

Chapter 7

CONCLUSIONS

In the Balanced Budget Act of 1997, Congress established the Special Diabetes Program for Indians to provide prevention and treatment services to address the growing problem of diabetes in American Indians and Alaska Natives (AI/ANs). The Balanced Budget Act also required an Interim (2000) and Final Report to Congress (2002). Since the Special Diabetes Program for Indians funding was extended to FY 2008, the Indian Health Service (IHS) National Diabetes Program decided to conduct an interim evaluation to provide Congress with a progress report on how the Indian health system is meeting the original legislative intent.

The information provided in the preceding chapters was assembled to meet the **original objectives of this evaluation:**

- 1) To determine whether the Special Diabetes Program for Indians did implement prevention and treatment services to address the growing problem of diabetes in AI/ANs.
- 2) To measure whether the prevention and treatment services implemented through the Special Diabetes Program for Indians resulted in short-term, intermediate, or long-term positive outcomes.

This evaluation is the most comprehensive evaluation of this initiative to date. Using a variety of data sources, the IHS National Diabetes Program demonstrated significant accomplishments related to the first objective of the evaluation by comparing the level of prevention and treatment services available prior to the Special Diabetes Program for Indians funding, and **increased levels of services** after five years of funding.

The IHS awarded Special Diabetes Program for Indians grants to 318 programs under 286 administrative organizations within the 12 IHS Areas in 35 states. The IHS distributed:

- 27 (9%) grants to IHS programs
- 33 (10%) grants to urban Indian health programs
- 258 (81%) grants to tribal programs

Short-term Outcomes

Compared to their level of services prior to the funding (before 1998), the programs funded under the Special Diabetes Program for Indians achieved the following improvements (**short-term outcomes**) in diabetes prevention and treatment services as of FY 2002:

- Availability of **basic clinical exams** increased (foot exams, eye exams, dental exams)
- Availability of **newer medications and therapies** for diabetes treatment increased (medications for glycemic control, lipid lowering, ACE inhibitors, medical nutrition therapy)
- Availability of **laboratory tests** to assess diabetes control and complications increased (A1C, lipids, urinary microalbumin, urinalysis)
- **Screening** for diabetes and pre-diabetes increased
- **Adults and elders** were screened for several risk factors of diabetes (screening for pre-diabetes, overweight and obesity, acanthosis nigricans, offspring of a diabetic pregnancy)
- **Children and youth** were screened for several risk factors of diabetes (screening for pre-diabetes, overweight and obesity, acanthosis nigricans, offspring of a diabetic pregnancy)
- Screening occurred in a **variety of locations** (community events, health fairs, community and senior centers, schools and day cares, home visits, hospitals and clinics)
- Use of **key elements of quality diabetes care** increased (diabetes registries, flowsheets, diabetes teams, diabetes clinics)
- Multidisciplinary diabetes **team staffing** increased (registered dietitians and nutritionists, diabetes educators, medical specialists, physical activity specialists)
- Availability of **nutrition education services** by registered dietitians and public health nutritionists increased (registered dietitian or public health nutritionist on diabetes team, medical nutrition therapy services, nutrition activities and classes for family members)
- Conduct of **community diabetes needs assessments** increased
- Partnerships of **tribal leaders and tribal members** on diabetes-related issues increased
- Local **community partnerships** increased
- Partnerships with **outside organizations** increased
- **Policies** addressing diabetes prevention and care increased

- Availability of **organized diabetes education programs** and support services increased (organized diabetes education programs, diabetes support groups, community behavioral health program services)
- Availability of **culturally appropriate diabetes education materials** and education approaches increased (access to materials, budget for materials)
- A variety of **methods of diabetes education** were provided (settings, types of materials, community-based methods)
- Availability of **continuing education** opportunities for health care providers increased
- A variety of **traditional approaches** were implemented
- **Primary prevention** activities were funded (health behavior change, nutrition, physical activity)
- **Diabetes awareness** activities increased
- Availability of **physical fitness activities** increased (walking and running activities; aerobics and strength training; exercise consults; recreation, wellness, fitness, and facilities)
- Availability of **community nutrition services** increased (cooking classes and grocery store tours, traditional food and nutrition activities, weight management programs)
- Programs **collaborated with the U.S. Department of Agriculture** to improve nutrition in communities (commodity food program, school lunch program, summer feeding program)
- Diabetes primary prevention programs for **children and youth** increased
- **Screening and management of overweight and obesity** among children and youth increased
- **Nutrition education programs for children and youth** increased
- **Community-based healthy eating programs** for children, youth, and families increased
- **Physical activity programs for children and youth** increased (community and school-based walking and running activities, fitness classes, playgrounds, physical activity programs)
- **Breastfeeding promotion** programs were implemented

