

**A REPORT ON THE MONTANA-WYOMING TRIBAL LEADERS COUNCIL  
BUILDING COMMUNITY SUPPORT FOR DIABETES CARE PROJECT**

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**INCREASING DIABETES SELF-MANAGEMENT EDUCATION IN TRIBAL  
SETTINGS: A TRIBAL-ACADEMIC-IHS COLLABORATION**

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## **Background and Purpose**

American Indians and Alaska Natives are 2.6 times more likely to be diagnosed with diabetes than non-Hispanic Whites<sup>1</sup> and diabetes is the fourth leading cause of death among American Indians living on the Northern Plains. The adjusted death rate from diabetes for this population group is over five times that of the U.S. All Races rate and is over 50 percent higher than the diabetes death rate of all American Indians/Alaska Natives served by the Indian Health Service (IHS).<sup>2</sup> Diabetes self-management education (DSME) that leads to lifestyle changes offers the potential to reduce both premature mortality and the development of life-threatening and debilitating complications, including diabetic retinopathy, cataracts, foot ulcers and amputation, kidney disease, periodontal disease, and cardiovascular disease.

Evidence is building that community-based education programs improve self-management of diabetes and have positive effects on people who are at-risk of developing diabetes. A recent review of diabetes self-management education research<sup>3</sup> notes that the traditional medical approaches alone have resulted in low patient compliance, whereas partnering with community organizations that provide geographically and culturally appropriate interventions increases compliance. The review also includes a summary of studies that analyzed the effectiveness of diabetes self-management education in community settings and concludes that this approach improves glycemic control, but there is insufficient evidence to show that it positively impacts other outcomes. Interventions used in these studies included use of lay health educators, involvement of family members in learning sessions, exercise classes in the community, support groups, and cooking demonstrations, as well as structured self-management education. Another recent review of the evidence on the effectiveness of self-management education<sup>4</sup> found positive outcomes associated with skill building, involvement of patients, physicians, and other practice team members in self-management interventions, and use of technologies to reinforce self-management education. The authors also note that community-based interventions offer the opportunity for increased participation rates, cultural relevance, and increased involvement of family members and support.

Limited funding of the Indian Health Service and difficulties in recruiting and funding trained diabetes educators by Tribal health programs present substantial barriers to providing DSME to American Indians with diabetes. This paper reports on a Tribal-academic-IHS partnership to develop and implement a community-based Diabetes Self-Management Education Program that relies on providing training to Tribal staff with little prior knowledge of DSME and Tribal leadership for implementation of the DSME program. Findings of the evaluation of the implementation process and lessons learned for expanding the program to other Tribal

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<sup>1</sup> National Diabetes Information Clearinghouse. National Diabetes Statistics. (NIH publication 02-3892. Fact sheet). [www.niddk.nih.gov/health/diabetes/pubs/dmstats/dmstats.htm](http://www.niddk.nih.gov/health/diabetes/pubs/dmstats/dmstats.htm), accessed May 12, 2002.

<sup>2</sup> U.S. DHHS, Indian Health Service. Regional Differences in Indian Health, 2000-2001. Rockville, MD, 2003.

<sup>3</sup> Leonard Jack, Jr., "Diabetes Self-Management Education Research," *Dis Manage Health Outcomes* (2003): 11 (7): 415-428.

<sup>4</sup> D. K. King and R. E. Glasgow, "Behavioral Self-Management of Type 2 Diabetes: Key Issues, Evidence-Based Recommendations, and Future Directions," Kaiser Permanente Colorado (undated).

communities and the impacts of that program on knowledge and attitudes about diabetes and on clinical measures that are associated with improved management of diabetes are also presented.

### **The Program: *Building Community Supports for American Indian People with Diabetes***

In early 2003, the Robert Wood Johnson Foundation *Diabetes Initiative* announced a new grant program, *Building Community Supports for Diabetes* (BCS). The objective of the BCS grants were to identify barriers to community support for people with diabetes and to provide funding for selected communities to plan and implement programs that would assist and encourage people with diabetes to make lifestyle changes to prevent or delay onset of complications of diabetes. The Montana-Wyoming Tribal Leaders Council, with the Eastern Shoshone Tribe and the Fort Peck Reservation Tribes, was awarded a 15-month BCS planning grant in May 2003. The planning grant period provided support for activities designed to obtain community input to identify barriers to diabetes support and self-management faced by people with diabetes, raise awareness of diabetes and the potential to avoid complications through healthy lifestyle choices, and develop community-specific strategies that would increase supports for people with diabetes to make beneficial lifestyle changes. The Robert Wood Johnson Foundation BCS program subsequently awarded a 30-month grant to support implementation and evaluation of the community-based programs developed.

### **The Planning Phase**

With the award of the Planning Grant, each of the two Tribal Health Departments identified an individual who served as the Tribal Liaison for the grant. The Tribal Liaison's responsibilities included serving as the point-of-contact between Tribal Health, the community, local Indian Health Service staff, and the Sanford Research/USD research partners for the project. Activities conducted during the planning period included:

- Establishment and meetings with Tribal/IHS Working Groups on Diabetes on each Reservation, comprised of the Tribal health director, Tribal diabetes program director, Community Health Representatives (lay health educators) director, the local Indian Health Service diabetes program director, community representatives, and one or more elected Tribal leaders at each site.
- Identification of barriers to diabetes management on each Reservation.
- Development and dissemination of Tribal-specific communications materials to raise community awareness of diabetes and the positive effects of lifestyle changes on prevention and management of diabetes.
- Development of strategies to address barriers to diabetes management and an implementation plan for these strategies.

