

Engaging American Indian/Alaska Native Adults in Chronic Disease Self-Management Education

This tip sheet provides an overview of health disparities in chronic diseases among American Indians/Alaska Natives (AI/AN) and discusses effective strategies for increasing access to chronic disease self-management education (CDSME) programs to improve their health status. It highlights the Wisdom Warriors program in Washington and summarizes activities of current and former grantees funded by the Administration for Community Living (ACL) to expand and sustain CDSME programs in their states, including tribal communities.



Health Disparities

The AI/AN population experiences poorer health status than the general United States populationⁱ and carries a much heavier burden of chronic illness. One in five of 5.4 million AI/ANs have two or more chronic conditions, and heart disease and cancer are the leading causes of death. Other chronic conditions, such as obesity, heart disease, and diabetes are also prevalent among AI/ANs.

- Forty percent of AI/AN adults are classified as obese, compared to 28% of non-Hispanic Whites.ⁱⁱ
- Over 30% of AI/AN adults reported at least one form of heart disease in 2012, compared with 11% of non-Hispanic Whites.ⁱⁱⁱ
- Twenty percent of AI/ANs have been diagnosed with diabetes, compared to 12% of non-Hispanic Whites.^{iv}

A combination of complex factors contribute to health disparities among AI/ANs, including the lack of or discrimination in the delivery of education and health care services, disproportionate rates of poverty, and high numbers of uninsured individuals. Environmental factors, cultural traditions and beliefs, and lifestyle behaviors can also play a role.^{vii}

Benefits of CDSME Interventions

Evidence-based chronic disease self-management education (CDSME) interventions, such as Stanford

University's Chronic Disease Self-Management Program (CDSMP),^{viii} have been proven to help people with chronic conditions manage their health and improve their quality of life.^{ix} Research has shown that CDSMP significantly improves self-reported health, communication with doctors, and appropriate medication use, while lowering health care costs.^x When provided in a culturally competent manner, with respect for the traditions, beliefs, practices, and needs of AI/ANs, CDSME programs can be an effective intervention. Many ACL grantees across the country have successfully offered CDSME programs in partnership with tribes to help AI/ANs learn how to manage their chronic conditions and improve their health status.

Strategies for Collaborating with Tribal Communities

As you work to grow and sustain your CDSME programs, the strategies outlined below can help you develop relationships with tribal representatives and increase the likelihood that your outreach and CDSME program implementation efforts will be successful.

Plan for success

Consistent with CDSME programs' focus on setting achievable, short-term goals, it is important to start

out small with specific, attainable goals and a realistic timeline. For example, consider the number of tribal members that will enroll in the program over the next six months or the number of tribal members that will be trained to lead workshops over the next year. Participation may be smaller than you would expect in a mainstream community. In getting started, it will be helpful to develop a written program implementation plan, which includes quality assurance activities, the necessary partnerships, and potential funding streams to sustain your program.

Tribal members should provide important input into the planning process, as well as help solve challenges that may be faced during implementation of the program. Involving tribal representatives and other key partners and stakeholders in the planning, implementation, and evaluation phases of your program will help assure its success.

Assess your organizational readiness to serve tribal communities

A great deal of time and effort will be required to build trust and establish a culturally-relevant, sustainable program infrastructure. It is important to carefully assess to what extent your organization has sufficient human and financial resources for a long-term commitment before you initiate the relationship. As part of this process, ensure that you have an understanding of the population and their specific preferences and needs. Additionally, you should identify champions within the tribe(s) and partners who can help you get started and build capacity for your program. Below are some questions to consider as you determine your readiness:

- Are your senior management, staff, and volunteer leadership committed to this effort for the long term?
- Is the commitment backed up by the allocation of adequate human and financial resources?
- What formal mechanisms are in place within your organization to ensure that the work with tribes is embedded within your organization and not dependent on one person?

