MEMORY SCREENING IN THE COMMUNITY

How to Administer Community-Based Memory Screens





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Using the Manual

This manual is intended for use by community-based agencies granted permission by the Wisconsin Department of Health Services (DHS) to provide memory screening to the general public. The primary audiences are community-based entities including aging and disability resource centers, aging units, Medicaid managed care organizations and independent living centers. This manual is required by Wisconsin's Dementia Care Specialist Program as the reference and training guide for providing the Community-Based Memory Screening Program. Dementia care specialists will use this manual to train additional staff to provide the program.

Other community-based entities may also provide memory screening under this program if granted permission. This manual provides information to assist community-based agencies in serving individuals who speak Spanish or Hmong, have a vision or hearing impairment, have developmental disabilities, or are tribal members and other communities of color.

Entities interested in providing memory screens under this program should contact the Bureau of Aging and Disability Resources at 608-266-2536 or <u>dhsdementiawebmail@dhs.wisconsin.gov</u>.

All entities are prohibited from charging fees for this screening protocol or otherwise profiting from dissemination or use of the material in the manual.

This manual was developed as a joint project between the Wisconsin Department of Health Services and the Wisconsin Alzheimer's Institute.





Section I: Introduction

Why Offer Memory Screening?

According to the Department of Health Services, Wisconsin has approximately 120,000 people living with dementia. Because age is the greatest risk factor for Alzheimer's disease, the number of people with dementia is expected to rise dramatically as the population ages. Projections indicate that by 2040, the number of people with dementia in Wisconsin will double to approximately 242,000. Providing access to memory screening and other methods to detect dementia early can benefit people with dementia and their families.

One benefit of providing memory screens is detecting a treatable cause of memory change early. Changes to a person's memory or thinking can occur for a variety of reasons that can be addressed or treated, including but not limited to:

- Adverse medication interactions and side effects.
- Untreated infections or other medical issues.
- Depression.
- Anxiety.
- High levels of stress.
- Lack of sleep.
- Chronic pain.
- Hypothyroidism.
- Vitamin deficiency or electrolyte imbalance.

All of these possible causes of memory loss or changes in cognitive abilities can be resolved with proper diagnosis and treatment. If left untreated, they can result in poor health outcomes and even hospitalization.

Early intervention is important when a person experiences changes in his or her cognition even when the cause of the change is from an irreversible condition such as Alzheimer's disease. Early detection of dementia can allow individuals to work with their doctors to determine what lifestyle changes they can make or what other treatment options may be available to address the progression and ease symptoms. Early detection allows individuals and families to make plans for the future, such as making health care and financial decisions at a time when the person with dementia can participate. Early detection also allows time for families to learn about dementia and caregiving for a person with dementia and to arrange support. Making plans for the future and connecting with information and support can help families and people with dementia to avoid potential crisis situations related to the condition and enjoy better quality of life.

A person can also benefit from a memory screen even if the screen indicates that there are no concerns. If they were worried about memory loss, screening may bring a sense of relief and can serve as a baseline for comparison with future memory screens. This baseline can help to track changes in memory and cognition over time.

Purpose of Community-Based Memory Screening

Unlike screening for other diseases such as cancer, screening for dementia is only recommended if there are reasons to suspect the person has cognitive impairment.¹ Once cognitive impairment is suspected, protocols exist that physicians can use to diagnose the condition.² However, dementia can remain undiagnosed throughout its progression,³ or not be diagnosed until late in the progression, by which time a person's abilities are often greatly diminished.⁴ A recent study indicates that 45% of individuals with dementia say they were never informed of their diagnosis by their doctor.⁵

Many factors contribute to the high number of people with dementia who say they are not provided with a diagnosis, including the attitudes and knowledge of the physician and of people with dementia and their caregivers.⁶ The stigma and lack of understanding of dementia can prevent people from talking to doctors about concerns for themselves or for family members. Some people believe that loss of memory and other cognitive abilities are a normal part of aging, and will not talk to their doctor or seek information specifically about dementia.

If these individuals seek assistance, it may be to deal with the practical challenges that accompany dementia, such as needing assistance with housekeeping, yard work, meal preparation, and other daily activities. They may not realize the benefits of pursuing information about memory loss and the improvement to quality of life that can accompany an early diagnosis. A dementia-capable, community-based agency will be able to appropriately offer a memory screen and make a helpful referral based upon the results.

Community-based agencies provide information and assistance on a variety of issues to a variety of people in a variety of settings. When working with an individual or family on an issue, the agency staff member may notice signs of memory loss or confusion. The offer to do a memory screen can open the door to a conversation about memory loss or other cognitive concerns that may not occur otherwise. Having information to provide in the moment is the best way to encourage a conversation that may be difficult for some people. If the screen indicates it is appropriate, encouraging the person to speak with their doctor about concerns can lead to early detection and diagnosis with benefits for the person experiencing memory loss and caregivers.

¹<u>Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors - PMC (nih.gov)</u>

² Practical Guidelines for the Recognition and Diagnosis of Dementia | American Board of Family Medicine (jabfm.org)

³ https://www.alz.org/media/documents/2015factsandfigures.pdf

⁴ Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors - PMC (nih.gov)/

⁵ https://www.alz.org/media/documents/2015factsandfigures.pdf

⁶ Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors - PMC (nih.gov)

Benefits of the Memory Screening in the Community Program

In addition to promoting the program and encouraging individuals to seek a medical evaluation with the goal of timely and appropriate diagnosis, there are other benefits to the program. The dementia care specialists train ADRC specialists to provide the screening program, including answering basic dementia questions, in order to increase dementia capability throughout the agency. Because the program is primarily about the conversation with the person being screened and anyone who is with them, there are other opportunities to provide targeted outreach and education beyond the screening results.

The conversation before and after the completion of the screening tools is an opportunity to provide personally tailored information about a variety of topics. Depending upon who is present, education can be provided on:

- Normal aging.
- Brain health maintenance.
- Signs and symptoms of dementia.
- Dementia-friendly community opportunities.
- Available caregiver supports and resources.
- Anything else that might be helpful.

Individuals who do not have any indication of cognitive concerns after screening and discussion will benefit from the program by receiving a baseline screening result. Baseline results are important to be able to spot changes in cognition over time. Some individuals may choose to receive annual screening for this purpose. Health fairs and public health events also offer the opportunity to reduce the stigma associated with dementia by normalizing memory screening in a setting where many other health screens are also performed.

Wisconsin's Early Detection Engine

The Memory Screening in the Community program and the Wisconsin Alzheimer's Institute Dementia Diagnostic Clinics Network comprise Wisconsin's "Early Detection Engine." This engine uses the reach of the screening program into the community to encourage the connection of individuals with concerns about their cognition with a medical evaluation. Ideally, this evaluation would occur during an appointment with the individual's primary care physician, but there are many barriers to evaluation and diagnosis in the primary care setting such as lack of time and training for physicians. Only half of all individuals living with dementia have a diagnosis.⁷ Screeners follow up with individuals they have referred to their family doctor, with permission, to ask how the appointment went and provide additional information based upon the outcome. If the individual is not satisfied with the visit to their family doctor, the screener can provide a referral to one of the WAI Dementia Diagnostic Clinics for further evaluation.

The Wisconsin Alzheimer's Institute (WAI) <u>Dementia Diagnostic Clinic Network</u> consists of clinical physicians that are trained and supported to provide the diagnostic model developed by WAI. This unique model allows individuals to access a cognitive evaluation, even if their

⁷ Advancing Early Detection (cdc.gov)

primary care physician is unable. Located across the state, WAI-supported physicians provide evaluation and diagnosis to patients within their health systems during clinic times dedicated specifically to diagnosing dementia.

Wisconsin's Early Detection Engine combines the Memory Screening in the Community Program with the WAI Dementia Diagnostic Clinics Network. If the individual would like a follow-up appointment, or the physician would like to make a referral, screeners can provide a connection to the WAI Dementia Diagnostic Clinic Network. Working together, the Memory Screening in the Community Program and the WAI Dementia Diagnostic Clinics Network provide a unique support structure to assist individuals with concerns about dementia to receive an appropriate and timely evaluation.

Section II: Dementia Basics

What is Dementia?

The term "dementia" refers to a set of symptoms that affect a person's memory and thinking ability, known as cognition, and the person's ability to function independently. There are many diseases and conditions that cause the symptoms of dementia. Alzheimer's disease is the most common cause, estimated to affect between 60% and 80% of all people with dementia.⁸ People can be confused about the difference between Alzheimer's disease and dementia and may say they have one but not the other.

The diagnostic categories "Mild Neurocognitive Disorder" (mild NCD) or "Major Neurocognitive Disorder" (major NCD) have replaced the term "dementia" in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) used by physicians.⁹ This change has added confusion among the general public regarding the definition of "dementia." For the sake of clarity when speaking to the public, the terms "memory screen," and "dementia" will be used in this manual as the most commonly understood terms.

As previously indicated, many curable or reversible conditions may cause symptoms of dementia. For example, delirium shares many of the same symptoms including confusion, disorientation, memory loss, and others. The key difference between delirium and dementia is the rate of onset. Delirium happens quickly and is reversible when the cause is treated. Unless the cause is stroke, symptoms of dementia appear gradually over time, so a sudden change in ability or behavior is most likely delirium, not dementia.

Dementia can be understood on the most basic level by realizing it is a process of brain cell death. The reasons the brain cells die varies depending upon the cause of dementia, and the resulting symptoms depend upon where in the brain the cells die. Different parts of the brain control different cognitive skills. For instance, the hippocampus, which is a part of the brain responsible for important functions related to memory, is affected by Alzheimer's disease.

Appendix A has a list of the areas of cognition that can be affected by the diseases and conditions that kill brain cells and cause the symptoms of dementia. They are not listed in any particular order because there is no set progression of symptoms that all people follow. Any of the symptoms listed may appear or not, and everyone experiences dementia differently. There are some commonalities in the progression within certain types of dementia, but it is important not to compare the experience of one person with anyone else.

⁸ https://www.alz.org/media/documents/2015factsandfigures.pdf

⁹ Dementia and DSM-5: Changes, Cost, and Confusion (todaysgeriatricmedicine.com)

Types and Symptoms

Alzheimer's disease is the most common cause of the symptoms of dementia. The hallmark symptom is memory loss, and the largest risk factor is age. While the stereotype of a person with dementia is someone old and forgetful, memory loss is only one symptom among many, and cognitive changes or decline can occur at any age. The majority of older adults do not experience dementia but may be affected by confusion or memory loss that can be treated. Cognitive screening can benefit anyone who is concerned about increased confusion or other cognitive difficulty that is new.

Dementia of the Alzheimer's Type

The exact cause and process that leads to the development of Alzheimer's disease is still not understood. However, it is currently thought to begin in middle age and can last more than two decades from initial onset until death.¹⁰ Alzheimer's disease is the sixth leading cause of death in the United States.¹¹ Symptoms appear slowly and gradually over time and may seem to come and go with good days and bad days, but progression is of steady decline. Some people will decline much faster than others. Most people with Alzheimer's disease are over the age of 65, but 5% of people are younger,¹² some by a decade or two.

Some of the most common symptoms of Alzheimer's disease include memory loss, difficulty with finding words and remembering names, becoming lost in familiar places, increased irritability and changes in mood, loss of ability to perform tasks that were previously easy, and paranoid thoughts. People with Alzheimer's can become passive and quiet or frustrated and aggressive. Pacing and wandering are common, and wandering can become dangerous if the person with dementia becomes lost. Depression and anxiety are treatable conditions that can also occur when someone has Alzheimer's disease.

Vascular Dementia

Vascular dementia can be the result of a large stroke event, or many small strokes known as transient ischemic attacks (TIAs), or even micro-strokes that happen over time and may go unnoticed. The location in the brain where the stroke or strokes occur determines which symptoms appear. Progression of vascular dementia involves sudden changes and plateaus where abilities remain stable until the next vascular event or stroke. It is not uncommon for an individual to have both Alzheimer's disease and vascular dementia, known as mixed dementia. Most of the risk factors that lead to stroke are also risk factors for Alzheimer's disease.

Symptoms of vascular dementia are similar to those of Alzheimer's disease, although memory loss may or may not be present. Because any of the areas of cognition and physical function can be affected, the symptoms that occur will vary greatly from person to person.

