

VORTHWEST VORTLAND NREA NDIAN HEALTH VOARD

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SUBMITTED VIA consultation@ihs.gov

May 18, 2018

RADM Michael D. Weahkee, Acting Director Indian Health Service 5600 Fishers Lane Rockville, MD 20857

RE: Distribution of Funding for the Special Diabetes Program for Indians (SDPI) in Fiscal Year (FY) 2019

Dear Acting Director Weahkee:

On behalf of the Northwest Portland Area Indian Health Board (NPAIHB), I submit the following comments on the distribution of funding for the Special Diabetes Program for Indians (SDPI) in fiscal year (FY) 2019 in response to IHS Dear Tribal Leader Letter (DTLL), dated April 13, 2018, and Portland Area DTLL letter, dated April 18, 2018, with comment deadline of May 18, 2018. NPAIHB is a Public Law 93-638 tribal organization that advocates on health care issues for the forty-three federally-recognized tribes in the states of Idaho, Oregon, and Washington¹.

NPAIHB appreciates the opportunity to participate in tribal consultation on the funding distribution for successful diabetes treatment and prevention activities and is grateful to the Tribal Leaders Diabetes Committee (TLDC) for requesting consultation with all 12 IHS Areas. However, we have not received sufficient information from IHS to fully comment on the SDPI funding distribution for FY 2019 and request an additional 90 days to submit comments and a face-to-face consultation once adequate data and funding information is available to tribes.

BACKGROUND

At a rate of 2.8 times the national average, American Indians/Alaska Natives (AI/ANs) have the highest prevalence of diabetes. In some AI/AN communities, over 50% of adults have been diagnosed with type 2 diabetes and AI/ANs are 177% more likely to die from diabetes. Congress established SDPI through the

¹ A "tribal organization" is recognized under the Indian Self-Determination Education Assistance Act (P.I. 93-638; 25 U.5.C. § 450b(1)) as follows: "[T]he recognized governing body of any Indian tribe; any legally established organization of Indians which is controlled, sanctioned, or chartered by such governing body or which is democratically elected by the adult members of the Indian community to be served by such organization and which includes the maximum participation of Indians in all phases of its activities."

Balanced Budget Act of 1997. The SDPI has been funded at \$150 million per year,² and has grown to become the nation's most strategic and effective federal initiative to combat diabetes. The SDPI has successfully implemented evidence-based and community-driven strategies to prevent and treat diabetes. SDPI is changing these disproportionate and devastating statistics with improvements in average blood sugar levels, reductions in the incidence of cardiovascular disease, reductions in the incidence of kidney failure, prevention and weight management programs for our youth, and a significant increase in the promotion of healthy lifestyle behaviors. SDPI successes in Northwest are due to the structure of the grant program that allows tribal communities to design and implement their diabetes interventions for at risk tribal members.

During the 2016 calendar year, there were 7,075 active AI/AN patients in the Northwest area with diabetes. Of the 7,109 AI/ANs, 90% are overweight (17%) or obese (73%). In the Portland Area, the 38 SDPI programs represent 10% of the SDPI grantees and are making a significant difference to prevent and treat diabetes. SDPI is changing these disproportionate AI/AN community statistics with reductions in average blood sugar (A1C) levels, reduced cholesterol levels, reductions in the incidence of cardiovascular disease, reduction in weight, an increase in prevention and weight management programs, and a significant increase in the promotion of healthy lifestyle behaviors.

SDPI funding supports 404 Indian Health Service (IHS), tribal, and urban (I/T/U) diabetes treatment and preventions programs in 35 states. In the Northwest, there are five tribal communitydirected SDPI programs in Idaho, seven tribal programs in Oregon (including one Urban program and one IHS program), and twenty-six tribal programs in Washington (including two Urban programs). Northwest tribal members have described SDPI as a life-saver and life-extender. SDPI program staff go above and beyond to support and assist tribal members in customizing a plan to suit the patient's needs to become successful in improving their overall health.

SDPI is currently funded through a competitive grant process, which creates barriers to care and requires tribal programs to compete for critical funding. SDPI should not involve a competitive grant process. IHS must take into consideration that smaller Northwest tribes do not have the same grant writing capacity as larger tribes do, smaller tribes usually do not have a grant writing position. For SDPI grantees who need to work to improve their grant application, we believe they should not be locked out of the five years of grant funding. Tribes should be able to implement an improvement plan and be able to apply for the funds the following year instead of waiting until the next five-year grant cycle.

FY 2019 PRESIDENT'S BUDGET RECOMMENDATION FOR SDPI

NPAIHB opposes President Trump's FY 2019 budget request to move the SDPI out of mandatory funding and into discretionary funding (NPAIHB resolution 18-03-06). There are 40 successful SDPI programs in the Northwest serving AI/ANs in the Portland Area with consistent positive clinical and community outcomes. A change from mandatory to discretionary could lessen SDPI as a priority compared to other IHS programs leading to decreased funding and program instability. For these reasons, NPAIHB supports continued mandatory funding for SDPI to uphold the trust responsibility and treaty obligations between the United States and Tribes. Mandatory funding provides for stability and allows participating programs more continuity and the ability to plan

² Indian Health Service Special Diabetes Program for Indians 2014 Report to Congress

more long-term interventions and activities. We also respectfully request that permanent authorization be considered with an increase to \$250 million annually and with medical inflation rate increases thereafter.