- Are any of your organization's staff, board of directors, or volunteer tribal members? If so, these individuals may become your champions.
- Has your organization involved community leaders from tribes in planning? If not, what steps can you take to involve tribal representatives?
- How will you assure that your organization's staff and volunteers are culturally competent?
- What partners can you engage to help with your outreach efforts?
- Has your organization already provided services to any tribal communities? What feedback did you receive that could be applied to this effort?

Ask the tribe about their needs

Conduct background research, and be eager to learn from the tribe itself. Below are tips to help you in learning about the tribe.

- Understand how to pronounce tribal names and places.
- What public data is available about the prevalence of chronic diseases within the tribe? (e.g., state public health department or state unit on aging reports, Centers for Disease Control and Prevention data, etc.)
- What tribal needs assessments are already available that could help determine if CDSME programs are a good fit? The National Resource Center for Native American Aging supports tribes in completing community needs assessments. These reports are available only if the tribe is willing to share them. Needs assessments can help identify issues such as high prevalence of chronic illnesses, frequency of falls, etc.
- What are the tribe's goals related to chronic disease? What specific goals does your tribal partner have, e.g., reducing complications from diabetes among their members, improving overall community health, or developing champions for CDSMP within the tribe?



Learn more about the tribe's governmental and social structure

Understand how the tribe is structured so that you can appropriately target your outreach efforts. Below are some key considerations.

- What is the tribal government/council structure and membership and who are the leaders and respected decision makers within the tribe?
- Does the tribe have departments or other entities that could assist with CDSME efforts (e.g., a tribal aging unit, health clinic, elderly or health advisory board, nutrition and/or health education department, tribal outreach department, etc.)?
- Where does the tribal population live and what is the geographic reach of the tribe? Where would they like to focus outreach efforts?
- What is the preferred language in the tribe?

Leverage existing resources

Consider how you can leverage existing resources to help with your efforts to engage the tribe in offering CDSME programs.

- What health professionals, medical centers, health departments, area agencies on aging, technical assistance centers, or other agencies are already serving the community?
- What types of chronic disease prevention and health promotion programs are already being offered to the community?
- What other grants has the tribe received that support chronic disease prevention or treatment? For example, the Indian Health Service Division of Diabetes Treatment and Prevention provides [Special Diabetes Program](#)

[for Indians \(SDPI\)](#) grants. This funding provides support for evidence-based interventions in over 300 AI/AN communities in 35 states to treat and prevent diabetes.

Ensure a culturally competent workforce

Develop sound policies and practices within your organization to assure that staff and volunteers understand the tribal culture and are sensitive to their needs. An important part of cultural sensitivity is understanding the tribe's beliefs about chronic illnesses and self-care practices. Further, learning about the role of clinics, health centers, or other medical services, as well as traditional healers will help with your efforts to engage the tribe. Below are some key points to keep in mind as you work toward building a relationship.

- Recognize that what has worked with one tribe will not necessarily work with another.
- Approach the community with an open mind and an interest in and respect for the tribe's culture.
- Honor the tribe's self-determination and respect their sovereignty.
- Acknowledge that your organization doesn't have all the answers. Be prepared to ask: "What next steps would be the most helpful?"
- Recognize that elders are not only "participants" but also important and well-respected parents, grandparents, healers, and leaders in their communities.
- Understand that tribal members may not have had positive interactions in the past with outside people or organizations that provided short-term, "flash in the pan" health promotion offerings.
- Expect that building relationships will take a long time. Be patient and understand that this needs to be an ongoing process, not just a one-time effort. If possible, identify a problem with a quick solution and solve it. This will begin a foundation of credibility and a real interest in action.

Establish champions and strong tribal community infrastructure

As you develop your plan, identify key individuals who are known, respected, and influential within the community.

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- Who are the respected elders or other community leaders that you can engage as program champions?
- Which health professionals, allied health professionals, community health workers, and others already working with the tribe can help with your efforts?
- Are tribal members who offer other health promotion programs available to assist you?

The CDSME program delivery infrastructure needs to be integrated within the tribal community in order to be effective and sustainable. To establish a strong infrastructure, involve tribal members in planning and scheduling the workshops. Holding the workshops at times and locations that are convenient to potential participants will increase the success of the program. Places where tribal members typically congregate with accessible transportation are ideal. Considerations should be made for tribal holidays and other cultural events. Be prepared to cancel if there is a death in the community. This is a time when the tribe will band together to support each other and they will not expect the workshop to be held.

