Chapter 2
HISTORY, IMPLEMENTATION, AND PROCESS OF THE SPECIAL DIABETES PROGRAM FOR INDIANS

The Special Diabetes Program for Indians was funded through the Balanced Budget Act of 1997 and augmented by the Consolidated Appropriations Act of 2001. As a result, the Indian Health Service (IHS) National Diabetes Program implemented a grant process that provided a total of $390 million from FY 1998 to FY 2002 to over 300 IHS, tribal organizations, and urban Indian programs. This chapter reviews the legislative history of the Special Diabetes Program for Indians and describes how the IHS National Diabetes Program implemented this complex grant program in partnership with local and regional IHS, tribal, and urban Indian health programs, as well as other organizations.

David and Mary Catt are visited by a foot care nurse in their home in Cherokee, North Carolina. The tribe is a recipient of a grant from the Special Diabetes Program for Indians.

A. *Legislative History of the Special Diabetes Program for Indians*

The Special Diabetes Program for Indians appropriation was a result of a bipartisan plan to provide funds for the prevention and treatment of diabetes in American Indians and Alaska Natives (AI/ANs). This initiative came in the wake of increasing public concern about the human and economic costs of diabetes in the U.S. and its growing prevalence in vulnerable populations, particularly in AI/ANs. The Juvenile Diabetes Research Foundation; the American Diabetes Association; and key Congressional leaders including Congressman Newt Gingrich, Congressman George Nethercutt, and Senator Pete Domenici worked together to enact legislation for research on type 1 diabetes in the general U.S. population and for the prevention and treatment of type 2 diabetes in AI/ANs. The specific legislation for the Special Diabetes Program for Indians was enacted as follows:

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1. The Balanced Budget Act of 1997

In August 1997, Congress enacted the Balanced Budget Act (BBA) of 1997 to provide $30 million a year from FY 1998 to FY 2002 to establish the Special Diabetes Program for Indians. The legislation funded grants for "services for the prevention and treatment of diabetes" and the entities eligible for these funds included the IHS, tribes, tribal organizations, and urban Indian organizations. The BBA also required an interim report to Congress in 2000, and a final report in 2002.

2. The Department of the Interior and Related Agencies Appropriations Act of 1998

In 1998, the Department of the Interior and Related Agencies Appropriations Act provided an additional $3 million to the IHS budget for diabetes prevention and treatment. The Director of the IHS decided to add this funding to the Special Diabetes Program for Indians funding from the BBA, bringing the total amount of funding available for this Program to $33 million.

3. The Department of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act of 1998

Congress included $2 million in the Centers for Disease Control and Prevention (CDC) budget in FY 1998 to establish a National Diabetes Prevention Center — CDC's support for the Center is ongoing. Congress also requested that the IHS allocate $1 million annually from the Special Diabetes Program for Indians for the Center.

Congressional report language directed the CDC to establish the Center in Gallup, New Mexico, and focus the Center's activities on diabetes prevention in American Indians and on information dissemination. In addition, Congressional report language instructed the Center first to provide services for the Navajo and Zuni tribes, and then to provide services nationally for all tribes. The long-term goal of this Center is to address diabetes prevention for other racial and ethnic groups.

4. The Consolidated Appropriations Act of 2001

In December 2000, Congress passed the Consolidated Appropriations Act (CAA) of 2001, which provided additional funding for the Special Diabetes Program for Indians. This appropriation included an additional $70 million in FY 2001, an additional $70 million in FY 2002, and $100 million for FY 2003, which added one more year to the initiative. While the legislation did not provide specific details on how the IHS was to use this additional funding, members of Congress encouraged the IHS to:

- Follow a best practices approach in the implementation and development of models and strategies to prevent and treat diabetes.
- Continue and build upon its successful work with partner institutions and organizations, such as the National Institutes of Health, the Centers for Disease Control and Prevention, and other diabetes expert institutions.
- Evaluate the enhancements to and development of diabetes grant programs with the CAA funds in conjunction with the programs established with the BBA funds.