Dementia with Lewy-Bodies

The symptoms of Lewy-body dementia are also different than other dementias. While hallucinations can be a symptom of any dementia, they are more common for people with Lewy-body dementia. Visual hallucinations of friendly animals or people are not unusual

¹⁰ <u>Alzheimer's Stages - Early, Middle, Late Dementia Symptoms | alz.org</u>

¹¹ https://www.alz.org/media/documents/2015factsandfigures.pdf

¹² brochure earlyonset.pdf (alz.org)

and are non-threatening and not upsetting for the person. Increased risk of falls continues as long as the person is walking, and a person's abilities can fluctuate greatly throughout the day. Another common symptom is REM-sleep behavior disorder in which a person appears to "act out their dreams" during sleep.

Frontotemporal Dementias (FTD)

Frontotemporal dementias are caused by various diseases that affect the frontal and temporal lobes of the brain. These are areas responsible for planning and decision making, assessing risk, understanding social behavior and norms, speech and language abilities, and large and small motor function. FTDs fall into three main categories: behavior variant (bvFTD), primary progressive aphasia (PPA), and disturbances of motor function. Behavior variant FTD and PPA are as common among people between the ages of 45 and 65 as young onset Alzheimer's, which is estimated to be between 50,000 and 60,000 people in the U.S.¹³ The progression of FTDs can be much faster than Alzheimer's disease.

Symptoms vary by type of FTD, with bvFTD causing the largest changes in interpersonal relationships and understanding of risk. The affected areas of cognition include judgment, empathy, foresight, and control over personal behavior. PPA can affect both a person's ability to communicate with words, and to understand words spoken to them. This can lead to frustration and depression. The type of FTD that creates disturbances in motor function includes amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease; progressive supranuclear palsy, or PSP; and corticobasal syndrome. All of these diseases affect a person's ability to use various parts of the body.

Other Dementias

Other types of dementia are less common, including Huntington's disease, Korsakoff Syndrome, Creutzfeldt-Jakob disease and others. Because symptoms of dementia vary widely depending upon the cause, it is important to get a proper diagnosis to be able to provide the care needed.

Changes in Perception of the Environment

People with dementia experience changes in their perception of the environment as the parts of the brain that interpret external information become damaged. The changes can lead to unusual behavior. **Appendix B** lists some of the possible changes in perception of the environment, and the behavior that results from those changes. Understanding how a person with dementia is interpreting the environment can help to explain unusual behavior.

¹³ Frontotemporal Dementia (FTD) | Symptoms & Treatments | alz.org

Section III: Memory Screening

Benefits of Memory Screening

Screening for dementia, much like screening for other diseases or chronic conditions, is a good way to detect the changes that can be signs of the onset of disease or other change in cognition. Memory screening and early detection provide:

- The ability to make lifestyle and other beneficial changes earlier in the disease process when they have the greatest potential for positive effect.
- The opportunity for the individual with dementia to participate in making future health care and financial decisions.
- An early start for families to learn about dementia and caregiving for a person with dementia, before the person's need for care is at its greatest.
- Time to connect with community-based information and supportive services prior to a potential crisis situation related to the needs of the person with dementia or the caregiver.

To enable people with dementia and their caregivers to benefit from memory screening and early detection, a community-based memory screening program was developed by the Wisconsin Department of Health Services and the Wisconsin Alzheimer's Institute using the Animal Naming Screen, the Mini-cog, AD8, and the Montreal Cognitive Assessment (MoCA) tools.

Selection of Screening Tools

The Animal Naming and Mini-cog tools were selected after a pilot study in Portage County in 2009. The Wisconsin Alzheimer's Institute, the Aging and Disability Resource Center (ADRC) of Portage County, and the Wisconsin Department of Health Services demonstrated the acceptability and effectiveness of using the Animal Naming and Mini-cog screens in a community setting. The Animal Naming screen is attached as **Appendix C** and the program-adapted Mini-cog as **Appendix D**.

Results from the pilot demonstrated ADRC customers' high level of acceptance of screening. The offer of a memory screen was accepted by 243 out of 254 people, a 96% acceptance rate. This result contradicts the idea that people do not want to be screened for dementia. The tools were also effective in detecting cognitive issues. Of the 243 people who were screened, 150 (63%) had results that indicated they should follow up with their physician. This result may seem surprisingly high, but screens were only offered to individuals who expressed a concern about their memory, so those with cognitive issues self-selected into the study. Of those 150 people, 120 or 80% agreed to have the results sent to their physician.

The Animal Naming and Mini-cog screens were selected not only for their acceptability and effectiveness, but also because they are brief, easy to administer and score, and are sensitive to early cognitive changes. Some screens must be administered by physicians or psychologists and can take more than an hour. The minimum level of training required and the short length of time necessary to administer the screens was a critical component in their acceptance for use by ADRC staff.

The screens were also selected because they have documented utility as dementia screens and tap key skills likely to be affected in mild to moderate dementia. The Animal Naming screen involves retrieval from semantic memory and executive function, two areas of cognition that reliably decline in people with Alzheimer's disease. In a study of memory clinic clients with a high base rate of dementia, the Animal Naming screen was shown to have 85% sensitivity and 88% specificity for differentiating Alzheimer's disease and other dementia from normal cognition. The Mini-cog screen tests memory as well as visuoconstruction and executive function, with studies showing sensitivity for dementia of 76% to 99% and specificity of 83% to 93% in analyses that excluded patients with mild cognitive impairment¹⁴.

Memory screens are voluntary, so there will be individuals who decline to participate. On these occasions, if family caregivers are uncertain whether their concerns about the person they are caring for are valid, the AD8 screen can help determine whether a visit to the doctor is recommended. The <u>AD8 tool</u> is available in both English and Spanish. This screen is intended to help the caregiver think through the changes they see in a family member, and may help them to realize it is time to take action. The screen can be provided to the family caregiver to complete on their own, or the questions can be asked by the screener in a private setting. The AD8 has sensitivity for dementia of greater than 84% and a specificity of greater than 80%¹⁵.

In 2020, the Montreal Cognitive Assessment (MoCA) tool was added to the approved tools for use by dementia care specialists (DCS). This tool is not for use by ADRC staff other than the DCS. The intention behind the addition of the MoCA screen is to give DCS an additional tool for situations that are more complex. While the Mini-cog and the Animal Naming screens are more sensitive to earlier changes than other screens, they are limited to a few areas of cognition. The MoCA covers a wider variety of cognitive tasks and provides additional insight into possible cognitive impairment when the Animal Naming and Mini-cog results do not reflect the changes in cognition and behavior reported by the individual or their family.

New dementia care specialists should become very familiar with the Animal Naming and Mini-cog tools prior to adding the MoCA to their toolkit. There are some similarities and some differences between the activities of the Animal Naming and Mini-cog and those in MoCA. Learning all the screens at the same time can be confusing, so it is advised for new staff to focus on the Animal Naming and Mini-cog screens, as well as the AD8, prior to becoming certified to provide the MoCA screen. Training and certification for the MoCA, and the approved form, are available from the official <u>MoCA website</u>. There is a cost to the training and certification for the MoCA. The MoCA is not required to be provided as a part of this program but is available as a supplemental tool.

¹⁴ The Mini-Cog as a screen for dementia: validation in a population-based sample - PubMed (nih.gov)

¹⁵ AD-8 for detection of dementia across a variety of healthcare settings - PMC (nih.gov)

How to Screen

Conversation Tools

The primary intent of this memory screening protocol is to enable and enhance conversations about memory concerns. The screens are not diagnostic tools and do not make any determinations about mental status. The screens are similar to a blood pressure check, in that a high blood pressure reading does not mean an individual has cardiovascular disease but is a signal to talk to a physician about the results. The screens can be a reason to bring up the topic of memory issues because they can be offered in the moment. A referral to the physician can be more meaningful if an objective tool verifies that an individual's concerns with memory and cognition should be further assessed.

When to Offer Screening

It is appropriate to offer a memory screen when one is requested, or when working with a customer who displays signs of possible memory loss or confusion. ADRC specialists are able to offer the screening program during a visit for another purpose, if time allows. It is preferable to address the concerns around memory at the time, rather than putting off the discussion for another appointment. Memory screening is always voluntary.

Staff members may feel uncomfortable offering a memory screen if they are not used to asking and answering questions about memory and dementia. It is important that staff who are offering the screens understand why screening is important and helpful to the customer. Practicing offering the screen to coworkers and family members can be a good way to become more comfortable. Staff must be trained to follow the guidance in this manual before performing memory screens with the public.

Completing the Tools

Once an individual has agreed to be screened, assemble all necessary materials and locate a suitable, non-disruptive environment. Materials include:

- A paper copy of the Animal Naming tool and Mini-cog tool.
- A writing utensil for yourself and one for the participant.
- A time-keeping device that shows minutes and seconds.
- A location that includes a writing surface and is comfortable, quiet, and well lit.

If other people are present for the screening, let them know they will need to remain quiet and not help the person answer the questions. Ensure the participant cannot easily view and copy a clock in the room.

Animal Naming Tool

Begin with Animal Naming. It is critical to read the instructions for each task on both screens exactly as they are written. Do not explain how the screen is scored prior to performing the screen, and only afterwards if the individual asks you to do so. To adhere to the fidelity of the tools, they must be performed exactly the same way every time to ensure the results are valid. Read the instructions to the participant: "Please name as many animals as you can think of as quickly as possible." Be prepared for the person to start listing animals immediately or, if they do not, prompt them with "Go."

Once the person begins to name animals, start the timer and record all the animals named within 60 seconds in the spaces provided on the worksheet. If the person is speaking quickly, write as much of the word as needed to remember what was said and fill in the remaining letters afterward. If the person falls silent, follow the prompting instructions. Once the Animal Naming screen is done, administer the Mini-cog, even if the score of the Animal Naming screen was very high. The two screens should always be used together.

Mini-cog Tool

The Memory Screening in the Community program is intended for the Animal Naming tool and the Mini-cog tool to be used in combination. In this non-clinical program, the standard Mini-cog tool available online has been adapted to work in concert with the Animal Naming tool. Refer to **Appendix D** to access the form to record results.

Begin the Mini-cog by telling the participant, "I am going to say three words I want you to remember," and repeat the three words listed on the worksheet. Be sure to read the instructions exactly as they are written. It is important to the fidelity of the screen to use the same three words every time the screen is performed. Give the participant three chances to repeat the words back. If the participant does not repeat the words, or does not repeat them correctly, the screener can repeat the words up to three times until the words are repeated correctly. If they are not correct after the third time, move on to the clock draw.

Provide a blank, standard, letter-size sheet of paper for the participant to draw on and a writing utensil. This can be the back of the Animal Naming worksheet or another blank sheet. Allow the participant time to adjust to the new task, pick up the writing utensil, and adjust the paper. Once the participant is settled, read the instructions for the clock draw exactly as they are written, pausing when indicated to allow the participant to complete the task. Move on from this task if the clock is not complete within three minutes.

Once the clock is completed ask the participant, "What were the three words I asked you to remember?" There is no prompting allowed on this question.

There will be individuals that frequently request to be screened. If they express the desire for an alternate set of words used for the three-word recall portion, refer to the words listed in the <u>Health Equity section</u> for Hmong translation. The need for an alternative set of words was first identified in the need for the translation of the words into Hmong. They do not easily translate into that language, so an alternative set of words was identified for that purpose. That substitution can also be applied for individuals who request frequent screening.

The AD8 Tool

The AD8 can be administered to the person with possible memory loss, but often individuals with dementia lose insight into their condition and are not reliable self-reporters. The questions on the screen can either be read aloud or a caregiver can fill out the form on their own. In situations where the person with possible memory loss is together with the caregiver, allowing the caregiver to fill out the questionnaire silently may be less upsetting for the person with possible memory loss than if the questions are asked aloud. The caregiver may also provide different answers if the person with possible memory loss is listening to the answers.

Montreal Cognitive Assessment (MoCA)

The MoCA tool, including training, certification, and the downloadable version of the paper tool can be found on <u>the MoCA website</u>. The MoCA is also available to be used digitally. Instructions for how the MoCA tool is scored are a part of the training and certification process.

