edition (DM-ID-2) [25] has an extensive chapter on neurocognitive disorders. Findings from the NTG-EDSD can be linked with the criteria within the DM-ID-2. Guidelines can be provided to medical and non-medical healthcare practitioners linking findings from the EDSD with treatment and support planning.

The NTG-EDSD is an evolving instrument. Since it is a "work in progress," studies and reports of usage outcomes are welcome, as are questions which can help guide further development of the tool. Although Deb and colleagues [14] did propose a threshold 'score' when using the DSQIID, there is no comparable "score" for the overall NTG-EDSD. Whereas the DSQIID is intended as a diagnostic screening, the NTG-EDSD is intended to collect broader information and to be an administrative tool to support healthcare decision-making. The ratings on the tool correspond to observed changes in functioning. Family and professional carers can share these ratings with a healthcare provider. Currently, DSM-5 and DM-ID-2 criteria for dementia can 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.

Lastly, the authors have received correspondence from worldwide sources providing anecdotal support for the NTG-EDSD as a useful means for capturing information about change. Future directions include surveying groups that have identified themselves as "superusers" of the instrument in order to determine how findings are being used to advance the healthcare and support needs of persons with disabilities with suspected neurocognitive disorder.

The ratings from the NTG-EDSD can be used to train carers on case-based characteristics of change over time for individuals with suspected neurocognitive disorder [13]. Moreover, the rating schema within the NTG-EDSD highlights which behaviors to observe for change; this can serve to advance carers' ability to advocate for individuals with dementia with their healthcare providers [23]. Research undertaken could examine the utility of serial re-assessments and the influence of variations in staff/family completers, impact on clinical determinations, and relationships among marker items, as well as compare the validity of the threshold score cited by Deb and colleagues [14] with that potentially derived via the adapted DSQIID items

within the NTG-EDSD. We encourage the open access to and use of NTG-EDSD and trust that both practitioners and researchers will find ways to enhance the instrument and undertake studies illustrating its utility and reliability.

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Appendix I: NTG-EDSD

NTG-EDSD

v.1/2013.2

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: _____

(10) General characterization of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(11) Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(12) Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(13) Conditions present (*check all that apply*)

	Vision impairment
	Blind (very limited or no vision)
	Vision corrected by glasses
	Hearing impairment
	Deaf (very limited or no hearing)
	Hearing corrected by hearing aids
	Mobility impairment
	Not mobile – uses wheelchair
	Not mobile – is moved about in wheelchair

(14) Significant recent [in past year] life event (*check all that apply*)

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

(15) Seizures

	Recent onset seizures
	Long term occurrence of seizures
	Seizures in childhood, not occurring in adulthood
	No history of seizures

If MCI or dementia is documented complete 16, 17, &18

(16) **Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:

[ ] No

[ ] Yes, MCI

Date of Dx:

[ ] Yes, dementia

Date of Dx:

Type of dementia:

Diagnosed by:
- □ Geriatrician
- □ Neurologist
- □ Physician
- □ Psychiatrist
- □ Psychologist
- □ Other:

(17) Reported date of onset of MCI/dementia
[When suspicion of dementia first arose]
Note approximate year and month:

(18) Comments / explanations about dementia suspicions:

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
[19]**Activities of Daily Living**				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
[20]**Language & Communication**				
Does not initiate 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 printing own name)				
[21]**Sleep-Wake Change Patterns**				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
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				
[22]**Ambulation**				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	New symptom in past year	Does not apply
[23]**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				
[24]**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				
[25]**Adult's Self-reported Problems**				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
[26]**Notable Significant Changes Observed by Others**				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was 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)				

[Check column option as appropriate]

	[27]Chronic Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	Bone, Joint and Muscle				
1	Arthritis				
2	Osteoporosis				
	Heart and Circulation				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	Hormonal				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	Lungs/breathing				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	Mental health				
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	Pain / Discomfort				
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	Sensory				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	Other				
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

