What Can I Eat? For American Indians:
A Culturally Sensitive Nutrition Focused Diabetes Self-Management Support Program for Tribal Communities Living with Type 2 Diabetes

A Collaborative Initiative between the American Diabetes Association and Shakopee Mdewakanton Sioux Community
BACKGROUND

The Problem
The Centers for Disease Control and Prevention (CDC) estimates that almost 15.1% of the American Indian/Alaska Native (AI/AN) population has been diagnosed with diabetes, as compared to 7.4% of Non-Hispanic whites, 12.7% of non-Hispanic blacks, 12.1% of Hispanics and 8% of Asian Americans. Among AI/AN adults, the age-adjusted rate of diagnosed diabetes varies by region from 6% among Alaska Natives to as high as 50% among American Indians in southern Arizona.1

The implications are staggering. The incidence rate of comorbidities due to diabetes in AI/AN people, including kidney failure and heart disease death rates, is 2 to 4 times higher than that of the general U.S. population. As a result, diabetes is the fourth leading cause of death, with mortality attributed to diabetes nearly three times higher in this group than other racial/ethnic groups in the U.S.2,3

Many genetic, historical, behavioral, and environmental factors contribute to the high rates of diabetes in this population. For example, higher disease rates have been linked to relocation from homeland to reservations, the subsequent adoption of highly processed meals in lieu of nutrient-dense traditional foods, poverty, access to health care, mental health issues, and food insecurity.4,5

Gaps in Current Resources
In the past decade, several federal programs have been developed to address the prevention and treatment of type 2 diabetes in AI/AN communities (e.g., the Special Diabetes Program for Indians, the National Diabetes Wellness Program, CDC’s Traditional Food Project, and CDC’s Good Health and Wellness Program). These programs have reported positive impact, including improved A1Cs and decreased cardiovascular and kidney disease risk.6,7 Resulting resources, such as the Food Project stories, should continue to be leveraged to improve outcomes. However, the gaps in services are nonetheless notable.8,11

- There are currently no large-scale culturally competent diabetes self-management support (DSMS) programs that focus exclusively on diet- a key behavioral risk factor for diabetes complications.
- Federal program resources are not available and accessible to all tribal communities, particularly hard-to-reach rural communities.
- Programs that do exist offer inadequate support to address the psychosocial aspects of diabetes in this population (e.g., depression, trauma, and lack of family/social support).
- Programs too often focus exclusively on those individuals with diabetes instead of incorporating a family-targeted or multi-generational approach that also address diabetes risks.
- Some programs don’t incorporate the community (e.g., tribal leaders, peers, community health workers/representatives, and community advisory boards) to the extent needed to see sustainable impact.
- Many resources have not been culturally- and/or linguistically-tailored to meet the individual needs of each tribal community.
The Need for Culturally Innovative Interventions
Culturally-tailored approaches are particularly important to address regional and tribal differences pertaining to food choices, social/environmental determinants, and health beliefs. Key considerations for a nutrition-based program focusing on diabetes self-care in AI/AN populations include: 1) the historical and cultural role of food; 2) relevant communication styles and activities (e.g., storytelling, talking circles); 3) barriers to health care; 4) the Native spirituality and healing beliefs with regard to health; 5) differences in urban versus rural populations; 6) the use of traditional art, literature, and music to support messaging; 7) the influence of tribal elders in the local food system.4,12

The ADA-SMSC “What Can I Eat?” adaptation for Native populations will be a culturally competent, evidenced-based program that focuses on improving dietary risk factors for individuals with type 2 diabetes within the context of cultural, social, historical, and environmental aspects of daily life in AI/AN communities. With thoughtful investment in appropriate cultural adaptations, this program can be collaboratively leveraged by AI/AN communities across the country.

PROGRAM OVERVIEW

In 2015, the American Diabetes Association created an intensive, outcomes-based nutrition program entitled, “What Can I Eat?: Choices for People with Type 2 Diabetes and their Families”. This program, which consists of five 90-minute interactive sessions, is designed to promote positive dietary behaviors among disparately impacted adults with type 2 diabetes in high-risk minority populations.

To date, the program has been piloted and evaluated in high-risk rural and urban African American communities. Findings indicate significant impact on a number of key food consumption, shopping, and preparation behaviors (See Table 1). Program participants were also more confident in their ability to change their diet and make healthy choices in social settings. Positive trends in A1C, weight, and blood pressure were observed.

