ACTIVITY/MECHANISMS BUDGET SUMMARY
Department of Health and Human Services
Indian Health Service - 75-0390-0-1-551
DIABETES

Program Authorization:

Program authorized by 111 STAT. 574, 1997 Balanced Budget Act (P.L 105-33) and H.R. 4577, Consolidated Appropriation Act 2001 (P.L. 106-554) and Interior Appropriation IHS National Diabetes Program.

Indian Health

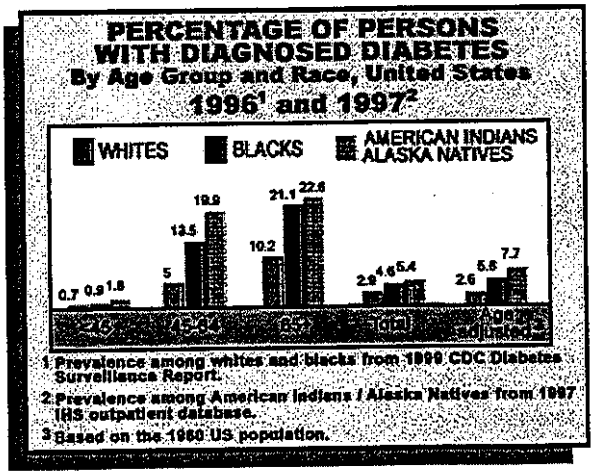
Diabetes	2000 Actual	2001 Appropriation	2002 Estimate	2002 Est. +/- 2000 Actual	2002 Est. +/- 2001 Approp.
Budget Authority	$30,000,000	$100,000,000	$100,000,000	+$70,000,000	0

The Balanced Budget Act of 1997 (P.L. 105-33) provides that $30 million per year appropriated to the Children's Health Insurance Program be transferred to IHS for diabetes prevention and treatment. An additional $70,000,000/year was received under the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 for FY 2001 and FY 2002, and $100,000,000 is available for FY 2003. Total IHS diabetes funding also includes the IHS National Diabetes Program with 12 Area Diabetes Consultants and 19 model diabetes sites ($7.7 million per year) and, starting in FY 1998, an annual $3 million in IHS diabetes grants and $.3 million for a periodontal disease project.

PURPOSE AND METHOD OF OPERATION

Program Mission and Responsibilities

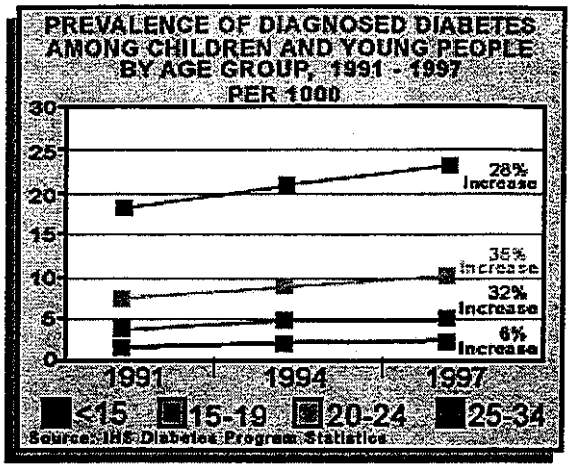
The mission of the IHS National Diabetes Program is to develop, document, and sustain a public health effort to prevent and control diabetes in American Indian and Alaska Native. The agency promotes collaborative strategies for the prevention of diabetes and its complications in the 12 IHS Service Areas through a network of 19 Model Diabetes Programs and 13 Area Diabetes Consultants. The agency also disseminates current information about all aspects of diabetes surveillance, treatment, education, and prevention.



Diabetes was the most frequently identified health problem in the IHS Area I/T/U budget formulation workshops for FY 2001.

Type 2 diabetes occurs at dramatically higher rates among AI/AN adults who are almost 3 times more likely to have diabetes than the general U.S. population.

A recent alarming trend is the increase in prevalence of type 2 diabetes in young AI/AN. Over a seven-year period, from 1991-1997, the prevalence of diabetes rose 28-36 percent in AI/AN children and adolescents.



