Wisconsin Alzheimer's Institute
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



Implementing Effective Dementia Screening for Persons Living with an Intellectual Disability

A comprehensive guide on how to implement trainings on the National Task Group-Early Detection Screen for Dementia (NTG-EDSD) for specialists in the intellectual disability field.

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Chapter 1

Screening Individuals Living with an Intellectual Disability

Alzheimer's disease affects nearly 5 million older adults in the United States, a number expected to increase to 13.8 million by the year 2050 (Alzheimer's Association Facts and Figures, 2020). Of the more than 7 million individuals with intellectual disabilities (ID) living in the United States, those with Down syndrome are at particularly higher risk for developing dementia than those without ID (Ball et al., 2006). In people with Down syndrome, the first biomarkers of Alzheimer's disease tend to emerge around age 30, and signs of cognitive decline around age 40. (Fortea et al., 2020).

Detecting cognitive decline can be challenging without thorough knowledge of the person's baseline cognitive and functional abilities. The level of severity of cognitive impairment can vary among people with ID; some may have poor ability in reporting difficult symptoms, while others may lack verbal communication abilities at all. It is imperative that these individuals have strong advocates who are able to gather as much baseline information as possible about their functional abilities, screen for changes that occur utilizing the NTG-EDSD, and be able to report this information to medical providers on behalf of the person with ID.

The National Task Group on Intellectual Disabilities and Dementia Practice (NTG)

Individuals with Down syndrome are living longer, in part due to advancements in research and medicine, as well as improvements in the delivery of services. According to the National Down Syndrome Society (2020), the life expectancy for people with Down syndrome has increased from 25 years in 1983 to 60 years in 2020. As these individuals have an extended life span, some are at higher risk for developing dementia, particularly those with Down syndrome.

Screening for dementia with this group requires different practices as they have unique needs compared to older adults without an ID. Current methods for assessing cognitive decline in the general population are not appropriate for individuals with ID. The instruments are based on average cognitive functioning at baseline and do not consider pre-existing cognitive

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impairment. For example, a person with ID might not be able to draw a clock at baseline, making the Mini Mental Status Exam and Clock Draw test unsuitable.

Using an effective dementia screening tool for cognitive changes geared toward persons with ID can improve the detection of changes that merit diagnostic evaluation. An individualized diagnostic evaluation will determine differential diagnoses and an appropriate treatment plan.

The NTG-EDSD is a screening tool that establishes baseline abilities and helps to document subtle changes in behavior and functioning that could indicate the onset of dementia. According to the developers, the NTG-EDSD tool 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… The NTG-EDSD was not designed to diagnose dementia, but to be a help in the early identification and screening process" (Esralew et al., 2013).

The NTG-EDSD is not designed to assess or diagnosis dementia, but rather can highlight if there are warning signs that could indicate the need for a more thorough evaluation. When changes associated with dementia are suspected, a comprehensive medical evaluation is recommended to rule out reversible causes that might mimic dementia. The NTG-EDSD tool is instrumental for caregivers of individuals with ID to help track changes occurring and provide medical providers the critical information they need in order to appropriately evaluate and design individualized treatment plans.

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Chapter 2

Development of Training

Steering Committee

In 2018, the Dementia Capable Wisconsin grant team convened a steering committee of eight experts in the field of ID to brainstorm and develop a project that would improve the service provision of people with ID. The committee members represented state and local community-based and healthcare organizations including the Waisman Center and Waisman Wellness Inclusion Nursing (WIN) Program of Madison, WI, Special Olympics of Wisconsin, The Management Group, Care Wisconsin, the Wisconsin Board for People with Developmental Disabilities through the Department of Health Services, and the Wisconsin Alzheimer's Institute.

The steering committee met on a monthly basis to discuss areas that the Dementia Capable Wisconsin grant team could consider for developing an innovative project that would improve the care and services of adults with ID at risk for dementia. As an outcome of these discussions, it was agreed many professionals working with persons with ID may be aware of the higher risk for developing dementia their clients with ID faced; however, they may have limited or no knowledge of how to discern potential indicators of cognitive decline, how to document these changes being observed in their clients, or steps to take to advocate for a follow-up evaluation. Specifically, the committee felt the professionals working with persons with ID would benefit from having more knowledge about the National Task Group-Early Detection Screen for Dementia (NTG-EDSD) and how to put it into practice.

Identifying Practice Gap

Many regional and national trainings have been conducted on the NTG-EDSD; however, based on informal conversations with WAI partners and affiliated memory diagnostic clinics, there were minimal findings on the actual utilization of the tool. WAI and the steering committee saw this as an opportunity to take the regional NTG trainings a step further by training professionals on how to operationalize the screening tool.

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Trainings Content

To address this gap from knowledge to practice, we developed and implemented five training sessions for professionals who are working with individuals with ID throughout the state to improve their understanding and utilization of the NTG-EDSD.

Our mission was to educate and prepare professionals from community agencies to immediately use the NTG-EDSD tool to detect possible cognitive changes and address reversible causes in their clients. The primary objective was for participants to gain knowledge on how to effectively utilize the NTG-EDSD tool with persons with ID. These trainings were approximately four hours and covered the topics of:

- Assessment of Dementia in Persons with an Intellectual Disability
- Addressing Behavioral Symptoms in Persons with an Intellectual Disability and Dementia
- How to Use the NTG-EDSD Tool and Testimonials
- Implementing Screening for Dementia to Enhance Service Delivery

Following education covering ID, dementia, and behavioral and psychological symptoms of dementia in persons with ID, the attendees practiced using the NTG-EDSD with case examples from their own work experiences or with a provided case example. During this portion of the training, WAI staff and presenters circulated to help answer questions, provide guidance, and problem-solve with attendees using the tool.

Training Locations and Attendees

The NTG-EDSD training sessions took place throughout the state of Wisconsin:

- November 2018 – LaCrosse, WI, 22 attendees
- January 2019 – Madison, WI, 38 attendees
- February 2019 – Appleton, WI, 16 attendees
- April 2019 – Menomonie, WI, 22 attendees
- April 2019 – Brookfield, WI, 56 attendees

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- An additional training was conducted solely with Inclusa, Inc., a Managed Care Organization (MCO) in Menomonie, WI, which serves 51 of the 72 Wisconsin counties.

Assessments and Outcomes

We assessed knowledge and attitudes at baseline prior to the start of the training, immediately after training, and one week, one month, and six months after training. Findings were overall positive; participants reported very high satisfaction with the training and strongly agreed that it is feasible for them to use the NTG-EDSD with their clients. Additionally, participants reported a marked increase in confidence in their ability to detect changes associated with mild cognitive impairment or dementia, decline in activities of daily living, and changes in behavior and affect. Following the training, Inclusa, Inc., serving 51 of 72 counties in Wisconsin, made the NTG-EDSD a standard part of the assessment of adults with Down syndrome starting at age 40.

Target Audience and Recruitment

Knowing who your target audience is for the training will help assure participants will receive the most benefit from the information you present to them, and that you as the host or presenter will reach your teaching objectives.

For the purposes of the NTG-EDSD trainings, we decided those who could most benefit and have the greatest impact on the ID population, including professionals employed through the Managed Care Organizations in the Family Care, Partnership and PACE programs of Wisconsin; Adult Family Home providers; day service providers; supported employed providers; and other professionals that deliver assessment, care, and case management services. Professionals in these organizations deliver assessment and case management services directly with adults with ID and were identified as best equipped to complete the NTG-EDSD based on the knowledge they have on their clients.

Participants were recruited through phone calls, emails and training fliers mailed to them. Incentives for participation included a free meal during the training and free continuing education units.

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In Wisconsin, Family Care is the Medicaid covered long-term care waiver program for frail elders and adults with physical and developmental disabilities that will help support their independence and remain in their homes as long as possible. This program helps provide services to people who need assistance managing their activities of daily living (ADLs) such as bathing, dressing, and transferring, and instrumental activities of daily living (IADLS) such as preparing meals, managing money, and grocery shopping.

Similar to Family Care are the Partnership and PACE programs; these two integrate the long-term care services along with health/medical services into one unified benefit package.

Individuals who enroll in Family Care select a Managed Care Organization (MCO) to work with that contracts with providers to deliver the direct, individualized ADL/IADL care. Under funding provided by the Department of Health Services, the MCOs arrange services for members and provide case management for ensuring quality delivery of care. These services can include residential, vocational, and healthcare services that will enable individuals with ID to remain in their own homes.

Many adults with ID reside in Adult Family Homes (AFHs) in the community, which generally house 3-4 unrelated adults to provide room and board, laundry, meals, assistance with activities of daily living, and supervision, as well as other care services in the home. Individuals with ID residing in AFHs are able to receive around-the-clock care in a supportive, respectful, and compassionate home-like setting. Trained AFH professionals providing this 24/7 care are a special niche in that they are able to observe the residents in different environments throughout the day. By having this lens, residential staff know the daily activities for the person with ID, and they are well equipped to observe, monitor, and track behavioral changes that can occur over time.

Supported Employment Agencies (SEAs) include organizations that help people with disabilities obtain and maintain meaningful employment in community settings. SEAs can help individuals with ID seek employment, prepare them for job interviews and orientation, and provide direct on-the-job support through job coaching. Professionals from SEAs supporting clients with ID have the unique perspective of the abilities, challenges, and functional changes that their individuals have that can be tracked with the NTG-EDSD. The vast majority of the

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attendees that participated in our NTG-EDSD training were from the MCOs serving the 72 counties in Wisconsin. These MCOs included Inclusa, Inc (serving 51 WI counties), Community Care (serving 15 counties), and My Choice Family Care (serving 26 WI counties).

How to Use the Training Modules

The NTG-EDSD Training Guide is designed to help an organization replicate the WAI training sessions. This guide provides the following information:

- Why the NTG-EDSD is important as a gateway tool to further assessment of dementia in people with ID
- Ways to identify the appropriate target audience for your training
- How to recognize your organization's capacity to conduct a similar training and implement the NTG-EDSD
- Steps to get started and considerations to make to increase the success of your training
- Getting the NTG-EDSD standardized in your organization or partner organizations
- Feedback from participants in the Wisconsin trainings
- Common questions from past training attendees that may influence your training format
- Resources available to you for the replication of the trainings in your community, including the PowerPoints, reference notes, and materials used by WAI presenters

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Chapter 3

Developing and Implementing the Early Detection Screen for Dementia Training

Determine Your Organization's Need, Capacity, and Readiness

Organizations vary in their structure and daily operations in regard to staffing levels and the ability of staff to deliver services. Therefore, it is essential to evaluate your organization's capacity to conduct the training.

Need: Consider staff's knowledge and experience in regard to dementia in persons with ID and the NTG-EDSD to determine if this training is a good fit for the organization. Professionals targeted for our trainings included staff who worked directly with people with ID, conducted annual assessments and care management for those individuals, and were in positions to help advocate to the primary care providers about physical, cognitive and functional changes in their clients. It is recommended that organizations who plan to use this training review current assessment procedures used by staff with clients with ID, and determine if knowledge and utilization of the NTG-EDSD in those assessments could benefit the people with ID.

Capacity: Determine the organization's ability to provide the training. Consider who will be responsible for coordinating and providing the training and who will be trained. There are many factors that influence capacity to perform a training, including availability of staff to attend a training, training leaders' comfort with the material and availability to prepare the training, space to conduct the training, and equipment to carry out the training (e.g., access to the PowerPoint). For our trainings, we used the expertise of a neuropsychologist, geriatric psychiatrist, and a social worker and recreational specialist, who were both NTG-EDSD affiliated regional trainers to present on the training modules. These professionals were either employed by WAI or affiliated with WAI through our memory clinic network. Organizations interested in replicating this training should use professionals in the same or similar capacity to those used by WAI, to deliver the educational content on working with people with ID. If these experts are

not part of your organization, consider recruiting presenters from another healthcare or community based organization to assist with the training.

Readiness: Determine if staff are able to utilize the NTG-EDSD tool ongoing with clients. If staff utilize the NTG-EDSD, have a plan for when and how it will be used. This includes whether the screening tool will be used on an annual/semi-annual basis or only when there are notable changes or concerns. Other readiness considerations include whether the screening will be completed on paper or in electronic form, and whether it will be stored in the client's paper file or electronic file. Finally, organizations should prepare staff for how they will be asked to use the NTG-EDSD; whether it will be required for staff to use with all clients with ID or only for those above a certain age or at higher risk for developing dementia. Furthermore, make a plan for examining the effectiveness of using the tool, including outcomes. This can be accomplished through development of instruments or outcome measures to evaluate if the use of the NTG-EDSD resulted in dementia diagnosis or if dementia could be ruled out due to other factors.

Training Logistics

It is important to consider your target audience and who you want to benefit from these trainings. In your particular community, you may have similar organizations and long-term care providers that were identified in Wisconsin. However, there may be other community-based and healthcare organizations or partners you know of that could equally benefit from the knowledge shared at this training.

Start with brainstorming with your internal team to identify the providers and professionals in your area that directly work with individuals with intellectual disabilities and who could directly utilize the NTG-EDSD screening tool with their clients. This includes pinpointing individuals in your team who will take on certain responsibilities of coordinating the trainings, including managing registration links, preparing training forms and folders for participants, and setting up the logistics of the training.

