

# National Indian Health Board



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December 3, 2018

The Honorable Robert R. Redfield, M.D.  
Director  
U.S. Centers for Disease Control and Prevention  
U.S. Department of Health and Human Services  
1600 Clifton Rd.  
Atlanta, GA 30333

**RE: U.S. Centers for Disease Control and Prevention: Formative and Summative Evaluation of the National Diabetes Prevention Program, Docket No. CDC-2018-0089**

Dear Secretary Redfield:

On behalf of the National Indian Health Board (NIHB), I write to submit comments on the proposed revision of information collection, published in the Federal Register on October 4, 2018, entitled “*Formative and Summative Evaluation of Scaling the National Diabetes Prevention Program (National DPP) in Underserved Areas.*” Centers for Disease Control and Prevention (CDC) states that the purpose of this revision is to allow the Agency to continue collecting the information needed to assess the effectiveness of its program, “Scaling the National DPP in Underserved Areas,” and to collect more targeted information on CDC grantees' success in reaching both general and priority populations in underserved areas. NIHB thanks the CDC for the opportunity to provide input on this important topic that impacts the 573 federally recognized Tribes we serve.

Established in 1972, the NIHB is an inter-Tribal organization that advocates on behalf of Tribal governments for the provision of quality health care to all American Indians and Alaska Natives (AI/ANs). The NIHB is governed by a Board of Directors consisting of a representative from each of the twelve Indian Health Service (IHS) Areas. Each Area Health Board elects a representative to sit on the NIHB Board of Directors. In areas where there is no Area Health Board, Tribal governments choose a representative who communicates policy information and concerns of the Tribes in that area with the NIHB. Whether Tribes operate their entire health care program through contracts or compacts with IHS under Public Law 93-638, the Indian Self-Determination and Education Assistance Act (ISDEAA), or continue to rely on IHS for delivery of some, or even most, of their health care, the NIHB is their advocate.

NIHB commends the CDC for their continued dedication to advancing the public health infrastructure and capacity of Tribal Nations. AI/AN communities face some of the starkest disparities in preventable chronic health conditions including diabetes, obesity, and cancer. Increasing investments in upstream, holistic, and culturally appropriate prevention policies and programs can help Tribes turn the tide on many of these debilitating illnesses. Additionally,

investing in primary prevention can yield tremendous cost savings in future Tribal or IHS health care expenditures. Indeed, utilizing a preventative public health approach to reducing obesity rates by merely 5% could save nearly \$30 billion within 5 years.<sup>1</sup> At a rate of 2.8 times the national average, American Indians and Alaska Natives (AI/ANs) have the highest prevalence of diabetes. In some AI/AN communities, over 50% of adults have been diagnosed with Type II diabetes, and AI/ANs are 177% more likely to die from diabetes.

## ***Background***

The National Diabetes Prevention program – or National DPP – is a partnership of public and private organizations working to prevent or delay type 2 diabetes. The partners work to make it easier for people with prediabetes to participate in evidence-based, affordable, and high-quality lifestyle change programs to reduce their risk of type 2 diabetes and improve their overall health.<sup>2</sup>

CDC has conducted a formative and summative evaluation of this program and used the evaluation findings and lessons learned to provide data-driven technical assistance to the grantees and other organizations delivering the National DPP lifestyle change program. The data and lessons learned from 2012 grantees were also used to inform decision-making and policy, including the development of the Centers for Medicare & Medicaid Services (CMS) Medicare Diabetes Prevention Program (MDPP). As of April 1, 2018, the MDPP Expanded Model provides coverage for the National DPP lifestyle change program for eligible Medicare beneficiaries. CDC funded a new, five-year cooperative agreement with ten new national organizations in September 2017.

Currently, there are over eighteen-hundred CDC-recognized organizations in the contiguous United States, the District of Columbia, and U.S. territories that offer the National DPP lifestyle change program. However, there are still many geographic areas with few or no in-person delivery programs. In addition, some populations, including Medicare beneficiaries, AI/ANs, and people with visual impairment or physical disabilities, are under-enrolled relative to their estimated numbers and disease burden.