Complications of diabetes lead to much higher incidence rates of blindness, vascular insufficiency leading to amputation, and End Stage Renal Disease (ESRD) than in the general U.S. population. Most recent data show that diabetes mortality is 4.3 times higher in the AI/AN population than in the U.S. population. There has been a 24 percent increase in the American Indian age-adjusted death rate from diabetes since 1991-1993. There is clear evidence that for American Indian/Alaska Natives the health disparity related to diabetes is increasing.

The Balanced Budget Act (BBA) of 1997 provided $30 million per year for 5 years through the *Special Diabetes Program for Indians* (SDPI) to provide grants for the prevention and treatment of diabetes to Indian Health Service (IHS), tribal, and urban Indian health programs. The IHS completed a tribal consultation process on the approach to the provision of diabetes services in AI/AN communities. The process included national and regional input from tribal and urban program representatives.

A Tribal Leaders Diabetes Workgroup was established to review the tribal input and make recommendations on the administration and distribution of the BBA funds. Based on the Workgroup recommendations, funds were awarded through non-competitive grants for a five-year project term. The Workgroup recommended that IHS distribute the funding by IHS Area according to a formula based primarily on disease burden (53 percent) and user population with an adjustment to increase funding for very small tribes (42 percent). They also recommended that $1.5 million be set aside for the urban programs who were to be exempt from the distribution formula process. In addition, 5 percent of the overall funds were reserved for improved data collection to enhance the evaluation process. Distribution of the grant funds within each Area to local IHS and tribal programs was determined by an Area-wide consultation process. An evaluation process was created for both the national and Area levels.

There were 286 grants awarded in the first year cycle. Contracts with several tribal organizations were written at the national and regional level to enhance and facilitate evaluation and data collection activities. Ongoing evaluation of the grants, using a mixed methods approach (both qualitative and quantitative methods) has been implemented.

Tribal programs determined how their funding was to be used. Sixty six percent of programs chose to focus on both primary (such as offering exercise and nutrition programs to prevent the incidence of diabetes) and secondary (managing diabetes to prevent complications such as kidney failure, amputations, heart disease and blindness) diabetes prevention efforts. Thirty three percent of programs decided to implement tertiary prevention efforts to reduce morbidity and disability in those who have complications from diabetes. And forty one percent indicated the need for additional planning for their diabetes efforts. Chief Medical Officers, Area Diabetes Consultants and other IHS Area Office Staff were available to assist tribes in choosing promising prevention efforts and in selecting appropriate evaluation measures.

In addition to grants, $1 million of the BBA funds were allocated for the development of a National Diabetes Prevention Center (NDPC) in Gallup, NM. IHS collaborated with CDC Division of Diabetes in this effort. The NDPC agreement was awarded to the University of New Mexico who has established a Steering Committee and a Center Advisory Board. The Tribal Leaders Diabetes Committee, established as a result of the BBA funds to advise IHS on diabetes-related issues, will also advise the Steering Committee of the NDPC.

Tribes have begun to exert a growing influence in the management of diabetes programs. The number of tribally managed programs continues to grow steadily. Eighty one percent of the *Special Diabetes Program for Indians* grant recipients are tribal programs. To responsibly manage a health program requires data that supports an assessment of the health needs of the population. To meet this need, tribal programs were well represented in the IHS 2000 *Diabetes Care and Outcomes Audit* of AI/AN with diagnosed diabetes and will have the opportunity to participate in the 2001 survey. Data gathered by these surveys provides tribes information from which to make rational decisions regarding their diabetes programs.

Best Practices/Industry Benchmarks

The IHS Diabetes Program has a long and distinguished history of serving as a benchmark of diabetes clinical and public health excellence. The IHS developed the *IHS Standards of Care for Diabetes* in 1985, prior to those published by the American Diabetes Association in 1987, and are updated every 2 years based on the latest diabetes science. The IHS has been a leader in developing a diabetes care surveillance system, the *Annual Diabetes Care and Outcomes Audit,* carried out voluntarily in Indian health facilities, to track performance on more than 87 indicators to study trends over time. The *Diabetes Care and Outcomes Audit* monitors use of standards and outcomes of diabetes care, including blood sugar and blood pressure control, screening for complications, and preventive health services such as immunizations and smoking history. In the 1999 IHS *Diabetes Care and Outcomes Audit,* 13,248 charts were reviewed representing care to 80,827 patients at 190 IHS and tribal health facilities in the 12 IHS Areas.