Collaborate with your colleagues to establish potential speakers to present the NTG-EDSD information. Identify the best experts to cover the training material on ID and medical diagnoses and someone who has knowledge and experience using the NTG-EDSD. This can

include professionals directly within your organization or colleagues from an outside organization or clinic.

Next, contact a manager, supervisor, or someone in leadership about your plans to conduct this type of training, and conduct an informal survey to determine level of interest in participation in the training.

Once an estimated number of interested participants is known, the designated coordinator should initiate the process of situating a training location that will accommodate the attendees and can provide or accommodate A/V equipment. When settling upon the training location, take into consideration if they can provide food for a meal or breaks, or if they allow outside food to be catered. Test A/V equipment to ensure it is operating properly prior to the day of the training

Training location, ample room capacity, and functioning technical equipment will be vital in the success of sharing the presentation materials and being able to navigate the room while assisting participants with the NTG tool. For the purposes of our NTG trainings, we determined location and space needed for our trainings based on the estimated number of people interested in participating and the number of those individuals who agreed to participate in our grant study, which included completing follow-up evaluations on their use of the screening tool.

In our trainings that took place from November 2018 to April 2019, attendee numbers ranged from 16 to 56 people. The lowest number was due to an unanticipated snow storm that impacted people's ability to safely travel to the meeting location. Due to the timeframe of the training and schedule of our presenters, we were unable to cancel or postpone this training. As a resolution, we invited back those who could not attend the February training to our April trainings.

Training Agenda Example

The five trainings followed the same scheduled agenda across all dates and locations:

- 8:00 a.m. - Check-in/Registration began and pre-training evaluations handed out and collected from attendees when completed. WAI staff helped at the entrance, distributed name tags and evaluations, and explained the forms that were included in their folders.
- 8:45 a.m. - Dementia Program Manager offered an official welcome. This included reminders to participants to complete their pre-training evaluations, an overview of housekeeping items for the day, a brief explanation about the goals of the trainings, and introductions of the presenters.
- 9:00 a.m. - Presentation by Greg Prichett, PsyD (Gunderson Health System, LaCrosse, WI) on the Assessment of Dementia in Persons with Intellectual Developmental Disabilities
- 10:00 a.m. - Presentation by Art Walaszek, MD (WAI Public Health and Education Leader and geriatric psychiatrist at UW Health) on Addressing Behavioral Symptoms in Persons with Intellectual Developmental Disability and Dementia
- 11:00 a.m. - Lunch provided by WAI. During this time, presenters sat with participants to learn about their organizations and experience using NTG-EDSD.
- 11:30 a.m. - Presentations by Mickell Wilcenski (Lead Recreational Specialist at Aptiv, Inc., LaCrosse, WI) on How to Use the NTG-EDSD Tool and Testimonial, and Jody Krainer (WAI Dementia Diagnostic Clinic Network Manager) on Implementing Screening for Dementia to Enhance Service Delivery. In addition to the presentations on the purpose and need for using the NTG-EDSD with people with ID, this hour was used for direct hands-on learning with the EDSD tool. During registration, attendees were asked to bring case examples to use with the EDSD to the training. If they did not have one, staff provided a case example (see appendix Example #1). Participants used examples to complete an EDSD form, while staff and the presenters made rounds to answer questions using the tool.
- 12:50 p.m. - Post-Training Evaluations distributed and collected from attendees
- 1:00 p.m. - Adjourn

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Additional measures taken to support the success of the program included:

- Coordinated locations with ample room space for individuals to move around and for presenters to work with training attendees at their tables when going through the NTG-EDSD practice session
- Ensured access to audio/visual capabilities including a projector for our PowerPoint presentations and a microphone for the presenters
- Allowed ample time for questions and answers from participants
- Provided a lunch for participants to help keep them engaged. Presenters also used this meal time to gain more insight about attendees' roles and organizational structures.

Interfacing with Healthcare Providers and Systems

Taking a multidisciplinary approach when working with an individual with ID brings in different perspectives to better understand that individual. Having open communication with healthcare providers who care for people with ID is essential to ensuring they receive quality care, appropriate assessments, and ultimately accurate diagnoses and equal access to services. The NTG-DSD can serve as a guide for communicating with healthcare providers, especially if caregivers are observing changes documented when the screen is completed.

To help facilitate communication between training participants and primary care providers, we created a letter about the NTG-EDSD and the trainings provided by WAI. The purpose of the letter is to help educate healthcare providers on the importance of utilizing the NTG-EDSD for screening for possible dementia in persons with ID. Furthermore, this letter informs healthcare providers that the completed screening tool can be included in patient health records for reference with future evaluations. This letter was reviewed and approved by the developers of the NTG-EDSD including Matthew Janicki, MD, and Lucy Esralew, MD, and signed by Art Walaszek, MD, and Dr. Greg Prichett, PsyD.

If a person's healthcare provider has questions on next steps for evaluating dementia in persons with ID, refer them to the Assessment and Diagnosis of Dementia in Individuals with Intellectual Disability: A Toolkit for Clinicians and Caseworkers on the WAI website.

Chapter 4

Training Module 1: Assessment of Dementia in Persons with Intellectual Developmental Disability

Slides and Talking Points

Slides have been updated since the time of trainings to reflect current data from more recent research studies. In the following sections, the reader should reference the PowerPoint presentations to accompany the training module slides and talking points. Also, readers should refer to the Frequently Asked Questions in Chapter 7, section 'e' to familiarize themselves with the most common questions participants asked during the training. This will prepare the presenters to answer questions or elaborate on the training content. Finally, users should follow the sequence of modules and not jump prematurely to module 3.

The combined slide set for Modules 1, 2, and 3 is available in a separate PowerPoint file:
NTG_TrainingSlideDeck_AllModules.pptx
The slide set for Module 1 is available in a separate PowerPoint file:
NTG_TrainingSlideDeck_Module1.pptx

Slide 2

Learning Objectives

- Provide an overview of the clinical manifestations, incidence/prevalence, and risk factors for Alzheimer's disease and related dementias (ADRD) in persons with Intellectual Disability (ID) with emphasis on Down syndrome.
- Review assessment challenges encountered in diagnosing dementia in persons with ID.
- Provide an overview and rationale for use of the EDSD — an administrative screen designed to detect dementia-related changes in individuals with ID.

Slide 3

According to the *World Alzheimer Report* (2009) the number of people with dementia is forecast to double every 20 years from 36 million in 2010 to 115 million in 2050.As many as ¾ of the estimated 36 million people worldwide living with dementia have not been diagnosed and hence cannot benefit from treatment, information, and care resulting in a significant "treatment gap."

Failure to diagnose dementia typically results from 3 barriers:

- Stigma of dementia that prevents open discussion
- False belief that dementia is a normal part of aging
- False belief that nothing can be done about it

Research shows that medications and psychological and behavioral interventions for early-stage dementia can increase cognition, independence, and quality of life. Support and counseling can improve mood, reduce caregiver strain, and delay institutionalization of people with dementia. Early diagnosis may also help reduce the overall cost of long-term care.

Persons with intellectual disability (ID) share the same plight. As a group, they are living longer and at increasing risk of age-related conditions including dementia. Persons with ID and their families also share unique barriers. The diagnosis of dementia in persons with ID is more challenging due to their baseline cognitive impairments and psychosocial deficits. Many physicians and healthcare workers are ill-prepared to address the needs of ID persons or to recognize the signs and symptoms of dementia, and/or may not have access to providers with specialist assessment skills.

Medical treatments and other interventions are only available to those who have sought and received a diagnosis. In order for patients/families to gain access to interventions that might lessen the impact of dementia, providers and healthcare workers need to be prepared, skilled, and trained to provide timely and accurate diagnosis that is communicated sensitively and with appropriate support. A coordinated early detection screening process tailored for adults with ID is a key component in our efforts to narrow this "treatment gap."

Slide 4

Down Syndrome

- Most common genetic cause of intellectual disability (ID) resulting in significant limitations in intellectual function and adaptive behavior (ID Definition, AAIDD.org; n.d.) and classic physical stigmata
- 1/691 live births annually or ~6000 born in US each year (CDC, 2012)
- More than 400,000 people are living with Down Syndrome in the US (National Down Syndrome Society, 2012)
- Prevalence of children (5-19) with ID-2.5% (mild); 0.4% (moderate); 0.1% (severe) (Roeleveld, 2008).
- 1.2 million non-institutionalized adults had ID in 2010 (Brault, 2012)

Slide 5

Before discussing the link between Down Syndrome (DS) and Alzheimer disease (AD) a brief overview of each syndrome is in order. **Trisomy** or non-disjunction results from an extra full copy of chromosome 21. **Translocation** is the attachment of the long arm of an extra chromosome 21 to either chromosome 14, 21 or 22. **Mosaicism** occurs when some but not all cells are trisomic.

Slide 6

Alzheimer's disease

- Most common cause of progressive dementia among older people
- Insidious onset/gradual deterioration is typical but impairments can be abruptly unmasked by significant stressor or inter-current illness or injury
- As disease progresses there is slow erosion of cognition resulting in increased functional dependence and eventual death

Slide 7

Prevalence of Alzheimer's disease

- 5.4 million Americans; 200,000 early onset (Alzheimer's Association, 2016)
- 2:1 women to men
- Estimated 7.1 million by 2025; 13.8 million by 2050 (Alzheimer's Association, 2016)
- Biggest risk factor for Alzheimer's disease is age
- Prevalence of Alzheimer's disease increases markedly with age

Slide 8

Protein beta amyloid collects outside the neurons while an abnormal form of protein tau (tau tangles) collects inside the neurons. The Tau tangles block transport of nutrients and other essential molecules while beta amyloid collection is believed to interfere with neuron-neuron communication, both of which lead to memory loss and other symptoms. As the brain changes advance, information transfer at the synapses begins to fail, leading to cell death and degeneration.

These brain changes can begin > 20 years before cognitive and behavioral symptoms emerge. Typically, our brains are able to compensate at first due to "cognitive reserve" to allow us to function normally, but as neuronal damage increases, subtle decline occurs leading to obvious decline over time.

AD accounts for 60-80% of dementias; one half of the cases involve sole AD pathology.

Slide 9

Except in rare cases there is no specific genetic link between AD and other causes of ID. Rather, the "**brain reserve hypothesis**" has been proposed to explain the increased risk of dementia in individuals with non-DS ID.

Slide 10

This hypothesis proposes that there is a critical threshold of reserve capacity that must be exceeded by pathological processes in the brain before clinical or functional symptoms develop. It is useful for explaining how individuals can have significant Alzheimer type changes in the brain and still function reasonably well (at least for a while).

Slide 11

Another reason why this is so important is that people with ID are living longer. If you look at the data about life expectancy that have been reported, persons born with an ID in the early 1900s had a short lifespan - the highest mortality rates were in the 1st and 10th year of life for individuals with DS for example. Flash forward to the 1990's and we see much longer life expectancy largely due to improvements in healthcare, nutrition, and public policy. For people with DS, they can potentially live past 60 years old. (Fortea, et al, 2020)

Slide 12

Research has also shown that life expectancy is influenced by a number of factors including level of ID and presence of multiple disabilities. Shorter life expectancy is associated with greater level of ID and number of disabilities, and other complex medical conditions.

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The takeaway message is that persons with ID are living longer and as such at increased risk for age-related problems including dementia, they will require a longer period of care, and if they develop dementia, a longer period of specialized care. The question is are we prepared for this "silver tsunami?" in a way that allows us to recognize the early signs and symptoms, and carry out the appropriate diagnostic assessments so that we can initiate prompt and appropriate medical and care management at a time when it is most likely to be of the greatest benefit.

Slide 13

One additional factor relevant to persons with DS is the syndrome of precocious aging. Changes in appearance and function that occur normally as a process of aging in the general population tend to occur earlier in persons with DS, sometimes 20 years prior to the "onset" of dementia when biomarker changes can be seen. These likely account in part for the earlier onset of AD in these individuals. In a study by Fortea et al, cognitive impairment scores started to decline around age 40 in people with DS; about 10 years before the average age of onset of AD. Other biomarker changes found earlier in people with DS include a reduction in cerebral metabolism as early as age 37.5, an increase in amyloid deposition around late 40s, CSF beta-amyloid decreased as early as their 30s, p-tau changes in late 30s and plasma beta-amyloid concentrations 58% higher in people with DS. Most notably, the two biomarker changes to be observed the earliest (by age 28-30 years) were the CSF beta-amyloid and plasma NFL concentrations (Fortea et al., 2020). Although biomarker changes in the brain can be observed decades earlier in people with DS, the pattern and cortical areas of the brain that they target, occur similarly to those with non-DS.

Slides 14 & 15

(At this juncture the presenter can ask attendees who have families (children), if at the time they started their families, did they ever envision having their children living with them at their age of retirement.)

The reality for many families is that many persons with ID live with their families as they grow older often to the point that very elderly parents - who may themselves be developing cognitive changes - are caring for senior-aged adult children with ID who are also developing dementia. That is a not too uncommon scenario and serves as a significant source of caregiver pressure.

Slide 16

This study by Brookmeyer and company provides data on individuals over the age of 70. Approximately 2% of individuals age 64 or older have dementia in the United States and the rates double every 5 years or so.

Slide 17

Brookmeyer and colleagues also looked at the median life span following diagnosis; this depends on age and presence of comorbid medical conditions. The mean duration between onset of symptoms and diagnosis is 2.8 years. In a more recent study by Fortea and colleagues, the average age of a diagnosis is 53.7, with the mean duration between onset of symptoms and

diagnosis of 3.5 years. What they found is a long preclinical phase with biomarker changes spanning over 20 years before functional changes are observed.