(28) **Current Medications**

Yes	No	Indicate type
□	□	Treatment of chronic conditions
□	□	Treatment of mental health disorders or behavior problems
□	□	Treatment of pain

For reviews, attach list of current medications, dosage, and when prescribed

□ List is attached for reviews

(29) **Comments related to other notable changes or concerns:**

(30) **Next Steps / Recommendations**

□ Refer to treating physician for assessment

□ Review internally by clinical personnel

□ Include in annual review / annual wellness visit

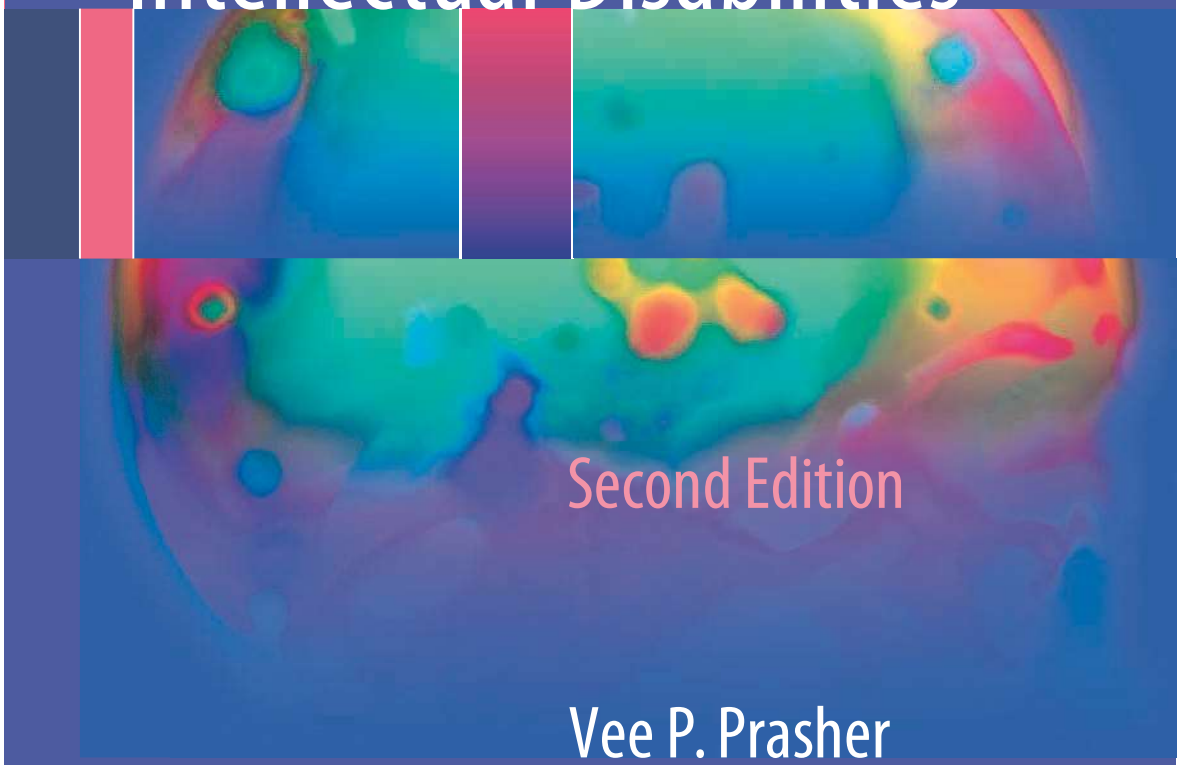
□ Repeat in _____ months

Form completion information

(31) Date completed	(32) Organization / Agency
Name of person completing form	
Relationship to individual (staff, relative, assessor, etc.)	
Date(s) form previously completed	

Acknowledgement: Derived from the DSQIID (*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

Neuropsychological Assessments of Dementia in Down Syndrome and Intellectual Disabilities



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