Meetings of the Tribal/IHS Working Group were held monthly to discuss project goals, activities, and to obtain guidance at all stages of the planning process. Six focus groups were held with Tribal members with diabetes on each Reservation to discuss their experiences and obtain their views on barriers to diabetes management, as well as their suggestions for strategies that would assist them to better understand and manage their condition. The focus group guide was developed jointly by the Tribal liaisons and researchers and focus groups were facilitated by

the Tribal liaisons, with research team members attending to listen and take notes. In addition, key informant interviews were held with IHS diabetes staff and providers, Tribal Health staff, Tribal Diabetes Program staff, and Community Health Representatives (Tribal lay health educators) to obtain their perspectives on barriers and strategies for improving outcomes for Tribal people with diabetes. Key informant interview guides were developed by the research team, with input from the Tribal liaison, and interviews were conducted jointly by the research team and the Tribal liaisons. To supplement the information received from the focus groups and key informant interviews, the research staff also conducted an environmental scan on each Reservation to identify the availability of healthy foods and exercise opportunities for people with diabetes. In addition, the researchers documented the existing medical and community supports available to people with diabetes.

The most important barriers to diabetes management faced by Tribal members with diabetes included:

- Inadequate knowledge of Tribal members at-risk or diagnosed with diabetes about diabetes and lifestyle changes that could prevent or delay the onset of complications of diabetes and a fatalistic view that there is nothing that could be done to manage the condition.
- Lack of training for Tribal health, diabetes, and lay health educator staff on diabetes and diabetes management, making it difficult for these community-based staff to assist and support Tribal members with diabetes.
- Inadequate resources at the Indian Health Service to permit IHS diabetes staff to provide other than minimal information and support for Tribal members with diabetes.
- Cultural differences and ineffective communication between Tribal members with diabetes and non-Indian health providers also were identified as a barrier to improving diabetes outcomes.

Once the major barriers to improving diabetes outcomes were identified, the Tribal staff and researchers met several times to discuss strategies for providing community supports for Tribal members with diabetes and to design the program that would be implemented. All three Tribes agreed on a common approach that included the following elements:

- Design of a culturally-appropriate Diabetes Self-Management Education curriculum that incorporated Tribal-specific cultural activities and perspectives and was appropriate for delivery by Tribal diabetes program staff.
- Training of Tribal diabetes staff on the DSME curriculum and technical assistance to assist them to recruit DSME participants and conduct the classes.
- Training of Tribal health, diabetes, and CHR staff about the clinical aspects of diabetes, the positive effects of lifestyle changes on diabetes management and prevention of complications, and on motivational interviewing techniques and methods that could encourage Tribal members with diabetes to set goals and make lifestyle changes.
- Developing and disseminating Cultural Guides for IHS providers and staff to assist them to work more effectively with Tribal members with diabetes.
- Developing and disseminating Tribal-specific brochures and other materials to raise community awareness about diabetes and the positive effects of healthy lifestyle changes.

During the remaining three months of the planning period, activities were initiated to develop and prepare for the implementation of this approach to building community supports for Tribal members with diabetes.

## **Program Implementation**

The central goal of the Tribal BCS implementation grant was to provide effective, community-based and culturally-appropriate diabetes self-management education programs to American Indian people with diabetes and to offer community-based support and follow-up services that will encourage and assist program participants to make changes that will improve the management of their diabetes.

There is substantial evidence that well-designed self-management programs can result in significant improvements.<sup>5 6</sup> There is, however, little prior research and evidence on the feasibility and effectiveness of community-based approaches to improving outcomes for American Indians with diabetes who reside on Reservations. The implementation phase of the Tribal BCS program offered the opportunity to test this model with a unique population and to assess the feasibility and impacts of this approach. The activities that were conducted to support and implement the BCS program are described in the sections below.

*DSME Curricula:* The initial activity of the implementation phase of the project was development of Tribal-specific DSME curricula. Key components of the DSME curriculum included sessions on diabetes and its effects, the positive effects of diabetes self-management, blood pressure, cholesterol, physical activity, healthy weight and healthy eating, “you and your provider—working together,” and skills training to set and achieve self-management goals. Each Tribe has a unique culture, geography, and local resources that were identified and incorporated into the DSME curriculum.<sup>7</sup> The Tribal/IHS working group for each Tribe reviewed the draft DSME curriculum and provided cultural guidance on language and specific recommendations for modifications to reflect the local mores and culture. In addition, the working groups provided input on local resources for physical activity, food shopping, and other community supports that were incorporated into the DSME curriculum for each Tribe. The Tribal/IHS Working Group also recommended that a set of culturally-relevant activities (e.g. games, singing, physical activities) be incorporated into each session and assisted in developing those activities.

Based on pilot testing, additional modifications of the curriculum were made. These modifications primarily involved simplifying the language and developing slides for each session that could be used by Tribal staff who would be conducting the DSME classes. Modifications to

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<sup>5</sup> Leonard Jack, Jr., “Diabetes Self-Management Education Research,” *Dis Manage Health Outcomes* (2003): 11 (7): 415-428.

<sup>6</sup> D. K. King and R. E. Glasgow, “Behavioral Self-Management of Type 2 Diabetes: Key Issues, Evidence-Based Recommendations, and Future Directions,” Kaiser Permanente Colorado (undated).

<sup>7</sup> As one example, a member of the Blackfeet Tribe reviewed the nutritional guidelines being developed for the DSME program and noted that fish are considered “people of the waters” by the Blackfeet and cannot be eaten. Consequently, nutritional guidelines that suggest substituting fish for red meat would be inappropriate for the Blackfeet Tribe, if the project were replicated there.

the DSME curriculum were ongoing throughout the project. Researchers and Tribal staff involved in the project met frequently to review the curriculum and discuss the Tribal DSME facilitators' experiences and participants' suggestions. Each of the participating Tribes' staff made adjustments and changes to the curriculum, as they learned more about what worked well and what sessions were less successful in terms of DSME class participant responses and questions.