Virtual Screening

The Memory Screening in the Community program was adapted in 2020 during the COVID-19 pandemic for use when screening was required to be completed virtually¹⁶. The ability to provide screening virtually for dementia risk has been identified as an ongoing need.¹⁷ Please consult <u>Section IV: Accessibility and Health Equity Considerations</u> for a description of the adaptation for virtual access.

Scoring Cognitive Screening Tools

The use of the Animal Naming and Mini-cog tools in the Memory Screening in the Community Program is different than as a part of Wisconsin's Long-Term Care Functional Screen (LTCFS). The purposes for the use of these tools in the Memory Screening in the Community Program are to enable a conversation and assist in determining whether speaking to a physician is advisable. The LTCFS uses the tools to represent "memory loss" if the individual being screened states that they have memory loss but do not have an accompanying diagnosis of dementia. The LTCFS is used to determine functional eligibility for long-term care programming and uses the results of the screens independently. The scoring key for the Memory Screening in the Community Program to determine if a referral is recommended is attached in <u>Appendix E</u>.

Animal Naming Tool

The Animal Naming tool is a categorical fluency test. The person is asked to recall specific labels for items in a specified category, such as animals. The tool is scored by tallying the number of correct responses. If the person names fewer than fourteen correct animals, that is considered "not passing."

Rules for Scoring

- If a name is listed more than once it should only be counted once.
- Different names for life stages, such as "cat" and "kitten," are only counted once as a "cat."
- Different names for different sexes, such as "rooster" or "hen," are only counted once as a "chicken."

Correct Responses

- Human beings
- Insects, fish, birds, and reptiles—anything that slinks, crawls, swims, flies, etc.
- Extinct animals, such as dinosaurs
- Imaginary animals, such as unicorns

¹⁶ Remote cognitive and behavioral assessment: Report of the Alzheimer Society of Canada Task Force on dementia care best practices for COVID-19 - Geddes - 2020 - Alzheimer's & amp; Dementia: Diagnosis, Assessment & amp; Disease Monitoring - Wiley Online Library

¹⁷ Telehealth-based assessment of cognition in older adults during COVID-19 and beyond - Cullum - 2021 - Alzheimer's & amp; Dementia - Wiley Online Library

Because this is a categorical fluency test using animals, which is a very large category, there are categories within the category "animals" that are also acceptable as correct answers. Within the category "animals" there are sub-categories of animals that contain 14 or more unique labels. An example is "dog breeds." There are more than 14 different breeds of dogs, and listing 14 or more unique dog breeds in response to the request to list animals is acceptable.

An example of a completed Animal Naming screen is attached in <u>Appendix F</u>. In this example, the final tally would be 11, even though 14 lines are completed, because cat is repeated and spray and dandelion are not animals.

Mini-cog Screen

The Mini-cog has two areas that are scored. Three points are awarded for recalling the three words correctly, and a score of either zero or two is awarded for the clock draw. For the three-word recall, one point is given for each word remembered. The words do not have to be in the same order in which they were presented.

The clock draw test requires some interpretation by the screener. The rules for scoring the clock draw are attached in **Appendix G**. There are examples of clocks drawn by participants in the pilot study that can be used to practice interpreting results in **Appendix H**. It is important not to overthink the interpretation of the clock; the clock is only one piece of the screening program. If a clock drawing looks correct but there are some questionable features, use your best professional judgment to make a decision and then move on.

The screens are conversation tools and do not provide a diagnosis; they are used to determine the need for an appropriate referral to a physician. If the scores from the screens do not indicate the need to make a referral to a physician, but the conversation about the individual's memory concerns suggests that a referral would be helpful, a referral should still be offered.

The AD8 Screen

The AD8 is scored by tallying the number of items noted as "Yes, a change." If the score is two or more, a referral to the physician is appropriate. The instructions for determining the score of the AD8 can be found after the screening questions on the <u>AD8 tool</u>.

Montreal Cognitive Assessment (MoCA)

Training for the scoring of the MoCA tool can be found on <u>the MoCA website</u>. The MoCA is available to be used digitally, which can assist in scoring the results.

After Completing the Tools

Once the tools have been completed and scored, the results should be shared with the person being screened and any caregiver present. If the score falls within the range where a referral to a physician is recommended, the screener will offer to send the screening results along with a letter to the individual's physician. The person who was screened then has three options:

- The person can accept the offer.
- The person may choose to take the results to a physician on their own.
- The person can choose to do nothing with the results.

It may take some time before the person is ready to discuss their concerns with a physician, and it is important to respect that need.

The screener can also offer to send in screening results for individuals whose scores do not fall into the range where a referral is recommended for the purposes of providing a baseline screen for their medical records. A baseline score is useful in detecting change over time. If an individual has several years of baseline scores in his or her record, detecting a change in cognitive abilities is easier to track and therefore easier to detect and respond accordingly.

If the person who was screened chooses to have the screening results shared with a physician, the screener must first obtain a signed 'release of confidential information' form giving permission to the screener to share the information. An example of this type of form is located in <u>Appendix I</u>, although most agencies will have their own form that must be used for this purpose.

Sending the screening results to the physician is also an opportunity to make the physician aware of the agency and its services as well as the community screening program. Cover letters should include information about the person who was screened, a short explanation of the screening process, information about the agency and a statement encouraging the physician to refer patients who receive a diagnosis back to the agency for ongoing support. A sample letter to the physician is attached in <u>Appendix J</u>.

The Wisconsin Alzheimer's Institute (WAI) and the dementia care specialist from Eau Claire County developed additional resources for use after the tools have been completed. For individuals whose screening results show they should talk to their doctor, Dr. Cindy Carlsson at the WAI developed a one-page document to accompany screening results sent to the physician by the screener. The document includes best practices around evaluation for possible dementia and when to refer a patient to the <u>WAI Memory Diagnostic Clinics</u> network. This resource can be found in <u>Appendix K</u>. <u>Appendix L</u> is the Memory Screening Results and Recommendations form available to provide the person after screening and is optional. Having the results and recommendations written in one place can be helpful to the person. Additional information and resources can be provided at the time or sent in a follow-up correspondence.

Once the tools are completed and a physician referral is recommended, the screener should ask permission to follow up after two to six months, even if the individual does not want the results sent to the physician. Agreeing to a follow-up call indicates openness to additional support in the future. If the person who was screened does indeed have dementia, they will need information and support in the future, and following up after a screen can allow that to happen in a planful way and not in crisis.

Appropriate Settings for Community-Based Memory Screening

The Memory Screening in the Community Program can be provided in a variety of settings. Typically, screens are available whenever a customer requests a screen, or when a trained ADRC specialist or dementia care specialist identifies a customer that would benefit from the program. They are also usually performed in person. This can be during a home visit or office visit scheduled for another purpose. However, there are many possible locations for memory screening to be performed in the community. Partnering with municipal and other local governmental agencies to offer screens is one option. For example, public libraries are welcoming places free from the stigma associated with dementia and are often willing to host screening events in a private study room or other private space. Community or large employer health fairs also offer opportunities to screen, and to normalize screening for cognitive decline along with other health conditions.

County-based programs, healthy aging programs, public health departments, and other community-based partner agencies may also have staff trained and supported by the dementia care specialist at the ADRC to provide the Memory Screening in the Community Program. The same requirements for fidelity, oversight, and yearly refresher training apply to all screeners trained by the DCS.

The Memory Screening in the Community Program was adapted during the COVID-19 pandemic to be available virtually. When the program cannot be provided in person, there is a substitute protocol for use of the program virtually. Please consult <u>Section IV: Accessibility and Health Equity Considerations</u> for a description of the adaptation for virtual access.

Section IV: Accessibility and Health Equity Considerations

Introduction

The screening tools in this manual are not universally accessible and have some limitations. The tools have not been validated in all populations and that may affect the interpretation of the score. Cultural background can also influence the acceptance of memory screening, depending upon where and how the screens are offered and the level of understanding individuals and families have about dementia. Memory screens can be successfully provided to many individuals using the following considerations.

Accessibility

People Who Are Blind and Visually Impaired

It can be challenging for people who are blind or have low vision to find transportation to appointments. Providing memory screening in the home or another location convenient for the individual can address that obstacle. The Animal Naming tool, the AD8 tool, and the three-word recall portion of the Mini-cog are accessible and appropriate to use for people who are blind or visually impaired. An individual with low vision may still be able to draw the clock when provided with a large sheet of paper and a dark marker to use when drawing. However, someone who is blind should not be asked to draw a clock.

In place of the clock drawing task, use the "Attention" section of the Montreal Cognitive Assessment tool for people who are blind. The MoCA-Blind assessment can be accessed on <u>the MoCA website</u>:

A description from the link includes the following instructions:

Forward Digit Span: Give the following instruction. "*I am going to say some numbers and when I am through, repeat them to me exactly as I said them.*" Read the five number sequence at a rate of one digit per second. Digits- 2 1 8 5 4

Backward Digit Span: Give the following instruction. "*Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order.*" Read the three number sequence at a rate of one digit per second. Digits-7 4 2

Scoring: Allocate one point for each sequence correctly repeated. The correct response for the backwards trial is 2-4-7.

Virtual Screening

The adaptation made in 2020 for use of the Memory Screening in the Community Program to allow for virtual screening during the COVID-19 pandemic was based upon the adaptation described above for people who are blind or visually impaired. This adaptation for virtual use will remain available as an ongoing option for the program.

People Who Are Deaf or Hard of Hearing

For individuals who are deaf or hard of hearing, it is important to determine if concerns with memory and cognition are the result of communication challenges. People with hearing loss could appear to have cognitive decline if they are unable to hear what is being communicated. Use of sign language interpreters and assistive technology, such as written or video remote interpreting, can assist in facilitating clear and effective communication. More information on interpretation and communication assistance can be found on <u>the Department of Health Services</u> website.

The Mini-cog screen and the AD8 screen are accessible screens for people who are either deaf or hard of hearing. Individuals who are able to read English can receive instructions in writing for completing the screens. The Animal Naming screen was validated for use only with individuals who are able to respond to the request verbally. Because the responses are timed, the additional time spent communicating using American Sign Language can affect the results, and therefore is not a valid use of the screen. The results of the Mini-cog or AD8, in addition to other information gathered during the discussion, will inform the decision whether or not to encourage the individual to talk to their doctor.

People Living with Intellectual and Developmental Disabilities

For individuals with intellectual or developmental disabilities (I/DD), a separate screening tool is available. The National Task Group-Early Detection Screen for Dementia (NTG-EDSD) can be completed by any person familiar with the person with I/DD, such as a family member, caregiver, or health specialist. It is recommended that the tool be used annually with adults with Down syndrome beginning at age 40, and with other people with I/DD when cognitive changes are suspected. Individuals with Down syndrome have a substantially greater risk of developing Alzheimer's disease than any other population, so regular screening is recommended. Annual screening provides a baseline for each individual's unique abilities, allowing future screens to be compared in order to track change over time. The NTG-EDSD is attached in **Appendix M** and the accompanying instruction manual is **Appendix N**. Both manuals are available in multiple languages, which can be found on the National Task Group website. Another resource to support the use of the NTG-EDSD is the Implementing Effective Dementia Screening for Persons Living with an Intellectual Disability guide developed by the Wisconsin Alzheimer's Institute.

Illiteracy

For the purposes of this training manual, illiteracy means the inability to read or write language. Illiteracy can impact multiple cognitive tests, not just tests that would seem obvious such as reading text, and that makes it challenging to interpret cognitive screening scores. Specifically, illiteracy can affect how well people perform on the animal naming screen. When someone is illiterate, screeners should rely more on what that person and their family members say when determining whether to refer them to their physician. For individuals who are illiterate, the AD8 is recommended for use as the screening tool and should be performed with the family caregiver, rather than screening the individual.

Mental Illness

There are also limitations in the interpretation of screening results for individuals with certain mental illnesses. Cognitive impairment is part of the presentation for people with schizophrenia and for some individuals with bipolar disorder, so if an individual's screens reflect a reason for referral, it may be part of the mental illness. In these cases, the AD8 is recommended for use as

the screening tool and should be performed with the family caregiver regarding changes they have noticed. If needed, a referral should then be made to the physician for further evaluation.

