Chapter 1
BACKGROUND

The Balanced Budget Act of 1997 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 required an Interim (2000) and Final (2002) Report to Congress. Subsequent legislation extended and increased the amount of funding for this initiative, and delayed the Final Report to Congress to 2003 (the Consolidated Appropriations Act of 2001) and then to 2008 (PL 107-360).

Given the current interest of Congress, the Indian Health Service (IHS), and other stakeholders in the status of this initiative and its progress in meeting the original legislative intent, the IHS National Diabetes Program conducted an interim evaluation and produced this progress report to Congress on the Special Diabetes Program for Indians. Therefore, the objectives of this evaluation are:

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 have resulted in short-term, intermediate, or long-term positive outcomes.

AI/ANs now have the highest published prevalence of diabetes in the world. In 2000, 14.9% of AI/ANs aged 20 years or older had diagnosed diabetes, compared to 8.4% for non-Hispanic whites.[1]

"Our mother had diabetes, and we lost her to it. We both have diabetes. That makes four out of seven of us children who have diabetes. We wonder, where did diabetes come from? Is it hereditary? Can our children prevent it with good nutrition and exercise?"

Evelyn Eagleman, right, with Valerie SunChild (Rocky Boy)

Between 1997 and 2001, the prevalence of diabetes increased 33% in all major regions served by the Indian Health Service.[2]

The IHS National Diabetes Program is pleased to submit this Interim Progress Report to Congress on its evaluation of the Special Diabetes Program for Indians. This report contains information on the background and implementation of the Special Diabetes Program for Indians, a description of the methodology for the evaluation of this initiative, and the results of the evaluation, including data on activities that resulted in short-term, intermediate, and long-term positive outcomes. **Information on the epidemic of diabetes in AI/AN communities and a discussion of scientific evidence on diabetes treatment and prevention are included in Appendix I.**

A. The Special Diabetes Program for Indians

Balanced Budget Act of 1997

The Balanced Budget Act of 1997, enacted by Congress in August 1997, provided $150 million to the IHS over a five-year period (from FY 1998 to FY 2002) to establish grants for the "prevention and treatment" of diabetes in AI/ANs. The entities eligible to receive these grants included IHS programs, tribes and tribal organizations, and urban Indian organizations. The IHS distributed this funding to over 300 such entities through a process that included extensive tribal consultation, the development of a formula to distribute funds to eligible programs, and a formal grant application process. These programs were allowed to use this funding to design programs and activities according to local priorities and needs. The initial distribution of this funding and the types of programs and activities implemented were summarized in the IHS National Diabetes Program's 2000 Interim Report to Congress.

Among all age groups, the highest increase in diabetes prevalence has occurred among AI/AN adolescents aged 15–19 years, with a 106% increase from 1990 to 2001.[3]

Consolidated Appropriations Act of 2001

In the Consolidated Appropriations Act of 2001, Congress appropriated additional funding for the Special Diabetes Program for Indians. This appropriation included an additional $70 million in FY 2001, $70 million in FY 2002, and $100 million in FY 2003, thereby extending the program for another year. While the legislation did not contain specific language on how the IHS should use this funding, Congressional input encouraged the IHS to implement a best practices approach, build upon partnerships with other organizations, and evaluate these activities in conjunction with the programs established with the Balanced Budget Act of 1997. Using a distribution formula that was developed through a formal tribal consultation process, the IHS distributed the additional funding to IHS, tribal, and urban Indian organizations.

Extension of the Special Diabetes Program for Indians (PL 107-360)

In 2002, Congress passed HR 5738, which extended the Special Diabetes Program for Indians through 2008, and increased the amount of funding to $150 million per year. Although this legislation delayed the Final Report to Congress until 2008, the IHS National Diabetes Program conducted this interim evaluation and progress report for 2003.

B. The Indian Health Service

The IHS, an agency within the U.S. Department of Health and Human Services, was established in 1955 as the principal federal health care provider and health advocate for AI/ANs. The IHS provides health services to AI/ANs as a result of the trust responsibility of the federal government to provide health care for AI/ANs. This trust responsibility has been reaffirmed through treaties, multiple Supreme Court decisions, and specific Indian health legislation, including the Snyder Act of 1921 and the Indian Health Care Improvement Act of 1976 (P.L. 94-437).

Diabetes mortality is 4.3 times higher in the AI/AN population than in the general U.S. population.[4]

The mission of the IHS is to raise the physical, mental, social, and spiritual health of AI/ANs to the highest level. The agency is a comprehensive, primary health care system of hospitals and clinics located on or near reservations in 35 states. IHS services are administered through a decentralized system of 12 Area offices and 155 IHS and tribally managed service units, which collectively serve 1.6 million AI/ANs. Many AI/ANs rely on IHS services as their only source of health care coverage. The IHS provides direct primary care, referrals for specialty care, and public health services. Since passage of the Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638), tribes can enter into agreements (i.e., contracts or compacts) with the federal government to manage their own health programs that were previously managed by the IHS. In FY 2003, tribes managed 52% of the IHS budget. The IHS also provides funding for 34 urban Indian organizations to provide health services to AI/ANs living in urban areas.

