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Elder Care in Indian Country

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Over many years the May Issue of the IHS Primary Care Provider has been devoted to sharing information and resources to support care of older American Indians and Alaska Natives, in recognition of May as Older Americans Month. This year's May and June issues are notable then not for the topic, but for the breadth and scope of the content. In these issues you will find:

- A clinical case study focusing on recognition of dementia in the community and in the clinical setting.
- The description of an evaluation of the programs funded by Title VI of the Older Americans Act, the foundation of elder services in Tribal communities.
- An update on the REACH into Indian Country initiative, an initiative that trains and certifies clinical staff (public health and community health nursing, social workers, and others), paraprofessionals (Community Health Representatives), and elder services staff (Tribal aging programs) to provide structured, evidence-based support to caregivers of elders with dementia

- UNITE, a collaborative of Tribal Nursing homes working to improve availability and quality of culturally respectful and Tribally operated facility-based long term services and supports.
- An introduction to Dementia-Friendly America, a nation-wide initiative of communities working to bring together all available resources to enable people with dementia to live well and remain vital in the lives of their families, Tribe, and community.

Collectively, these articles provide a view of care for the elderly that ranges from clinical to community-based, from nursing homes to family homes, from caregiving by families to weaving together a community that cares. That's what it takes and that's what it means to respect and care for the elderly.

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Warning Signs: a Case in Dementia Assessment

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Mrs. Beye brings in her 73 year-old husband because she saw one of the posters you had given out at a senior health fair. It lists warning signs for memory loss. She is concerned because he has some of those and this has been occurring for at least the past year or so. She had to convince him to come in because “he hates doctors”. Your clinic staff contacted them and told him that he should come in for an elder check-up, that it would be like a Jiffy Lube oil change: you would go over his meds, exercise his brain, check him out, and make sure he was aging the best way he could.

Your nurse takes both of them into the clinic because he is ok with her being there, and he thinks he is doing “pretty darn good”. His wife is concerned because one of the warning signs says “asking the same questions over and over again”, or bringing up the same story. She says Mr. Beye does this “all of the time”, even a few minutes after he just said something. Sometimes it drives her crazy! Mr. Beye says he does NOT do this, and if he repeats himself it’s because his wife can’t hear and she makes him do that. She also mentions that one of the warning signs is “not being able to follow directions”. Even though she tells her husband what to do to pay the bills (something he has done a thousand times) he made mistakes a few times over the last couple of months-- she is furious. He says if she wasn’t making him run around and do so much he would be able to keep things straight. He is obviously getting upset.

You can see that Mr. Beye is not very open to talking about problems he may be having with his memory, so you hand Mrs. Beye an assessment called the AD8ⁱ, so she can privately fill out questions regarding Mr. Beye’s memory while you talk to him some more. While she is occupied Mr. Beye tells you he does acknowledge that he forgets things like names and dates sometimes, but that he feels it is just “old age”. He still drives, denies any accidents, tickets, or getting lost. He does misplace items at home sometimes and even laughed when he put his reading glasses in the freezer; but he asks, “doesn’t everybody do that?” He feels his mood hasn’t changed, and he completes all of his activities of daily living and instrumental activities of daily living without difficulty. He graduated high school and

denies any family history of dementia. He doesn’t get regular exercise and sleeps fairly well, getting about eight hours of sleep per night. He has no movement problems and denies any hallucinations or delusions. He has a medical history significant for high blood pressure, diabetes with a recent Hemoglobin A1c of 9, some occasional heartburn, hyperlipidemia, and had a small right parietal lobe infarct several years ago that left no residual deficits. He also got in a fist fight when he was younger that caused him to lose consciousness and be seen in the ER with a diagnosis of a concussion. He quit smoking 10 years ago and lives happily with his wife of 50 years. They have three adult children. Two live around town, one died of cirrhosis three years ago. His vital signs are ok except his pulse is 50.

On the AD8 back from Mrs. Beye he scores 6 (a score of 2 or more is suggestive of possible dementia). He really doesn’t feel like he has memory problems but based on what you’re hearing you are worried. He does need some improvement in some lifestyle changes and other medical problem management, but how do you know if he has dementia?

You do your physical exam, including a pretty good neurologic exam to check for tremors, rigidity, strength, reflexes, gait examination, etc. Nothing seems abnormal on exam.