This diabetes care surveillance system has been instrumental in the improvement of diabetes care practices in many Indian health settings. For example, in a special program in Alaska and in northern Minnesota from 1989-93, lower extremity amputation rates were reduced by 50 percent in people with diabetes who received complete foot screening and protective footwear. This same system enabled IHS to measure improvements in blood pressure control in Montana after an intensive intervention in 1993.

Beginning in the late 1970s, the IHS Diabetes Program was a pioneer in developing a public health approach to diabetes. In the early 1980's the program began to publish some of the first national epidemiologic surveillance data regarding the problem of diabetes in AI/AN. The IHS Diabetes Program staff tailored American Diabetes Association education program criteria to fit the unique needs of Indian communities and disseminated the adapted criteria nationally. Later in the 1980s and early 1990's, the IHS began to publish in peer-reviewed journals its experience with using the *Annual Diabetes Care and Outcomes Audit* to measure improvements in diabetes care for Indian communities. A 1994 GAO report outlining diabetes care to elderly Americans was compared to 1995 data from IHS. IHS performed significantly better on all five measures of quality care. In 1998, the IHS Diabetes Program recognized by the Diabetes Quality Improvement Coordinating Committee as one of only two federal agencies who had collected quality improvement data so that it was available for comparison when the Diabetes Quality Improvement Project (DQIP) guidelines were announced. In the January 2001 issue of the medical journal *Diabetes Care* the IHS published an article describing its experience with guidelines and the DQIP measures.

The IHS Diabetes Program has been cited internationally as a model of community involvement and program effectiveness. In 1999 the program was invited to the World Congress on Diabetes Prevention conference to present a description of the Balanced Budget Act of 1997 diabetes grant program. In 2000 the program presented the same information at the 3rd Annual Indigenous People's Conference on Diabetes in New Zealand. As part of its ongoing programmatic activities, the IHS Diabetes Program collaborates with the Centers for Disease Control, the National Institutes of Health, the American Diabetes Association, the National Diabetes Education Program, the American Association of Diabetes Educators, many state Department of Health Diabetes Control Programs, and tribal colleges and universities.

Findings Influencing the FY 2002 Request

The Balanced Budget Act of 1997 *Special Diabetes Program for Indians* (SDPI) provided IHS $30 million per year for 5 years for the prevention and treatment of diabetes. The amendment to the 1997 Balanced Budget Act SDPI through H.R. 4577, the Consolidated Appropriations Act, 2001 provided additional funding for FY 2001, 2002 and 2003. The 1997 BBA funds have provided "seed money" to 318 new programs to begin, or in some cases significantly enhance, diabetes prevention programs in Indian communities. Many of these programs, the majority of which are tribally run, are creating innovative, culturally appropriate strategies to address diabetes. The SDPI funds have enhanced diabetes care and education in AI/AN communities. In FY 2002, some of the funds will be targeted to additional trained personnel, support, technical assistance. The additional funds received from BIPA will enable IHS to implement these grants programs and complicated monitoring and evaluative activities of diabetes prevention and treatment efforts at an increased level.

The Consolidated Appropriations Act of 2001 provides an additional $70 million in new diabetes funding to the IHS for year 2001 and 2002, and then $100 million in Year 2003. The IHS is currently conducting a nationwide tribal consultation process on this new funding. Plans are to provide grants to strengthen clinical diabetes and complications prevention programs and/or to develop and strengthen primary diabetes prevention programs. Whenever possible, the IHS Diabetes Program will strengthen the IHS diabetes

infrastructure at the Headquarters and Area office levels to maintain and improve diabetes surveillance, technical assistance, provider networks and clinical monitoring. Support for the Area Diabetes Consultants, who serve a crucial role in coordinating these functions at the Area level, must be strengthened. In addition, a role for Community Diabetes Advocates will be developed and expanded to coordinate community-based activities to obtain qualitative data and support prevention and treatment programs that are culturally sensitive and focused.

The next challenge for IHS on a national level will be to disseminate the new ideas learned in these grant site settings to other tribal communities for adaptation and implementation.