Health Equity

People of Latino ethnic heritage and African Americans are at greater risk than whites of developing dementia.¹⁸ Many factors are thought to contribute to the increased prevalence of dementia in communities of color, including socioeconomic status and lack of access to quality housing, good nutrition, and health insurance. The latter reduces access to regular preventive care and management of chronic conditions, including those that increase the risk of dementia.¹⁹

Communities of color also continue to face disparities in access to and appropriate care from the health care system.²⁰ From preventive care to surgical procedures, people of color are less likely to receive treatment, or may receive treatment later in the disease than people who are white would experience.²¹ A lack of access to appropriate medical care and a lack of trust of the medical system make outreach and community-based access to screening and information about dementia important in these communities. Offering memory screening in agencies that serve communities of color can allow individuals and families that may be concerned about dementia to access culturally tailored information and make connections to support within the community.

American Indian and Alaska Native Communities

American Indian and other indigenous groups will experience a growth rate of five times the number of people over age 65 experiencing memory loss between 2014 and 2060²². Risk factors, including chronic conditions such as diabetes and cardiovascular disease, are also more prevalent in these groups. In providing memory screening to American Indian and other indigenous groups, the screening tools used in this manual do not need modification.

Hmong Communities

Cultural considerations when providing screening for Hmong families include the significant value placed on family involvement in the process. Hmong elders may wish to be accompanied specifically by their eldest son or daughter, if not several family members, when meeting with the screener. Many first-generation Hmong elders may not speak English, and the screener will need to be fluent in the Hmong language. Best practice guidance for screening and assessment state that family members should not be used for interpretation during the screening process.²³ The Animal Naming screen and the AD8 do not need modification for use.

Use of the Mini-cog is appropriate as long as the individual being screened is comfortable with the use of analog clocks. For Hmong speakers, the three words used in the recall section are

¹⁸ Race, Ethnicity, and Alzheimer's

 ¹⁹ RACIAL AND ETHNIC DISPARITIES IN DIAGNOSIS AND TREATMENT: A REVIEW OF THE EVIDENCE AND A CONSIDERATION OF CAUSES - Unequal Treatment - NCBI Bookshelf (nih.gov)
 ²⁰ RACIAL AND ETHNIC DISPARITIES IN DIAGNOSIS AND TREATMENT: A REVIEW OF THE EVIDENCE AND A CONSIDERATION OF CAUSES - Unequal Treatment - NCBI Bookshelf (nih.gov)
 ²¹ RACIAL AND ETHNIC DISPARITIES IN DIAGNOSIS AND TREATMENT: A REVIEW OF THE EVIDENCE AND A CONSIDERATION OF CAUSES - Unequal Treatment - NCBI Bookshelf (nih.gov)
 ²¹ RACIAL AND ETHNIC DISPARITIES IN DIAGNOSIS AND TREATMENT: A REVIEW OF THE EVIDENCE AND A CONSIDERATION OF CAUSES - Unequal Treatment - NCBI Bookshelf (nih.gov)

²² Road Map for Indian Country | Alzheimer's Disease and Healthy Aging | CDC

²³ That I won't translate! Experiences of a family medical interpreter in a multicultural environment - PubMed (nih.gov)

difficult to translate. In place of "Banana, Sunshine, Chair," the words "Daughter, Heaven, Mountain" can be substituted.

When providing memory screens, screeners should keep in mind the screening tools are primarily conversation tools. If none of the screening tools in this manual work for an individual or a family, but the screener can still have meaningful conversation about cognitive concerns and provide education and referral, the intended outcome of the memory screening program has been achieved.

Spanish Language Tools

Spanish versions of the tools are attached as **Appendices** \underline{O} , \underline{P} , and \underline{Q} , with MoCA translations available on the MoCA website. It is important that the screener be proficient in Spanish. It is appropriate for interpreters to be trained to complete the tools when an interpreter is available. Best practice guidance for working with interpretation in the context of an evaluation states that family members should not be used as interpreters.²⁴ The use of Language Line is also not appropriate in performing the screens. Except for the MoCA, screen tools are not currently available in additional languages.

²⁴ That I won't translate! Experiences of a family medical interpreter in a multicultural environment - PubMed (nih.gov)

Section V: Certification and Reporting

Staff Training

Agencies approved by DHS can use this manual to train staff to provide memory screens using the following protocol.

Agency Requirements

All agencies providing memory screening through this program must receive approval from DHS and provide a program manager to oversee the memory screening program at the agency level. The program manager will oversee the training of screeners and ensure ongoing fidelity in use of the screens. Agencies interested in offering the memory screening program may contact <u>dhsdementiawebmail@dhs.wisconsin.gov</u> for more information.

Dementia-Specific Training

It is important for staff members who provide memory screens to be able to answer questions about dementia that will come from the person being screened and their family. Screeners should feel confident and comfortable talking about memory loss and dementia with their customers. Fear or anxiety about dementia on the part of the screener can be a barrier to acceptance of the screen. Dementia care specialists are not expected to provide all the dementia training to all new ADRC specialists. Training on the topic of dementia is widely available, and a list of training resources can be found in the following section on resources.

Practice

Before performance of the screens, new screeners must practice the conversation that leads up to the offer of a memory screen, and the conversation that happens afterwards. The screens are the tools used to have the conversation, with the conversation having more importance in the interaction. Finding words or an approach to the subject that is comfortable for the screener can make the difference in acceptance of the screen. Describing the results in a calm and reassuring way to someone who should speak with their physician can help the individual understand what can be done, and how to take action to address the symptoms they are experiencing.

Ongoing Fidelity

Prior to working with customers, screeners also need to demonstrate proper administration of the screens witnessed by the agency-designated memory screening program manager. Once the screener demonstrates proficiency in providing the screen, he or she can be designated as an "agency certified screener." A sample certificate is located in **Appendix R**. It can be provided to screeners and should be kept in the employee record as evidence of training.

Annually, all agency-certified screeners must demonstrate fidelity with the screens. The memory screening program manager must observe screeners providing the screens with fidelity once a year to maintain certification status. Documentation of ongoing fidelity to the screening protocols can simply be a note from the memory screening program manager added to the employee file. A current list of all agency-certified screeners must be kept on file by the agency and provided to DHS upon request.

Data Collection

Agencies providing the screen must collect data on the use of the memory screening program. At a minimum, the number of screens performed must be collected and made available to DHS upon request. Additional data will also be collected regarding the number of screens indicating a referral is recommended, number of individuals who agreed to have the screening results shared with their physician, and number of individuals who received a diagnosis of dementia. Personally identifiable data regarding the use of memory screens should not be shared with DHS.

Section VI: Resources

Training Resources

ADRC staff that are trained to perform memory screening must also be able to answer basic questions about dementia, family caregiving for a person with dementia, and basic resources available to support everyone involved. The DCS is not required to provide the basic dementia and caregiver support training and may refer staff to other training resources to provide basic content. This list is not all inclusive, and some training may have a cost.

- Information on the Alzheimer's Association Annual Conference <u>Wisconsin (alz.org)</u>
- Alzheimer's and Dementia Alliance of Wisconsin educational programming. Alzheimer's and Dementia Alliance of Wisconsin | Support (alzwisc.org)
- The University of Wisconsin Oshkosh learning series. Learning Center (uwosh.edu)
- Online training for family caregivers hosted on the DHS website is also a good source of information about dementia and caregiving for new staff.
 Dementia: Online Training for Family Caregivers | Wisconsin Department of Health Services
- Teepa Snow educational videos on dementia care. Homepage - Positive Approach to Care (teepasnow.com)
- Healthcare Interactive provides training and certification in the CARES® and the Memory Care Connections programs.
 <u>HealthCare Interactive Online Dementia Care Training and Certification Programs</u> <u>HealthCare Interactive (heinteractive.com)</u>
- National Alzheimer's Disease Resource Center webcasts <u>NADRC | Home (acl.gov)</u>
- My Two Elaines, a book about spousal caregiving My Two Elaines book

Additional Information on Dementia, Caregiving, and Resources

- Alzheimer's Disease Education and Referral Center (ADEAR) Alzheimer's Disease and Related Dementias | National Institute on Aging (nih.gov)
- National Institute of Neurological Disorders and Stroke <u>NINDS Brain Educational Resources | National Institute of Neurological Disorders and</u> <u>Stroke (nih.gov)</u>
- AARP AARP Resources for Caregivers and their Families
- National Alliance for Caregiving Home | The National Alliance for Caregiving

Wisconsin Alzheimer's Institute Memory Clinics

The Wisconsin Alzheimer's Institute offers a network of Memory Clinics across the state that specialize in performing assessment and diagnosis of dementia. Information on the clinics and how to contact them can be found at <u>About the Clinic Network—Wisconsin Alzheimer's</u> <u>Institute—UW–Madison</u>

Twenty-Four-Hour Helpline

The Alzheimer's Association 24-hour helpline can be contacted by anyone with questions about dementia and caregiving for people with dementia. 800-272-3900

Answers to Legal Questions

The Wisconsin Guardianship Support Center (GSC) provides information and assistance on issues related to guardianship, protective placement, advance directives, and more. Operated by the Greater Wisconsin Agency on Aging Resources, the GSC is staffed by an attorney who responds to requests for information through a toll-free helpline or by email. Calls are returned in the order in which they were received.

Guardianship Support Center 855-409-9410 <u>guardian@gwaar.org</u> Guardianship Support Center Resources (gwaar.org)

Wisconsin Department of Health Services

DHS has information about dementia and caregiving programs and resources available in the community across the state. Dementia Care in Wisconsin | Wisconsin Department of Health Services

Aging and Disability Resource Centers (ADRC)

ADRCs provide information on a broad range of programs and services, help people understand the various long-term care options available to them, help people apply for programs and benefits, and serve as the access point for publicly funded long-term care. More information about ADRCs can be found at <u>ADRC: Help for Older People and Adults with Disabilities</u> <u>Wisconsin Department of Health Services</u>

Questions on the Memory Screening Program

Questions should be directed to the Bureau of Aging and Disability Resources at DHS at 608-266-2536 or <u>dhsdementiawebmail@dhs.wisconsin.gov</u>.

Thinking Processes Impaired by Dementia

- 1. **Judgment***: problem solving, consideration of outcomes, consequences & risks.
- 2. Attention*: ability to stay on task, to concentrate.
- 3. **Perception***: ability to interpret sensory information (sights, smell, touch, taste and sounds)
- 4. **Reasoning***: cause and effect realization, ability to bargain and negotiate, perception or appreciation of levels of danger and risk
- 5. Organization*: planning, initiating, following through with an activity
- 6. **Memory***: ability to store, retain and retrieve information (especially short term memory)
- 7. Communication*: giving and receiving verbal and non-verbal language
- 8. **Abstract Thinking***: ability to perceive concepts, hold multiple thoughts simultaneously
- 9. Orientation to Time and Place: know current day, date, time, location, purpose
- 10. Awareness of Socially Appropriate Norms: impulse control, respecting others' space, values, etc.
- 11. Ability to Filter Emotional Responses: use 'common sense' or other information to gauge emotional reactions

An individual can be said to have a dementia when at least two of the functions with an '*' next to them are impaired and declines are severe enough to interfere with social or occupational functionality. Importantly, the decline must represent a decline from a previously higher level of functioning.

Appendix B

Progressive Declines of Alzheimer's Disease and Related Dementias: Physical Changes That Affect Perception of the Environment

Sensory Overload – too much information coming at the person for them to process it and make sense of it – can cause catastrophic reaction

Out of Sight, Out of Mind – things outside the person's visual field are not perceived as present or in the person's awareness

Tunnel Vision – narrowing of the perimeters of the visual field (peripheral vision)

Depth Perception Problems – items that don't have much contrast are perceived as being continuous; patterns or color contrasts are perceived as having different depths even when they don't

Preoccupation with Small or Busy Patterns – small prints may seem to resemble a lint or bugs, person may try to remove them from the fabric.

Visual Cliffs – dark or black surfaces are perceived as cliffs or holes

Loss of Reading Skills – unable to read sentences first, then eventually words

Visual Cues – when items are in the person's line of sight, they trigger the person's attention, and association with a particular response or activity

Repetitive Themes – subjects or situations that the person tends to return to frequently through questioning, talking about, searching for, or rummaging for, etc. They usually relate to important people, emotionally charged events, fears, occupations, habits/routines or things that provide/provided the person with a sense of security or importance

Heightened Intuition – loss of reasoning ability to navigate the environment leads to heightened sensitivity to others' emotions and non-verbal communication

Originally compiled by WI Bureau of Aging and Disability Resources, Department of Health Services 2002. 10/08/13 rev.