5. Summary of the Special Diabetes Program for Indians Legislation

The Special Diabetes Program for Indians legislation provided for the following funding amounts in each fiscal year:

Fiscal Year	Annual Discretionary Appropriation	Balanced Budget Act of 1997	Consolidated Appropriations Act of 2001
FY 1998	$3 million	$30 million	
FY 1999	$3 million	$30 million	
FY 2000	$3 million	$30 million	
FY 2001	$3 million	$30 million	$70 million
FY 2002	$3 million	$30 million	$70 million
FY 2003	$3 million		$70 million

B. Implementation of the Special Diabetes Program for Indians

Congress directed the IHS to implement a grant process to distribute the funding from the Special Diabetes Program for Indians. The IHS is a health care agency with expertise in providing primary health care services, and had not previously administered a large grant program of this nature. Over a very short period of time, the IHS implemented the Special Diabetes Program for Indians according to its legislative intent through a process that included a formal tribal consultation, development of a formula for distribution of the funds to eligible entities, and a formal grant application and administrative process.

1. The Need for Tribal Consultation

Tribal consultation is an integral part of federal program development given the government-to-government relationship between the federal government and Indian tribes. This relationship was established in Article I, Section 8 of the U.S. Constitution and reaffirmed in numerous treaties, laws, and Supreme Court decisions.

During the last ten years, several Presidential Executive Memoranda and Orders were issued instructing the Department of Health and Human Services (DHHS) to consult with federally-recognized tribes on policies that may affect the health of AI/ANs.[1] The DHHS established a formal tribal consultation policy and asked each DHHS Agency to develop their own tribal consultation policies and processes. In response to this request, the IHS developed its own tribal consultation policy that allows tribes to participate fully in the planning and process for consultation.

2. The Distribution Formula for the Special Diabetes Program for Indians Funding

Soon after the funding for the Special Diabetes Program for Indians was announced, the IHS held a meeting with tribal leaders at the 1997 National Indian Health Board Annual Consumer Conference to gather input and recommendations from tribal leaders and urban Indian health program leaders on the new diabetes grant funding. At that meeting, tribal leadership recommended a formal tribal consultation process that included consultation at the local, IHS Area, and national levels. In November 1997, the IHS Director established the Indian Health Diabetes Workgroup to review the recommendations from the local and IHS Area consultations and to determine

a mechanism for the distribution of the funds. The Workgroup consisted of members from the National Indian Health Board, the Tribal Self-Governance Advisory Committee, urban Indian health programs, the Association of American Indian Physicians, the Indian Health Service, and a diabetes expert from the International Diabetes Center.