*Trainings:* Three types of trainings for Tribal staff were conducted during the project:

- *General training on diabetes, management, and the DSME curricula.* During the initial months of the implementation period, the research team conducted sessions on diabetes and the positive changes that could be accomplished from self-management to groups of Tribal health staff, Tribal diabetes staff, Tribal wellness/fitness program staff, and to Tribal CHRs (lay health educators). Then, a three-day training session was conducted on the DSME curriculum for the Tribal DSME coordinator, Tribal liaison, and additional Tribal staff who would be involved in recruiting, facilitating, and participating in the DSME classes. Additional DSME curriculum trainings were held throughout the project as refreshers and to provide training to new staff involved in the DSME classes.
- *Motivational Interviewing Trainings:* Trainings were held to assist Tribal staff to develop skills for motivating and supporting clients to make lifestyle changes. The initial training was provided approximately one month prior to the scheduled implementation of the project and a second round of training was provided six months after the initial DSME class was completed.
- *Data Collection and Confidentiality Trainings.* Tribal staff that would be responsible for data collection and reporting on an ongoing basis throughout the project was provided training to explain the study objectives and the relationship of each data collection component to the study requirements. Each data collection form was reviewed and discussed with the Tribal training coordinator and staff to ensure that they were aware of its purpose and the time frame for administering the form. In addition, training was provided on privacy and confidentiality issues and on HIPAA rules and each individual who would be collecting data was required to sign a statement indicating that they understood the importance of maintaining confidentiality of individual data and would comply with privacy and confidentiality requirements of the study. This training session was conducted prior to initiation of the first DSME classes, with a refresher session after completion of the first round of data collection.

*Implementation of the Tribal DSME Classes.* While it was anticipated that the initial DSME classes would begin by the eighth month of the implementation grant, significant delays occurred. There was turnover in staff at each site that required providing additional training for the new staff. Another issue that contributed to the delay in start-up of the DSME classes was difficulty in recruiting Tribal members with diabetes to participate in the classes. A strategy session was arranged with all of the Tribal training coordinators to discuss recruitment and develop new approaches that ultimately were more successful. By the end of the first year of the Implementation Phase, the Eastern Shoshone Tribe had recruited its first 20 DSME participants and began holding classes. Due to a number of reasons, the Fort Peck Tribe replaced its Tribal

liaison and DSME coordinator and the initial classes were delayed until the second year of the implementation phase.

The class structure and schedules varied between the two Tribes. The Eastern Shoshone program offered each class twice – once during the day and once in the evening – over an 11 week period and provided “catch up” classes for those who missed a class, when necessary. The Fort Peck program offered a number of options for participants, including day and evening classes, Saturday classes, and an intensive two-to-three day workshop.

Once the initial DSME classes concluded, recruitment for additional DSME participants was no longer a problem as “word of mouth” quickly advertised the class to other potential participants and, over the remaining implementation period, the Eastern Shoshone Tribal staff offered the classes six times and provided formal DSME classes to 76 Tribal members with diabetes. The Fort Peck Tribes offered the DSME classes eight times, serving 94 Tribal members.

## **Evaluation Methods and Findings**

### Evaluation Questions and Data Sources

The evaluation of the Tribal BCS program was designed to include implementation/operational processes and outcomes and quantitative outcomes. The key implementation/operational issues included:

- What implementation/operational problems were encountered? How were they resolved? What successes did Tribal staff and DSME participants perceive to have occurred?
- What lessons were learned that could improve the program and serve as guidance for future replication by other Tribes and academic and IHS partners?
- Is the program sustainable at Eastern Shoshone and Fort Peck, after grant funding ends?

The quantitative evaluation focused on two central questions:

- How effective was the DSME program in increasing knowledge and understanding of diabetes, effective strategies for managing diabetes, and ways to set and achieve goals for self-management?
- Did DSME participants show improvement in clinical measures (i.e. weight loss, decreased blood pressures, cholesterol, triglycerides, and HbA1c levels)?

Data for the implementation/operational evaluation relied on meeting notes, training notes and summaries, and monthly progress reports submitted by each Tribe, key informant interviews conducted at each site with the Tribal training coordinators and Tribal diabetes staff, and focus groups with DSME participants. The key informant interviews and the focus groups were conducted during the final four months of the project.

Data required for the examination of the impact of DSME on knowledge and attitudes about diabetes and diabetes self-management were collected through pre- and post-intervention surveys of DSME participants to assess the change in knowledge of diabetes, benefits of self-management, and strategies to make changes to manage diabetes. The University of Michigan Diabetes Research and Training Center survey instruments to measure Diabetes Knowledge and

Diabetes Attitudes were used for these pre-post measurements.<sup>8</sup> Analysis of the Knowledge survey responses was a simple comparison of the percent correct obtained by respondents on the pre-intervention survey and percent correct obtained by respondents on the post-intervention survey. The analysis of the Attitudes survey data was conducted using the subscales developed by Anderson *et al.* for the third version of the Diabetes Attitude Scale (DAS-3).<sup>9</sup> These subscales reflect patient attitudes on a scale of 1 to 5 toward: 1) need for special training in education for health professionals who treat people with diabetes; 2) seriousness of Type 2 diabetes; 3) overall value of tight glucose control; 4) psychosocial impact of diabetes on patients; and 5) patient autonomy. Participants' pre-post intervention responses to these attitudinal questions were analyzed to assess whether significant changes in attitudes in each of these subscale areas occurred.

The Billings Area Office of the Indian Health Service (IHS) Diabetes Program Director provided data from the IHS RPMS<sup>10</sup> data base and diabetes registry on the clinical measures of interest, for DSME participants who had signed Consent Forms and HIPAA Release Forms. Baseline data were obtained for each consenting individual at the time that they enrolled in the DSME program. Follow-up data on each consenting DSME participant were then requested from IHS for the 12-month period after the end of the DSME classes in which they participated. Due to the delays in start-up of the DSME classes which were particularly extended at Fort Peck and other reasons described below, follow-up data were available only for about 25 percent of DSME participants. For this reason, analysis of significance of the changes observed was not conducted, although the data on the percent showing improvements in each clinical measure are presented below.