Appendix C

ANIMAL NAMING

ID # _____

Name ______

Date _____

Instruction: "Tell me the names of as many animals as you can think of, as quickly as possible."

Procedure: Time for 60 seconds and record all responses.

If the person stops before 60 seconds, say "Any more animals?"

If the person says nothing for 15 seconds, say "A dog is an animal. "Can you tell me more animals?"

1	12
2	13
3	14
4	15
5	16
6	17
7	18
8	19
9	20
10	21
11	22

Scoring: Count the total number of animals (NOT including repetitions or non-animal words):

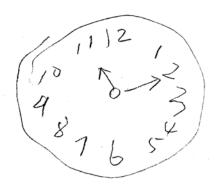
Next step: Do the Mini-cog screen

DATE_	ID	AGEGENDER M	F LOCATION	TESTED B	Y	
Append	ix D		MINI-COC	G TM		
2)	Please say them for r (Fold this page back SAY ALL THE FOLLC	WING PHRASES IN THE ORDI	Sunrise ries to repeat the w W to make a blank ER INDICATED: "Ple	Chair. ords. If unable after 3 t space and cover the me ease draw a clock in the		a large

3) SAY: "What were the three words I asked you to remember?"				
<u>_</u>		(Score 1	I point for each) 3-Item Recall Score	
Score the clock (see other side for instructions):	Normal clock Abnormal clock	2 points 0 points	Clock Score	
Total Score = 3-item recall plus clock score		0, 1, or 2 possible impairment; 3, 4, or 5 suggests n		impairment

CLOCK SCORING

NORMAL CLOCK



A NORMAL CLOCK HAS ALL OF THE FOLLOWING ELEMENTS: All numbers 1-12, each only once, are present in the correct order and direction (clockwise). Two hands are present, one pointing to 11 and one pointing to 2.

ANY CLOCK MISSING EITHER OF THESE ELEMENTS IS SCORED ABNORMAL. REFUSAL TO DRAW A CLOCK IS SCORED ABNORMAL.

SOME EXAMPLES OF ABNORMAL CLOCKS (THERE ARE MANY OTHER KINDS)



Abnormal Hands



Missing Number

Mini-Cog[™] [Versions 1.0 and 2.0], Copyright 2000, 2003, 2005 by S Borson and J Scanlan. All rights reserved. Licensed for use in the Wisconsin Memory Screening Initiative (Wisconsin DHS/CMS). Any other use is strictly prohibited without permission from Dr. Borson, <u>soob@u.washington.edu</u>.

SCORING Memory Screen Tools

In the Memory Screening in the Community program, the screening tools are used as a part of a larger conversation. If a screener observes or receives information indicating a cognitive concern is present, a referral should be made to the physician regardless of the outcome of the tools. Referrals are only made with permission from the individual.

Animal Naming

In scoring this tool, 14 correct animals or more is considered 'not impaired'.

Mini-Cog

Word Recall

• Score one point (1) for each correct word recalled after the clock draw.

Clock Draw

- Correct clock scores two (2) points
- All other clock drawings are scored zero (0)
- Refusal to draw a clock is also scored zero (0)

Mini-cog tool result is the combined total of the word recall and clock draw tasks:

- 0-2 =Impaired
- 3-5 = Not impaired

AD8

The AD8 is scored by tallying the number of items noted as "Yes, a change." A score of two or more indicates cognitive impairment is likely to be present.

When to Make a Referral to the Physician

Refer to the primary care practitioner or dementia diagnostic clinic when:

Total Mini-Cog score = 0 - 2

OR

Animal Naming is less than 14 **and** score is zero (0) on either the word recall or the Clock Draw.

OR

The total score on the AD8 is 2 or greater.

OR

When additional information is available that indicates a discussion with a physician would be beneficial.

Material obtained through DHS activities performed under AoA ADSSP grant #90AI0027, 2010. Updated May, 2022.

Appendix F

Animal Naming

Introduction: "I'd like to ask a question to check your memory."

Instruction: "Tell me the names of as many animals as you can think of, as quickly as possible."

Procedure: Time for 60 seconds and record all responses.

If the person stops before 60 seconds, say "Any more animals?" If the person says nothing for 15 seconds, say "A dog is an animal. Can you tell me more animals?"

doa 1. 12. spray dandelion cat 2. 13 14. bírd COW 3 15. _____ pig 4 sheep 5: 16. _____ horse 6 17. _____ líon 7 18. _____ tiger 8. 19. _____ cat 20. _____ 9 10. mouse 21. _____ 11. ant 22. ______

Scoring: Count the total number of animals (NOT including repetitions or non-animal words):

Appendix G

Scoring the Clock Draw

Any of the following should be scored as **<u>zero</u>**:

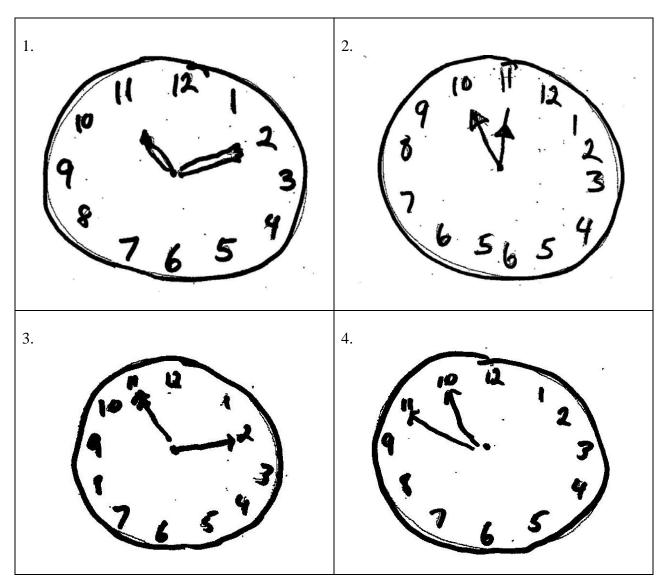
Error Time incorrect	Description Hands set incorrectly
No hands	No hands drawn
Missing numbers	One or more numbers missing, including the tick marks in place of numbers
Repeated numbers	Same number appears more than once
Substitution	Symbols or marks used in place of numbers, or time written out rather than shown by hands
Number orientation	Numbers counterclockwise
Number order	Number sequence incorrect
Numbers outside circle	Numbers placed outside exterior boundary of circle
Clock-like figure	Image, figure, symbols, or characters drawn do not resemble a clock or features expected on an analog clock face
Number spacing (major)	Gross error of spacing including a completely empty quadrant
Refusal	Test form blank, or tester recorded refusal to start or finish a partial attempt

NOTE: How long the hands are and pointing to the exact number aren't extremely important.

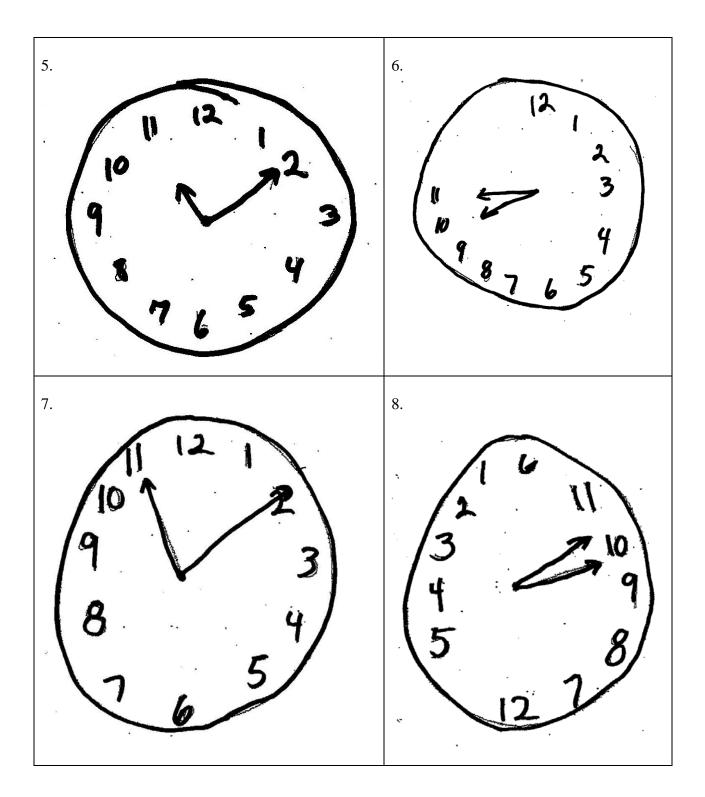
Appendix H

Sample Clocks

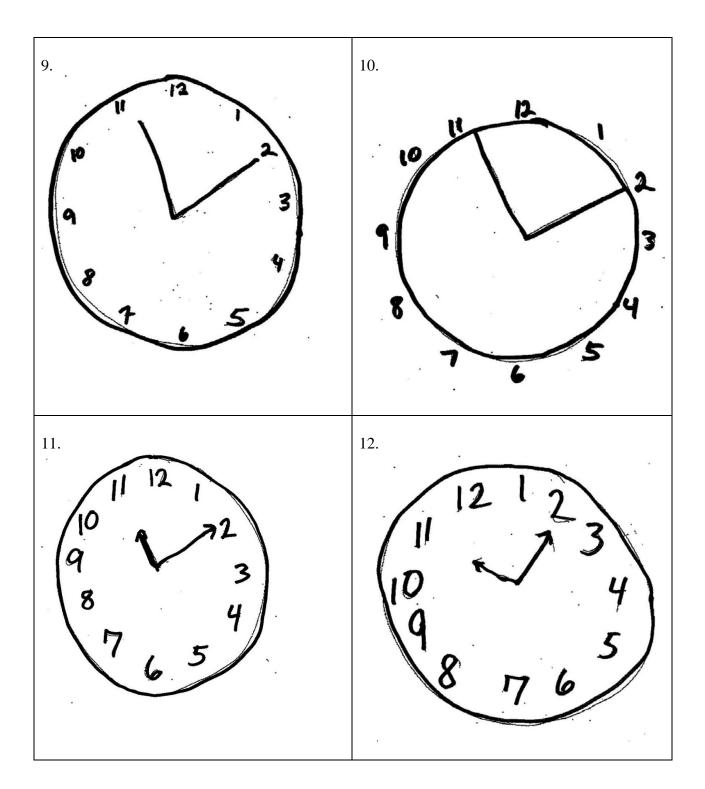
The following examples are of clock drawings performed by the individuals who were screened as a part of the pilot study. These examples may be used to practice scoring the clock draw. The score and interpretation for each clock is listed on the answer key following the example clock drawings.