Use culturally-relevant marketing strategies and materials

Successful marketing is an ongoing process which should include multiple channels that are familiar to the tribal community. Learn how tribal members receive health-related communications, which may include community or health center newsletters, group meetings, word of mouth, and media sources.

Build upon other approaches that have been shown to be effective. For example, the Centers for Disease Control and Prevention’s [“Spread the Word: Marketing Self-Management Education Through Ambassador Outreach”](#) program is a model for training CDSME graduates to serve as “ambassadors” to help recruit and enroll participants in CDSME workshops. This approach could easily be implemented within the tribe. Another approach that can be helpful with enrolling and retaining participants is to conduct a pre-workshop [“Session Zero,”](#) an informational session to increase understanding and acceptance of the program. An example of a product that works well

for Session Zero is Stanford University’s [“You Can Break Your Symptom Cycle.”](#) It contains six 10-minute activities that provide an example of what a participant will experience in a workshop. Other organizations have implemented the [“Living Healthy with High Blood Pressure”](#) module developed by the Quality and Technical Assistance Center of New York State or developed their own content.

Target marketing materials to the AI/AN population:

- Develop and distribute marketing materials with substantial input from your champions.
- Incorporate pictures of individuals from the community and/or images that are meaningful to the tribe.
- Use appropriate language and reading level.
- Use messages that resonate with the tribe. For example, in many tribal communities, it is rude to focus on yourself, rather than on the community. Self-help messages that focus on the individual should be reframed to focus on how self-management education skills can be used to support their family, be a better parent or grandparent, and contribute to the community.



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Be flexible, while assuring program fidelity

Some organizations have made minor adaptations to increase receptiveness to the program among AI/ANs, while assuring that the program fidelity is maintained. If you plan to make adaptations to the program, you should request permission from Stanford University to assure that the program fidelity is not compromised. Below are minor adaptations that organizations have reported making when offering the program to AI/ANs.

- Conduct workshops seated in a circle, like a traditional “talking circle.”
- Use culturally appropriate words like smoke house, pulling bark, etc.
- Refer to traditional foods like nettles and fiddleheads.
- Use a talking stick to designate speakers/discussants.^{xi}
- Be flexible about starting sessions late if transportation issues arise and consider postponing a session when there is a death in the tribe.

Minimize barriers and provide incentives to increase program participation and retention

- Coordinate with meals or nutrition programs to provide healthy snacks for breaks or meals before or after the program.
- Identify resources to provide childcare and respite care. For example, in Wisconsin, parents, grandparents, and caregivers were recruited to participate in a CDSME workshop held at a head start child care center. The workshop was held while the students were cared for by the center and the center provided the workshop space as an in-kind contribution.
- Offer small incentives. These might include a measuring cup from the dollar store to reinforce what is taught in the workshop; a raffle for small items that would be meaningful to the population; certificates of completion; or a symbol of their achievement.
- Hold a graduation ceremony at the end of each workshop and invite tribal leaders and other stakeholders to recognize participants and keep them engaged.

The Wisdom Warriors Success Story

To illustrate how ACL grantees have successfully built partnerships with tribal communities to implement CDSMP in a culturally appropriate way, we share the story of the [Wisdom Warriors](#) in Washington State.

“We recognized there is a high prevalence of chronic conditions in the tribal community and a need to enable tribal members to help themselves.”

-Becky Bendixen

Wisdom Warriors was developed by Shelly Zylstra, Melody Coleman, and Becky Bendixen at the Northwest Regional Council (NWRC) tribal outreach program in Bellingham, Washington in 2011. It offers culturally appropriate incentives to support tribal elders with their self-management goals, while maintaining fidelity to the CDSMP model. This ongoing program gives participants the education, support, and tools to make healthy choices resulting in lifestyles that promote self-care, improved quality of life, and longevity. Wisdom Warriors is true to the CDSMP model, with some added cultural components. It is patterned after Wisdom Steps in Minnesota, a successful tribal program that enrolled over 1,000 tribal members.

