

Congress Faces Calls to Extend Funding for Special Diabetes Programs

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Under the Balanced Budget Act of 1997 ([P.L. 105-33](#)), Congress amended the Public Health Service Act (PHSA) to create two special diabetes programs. The first—the [Special Diabetes Program for Type I Diabetes](#) (PHSA §330B; [U.S.C. 42 §254c-2](#)) provides funding for the [National Institutes of Health](#) (NIH) to award grants to study type I diabetes. The second—the [Special Diabetes Program for Indians](#) (PHSA §330C; [U.S.C. 42 §254c-3](#))—provides funding to the [Indian Health Service](#) (IHS) to award grants for activities related to preventing and treating diabetes for American Indians and Alaska Natives who receive services at IHS-funded facilities. This Insight describes both programs and their funding histories.

An [estimated 9.4% of the U.S. population](#) has diabetes (type 1 and type 2), and diabetes was the [seventh leading cause of death](#) in 2016. Diabetes disproportionately affects certain subpopulations, especially [American Indians and Alaska Natives](#), who have the highest prevalence among racial/ethnic groups. The special diabetes programs are aimed at two subpopulations of those with diabetes: people with type 1 diabetes and American Indians and Alaska Natives.

Program Funding

Since enactment, both programs have received direct (i.e., mandatory) appropriations. Both NIH and IHS generally receive their funding through [annual discretionary appropriations](#). For both agencies, the special diabetes programs represent one of the only direct (i.e., mandatory) budget authorities.

The amount directly appropriated to both programs has increased over time. Initially, they were each funded at \$30 million in FY1998. This amount increased to \$150 million annually for each program [beginning in FY2004](#). Most recently, funding was extended in [Section 50902](#) of the Bipartisan Budget Act of 2018 ([P.L. 115-123](#)), which provided each with \$150 million for each of FY2018 and FY2019. Under current law, no new funding for these programs will be available after September 30, 2019; however, previously appropriated funds are available until expended.

The NIH Program

[Type 1 diabetes](#) is an [autoimmune disease](#), where a person's pancreas cannot create insulin—the hormone that regulates

blood sugar levels. People with type 1 diabetes must take daily insulin and monitor their blood sugar levels. Even with proper management, people with type 1 diabetes face increased risk of serious complications such as [cardiovascular disease, renal disease, and diabetic coma](#). In 2015, about [5% of the estimated 23.1 million](#) people with diabetes had type 1 diabetes. Unlike [type 2 diabetes](#) which is often linked to lifestyle factors and is more commonly diagnosed in adults, [type 1 diabetes](#) is more commonly diagnosed in children and adolescents and has no known cause.

[The Special Diabetes Program for Type 1 Diabetes](#) provides funds to NIH's [National Institute of Diabetes and Digestive and Kidney Diseases \(NIDDK\)](#) for research into the prevention and cure of type 1 diabetes. The program is the only [disease-specific direct funding authority](#) for NIH. [NIDDK collaborates](#) with other NIH institutions and the Centers for Disease Control and Prevention (CDC) to implement the program.

In total, NIH spent [\\$1.17 billion on diabetes research](#) (both type 1 and type 2) in FY2018 (most recent data available). The Special Diabetes Program for Type 1 Diabetes represented about 13% of total funding on all NIH diabetes research activities. Notably, NIH does not categorize its research funding for diabetes by type (1 or 2). Therefore, the percentage of total type 1 diabetes research funding that the Special Program for Type 1 Diabetes accounts for cannot be determined by CRS.

In its FY2019 Congressional Budget Justification, [NIDDK specifies](#) how the \$150 million appropriated in FY2019 is allocated among six scientific goals, including one related to preventing and reversing the disease and another on developing pancreatic cell replacement therapies. [NIDDK reports](#) that the funding has helped researchers identify genes and environmental factors linked with type 1 diabetes, improve blood tests to assess risk of developing the disease, and support clinical trials on therapeutics to prevent and treat the disease. A [2011 program evaluation](#) stated that it "has catalyzed and synergized the efforts of a wide range of NIH and HHS components to combat type 1 diabetes and complications, making it a model trans-NIH and trans-HHS program."

The IHS Program

American Indians and Alaska Natives [have high rates of diabetes](#). Prior to the inception of the Special Diabetes Program for Indians (SDPI), [these rates had been increasing over time](#). The SDPI program was enacted to reduce both new cases of diabetes and the rates of complications among the IHS's diabetic population. Although diabetes rates among the IHS service population remain high, they [have not increased since 2011](#), which some [advocates](#) and the [IHS](#) attribute to the program.

SDPI provides grants to fund more than [300 programs](#) administered by Indian Tribes and Tribal Organizations that undertake evidence based-community programs to prevent and treat diabetes. It supports activities such as [nutrition and exercise counseling](#) that seek to prevent diabetes and activities to monitor diabetes related complications, such as [foot and eye screening](#). The program also provides support for [IHS's diabetes surveillance efforts](#).

IHS funds health services, but the needs for services generally exceed available funding. For example, IHS data indicate that it denied or deferred referrals for more than [92,000 services in FY2016](#). As part of IHS's strategy to manage resources, it [focuses on prevention](#) of common conditions among its service population, [including diabetes](#). IHS's prevention efforts may complement SDPI programs, as both can be used to support [wellness and nutrition programs](#).

Policy Considerations

Congress may face a number of policy questions with regard to the two diabetes programs. These include the following:

- Should program funding be extended?
- Can some or all of program activities be undertaken using the NIH and IHS discretionary appropriations?
- Do the activities funded under these program supplement or duplicate other agency activities?
- Are there advantages or drawbacks to disease-specific funding authorities?
- If program funding is extended, is the program's current funding level appropriate? As noted above, funding for these programs has not increased since FY2004. During this time period, the [cost of research has increased](#), as has the [size of the IHS service population](#) and the [cost of medical care](#).