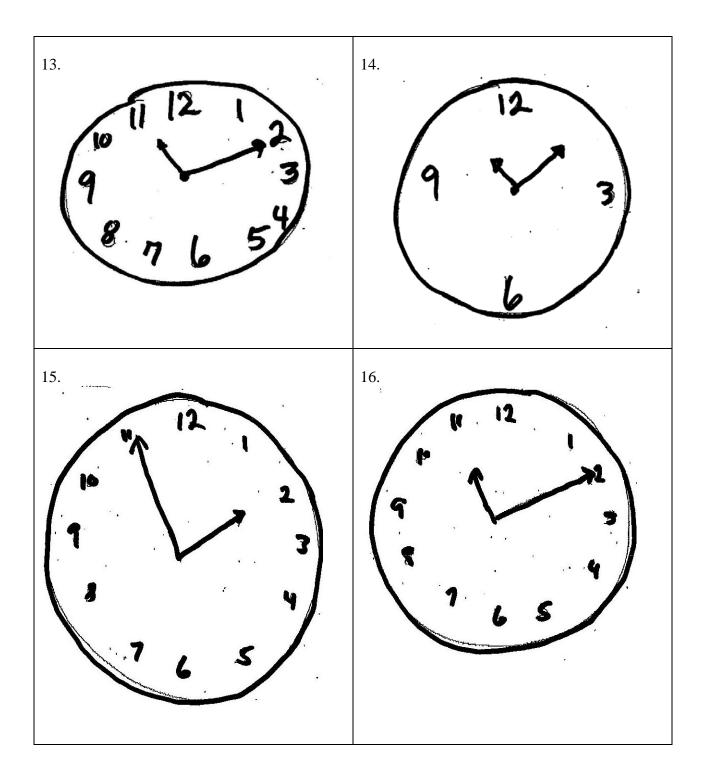
Sample Clocks



Sample Clocks







Scoring Clock Drawing Answer Key

- 1. Correct clock score 2.
- 2. Incorrect clock score 0.
- 3. Correct clock score 2. The slight error in hand length and placement are minor.
- 4. Incorrect clock score 0. This is a classic example of a clock draw from someone with cognitive impairment.
- 5. Correct clock score 2.
- 6. Incorrect clock score 0.
- 7. Correct clock score 2. The hand length error is minor.
- 8. Incorrect clock score 0.
- 9. Correct clock score 2.
- 10. Incorrect clock score 0. Directions state to "put all the numbers in the circle". The numbers are outside of the circle.
- 11. Correct clock score 2.
- 12. Correct clock score 2. The number placement error is minor.
- 13. Correct clock score 2.
- 14. Incorrect clock score 0. Directions state to "put all the numbers in the circle". Not all the numbers are included.
- 15. Incorrect clock score 0. The hand length error is severe and shows the incorrect time. (It actually reads 1:55, or 5 minutes to 2:00.)
- 16. Correct clock score 2.

Appendix I

SAMPLE AUTHORIZATION TO RELEASE CONFIDENTIAL INFORMATION

I, the undersigned, hereby authorize the disclosure, release, re-release, and exchange of the records and information specified below concerning

NAME	_ whose date of birth	ו is	between the following organizations:
Aging & Disability Resource Center of Portage County	AND	Ministry Medical Gro St. Michael's Hospit Attention:	
1519 Water Street		824 Illinois Avenue	
Stevens Point, WI 54481		Stevens Point, WI	54481
TYPE OF INFORMATION TO BE RELEAS	SED: Verba	al Written	
INFORMATION TO BE RELEASED:			
Psychiatric/Psychological Evaluations	Staffing/Progree Medical Evalua Education Eval Income Maintee Other (Specify)	ations/ H & P / Record luations/Records nance Records	HIV (AIDS) Laboratory Reports Medications Discharge Summary
PURPOSE FOR NEED OF DISCLOSURE:	(Check applicable	categories)	
 Disability Determination (SSI/SSDI) Benefit Applications (FS/Medicaid) Other (Specify):			Medical Care Personal

I understand that if the person and/or agency listed above is not governed by applicable federal and state laws and administrative codes, the confidential information disclosed as a result of this authorization may no longer be protected from further re-disclosure without obtaining my authorization.

YOUR RIGHTS WITH RESPECT TO THIS AUTHORIZATON:

WITNESS: _____

I understand that I have the right to inspect or have a copy of the confidential information I have authorized to be used or disclosed by this authorization form. I understand that if I agree to sign this authorization, which I am not required to do, I must be provided with a signed copy of the form. I understand that I am under no obligation to sign this form and that the person and/or agency listed above who I am authorizing to use and/or disclose my information may not condition treatment, payment, enrollment in a health plan or eligibility for health care benefits on my decision to sign this authorization. I understand written notification is necessary to cancel this authorization. To obtain information on how to withdraw my authorization, I may contact the staff providing/coordinating my services. I am aware that my withdrawal will not be effective as to uses and/or disclosures of my health information that the person and or agency listed above have already made in reference to this authorization.

EXPIRATION DATE: This authorization is good until the completion of active services with PORTAGE COUNTY unless a specific date is entered here ______ or unless a written notice of revocation is submitted.

I have had an opportunity to review and understand the content of this authorization form. By signing this authorization, I am confirming that it accurately reflects my wishes. A copy of this authorization will be considered as valid as the original.

PRINT NAME:	:	
	•	

SIGNATURE PATIENT/LEGAL REP:			DATE:		
Signature is that of the:	Client/Patient _	Parent of Minor	Legal Guardian	Client/Patient's Representati	ve

Physician Name	
Clinic Name	
Address	
City/State/Zip	
Name	Phone

Enclosed you will find the results of a community-based cognitive screen for your patient listed above. The results indicate that this person may be experiencing cognitive impairment and should discuss related concerns with a physician. An explanation of the wide range of possible causes for memory loss or confusion was provided, including information about both treatable and untreatable conditions. Our agency recommended schedule an appointment to discuss these concerns with you.

has been approved by the Wisconsin Department of Health Services to provide community-based memory screening to promote early detection of cognitive changes as well as to encourage diagnosis of persons with Alzheimer's disease or related dementias. The screening process is voluntary and offered when an individual expresses concerns about memory loss or confusion to agency staff. Your patient requested the results of the screening be shared with you. Results of the Animal Naming, Mini-cog or AD8 screens are attached for your review.

If your patient is diagnosed with a form of dementia, the agency is available to provide information and connection with supportive programming for both the person with dementia and the family caregiver. Agency staff received training on the specific needs of people with dementia and their families and can offer ongoing support in the community.

If you have any questions, please do not hesitate to contact me at_____.

Sincerely,



Completing a targeted medical evaluation with individuals that have findings on standardized cognitive screening is an important next step. The Wisconsin Alzheimer's Institute offers these tips for primary care providers in completing such a medical evaluation.

Best practices when medically working up a patient's memory concerns

- Review prescriptions and over-the-counter products to identify those that could affect cognition (e.g., allergy medicines, sleeping medicines, medications for urinary incontinence, etc.)
- ✓ Screen for obstructive sleep apnea (e.g., snoring, excessive daytime sleepiness, etc.) and other sleep disorders
- ✓ Ask about depression symptoms, which can affect sleep and reduce concentration
- ✓ Screen for stroke symptoms
- ✓ Review vascular risk factors
- ✓ Query about tremors, falls, incontinence, dysphagia, prior serious head injuries, and alcohol and drug use
- ✓ Review changes in daily function that are attributable to cognitive decline (e.g., managing finances, keeping appointments, etc.)
- ✓ Complete targeted neurological and cardiovascular exams
- ✓ Check basic lab tests: vitamin B12, TSH, 25-OH vitamin D, CBC, basic metabolic profile, liver enzymes, and HIV

When to refer to a memory clinic

From the above work-up, referring to a dementia specialist may be prudent if the patient:

- ✓ Is <65 years old</p>
- ✓ Has tremors, falls, hallucinations, or ataxia
- ✓ Has numerous confounding factors
- ✓ Has an atypical presentation
- ✓ Has difficult behavioral symptoms
- ✓ Has functional impairment out of proportion to cognitive screening test score

Unfortunately, more than 50% of people with dementia are not diagnosed, yet early detection can make a big difference in helping protect brain function and with ongoing chronic disease management. In addition, there are many community resources to help patients, families, and primary care clinicians access the quality cognitive care they need. Your local Aging and Disability Resource Center is a great place to start to make those connections.

Suggestions provided by Cynthia Carlsson, MD, MS, professor of medicine, University of Wisconsin School of Medicine and Public Health

Appendix L

Memory Screening Results and Recommendations

Date:

Participant's Name:

Screening Results:

Animal Naming (score < 14 suggests follow-up) Mini-Cog[©] (score < 4 suggests follow-up)

Recommendations:

 \Box Follow-up with your primary care provider to discuss screening results

□ Have a memory screening in one year

Advance Directives:

- Complete a Power of Attorney for Healthcare (POA-HC)
- Give a copy of your POA document to your primary care provider
- Complete a Power of Attorney for Finance (POA-F)

\Box Other:

Your contact person for questions about today's screening:

Phone:

Email:

Keep in mind the services the ADRC can assist with such as:

- □ Eligibility screening for financial assistance programs
- □ Information on community services
- □ Benefit specialist assistance
- □ Healthy living programs Stepping On Fall Prevention, Living Well with Chronic Conditions/Diabetes, Strong

Bodies, Better Brain Fridays, Powerful Tools for Caregivers, Boost Your Brain and Memory Other:

We recommend you learn about healthy aging lifestyle practices and safety considerations:

- □ Brain health and cognitive exercises
- □ Home safety
- \Box Good sleep habits
- \Box Family and friend support
- □ Driving safety
- □ Nutrition
- □ Gun safety
- \Box Physical health and exercise
- □ Other:

Learn about the conditions that can affect the brain and services that are available to assist:

- Alzheimer's Disease Research Center, https://www.adrc.wisc.edu/, 608-265-0407
- Alzheimer's and Related Dementias Education and Referral Center, https://www.nia.nih.gov/health/alzheimers
- Alzheimer's Association, <u>www.alz.org/wi</u>, 800-272-3900
- □ Frontotemporal Disorders, <u>www.theaftd.org</u>
- Lewy Body Dementia, <u>www.lbda.org</u>

Frequently Asked Questions

What is dementia?

Dementia is a general term used to describe thinking and memory issues severe enough to interfere with daily life. Alzheimer's disease is the most common cause of dementia. Other conditions can cause dementia as well, such as Lewy body disease, head injuries, Parkinson's disease, frontotemporal disorders, and stroke. Some people experience dementia-like symptoms that can be treated, resulting in the symptoms going away. These types of reversible dementia-like symptoms in older adults can be caused by such conditions as poor nutrition, sleep apnea, clinical depression, and infection. The ability to treat and/or reverse dementia-like symptoms is a primary reason the person should have a medical evaluation if they experience memory and thinking changes.

What does the memory screening measure?

The memory screens are a simple, safe, confidential, and validated evaluation tool that checks memory and thinking skills. It can indicate whether an additional checkup by a qualified healthcare professional is needed. A memory screen is not used to diagnosis any type of dementia or other illness, but rather to see if something else might be going on. It also does not replace consultation with a qualified physician or other healthcare professional.

Does insurance cover the cost of a memory evaluation?

Typically, doctors and other healthcare professionals do memory evaluations in outpatient settings. Medicare and commercial insurances usually cover such outpatient services done by approved healthcare providers. To be sure, check with your insurance provider and ask the memory clinic if your insurance benefits cover the evaluation service. This will help you determine if there are any co-pays or benefit restrictions, or if pre-authorization is required.

Eau Claire County has three memory clinics that are part of the Wisconsin Alzheimer's Institute (WAI) Affiliated Dementia Diagnostic Clinic Network. Network clinics differ from other memory clinics in that they follow a set of best practice guidelines that include use of an interdisciplinary care model. In addition, clinic team members receive ongoing training and support from WAI regarding cutting-edge approaches to the diagnosis and treatment of Alzheimer's dementia and related disorders. Clinics in the Network remain autonomous, meaning they are a part of various healthcare systems and are not entities within WAI.

Is there financial assistance to cover the cost of services if needed?

The Aging & Disability Resource Center (ADRC) is the access point for publicly funded programs, such as Family Care and IRIS. ADRCs also have benefit specialists that can help with questions related to Social Security, Medicare, and private health or long-term care insurance.

Another program through the ADRC is the Alzheimer's Family Caregiver Support Program (AFCSP). In response to the stress and services needs of families caring for someone with irreversible dementia in the home, funds are available to assist eligible families to purchase services and goods related to the care of someone living with Alzheimer's disease or related dementia.