Slide 18

Family risk is approximately 30%. For example, the age risk at 65 is 2% (or 20/1000 persons) and ~5% (50/1000 persons). Combining the two the composite risk at age 65 with family history of dementia would be 26/1000 persons and 65/1000 persons at age 70.

Genetic risk from the familial form usually develops before the age of 60 and may appear as early as 30-40 years of age; it accounts for less than 5% of all cases.

Modifiable risk factors refer to the fact that the health of the brain is linked to overall health of the heart and blood vessels. Factors that increase the risk of cardiovascular disease are associated with greater risk of dementia. These factors include such things as mid-life obesity, diabetes, high blood pressure, high cholesterol, smoking, excessive alcohol consumption or drug abuse, as well as physical inactivity, diminished social engagement and lack of cognitive stimulation. Of these factors, the top three in order of importance are: 1-physical activity, 2-physical activity, and 3-physical activity! What is good for the heart is good for the head (brain). Increased physical activity improves health and reduces medical risk; you are usually doing it with or around others and often it stimulates your mind. The best advice is to do two things to reduce the risk of dementia: see your doctor regularly (and do what he/she says) and get busy and stay busy!

Slide 19

This study by Ball and company show the dementia rates in adults with Down syndrome with the average age of onset of 51.67 years, while the study by Fortea and colleagues revealed prodromal Alzheimer's disease diagnosed at the median age of 50.2 years.

Slide 20

This table by from a study done by Strydom and colleagues indicate the dementia rates in adults with non-Down syndrome ID, with the average age of onset is slightly higher at 67 years of age.

Slide 21

Risk factors for ADRD in people with ID includes an individual over the age of 40 with DS; an individual over the age of 59 with ID of another cause; an individual with a head injury or multiple head injuries; or someone with a family history of ADRD

Slide 22 & 23

In summary, adults with DS are at higher risk of AD and the prevalence of this increases substantially after age 40. The Fortea study suggests that due to the nature and trajectory of early biomarker changes, individuals with DS may be an acceptable sample group for clinical AD trials. Certain factors and/or combination of factors attribute to an earlier onset of AD in people with DS. Rates of dementia in non-DS ID adults are typically higher than the generally population; the onset and progression are similar to the general population.

Slide 24
The manifestation of dementia in adults with ID is similar in terms of the progression of core symptoms, but the presentation is different in that personality and behavior changes are more observed in the early stages, especially in people with DS

Slide 25
The personality and behavior changes tend to fall into at least one (and usually more) of four interrelated categories: Emotional lability refers to rapid, often exaggerated changes in the expression of mood where strong emotions (uncontrollable laughing/crying, or heightened irritability or temper) occur. The expression of these moods is more frequent, intense and lasts longer than is typical of the individual and is often disproportionate to the context or situation. Irritability/agitation-irritability refers to the tendency to become easily annoyed and provoked to anger; agitation is characterized by anxiety associated with motor restlessness, nervousness and worry. Apathy refers to a lack of motivation to do, complete or accomplish anything often coupled with low energy levels. Often the apathy is pervasive and reflects a loss of interest in favorite foods, TV programs and past times, family and social gatherings with corresponding social withdrawal, and decreased initiative. This is coupled with a slowness affecting ALL aspects of functioning-walking, eating, speaking, and general movement.

Stubbornness/Coarsening of Social Behavior - Stubbornness refers to a general uncooperative mood with oppositional/resistive or defiant behaviors while coarsening of social behavior refers to a blunting or exaggeration of premorbid personality traits where the affected individual demonstrates a loss of unique aspects of their personality, e.g. mischievousness, jolliness, independence-minded, need for sameness and routine, conscientiousness, meticulousness, etc. Other changes include a lack of restraint, grossly insensitive behavior or hypochondriasis where the affected individual expresses frequent and numerous physical complaints and symptoms that are unfounded and out of character for the individual.

These changes can be confusing, embarrassing and difficult to understand for the person with ID. They may report awareness that they are forgetting things, say they “can’t think,” express frustration and loss, worry about negative reactions from others but also become more needy and insecure, worry excessively about anything and everything, cope by minimizing, covering up, being busy, withdrawing or constantly apologizing.

Slide 26
Although the progression of cognitive decline is similar to individuals with ID versus those with non-ID, these other factors can impact the presentation.

Slide 27
The presentation of memory loss between individuals with/without ID varies depending on severity of ID impairment.

Slide 28
Cognitive loss, including changes in verbal skills, information processing, attention and other impairments to cognitive functioning across those levels of ID appear here.

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Slide 29
Seizures occur in 50-80% of persons with ID with dementia compared to 10% AD in the general population; any late onset seizure, recurrence of previously well-controlled seizure, or emergence of new type of seizure is a strong indication for Alzheimer's.

Slide 30
The diagnosis of dementia requires documentation of changes in mood, motivation, memory, personality, and social behavior sufficiently to impact daily living skills. Zigman and his colleagues followed a group of persons with ID with dementia and measured changes in adaptive behavior using the Adaptive Behavior Scale and found declines in non-routine (IADLs) functional abilities were evident first followed by changes in routine (ADLs) skills.

Slide 31
Functional impairments in the early stages are generally seen in these areas of instrumental activities of daily living, such completing household chores, making meals, and using transportation.

Slide 32
In the mid to late stages, impairments are observed in the activities of daily living (eg, bathing, dressing, and eating.

Slides 33 and 34
These slides reflect the sequence of decline that occurs in persons with ID due to DS and non-DS. Note that the changes are listed in order of typical presentation.

Slide 35
Another way to look at the progression of dementia is with a staging model, for example, the citation at the top of the slide for more information. Not only do Jokinen and her colleagues do an excellent job of describing the stages of dementia but they provide stage specific interventions at each level of progression that are quite helpful. This article is highly recommended.

One area we have not talked about much is the pre-clinical stage of dementia or what has been referred to as mild cognitive impairment (MCI). This refers to deficits in memory and cognition that are greater than normal for age but the person's functioning remains intact. Although tasks may seem more cognitively challenging, and take greater time and effort, and they may have to rely more on external organization and memory aids, they remain essentially independent. However, they are at risk for developing dementia over time. 15-20% of people >64 have MCI in the general population. In studies of the general population ~32-38% of those with MCI go on to develop dementia within 5 years. Research has also documented a pre-clinical stage in persons with ID. The changes most common for people with ID at this stage are found in this slide.

Slide 36
As mentioned in slide 31, changes seen in the early stage of dementia impact ADLs but also decreased social interactions, increased confusion and anxiety, apathy and communication difficulties.

Slide 37
Mid-stage changes can include increased memory loss, confusion, language processing and commonly more behavioral and psychological symptoms of dementia such as agitation, wandering and repetitive statements. BPSD can occur in any stage of ADRD, however they generally present themselves in this stage.

Slide 38
In the late to end stage, or advanced dementia stage, functioning is significantly changed and increasingly grim. In this stage, there generally are increased falls or total loss of mobility, difficulties with swallowing, loss of communication, complete dependence on others for care, and eventual physical decline. Death is usually attributed to pneumonia.

Slide 39
Jokinen et al's staging model of decline is indicated here, broken down from pre-clinical to late stage. This model includes the general functional losses that occur and the average length of time each stage lasts. Since ADRD affects everyone differently, not everyone will fit neatly into these stages and there can many overlaps in conditions and functional declines. However, this exhibits the general progression.

Slide 40
Diagnosing dementia in someone with ID is usually different than in someone who doesn't have an ID. Standardized memory assessments are not effective for individuals with ID. Documentation of observed functional, behavioral and personality changes from previous baseline are needed to screen for possible dementia.

Slide 41
Listed here are some of the challenges for diagnosing dementia in someone with ID. Some of these include communication deficits in the person with ID, premorbid cognitive conditions, diagnostic overshadowing and lack of knowledge/skills in the care and assessment of someone with ID.

Slide 42
There are common medical issues that can cause memory and functional impairments, but when addressed, could potentially reverse a diagnosis of dementia. Hypothyroidism is a common one that has a 50% prevalence rate in people with dementia; Vitamin deficiencies, unmanaged mental health diagnoses and medication side effects are other common causes that if addressed properly, may reverse dementia.

Slide 43
Listed in this chart are other common conditions that mimic dementia and can easily be overlooked in both people with/without ID. The medical complications listed here commonly afflict individuals with DS, and can cause many of the same signs and symptoms of dementia (example: confusion, attention span issues, decline in function, social withdrawal).

Slide 44
Often there is a bias in many healthcare professionals and caregivers towards aging people with Down syndrome in expecting a deteriorating course, leading to delays in diagnosis and treatment, because the changes are assumed to be due to AD.

Slide 45-46
Deb & Braganza (1999) conducted a study of 62 demented and non-demented adults with ID utilizing the Mini-Mental State Exam (MMSE), one of the most commonly used cognitive screening instruments for the general population. They found that only 34 cases (55%) could perform a MMSE, 30 of those cases (95.2%) scored < 24 (which is in the abnormal range), and 23 of those subjects (77%) did not have a diagnosis of dementia.
These findings demonstrate the following points:

- There are often wide-ranging skills between individuals of the same ID level. Different "starting points" makes it difficult to interpret the significance to test results. Assessment methods must take account of variations in baseline skills and abilities.
- Assessment at a single point in time and with measurement instruments designed for use with the general population is inappropriate in persons with ID. Instruments must be scaled for use with persons with ID. Diagnosis of dementia requires documentation of change from a baseline not a normal level of function as is presumed in the general population.

Slide 47
Diagnostic overshadowing refers to the tendency to attribute all behavior problems to an individual's intellectual disability. Another common bias is to assume changes in behavior are due to psychiatric or behavioral disorders rather than potential underlying medical problems.

Slide 48
One of the most commonly misinterpreted behaviors in persons with Down syndrome is soliloquy, or self-talk. This is often viewed as an indication of psychiatric decompensation when for many it is quite normal and used as a coping mechanism to combat boredom or to self-soothe. It can be a sign of psychiatric deterioration if the incidents become numerous, extreme or public, if conversations become angry in tone and animated in content, or when the person becomes oblivious to the presence of others. As a group, persons with ID are highly vulnerable to the disorganizing effects of loss and life stress which can lead to psychiatric decompensation or what has been termed psychotoform reactions: brief episodes of reactive psychosis that remits once the stress subsides. Often this is mistaken for chronic mental illness such as schizophrenia and may lead to inappropriate treatment.

Differential diagnosis can be enhanced when diagnostic criteria are adjusted to account for the adaptive and expressive deficits of persons with ID, when behavior change is emphasized as opposed to subjective complaints, when other medical problems are ruled out, and by paying close attention to course.

Slide 49

There are few physicians and healthcare professionals who specialize in working with ID population across the lifespan. Furthermore, many of these clinicians and community ID professionals have the training or knowledge on how to screen/assess for changes that could be associated with dementia.

Slide 50

Individuals with ID require a specialized screening process tailored to their needs. This involves documenting their baseline level of performance, following them longitudinally, rescreening on an annual basis or when any other changes with behaviors and functioning occur, and referring them for a more formal dementia assessment when warranted.

Slides 51-56

The specialized screening process can start with using the NTG-EDSD (National Task Group-Early Detection Screen for Dementia. This tool is not a diagnostic assessment tool, but an administrative screen that ID professionals and caregivers can use for documenting information that physicians can use for further evaluations.

The NTG-EDSD was formed in response to National Alzheimer's Project Act (NAPA) signed into law by President Barack Obama. The goals of this tool are to allow caregivers and community support professionals be able document functional changes and decline in people with ID that could be caused by dementia, and to allow healthcare professionals have the necessary information to conduct further assessments tailored to this population.

The screen gathers information on demographics, medical history, mental health issue, chronic health conditions, multiple domains of functional ability, and signals for areas that could be indicative of early dementia. It serves as a running record that can be used annually, it supports caregivers and other ID supports to be good observers of their care recipients, and it provides physicians the vital information they need to conduct a more thorough assessment.

Slides 57-60

In sum, all of these diagnostic challenges point to the need for a coordinated screening process tailored to Adults with ID utilizing the NTG-EDSD.

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Chapter 5

Training Module 2: Addressing Behavioral Symptoms in Persons with Intellectual Developmental Disability and Dementia

Slides and Talking Points
The slide set for Module 2 is available in a separate PowerPoint file:
NTG_TrainingSlideDeck_Module2.pptx

Slide 2
We begin by presenting the learning objectives for this session:

- Describe how behavioral and psychological symptoms of dementia (BPSD) manifest in persons with intellectual disability (ID)
- Describe the pharmacological options that may help address BPSD in persons with intellectual disability
- Develop an approach to managing BPSD that includes behavioral & environmental interventions as primary and psychotropic medications as secondary

Note that we will use the term "behavioral and psychological symptoms of dementia," or "BPSD," to refer to the emotional and behavioral changes that can take place when a person with intellectual disability (ID) develops dementia.

Some of the material presented in this session will overlap with material presented in the prior session. We hope that this repetition will be helpful in participants' absorbing this new information.

There is much less research on treating BPSD in people with ID and dementia than we do in people with other causes of dementia, like Alzheimer's disease, vascular dementia, and dementia with Lewy bodies. So, much of what we present today is based on research in people with BPSD and Alzheimer's disease.