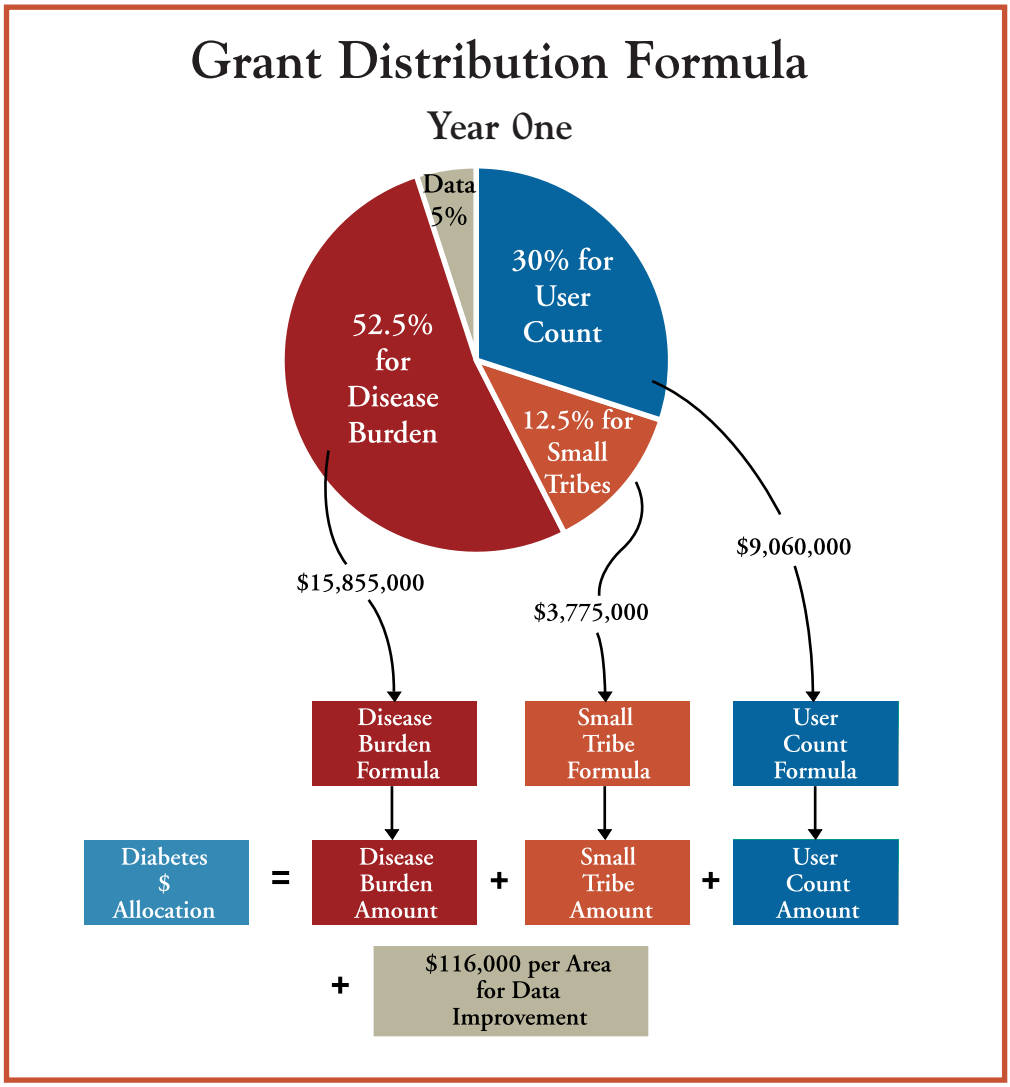
In late 1997, the Indian Health Diabetes Workgroup reviewed recommendations from the tribal consultation meetings in each IHS Area and determined a method for the distribution of the Special Diabetes Program for Indians funding. In its recommendations to the IHS Director, the Workgroup suggested that the new diabetes funds be distributed in a manner that followed four guiding principles:

- Funds should be distributed in a non-competitive grants process which is in line with a fundamental belief on the part of tribal leaders that tribes should not compete with one another for beneficial resources in a severely under-resourced situation (such as the diabetes epidemic in AI/AN communities).
- Local sites should retain decision-making authority in designing effective diabetes programs to address the specific, unique, and individual needs of their communities.
- A cap of 1% of the diabetes funds should be placed on administrative expenses.
- Funds should be allocated for the purpose of improving diabetes data collection and accuracy.