The NWRC now proudly provides Wisdom Warriors training and other services to 20 of the 29 tribes in Washington. Recently, tribal organizations in Alaska, California, Oklahoma, and Oregon have asked to be trained in the Wisdom Warriors program model.

“The monthly meetings are an opportunity to encourage others to join Wisdom Warriors and also for community members to celebrate with the elders – family members, clinic staff, police, Tribal Council, and others who value tribal elders and their role in the community.” -Becky Bendixen

Tribal elders are designated as Wisdom Warriors after they complete a CDSMP workshop. This designation is their commitment to leading a healthier lifestyle. Wisdom Warriors meet monthly for

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educational presentations or activities and receive a Wisdom Bag signifying their commitment to their health. As they make healthy lifestyle choices, they are rewarded with pony beads and charms to celebrate their efforts to improve their health. This sustaining support for the lessons learned recognizes the importance of community in a cultural context where “self-management” may be rejected as selfish. Communal support of the Wisdom Warriors in these group meetings allows continuing application of the concepts learned in a culturally appropriate context. Each tribe follows the basic structure of the program and can customize it by designing their own incentives and developing other guidelines to help their members maintain the gains they made through the initial six-week program.

Progress in the Field

The National CDSME Resource Center compiled the following listing of activities that have been successful in engaging tribal communities in CDSME programs. These examples represent the efforts of [ACL's CDSME 2012, 2015, and 2016 grantees](#).

- The **Arizona** Department of Health Services developed a relationship with the Navajo Nation Special Diabetes project and expanded implementation of the Diabetes Self-Management Program (DSMP) to the Salt River Pima-Maricopa Indian community. Eight tribal councils have embedded processes to deliver or refer people with chronic disease to CDSME programs.
- In **California**, the Lake County Tribal Health Consortium plans to deliver DSMP to 80 new AI elders and facilitate maintenance of healthy habits. To implement CDSME programs in tribal communities, partnerships were developed with the Southern California Indian Center to reach AIs in Orange County and with the Southern Indian Health Council, in collaboration with the American Diabetes Association. An AI community health worker was hired to facilitate DSMP workshops.
- The **Colorado** Department of Health collaborated with the Southwestern Colorado Area Health Education Center to host CDSMP

and DSMP training for 11 representatives of the Ute Mountain Ute and Southern Ute Indian tribes at no cost to them.

- In **Connecticut**, the Eastern Regional Coordinator with the State Department on Aging partnered with lay leaders from the Mohegan Tribe to conduct a CDSMP workshop at the Mohegan Tribe Retirement Community.
- In **Massachusetts**, the Healthy Living Center of Excellence established a relationship with the Mashpee Wampanoag Health Service Unit. Through this partnership, one CDSMP workshop was implemented and an information session about CDSME was conducted for tribal elders through the health system’s “Lunch and Learn” program. Massachusetts continues efforts to expand this partnership.
- The **Michigan** Office of Services to the Aging worked with the Nottawaseppi Huron Band of Potawatomi and other tribal groups to assist them in offering CDSMP workshops.
- The **Mississippi** State Department of Health is exploring the possibility of partnering with the Mississippi Band of Choctaw Indians’ eight tribal communities. The health department has met with the tribe’s Diabetes Health Educator to discuss training tribal members as CDSMP and DSMP leaders and recruiting participants for workshops.
- The **New Jersey** Department of Social Services Division of Aging Services provided funding support to the Nanticoke Lenni-Lenape Tribal Nation which has trained three CDSMP leaders and has had support from their Chief to offer workshops on tribal grounds during the elder luncheon program and to promote workshops during the annual Pow Wow. They have also conducted workshops for tribal elders in local senior centers.
- The **New Mexico** Department of Health developed a centralized hub to support the implementation of CDSMP across the state, including in 22 sovereign tribal nations. The Department of Health is engaged in partnerships to increase reach to tribal communities including collaboration between the Diabetes Prevention and Control Project and the Indian Area Agency on Aging. They are

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also a partner in the Four Corners Collaborative, along with Arizona, Colorado, and Utah, to increase access to CDSMP among the Navajo Nation, Jicarilla Apache Nation, Southern Ute Tribe, Ute Mountain Ute Tribe, and Hopi Tribe. Overall, 14% of CDSMP participants in New Mexico are AI.