The Diabetes Control and Complications Trial found that tight control of blood glucose levels was associated with reduced risk of complications of diabetes.[5]

C. The Indian Health Service National Diabetes Program

In the 1970s, the National Commission on Diabetes identified diabetes as a growing problem among AI/AN communities and recommended that Congress establish a special program to address diabetes within the IHS. Congress authorized funding for a national diabetes program within the IHS in the Indian Health Care Improvement Act of 1976, and the IHS National Diabetes Program was established in 1979.

In AI/ANs, diabetes is the strongest risk factor for cardiovascular disease, which is the leading cause of death for AI/ANs.[6]

The mission of the IHS National Diabetes Program is to develop, document, and sustain a public health effort to prevent and control diabetes in AI/ANs. The IHS National Diabetes Program network consists of a national program office in Albuquerque, New Mexico; Area Diabetes Consultants in each IHS Area; 19 Model Diabetes Programs in 23 sites; and local diabetes programs in AI/AN communities. Now the most comprehensive rural system of care for diabetes in the U.S., the program combines both clinical and public health approaches to the problem of diabetes. The IHS National Diabetes Program serves as the key IHS contact and source of information for outside organizations and agencies working on diabetes and disparities related to diabetes. In addition, the IHS National Diabetes Program:

- Provides comprehensive diabetes surveillance.
- Provides research translation through training and technical assistance.
- Conducts quality assurance and improvement activities in clinical and community programs.
- Provides technical support to IHS, tribal, and urban Indian sites nationwide.
- Provides resource information on a range of training opportunities.
- Disseminates health care provider and consumer education resources, as well as best practices information, to IHS, tribal, and urban Indian programs.
- Develops, field-tests, and distributes AI/AN diabetes education print and audio-visual materials to IHS, tribal, and urban Indian programs.

The IHS National Diabetes Program promotes collaborative strategies for the prevention of diabetes and its complications through the network of Area Diabetes Consultants and Model Diabetes Programs.

Area Diabetes Consultants – The Area Diabetes Consultants (formerly called Diabetes Control Officers) were established by the Indian Health Care Improvement Act of 1976. They provide orientation, training, and monitoring activities; translate and disseminate the latest scientific findings related to diabetes prevention and treatment; serve as a liaison between the diabetes grant programs and clinical staff at IHS, tribal, and urban Indian health care facilities; serve as project officers on the Special Diabetes Program for Indians grants; and play a critical role in the coordination of the extensive Indian health system diabetes network.

Model Diabetes Programs – The Model Diabetes Programs were established by the National Commission on Diabetes in 1979 and the Indian Health Care Improvement Act of 1976. These programs were designed to develop effective approaches to diabetes care, provide diabetes education, translate and develop new approaches to diabetes control. The 19 Model Diabetes Programs at 23 different sites in the Indian health system have made significant contributions, including state-of-the-art comprehensive, clinical diabetes care through a multi-disciplinary approach; diabetes education and nutritional counseling services; professional education; diabetes prevention activities in communities; support and technical assistance; development and testing of education materials; and scientific articles in peer-reviewed medical journals.

The IHS National Diabetes Program provided leadership and administrative support for the Special Diabetes Program for Indians, which is the largest grant program of its kind in the history of the IHS.

"Right when I found out I had diabetes, I went to see the diabetes educator. I got a blood sugar monitor and learned how to test my blood sugars. I learned about eating low-fat, low-sugar food. I went away feeling there was hope for me."

Richelle Garcia (Kiowa),
Lawton Model Diabetes Program

D. Other National Initiatives to Address Diabetes

Over the last decade, Congress and the Secretary of Health and Human Services increasingly recognized that minority populations, including AI/ANs, faced racial and ethnic disparities in health.[8] In response, the Secretary of Health and Human Services launched a number of initiatives and policies aimed at eliminating racial and ethnic health disparities. The following initiatives recognize that diabetes is a priority for eliminating disparities in health:

- Government Performance and Results Act of 1993
- National Diabetes Education Program (1997), a joint initiative sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases and the Centers for Disease Control and Prevention (CDC) Division of Diabetes Translation
- Department of Health and Human Services (DHHS) Initiative to Eliminate Racial and Ethnic Disparities in Health (1998)
- Steps to a Healthier U.S. (2000 and 2001)
- CDC Racial and Ethnic Approaches to Community Health (REACH) Initiative (1999)
- National Institutes of Health Center for Minority Health and Health Disparities (2000)
- DHHS Initiative Advisory Committee on Minority Health (2000)
- DHHS Secretary's Interdepartmental Council on Native American Affairs (2002)
- DHHS Secretary's Diabetes Detection Initiative (2003)

The IHS National Diabetes Program has participated in these efforts and regularly disseminates information and resources from these initiatives to the diabetes programs in the Indian health system.