### Implementation/Operational Findings

*Implementation Issues and Problem Resolution.* A number of issues were identified by Tribal staff and the involved researchers that required resolution for the BCS project to proceed successfully. These included:

- Extended start-up problems that resulted in a shortened implementation period.
- Staffing changes during the pre-implementation period.
- Greater requirements for training and technical assistance than planned.
- Slow recruitment for the initial classes.

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<sup>8</sup> See <http://www.med.umich.edu/mdrtc/survey/index.html>.

<sup>9</sup> Anderson, RM, Funnell, MM, Fitzgerald, JT, and Gruppen, LD. "The Third Version of the Diabetes Attitude Scale," *Diabetes Care*, Volume 21 (9), pp. 1403-1407, September 1998.

<sup>10</sup> The Indian Health Service Resource and Patient Management System (RPMS) database is an IHS-wide system designed to provide detailed and comprehensive clinical information for assessment and management of IHS performance. It has several components for reporting detailed information on patient characteristics, diagnoses, and specific services provided. The data included on the Ambulatory Patient Care System component are collected and entered daily, one record per ambulatory medical visit, and includes information on diagnosis, treatments, and specific examinations and tests performed and their results. In addition, results of special medical record audits are entered into the database. The RPMS has the capability to produce special reports, by IHS Region, Reservation, Service Unit, and by individual physician. For each of these units of analysis, patients with diabetes (Type 1 and Type 2, separately) can be identified and rates of specific examinations and tests can be calculated.

- Ongoing revisions to the DSME curriculum and supporting materials, as Tribal training coordinators gained experience and received feedback from DSME participants.

Extended Start-Up Period. The Tribes that participated in the BCS program had little or no previous experience with community-based participatory research that involves Tribes in the design of the program and assigns primary responsibility for implementation and data collection to Tribal staff. Thus, the Tribal staff and the researchers were embarking on two interdependent learning processes during the implementation of the BCS program – the concepts and application of Tribal Participatory Research principles and the specific diabetes support activities that were developed for the BCS program. This resulted in slow progress during the planning and implementation phases of the BCS program, as Tribal staff were accustomed to researchers taking the lead on all phases of research projects and it took considerable time and effort to assist each Tribe to become fully involved in the project and take on direct responsibility for implementation. At the Eastern Shoshone site, the initial DSME class started in Month 11 of the 30-month implementation period. At the Fort Peck site, the initial DSME class started in Month 18 of the 30-month implementation period.

Staffing Changes. Delays in implementation also occurred due to several changes in assignment of the BCS project within each Tribe. At the Eastern Shoshone site, the initial Tribal staff assigned to the BCS implementation phase was replaced after several months and then the replacement staff was replaced after several additional months. With each of these staff changes, it was necessary to provide training to the newly assigned Tribal staff about the project objectives, the DSME curriculum, motivational interviewing techniques, data collection instruments and methods, and patient confidentiality and HIPAA requirements. At the Fort Peck site, Tribal staff that was involved in the planning phase of the project was replaced for the implementation phase. The new Tribal training coordinator at Fort Peck was unable to initiate the project and did not offer any classes through the first 18 months of the 30 month implementation period. A new Tribal training coordinator ultimately was assigned to take over the BCS implementation and was able to successfully initiate the BCS activities.

Need for Additional Training and Technical Assistance. It was initially assumed that training on the DSME curriculum and supporting materials would be conducted once at each Tribal site and then additional training would be provided during and after the initial DSME class, as the Tribal training coordinators gained experience and identified areas where they felt additional training would be useful. However, the Eastern Shoshone Tribal training coordinators had limited formal training on diabetes and self-management concepts prior to being assigned to the BCS project. As a result, several additional training sessions were necessary before they became comfortable with leading the DSME classes. This additional training was critical to the success of the BCS program, as it provided the training coordinators with the knowledge to permit them to answer DSME participants' questions and concerns and be viewed as "legitimate" educators.

Recruitment and Retention of DSME Participants. Tribal training coordinators indicated that initial recruitment was difficult, in part, because Tribally-provided DSME classes were a new concept on the Reservation. Tribal members with diabetes were uncertain and skeptical about whether the Tribally-offered classes would be worthwhile, even though they recognized that IHS did not have the resources to offer DSME classes. Both the Eastern Shoshone program and the Fort Peck program developed a variety of recruitment strategies, including incentives for

completion, offering healthy snacks and meals during the classes, and a range of enjoyable activities during the classes. Once the first DSME class was completed at each site, recruitment of participants for additional classes was facilitated by “word of mouth” and Tribal members with diabetes began actively contacting the Tribal health and diabetes staff to enroll in future classes.

Retention of DSME participants through the full set of class sessions was also identified as an issue and the Tribal training coordinators developed a number of strategies to assist and encourage participants to attend all class sessions. At the Eastern Shoshone site, each class was offered at least twice each week, once during the day and once in the evening. Make-up classes were offered to those who missed sessions, either in a group or one-on-one. The Fort Peck classes were initially quite large and the large number of attendees made it difficult to effectively communicate with all of the participants and answer the wide range of questions raised. After the initial DSME class, a decision was made to limit the size of the classes and to offer the classes more frequently, which resulted in higher retention.

Ongoing Modification of the DSME Curriculum and Materials. The Tribal training coordinators and DSME participants at both sites found that the original DSME curriculum and supporting materials were difficult for many participants to grasp, due to literacy levels and lack of familiarity with diabetes and clinical measures. At Fort Peck, the Tribal training coordinator sought assistance from a fifth grade teacher who modified the curriculum and materials to be understandable by people with a fifth grade reading level. In addition, the training coordinator and Tribal diabetes staff augmented the supporting materials to include for visual aids and videos in order to rely less on written materials and emphasize oral and visual learning. At the Eastern Shoshone site, the Tribal training coordinators modified the curriculum on an ongoing basis, responding to feedback from DSME participants during class and in one-on-one follow-up sessions.