![Table 1. Key BEHAVIORAL Outcomes](image)

<table>
<thead>
<tr>
<th>INCREASED PROMOTED BEHAVIORS: Participants increased behaviors that were encouraged</th>
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</thead>
<tbody>
<tr>
<td>• Consumption of non-starchy vegetables, lower fat protein (e.g., chicken, fish), and water</td>
</tr>
<tr>
<td>• Use of the diabetes plate method</td>
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<tr>
<td>• Use of food labels</td>
</tr>
<tr>
<td>• Purchasing of healthy sides at restaurants</td>
</tr>
<tr>
<td>DECREASED UNDESIRABLE BEHAVIORS: Participants decreased behaviors that were undesirable</td>
</tr>
<tr>
<td>• Consumption of red meat, sweets, salty snacks, and sugary drinks</td>
</tr>
<tr>
<td>• Use of solid fats and frying in cooking</td>
</tr>
<tr>
<td>• Overall frequency of eating at restaurants</td>
</tr>
<tr>
<td>• Purchasing of fried foods at restaurants</td>
</tr>
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Additional efforts are underway to expand the program to positively impact other communities. The ADA-SMSC Award will support the adaptation and scaling of “What Can I Eat?” to multiple AI/AN communities across the United States. The project will support:

- Formative research
- Culturally-competent program adaptation
- A train-the-trainer program for tribal facilitators
- Program implementation in multiple tribes across the US
- Program monitoring and evaluation
- Programmatic enhancements for national scaling
The initiative will include the following activities, carried out over three years (see Table 2). **Funding for years 2 and 3** (in grey) **is pending funding and performance.**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Project Activities</th>
<th>YEAR 1 (Phase 1)</th>
<th>YEARS 2-3 (Phases 2 &amp;3)</th>
<th>Pending Funding &amp; Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Community Identification &amp; Engagement*</td>
<td>0-3</td>
<td>12-18</td>
<td>30-36</td>
</tr>
<tr>
<td>1</td>
<td>Formative Research</td>
<td>3-6</td>
<td>18-24</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Analysis, Reporting, and Recommendations for Adaptation</td>
<td>6-9</td>
<td>24-30</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Program Adaptation &amp; Implementation</td>
<td>9-12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Monitoring and Evaluation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Analysis, Reporting, and Application of Enhancements for National Scaling</td>
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*See inclusion criteria below

The program should initially be carried out in **four to six tribal communities. Inclusion criteria for selection of communities include:** 1) a disproportionately high risk of diabetes in general; 2) availability of and access to community resources to support implementation of the program; 3) a gap in existing programs/resources for diabetes management. To ensure geographic and dietary diversity to support future scalability, we strongly encourage one tribal community in each of the following settings:

- Rural Northwest
- Rural Southwest
- Urban Midwest (SMSC)
- Urban Northwest
- Urban Southwest

**PROGRAM PLANNING & FORMATIVE RESEARCH**

**Program planning** will involve 3 key processes:

1) *Tribal community identification.* University collaborators will identify settings that meet the inclusion criteria. We will also target those areas where ADA and/or our collaborators have existing linkages to facilitate a community-based approach.

2) *Community engagement.* University collaborators will engage key community members to help facilitate program development, implementation, and evaluation. During this phase, we will also identify complementary community partners and resources that can be leveraged to carry out the program.

3) *Formative research.* University collaborator will conduct comprehensive formative research to better understand needs, barriers, existing resources, and key behavioral moderators in each target community. Data will be used to drive culturally-specific strategies and educational content that are unique to each participating community.
The **formative research** strategy should include, but is not limited to:

- **A literature review** of existing data on gaps in diabetes care/education in Native communities, barriers and catalysts to healthy eating, cultural/social influences, and food preferences.
- **Semi-structured ethnographic interviews** with tribal leaders and providers to better understand community-specific needs, existing resources and policies, environmental/cultural barriers, and challenges to diabetes treatment and care.
- **Semi-structured ethnographic interviews** with program leads of other community programs in target communities to better understand potential barriers and facilitators to success.
- **Focus groups** with representative samples of community members to better understand perceived individual needs/priorities, individual preferences (e.g., foods, communication channels), the role of mental health (e.g., depression) in eating habits, perceived barriers (e.g., familial support, healthy food access), and cultural influences (e.g., spirituality, healing).

**PROGRAM ADAPTATION AND IMPLEMENTATION**

The adapted program will be based on the core structure of the existing “What Can I Eat?” program. The current iteration of the program consists of four 90-minute interactive sessions carried out over four weeks and one reinforcement session three months after the fourth session. Sessions include:

- **Food Is Love:** This introductory session focuses on managing diabetes regarding food and how it relates to family, friends, and social gatherings. Discussions include the interplay among diabetes, food, and emotions. The final section explains how to use the healthy “diabetes plate.”
- **Nutrition 101:** This session covers basic information for participants to understand the relationship between diabetes and specific nutrients, regarding blood glucose (sugar) levels.
- **Shopping and Cooking:** The topics of this session include shopping and cooking to manage diabetes, using the healthy plate method and how to make healthy swaps in cooking.
- **Eating Out and Special Occasions:** This session emphasizes ways to manage holidays, family get-togethers, and eating in restaurants, to better ensure making healthy choices in the context of the challenges of special occasions.
- **Three-Month Reunion Session:** This session is designed to share successes and challenges, to answer participant questions, and to offer ways to reinforce and maintain positive behaviors.

Each session also includes a brief component on the role of **physical activity and stress reduction** in diabetes management, with participants taking part in a short exercise and/or relaxation activity that can be easily practiced at home. The interactive sessions are carried out by trained professionals and integrate behavioral change theories, goal setting, action plans, problem solving, assessing progress, and other hands-on activities. **Sessions also address environmental barriers to healthy eating**, and facilitators provide targeted resources to help participants eat healthy within the context of their environment.