The Workgroup recommended that the distribution of the funds follow a formula that used data to ensure that more funding would go to communities with a significant burden of diabetes. In addition, they felt that since the funding was also intended to provide prevention services, the formula should address the user population of each program. They also wanted to ensure that small programs had at least a base amount of funding to be able to implement programs. Therefore, the final formula included the following factors:

- **Disease burden**
  Defined by diabetes prevalence and diabetes mortality
- **User population**
  The number of active users of health services in a tribal community
- **Tribal size adjustment**
  Ensures that additional consideration is given to the very small communities that may not have an infrastructure to support the development of new diabetes programs

The IHS Director reviewed the Workgroup's recommendations and issued his final decision on the distribution of the funds in January 1998.[2] The final formula for distribution is illustrated below:



Following the IHS Director's decision, each IHS Area held tribal consultation sessions to achieve two goals: 1) identify tribal programs that were eligible to apply for the grant funds; and 2) decide how the funds were to be divided among the IHS, tribes, and tribal organizations within each Area. Although urban Indian programs were not eligible for Area funds because they were funded separately (see below), they were encouraged to participate in the Area meetings to promote coordination among the Area diabetes programs and their tribal and urban Indian health partners. Following the tribal consultation sessions, each Area submitted a report to the IHS Director that identified which programs were eligible to apply for grant funds and documented the tribal consultation process to ensure that it had been fair and representative.

In the first and second years of the Special Diabetes Program for Indians, the diabetes funds were distributed to each Area using a funding mechanism that accounted for disease burden, user population, and tribal size adjustment. Since each Area had expressed concern about the lack of accurate and complete disease burden data, a portion of the funding was set aside for improvement of data collection in each Area. Additional funds were devoted to the urban Indian health programs, the National Diabetes Prevention Center, and administrative costs. In the third year of the program, the same distribution methodology was used, but funds for data improvement and urban programs were reduced to correct for a mistake in the California Area's tribal size adjustment. (See Appendix for the funds distribution formula.)

3. The Tribal Leaders Diabetes Committee

In 1998, elected tribal officials on the Indian Health Diabetes Workgroup recognized the need for tribal leaders to provide direct and ongoing tribal consultation on the Special Diabetes Program for Indians and to provide input and consultation on other diabetes-related activities. The Workgroup voted to change the composition of the committee to include only elected tribal representatives from each IHS Area and establish itself as the Tribal Leaders Diabetes Committee (TLDC). In October 1998, the TLDC was formally recognized by the IHS Director to provide input on diabetes-related issues. The mission and vision statements of the TLDC are as follows:

- **Mission:** To make recommendations to the IHS Director on issues related to diabetes and its complications in AI/ANs.
- **Vision:** Empowering AI/AN people to live free of diabetes through healthy lifestyles while preserving cultural traditions and values through tribal leadership, direction, communication, and education.

The mission of the Tribal Leaders Diabetes Committee is to make recommendations to the IHS on issues concerning diabetes. Members have a vision of American Indians and Alaska Natives living lives that are free of diabetes.