Follow-up of DSME Participants after the Final DSME Class. The implementation plan included monthly follow-ups of DSME participants for six months after the final DSME class, by the Tribal training coordinator and/or Tribal diabetes program staff. These follow-up contacts were intended to reinforce the DSME messages and to assist and support the DSME participant to set goals and overcome barriers to making lifestyle changes. A follow-up Contact Report was to be completed for each follow-up visit or telephone contact that would permit evaluation of the effectiveness of follow-up, apart from the effectiveness of the DSME classes. While follow-up contacts were made with some of the DSME participants, the Tribal diabetes staff did not complete the Contact Reports in most cases. Consequently, it was not possible to assess the value of this component of the intervention.

*Lessons Learned from the Implementation/Operational Experience.* Tribal training coordinators and DSME participants who were interviewed during the final months of the BCS program uniformly indicated positive benefits from the program:

- Tribal health and diabetes staff gained increased knowledge about diabetes and diabetes self-management and were better prepared to support and assist Tribal members with diabetes.

- The Tribal training coordinators became effective teachers who were able to provide informed and knowledgeable information about diabetes and diabetes self-management to Tribal members with diabetes and are viewed as valuable resource staff by the community.
- 170 Tribal members with diabetes participated in the DSME classes who would not have had access to these classes, in the absence of the BCS program.
- Tribal health and diabetes staff also noted that Tribal members who had taken the DSME classes were more knowledgeable about their HbA1c levels, blood pressures, and cholesterol levels and were more likely to report asking their IHS physicians about these measures.

While the consensus was that the Tribal BCS program was successful, a number of lessons were learned from the planning and implementation experience that can be useful for replication of the BCS model with other Tribes and for development of new Tribal-researcher collaborative partnerships to address other health issues. These lessons include:

- *Community-based participatory programs require extensive time for planning and development.* The BCS program was structured to include 15 months for planning and 30 months for implementation of the interventions and evaluation. However, the interventions were not implemented until 12 months after the initial planning period by the Eastern Shoshone BCS program and 18 months after the planning period by the Fort Peck BCS program. There were many reasons that contributed to the extended start-up period, including that neither Tribe had previously been involved in a Tribal Participatory Research project where they took the lead on implementation and that the research team had previously only limited experience in working collaboratively with these Tribes. Subsequent to the BCS program, this Tribal-researcher collaboration has developed additional joint research and intervention projects that have been successfully implemented and build on the lessons learned from the BCS project.
- *Extensive training and technical assistance to Tribal community-based staff may be required to support community-based interventions.* Tribes located in rural and frontier areas are likely to have difficulties recruiting staff with formal training and credentials. On-the-job training may be the primary method for building staff qualifications in health areas. Introducing a new program, requiring new knowledge and skills, will likely require extensive training and technical assistance to the Tribal staff that will be responsible for implementation of new interventions. Research partners should recognize these needs and plan to provide training prior to the implementation of the interventions, reinforce the training during the initial implementation period, and provide ongoing technical assistance throughout the interventions.

A final lesson learned from the BCS program is a very positive and important one – once Tribal partners were fully engaged in the project, they took full ownership and responsibility for adapting and modifying the DSME curriculum and supporting activities to improve their usefulness, relevance, and value to Tribal members with diabetes. The Tribal DSME program became an integral part of the Tribal health and diabetes services and was no longer an outside-directed researcher-initiated project. While this shift in perspective took considerable time, the

benefits to the Tribal staff and to Tribal members with diabetes are a major accomplishment of the BCS program.

*Sustainability.* Sustainability of interventional programs after grant funding ends is always an issue in communities and settings with limited resources. The BCS program was designed to support and encourage sustainability through several mechanisms. The program involved extensive training of Tribal health, diabetes, and lay health educator staff on diabetes, diabetes self-management, and strategies to support and assist Tribal members with diabetes to make lifestyle changes. In addition, the 30-month implementation time frame was a sufficiently long time period for this training to be translated into effective experience and institutionalized in the local diabetes programs. The specific interventions – both the DSME program and the skills-building training for Tribal diabetes/CHR staff – provide materials, tools, and knowledge that are transferable to new staff and created the foundation for sustainability at little ongoing costs once the BCS implementation grant ended. Finally, the number of Tribal members with diabetes who have enrolled and completed the DSME classes offered by the Tribal health/diabetes staff has created an expectation in the community that these classes will be available to those who seek more education about diabetes and steps that they can take to manage diabetes and prevent complications.

The Tribal staff at both the Eastern Shoshone and Fort Peck BCS sites continued offering DSME classes to community members, as Tribal members with diabetes were regularly contacting them to ask about the schedule for new classes in which they could enroll. At the Eastern Shoshone site, in addition to planning for new DSME group classes, the Tribal training coordinator has also initiated one-on-one DSME counseling and education of individuals with diabetes who are not able to attend group meetings. At the Fort Peck site, the Tribal Diabetes Program Manager planned to continue offering DSME classes on a regular schedule. Staff of both programs indicated that they would be seeking additional grant funding that would permit them to expand the number of DSME classes they could offer, in order to serve more people and to expand the BCS program to Tribal members who are pre-diabetic or at-risk of developing diabetes.