## ***Formative and Summative Evaluation of Scaling the National Diabetes Prevention Program in Underserved Areas—Proposed Revisions***

CDC requests an additional three years of OMB approval to continue collecting information needed to evaluate the effectiveness of CDC's funding for the new grantees. The notice proposes that the data collection will allow CDC to continue to provide data-driven, tailored programmatic technical assistance to ensure continuous quality improvement for each year of the cooperative agreement. Within the revised information collection protocol, a number of changes to the evaluation forms are proposed to ensure that reporting and evaluation requirements are consistent with the aims of the new cooperative agreement and reflect the lessons learned from the original 2012 funded national organizations and their affiliate delivery sites. Moreover, the method of data

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<sup>1</sup> Bending the Obesity Cost Curve: Reducing Obesity Rates by Five Percent Could Lead to More than \$29 Billion in Health Care Savings in Five Years. Washington, D.C.: Trust for America's Health, January 2012. Available online at: <http://healthyamericans.org/assets/files/TFAH%202012ObesityBrief06.pdf>

<sup>2</sup> Centers for Disease Control and Prevention, National Diabetes Prevention Program. 2018. What is the National NDPP? Retrieved from <https://www.cdc.gov/diabetes/prevention/about/index.html>

collection has converted from using an Excel spreadsheet to a web-based data system to allow for real-time feedback and technical assistance.

***Programmatic Changes:***

The newly funded grantees and affiliate sites under the recent cooperative agreement will submit evaluation data directly to CDC through a web-based data system called the Data Reporting for Evaluation and Monitoring of 1705 (1705 DREM) System, accessible using a web browser on a PC, MAC, or mobile device. CDC's assertion is the web-based data system will allow real-time data entry by grantees and affiliate delivery sites and real-time feedback and technical assistance (TA) from CDC to facilitate continuous quality improvement by grantees and sites. The web-based data system will allow data entry directly by affiliate delivery sites instead of requiring the grantees to compile and submit a consolidated response based on each of their affiliate delivery sites.

NIHB represents 573 federally recognized Tribes who reside in some of the most rural locations. Many Tribes that are located in rural areas experience high unemployment, poverty, and lower health outcomes than the general population. These geographic factors could reduce the ability of grantees to participate in electronic submission of reporting requirements to CDC. The rural nature of what is referred to as "Indian Country" not only causes difficulty with IT infrastructure, but even the most basic technological needs like access to running water or electricity can be hard to come by in some places. NIHB requests that CDC take into consideration the lack of availability of internet access and barriers for rural Tribal health care organizations to obtain a vast up-to-date IT infrastructure and make efforts to accommodate non-electronic reporting submission.

***Collection of additional organizational information from grantees:***

Within the Notice, CDC proposes to collect some additional information about the grantees to allow for a more robust and targeted evaluation of the new cooperative agreement. CDC asserts this is necessary as the agency attempts to scale and sustain the National DPP to reach priority populations in underserved areas. As a result of the evaluation of the 2012 grantees, CDC learned that the quality of the TA provided by grantees to affiliate delivery sites was critical in improving outcomes at the delivery site level. Therefore, CDC proposes to expand their collection of information about TA, with a specific focus on reaching priority populations.

NIHB appreciates the CDC's effort to include additional information from grantees to improve the evaluation methodology so that adequate TA is incorporated for the new grantees and their respective delivery sites as they obtain CDC recognition.

Additionally, CDC proposes to add fields relating to the engagement of healthcare providers to screen, test, and refer priority populations with prediabetes to a CDC-recognized organization. The notice proposes implementation of administrative systems required to bill and receive payment from payers.. More specifically,, the information collection protocol seeks to obtain: 1) information related to the types of value-based payment methods used to reimburse affiliate sites for delivering the NDPP program, 2) the strategies used to increase retention of priority

populations in the program, and 3) descriptions of the activities and tools developed and implemented to attain coverage from the NDPP .

NIHB recommends that CDC consider the unique nature of Tribal health systems, and strongly consider limiting required information that may be duplicative with other program reporting. Tribal health programs are often under resourced and under staffed, so additional reporting requirements often just lead to diminished patient care. Instead, CDC should consult with their Tribal grantees to develop reporting requirements that are streamlined with other information currently being collected by the Indian Health Service and other agencies of the Department of Health and Human Services.

