MEMORY SCREENING IN THE COMMUNITY

How to Administer Community-Based Memory Screens

WISCONSIN DEPARTMENT *of* HEALTH SERVICES
Division of Public Health | P-01622 (07/2022)

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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 dhsdementiawebmail@dhs.wisconsin.gov.

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.

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[1] Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors - PMC (nih.gov)
[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) Dementia Diagnostic Clinic Network 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] Alzheimer's Stages - Early, Middle, Late Dementia Symptoms | alz.org
[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 impairment[14].

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 AD8 tool 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 MoCA website. 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 Health Equity section 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 the MoCA website. 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 virtually[16]. The ability to provide screening virtually for dementia risk has been identified as an ongoing need.[17] Please consult Section IV: Accessibility and Health Equity Considerations 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 **Appendix E**.

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 & Dementia: Diagnosis, Assessment & Disease Monitoring - Wiley Online Library
[17] Telehealth-based assessment of cognition in older adults during COVID-19 and beyond - Cullum - 2021 - Alzheimer's & 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 **Appendix F**. 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 AD8 tool.

Montreal Cognitive Assessment (MoCA)
Training for the scoring of the MoCA tool can be found on the MoCA website. 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 **Appendix I**, 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 **Appendix J**.

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 WAI Memory Diagnostic Clinics network. This resource can be found in **Appendix K**. **Appendix L** 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 Section IV: Accessibility and Health Equity Considerations 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 the MoCA website:

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 the Department of Health Services 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 2060[22]. 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)
[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 O, P, and 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 dhsdementiawebmail@dhs.wisconsin.gov 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
  Wisconsin (alz.org)
- 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.
  HealthCare Interactive Online Dementia Care Training and Certification Programs | HealthCare Interactive (hcinteractive.com)
- National Alzheimer's Disease Resource Center webcasts
  NADRC | Home (acl.gov)
- 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
  NINDS Brain Educational Resources | National Institute of Neurological Disorders and Stroke (nih.gov)
- 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 About the Clinic Network—Wisconsin Alzheimer's Institute—UW–Madison

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
guardian@gwaar.org
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 ADRC: Help for Older People and Adults with Disabilities | Wisconsin Department of Health Services

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 dhsdementiawebmail@dhs.wisconsin.gov.