One major point to emphasize (on this slide and throughout the session) is that we really try to avoid adding new medications to treat BPSD. In fact, "deprescribing" – or stopping medications – is a strategy that clinicians frequently use in people with dementia, since medications themselves can cause problems with memory, emotion and behavior. The third objective highlights that behavioral and environmental interventions are preferred over pharmacological options.

Slide 3
This slide presents how a person's cognition and functioning change as they develop mild cognitive impairment (MCI) and then dementia. Cognition refers to memory, language,

attention, judgment, and other aspects of thinking. Functioning includes more basic tasks, called activities of daily living (ADLs), and more complex tasks, called instrumental activities of daily living (IADLs). ADLs include dressing oneself, eating, walking, toileting and hygiene. IADLs include shopping, housekeeping, finances, medications, transportation, and using a telephone.

Dementia is most simply thought of as the combination of cognitive decline and functional decline. IADLs are affected first, then ADLs.

MCI occurs when someone has cognitive decline, but does not yet have functional decline – so, it is a stage in between normal aging and dementia.

Preclinical refers to people having brain changes that could result in dementia, but not yet having cognitive decline or functional decline. In a way, people with Down syndrome are preclinical most of their lives, since they are born with a chromosomal condition that markedly increases their risk of dementia. We will discuss this more on slide 5.

We should note that the changes in cognition and functioning are measured from each person's baseline. Also, with normal aging, we expect there to be changes in cognition anyway – but these changes (in MCI and dementia) are greater than expected.

Slide 4

MCI and dementia refer to the symptoms that people experience. The next step is determining why someone has MCI or dementia. This slide lists the most common causes of MCI and dementia in general, and is not specific to people with Down syndrome or other causes of ID:

- Alzheimer's disease (AD) is the common cause of dementia both in general and in people with Down syndrome. The main early findings are changes in memory and language.
- Parkinson disease (PD) and dementia with Lewy bodies are both considered Lewy body diseases. People with these conditions have problems with movement (shuffling walk; tremor in hands and elsewhere; slowed movement) and sometimes have hallucinations.
- Strokes can result in vascular dementia.
- Frontotemporal dementia usually occurs in relatively young people (45-60 years old) and results in changes in behavior and/or language.
- The exact relationship between alcohol and dementia is not clear, but in general more alcohol use, especially beyond one drink per day, results in a higher risk of dementia.
- Traumatic brain injury (TBI) can contribute to dementia or, when repeated and severe, can be the cause of dementia (e.g., chronic traumatic encephalopathy in football players).
- Mixed dementia is a combination of two or more of the above. The most common mixes are AD and vascular, and AD and PD.

Slide 5

Why are people with Down syndrome at such high risk of developing dementia? As best as we can tell, it has to do with them having three copies of chromosome 21 instead of the usual two. People without Down syndrome have two copies of chromosome 1 through 22, plus either two XX chromosomes (resulting in female sex at birth) or one X and one Y chromosome (resulting in

male sex at birth). The image on the left, called a karyotype analysis, is from a person with Down syndrome, and it shows three copies of chromosome 21.

Chromosome 21 includes a gene called *APP*. This gene codes for a protein also called APP, amyloid precursor protein. The image in the middle shows *APP* on chromosome 21.

Within the brain, amyloid precursor protein is cleaved (sliced) into beta-amyloid. In turn, beta-amyloid clumps together into amyloid plaques, one of the two pathological hallmarks of Alzheimer's disease (the other is neurofibrillary tangles). The image on the right illustrates this process.

So, it is thought that people with Down syndrome develop AD very commonly and at a young age because, since very early in life, they have been producing too much amyloid, in turn resulting in amyloid plaques.

Slide 6

We now turn to the BPSD most commonly seen in people with Down syndrome. We are going to use the framework of the NTG-EDSD screening tool, which categorizes the most common BPSD in Down syndrome into:

- Changes in behavior and affect (see slide 7 for details)
- Changes in sleep-wake patterns (see slide 8 for details)
- Other notable significant changes observed by others (slide 8)

The presenter should review a copy of the NTSD-EDSD ahead of time to become familiar with the tool and with these specific symptoms/behaviors.

Slide 7

A caregiver who is very familiar with the person with Down syndrome completes the NTG-EDSD tool. For each of the symptoms listed here (and on slide 8), the informant states whether this has always been the case, always but worse, or new symptoms in the past year. The "always but worse" or "new symptoms" could indicate that the person with Down syndrome has developed dementia or that dementia is progressing. The NTG-EDSD can be repeated regularly to detect changes over time.

In the prior session, we discussed "internalizing" and "externalizing" behaviors. This slide follows that convention, with internalizing behaviors on the left and externalizing behaviors on the right.

It may be useful for the presenter to illustrate some of these with examples from their own experience. For example, we have illustrated apathy as follows:

This is one of those early warning signs that I've seen in my patients with Down syndrome who have developed Alzheimer's disease: They go from being enthusiastic and pleasant people who regularly go to their place of employment or community-based activity, to starting to lose interest in that. It's harder to get them motivated, to get dressed, and to actually go do the activities. When they're at the activity, they aren't participating as much, they don't seem to have that same social interaction that they used to have. It looks like depression – that is the first thought that can come to mind. Depression is possible, but it could also be a signal that they're starting to develop dementia, apathy and withdrawal.

The behaviors on the right tend to get attention from family members and caregivers, sometimes because the behaviors can result in safety concerns. Another vignette:

> I have heard caregivers say that their 57-year old client with Down syndrome now has OCD, or obsessive-compulsive disorder, because they now have really repetitive behaviors, to the exclusion of other activities, or really repetitive statements. It's not actually OCD – the mean age of onset of OCD is much, much younger – but instead it's a possible sign of dementia in their client.

Slide 8

Sleep disturbances are very common in dementia. For example, people with Alzheimer's disease develop problems with melatonin, a hormone that is involved in regulating the sleep-wake cycle. People with dementia may also have less energy and interest, spend more time in bed during the day, and then have trouble with getting to sleep or staying asleep at night. Problems with sleep can be especially difficult for roommates/housemates and caregivers.

Other changes found in people with ID and dementia include personality changes, being less friendly, being less attentive, having changes in weight, or demonstrating abnormal movements like tremor. The changes in weight could be due to loss of appetite (resulting in weight loss) or carbohydrate craving (resulting in weight gain).

Slide 9

This slide and following one present two models of why BPSD arise. There are many other models, including a purely neurobiological one (brain changes result in changes in mood and behavior) and a strictly behavioral one (antecedents lead to behaviors, which in turn are followed by consequences). This slide presents a model called the progressively lowered stress threshold (PLST) model.

The model says that we all have a threshold for stress levels: as we get closer to that threshold, we can get anxious; when go past the threshold, we can have dysfunctional behavior, such as aggression. A person with dementia may have a threshold that is lower than a person without dementia. The threshold could also change over the course the day, e.g., be lower in the afternoon or evening, which might help explain sundowning.

This model can be very useful for caregivers, who can be vigilant for anxiety (a sign that the person with dementia is approaching the threshold) and then respond accordingly, e.g., switch to a less stimulating activity.

For more information, we recommend the presenter review this article:

> Smith M, Gerdner LA, Hall GR, Buckwalter KC, "History, development and future of the progressively lowered stress threshold: a conceptual model for dementia care." *JAGS* 2004;52:1755-1760.

Slide 10

The unmet needs model could also explain BPSD. A person with dementia may not be able to express a problem (e.g., pain) or need (e.g., loneliness) verbally – instead it comes out as a

behavior, which is viewed as a symptom of unmet needs. Background factors include biological changes of dementia, problems with language, and premorbid personality traits. Proximal factors could include pain, fatigue, a noisy environment, or uncomfortable room temperature.

If the unmet need is not addressed, then the situation can spiral. In fact, treating a behavior without addressing the unmet need could worsen the situation. For example, if a person with constipation and resultant aggression is treated with a psychotropic medication that causes constipation, the underlying unmet need is not only not addressed, but actually worsened.

For more information, we recommend the presenter review this article:

Kovach CR, Noonan PE, Schlidt AM, Wells T, "A model of consequences of need-driven, dementia-compromised behavior." *Journal of Nursing Scholarship* 2005;32:134-140.

None of these models are meant to be all-encompassing or exclusive. Rather, a particular model may serve as the best explanation for a particular behavior. Also, these models highlight that the person with BPSD is not being willful or manipulative.

Slides 11 to 14

We recommend that the presenter read the following article for a better understanding of the evaluation of dementia in people with ID:

Moran JA, Rafii MS, Meller SM, et al., "The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities." *Mayo Clinic Proc* 2013;88:831-840.

The first step in assessing BPSD is to get a comprehensive understanding of each symptom, as detailed on slide 11. Also, because multiple BPSD can exist at the same time, it is important to screen for all BPSD. The NTG-EDSD tool is very handy for this.

The next steps are to carefully review the medication list (to be discussed in detail on slide 13), to review medical problems (to be discussed in detail on slide 14), to screen for abuse (people with dementia and BPSD are at higher risk of being abused), and to screen for depression in caregivers using the PHQ-2 (about 1/3 of dementia caregivers have clinically significant depression). Again, the NTG-EDSD is a great way to collect a lot of the information needed for an assessment.

The PHQ-2 is a quick screening tool for depression and is available online.

On slide 14, it would be especially important to note that hearing loss, vision loss, hypothyroidism, sleep apnea and pain can contribute to cognitive impairment and BPSD in people with ID.

Slide 15

Again, the Moran et al. (2013) article will be very handy for the presenter. This slide presents the steps involved in managing BPSD in people with ID and dementia.

The presenter should reiterate that medications are best avoided, except in situations when behavioral and environmental measures have failed or when behavior poses a threat to the person with dementia or others.

The presenter should note that many of the studies regarding how to manage BPSD were conducted in people with Alzheimer's disease, and it can be a challenge to apply those results to people with ID.

Slide 16

Again, use nonpharmacological interventions before adding new medications, especially antipsychotics.

Slide 17

This is not meant to be an exhaustive list of the environmental and behavioral interventions that could be helpful in people with ID and dementia. The presenter may want to pick one of these and provide more detail.

For example, promoting sleep hygiene is very important in people with dementia, both to prevent and address problems with the sleep-wake cycle. Sleep hygiene practices could include:

- Limit the amount of time in bed or resting during the daytime.
- Allow for up to an hour-long nap in the early afternoon (around 1-2 p.m.), but not later or longer.
- Schedule stimulating activities, especially outdoors or involving bright light, in the morning.
- Reduce stimulating activities (e.g., TV, computer) and stimulants (e.g., coffee, tea, tobacco) in the afternoon/evening. No alcohol before bed.
- Limit fluids before bedtime, and toilet right before bedtime.
- The bed should be a place for sleep. At night, limit the amount of time in bed, but not sleeping.
- Avoid adding medications for sleep. Melatonin is not very effective, and other medications may not be tolerable.

Slide 18

Donepezil, which is FDA-approved for the treatment of Alzheimer's disease, may help slow cognitive decline in people with Down syndrome – but can have many side effects; doses should be lower in people with Down syndrome than in people with AD. Memantine (also FDA-approved for AD) and vitamin E have not been found to be helpful in ID dementia.

Slide 19

The presentation now turns to when medications may be indicated in the treatment of BPSD.

Slide 20

Almost all of these data come from studies of people with dementia due to AD rather than ID dementia. In general, medications are not very effective, and can have many side effects. This is

probably even the case in people with ID. All of these medications are off-label, meaning that the FDA has not approved their use for BPSD.

Slide 21

All of these side effects have been found to be more common with antipsychotics than with placebo. There is a higher risk of death with antipsychotics than with placebo in people with dementia. Death could be due to aspiration pneumonia or due to a cardiac arrhythmia.

"Extrapyramidal symptoms" refer to muscle cramps (dystonia), restlessness (akathisia), and tremor & slow movements (parkinsonism).

Slide 22

The presenter should emphasize that, if an antipsychotic is prescribed, the goal should eventually be to stop the antipsychotic. This is because the on-going benefits of being on antipsychotic are probably low and because the increased risk of death persists.

Slide 23

Other medications have been used to treat BPSD in people who do not have ID, as listed under the first bullet point.

Acetaminophen can be a particularly helpful and well tolerated treatment for pain contributing to BPSD. Scheduling it 2-3 times daily is more effective than as needed (prn) dosing. There are other pain control medications (e.g., pregabalin) but they may not be tolerated by people with ID and dementia.

Finally, there are some data regarding lithium being helpful in people with Down syndrome and BPSD, but lithium may be difficult to tolerate. Lithium is excreted by the kidneys, and kidney function decreases with age. Lithium can cause tremor, thirst, and frequent urination. Lithium can interact with other medications, including NSAIDs (e.g., ibuprofen), diuretics (e.g., hydrochlorothiazide), and ACE-inhibitors (e.g., lisinopril).