### Impacts on DSME Participants

Evaluation of the impacts of the Tribally-provided DSME intervention on participants was examined using baseline information obtained through the Enrollment Intake Form, pre-post Knowledge and Attitudes survey, and baseline and follow-up clinical data provided by the Billings Area Office of the Indian Health Service for DSME participants who had signed consents to participate in the study and HIPAA Release Forms. Although a total of 170 Tribal members with diabetes enrolled in the DSME classes, not all completed the Enrollment Form and some did not sign Consent and HIPAA Release forms. In addition, due to the delayed start-up at both sites, some of these DSME participants attended classes during the final six months of the implementation period and insufficient time was available to permit obtaining follow-up clinical data. Thus, the analysis in this section is based on fewer than 170 participants. However, the results provide useful information on the characteristics of Tribal DSME participants, the

impact of the classes on knowledge of diabetes and attitudes toward diabetes self-management, and some limited evidence on the impact of the intervention on clinical measures of interest.

*Characteristics of DSME Participants.* Participants in the DSME classes were asked to complete an Enrollment Intake Form at the initial class session that included demographic questions and a question about the number of years since they were diagnosed with diabetes. The Tribal training coordinator also explained the objectives of the evaluation, the data collection that would be required for the evaluation, and that the evaluation was also focused on assessing the extent to which their participation affected clinical measures of importance to diabetes self-management. Each participant was encouraged to ask questions, if they were unclear about the study, and to read the Consent to Participate in the Study Form and the HIPAA Release Form that would give IHS permission to provide baseline and follow-up clinical measures from their medical record.

At the Eastern Shoshone site, 79 percent of the 76 DSME participants completed the Enrollment Form and signed both the Consent Form and the HIPAA Release Form (see Table 1). At the Fort Peck site, 65 percent of 94 DSME participants completed the Enrollment Form and signed the Consent and Release forms. Of the 170 total DSME participants at the Eastern Shoshone and Fort Peck sites, 121 completed the Enrollment Intake Form, consented to participate in the study, and agreed to release of their medical data.

Analysis of information on the Enrollment Intake Form and clinical data provided by the Indian Health Service provided a baseline profile of the characteristics of DSME participants. Women were twice as likely to enroll in the DSME classes as men at Eastern Shoshone and Fort Peck (Table 2). This may be due to the fact that a higher proportion of women are diagnosed with diabetes since the IHS Diabetes Registry data for these two Tribes indicate about 60 percent of those on the Registry are women and 40 percent are men. It is unclear whether men are less likely to have diabetes, less likely to seek medical care for diabetes than are women, or less likely to enroll in DSME classes.

The mean age of DSME participants was 44.1 for men and 53.2 for women. Thirty-eight percent of male participants were under age 40, compared with 24 percent of female participants at Eastern Shoshone and Fort Peck. There were minor differences in age distribution between the two sites, with Fort Peck enrolling somewhat younger men and somewhat older women than Eastern Shoshone.

Average BMI across both sites was 35.6 for men and 34.7 for women. At Fort Peck, the average BMI for men (37.3) was higher than for Eastern Shoshone men (34.6). Average BMI for women participants at Fort Peck (33.4) was somewhat lower than the average BMI (35.7) for Eastern Shoshone women participants.

One third of Eastern Shoshone DSME participants reported that they had been diagnosed with diabetes less than seven years prior to taking the class and 15 percent reported that they had been diagnosed over 15 years previously. By comparison, 22 percent of participants at Fort Peck had been diagnosed within the prior seven years and 23 percent reported being diagnosed over 15

years previously. Nearly one-third of participants at both sites reported being uncertain about when they had first been diagnosed with diabetes.

Baseline clinical measures were provided by the Billings IHS diabetes coordinator for each DSME participant who had signed a HIPAA release form. Baseline clinical measures were not available for every participant, for a number of reasons (discussed below); as a result, full clinical baseline data were available for only 61 Eastern Shoshone participants and 47 Fort Peck participants. Participants at both sites exhibited total cholesterol, LDL, and HDL levels that were within the desirable range or only slightly elevated.<sup>11</sup> Average triglyceride levels were above the desirable level (150 mg/dl or lower) at both the Eastern Shoshone and Fort Peck sites. Average blood pressure levels at both sites were also within the normal to borderline levels.

The average HbA1c level of DSME participants, across both sites, was 8.7, with the Eastern Shoshone average at 8.8 and the Fort Peck average at 8.5. HbA1c levels were at the desired level (less than 7.0) for only 23 percent of DSME participants at the Eastern Shoshone site and for only 37 percent of participants at Fort Peck. Thirty-eight percent of DSME participants at the Eastern Shoshone site and 31 percent of participants at the Fort Peck site had recorded HbA1c levels between 7.0 and 8.9, while 39 percent of Eastern Shoshone participants and 32 percent of Fort Peck participants had HbA1c levels above 9.0 at baseline.

*Impacts on Knowledge of Diabetes and Attitudes toward Self-Management.* The University of Michigan Diabetes Knowledge and Attitudes questionnaire was administered to each individual who consented to participate in the study at the first DSME class and again at the final class. A total of 94 participants took both the pre- and post survey of knowledge and attitudes. Analysis of the Knowledge surveys showed a significant ( $p < .001$ ) increase in knowledge about diabetes. Over the entire sample, 65 percent increased their knowledge about diabetes after completing the DSME program.

There are five dimensions of attitudes toward diabetes on the University of Michigan Diabetes Attitudes Survey:

- Need for special training of diabetes professionals
- Seriousness of Type 2 diabetes
- Value of tight glucose control
- Psychosocial impact of diabetes
- Patient autonomy

Over the entire sample, a higher proportion exhibited more positive attitudes toward diabetes self-management after the DSME classes than at the beginning of the classes. However, this change was not significant for any of the dimensions of the survey. Areas in which there was a positive shift in attitudes included:

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<sup>11</sup> Desirable Total Cholesterol levels are less than 200; desirable LDL levels are less than 100; and desirable HDL levels are 40 or above.