NTG-EDSD

v.1/2013.2

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

¹⁾ File #:		⁽²⁾ Date:	
Name o	f person: ⁽³⁾ First	⁽⁴⁾ Last:	
⁵⁾ Date	of birth:	⁽⁶⁾ Age:	
⁷⁾ Sex:			
Г	Female	Г	Instructions:
	Male		For each question block, check the item that
	No discernible intellectual disability		
-	No discernible intellectual disabilityBorderline (IQ 70-75)Mild ID (IQ 55-69)Moderate ID (IQ 40-54)		
-	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39)		
-	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54)	ſ	
-	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39)	[Current living arrangement of person:
- - - 1) Diagn	Borderline (IQ 70-75)Mild ID (IQ 55-69)Moderate ID (IQ 40-54)Severe ID (IQ 25-39)Profound ID (IQ 24 and below)		 Lives alone Lives with spouse or friends Lives with parents or other family members
- - - - Diagn	Borderline (IQ 70-75)Mild ID (IQ 55-69)Moderate ID (IQ 40-54)Severe ID (IQ 25-39)Profound ID (IQ 24 and below)Unknown		 Lives alone Lives with spouse or friends Lives with parents or other family members Lives with paid caregiver
) Diagn	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39) Profound ID (IQ 24 and below) Unknown osed condition (check all that apply)		 Lives alone Lives with spouse or friends Lives with parents or other family members Lives with paid caregiver Lives in community group home, apartment,
) Diagn	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39) Profound ID (IQ 24 and below) Unknown osed condition (<i>check all that apply</i>) Autism Cerebral palsy Down syndrome		 Lives alone Lives with spouse or friends Lives with parents or other family members Lives with paid caregiver Lives in community group home, apartment, supervised housing, etc.
) Diagn	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39) Profound ID (IQ 24 and below) Unknown osed condition (check all that apply) Autism Cerebral palsy Down syndrome Fragile X syndrome		 Lives alone Lives with spouse or friends Lives with parents or other family members Lives with paid caregiver Lives in community group home, apartment, supervised housing, etc. Lives in senior housing
") Diagn	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39) Profound ID (IQ 24 and below) Unknown osed condition (<i>check all that apply</i>) Autism Cerebral palsy Down syndrome		 Lives alone Lives with spouse or friends Lives with parents or other family members Lives with paid caregiver Lives in community group home, apartment, supervised housing, etc. Lives in senior housing Lives in congregate residential setting
³⁾ Diagn	Borderline (IQ 70-75) Mild ID (IQ 55-69) Moderate ID (IQ 40-54) Severe ID (IQ 25-39) Profound ID (IQ 24 and below) Unknown osed condition (check all that apply) Autism Cerebral palsy Down syndrome Fragile X syndrome		 Lives alone Lives with spouse or friends Lives with parents or other family members Lives with paid caregiver Lives in community group home, apartment, supervised housing, etc. Lives in senior housing

⁽¹⁰⁾ General characterization of <u>current</u> physical health:

Excellent
Very good
Good
Fair
Poor

⁽¹¹⁾ Compared to <u>one year ago</u>, current <u>physical</u> health is:

Much better
Somewhat better
About the same
Somewhat worse
Much worse

⁽¹²⁾ Compared to <u>one year ago</u>, current <u>mental</u> health is:

Much better
Somewhat better
About the same
Somewhat worse
Much worse

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

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

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

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

(15) Seizures

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

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

⁽¹⁶⁾ Diagnostic History				
Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:				
[] No				
[] Yes, MCI				
Date of Dx:				
[] Yes, dementia				
Date of Dx:				
Type of dementia:				
Diagnosod by:				
Diagnosed by: Geriatrician 				
Neurologist				
Physician Revehiatrist				
 Psychiatrist Psychologist 				
 Differ: 				

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

⁽¹⁸⁾ Comments / explanations about dementia
suspicions:

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
⁽¹⁹⁾ Activities of Daily Living				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete,				
inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
⁽²⁰⁾ Language & Communication				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
⁽²¹⁾ Sleep-Wake Change Patterns				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
(22)				
⁽²²⁾ Ambulation				
Not confident walking over small cracks, lines on the ground,				
patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	New symptom in past year	Does not apply	
⁽²³⁾ Memory					
Does not recognize familiar persons (staff/relatives/friends)					
Does not remember names of familiar people					
Does not remember recent events (in past week or less)					
Does not find way in familiar surroundings					
Loses track of time (time of day, day of the week, seasons)					
Loses or misplaces objects					
Puts familiar things in wrong places					
Problems with printing or signing own name					
Problems with learning new tasks or names of new people					
(24) Behavior and Affect					
Wanders					
Withdraws from social activities					
Withdraws from people					
Loss of interest in hobbies and activities					
Seems to go into own world					
Obsessive or repetitive behavior					
Hides or hoards objects					
Does not know what to do with familiar objects					
Increased impulsivity (touching others, arguing, taking things)					
Appears uncertain, lacks confidence					
Appears anxious, agitated, or nervous					
Appears depressed					
Shows verbal aggression					
Shows physical aggression					
Temper tantrums, uncontrollable crying, shouting					
Shows lethargy or listlessness					
Talks to self					
(25) Adult's Self-reported Problems					
Changes in ability to do things					
Hearing things					
Seeing things					
Changes in 'thinking'					
Changes in interests					
Changes in memory					
⁽²⁶⁾ Notable Significant Changes Observed by Others					
In gait (e.g., stumbling, falling, unsteadiness)					
In personality (e.g., stumpling, failing, unsteadiness)					
In friendliness (e.g., now socially unresponsive)					
In attentiveness (e.g., now socially unresponsive)					
In weight (e.g., weight loss or weight gain)					
In abnormal voluntary movements (head, neck, limbs, trunk)					

[Check column option as appropriate]

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

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

NTG-EDSD - page 6

⁽²⁸⁾ C	(28) Current Medications				
Yes	No	Indicate type			
		Treatment of chronic conditions			
		Treatment of mental health disorders or behavior problems			
		Treatment of pain			
		ws, attach list of current medications, dosage, and when prescribed s attached for reviews			
⁽²⁹⁾ C	omm	ients related to other notable changes or concerns:			

⁽³⁰⁾ Next Steps / Recommendations

- □ Refer to treating physician for assessment
- □ Review internally by clinical personnel
- □ Include in annual review / annual wellness visit
- □ Repeat in _____ months

Form completion information

⁽³¹⁾ Date completed	⁽³²⁾ Organization / Agency				
Name of person completing for	m				
Relationship to individual (staff,	relative, assessor, etc.)				
Date(s) form previously comple	sted				
Date(3) form previously comple					
Relationship to individual (staff, relative, assessor, etc.) Date(s) form previously completed					

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



National Task Group Early Detection Screen for Dementia

NTG-EDSD

Manual

Version 1 May 2013-e

Available at www.aadmd.org/ntg/screening

For suggestions, comments, or more information, contact Dr. Lucille Esralew at drlucyesralew @gmail.com

Recommended citation:

Esralew, L., Janicki, M.P., DiSipio, M., Jokinen, N., Keller, S.M. and Members of the National Task Group Section on Early Detection and Screening. (2013). *National Task Group Early Detection Screen for Dementia: Manual*. Available from www.aadmd.org/ntg/screening.

Version 1 May 2013-e

BACKGROUND

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

Why Early Detection?

Early detection is one of the aspects stressed by the *National Plan to Address Alzheimer's Disease*. With early detection, assessment and diagnosis can be carried out to determine whether cognitive changes are the result of a neuropathological process related to disease or trauma to the brain, or attributable to other causes, often treatable and reversible. However, early detection among persons with lifelong cognitive impairments can often be difficult and problematic (Prasher, 2005). Specialized measures are needed that help take in account lifelong impairment and assist in picking up on subtleties in dysfunction. The NTG-EDSD was developed to address these issues, capturing early changes in function and specializing in accounting for subtleties in these changes.

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

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

Early detection can be an outcome of individual screening (Borson et al., 2013). There is an important distinction between *screening*, involving the use of the NTG-EDSD and *evaluation or assessment* which is conducted using formal instruments designed to diagnose dementia. The function of screening is the identification of current atypical functioning indicative of decline or cognitive impairment. A screening tool does not help establish the origins of change; but, it is useful in substantiating change. On the basis of this observation, the person with suspected dementia can be referred for an assessment using a standard dementia assessment instrument and other medical measures. Screening tools generally are quick, easy to administer, can be completed by a family member or staff caregiver, and can be used at intervals to ascertain changes. Such screening results in a determination that the adult meets a clinical, behavioral, or functional threshold to be referred for assessment and / or to initiate dementia-related services and supports.

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

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

Why the need for an administrative tool?

The NTG-EDSD is considered an administrative tool. Such a tool is meant as a first pass screening to identify individuals who might need more comprehensive assessment. Each service setting may develop its own protocol regarding how information from this assessment can best be utilized on behalf of the consumer. However, it is conceivable that care paths might include sharing the information with the consumer's physician, deciding if there needs to be a change in programmatic or personal care supports, a reallocation of resources, or provide an implication for the residential setting. The team may want to adopt a "watchful waiting" approach in which certain areas of identified change are further monitored through additional data collection. As many agencies indicated that they did not have access to professionals who could provide a cognitive screening, the NTG wanted to make a tool available that was accessible to caregivers who were not necessarily trained to do assessment, but had valuable information regarding dayto-day changes in functioning. The tool needed to be easy to administer, cannot be time consuming, and should be sufficiently robust to yield information that could be used as an aid in shared decision making.

The items that make up the NTG-EDSD are associated with the changes typically observed in dementia. Via the use of this screening tool caregivers or staff can substantiate if a person with and intellectual disability manifests these changes and can then share the information with health care providers.

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

DEVELOPMENT OF THE NTG-EDSD

Historical basis

The NTG-EDSD has its roots in a meeting held in the mid-1990s, which was the first time a collection of researchers interested in dementia and intellectual disabilities came together. In 1994, a conference support grant from the National Institute for Health helped support a meeting held in Minneapolis, Minnesota, held in association with an international Alzheimer's conference, which was one of the early iterations of the international Alzheimer's conference now known as the ICAD [International Conference on Alzheimer's disease]. The outcomes and products of this meeting included a number of reports and publications as well as the formation of an informal network of the researchers in the field of intellectual disabilities and dementia. One of the papers that resulted from the meeting was co-authored by a team lead by Drs.

Elizabeth Alyward and Diana Burt (see Alyward et al., 1996) and published in the *Journal of Intellectual Disability Research*. The paper addressed the rationale for and reviewed assessment and diagnostic tools relevant to conducting research on individuals with intellectual disabilities affected by dementia. These tools were for direct assessment of adults with intellectual disabilities suspected as having cognitive changes associated with dementia and were in use for various purposes (some purely clinical and some research based). The interested reader is directed to the work of Alyward and Burt (Alyward et al., 1996; Burt et al., 2000). See also Jokinen et al. (2013) for a listing of prevalent assessment instruments currently in use and their applications.

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

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

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

the original members of the 1994 workgroup on diagnosis and assessment. Group S members elicited feedback from the other NTG members regarding tools that were in current use and which have proved helpful in identification of individuals who might have dementia.

Development process

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

The members of Group S then reviewed the instruments on a variety of indicators. On the basis of this review, the members endorsed the use of the DSQIID (Deb, 2007). This recommendation was reviewed when the full NTG convened at its June 2011 meeting in St. Paul in conjunction with the AAIDD's annual conference. At this meeting, Group S was further tasked to come up with an early detection screen that included an augmentation and adaptation of the DSQIID and which could be used by family and staff caregivers. It was decided also to include ancillary information so as to broaden its content and usefulness for clinicians. Thus, items gathering information on individual demographics, co-incident medical conditions and impairments, and significant life factors were added.

Coincident, with the working group's efforts, the Philadelphia PMHCC also undertook a secondary adaptation of the DSQIID with the assistance of Dr. Karl Tyler of the Cleveland Clinic (Philadelphia Coordinated Health Care Group, 2011). This version was further adapted by the working group to include items felt to be pertinent to early detection. The draft composite instrument went through several revisions and then was field tested over the summer of 2012 in eight sites, including agencies in the continental U.S., Canada, and Austria. The Austrian field test used a German language translation.

Field Testing of the NTG-EDSD

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

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

THE NTG-EDSD

Description of the NTG-EDSD

The NTG-EDSD is composed of four primary sections containing some 40 questions or question groupings about relevant demographics, ratings of health, mental health and life stressors, a review of multiple domains associated with adult functioning, and a review of chronic medical conditions. It also provides for a notation on the number and nature of medications being taken, and permits comments on observations to be entered. Specifically, the NTG-EDSD contains ten basic demographic items (such as identification data, personal characteristics, diagnostic, and residential setting information, eight health and function items, and the adaptation of the DSQIID (including queries as to Activities of Daily Living, Language and Communication, Sleep-Wake Change Patterns, Ambulation, Memory, Behavior and Affect, the Adult's Self-Reported Problems, and Notable Significant Changes Observed by Others. The NTG-EDSD also contains an adapted form of the University of Illinois at Chicago's Longitudinal Health and Intellectual Disability Survey (Rimmer & Hsieh, 2010) which is used to

note co-incident conditions (these include the following categories: Bone, Joint and Muscle; Heart and Circulation; Hormonal; Mental Health; Pain-Discomfort; Sensory; and Other). The last section of the NTG-EDSD contains an item on current medications, a place to note comments related to other notable changes or concerns, and next steps and recommendations, as well information on the form completion.