Program materials include a **facilitator guide** with empowerment/question-based conversation starters, a PowerPoint **slide deck** to help guide discussions and provide visual examples, and a **workbook** for participants to take home.

**Program Adaptation:**

Adapting the program to meet the needs of communities may involve any or all of the following:

- Reviewing and updating **program materials** to ensure that recommended foods, shopping options, cooking methods, psychosocial support strategies, and physical activities are culturally appropriate and sensitive to social and environmental barriers. We will also ensure that pictures of all items are culturally appropriate and relatable to the community.
• Determining if the order of sessions is appropriate and adapting as needed. For example, in the African-American community, it was determined that “Food is Love” must come first to set the stage for further discussion about eating habits and choices.

• Determining if the cadence of sessions is appropriate and adapting as needed. For example, we may find a preference for seven 60-minute sessions as opposed to five 90-minute sessions.

• Considering who should participate in the sessions. For example, caregivers or other family members may choose to attend all or some sessions.

• Considering the addition of sessions focused exclusively on family members, including:
  o Caring for and living with a loved one with diabetes;
  o Familial risk factors for diabetes;
  o The importance of lifestyle changes for prevention.

• Determining if home visits are feasible and appropriate strategy to supplement the core program.

• Deciding who the most effective tribal facilitators would be (e.g., dietitian, other health professional, community health worker). The Association will work with existing groups such as the National Association for Community Health Representatives and other relevant groups who may be able to lend assistance in identifying the most effective facilitators.

• Deciding who will conduct ongoing training of facilitators. A “train the trainer” approach will leverage ADA staff, University collaborator staff, and community facilitators.

• Determining the appropriate environment for sessions. For example, sessions are currently held in community clinics. However, we anticipate this environment may not be appropriate for individuals in target AI/AN communities.

• Finding community resources to assist with mental health issues including depression, anxiety and distress that are outside of the scope of this program but common in people with diabetes. Facilitators would help refer participants to those resources.

• Determining how best to evaluate the program in the community to ensure:
  o The methodology (e.g., in-person surveys) is appropriate and has a high likelihood of gleaning the desired information;
  o The language used is relevant and understandable to the target population.

Program Implementation:
The implementation of the adapted “What Can I Eat?” pilot program will be based on core elements of the existing implementation guide (Addendum A) that are adapted based on formative research findings. **Roles and responsibilities will be further defined by SMSC and the University collaborator(s).**

• ADA or the ADA Trained University Collaborators will train master trainers who are members of the participating tribal communities. The Association trained 21 dietitians across the country in the facilitation of the “What Can I Eat?” program in 2017. Participating dietitians could be leveraged as master trainers in communities targeted by this proposed grant.

• The local master trainer will train tribal community members. Training will include basic background information on diabetes, facilitation training utilizing “See One, Do One, Teach One” methodology, and data collection training.

• Using the “Do One” training methodology, a pilot group of willing participant volunteers from AI/AN communities will participate in mock sessions with newly trained facilitators. The local master trainer will oversee the mock sessions. Similarly, evaluators will be asked to conduct mock data collection (e.g., surveys) with trainer oversight.
A rigorous, dynamic monitoring and impact evaluation strategy will be employed to measure progress and results, and inform strategies for adaptations and scaling. Course corrections will be made to maximize fidelity, reach, and impact.

**Monitoring** strategies will, minimally, include a comprehensive process evaluation to track the progress and adaptation of predetermined deliverables and processes. The current iteration of “What Can I Eat?” employs web-based forms/checklists and observation assessments to capture program reach/participation, perceived acceptability, and program adaptation and needs for modification. This will be supplemented with new monitoring strategies to assess processes, satisfaction, and adaptation associated with the train-the-trainers program.

**Impact evaluation strategies** will be designed collaboratively by all participating institutions. However, to ensure impartiality, the ADA recommends that independent evaluators/biostatisticians drive data management and analysis. At minimum, strategies will include:

- Quantitative pre/post surveys to assess key expected dietary and psychosocial outcomes in a sample of participating adults.
- Biometric/health outcomes (e.g., weight, blood pressure) assessed before and after program engagement to explore health impact.
- Mediator and moderator analyses to understand the mechanisms (e.g., geographic/demographic indicators) through which the intervention affects desired outcomes.

The ADA also recommends post-intervention interviews conducted with site staff/volunteers to assess feasibility, cultural relevance, and barriers to expansion. REDCap or a comparable alternative, a secure open-source database, is currently hosted by the ADA for “What Can I Eat?” and will be available for this initiative. The ADA’s pre-tested evaluation tools will also be available to collaborators to leverage and modify as appropriate.

**REFERENCES**


**ADDENDUM**

A. “What Can I Eat?” Program Materials can be accessed via Dropbox at the following link: https://www.dropbox.com/sh/gh4qm9ipv9nqqod/AAASxYdnybjbKwA3FYFzuD1Fa?dl=0

B. “What Can I Eat?” Plan Your Portion placemat samples can be viewed at the following link: http://www.shopdiabetes.org/search/placemats.aspx