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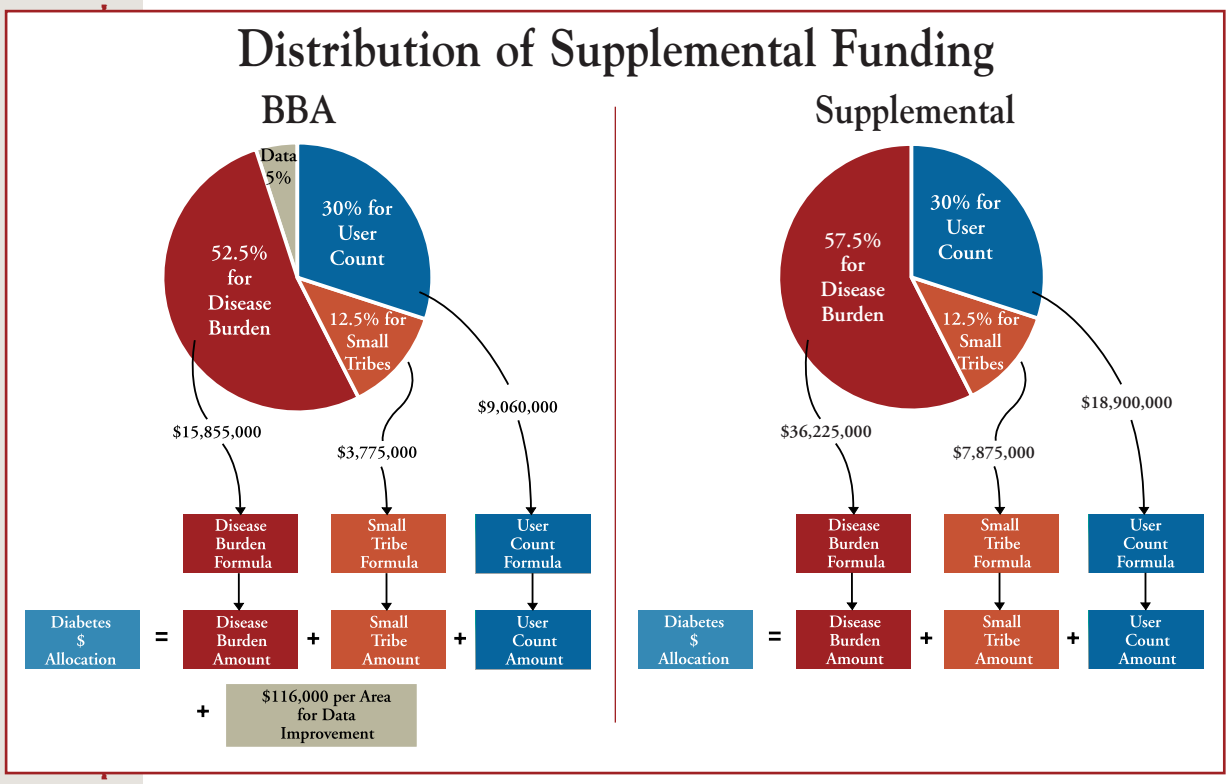
4. Distribution of the Supplemental Funding through the Consolidated Appropriations Act

The TLDC recommended another formal tribal consultation process in the spring of 2001 for the new funding provided through the CAA. This consultation process was similar to the previous consultations for the Special Diabetes Program for Indians and included a review of each IHS Area consultation. The TLDC recommended a similar distribution methodology for this funding, which included a set aside for urban diabetes grant programs, administrative and support costs, and data improvement. The formula for distribution of the remaining funds consisted of the same factors (i.e., disease burden, user population, and tribal size adjustment), but since the data improvement funds were now a set aside, the TLDC increased the disease burden factor by 5%. The weights for user population and tribal size adjustment remained the same as the 1997 distribution methodology. In October 2001, the IHS Director announced his decision to distribute the CAA funds using the distribution methodology recommended by the TLDC as follows:



C. *The Special Diabetes Program for Indians Grant Program*

The IHS National Diabetes Program and the IHS Grants Management Branch collaborated to develop the grant program for the Special Diabetes Program for Indians. This was the first large grant program of its kind in the history of the IHS, and a number of administrative processes needed to be developed.

1. The Request for Grant Application

Once tribes, Indian health programs, and urban Indian organizations were determined to be eligible for the funding, the IHS issued a Request for Application (RFA) to all eligible programs. The RFA described eligibility criteria, application requirements, and available resources. Acceptable activities included primary, secondary, and tertiary diabetes prevention and treatment programs and related data collection. Grants under the program were renewable on an annual basis for five years, and covered both direct and indirect costs.

The types of programs eligible for grant funds included:

- IHS programs (both inpatient and outpatient facilities)
- Tribes and tribal health programs operating under a contract, grant, cooperative agreement, or compact with the IHS under the Indian Self-Determination Act
- Urban Indian health organizations, including those functioning under a grant or contract with IHS under Title V of the Indian Health Care Improvement Act, Scope of Grant Programs

Grant applicants were required to submit a program narrative that described the program, work plan, timeline, target audience, evaluation measures and data sources, partnerships and collaborations, key personnel, budget estimates, and results of the IHS Diabetes Care and Outcomes Audit. Each following year, the diabetes grant programs were required to submit an annual progress report that described their goals and objectives, accomplishments, challenges, and problems in achieving program goals and objectives.