- Need for special training of diabetes professionals: More DSME participants responded post-intervention that “health care professionals should learn how to set goals with patients, not just tell them what to do” and “to do a good job, diabetes educators should learn a lot about being teachers.”
- Seriousness of Type 2 diabetes: Fewer DSME participants responded post-intervention that “people who do not need to take insulin to treat their diabetes have a pretty mild disease” ( $p < .05$ ), and “people whose diabetes is treated by just diet do not have to worry about getting many long term complications.”
- Value of tight glucose control: More people responded post-intervention that “keeping the blood sugar close to normal can help to prevent the complications of diabetes,” and fewer people responded that “low blood sugar reaction makes tight control too risky for most people,” “people who have Type 2 Diabetes will probably not get much payoff from tight control of their blood sugar,” and “tight control of blood sugar makes sense only for people with Type 1 Diabetes.”
- Psychosocial impact of diabetes: More people responded that “diabetes affects almost every part of a diabetic person’s life” and fewer people responded that “the emotional effects of diabetes are pretty small.”
- Patient autonomy: More people responded that “the important decisions regarding daily diabetes care should be made by the person with diabetes,” and “people with diabetes should have the final say in setting their blood glucose goals.”

*Impacts on Clinical Measures.* Baseline clinical measures were obtained from the Billings IHS diabetes coordinator for 108 of the 170 DSME participants.<sup>12</sup> However, post-intervention clinical measures were only available for 43 DSME participants and not all clinical measures were available post-intervention for this group. The reasons for the limited number of people for whom both baseline and follow-up data were obtained include:

- Some of the DSME participants did not visit their IHS provider for diabetes monitoring during the follow-up period or, if they did, their data were not recorded at the time the follow-up data were drawn from the IHS database. This was particularly an issue for participants in the Fort Peck BCS program, where many of the DSME participants for whom baseline data were available had only a six-month window for a visit to their IHS provider. At the Eastern Shoshone site, the majority of those who completed the DSME classes had a 12-month follow-up period for a visit to an IHS provider.
- Some Tribal members with diabetes may not always use IHS for routine diabetes monitoring; if they visited a non-IHS provider, those data would not be in the IHS database.

Although the number for whom pre- and post-intervention clinical measures were available is small, the results observed suggest that the DSME classes had a positive impact on participants (Table 3). Eastern Shoshone pre- and post- intervention data on some of the clinical measures were available for 30 DSME participants. Of these, 57 percent had achieved some reduction in

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<sup>12</sup> Because Fort Peck did not begin offering DSME classes until the last 12 months of the intervention period, only about one-third of that site’s DSME participants had completed the class by the mid-point of the last intervention year. Due to this timing and the need for a minimum of six months post-intervention clinical data, baseline data were not requested from IHS for those who completed classes during the final six months of the intervention period.

their weight, 57 percent had lower overall cholesterol levels, 46 percent had lower triglyceride levels, 50 percent had achieved a reduction in their systolic and diastolic blood pressures, and 34 percent had reduced their HbA1c levels. At the Fort Peck site, there were only eleven individuals for whom some pre- and post-intervention clinical measures were available. Of these, 36 percent had lost weight, 44 percent had reduced cholesterol levels, 50 percent had lowered their triglyceride levels, 45 percent had achieved a reduction in systolic blood pressure and 82 percent had achieved a reduction in diastolic blood pressure, and 25 percent had reduced their HbA1c level.

Due to the small numbers for which both pre- and post-intervention data were available and the fact that complete pre-post intervention data were not available for all of these individuals, none of the changes reported in Table 4 were statistically significant and we did not do further analysis of the magnitude of the change in clinical measures and the factors that were associated with impacts on clinical measures. However, the limited data available suggest that some DSME participants did make effective use of the information they gained from the DSME classes and were able to make lifestyle changes that allowed them to better manage diabetes.

The lack of follow-up clinical data for 65 of the 108 DSME participants for whom baseline data were available is a substantial limitation of this evaluation. For follow-up data to be available, the participants needed to have visited their IHS provider for diabetes monitoring at least once in the six to twelve month period after completing the DSME classes. The fact that two-thirds of those who participated in the DSME classes did not visit their provider for a diabetes check up in this period (or, if they did, the data were not in the IHS records) is clearly a concern, particularly since they had just completed the classes that emphasized the importance of regular monitoring and glucose control. Further investigation of the reasons that these individuals did not visit their provider is clearly warranted. In addition, it would be useful to know whether this infrequency of routine diabetes visits is common among this population to determine the extent to which the DSME classes may have positively or negatively affected participants' decisions about making and keeping diabetes monitoring appointments with their providers.

It is also likely that the positive results for those participants for which pre- and post-intervention clinical data were available are based on a highly biased sample. That is, those DSME participants who were motivated to make lifestyle changes were more likely to make and keep appointments for diabetes check-ups in order to monitor the effects of the changes they were making on the clinical measures of diabetes self- management. Given the limitations of the data and the substantial probability that those for whom both pre- and post-intervention clinical measures are available represent a biased subgroup of the population, we can only note that about 15 percent of those who participated in DSME classes were able to reduce their HbA1c levels within six to twelve months after the last class.

## **Discussion and Next Steps**

American Indians experience rates of Type 2 diabetes that are two to three times higher than for the general population. At the same time, this population has fewer resources available to prevent and to manage diabetes than many other groups due to poverty, rural/frontier geography, difficulties in recruiting trained diabetes professionals, and limited funding of the Indian Health

Service that provides most medical care for American Indians living on Reservations. The RWJ Building Community Supports for American Indian People with Diabetes offered an opportunity to increase services available to educate Tribal members with diabetes about diabetes and the positive value of lifestyle changes to prevent complications and improve outcomes. In addition, the community-based intervention process supported increased training for Tribal health and diabetes program staff about diabetes, diabetes self-management, and strategies for supporting Tribal members with diabetes.