Your staff had already told him you would exercise his brain today, and you or your nurse do a mini-COG, an easy to use initial dementia screen that has been tested in multiple ethnic and language cohortsⁱⁱ. (http://www.alz.org/documents_custom/minicog.pdf). The Mini-Cog uses simple three-item recall and a clock draw. Mr. Beye recalls two out of three items, and his clock is shown (his instructed time was 10:50).

It is clear that Mr. Beye has an abnormal Mini-COG. Because these changes have occurred slowly over the past years and nothing unusual has come up in your history/exam/work-up so far, you know that you have some time to make the complete diagnosis. With gradual onset and no recent history of falls or trauma you decide you don’t need to do any head imaging at this time.

You make a plan for better managing his diabetes with diet, medication adjustments, and an exercise plan and schedule follow-up with them in 2-4 weeks. In the meantime you do the basic set of labs you’ll need to make a diagnosis, including a complete blood count and complete

metabolic panel (with glucose, electrolytes, calcium, total protein, and liver function tests), TSH, B12, and folate.

At the next visit we'll plan to make a firm diagnosis and complete a baseline assessment for Mr. Beve and his family. In the next part of this case we'll cover what happens at Mr. Beye's next visit.

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Understanding the Impact of the Older Americans Act Title VI Program

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Background

In 1978, the Older Americans Act (OAA) was amended to include nutrition and supportive services for Native American elders (American Indians and Alaska Natives). The Act was amended again in 1985 to include Native Hawaiians (Administration for Community Living, n.d.). This program, known as the Title VI grant program, has since been expanded to also include caregiver support services. In FY 2014, 263 three-year Title VI grants were awarded to tribes/tribal organizations and one organization serving Native Hawaiian elders for the provision of Nutrition and Supportive Services; 231 grants were awarded for the Native American Caregiver Support Program (Title VI Part C).

Developing a Program Evaluation Approach

As part the ongoing evaluations of OAA programs, the Administration for Community Living (ACL)/Administration on Aging (AoA) conducted an Evaluability Assessment (EA) of the Title VI grant program. The purpose of the EA was to examine the Title VI programs' characteristics, context, activities, processes, implementation, and outcomes and determine the extent to which the activities improve the lives of Native elders and their family members. In this case, the EA examined the program characteristics of Title VI grantees'

nutritional, supportive, and caregiver support services to assess the feasibility of, and best approaches for, further evaluation of the Title VI program.

The first step in the EA was to establish a 20-member advisory group including representatives from the National Indian Council on Aging (NICOA), the National Resource Centers on Native American Aging (NRCNAA), and Title VI grantees. The advisory group was convened to review and provide feedback on each step of the EA process including: 1) program description; 2) design of survey instruments; and 3) recommendations for the feasibility of a full scale evaluation. A small number of grantee program staff were selected to participate in in-depth interviews to gain a more nuanced understanding of the Title VI service areas (Nutrition Services, Supportive Services, and Caregiver Support Services). Grantees were selected based on geography and program size in order to gain a richer and more representative perspective of tribal programs.

The second step in the EA was to design a logic model to evaluate the effectiveness of the Title VI program. Logic models are typically graphical depictions of the relationships between the resources, activities, outputs, and outcomes of a program (see figure 1). As part of the EA, a comprehensive logic model was developed that outlines the expected activities and outcomes of Title VI programming and is divided by service area (Nutrition, Supportive Services, Caregiver Support, and Program Management).