When the CAA was enacted in 2001 to provide supplemental funds for the diabetes grant programs, Congress directed the IHS National Diabetes Program to use the funds to build upon the successes of the original Special Diabetes Programs for Indians by using a *best practices approach*. To help the diabetes grant programs implement a best practices approach in their program activities, the IHS National Diabetes Program included a section on 14 consensus-based, Indian health best practices in the RFA for FY 2001–2003. Each year

Congress directed the IHS National Diabetes Program to use the CAA funds to build upon the successes of the original Special Diabetes Programs for Indians by using a *best practices approach*.

thereafter, the RFA included an assessment tool to help programs identify specific local needs and to evaluate program outcomes.

2. Grant Application Review

The IHS Grants Management Branch reviewed all applications for eligibility and compliance with the RFA. The Chief Medical Officers and Area Diabetes Consultants in each IHS Area Office also reviewed the applications for programmatic compliance. Reviews of the grant applications addressed the soundness of proposed services, compliance with the legislation and grant regulations, and projected expenditures. If the reviewers decided that the proposal needed revisions, the Area Diabetes Consultants provided technical assistance to the applicants to bring proposals into compliance.

3. Monitoring and Review of Diabetes Grant Programs

The IHS Grants Management Branch, Area Diabetes Consultants, and the Chief Medical Officers from each IHS Area were responsible for ongoing monitoring and review of the diabetes grant programs. The IHS Grants Management Branch focused on ensuring that the grants were appropriately managed in accordance with applicable law and management policy. With expertise in financial management and the laws, regulations, and policies governing grants, the IHS Grants Management Branch ensured that the diabetes grant programs followed good business and financial practices and complied with the established grant guidelines. To perform these functions, the IHS Grants Management Branch reviewed reports that were submitted by each diabetes grant program, including an annual progress report, the yearly IHS Diabetes Care and Outcomes Audit, a financial status report, and a cost analysis.

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The 12 Area Offices provided programmatic oversight to the diabetes grant programs to ensure that program activities complied with Congressional intent. The Chief Medical Officers and Area Diabetes Consultants from each IHS Area were responsible for program management, including monitoring and evaluating each diabetes grant program's technical performance and program achievements. To address any data and surveillance problems, the IHS National Diabetes Program provided the diabetes grant programs with an optional grant-reporting requirement. As an alternative to reporting diabetes data elements (e.g., amputations, end-stage kidney disease, retinopathy, and obesity), the diabetes grant programs were given the option to report on the 87 data elements from the annual IHS Diabetes Care and Outcomes Audit. Sites without a clinic-based diabetes grant program were allowed to report diabetes audit data from their local IHS or tribal clinic. This reporting option provided each diabetes grant program with the opportunity to contribute valid data related to the diabetes care and outcomes within their communities. In

addition, the IHS Grants Management Branch and Area Diabetes Consultants worked in partnership to monitor the diabetes grant programs and provide assistance on matters related to changes in project scope, key personnel, and budget.

4. Budget Cycles and the Payment Management System

The IHS Grants Management Branch offered four cycles for annual renewals of the diabetes grant programs. These cycles enabled the diabetes grant programs to choose an annual renewal date that was consistent with the federal or tribal fiscal year cycle, allowing for better fiscal management and tracking at each program.

The IHS Grants Management Branch also provided diabetes grant programs with technical assistance on the Payment Management System. The Payment Management System is an electronic, centralized grant payment and cash management system. All diabetes grant programs began using the Payment Management System in FY 2002 to comply with instruction from the DHHS.

D. Summary

As directed by Congress, the IHS National Diabetes Program developed and implemented the Special Diabetes Program for Indians for the prevention and treatment of diabetes in AI/AN communities. Through a collaborative, in-depth tribal consultation process that involved the IHS, tribal organizations, and urban Indian health programs, over 300 diabetes grant programs were established throughout Indian Country.

