MEMORY SCREENING IN THE COMMUNITY

How to Administer Community-Based Memory Screens

Wisconsin Department of Health Services
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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.

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 dhsdltcaging@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.

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Wisconsin Department of Health Services

Wisconsin Alzheimer’s Institute
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH
Home of WRAP: Wisconsin Registry for Alzheimer’s Prevention
Section I: Introduction

Why Offer Memory Screening?

In 2016, Wisconsin has approximately 115,000 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 grow to approximately 242,000. Providing access to memory screening and other methods to detect dementia early can benefit people with dementia and their families.

Changes to a person’s memory or thinking can occur for a variety reasons that can be 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 and 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 his or her doctor about concerns can lead to early detection and diagnosis with benefits for the person experiencing memory loss and caregivers.

¹ http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2787842/
² http://www.jabfm.org/content/25/3/367.full
⁴ http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2787842/
⁶ http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2787842/
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. People can be confused about the difference between Alzheimer’s disease and dementia and may say they have one but not the other.

The new diagnostic categories “Mild Neurocognitive Disorder” (mild NCD) or “Major Neurocognitive Disorder” (major NCD) have replaced the term “dementia” in the most recent version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) used by physicians. 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,” even though other areas of cognition are also tested, 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.

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8 http://www.dsm5.org/documents/changes%20from%20ds-m-iv-tr%20to%20ds-m-5.pdf
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. Alzheimer’s disease is the sixth leading cause of death in the United States. 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, 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-

9 http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp
body dementia. Visual hallucinations of friendly animals or people are not unusual, 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.\(^\text{12}\) 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.

\(^\text{12}\) [http://www.alz.org/dementia/fronto-temporal-dementia-ftd-symptoms.asp]
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, and the AD8.

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 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.

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 is attached as Appendix E. This screen is a conversation tool, 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 AD8 has sensitivity for dementia of greater than 84% and a specificity of greater than 80%.

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. Offering memory screening at a health fair or other community event is also appropriate. 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

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13 Sager, Hermann, LaRue, & Woodard, 2005
comfortable. Staff must be trained to follow the guidance in this manual before performing memory screens with the public.

Performing the Screens
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 screen and Mini-cog screen;
- a writing utensil for yourself and one for the participant;
- a time keeping device that shows minutes and seconds; and
- a location that is comfortable, quiet, well-lit, and includes a writing surface.

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 Screen
Begin with the Animal Naming screen. It is critical to read the instructions for each task on both screens exactly as they are written. Performing the screens in exactly the same way every time ensures 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 measure different parts of cognition, so they should always be used together.

Mini-cog Screen
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. There is no time limit on this screen.
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.

**The AD8 Screen**
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.

Once the screens are complete, determine the final score. An answer key for scoring all screens and determining if a referral is recommended is attached in Appendix F.

**Scoring Cognitive Screening Tools**

**Animal Naming Screen**
The Animal Naming screen is scored by tallying the number of correct responses. Fourteen or more correct responses is considered to be within normal range. If an animal is listed more than once it should only be counted once. Animals with different words for each sex or life stage, such as rooster and chicken or kitten and cat, are only counted once. Multiple names for the same animal, such as hog, swine and pig, are only counted once. Extinct animals, human beings, insects, fish, birds and reptiles all count as correct responses. Different species within a category, such as breeds of dogs, all count as correct responses. An example of a completed Animal Naming screen is attached in Appendix G. 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 H. There are examples of clocks drawn by participants in the pilot study that can be used to practice interpreting results in Appendix I. 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.

After the Screens

Once the screens 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.

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 J, 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 K.

Once the screens are completed and a physician referral is recommended, ask permission to follow up after two 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, he or she 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.
Section IV: Accessibility and Cultural 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

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 screen, the AD8 screen, 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 at the following web address: http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-BLIND.pdf

- 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.

Deaf and 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 at https://www.dhs.wisconsin.gov/odhh/tech-accommodations.htm.

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.

**Spanish Speaking**
Spanish versions of the tools are attached as Appendices L, M, and N. It is important that the screener either be proficient in Spanish or have an interpreter present for the screening. Best practice guidance for working with interpretation in the context of an evaluation, states that family members should not be used as interpreters.\(^{15}\) The use of Language Line is also not appropriate in performing the screens. Screens are not currently available in other languages.

