

Special Diabetes Programs Expire in FY2020: Policy Considerations and Extension Proposals

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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 at IHS-funded facilities. This Insight describes both programs and their funding histories.

An [estimated 9.4% of the U.S. population](#) has diabetes (including both type 1 and type 2), and diabetes was the [seventh leading cause of death](#) in 2017. 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 spending budget authorities.

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The amount 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](#). The programs' most recent multiyear funding extension was in [Section 50902](#) of the Bipartisan Budget Act of 2018 (P.L. 115-123), which provided each with \$150 million annually for FY2018 and FY2019. Partial FY2020 funding at similar funding levels to FY2019 has been provided in [P.L. 116-94](#) through [May 22, 2020](#), and in earlier continuing resolutions ([P.L. 116-69](#); [P.L. 116-59](#)). A longer funding extension has not been enacted; however, previously appropriated funds will be available until expended after expiration. Several introduced bills would provide longer extensions as discussed below.

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 regular insulin and monitor their blood sugar levels. Even when managing the disease, people with type 1 diabetes face increased risk of serious [complications](#) such as cardiovascular disease and renal disease. 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. [NIDDK collaborates](#) with other NIH institutions and the Centers for Disease Control and Prevention (CDC) to implement the program. [NIDDK reports](#) that, among other things, 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.

In total, NIH spent [\\$1.04 billion on diabetes research](#) (both type 1 and type 2) in FY2018 (most recent data available). The NIH Special Diabetes Program represented about 14% 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, CRS cannot determine the percentage of total type 1 diabetes research funding made up by the Special Diabetes Program compared to discretionary funding sources.

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. [HHS research](#) also estimated that the program reduced Medicare diabetes treatment costs under two scenarios over a ten-year period by as low as [\\$436 million](#) and as high as [\\$520 million](#).

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 [163,000 services in FY2018](#). As part of

IHS's strategy to manage resources, it [focuses on prevention](#) of common conditions, [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, including:

- Should direct program funding be extended?
- Can some or all of program activities be undertaken using the NIH and IHS discretionary appropriations?
- Are there advantages or drawbacks to disease-specific funding authorities?
- If direct 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](#).

Legislative Options That Extend Funding

Legislation has been introduced in the 116th Congress that would extend these programs for five years (H.R. 2668, H.R. 2680, and S. 192). Both House bills would increase each program's funding from FY2019 levels of \$150 million to \$200 million annually, whereas the Senate bill would maintain FY2019 funding levels. In addition, full-year FY2020 funding at the FY2019 level is included in a larger health care package under consideration related to prescription drug prices (H.R. 2700). Separately, a five-year funding extension at the FY2019 level for both programs is included in legislation that aims to address [surprise medical billing](#) (S. 1895).

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