NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

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Yakama Nation

2121 S.W. Broadway
Suite 300
Portland, OR 97201
Phone: (503) 228-4185
Fax: (503) 228-8182
www.npaihb.org

SENT VIA TELEFAX/EMAIL: consultation@ihs.gov

February 4, 2014

Yvette Roubideaux, M.D., M.P.H
Acting Director
Indian Health Service
801 Thompson Avenue, Suite 440
Rockville, MD 20852

Dear Dr. Roubideaux:

The Northwest Portland Area Indian Health Board is a P.L. 93-638 Tribal organization that represents health care issues of forty-three federally recognized Tribes in Idaho, Oregon, and Washington. At our recent Quarterly Board Meeting held on January 21-23, 2013, our Tribes discussed the IHS Dear Tribal Leader Letter (DTLL) dated December 20, 2014 regarding consultation recommendations on the distribution of the SDPI funds for FY 2015. The IHS Portland Area Office (IHS-PAO) also conducted a tribal consultation session to discuss and develop recommendations to your DTLL on February 3, 2014.

The following is a consensus of recommendations of Portland Area Tribal leaders, Board Delegates and Tribal Health Directors responding to your December 20, 2013 DTLL concerning the Special Diabetes Program for Indians (SDPI). Your DTLL requests comments and recommendations on five areas which are discussed below.

1. **SDPI Grant Application process**: If 1 year of funding is authorized, would Tribes prefer that a continuation (not a competitive) application process be used if possible? NOTE: If funding is authorized for more than 1 year, a competitive application process must be used per administrative requirements.

   Portland Area Tribe's Recommendations:

   a. Whether one year, or multiple years, Portland Area Tribes recommend that the current structure of the SDPI must change.
   b. Portland Tribes recommend that the Community-Directed and Special Demonstration (also referred to as the *Diabetes Prevention/Healthy Heart*) Programs be combined into one program.
   c. We recommend that the TLDC and IHS form a technical workgroup of diabetes subject matter experts and Tribal leaders to work out the programmatic structure for how this should be done.

   Discussion on Recommendation:

   In our February 21, 2011 and December 9, 2013 letters to you about funding related to the SDPI competitive grant program, we explained the basis for why Portland Tribes believe that the Community Directed and Special Demonstration Programs be combined. In our interactions with Members of Congress and the House Diabetes

Caucus, we do not believe the Special Demonstration program was never intended to become a permanent program (see attached Rep. Nethercutt letter). As our December 9th letter explains, the funding under this program has resulted in a considerable investment in only a few selected diabetes programs and it is now time to give other Tribes the same opportunity to benefit from the outcomes of the Diabetes Prevention and Healthy Heart Programs. The outcomes of the special demonstration program have been extremely effective and it is time to integrate its practices into the overall program so that all SDPI grantees are using the latest scientific findings on this subject. This is explained in Rep. Nethercutt's letter which we have included for your review and purpose.

2. **Changes to the SDPI national funding distribution**: Should there be any changes in the national SDPI funding distribution and, if so, in what way? Currently, the funding distribution is as follows:

- Community-directed grant program $108.9 million
- Diabetes Prevention/Healthy Heart Initiatives $ 27.4 million
- Set-asides:
- Urban Indian Health Programs $ 7.5 million
- Data Infrastructure Improvement $ 5.2 million
- CDC Native Diabetes Wellness Program $ 1.0 million

Portland Area Tribe's Recommendation:

Portland Area Tribes do not support maintaining the current distribution of SDPI funding in FY 2015 and beyond. As discussed above in Item #1, Portland Tribes recommend that the Community Directed and Special Demonstration Programs and associated funding be combined into one program. Portland Area Tribes continue to support their general position—with slight modifications—on the SDPI distribution communicated in their February 21, 2011 letter to the IHS Director. Portland Area Tribes recommendations are summarized as follows:

A. Competitive Set-aside:

i. We recommend that funding and time be allowed for current Special Demonstration grantees to phase in existing staff into their Community Directed Programs. We suggest transition funding for a period of one year.
ii. Portland Tribes recommend combining 90 percent of the set-aside from the Special Demonstration ($27.8 million) into the Community Directed grant pool. The remaining 10 percent should be made available to the twelve IHS Areas to translate the findings and best practices of the Special Demonstration initiative into the Community Directed Programs.
iii. If the two programs cannot be combined, then Portland Area Tribes recommend a new round of competition for in the Special Demonstration Program be conducted. Other Tribes want to be able to benefit from the same opportunity that the Special Demonstration grantees have been provided. This is fair and just for other tribal communities.

B. Administrative Set-aside:

We recommend decreasing the administrative set-aside from $4.1 million to $3 million due to a reduction in the administrative costs.

Discussion on recommendation: Portland Tribes support funding an appropriate level for the administrative requirements of carrying out the SDPI, however do not support funding the current level of set-aside amount. Our justification is that if the Special Demonstration and Community Directed Programs are combined into one program as we discuss above, than the workload and level of administrative requirements will be greatly reduced. This cost savings should be returned to the Program and made available to Tribes.

C. Data Set-aside:

Portland Tribes recommend that the data set-aside be discontinued and the $5.2 million be provided to the Community Directed Program.