Uses of the instrument

The NTG-EDSD can be completed at any point in time on an adult with an intellectual disability. Minimally it can be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change.

The NTG-EDSD can also be used in preparation for the annual wellness visit under the Affordable Care Act. Having concise information available for the examining physician can help instigate queries and any follow-up assessments. For recommendations on it use as part of any physician visit, see Moran et al. (2013).

The initial review using the NTG-EDSD can be accompanied by notes indicating onset of conditions. Following the initial review which would serve as a baseline, the caregiver completing the form can indicate whether there has been a change within the last year since the last review. At the point that the individual is determined to need more comprehensive assessment, a referral should be made for more comprehensive work-up that would include medical and psychological testing.

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

Who can complete the NTG-EDSD?

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record.

Useful information to have available to aid completion

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

How to complete the form

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

How to use the information obtained from this review

The information may be used in various ways: (1) if no signal items pop up as warranting further attention, then the form should be retained for comparison against any future administrations; (2) if select signal items begin to show, then the form can be used to begin a conversation with available clinicians to determine their relevance and immediacy for concern; (3) the information on the form can be shared with the examining physician during any health visit (and in particular during the annual wellness visit as provided for under the Affordable Care Act); and (4) the form may be shared with the agency's consulting psychologist as part of any follow-up procedures put in place specific observations for noted change areas

What are some signal items?

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

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

Limitations

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

Areas for further development

There is no scoring system currently associated with the use of the NTG-EDSD. This instrument provides the opportunity for a qualitative, not a quantitative review of changes that

may be associated with the types of changes in cognition and adaptive functioning observed in dementia. As the instrument gains more widespread use there would be value in collecting data linking confirmed diagnoses with results of screening. This may result in a scoring system or allow for identification of signal items most likely indicative of dementia.

Versions of the NTG-EDSD

The NTG-EDSD is currently available in English, German, Greek, and Italian language versions. Versions in Dutch, French, and Spanish are in development. See <u>www.aadmd.org/</u><u>ntg/screening</u> for copies of available language versions.

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ACKNOWLEDGEMENTS

This screening tool has had multiple permutations since development of the DSQIID by Dr. Shoumitro Deb in 2007. Thanks to Dr. Deb for his hard work in developing the DSQIID, which is still in use to assess dementia, worldwide. Thanks to Melissa DiSipio, Dr. Karl Tyler, and the team at PMHCC [Philadelphia Mental Health Care Corporation] who adapted the DSQIID in order to monitor individuals of the Pennhurst class, who were originally residents of an institution in the Philadelphia, Pennsylvania area and who now reside within the community. The work of that team in monitoring health status is still on-going and has resulted in three years of data collection. Special appreciation is extended to members of the NTG who offered input into the process and the NTG steering committee who provided input, suggestions and encouragement.

The following NTG Steering Group members are acknowledged for their direction and helpful comments during the development and production of the NTG-EDSD and its Manual: Kathleen Bishop, Melissa Disipio, Lucy Esralew, Lawrence Force, Mary Hogan, Matthew Janicki, Nancy Jokinen, Seth Keller, Ronald Lucchino, Philip McCallion, Julie Moran, Dawna Torres Mughal, Leone Murphy, Lin Nelson, Kathleen Service, Baldev Singh, Kathy Srsic-Stoehr, Michael Rafii, Nabih Ramadan, Sara Weir. Special thanks are extended to Dr. Esralew's graduate assistant, Elizabeth Uccello.

For suggestions, comments, or more information, contact Dr. Lucille Esralew at <u>drlucyesralew@gmail.com</u>

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

Item #	Item Title	Comment
1	File#	For agency use
2	Date	Date form completed
3/4	Name of person	Fill in first and last name of person being
		screened
5	Date of birth	Provide day, month, year
6	Age	Age when form was completed
7	Sex	Indicate male or female
8	Best description of level of intellectual	Draw from any previously completed
	disability	assessments or estimate if none ever done
9	Diagnosed condition	Draw from any previously completed
		assessments or estimate if none ever done
-	Current living arrangement of person	Pick most appropriate item
10	General characterization of current physical health	Pick most appropriate item
11	Compared to one year ago, current physical health is:	Pick most appropriate item
12	Compared to one year ago, current mental health is:	Pick most appropriate item
13	Conditions present	Indicate those diagnosed as well as observed
14	Significant recent [in past year[life event	Indicate those that occurred
15	Seizures	Pick most appropriate item
16	Diagnostic history	Complete this item only if the person has been
		formally assessed and diagnosed; use
		information provided in diagnostic report
17	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms
		were noticed
18	Comments/explanation about dementia	Indicate any behaviors that triggered
	suspicions	suspicions or referral for assessment
19	Activities of daily living	Pick most appropriate column item for each
		'Always been the case' means the need,
		problem or behavior has been present for a
		very long time
		'Always but worse' means the existing need,
		problem or behavior has further declined
		requiring more personal assistance
		'New symptom in past year' means this need,
		problem or behavior was not present until
		recently
		'Does not apply' means these needs, problems
		or behaviors are not present
20	Language & communication	Pick most appropriate column item for each

21	Sleep-wake change patterns	Pick most appropriate column item for each
22	Ambulation	Pick most appropriate column item for each
23	Memory	Pick most appropriate column item for each
24	Behavior and affect	Pick most appropriate column item for each
25	Adult's self-reported problems	Pick most appropriate column item for each 'Self-reported' means the adult has expressed one or more of these things
26	Notable significant changes observed by others	Pick most appropriate column item for each Assume that these are new behaviors
27	Chronic health conditions	Pick most appropriate column item for each Draw from any previously completed medical evaluations or current health notes in record
28	Current medications	This item is to help the physician or other clinician assess whether current medications may be the cause of behavioral or functional changes. Best to include a listing of current medication, with dosages, when sending or bringing form to assessment.
29	Comments related to other notable changes or concerns	Use this item to make comments of use related to behavior, function, or any events that may influence behavior
30	Next steps/recommendations	Check most relevant item
31	Date completed	Date form completed
32	Organization/agency	Name of organization providing services to the adult
-	Name of person completing form	Indicate your name
-	Relationship to individual	Indicate whether you are staff, a relative or someone else
-	Date(s) form previously completed	If the NTG-EDSD has been completed before, indicate when

www.aadmd.org/ntg/screening

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APPENDIX B: Some of the laboratory and medical tests that might be used to rule out other sources of cognitive change among persons with intellectual or developmental disabilities

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

Recent Blood work (within 3 months) that includes

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

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

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

Special thanks to Isabelle Grenon, Ph.D. and Melissa DiSipio, MSA for their assistance in compiling this list.

Appendix O

NOMBRAR ANIMALES

Nombre _____

de ID_____

Fecha _____

Instrucción: "Dígame los nombres de tantos animales como usted pueda pensar, lo más rápido posible."

Procedimiento: Designe un tiempo de 60 segundos y anote todas las respuestas.

Si la persona se detiene antes de 60 segundos, pregunte "¿Algún otro animal?"

Si la persona no dice nada durante 15 segundos, diga "un perro es un animal.

"¿Puede nombrar más animales?"

1	12
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	22

Puntaje: Cuente el número total de animales (SIN incluir repeticiones o palabras que no sean nombres de animales):

Siguiente paso: Haga el test de Mini-Cog

FECHA	EDAD	SEXO M F	Localidad		Administrac	o por	
Appendix P				<u>MINI-COG</u> ™ -S	panish		
,	ENGA LA ATENC voy a decir tres				ı y más tarde. Las p	alabras son	
Por	favor, dígamela	as ahora."		Manzana	Amanecer	Silla	
	Intento 1						
	Intento 2 (administre sól dígamelas ah	•	as no fueron rep	etidas en el Intento 1.	Diga " Las palabras sc	on Manzana, Amanecer, Si	lla. Por favor,
	Intento 3 (administre sól dígamelas ah	•	as no fueron rep	etidas en el Intento 2.	Diga " Las palabras so	on Manzana, Amanecer, Si	lla. Por favor,

(Indique con una marca de verificación $[\sqrt{}]$ cada palabra que es repetida correctamente. Dele 3 intentos para repetir las palabras alparticipante. Si es incapaz de repetir las palabras después de 3 intentos, continúe con el siguiente ítem.)

- 2) Dele al participante la Página 2 de este formulario y un lápiz/lapicero. DIGA LAS SIGUIENTES FRASES EN EL ORDEN CORESPONDIENTE: "Por favor, dibuje un reloj en este espacio. Comience dibujando un círculo grande." (Cuando esto haya sido completado, diga) "Coloque todos los números en el círculo." (Cuando esto haya sido completado, diga) "Ahora coloque las manecillas del reloj para que marquen las 11 y 10." Si el participante no ha terminado de dibujar el reloj en 3 minutos, suspenda este ítem y pídale al participante que le diga las tres palabras que le pidio que recordara antes.
- 3) DIGA: "¿Cuáles fueron las tres palabras que le pedí que recordara?"

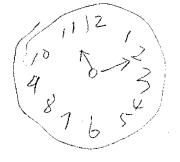
		(Puntúe 1 por cada una)	Puntaje de las Palabras	
Puntúe el reloj (según el formulario de Puntaje del Reloj):	Reloj Normal Reloj Alterado	2 puntos 0 puntos	Puntaje del Reloj	
Puntaje Total = Puntaje de Palabras más Puntaje del R	eloj	0, 1, o 2 posible trastorno 3, 4, o 5 indica que no hay		

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RELOJ

PUNTAJE DEL DIBUJO DEL RELOJ

RELOJ NORMAL



UN RELOJ NORMALCONTIENE TODOS LOS SIGUIENTES ELEMENTOS:

Todos los números 1-12, cada uno solo una vez, están presentes en el orden y dirección correctas dentro del círculo. Dos manecillas están presentes, una apuntando al 11 y la otra al 2.

CUALQUIER RELOJ AL QUE LE FALTE ALGUNO DE ESTOS ELEMENTO SE CONSIDERA ANORMAL. SI EL PARTICIPANTE SE REÚSA A DIBUJAR EL RELOJ, ENTONCES ÉSTE SE CONSIDERA ANORMAL.

ALGUNOS EJEMPLOS DE RELOJES ANORMALES (EXISTEN MUCHAS OTRAS CLASES)



Agujas Incorrectas



Faltan algunos números

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CUESTIONARIO AL INFORMADOR AD8 (versión española) (Carnero Pardo C, et al. Neurología 2012. doi:10.1016/j.nrl.2012.03.012)

Con respecto a la persona a la que acompaña, ¿qué opina sobre los siguientes aspectos?:

Recuerde, "Sí, ha cambiado" significa que usted piensa que ha habido un cambio en los siguientes aspectos en los últimos años causado por problemas cognitivos (razonamiento y memoria)	Sí , Ha cambiado	No , No ha cambiado	NS/NC No sabe/ No contesta
Problemas para emitir juicios y tomar decisiones adecuadas (ej.: le engañan o timan, toma decisiones financieras erróneas, hace regalos inapropiados, etc.)			
Pérdida de interés en sus aficiones y actividades (ej.: ha dejado de hacer actividades que le gustaban)			
Repite las preguntas, los comentarios o las cosas que cuenta			
Dificultad para aprender a usar herramientas, aparatos o dispositivos (ej.: video o DVD, ordenador, microondas, mandos a distancia, teléfono móvil o inalámbrico)			
Olvida el mes o año correcto			
Dificultad para manejar asuntos financieros complicados (ej.: ajustar cuentas, talones, impuestos, facturas, recibos, etc.)			
Dificultad para recordar las citas y cosas que tiene que hacer			
Los problemas de razonamiento y/o memoria son cotidianos y no ocasionales			
TOTAL			

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Appendix R

Certificate of Achievement

Awarded to

NAME

For Participation in the

Cognitive Screen Training: Skills Building

Month, date, year Contact Hours: XX Hours

Presented by:

Trainer Name Agency Name Date Awarded: Month, date, year