While implementation of the BCS program with these two Tribes required extensive preparation, training, and technical assistance, due to initial inexperience with community-based participatory projects, the outcomes of the project were positive:

- Tribal health and diabetes staff received extensive training on diabetes and diabetes self-management and on motivational interviewing strategies that are being applied on an ongoing basis for the benefit of Tribal members with diabetes and other chronic conditions.
- Tribal health and diabetes staff took “ownership” of the BCS program, once implementation was underway, and made modifications to the DSME curriculum and protocol on an ongoing basis in response to their experience and feedback from participants.
- 170 Tribal members with diabetes enrolled in Tribal DSME classes that would not otherwise be available, due to limited resources of the Indian Health Service.
- DSME participants were more knowledgeable about diabetes and had more positive attitudes toward self-management after completing the classes.
- Some DSME participants (about 15%) had achieved improved glucose control, six to twelve months after completing the classes and a somewhat higher percentage had lost weight, reduced cholesterol or triglyceride levels, or achieved improved blood pressure levels.
- Six months after the end of the funded intervention period, both Tribes were continuing to offer DSME classes and one-on-one support to Tribal members with diabetes.

These results suggest that community-based approaches to assisting Tribal members with diabetes to improve outcomes are feasible and offer potential as a sustainable strategy for reducing diabetes mortality and morbidity among American Indians living on Reservations in rural/frontier areas. A number of lessons were learned during the implementation phase of the project that, if the program is replicated, would yield additional information and more quantitative evidence for this approach. Because of the inexperience of the Tribal staff, more training and technical assistance would have been helpful during start-up and on an on-going basis, particularly with respect to the DSME follow-up component of the program that was intended to reinforce and support those who had completed the classes to set goals and overcome barriers to self-management. In addition, a better assessment of the impact of the interventions on clinical measures of interest would require much more extensive follow-up with DSME participants to ensure that they made and kept appointments for diabetes monitoring. Alternatively, the research component could have included regularly scheduled appointments, outside of IHS, to obtain clinical laboratory data and other measures. While this alternative is

probably best, it would also significantly add to the costs of the research and evaluation of the program.

**Table 1: Study Participation**

<b>Participation</b>	<b>Eastern Shoshone</b>	<b>Fort Peck</b>	<b>Total</b>
Number Enrolled	76	94	170
Enrollment (Intake) Form Completed (Percent)	83%	75%	77%
Consented to Participate in Study (Percent)	86%	88%	87%
Signed HIPAA Release Form (Percent)	84%	84%	84%
Both Consented and Signed HIPAA Release	83%	81%	82%
Intake, Consent And HIPAA release completed	79%	65%	71%

**Table 2: Characteristics of Participants at Enrollment**

<b>Characteristics</b>	<b>Eastern Shoshone</b>	<b>Fort Peck</b>	<b>Total</b>
<u>Gender:</u>			
Percent Female	66%	63%	64%
Percent Male	33%	32%	32%
<u>Age:</u>			
Males	N=23	N=25	N=48
% <40 Years	39	36	38
% 41-50 Years	26	44	35
% 51-60 Years	9	16	12
% > 60 Years	26	4	15
Females	N=43	N=60	N=103
% <40 Years	30	20	24
% 41-50 Years	16	20	19
% 51-60 Years	33	20	25
% > 60 Years	21	40	32
<u>Mean Age:</u>			
Male	45.9 (19.9)	42.5 (11.0)	44.1 (14.1)
Female	51.6 (14.2)	54.3 (14.8)	53.2 (14.6)
<u>Mean Height:</u>			
Male	69.9 (4.0)	67.4 (8.2)	69.0 (5.9)
Female	63.5 (2.7)	64.0 (2.4)	63.7 (2.6)
<u>Mean Weight:</u>			
Male	247.4 (50.2)	234.6 (73.6)	242.5 (59.5)
Female	203.3 (44.8)	195.4 (54.4)	199.9 (49.0)
<u>Mean BMI:</u>			
Male	34.6 (6.4)	37.3 (13.6)	35.6 (9.7)
Female	35.7 (8.0)	33.4 (9.3)	34.7 (8.6)
<u>Years Since DX</u>			
% < 7 years	33	22	27
% 7- 14 years	18	23	21
% 15+ years	15	23	19
% Uncertain	31	32	33

**Table 2: Continued on next page**

**Table 2: Continued**

<u>Clinical Values:</u>			
Total Cholesterol			
LDL	186.6 (36.4)	188.1 (57.8)	187.2 (46.2)
HDL	110.3 (35.4)	113.3 (42.2)	111.9 (38.9)
Triglycerides	40.0 (10.5)	48.5 (23.8)	43.9 (18.3)
Blood Pressure:	205.2 (147.0)	178.3 (104.5)	193.6 (130.3)
Systolic			
Diastolic	127.46 (18.1)	131.7 (15.2)	129.3 (17.0)
HbA1c	71.24 ( 7.4)	73.6 (9.0)	73.6 (9.0)
Mean value			
% < 7.0	8.8 (2.1)	8.5 (2.5)	8.7 (2.2)
% 7.0-7.9	23	37	28
% 8.0-8.9	21	17	19
% > 9.0	17	14	16
	39	32	37

**Note:** Standard deviation is indicated in parentheses.

**Table 3: Change in Clinical Measures**

<b>Clinical Measures</b>	<b>Eastern Shoshone</b>		<b>Fort Peck</b>		<b>Both Sites</b>	
	<b>Total Number</b>	<b>Percent</b>	<b>Total Number</b>	<b>Percent</b>	<b>Total Number</b>	<b>Percent</b>
Weight Reduction	30	57%	11	36%	41	51%
Lower Cholesterol	21	57%	9	44%	21	53%
Lower Triglycerides	13	46%	8	50%	21	48%
Lower Systolic BP	26	50%	11	45%	36	49%
Lower Diastolic BP	26	50%	11	82%	36	60%
Lower HbA1c	35	34%	8	25%	43	33%