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Chapter 6

Training Module 3:
How to Use and Implement the NTG-EDSD Tool

Slides and Talking Points
The slide set for Module 3 is available in a separate PowerPoint file:
NTG_TrainingSlideDeck_Module3.pptx

Slide 2
Review of objectives for this section:

- Increase overall knowledge of the NTG-EDSD tool
- Increase understanding of how to complete the tool
- Increase understanding of when the tool could be administered
- Increase awareness of other individuals to involve when administering the NTG-EDSD tool
- Discuss the challenges in diagnosing dementia with individuals living with an intellectual disability (ID)
- Review rational for using the NTG-EDSD tool
- Utilize the NTG EDSD tool to complete a screen

Slide 3
Items to consider throughout today's session in preparation for administering the NTG-EDSD tool include:

- Who would you need to consult with to compete the NTG-EDSD tool?
  Who is in this individual's support system? Who spends the most time with this individual currently? Who has known this individual the longest? Seek out the people that hold qualitative data, the personal picture of this individual. They will be a key asset in the completion of this tool, especially the baseline or initial administration.
- At what point should you take this tool to a physician?
  What benchmarks would signify the need to seek further medical support and evaluation? How much information should be collected beforehand?
- What is the best way for you to obtain this information?
  With or without the individual present? At a regularly scheduled planning meeting or scheduled as needed?
- Who could you involve and in what capacity?
  Is there a supporting team that can assist in gathering longer term information? An example of this could be a Behavior Specialist team.

Slide 4

NTG-EDSD – Background Information

The NTG-EDSD tool is an informant-based rating tool that was designed for adults with intellectual disabilities (ID). It gathers qualitative data in relation to very relevant aspects of an individual's life. Although it is recommended the tool be used on an annual or as needed basis for individuals with Down syndrome beginning at the age of 40, it can be completed at any point in time in adults with ID, particularly if there are cognitive changes. Our team suggests the completion of the tool when a person with ID transitions out of secondary school. This will be discussed more on slide 25.

Consider it as an administrative tool. A review of the relevant information. This information includes memory, sleep, level of functioning regarding daily living skills. It is establishing a baseline that is focused on that individual. A baseline that can be reviewed regularly and compared with previous versions to see relevant changes.

Slide 5

So why is this important? If it's not a clinical tool and it is not used to diagnose dementia, then why should time be spent on this tool?

There is an enormous need to gather and maintain relevant information. Often times there is information that is lost when a staff member working with someone moves onto a new role or starts employment with a new company. Times when an individual's guardian is no longer with us or has their own degenerative diagnosis and is losing details themselves. There are numerous circumstances in which very important and relevant information is just not accessible anymore. This tool is one way to counteract the potential of losing relevant information.

Increasing a team's collaborative efforts and ability to have access to relevant information is another point to this tool's importance. This tool can be used as a way to communicate those subtle changes that can happen over time. Those things that strike you one day as odd or off and you start wondering how long this particular behavior or instance has been occurring.

Additionally, keeping the areas of an individual's life that this tool measures front of mind will assist in appropriate, proactive measures to assure improving or maintaining that individual's quality of life. Catching something that is reversible or ruling out reversible illnesses and adapting to changes or the need for changes in all areas of that individual's life: social/emotional, environmental, behavioral.

Slide 6

Our organization provides a wide spectrum of life services that assists those living with a disability. These programs include (but are not limited to) employment services, residential services, community-based day services, and youth services.

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We had had already committed to a strategic roll-out of the National Task Group-Early Detection Screen for Dementia (NTG-EDSD or EDSD) tool; when the needs of a resident in one of our adult family homes (AFH) prompted us to start with them. Staff members working with this individual were noticing some intense changes for this resident. Notable changes in apathy, stubbornness, irritability, and a decrease in engaging in favorite things. There was no sign of physical distress and there were no immediately identifiable changes to this individual's usual routine.

Communication of these changes occurred between the staff and their supervisor. From there a team of individuals came together to gather as much information as possible to make proactive steps in identifying the potential cause and assisting the individual in the most appropriate manner. The team consisted of the AFH staff/supervisor, the Behavior Services team, the EDSD administrator, and the resident's medical providers.

Slide 7

The members of the team had specific roles to play in gathering the necessary data for the resident. Starting with the staff noticing and communicating the initial changes in behavior, the team moved through the following steps.

A behavior specialist created an ABC tracking form for the identified behaviors. The form recognized the antecedent (what happened before the behavior occurred), what was the behavior and finally the consequence (how did the behavior end/identification of the staff response). Staff members working with the resident completed this form for a period of approximately 2 weeks. During this time the EDSD administrator met with the resident and the residential coordinator to complete the initial EDSD assessment.

While the staff was finishing the initial period of data collection, the EDSD administrator gathered relevant information about areas of concern identified on the EDSD as well as information about the resident's diagnosis.

Once all information was collected, the information was compiled and sent to the resident's medical provider for review. An appointment was conducted with the resident and the residential coordinator to review relevant information and review current medication lists. The EDSD administrator also sent relevant information to the staff members working with the resident to keep the team informed and share relevant information to successfully work with the resident.

The entire process allowed for the medical provider to quickly respond to the resident's needs. The first step was identifying if the resident was experiencing an illness or other cause (e.g., medication) that would present with changes like the ones observed and documented. This process evolved and follow-up was conducted by all members of the team. Eventually, the information and clinical assessments done by the resident's medical provider confirmed that this individual was experiencing non-reversible dementia.

The EDSD tool had a significant impact in capturing the information that the medical provider needed to start the diagnosis process. The medical provider gave feedback on the tool stating, 'I love this, this is amazing! This is the information I needed'.

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Slide 8

(***Information in this slides pertains to Wisconsin-specific organizations. Users should modify the information for their own purposes***)

Our organization will continue to move forward with the use of this tool. Next steps include:

- Continued training of staff members working in all programs
  - Dementia 101
  - Diagnosis Specific
- Implementation of the NTG-EDSD tool throughout our Residential Programs
  - Process and procedure for regular use of the NTG-EDSD tool in:
    - La Crosse & Janesville
      - Adult Family Homes
      - Community Supported Living Program
  - Evaluation of process and procedure
  - Identification of next program for implementation using, Plan, Do, Check, Act (PDCA) method

Slide 9

Moving into reviewing the NTG-EDSD tool, let's cover some helpful information and review some limitations. The following information can be found on Page 15, *appendix B* of the NTG-EDSD manual:

- Resources to have/use:
  - Individual's medical records, including lab tests
    - This information can assist in building the entire picture, especially if this is the initial implementation of the NTG-EDSD tool
    - Information regarding the living environment
    - Lives alone, lives with roommates, lives in an AFH, etc.
      - Environmental factors are important and understanding the individual's current living situation is not only important for immediate purposes but will continue to be important when considering future planning.
      - Information on personal functioning
      - If there is access to a functional screen or other relevant assessments regarding functioning, it is advised to review them.
      - If this is the initial assessment but it is being conducted after there have been noticed changes, you have already missed the baseline.
      - Information from others
      - Family and staff

- The manual recommends that someone who has known the individual for at least 6 months should complete the NTG-EDSD tool. The longer the relationship with the individual the better; the depth of knowledge should be tapped into for the best picture.

- Limitations:
  - Remember, the NTG-EDSD tool is not a diagnostic instrument
  - This is an administrative tool that gathers qualitative data; more needs to be done.
  - There is no scoring system
  - This is difficult for some, but as the information is more qualitative a score isn't necessary. Also, the tool does a really good job of capturing the activities of daily living (ADL's) and other information even without a scoring system.
  - Qualitative vs. Quantitative
  - Quantitative information is important, hard data makes sense. Qualitative information is just as important and adds to other data being collected. Qualitative data can capture to softer, subtler side of the information that needs to be collected.

Slide 10

The NTG-EDSD manual is a pretty quick read and gives detailed information about how the tool was developed and how to use it. We recommend giving a copy of the NTG-EDSD manual to family members or other individuals (House Leads, etc.) to refer to before or after the administration of the tool. It's a nice resource to hand out.

Slide 11

Appendix A on pages 13 and 14 of the NTG-EDSD manual are very helpful and give you a quick reference guide to the entire tool. This is a really good resource and would recommend having it handy.

Slide 12

Page 1 of the NTG-EDSD tool corresponds with sections 1 through 9 of appendix A (page 13). You can see that each area on the tool has a small number next to it; this corresponds to the number in the appendix. Continuing on, you will see that 8 and 9 state 'Draw from any previously completed assessments, or estimate if none ever done'. This is where the resources to have/use from earlier can be helpful. Also, if this isn't the initial implementation of the tool, referring to the previous tool for some of the information can be helpful as well. Additionally, you can use the same tool more than once with a different colored pen for each meeting. It's a more immediate way to see any changes from one tool to the next.

Slide 13

Page 2 of the NTG-EDSD tool corresponds to sections 10 through 18 of appendix A. Be mindful that many parts of this page refer to a status 'compared to one year ago'. If this is the initial assessment you can mark it 'as of today'. Moving onto section 16 – diagnostic history; complete this section only if someone has been diagnosed. If you have diagnostic history that fits here, place it in. Make notes in the margins and add information, especially if this is the initial implementation. More information is better than not enough.

Slide 14

Page 3 of the NTG-EDSD tool corresponds to sections 19 through 22 of appendix A (begins on page 13 and ends on page 14). Now the tool is entering the qualitative information you are looking to gather. You will notice that the columns on the right of page 3 are 'always been the case', 'always but worse', new symptom in the past year', and 'does not apply'.

This is set up very intentionally and allows the gathering of cognitive related information and other meaningful information about an individual's life without subjecting them to a standard test that isn't designed for them.

Appendix A does a great job describing the four different areas on the table. The explanations are as follows:

- Always been the case
    - the need, problem or behavior has been present for a very long time
- Always but worse
    - the existing need, problem or behavior has further declined requiring more personal assistance
- New symptom in the past year
    - this need, problem or behavior was not present until recently
- Does not apply
    - these needs, problems or behaviors are not present

Slide 15

Page 4 of the NTG-EDSD tool corresponds to sections 23 through 26 of appendix A. These sections move away from ADL's and into memory and behavior. The sections in the reporting table are the same. When you reach section 25, 'adult's self-reported problems', it specifies 'the adult has expressed one or more of these things'; if the participant is non-verbal or not a self-reporter it is ok to mark 'does not apply' for the section. If this is the initial implementation of the tool you can add a note for clarification if needed.

Section 26 – notable significant changes observed by others. It is assumed that the behaviors in this section are new behaviors. Leave the 'always been the case' section alone for this one; that is why it is a darker grey.

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Slide 16

Page 5 of the NTG-EDSD tool corresponds to section 27 of appendix A. This section is meant to capture chronic health conditions. Choose the most appropriate response at the top. You will notice that the columns for the table have changed slightly to 'recent condition (past year)', 'condition diagnosed in last 5 years', 'lifelong condition', and 'condition not present'. This is where previously completed medical evaluations or current health notes can be good resources.

As mentioned previously, make notes on this page as needed. If there was a condition diagnosed ten years ago instead of five, mark "lifelong" and leave a note with the year of diagnosis. Capturing information about chronic co-occurring medical conditions is essential. It will be critical information in the event there is indication a work-up is merited; such details will be needed to complete a differential diagnostic evaluation. In addition, knowledge of chronic-co-occurring medical conditions will definitely influence current and future treatment planning.

Slide 17

Page 6 of the NTG-EDSD tool corresponds to sections 28 through 32 of appendix A. This is a great spot to make any extra notes like "these are our concerns" or "this is what we've seen." This is also a place to reference other supporting materials like behavioral data or additional tracking. Anything that will help to make this a well-rounded picture of this individual. Section 30 is next steps/recommendations. This is where you make a choice regarding the information you have available to you. If you have seen changes in two or more major areas, from light grey to dark grey in the table, for this individual it is recommended that you refer to a physician. That could mean setting up an appointment or adding this information to that individual's next scheduled appointment.

Slide 19 *(*Information in this slide is specific to Wisconsin where the trainings originally took place. Users should modify the information for their own purposes).*

Wisconsin Alzheimer's Institute's Affiliated Dementia Diagnostic Clinic Network

There are highly specialized clinics that complete interdisciplinary diagnostic evaluations for individuals experiencing cognitive changes. The comprehensive evaluations help to determine if the cognitive changes are the result of mental health concerns, a medical condition, normal age-associated cognitive changes, mild cognitive impairment, and/or a dementia condition. In the mid-west, there is a network of these specialty clinics; it is called the Wisconsin Alzheimer's Institute's (WAI) Dementia Diagnostic Clinic Network. Even though these specialty clinics have experienced experts on their teams, they often struggle to do the differential diagnostic evaluation for those living with an intellectual disability (ID). Within the WAI Clinic Network, only seven of the forty affiliates indicate experience working with individuals living with an intellectual disability. How is it that even expert teams struggle to diagnose dementia within those living with an ID?

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Slide 20

To answer the question, "How is it that even expert teams struggle to diagnose dementia within those living with an ID?" you have to understand the criteria that needs to be met to diagnose dementia, and how it is determined that an individual's cognitive changes meets that criteria.

The National Institute of Aging (NIA) and the Alzheimer's Association's diagnostic criteria for dementia are:

Cognitive/behavioral symptoms that:

- Interfere with usual functional ability
- Represent a decline from previous function
- Are not explained by ***delirium*** or a ***psychiatric disorder***
- Are detected through a combination of history and objective cognitive assessment
- Affect at least 2 cognitive domains
    - Memory
    - Reasoning/judgment
    - Visuospatial skills
    - Language
    - Personality/behavior

(McKhann et al. *Alzheimer's & Dementia* 2011;7:263-269)

In a nutshell, if an individual's cognitive changes resulted in measurable functional and cognitive declines from a previous higher level; and those declines are not the result of a medical or psychiatric reason, then dementia can become a working diagnosis. Based upon the diagnostic criteria, a medical workup (i.e. labs, physical) is always the first step in the evaluation process.