ACCOMPLISHMENTS

Results of the 1999 IHS-wide *IHS Diabetes Care and Outcomes Audit* to assess diabetes care and education for over 80,000 diabetes patients completed in 1999 revealed an important finding. Data comparisons with 1994-97 results showed a statistically significant improvement trend in blood sugar control among AI/ANs with diagnosed diabetes. This encourging trend has occurred through improved management of diabetes retreats rather than the purchase of newer diabetes medication and equipment. The IHS National Diabetes Program attributes this trend to the extensive commitment that IHS and local communities have made to improve diabetes control. Blood sugar control has been definitively shown in large clinical trials to reduce the complications of diabetes over time and to save money.

Publications documenting our ability to improve care with low tech, low cost approaches have been numerous, even though the costs of providing diabetes care are high. Estimates from managed care organizations suggest that the average cost of diabetes care is $5000-9000 per patient per year, much of this a result of the costs of pharmaceuticals. The IHS per capita expenditure is $1,578. Resources for diabetes care in the Indian health system have mostly been devoted to the clinical care of diabetes and prevention of its complications, rather than to less well scientifically proven methods for primary prevention of diabetes in those without the disease.

Despite these advances, AI/ANs continue to have substantially higher rates of diabetes and its complications than the U.S. population at large.

Specific accomplishments include:

- The IHS National Diabetes Program works closely on diabetes-related issues with tribal leaders through the Tribal Leaders Diabetes Committee. This committee was established by Dr Trujillo to advise the agency on an ongoing basis.

  - The IHS National Diabetes Program staff play significant roles on numerous national diabetes activities:

    - ✓ The Director serves as a Steering Committee member on the National Diabetes Education Program; as a member of the Translational Advisory Committee of the CDC Division of Diabetes; as an ad hoc member of the Congressionally-mandated Diabetes Research Working

Group of the NIDDK/NIH; and as a member of the Federal Diabetes Interagency Coordinating Committee.

- ✓ Other staff serves on the National Board of the American Diabetes Association and the Task Force to Review the National Diabetes Education Standards for Diabetes Self-Management.

- The IHS National Diabetes Program initiated an Indian health task force to revise and develop a framework for integrating Diabetes Education Standards for AI/AN communities. The task force will develop a process for achieving formal recognition of quality programs in preparation for HCFA reimbursement of diabetes education.

- The IHS National Diabetes Program and the CDC Division of Diabetes collaborate closely. The IHS Diabetes Program prevalence and complications surveillance system have been automated through the assignment of a CDC Epidemiologist to the program. The prevalence data have been disseminated to the Tribal Leaders Diabetes Workgroup, Area Directors, Area Diabetes Consultants, and others. The data are now available by region on our website.

- A Workgroup has been established with CDC, IHS, the American Academy of Pediatrics and the American Diabetes Association to address the growing concern about type 2-diabetes in Native American children. IHS staff is leading the effort with requests for screening protocols, standards of care and treatment recommendations from these expert groups.

- The IHS established an obesity prevention initiative in 1998 to address the increasing trend of obesity in children ages 3-5 years of age. In partnership with other federal agencies, states and Tribes, the IHS Diabetes Program developed a comprehensive plan for a four-year initiative. Five pilot sites have recently been selected to implement obesity prevention interventions in tribal Head Start programs and communities.

- The IHS National Diabetes Program partnered with the National Indian Council on Aging (NICOA) to develop a pilot project to automate diabetes clinical data at the local and national levels. Eight sites are fully functional.

- The IHS National Diabetes Program collaborated with Macro International, INC, a consultant firm specializing in mixed methods evaluation, to develop an evaluation strategy for the SDPI grants program in 1999. These data served as a major portion of the analysis in the Year 2000 Interim Report to Congress. Data are currently being collected for a revised year 2001 evaluation report.

PERFORMANCE MEASURES

The performance measures associated with this budget request are under development and will be available in mid-July.

Following are the funding levels for the *Special Diabetes Program for Indians* for the last 5 fiscal years:

Year	Funding	
1997	$0	
1998	$30,000,000	
1999	$30,000,000	
2000	$30,000,000	
2001	$100,000,000	Enacted

THIS PAGE LEFT BLANK INTENTIONALLY