**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.\(^{16}\) 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 O and the accompanying instruction manual is Appendix P. Both manuals come in multiple languages, which can be found here: http://aadmd.org/ntg/screening

**Cultural Considerations**
People of Latino ethnic heritage and African Americans are between 1 ½ and 2 times more likely to develop dementia than Caucasians.\(^{17}\) 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.\(^{18}\) Not only do people of color have twice the risk of developing dementia, people with Latino heritage develop dementia an average of seven years earlier than their white counterparts.\(^{19}\)

\(^{15}\) http://www.ncbi.nlm.nih.gov/pubmed/20687185
\(^{16}\) http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf
\(^{17}\) http://www.alz.org/norcal/in_my_community_19449.asp
\(^{18}\) http://www.ncbi.nlm.nih.gov/books/NBK220337/
\(^{19}\) https://www.alz.org/national/documents/release_111507_spanish.pdf
Communities of color also continue to face disparities in access to and appropriate care from the health care system. 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.

The prevalence of dementia in the Native American population is currently unknown. Some of the same health disparities that impact African Americans and people with Latino heritage also affect tribal members, which may increase their risk of dementia. In providing memory screening to tribal members, the screening tools used in this manual do not need modification.

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 either need to be fluent in the Hmong language, or use a professional interpreter. Best practice guidance for screening and assessment state that family members should not be used for interpretation during the screening process. 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 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.

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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 dhsdlteaging@dhs.wisconsin.gov for more information.

Webcasts
To become an agency-certified screener, the staff member must watch two training webcasts that accompany this screening program. They were developed as a product of the successful pilot study of the screening program and include the original researchers and program staff. They are approximately one hour each. The webcasts are titled Dementia Capable Care in Wisconsin: Part 1 and Dementia Capable Care in Wisconsin: Part 2 and can be found at:

https://www.dhs.wisconsin.gov/aging/dementia-cogscreen.htm

Dementia-Specific Training
The webcasts provide information about dementia and the importance of memory screening. However, they do not provide an opportunity for trainees to ask questions or learn more about dementia. 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. Additional training on dementia is widely available, and a list of training resources can be found in the following resources section.

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 Q. 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. A data collection tool will be provided to collect this additional information. Personally identifiable data regarding the use of memory screens is not requested by DHS.

**Section VI: Resources**

**In-Person Dementia Training**
Dementia support agencies are an important resource and can provide in-person training on a variety of topics specific to dementia and family caregiving.

Alzheimer’s and Dementia Alliance of Wisconsin  
517 North Segoe Rd., Suite 301  
Madison, WI 53705  
608-232-3400  
888-308-6251  
support@alzwisc.org

Alzheimer’s Association, Greater Wisconsin Chapter  
3313 S Packerland Drive, Suite E  
De Pere, WI 54115  
920-469-2110  
Laurie Schill, Executive Director  
lschill@alz.org  
Kathy Davies, Outreach and Advocacy Director  
kdavies@alz.org
Alzheimer’s Association, South Central Wisconsin Chapter
2820 Walton Commons, Suite 132
Madison, WI 53718
608-203-8500
Kari Paterson, Executive Director
kpaterson@alz.org

Alzheimer’s Association, Southeastern Wisconsin Chapter
620 S. 76th Street, Suite 160
Milwaukee, WI 53214
414-479-8800
Diane Baughn, Education and Training Services Manager
dbaughn@alz.org

Online Dementia Training
The University of Wisconsin Oshkosh has a series of online training opportunities for a variety of audiences. www.uwosh.edu/dementia

The DHS has created a catalog of online trainings that are regularly available. The catalog can be found at https://www.dhs.wisconsin.gov/dementia/training-list

Links to Additional Information on Dementia and Caregiving
Alzheimer’s Association
http://www.alz.org

Alzheimer’s and Dementia Alliance of Wisconsin
http://www.alzwisc.org/

Alzheimer’s Disease Education and Referral Center (ADEAR)
https://www.nia.nih.gov/alzheimers/

National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/dementias/dementia.htm

AARP
http://www.aarp.org/home-family/caregiving/

National Alliance for Caregiving
http://www.caregiving.org/

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 http://www.wai.wisc.edu/clinics/overview.html
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

Wisconsin Department of Health Services
DHS has information about dementia and caregiving programs and resources available in the community across the state.
https://www.dhs.wisconsin.gov/dementia/

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 https://www.dhs.wisconsin.gov/adrc/

Questions on the Memory Screening Program
Questions should be directed to the Office on Aging at DHS at 608-266-2536 or dhsdltcaging@dhs.wisconsin.gov.