The "measurable cognitive declines" criterion is one of the primary challenges in diagnosing dementia for those living with an ID.

Slide 21

When we look at medicine in general, all conditions and diseases are based upon the individual's symptoms meeting pre-determined, standardized criteria. Such criteria is based upon norms. Norms are typically established through large research studies that have been repeated to make sure the results are valid. A set of norms familiar to most of us are the ones associated with cholesterol. The chart outlines the different types of cholesterol levels (i.e. overall, LDL, HDL); the acceptable to non-acceptable ranges (i.e. desirable, borderline, high risk); population specific differences (i.e. men versus women, age); and screening recommendations. To determine what your status is regarding cholesterol, you have blood drawn; the laboratory then tests your blood; and your results are compared to the cholesterol norms. If your blood levels fall in the high risk range, your primary care provider would discuss with you the diagnosis and possible treatment options. Other physical health norms you may be familiar with include: blood pressure, weight, blood composition…

Medicine also has norms for cognitive health. This is where the challenges become evident in diagnosing dementia for those that are living with an ID.

Slide 22

Testing a person's performance in the different cognitive domains is an essential part of a dementia diagnostic evaluation. The testing helps to determine whether or not the person has had a noticeable, measurable decline in their cognitive abilities. In addition, it provides insights into the extent and characteristics of deficits; which helps to differentiate what disease(s) or condition(s) is the underlying cause(s) of the changes (for example, Alzheimer's disease versus frontotemporal dementia). As with physical medicine, there are standardized cognitive tests that have established norms; the norms take into consideration aspects such as the person's age, education (e.g., as determined by reading level), and vocational background. For example, a person that grew up on a farm in the early 1940s and did not attend school, would not be expected to score the same as a physician that is currently in their 50's and has extensive specialized training. So, the norms serve as a baseline, where we would expect an individual of a specific age, with certain educational and vocational experience to perform. If the person's performance on the cognitive tests falls measurably below their norm, it is an indication that they have had measurable cognitive decline; one of the 3 criteria to diagnose dementia.

There are three widely used global cognitive screens that are typically a part of a cognitive battery that is used during a cognitive evaluation. They include the Mini-Mental Status Exam (MMSE), the Montreal Cognitive Assessment (MoCA), and the Saint Louis University Mental Status Exam (SLUMS). Part of the SLUMS is on the slide. Look at the questions and think about one or more of the individuals you work with that are living with ID. How many of them could answer the questions, "You have $100 go to the store, buy a dozen apples for $3 and a tricycle for $20, how much did you spend? How much do you have left?" Here is where the rubber meets the road; most individuals living with ID are not able to do the tasks in the standard battery of cognitive tests that are used in a typical dementia diagnostic evaluation. Hence, it is hard to determine if they have had a decline, if you can't test them by using standardized tools that have established norms. This makes it challenging to demonstrate the person living with ID has had a measurable cognitive decline, one of the 3 criteria to diagnose dementia. This is where the National Task Group's Early Detection Screen for Dementia (NTG-EDSD) comes into the picture.

Slide 23

Another challenge in diagnosing dementia in those living with ID, is establishing they have met the criteria; there has been a "measurable decline in function". Many individuals living with ID are not completely independent in all areas of activities of daily living (ADLs) and instrumental activities of daily living (IADLs). For example, how many of the individuals do you work with that are living with ID drive a car? Or independently manage a check book and pay bills? Or independently cook complete meals? What I am getting at, it can be difficult to demonstrate a decline in ADLs or IADLs if the person's initial skills set is already limited; there is less room for a decline to be noticed. It is easier to pick up on a change when someone starts getting lost driving, or is forgetting to pay bills, or is no longer able to make a complete meal. This is where the NTG-EDSD comes into the picture.

Slide 24

The NTG-EDSD is a key to overcoming the challenges of demonstrating the individual has experienced cognitive, behavioral, and/or functional changes from a previous higher level; criteria needed to diagnose dementia. The NTG-EDSD helps establish the person living with ID's baseline, or norms. It is a systematic way of documenting an individual's skills and abilities, and if there have been any changes.

Two other keys in overcoming diagnostic challenges include maintaining complete, whole person records, and the use of technology to document an individual's abilities and skills. Technology can help capture qualitative information. For example, video recording an individual making a peanut butter and jelly sandwich when they are not experiencing any health, behavioral, or cognitive issues would serve as a good baseline. As time goes on, if there are hints of changes with that individual, you could revisit the video to see if there are noticeable changes. You may find out that it now takes the individual 30 minutes to make the peanut butter and jelly sandwich versus 10 minutes when you initially video recorded them. Or that they no longer know how to put the two pieces of bread together to complete the sandwich.

Slide 25

As previously discussed, the National Task Group on Intellectual Disabilities and Dementia Practices has recommendations as to when to utilize the NTG-EDSD. I would like to add the suggestion of completing the tool when an individual living with ID transitions from secondary school to post-school options. This suggestion is the result of two observations; 1) individuals living with ID tend to have higher rates of seizure disorders, so they may have a higher risk for falls and a head injury; you would want a baseline NTG-EDSD prior to a head injury; and 2) the professionals working with the individual in secondary schools are well equipped to get capture the individual's skills and abilities; they know them well and have the training to document the skills and abilities. In addition, often when an individual living with ID leaves the highly structured school environment and goes into an adult environment, you can see some changes in their skills, abilities and behavior; so you would not be truly capturing the individuals' baseline or norms if done later. You would complete the baseline NTG-EDSD prior to the transition from secondary school; then put it away until the individual reaches the timeframe recommended by NTG; or they have an increase in skills and abilities; or if there is a change of condition with the individual.

Slide 26

The NTG-EDSD tool and the manual comes in multiple languages.

Slide 27

This slide was created to remind all of us the importance of doing a thorough evaluation, and not to jump to the conclusion that any change an individual displays means they have Alzheimer's disease. The change may be due to a treatable cause, for example, a urinary tract infection. When a possible change is noted, it is critical that the first step is a medical evaluation; not jumping to a conclusion of Alzheimer's disease.

Slide 28
Now it is time to utilize the NTG-EDSD tool. How many of you have used the tool before? Any words of wisdom or suggestions? Keep in mind, the person filling out the tool should know the individual living with ID fairly well, the manual recommends at least a 6-month relationship. Also note that multiple people can contribute to the completion of the tool. When completing the tool, think about possible contributors, such as family members, adult day center staff. Maybe you determine that there are two documents done simultaneously, one done by formal support staff (e.g., case manager, group home staff) and one done by family and other informal support system members. The goal is to capture as much relevant, quality information as possible in that snapshot of time.

To get started, you will need the NTG-EDSD tool and the NTG-EDSD instructions; you will find the instruction in the NTG-EDSD Manual. The first eight pages in the NTG-EDSD Manual provides a nice summary of the tool's background, the need for the tool, and the development process. The manual then goes over helpful parameters, including when to complete, who should complete the tool, and important red flags to look for. After the acknowledgements you will find the instruction in Appendix A: Instructions for the completion of the NTG-EDSD.

We will now go through the NTG-EDSD page by page so you can complete it with the case you brought with you. You will be provided with enough time to complete the respective page, feel free to ask questions as they come up. Prior to moving on to the next page as a group, we will ask if there are any additional questions. I have sample cases if you didn't bring a case with you.

Slide 29
On page one of the NTG-EDSD tool you will find fields 1 to 9.

Slide 30
On page two of the NTG-EDSD tool you will find fields 10 to 18.

Slide 31
On page three of the NTG-EDSD tool you will find fields 19 to 22. These fields capture functional skills and there is now the capacity to detect any changes.

Slide 32
On page four of the NTG-EDSD tool you will find fields 23 to 26. These fields capture cognitive skills and behavioral details; plus there is the capacity to detect any changes.

Slide 33
On page five of the NTG-EDSD tool you will find field 27. This field captures extensive details regarding chronic health conditions, as well as the capacity to detect any changes. Remember, the first step to investigating any possible change, is a medical workup.

Slide 34
On the final page of the NTG-EDSD tool you will find fields, 28 to 32.

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Slide 35
This slide provides an opportunity for a group discussion. Often testimonials regarding the usefulness of the tool is shared; as well as, ideas and tips. This slide is important, it further motivates participants to actually try the NTG-EDSD in their practice; some would call it the "hook". Hence, make sure you leave enough time for this slide's group discussion.

Slide 36
Implementing a new tool like the NTG-EDSD takes planning and often means going through formal organizational channels and processes. This slide allows for a group discussion on possible strategies participants can use to help facilitate the trial and/or implementation of the NTG-EDSD tool in their organization.

Slide 37
Trying something new or making changes to work tasks takes effort and energy; remembering those that will benefit from this activity is often helpful to keep us focused and moving forward.

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Chapter 7

Curriculum Resources

NTG-EDSD Tool and Manuals: https://www.the-ntg.org/ntg-edsd

Case Example

EXAMPLE #1

Consider Edy's case as you go through the NTG-EDSD tool. For each section of the tool, consider the following questions:

1) Who will you consult with to complete this section of the NTG-EDSD tool?
2) What resources will you use to complete this section of the NTG-EDSD tool?
3) When is the best time to obtain the information for this section of the NTG-EDSD tool?
4) At what point will you discuss results of the NTG EDSD tool with a healthcare provider?

Background: Edy is a 53 year old with Down syndrome. She has experienced occasional petite mal seizures since childhood, which have not required treatment. She lived with her parents, brother, and sister while growing up. She was an active child, who enjoyed dancing, family activities, and traveling with her family. She went to school from age 5 to 17. As a young adult to the present, she lived with her parents and she held a part time job sewing mops within a vocational program. She gets great joy from her job and colleagues.

Edy's father passed away ten year ago. Her mother, who is now 80 years old, continues to be her primary caregiver. Her brother and sister moved out of state, but keep in close contact with Edy and their mother. Edy has been independent with activities of daily living, including bathing, dressing, toileting, and eating. However, she has always required assistance with instrumental activities of daily living, including transportation, finances, shopping, and cooking. She enjoys helping her mother with chores around the house, including folding laundry, meal prep, and gardening.

Scenario A: Over the last six months, Edy's mother has noticed that it is getting harder for Edy to get dressed in the morning. It is taking longer for her to get ready and her mother is assisting with tasks that she did not have to help with in the past, including buttoning Edy's shirts or tying her shoes. Her mother reports Edy will stare at an article of clothing in her hands for a few minutes before putting it on. Edy is also having issues with her balance. She has not had any falls, but has to "catch her balance" on a daily basis.

Scenario B: Six months have passed. Edy's mother had a fall resulting in a hip fracture, and she is not able to care for Edy. Edy is now living in a group home. Edy's mother has concerns about Edy's transition to the group home. Edy is not eating well or sleeping well. She continues to take part in the vocational program. Staff at the vocational program have told Edy's mother that Edy recently started becoming upset at work because she occasionally has difficulty finding the bathroom there.

Example of Letter to Primary Care Provider

A letter about the NTG-EDSD was created for participants to share with their clients' primary care providers. This letter was intended to help educate medical providers and facilitate communication about the use of the NTG-EDSD by ID professionals, and requests that PCPs incorporate the screening tool into the patient's medical records for future reference and assessment purposes. This letter was reviewed and approved by the developers of the NTG-EDSD including Matthew Janicki, MD, and Lucy Esralew, MD. The example letter is available in a separate Word document:

MD_Letter_Template.docx

MD Letter Template:

Dear practitioner,

Attached to this letter is a completed NTG-EDSD tool completed by (name)_____ from(agency) _____on your patient:

Name:_____

DOB:_____

The National Task Group- Early Detection Screen for Dementia (NTG-EDSD) tool 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… The NTG-EDSD was not designed to diagnose dementia, but to be a help in the early identification and screening process" (The NTG-EDSD Manual).

Individuals with intellectual and developmental disabilities (IDD) are at higher risk for developing dementia than those without IDD. Detecting cognitive decline can be challenging without thorough knowledge of the person's baseline cognitive and functional abilities. The NTG-EDSD tool is a powerful resource for providers because caregivers who know the patient best provide this information.

The NTG-EDSD tool establishes baseline abilities and helps to document a change that could indicate the onset of dementia. When dementia changes are suspected, comprehensive medical evaluation is recommended to rule out reversible causes that might mimic dementia.

The completed NTG-EDSD tool is attached to this letter. The agency will complete this tool every 6 to 12 months, or more frequently for a change in baseline abilities and alert you to any changes. The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) considers this instrument to be in the public domain. It is available for use by anyone who does not sell it or use it for unintended or inappropriate purposes.

We hope you will find this information valuable. Further information about the NTG-EDSD tool can be found at http://aadmd.org/ntg/screening.

Dementia Capable WI:
Creating New Partnerships in Dementia Care

NTG-EDSD Pre-Training Survey

We are asking you to provide this information to help us comply with federal reporting requirements. Completing this form is in agreement with registration requirements. We also need it to help us analyze and evaluate programs that facilitate care and support for people with dementia. This information will be stored in a secure electronic database. We will not share your information with another agency without your permission. We will not sell this information to anyone. Thank you!