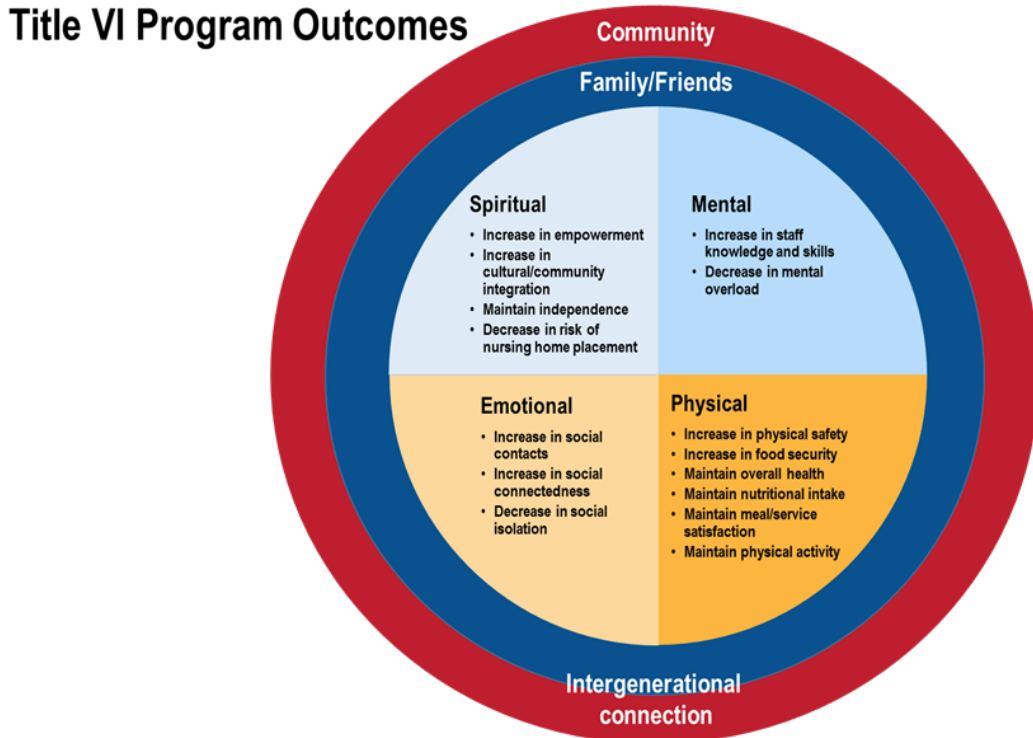
Figure 1. Example of traditional logic model



Because many tribal communities do not conceptualize their programming in the linear frame used by the logic model, a medicine wheel model was developed to orient the short term

and long-term effects/outcomes across the traditional quadrants of native practice: Spiritual, Mental, Emotional, and Physical. Each quadrant is housed within the context of community, family, and intergenerational connection—highlighting the importance of each to the spiritual, mental, emotional, and physical wellbeing of native communities and elders (see figure 2).

Figure 2. Title VI Medicine Wheel Model



The third step in the Title VI EA was to develop an evaluation approach. An in-depth literature review found Community-Based Participatory Action Research to be the most successful approach to use with Native populations. This approach integrates Native American communities and their members as full and equal partners in all phases of the research process (Salois et al. 2006; Holkup et al. 2004). AoA/ACL will work with the advisory group to identify strategies to engage tribal community members to tell their stories about the Title VI Program, the context of program activities, and the Title VI challenges and successes. The design framework assumes ongoing participation and engagement of tribal community members and active involvement in all phases of the evaluation (evaluating design input, data collecting measures and piloting of primary data collection, recruiting and engaging participants to tell their stories, overcoming challenges to evaluations in tribal communities, interpreting

Title VI data and analysis, and disseminating evaluation findings).

Next Steps

The EA was completed in 2015. ACL/AoA is now preparing to move forward with a full scale evaluation of the Title VI program. It is expected that in the summer of 2016 ACL will issue a competitive request for proposals to organizations interesting in conducting the evaluation and in May or June 2017 ACL/AoA will also offer a grant opportunity for Tribes who were awarded a Title VI grant in 2017 and apply to participate in the evaluation. This three-year study will look at how Tribal grantees provide Title VI nutritional, supportive, and caregiver support services and the effect those services have on tribal elders, their families, communities, and other tribal services. The purpose is to learn more about how different Tribes structure their Title VI programs in order to

identify best practices, need for training and technical assistance, and to assess the degree to which the programs are improving the lives of the older Native American, Alaskan Native, and Native Hawaiian elders.

This opportunity will be open to all Title VI grantees and will encourage the involvement of Title VI directors, tribal leaders, and tribal members during all phases of the evaluation process. The advisory group that was convened as part of the evaluability assessment will continue to review and provide feedback throughout the evaluation process. In addition, two to three members from each participating Tribe will be invited to take part in a national working group where they will share ideas, experiences, and join in training sessions designed to provide hands-on evaluation experience.

Benefits to Title VI Grantees

The Title VI evaluation grant will benefit Title VI grantees by helping to build and show program capacity, improve program implementation, and find new ways to manage programs with limited resources. Technical assistance will be available during the three-year grant process to help Tribes plan and implement their evaluations. Specifically, participating Tribes will receive assistance and data analysis to generate reports,

tables, and charts based on their own data. These can be used for reporting requirements, presentations, grant applications, and community information sessions. At the end of the evaluation grant period, grantees will have the experience and technical tools they need to document program accomplishments, strengthen grant proposals, and help determine the different types of community-based services that best meet the needs of their elders.

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