Intermediate and Long-term Outcomes

The IHS Diabetes Program also demonstrated significant accomplishments related to the second objective of the evaluation by demonstrating a variety of **intermediate and long-term outcomes** that have been achieved since implementation of the Special Diabetes Program for Indians:

- Control of **blood glucose** has steadily improved (decrease in mean A1C levels)
- Control of **blood pressure** has steadily improved (decrease in diastolic blood pressure levels)
- Control of **total cholesterol** levels has steadily improved
- Control of **LDL cholesterol** has steadily improved
- Control of **triglycerides** has steadily improved

These improvements in the control of diabetes were also associated with certain diabetes program elements implemented with funding from the Special Diabetes Program for Indians:

- Activities associated with **better glycemic control** (diabetes teams, availability of A1C tests, organized diabetes education programs, diabetes support groups, culturally appropriate diabetes education materials, self-monitoring of blood glucose)
- Activities associated with **better blood pressure control** (diabetes teams, availability of ACE inhibitors, diabetes clinics)
- Activities associated with **lower total cholesterol levels** (diabetes clinics; culturally appropriate diabetes education materials; diabetes education programs, recreation, wellness, fitness facilities)
- Activities associated with **lower LDL levels** (diabetes team; culturally appropriate diabetes education materials; organized diabetes education programs; recreation, wellness, and fitness facilities)
- Activities associated with **lower triglyceride levels** (medical nutrition therapy, registered dietitian or public health nutritionist, traditional foods and nutritional activities)
- Medical Nutrition Therapy associated with **better glycemic control**
- Nutrition-based interventions associated with **lower Body Mass Index** (diabetes clinic, registered dietitian or public health nutritionist, traditional food and nutrition activities, nutrition education budget)

Complications of Diabetes

The IHS National Diabetes Program also made significant improvements in treatments to **reduce risk factors for the complications of diabetes** since implementation of the Special Diabetes Program for Indians:

- Treatment of risk factors for **cardiovascular disease** has improved (lower diastolic blood pressure, increased tobacco free status, increased aspirin use)
- Treatments to prevent and delay the progression of **diabetic kidney disease** have improved (ACE inhibitor use, tests for microalbuminuria)
- Treatments to detect and treat **diabetic eye disease** have improved (Joslin Vision Network)

Baseline Measures

The IHS National Diabetes Program improved the accuracy of **baseline long-term outcomes measures** (prevalence and mortality) so that the ultimate successes and outcomes of the Special Diabetes Program for Indians can be measured accurately when they improve in the future:

- Accurate baseline data for ongoing measurement of the **prevalence** of diabetes was established (over time, by age groups, compared to the general population, compared to other racial and ethnic groups, among IHS Areas, increases in prevalence, prevalence in youth)
- Accurate baseline data for ongoing measurement of diabetes **mortality** was established (over time, compared with other races, by IHS Area, adjusted for undercounting)
- A Diabetes Data Warehouse using RPMS data was established to accurately measure the **long-term complications** of diabetes

Best Practice Models

In response to Congressional direction, the IHS National Diabetes Program used the supplemental funding from the Consolidated Appropriations Act to build upon the successes of the diabetes grant programs through a consensus-based Indian health best practices approach. Fourteen **Best Practice Models** were developed to assist grant programs:

- Basic diabetes care and education – A systems approach
- Cardiovascular disease and diabetes – Screening, treatment, and follow-up

Best Practice Models:

- Community advocacy – Winning support for your diabetes program
- Dental care for people with diabetes – Screening, treatment, and follow-up
- Eye care for people with diabetes – Screening, treatment, and follow-up
- Foot care for people with diabetes – Screening, treatment, and follow-up
- Kidney disease – Screening, prevention, treatment, and follow-up
- Medications for diabetes care
- Nutrition and physical fitness programs
- Pregnancy and diabetes – Screening, management, and follow-up
- School health – Nutrition and physical activity
- Diabetes screening programs
- Diabetes self-management education
- Type 2 diabetes in youth – Prevention and screening

Collaborations and Partnerships

The IHS National Diabetes Program developed and built upon **collaborations and partnerships** with federal and private organizations as a result of the Special Diabetes Program for Indians:

- Department of Health and Human Services Agencies (Centers for Medicare and Medicaid Services, National Institutes of Health, Centers for Disease Control and Prevention Division of Diabetes Translation, Head Start Bureau)
- AI/AN Organizations (American Indian Higher Education Consortium, National Indian Council on Aging, Association of American Indian Physicians, National Indian Health Board, American Indian Epidemiology Centers, Urban Indian Nurses Association)
- Diabetes Expert Organizations (American Diabetes Association, Joslin Diabetes Center, American Association of Diabetes Educators, American Academy of Pediatrics, Juvenile Diabetes Research Foundation, Diabetes Research and Training Centers, International Diabetes Center, MacColl Institute of Group Health Cooperative of Puget Sound)
- Academic Institutions (University of New Mexico, University of Arizona, University of Southern California)
- Other Organizations and Agencies (U.S. Department of Agriculture)

Challenges

In addition to their accomplishments, the diabetes grant programs also provided the IHS National Diabetes Program with information on their challenges after administering diabetes prevention and treatment services in AI/AN communities for over five years. Their **challenges** occurred in the following areas:

- Administrative
- Staffing
- Space
- Access
- Clinical
- Education
- Behavioral
- Evaluation
- Training and Technical Assistance

Five Years Later: Lessons Learned

The implementation of the Special Diabetes Program for Indians was a complex process that developed a variety of new diabetes prevention and treatment services in AI/AN communities and achieved numerous accomplishments as noted in this document. As a result of this interim report, the IHS National Diabetes Program staff reviewed the lessons that were learned from this initiative. The **lessons learned** are summarized below:

- **The important role of tribal consultation**
 - ▶ Tribal consultation played an important role in all aspects of this initiative.
 - ▶ The IHS developed a tribal consultation process during this initiative that now serves as a model for other consultation efforts.
 - ▶ The Tribal Leaders Diabetes Committee was formed during this initiative and serves as a model advisory group for federal agencies.
- **The important role of tribal leadership**
 - ▶ Diabetes emerged as a tribal priority during this initiative.
 - ▶ Tribal leaders played a critical role in advocacy efforts.
 - ▶ This was the first time that tribal leaders came together to fight a chronic disease.
 - ▶ The Tribal Leaders Diabetes Committee now provides advice and guidance to other national programs and agencies on diabetes.

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Community-based assessment and planning played an important role in the design of programs.

- **The important role of collaboration between tribes and federal programs and agencies**
 - ▶ This initiative required tribes and the IHS to work together.
 - ▶ The Indian health system and its federal partners learned the importance of working together.
 - ▶ IHS clinics worked in partnership with tribes, many for the first time.
 - ▶ The initiative was accomplished by incorporating both tribal and federal processes and procedures.
- **The important role of communities in the fight against diabetes**
 - ▶ This initiative successfully implemented treatment and prevention services in community-based programs.
 - ▶ Community awareness of diabetes and how to address it increased.
 - ▶ Community-based assessment and planning played an important role in the design of programs.
 - ▶ The community provided a cultural perspective on activity development.
 - ▶ The diversity and creativity of grant activities resulted from community involvement.
 - ▶ Communities implemented primary prevention programs based on their local needs, before research evidence was found.
- **The important role of training and building community capacity**
 - ▶ Most programs were the first of their kind in their communities.
 - ▶ Communities developed an infrastructure that did not exist prior to the initiative.
 - ▶ Programs learned what is involved in building a diabetes program.
 - ▶ Programs learned the importance of systems and public health approaches to diabetes care.
 - ▶ Programs built capacity in the field.
 - ▶ Programs learned grant writing skills.
 - ▶ Program learned how to assess community needs.
 - ▶ The IHS National Diabetes Program learned how to assist communities.

- **The important role of program evaluation**
 - ▶ Programs learned the importance of evaluation and how to link program elements with outcomes.
 - ▶ Training was needed on program evaluation.
 - ▶ Multiple methods of evaluation were needed for the diverse activities implemented in diverse settings.
 - ▶ The challenge of evaluating an initiative of this magnitude was appreciated.
- **The important role of sharing information**
 - ▶ The initiative showed that there is more than one way to address the problem of diabetes and to approach prevention and treatment.
 - ▶ Programs learned many lessons during program development and implementation that could be helpful to other programs.
 - ▶ Programs learned a lot about how to accomplish goals in communities and how to promote change.
 - ▶ Dissemination of diabetes information and information on successful programs is important.
 - ▶ Dissemination of diabetes information is applicable to other diseases.
 - ▶ The IHS National Diabetes Program learned how to improve communication with the field.
 - ▶ Dissemination efforts have placed Special Diabetes Program for Indians activities and programs on the national radar screen.
- **The important role of building programs based on best practices**
 - ▶ A consensus process was developed to determine a series of best practices to be used by programs.
 - ▶ The IHS National Diabetes Program shared the best practices among the programs.
 - ▶ Lessons learned from the Model Diabetes Programs were shared.
 - ▶ Most activities in this initiative built on prior successes.