Tell us about yourself and your organization…

1. What is your professional role? _____
2. How many years have you worked in this role? _____
3. How many years have you worked in the field of aging / dementia? _____
4. How many years have you worked in the field of intellectual and developmental disabilities? _____

5. Please indicate the most appropriate category for your organization: (**Check ✓ all that apply.**)
   - ❑ Adult family home
   - ❑ Managed care organization
   - ❑ Community-based organization focused on older adults
   - ❑ Community-based organization focused on people with intellectual and developmental disabilities
   - ❑ Other _____

6. Are you Hispanic, Latino, or Spanish origin?
   - ❑ Yes
   - ❑ No

7. What is your race? (**Check ✓ all that apply.**)
   - ❑ American Indian or Alaska Native
   - ❑ Asian or Asian-American
   - ❑ Black or African-American
   - ❑ Hawaiian Native or Pacific Islander
   - ❑ Hispanic
   - ❑ White or Caucasian

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- ❑ Other: _____

8. What is your gender? _____

9. Please circle the highest year of school you have completed:

1 2 3 4 5	6 7 8 9 10 11 12	13 14 15 16	17 18 19 20 21 22 23+
(primary)	(middle/high school)	(tech/college)	(graduate school)

10. Does your organization: (**Check ✓ all that apply.**)
    - ❑ Utilize the NTG-Early Detection Screen for Dementia (NTG-EDSD)?
      - If so, how confident are you with using the tool? Select one from the following: Not at all-0 A little bit-1 Quite a lot-2 Very much-3
    - ❑ Conduct a formal screen to detect cognitive changes in clients with ID?
      - If so, what screening tool is used? _____
    - ❑ Conduct an assessment of caregivers of people with cognitive impairment or dementia to determine their service needs?
    - ❑ Have a standard procedure for providing referrals to people with dementia?
    - ❑ Have a standard procedure for providing referrals to caregivers?
    - ❑ Have a list of dementia-capable providers and organizations to which people with dementia and their caregivers are referred?
    - ❑ Track referrals to determine if the person with dementia or their caregivers contact the organization they are referred to?

Thinking about your organization's current documentation procedures, how well do you feel you can <u>track the following health circumstances</u> in ID clients?	**Not at all**	**A little bit**	**Quite a lot**	**Very much**
1.) Intellectual disability	0	1	2	3
2.) Diagnosed intellectual conditions (ex. Autism, Down syndrome)	0	1	2	3
3.) Changes in physical health	0	1	2	3
4.) Changes in mental health	0	1	2	3
5.) Current health conditions (ex. Vision impairment, deafness, chronic health conditions)	0	1	2	3
6.) Current living arrangements	0	1	2	3
7.) Significant life events (ex. Death of someone close, change in living arrangements)	0	1	2	3
8.) Diagnostic history of mild cognitive impairment (MCI) or dementia	0	1	2	3
9.) Current medications	0	1	2	3

Thinking about your organization's current documentation procedures, how well do you feel you can <u>track functional decline</u> in the following characteristics in ID clients?	**Not at all**	**A little bit**	**Quite a lot**	**Very much**
10.) Activities of Daily Living (ex. Washing, dressing, eating, using the bathroom)	0	1	2	3

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Thinking about your organization's current documentation procedures, how well do you feel you can track functional decline in the following characteristics in ID clients?		**Not at all**	**A little bit**	**Quite a lot**	**Very much**
11.)	Language & Communication (ex. Conversation, reading, writing)	0	1	2	3
12.)	Sleep-Wake Change patterns (ex. Sleeping more or less, waking / wandering at night)	0	1	2	3
13.)	Ambulation (ex. Unsteady walk, falls, loses balance)	0	1	2	3
14.)	Memory (ex. Recognition of familiar persons, finding their way in familiar settings)	0	1	2	3
15.)	Behavior & Affect (ex. Withdrawal from social activities, repetitive behavior)	0	1	2	3
16.)	Patients' self-reported problems (ex. Changes in abilities to do things, thinking, and interests)	0	1	2	3
17.)	Significant changes observed by others (ex. Gait, personality, attentiveness, weight)	0	1	2	3

(For participants that used the NTG-EDSD tool before) Please provide your experience with using the tool:	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
1.) The questions allow an accurate representation of the person	0	1	2	3	4
2.) The response format allows an accurate representation of the person	0	1	2	3	4
3.) I have sufficient experience with persons with I/DD to complete questionnaire	0	1	2	3	4
4.) I have sufficient information about the person with I/DD to complete questionnaire	0	1	2	3	4
5.) I have sufficient medical knowledge to complete questionnaire	0	1	2	3	4
6.) The effort needed to complete questionnaire is adequate	0	1	2	3	4
7.) Questions violate privacy	0	1	2	3	4
8.) Questions are comprehensible	0	1	2	3	4
9.) Instruction for using the tool is comprehensible	0	1	2	3	4
10.) Instruction for using the tool is sufficient	0	1	2	3	4
11.) Questions are unambiguous	0	1	2	3	4
12.) Layout is suitable	0	1	2	3	4
13.) Tool is complicated	0	1	2	3	4
14.) Amount of time needed for completion is adequate	0	1	2	3	4

(For participants that used the NTG-EDSD tool before) Please provide your experience with using the tool:	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
15.) Amount of time needed for reading instruction is adequate	0	1	2	3	4
16.) Using the questionnaire for periodic reassessments would be realizable	0	1	2	3	4
17.) Aspects are missing	0	1	2	3	4
18.) There are unnecessary aspects	0	1	2	3	4
19.) The purpose of the questionnaire is clear	0	1	2	3	4
20.) The significance of the questions in relation to the purpose is clear	0	1	2	3	4
21.) Using the questionnaire for periodic reassessments would be meaningful	0	1	2	3	4

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One-Week Phone Survey:

Dementia Capable WI: Creating New Partnerships in Dementia Care

NTG-EDSD Week 1 Post Training Phone Survey

Hello, I am _____ calling on behalf of the Wisconsin Alzheimer's Institute. I am following up from the education session on dementia in persons with intellectual and developmental disabilities and the NTG-EDSD tool. I would like to discuss how implementing the NTG-EDSD tool into your practice is going. The information you provide will be confidential. We will not share your information with another agency without your permission. We will not sell this information to anyone.

The discussion will take no more than 10 minutes. Do you have time to talk now? If not, when would be a better time to talk this week?

_____

Since the NTG-EDSD training:
How many times have you used the NTG-EDSD tool with clients with intellectual disabilities?
_____ (If the participant has not used the NTG-EDSD tool, proceed to next page.)

If you do not work directly with clients, how many times have you assisted a team member with the NTG-EDSD tool? _____ (If the participant has not used the NTG-EDSD tool, proceed to next page.)

For participants who have used the NTG-EDSD tool:
Approximately how much time was needed to complete the tool? _____

What information sources did you use to complete the tool (client file, client, caregivers, etc.)?_____

Briefly describe your experience in using the tool, including advantages, barriers, ease of use:
_____
_____

How comfortable do you feel with using the tool?
_____

How do you plan to continue using the tool?
_____
_____

In your role, do you feel using the NTG-EDSD on a routine basis is useful?

If yes, how is it useful?_____

If no, what makes it not useful?_____

If no, what would make it useful?

_____

In your organization, do you feel using the NTG-EDSD on a routine basis is possible?

If yes, how is it possible?_____

If no, what makes it not possible?

_____

If no, what would make it possible?

_____

Go to All Participants section.

For participants that have not used to NTG-EDSD tool:
What has prevented you from using the NTG EDSD tool?

_____
_____
_____

How do you plan to use the tool in your role? _____

_____
_____
_____

What advantages and barriers do you anticipate in using the tool, including ease of use?

_____
_____
_____

How comfortable do you feel with using the tool?

_____

In your role, do you feel using the NTG-EDSD on a routine basis will be useful?
If yes, how will it be useful?

_____

If no, what makes it not useful?

_____

If no, what would make it useful?

_____

In your organization, do you feel using the NTG-EDSD on a routine basis will be possible?
If yes, how will it be possible?

_____

If no, what makes it not possible?

_____

If no, what would make it possible?

_____

For all participants:
Additional comments:

_____
_____
_____
_____

What questions do you have?

Thank you for your time! We will follow up on your progress in a month when the next evaluation survey will be sent to you. If you have questions about use of the tool in the meantime, please contact:

Name: _____

Phone: _____ or Email:_____

Date:_____Time:_____

Frequently Asked Questions (FAQ) from Trainings

Over the course of our NTG training sessions, participants asked a number of questions that helped clarify or expand upon points made during the presentation. Here we present some of these questions, with proposed responses. Users should be prepared to answer the following questions or similar ones that may arise.

Questions about specific symptoms

Q: What is the relationship between dementia and symptoms of Parkinson disease?
A: Parkinsonism refers to having one or more of the following signs or symptoms: tremor (shaking), slowness of movements, stooped postures, shuffling steps, problems with maintaining blood pressure (autonomic instability). Parkinson disease results from loss of brain cells in certain regions. People with Parkinson disease exhibit parkinsonism and can eventually develop dementia.
There are other possible causes of Parkinsonism, including cerebrovascular disease (stroke), medications (e.g., antipsychotics), and dementia with Lewy bodies (which also includes psychiatric symptoms such as visual hallucinations).

Medical and/or Dementia Specific Questions

Q: Are there certain conditions or characteristics of people that are more associated with dementia and can explain for the variance of prevalence in different people?
A: A biopyschosocial perspective is taken when examining changes in the brain and how symptoms manifest differently from person to person. In a case with someone with Alzheimer's disease, there are characteristic changes in the brain can be going on 15-20 year prior to symptoms being manifested. This is due to what is called "cognitive reserve." This means that brains are resilient and can compensate for long periods of time, even if there are changes occurring. Eventually however, there is a threshold where compensation is no longer able to occur and symptoms begin to appear. For a healthy individual, they may have a higher threshold point than someone who already has cognitive changes going on. Someone who is

hospitalized for a surgery or has some type of brain injury will be more vulnerable to showing signs biologically. Psychosocially, it's the same thing. These changes might have been going on all along, yet in a different environment, they might show those changes earlier on. But in a routine environment, things are familiar, there is nothing to adapt to and they are okay. This relates to something called the Yerkes-Dodson Law: too much or too little arousal leads to behavioral inefficiency.

Q: Does someone have to have Parkinsonism in order to be diagnosed with Parkinson disease?
A: Parkinsonism needs to be present to have a diagnosis of Parkinson disease, but Parkinsonism that can result in tremors, shuffling, stooped posture, slowness of movement, osteo-instability and so forth, can also be due to other causes such as vascular diseases and medication side effects.

Q: What are the stages of Alzheimer's disease?
A: Nancy Jokinen and her colleagues use a 3-part staging model to describe the changes that occur with Alzheimer's disease. The staging model helps individuals better understand where someone is at in the disease progression and what symptoms to anticipate later on. These stages are listed as early, middle, and late stages; however, there is also a pre-dementia stage known as mild cognitive impairment (MCI). In this stage, individuals may experience changes in memory and thinking that are more than expected for their age, however they are overall still very independent and functional. In the MCI stage, the individual may need more time to respond to a question or finish tasks, things may take more effort, they may rely more on external memory organizational behaviors, but they generally can still "get by"; they will remain independent with activities of daily living and instrumental activities of daily living. People with MCI are at higher risk for developing dementia over time; about 38% would develop dementia within 5 years. For the others, it could take longer to develop dementia or they revert back to normal cognition. It has been found that this also applies to people with an intellectual disability.

In the publication, "Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia" by Jokinen et al, they report in the preclinical stage there is a 33% conversion rate to dementia in 18 months. The benefit of this paper is that they not only talk about the stages of dementia, but they talk about appropriate interventions and supports that are necessary at each one of the stages.

Q: What can you do to help with sleep disturbances?
A: Sleep disturbances are a common issue in the medical and mental health practice. The general reaction is for people to want medications to help with sleep, but in general they do not work well and can have side effects. Best practice is to take a non-pharmacological approach to better sleep including good sleep hygiene, staying awake and active during the day, routinely getting daily exercise, and limiting caffeine consumption later in the day.

Q: What time in the evening should you start sleep hygiene routines?
A: Developing good sleep hygiene practices largely depends on the individual and their personal sleep patterns. Some individuals are naturally early risers, while others are night owls and prefer to sleep in. Understanding a person's baseline sleep pattern is important when considering rescheduling a bedtime routine. In general, it is advised that activities should start winding down at least an hour before bedtime; this includes turning off the tv, putting cell phones and electronic devices away, turning down lights, and completing nighttime hygiene tasks.

If melatonin is used to help promote sleep, this should also be given 2-3 hours before bedtime. The reason for that is because melatonin is actually not a sedative. It promotes a normal sedation rhythm which is the natural release of melatonin about 2-3 hours before it's time to go to sleep; that would be the optimal time to give melatonin supplements. When trying to reschedule a bedtime for someone with dementia, a lot of it is trial and error. One plan could work for a period of time, then several months later it could disintegrate due to the progressive nature of dementia. It requires constant reassessing and readjustment of plans.

Q: What about people who were diagnosed with dementia, then undiagnosed with dementia? Is there anything you would advise when working with this tool with someone who has been undiagnosed?