SDPI NATIONAL FUNDING DISRIBUTION

Portland Area TLDC representatives, and other areas, have specifically requested that FY 2019 tribal consultation on SDPI funding distribution not include the Community-Directed Grant Program (\$130.2 million) and the Urban Indian Health Program (\$8.5 million) funding, yet it was included in the DTLL. Our area has never proposed or intended to alter, or reduce, these funding amounts in any way. The Community-Directed Grant Program and the Urban Indian Health Program funds should only be discussed if there are additional funds available.

In addition, our Portland Area TLDC representatives have repeatedly requested a detailed breakdown on the funding for Program Support (\$6.1 million) and Data Infrastructure Improvement (\$5.2 million) funds.

We therefore request that IHS provide a detailed breakdown of national funding information for SDPI Program Support and Data Infrastructure Improvement. Without this information, our tribes cannot make informed recommendations as to how funding should be distributed for FY 2019. For this reason, we further request that IHS extend the comment period for 90 days to gather and provide this information to tribes as well as hold a face-to-face consultation.

SDPI PROGRAM SUPPORT FUNDING

Within the \$6.1 million for SDPI Program Support there are fixed, predictable expenses as well as variable, expected expenses. The SDPI Program Support variable, expected expenses include funding for the SDPI/Diabetes Conference in the amount of \$85 thousand, according to an IHS presentation to TLDC. We request that IHS provide us with the cost of the last SDPI/Diabetes conference and the estimated costs of the upcoming conference.

During a TLDC presentation, the IHS Division of Diabetes Treatment and Prevention (DDTP) highlighted \$1.02 million for DGM Grants Management Specialists within the fixed, predictable expenses. We request additional information on how fixed, predictable expenses are utilized between grant years.

The SDPI Program Support unplanned expenses is included in the \$6.1 million. The IHS DDTP has indicated to the TLDC that the unplanned expenses have provided supplemental funding during sequestration as well as three months for cycle 1 SDPI grantees for FY 2016. The unplanned expenses also included an SDPI video for the American Diabetes Association annual conference. However, we were not provided with how much funding is designated for the unplanned expenses. Therefore, we also request information on how IHS determines the use of the SDPI Program Support funding for unplanned expenses when funding is available and sequestration does not occur.

SDPI DATA INFRASTRUCTURE IMPROVEMENT FUNDING

We believe that there is a need to improve data capacity for tribes who do not utilize the Resource and Patient Management System (RPMS). For the past twenty years, IHS has used SDPI funds to build and support the RPMS system. We would like to take a deep dive into the \$5.2 million Data Infrastructure Improvement portion and reporting. Are there any other IHS programs or grants that financially support the RPMS IT functions (e.g. MSPI)? SDPI funds should not be used to support RPMS, especially since many Northwest tribes do not utilize RPMS. With the formidable challenges presented to tribes by RPMS over the years, many clinics and programs were driven to leave RPMS and implement a new commercial off-the-shelf Electronic Health Record (EHR) system. NPAIHB is concerned about the continued use of SDPI funds to build and support the RPMS EHR. Enhancement and improvements that would be needed for RPMS to interface properly would make for a sizeable and poor investment. We request that some funding from the set aside for data and support for RPMS be re-directed to the tribes that do not use RPMS.

We are interested in examining how tribes can start building a data repository infrastructure similar to IHS. Tribes who do not operate RPMS are unable to access their own data from the DPP data repository in Denver. Therefore, SDPI tribal funded programs that do not operate RPMS do not benefit. Additionally, tribes that do not utilize RPMS, must manually enter data for the annual diabetes audit. Manually entering the data for the audit is very labor intensive and prohibits use of per-visit audits, which provides information on gaps in care. Northwest tribes do not believe that their audit data is accurate and there is a need to improve the quality of the data for their SDPI program, including data entered into the National Data Warehouse. Tribes should have the option to decide if they would like their tribe or a Tribal Epidemiology Center to manage and support their SDPI data. Several of the Tribal Epidemiology Centers currently provide training and technical assistance to support tribes in completing the annual diabetes audit. NPAIHB requests that IHS provide tribes with the full detailed costs of performing the audit and the Congressional reports. We request that IHS provide information that would assist tribes with evaluating how funds for improving data capacity are used.

FUTURE OF SDPI

The SDPI has evolved over the past twenty years and Congress has appropriated the same level of funding (\$150 million per year) since 2004. SDPI has not been permanently reauthorized and funding has not increased for fourteen years. Increases to SDPI are critical to sustain the strides made in our tribal communities.

Therefore, we request a tribal consultation on the future of SDPI that would address tribes having more control over funding and data for future sustainability. During such consultation, we also propose exploring an option for tribes to move away from the grant process and including SDPI funding in Annual Funding Agreements (AFAs) for self-governance and contracting tribes.

CONCLUSION

We thank you for this opportunity to provide comments and recommendations on the FY 2019 SDPI funding distribution and look forward to further engagement with IHS to strengthen the SDPI program to combat the disproportionate diabetes epidemic in Northwest tribal communities. If you have questions or would like more information about our SDPI funding recommendations discussed above, please contact Laura Platero, Government Affairs/Policy Director at (503) 407-4082 or by email to <u>lplatero@npaihb.org</u>.

Sincerely,

Andrew C. Joseph Dr.

Andy C. Joseph, Jr. NPAIHB Chairperson Colville Tribal Council Member