Programs learned the importance of systems and public health approaches to diabetes care.

Programs learned the importance of evaluation and how to link program elements with outcomes.

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Conclusions

Programs learned how to accomplish goals in communities and how to promote change

Most activities in this initiative built on prior successes.

Programs faced challenges in hiring and retaining health professionals in rural areas.

The overall quality of diabetes care can now be measured, similar to quality report cards, among programs and for the entire system.

- **The important role of building on the existing network**
 - ▶ The IHS National Diabetes Program developed a network of diabetes programs prior to this initiative.
 - ▶ The strength of this network was enhanced during this initiative.
 - ▶ This network helped provide a foundation for the success of this initiative.
- **The challenge of staffing programs in rural areas**
 - ▶ Programs faced challenges in hiring health professionals in rural areas.
 - ▶ Programs faced challenges of retaining health professionals in rural areas.
 - ▶ Finding specialty staff was a challenge in rural areas.
- **The important role of data collection and surveillance**
 - ▶ Early in the initiative, it was clear that systems were not in place to measure common indicators.
 - ▶ The importance of ongoing measurement was realized.
 - ▶ A variety of methods were needed to measure diabetes data.
 - ▶ The IHS National Diabetes Program required that all programs participate in the IHS Diabetes Care and Clinical Outcomes Audit.
 - ▶ Participation in the audit increased, particularly in tribal programs.
 - ▶ The overall quality of diabetes care can now be measured, similar to quality report cards, among programs and for the entire system.
 - ▶ Complications data can now be followed.
 - ▶ The unique challenges of urban programs were recognized and a plan to address these challenges is being implemented.
 - ▶ Tribal epidemiology centers helped with data improvement efforts.
 - ▶ A non-clinical audit was developed for programs without clinical services.

- **The IHS developed a grant process for this complex initiative**
 - ▶ The grants were non-competitive, allowing local tribal priorities to emerge.
 - ▶ The IHS took a positive approach to help every program succeed.
 - ▶ The IHS developed an easy-to-use Request for Grant Application and application process that addressed local community needs.
 - ▶ The application process that was developed understood that tribes were not typical grantees.
 - ▶ A process was developed that incorporated federal and tribal ways of doing business.
 - ▶ Fewer resources than is usual in the federal system were used to administer this grant program.
- **The IHS implemented this complex grant process despite little experience with grant administration**
 - ▶ Programs learned how to develop and track budgets within a grant mechanism.
 - ▶ Programs learned basic grant writing skills.
 - ▶ Flexible payment options were needed (e.g., four grant timelines and lump sum payments to compacted tribes).
 - ▶ IHS learned to monitor a large number of grant programs to ensure accountability.
- **The importance of developing partnerships and utilizing other resources**
 - ▶ Partnerships were needed on the local and national levels.
 - ▶ Tribes learned how to leverage other funding (e.g., construction was not covered).
 - ▶ Partnerships with other federal agencies led to unanticipated outcomes (e.g. Diabetes-Based Science Education in Tribal Schools [DETS] Program).
 - ▶ Partnerships with urban programs were established.
 - ▶ Programs learned that Congress is responsive to our needs.
 - ▶ The Tribal Leaders Diabetes Committee now plays a role in advising other programs and agencies.

All of these lessons learned will not only help this initiative continue to be a success but also inform other national initiatives of this kind.

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Summary

In summary, the Special Diabetes Program for Indians funding resulted in over 300 new diabetes treatment and prevention services in AI/AN communities, consistent with its original legislative intent, and has resulted in numerous accomplishments so far. With five more years of funding, these programs will be able to continue to fight the epidemic of diabetes in AI/AN communities. While the ultimate outcomes of reducing the morbidity and mortality from diabetes will take more years, the programs and activities implemented under the Special Diabetes Program for Indians provide a strong foundation and a new beginning towards a diabetes-free future.



“As our ancestors looked out for us, we need to look out for our children and grandchildren. I want our people to have good lives. Together, let’s build a diabetes-free future for our children.”

Lorelei De Cora (Winnebago Tribe of Nebraska)