A: Some of the conditions that cause dementia or dementia-like symptoms are reversible or treatable. That is one of the primary reasons why you do the NTG-EDSD and the differential diagnostic evaluation for dementia. If the condition causing the cognitive declines can be treated, you would want to treat it. Such conditions include metabolic problems and endocrine abnormalities (i.e. thyroid problems), nutritional deficiencies (i.e. vitamin B-12), clinical depression, medication side effects, and normal-pressure hydrocephalus. Doing the NTG-EDSD helps the healthcare provider complete the evaluation, so an accurate diagnoses and treatment plan can be achieved. If the treatment results in the reversal of the dementia symptoms, you have achieved a desirable outcome. You would record that, and continue to utilize the NTG-EDSD as usual.

Q: Who is qualified to give the diagnosis? PCP? Psychologist? Neurologist?

A: Physicians, which includes primary care doctors, neurologists, geriatricians, and psychiatrists that have training in dementia, have the professional credentials to diagnose. The same goes for a neuropsychologist and psychologist that have training in dementia.

Risk Factor Questions

Q: What are the risk factors for other types of dementia, such as Vascular dementia, Lewy Body, and so on?

A: There are some risk factors that generalize to all types of dementia, while other factors have been shown to increase the likelihood of developing a specific type of dementia. Age, by far is the leading risk factor for several types of dementia. As age increases, the risk of developing dementia also increases. Other risk factors that transcend across all dementias include family history, genetic risk factors (APOE-e4), traumatic brain injury, mental health issues, and modifiable risk factors such as cardiovascular disease, smoking, obesity, heavy alcohol consumption, and sleep issues (see slide 18 for more information).

- Vascular dementia risk factors include heart disease, smoking, and history of strokes.
- Lewy body dementia risk factors include age (people over 60), sex (men are more at risk than women), and Parkinson disease.
- Frontal Temporal dementia risk factors include age (people under 60), brain injury, and family history.

Q: Has there been a study showing what environmental conditions, such as exposure to aluminum, can accelerate dementia?
A: Environmental conditions and their correlation to dementia has long been a source of controversy. Currently there is not empirical evidence to support that environmental elements or conditions are directly linked to Alzheimer's disease. More studies are needed to determine if significant exposure to environmental factors can impact memory and thinking.

Q: What does the research suggest is the link between alcohol and risk of dementia?
A: Alcohol is a direct neurotoxin that kills brain cells. Up until age 25, more brain cells are being produced than dying off; after age 25 it is vise versa. There are certain parts of the brain that are more susceptible to damage and cell death from alcohol than others. The severity of dementia that goes along with alcohol use depends on the extent of alcohol abuse. A type of dementia syndrome is called Wernicke Korsakoff syndrome. The "Wernicke's" part is the acute part; a person can very suddenly get very confused and agitated, which causes problems with memory. "Korsakoff" is the more permanent memory loss part of the syndrome. Even if someone stops drinking, they could still exhibit the Korsakoff part of the syndrome. This usually occurs with fairly heavy alcohol abuse, however it primarily depends on the person. Gender differences, genetic differences, and how much alcohol a person can tolerate are also contributing factors into whether or not someone develops cognitive impairments due to alcohol. For some people it may take years of alcohol abuse to cause problems, while younger people in their 30s and 40s can also have severe cognitive impairments. The general rule is that the more alcohol per day or the more binges, the increased risk of dementia and severity level of dementia. Cognitive impairments caused by alcohol use is irreversible; even when drinking

stops and the decline that goes along with the alcohol use, loss of brain cells cannot be retrieved.

Q: What is the role of thiamine in people with alcohol use disorders and their cognitive function?

A: Thiamine is a vitamin that is necessary for all kinds of neurologic functions. When someone consumes heavy amounts of alcohol, they are getting many of their calories from alcohol and may not be eating healthy, well-balanced diets. Once carbohydrates are ingested by food or alcohol, they get to the brain where thiamine is needed to process those carbohydrates. Without this function, it can reach a toxic level and reaction in the brain that destroys part of the brain. There are two bodies called mammillary bodies that are part of our memory systems. If there is not enough thiamine (due to alcohol or other causes), and carbohydrates are consumed, it can start destroying parts of the brain that are needed for memory. Stopping alcohol use is the best way to address this loss, or supplementing with thiamine.

Medications and Treatment Questions

(*Disclaimer: Trainers should address questions about medication and medical treatments if they are medical professionals. Otherwise, these questions should be referred to medical professionals.)

Q: Is there a difference between antihistamines that are non-drowsy vs. drowsy?

A: Yes, there are differences, however there are still some safety concerns with non-drowsy antihistamines. Brands such as Clariton, Allegra, Zertec, etc. tend not to cross the blood-brain barrier. There are antihistamines that affect our peripheral rather than our brain, but there can still be leakage into the brain. In general, non-drowsy antihistamines are safer, but nothing is guaranteed. It is important to still observe for side effects and weigh the costs and benefits. If the person seems confused or disoriented, it is best to stop the medication. If seasonal allergies are an issue and left untreated, this can also cause problem for the person with dementia. Having a backup plan for addressing the allergies is recommended.

Q: Can medications help with dementia?

A: There are two Food and Drug Administration (FDA)-approved medications for treating memory loss — cholinesterase inhibitors (ie, Aricet, Razadyne, and Exceleon) and memantine (ie, Namenda). Unfortunately, it has been 15 years since the last Alzheimer's drug was approved. Cholinesterase inhibitors can help treat symptoms related to memory, thinking, language, and judgment, while memantine can also help with memory, learning, attention, reason, and ability to complete simple tasks. Aricept is often used in all stages of the disease, while the other two drugs are more commonly used for mild-moderate stages. Memantine has been found to work effectively in conjunction with donepezil in moderate-severe stages of dementia. As with any drug, there are risks that come with the benefits. For the memantine, these side effects can include headache, constipation, confusion, and dizziness. The risks of the cholinesterase inhibitors can include diarrhea, nausea/vomiting, and a slower heart rate.

Overall, these medications have shown evidence to delay or slow worsening of symptoms, primarily in the earlier stages. However, they do not halt the progression of dementia and therefore lose effectiveness over time. The degree of this loss varies individually.

Q: Can CBD oil be used as a treatment for dementia?

A: To date, there is no evidence-based research to support the use of CBD oil for the treatment or management of symptoms in dementia. Although CBD oil is often touted as a miracle treatment for many ailments and can be purchased over the counter, it is important that note that it is not FDA approved or regulated for use in people with dementia. The long-term side effects of CBD oil and interactions with other medications remains unknown; more studies are needed to understand the benefits and risks of its use.

Mental Illness Questions

Q: What if someone has a mental health diagnosis?

A: You would treat the mental health diagnosis like any other diagnosis. You would list in the correction section; in this case it would be in the section *Chronic Health Conditions*, *Mental health*. There is an "other" option in the section if you don't see their diagnosis. You would then

also record any significant symptoms or details relevant to the diagnosis and the status of those symptoms. For example, if the person has been diagnosed with schizophrenia, and they have a history of visual and auditory hallucinations that are currently effectively being treated by medications, you would write that on the tool. That is one of the great features of the tool; you have the freedom to write relevant details on it. If in the future the individual began experience hallucinations, it would be a red flag meriting an investigation.

NTG-EDSD Specific Questions

Q: What is the best way to complete page 1 where it states, "If MCI or dementia is documented, complete 16, 17 & 18."

A: Complete this section as often as possible, especially if the individual in questions has medical records that only state an intellectual disability. It is advised to write in any diagnosis that can be obtained from medical records or person-centered planning documents (eg, functional screens, care coordinator reports, etc). Additionally, if the individual being screened has Down syndrome but has not be been diagnosed with MCI or dementia, mark "no" and use box #18 to describe why the screen is being administered. Examples of this can include, baseline screen, completed upon request (indicate who requested the screen), and the criteria for the request.

Q: What does it mean by wandering versus elopement?

A: There should be a predetermined understanding of the criteria for verbiage that could be left open to a measure of interpretation. The agency or facilitators of this screen should have these behaviors explained somewhere. When we say "wander" we mean X. It is important to clearly define terms like wandering so that the possibility of over reporting can be avoided.

Q: In section 30 of the NTG-EDSD screen, it says, "Next Steps/Recommendations." How often should the screen be repeated?

A: Implementing this screen as part of general intake to acquire a baseline regardless of age is a good practice. The baseline will be important in adequate information gathering.

Additionally, when to repeat the screen will depend on the individual's current state. A 24-year-old may not need the screen re-administered until the identified age in the manual or later depending on their specific diagnosis. Once it is determined that the screen should be routinely done, it could be easily incorporated into annual or bi-annual person-centered planning meetings.

Additionally, it could be administered more frequently if there are significant changes in which measures are being taken to care for that individual. A written standard operating procedure for your agency following the guidelines in the manual would be a good place to start. Once a baseline rating is completed, it is recommended that individuals are reviewed annually unless over the recommended ages in the manual and then more frequently if the team observes changes. Once the individual is diagnosed with a neurocognitive disorder, there is no need to continue using this tool.

Q: What if the individual has no cognitive ability to communicate in any way?
A: This is where NTG-EDSD demonstrates why it is so important to do. The tool can capture functional, cognitive, behavioral, mental health, and medical changes that will help provide critical insights for the healthcare provider. When paired with the medical and other diagnostic work-up (i.e. a neuropsychological evaluation), the healthcare provider will be able to develop a working diagnose and treatment plan.

Q: My client does not have any family involved; how do I gather information on their social history?
A: Gathering a thorough background on someone without family members involved can be challenging, but is not impossible. One recommended area to start is by reaching out the person's school system to see if there are records that can be obtained which may contain social history data and other baseline information. Educators and school support staff should have good documentation on the individual's skills and abilities prior to entering a post-school environment. Otherwise, it is best to start with the next person that has known that individual the longest (eg, neighbor, formal caregiver, adult day center staff, case manager) and whoever

spends the most time with the individual. Collaborate with others involved in the person's life; having different perspectives provides the qualitative information on that individual and can put the "pieces of the puzzle" together to create the whole personal picture and what the current baseline is. This will be vital information to have moving forward as you continue using the NTG-EDSD to track any functional and behavioral changes.

Q: How do I talk to medical providers about the NTG tool and advocate for my client if I am seeing changes that I think could be dementia?
A: Utilizing the NTG-EDSD is one of the best ways to advocate for your clients since you can accurately document and track changes over time about an individual's functional abilities. It is advised you provide the EDSD tool to the medical provider, along with a letter such as the one we developed about the NTG-EDSD training and information about the screening tool. Having a letter accompany the EDSD can help educate the healthcare provider on the importance of using the screening tool for possible dementia, and it can be kept in the patient's record for future reference. Discuss with the provider what changes have been observed and documented, and express areas of concern about deviations from that individual's normal baseline. When possible, include other people as well that noticed these changes and have the same concerns. Request the provider conduct a thorough medical and cognitive workup to rule out other causes of the changes observed. If the provider is unsure of how to evaluate the person with ID, refer them to the "Assessment and Diagnosis of Dementia in Individuals with ID: A Toolkit for Clinicians and Caseworkers" as mentioned in section three.

Q: How often should I use the NTG tool?
A: Having a good understanding of an individual's baseline functioning is helpful when comparing to any changes that may occur later on their life. It is suggested that the tool be used by age 40 for people with Down syndrome or other intellectual/developmental disabilities. However, there is benefit to screening individuals with I/DD prior to age 40, specifically between the ages of 18 and 40 when cognitive and functional changes can still occur. For organizations providing annual wellness visits or annual functional screens, it is beneficial to

conduct the NTG-EDSD tool simultaneously as information gathered during these visits can help answer questions of the EDSD tool.

Q: In what languages are the NTG-EDSD and manual available?

A: Both the NTG-EDSD and the manual are available in 11 languages including English, Dutch, Italian, Greek, German, French, Spanish (North American and European), Japanese, Scottish, and Finnish. These can all be found on the NTG-EDSD website: https://www.the-ntg.org/ntg-edsd

Other

Advance directives, advance care planning, and end of life care

https://www.aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life

https://aspe.hhs.gov/basic-report/advance-directives-and-advance-care-planning-people-intellectual-and-physical-disabilities

https://www.nia.nih.gov/health/getting-your-affairs-order

Wisconsin Alzheimer's Institute

The Wisconsin Alzheimer's Institute (WAI), an academic center of the School of Medicine and Public Health at the University of Wisconsin-Madison, was founded in 1998 by a coalition of service providers, community-based organizations, educational institutions, and advocates organized by the Wisconsin Bureau on Aging and Long-Term Care Resources and Bader Philanthropies. WAI is committed to helping people living with Alzheimer's disease or other dementia, their caregivers, and the health professionals working to support them. In 2008, the WAI Regional Milwaukee Office was established in Milwaukee, Wisconsin, with the goals of empowering the local community, improving access to quality care, and increasing African American research participation by building culturally tailored programs.

The hallmarks of the Public Health Pillar of WAI are community outreach and the development of culturally tailored, innovative programs to improve the quality of care for people with Alzheimer's disease and other causes of dementias. It is through generous grants

from agencies such as the U.S. Administration for Community Living (ACL) that we are able to create and share this guide.

WAI's mission is to promote the health equity and improve the quality of life of people living with Alzheimer's disease and other dementias and their families through research and community engagement. WAI is committed to helping in improving the lives of people with Alzheimer's disease and dementia, their caregivers, and other professionals who support them. Its purpose is to increase dementia awareness, provide education on Alzheimer's disease and related disorders, identify and disseminate strategies to reduce dementia risk, convene stakeholders across the state, improve access to quality dementia care services, and to develop and support culturally tailored, effective clinical and community-based models of care.

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