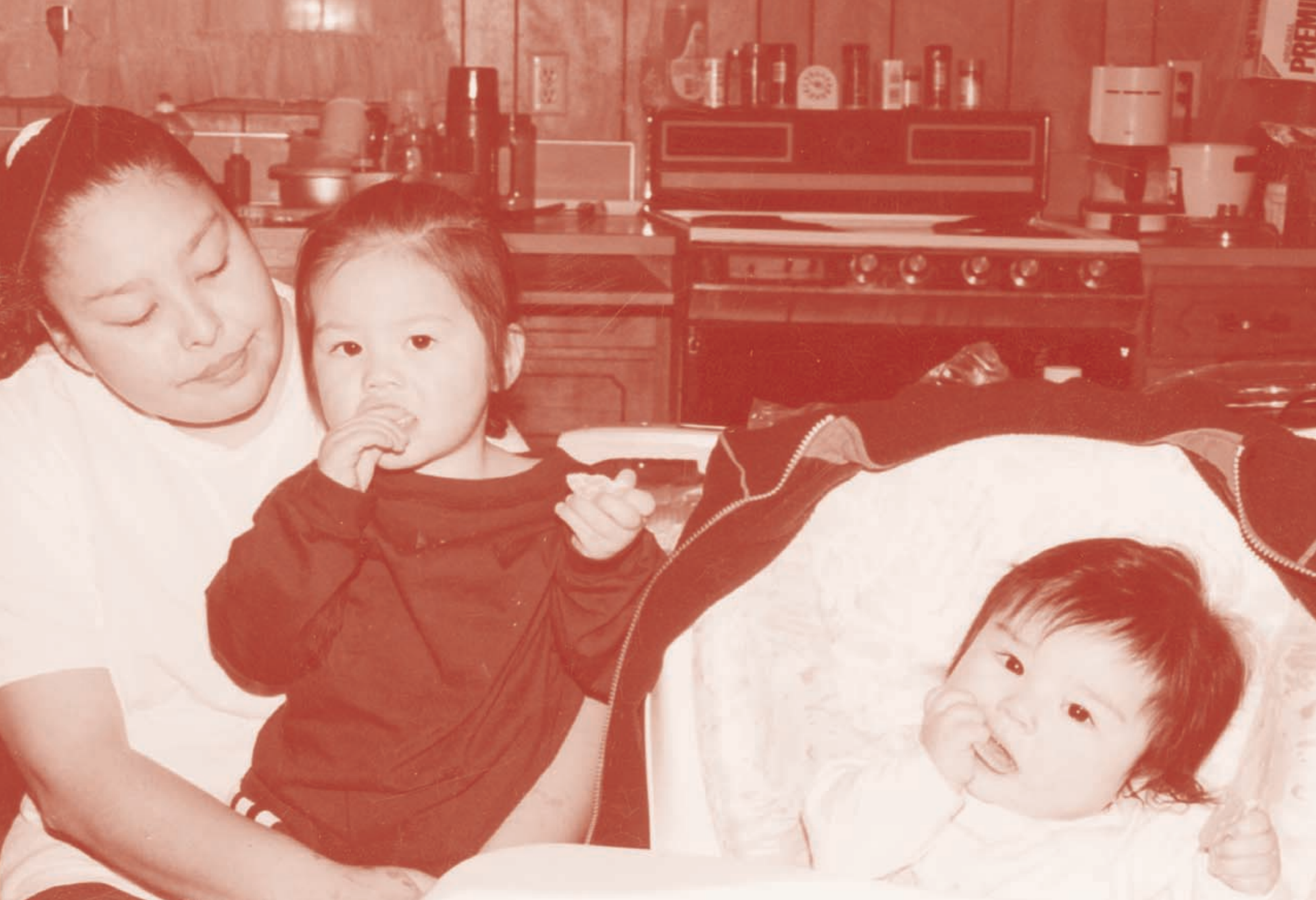
The Diabetes Prevention Program found that the onset of diabetes in those at risk can be reduced by simple lifestyle interventions (healthier diet and regular physical activity) or medication.[7]

E. Summary

The Special Diabetes Program for Indians was enacted with the recognition that diabetes is a growing problem for AI/AN communities. The IHS, through its National Diabetes Program, has worked to address diabetes through a number of initiatives and activities, and has been able to augment these activities significantly with the new funding under this initiative. This report summarizes the IHS National Diabetes Program's evaluation of the new programs and activities implemented under the Special Diabetes Program for Indians since FY 1998.

"My ancestors ate fish, elk, and venison and there was very little diabetes. Now, there is diabetes in my family. I found out I had it on my 50th birthday. Why do so many of us have it? Everybody, except a very few, seem to have diabetes in their families."

Darlene Taylor (Siletz)



"When I found out I had diabetes, I thought, 'Why did God do this to me?' I just hope and pray my children won't have to go through something like this."

Shelly Andrews (Colville)