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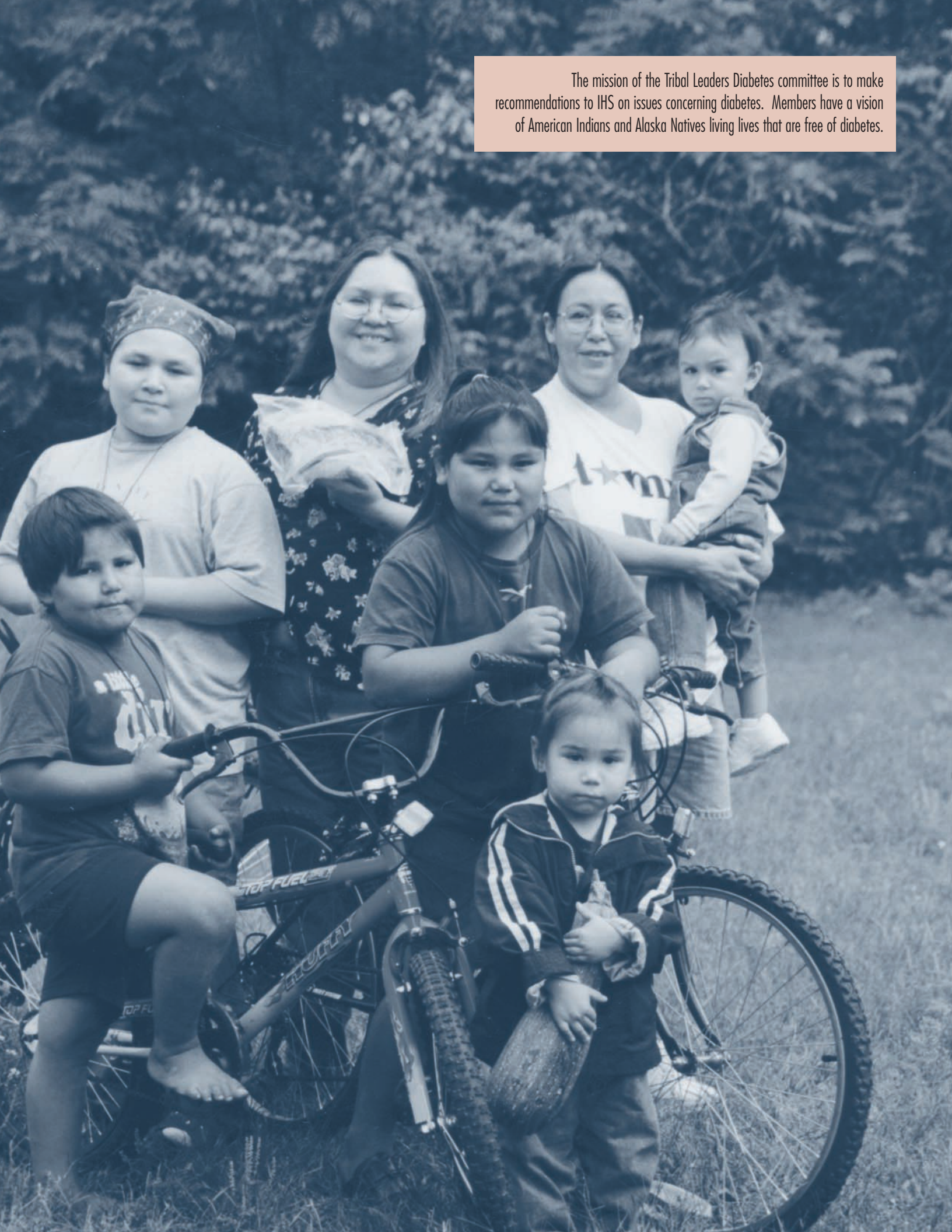

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