- The **New York** State Office on Aging supported the Saint Regis Mohawk Tribe Office for the Aging in sending two staff to be trained as master trainers to implement CDSMP workshops.
- The **Oklahoma** Department of Human Services has developed partnerships with tribal communities across the state to increase access to CDSMP among AIs. For example, they offered CDSMP in collaboration with the Indian Nations Council of Governments Area Agency on Aging (three counties), the Cherokee Nation, and the Chickasaw Nation Division of Health. They have explored grant opportunities to implement CDSMP with the Southern Plains Tribal Health Board.
- In **Oregon**, the Yellowhawk Tribal Health Center plans to implement CDSMP on the Confederated Tribes of Umatilla Indian Reservation and four additional tribes in Oregon.
- The **South Carolina** Lieutenant Governor's Office on Aging worked with the Catawba Indian Nation to train community members as CDSMP leaders and offer workshops for tribal members.
- The **South Dakota** State University (SDSU) and the Great Plains Tribal Chairmen's Health Board (GPTCHB) are implementing CDSMP in the state. SDSU designated one CDSMP Master Trainer Outreach Ambassador to increase outreach to and collaboration with tribal communities across the state. In late 2016, SDSU conducted their first workshop for tribal members on the Crow Creek Indian Reservation, led by an enrolled member of the tribe. This represents an opportunity to expand CDSMP implementation in the Crow Creek area. They have also discussed opportunities to integrate CDSMP in several health systems, including the Cheyenne River Indian Health Service, Oglala Sioux Tribe Health

Administration, Sisseton Wahpeton Oyate Health Administration, and the Oglala Sioux Tribe Diabetes Prevention Program. The GPTCHB plans to implement CDSMP in the 17 Great Plains tribal communities in South Dakota, North Dakota, Nebraska, and Iowa.

- In **Utah**, the Utah Department of Health partners with the Navajo Health System (NHS) which is implementing CDSMP in the Navajo Nation through outside sources of funding. The NHS conducted an on-site leader training for clinical staff and has conducted workshops at three of their clinics.
- The **Washington** State Department of Social and Health Services, in conjunction with the area agencies on aging, has developed partnerships to implement CDSMP in other tribal communities, in addition to the NWRC's Wisdom Warriors initiative. Relationships have been developed with the Confederated Tribes of the Colville Reservation, the Cowlitz Indian Tribe, the Tulalip Tribes, and the Muckleshoot Indian Tribe. Further, the Yakama Nation Area Agency on Aging has formed a partnership with the Yakama Indian Health Service Healthy Heart Program to train CDSMP leaders. Washington has also worked with health care organizations to deliver workshops at the Lower Elwha Tribal Wellness Clinic and the Sophie Trettevick Indian Health Center.
- The **Wisconsin** Institute for Healthy Aging, Lac Courte Oreilles Band of Lake Superior Chippewa Indians Health Center, and Sokaogon Chippewa Community are implementing CDSMP and DSMP in Wisconsin. WIHA has trained community health workers to deliver CDSME programs in tribal communities across the state. With CDC funds directed to the Division of Public Health, a community health worker serves as the lead support for tribes disseminating CDSME programs. The State Office on Aging provides funds to support the tribes with Older American Act Title IIID and VI funds, an area agency on aging provides funding for the Great Lakes Intertribal Council, and funds the Statewide Coordinator for evidence-based health promotion programs in the Office on Aging to provide technical assistance.

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If you would like additional information about the examples listed above and/or wish to share your experiences in working with tribal communities to offer CDSME, please contact the National CDSME Resource Center at healthyaging@ncoa.org.

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Footnotes

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