For example, many Tribal DPP grantees many also be working on other groundbreaking diabetes programming. The Special Diabetes Program for Indians (SDPI) – known for its unprecedented success in reducing the burden of type 2 diabetes among AI/ANs – is one of the most successful public health programs ever implemented in Tribal communities. SDPI blends traditional healing and community-based practices with Western medicine and prescription drugs to create a truly robust public health intervention. With over 300 Tribal grantees, SDPI is one of the most important community-based programs at work in Indian Country.

During the time that SDPI has been in existence, the AI/AN population has experienced a 54% reduction in incidence rates of End Stage Renal Disease (ESRD) – reducing millions of dollars in Medicare, IHS, and third party billing.<sup>3</sup> Moreover, SDPI has helped AI/AN communities reduce rates of diabetic eye disease by 50%<sup>4</sup>, while obesity and diabetes rates among youth have not increased in over a decade.<sup>5</sup>

### ***Tribal Consultation***

NIHB appreciates the opportunity to submit comments on the CDC’s “*Formative and Summative Evaluation of Scaling the National Diabetes Prevention Program*”. We note, however, that the public notice and comment period is not a substitute for Tribal consultation pursuant to the CDC Tribal Consultation Policy and Executive Order 13175. The Federal government’s trust responsibility provides the legal justification and moral foundation for Indian specific health policymaking— with the objectives of enhancing AI/AN access to health care and overcoming the chronic health status disparities of this segment of the American population.

Under the CDC/ATDSR Tribal Consultation Policy, CDC’s goals within the policy include, but are not limited to:

- Assisting in eliminating the health disparities faced by Indian Tribes,
- Ensuring that access to critical health and human services and public health services is maximized to advance or enhance the social, physical, and economic status of Indians;

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<sup>3</sup> Bullock A, Burrows NR, Narva AS, et al. Vital Signs: Decrease in Incidence of Diabetes-Related End-Stage Renal Disease among American Indians/Alaska Natives — United States, 1996–2013. MMWR Morb Mortal Wkly Rep 2017;66:26-32. DOI: <http://dx.doi.org/10.15585/mmwr.mm6601e1>

<sup>4</sup> CDC Vital Signs <https://www.cdc.gov/vitalsigns/aian-diabetes/index.html>

<sup>5</sup> IHS Teleophthalmology Program Data

- Promoting health equity for all Indian people and communities.

To achieve these shared goals, it is essential that Indian Tribal governments and CDC/ATSDR engage in open, continuous, and meaningful consultation.<sup>6</sup>

Indian health care programs are unique. Tribal health programs implement the United States' trust responsibility to provide health care services to AI/ANs.<sup>7</sup> The IHS is the primary federal agency tasked with carrying out this responsibility; however, the federal trust responsibility extends to every branch of the federal government and to every Executive Department and agency, including CDC. CDC must not abdicate its trust responsibility by failing to account for the unique needs of the Indian Health system as it finalizes this rule.

### ***Conclusion***

NIHB and the Tribes stand ready to work with the CDC to further build the public health capacity of Indian Country and reduce health disparities in Tribal communities. We thank you for this opportunity to provide our comments and recommendations, and look forward to further engagement with the CDC on leveraging public health resources to raise the health status of all AI/ANs to the highest level.

Please contact NIHB's Director of Federal Relations, Devin Delrow, at [ddelrow@nihb.org](mailto:ddelrow@nihb.org) if there are any additional questions or comments raised in this letter.

Sincerely,



Vinton Hawley  
Chairman,  
National Indian Health Board

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<sup>6</sup> Centers for Disease Control and Prevention, Tribal Consultation Policy. 2018. Tribal Consultation Policy. Retrieved from [https://www.cdc.gov/tribal/documents/tac/2014/cdcatsdr\\_tribal\\_consultation\\_policy.pdf](https://www.cdc.gov/tribal/documents/tac/2014/cdcatsdr_tribal_consultation_policy.pdf)

<sup>7</sup> See, e.g., 25 U.S.C. § 1601 (“Federal health services to maintain and improve the health of the Indians are consonant with and required by the Federal Government’s historical and unique legal relationship with, and resulting responsibility to, the American Indian people.”); The White House, Memorandum for Heads of Executive Departments and Agencies re: Tribal Consultation (Nov. 5, 2009), <https://www.whitehouse.gov/the-pressoffice/memorandum-Tribal-consultation-signed-president>.