Discussion on recommendation: The IHS has received in excess of $40 million for the data set-aside since the SDPI was reauthorized in FY 2003 with very little accounting to the TLDC or Tribes about how the funds benefited the diabetes clinical tracking system. During the past four Tribal consultations on the SDPI, Indian Country has been divided on recommendations to continue support for the data set-aside. The Portland Area's position on this issue is that costs associated with information technology are a residual function and the responsibility of the IHS or Tribes if they have taken their shares. Portland Tribes are concerned that a preponderance of SDPI data funds has enhanced information technology at direct federal sites with little funding provided to Title I contracting or Title V compacting Tribes. The IHS also received a sizeable investment in IT funding with the $85 million provided in the American Recovery and Reinvestment Act (ARRA) that also benefited the clinical data system. Portland Area Tribes do not believe that the benefits of funding the data set-aside have been mutually beneficial for all Tribes nationally and that it should be discontinued.

D. Urban Set-aside:

Portland Tribes support and recommend the continuance of a 5 percent set-aside (currently $7.5 million) to fund diabetes grants for the 34 Urban Indian Health Programs.

E. Native Diabetes Wellness Program:

Portland Tribes do not support the $1 million set-aide for the CDC Native Diabetes Wellness Program and recommend returning this set-aside to the Community-Directed and Special Demonstration Programs.

3. **Use of more recent user population and diabetes prevalence data:** The last time the SDPI national funding formula was changed was in 2003. Based on recommendations from Tribal consultation, the following national funding formula was used to determine allocation to each IHS Area for the Community-directed grant program:

   - User Population = 30%
   - Tribal Size Adjustment (TSA) = 12.5% (adjustment given for small tribes)
   - Disease Burden = 57.5% (diabetes prevalence)

   Since that time, user population and diabetes prevalence data from 2003 have been used in the national funding formula. Should more recent user population and diabetes prevalence data be used in the national funding formula?

   Portland Area Tribe's Recommendation:

Formula Component	Current Weight	New Recommended Weight
User Population	30.0%	37.5%
Tribal Size Adjustment	12.5%	12.5%
Disease Burden	57.5%	50.0%
	100%	100%

a. Recommend increasing the weighting on the user population criteria from 30 percent to 37.5 percent.

   Discussion on recommendation: Portland Tribes recommendations are intended to provide guidance to improve this very important program. The recommendations to change the formula components are based on the principle that the SDPI funds should provide the greatest opportunity to reduce the burden of diabetes for all AI/AN people served by Tribal programs. It is likely that our recommendations will result in less overall funding for the Portland Area, however Portland Tribes believe it is the appropriate thing to do for Indian Country. Our recommendations would enhance the ability of small and disadvantaged Tribes with additional funds to address diabetes issues in their communities. Since Congress has directed that no grant program be funded at less than its FY 2003 level, the best approach for changing this component of the formula would be to add a "hold-harmless" component to the formula to ensure that Tribes are funded at their current levels. The hold-harmless component could be financed by reducing the data, administrative, and Native Diabetes Program set-asides.

b. Recommend decreasing the disease burden criteria from 57.5 percent down to 50 percent.

   Discussion on recommendation: Our recommendations to put a greater weight on user population and reduce the weighting for disease burden is due to the fact that the data shows that allocating a

greater percentage of funds on diabetes prevalence has not translated to a reduction in diabetes since 1997. In fact, the prevalence of diabetes has gone up in all twelve of the IHS Areas. The continued weighting on diabetes data is not justified by the data. It is also important to shift this weighting to user population because Tribes are expected to provide diabetes education and prevention activities with all of the users in their patient population. If weighting the formula on disease burden has not resulted in a positive change than it should be changed to provide additional resources to serve a greater number of users.

c. Recommend using only current Active User Population for calculating diabetes burden; we do not support using Service Population in the disease burden nor in other calculations related to SDPI funding allocations.

4. Structure and activities of the SDPI Grant Programs: Should there be any changes in the SDPI Community-Directed grant program? If so, what changes do Tribes recommend? What do Tribes recommend for the Diabetes Prevention and Healthy Heart Initiatives?

(See recommendations discussed under Items #1 and #2)

5. Opportunity for Tribes not currently funded by SDPI: Should Tribes not currently funded by SDPI be allowed to apply with the next competitive application? This includes Tribes who have received federal recognition since 1998.

NPAIHB Recommendations:

a. Portland Tribes support allowing tribes not currently funded by the SDPI to be eligible and compete for diabetes funding.

Discussion on recommendation: The intent of Congress in reauthorizing the SDPI in FY 2003 was clearly intended to provide resources for all Tribes to target diabetes specific interventions throughout the Indian health system. Representative Nethercutt's letter explained, "as with all federal funding provided for very specific initiatives such as this program, any tribes or organizations that are having difficulty meeting the diabetes objectives outlined in the legislative history accompanying the funding, should be assisted by IHS..." [Emphasis added]. The Congressional intent reflected in Representative Nethercutt's letter makes clear that Congress intended all federally recognized Tribes to participate in the SDPI whether they are new or existing programs.

b. Funding for new Tribes should come out of the national SDPI pool and not out of the Area level pool.

Consistent with the Congressional appropriations process and IHS policy for new Tribes funding, the funding for any new tribes coming online for the SDPI should be taken out of the national

apportionment. In FY 2003, the Portland Area had one new Tribe come into the SDPI program. The funding for the new Tribe was taken out the Portland Area allocation and not the national apportionment. Portland Area Tribes further recommend that the Portland Area allocation of SDPI funds for the new Portland Tribe coming online in FY 2003 be restored out of the national apportionment if it is decided to fund new Tribes out of the national apportionment. It is not fair to Portland Area Tribes to have had their SDPI allocation reduced in order to phase in funding for the new Portland Tribe if the Agency decides to do this out of the national pool.

I want to thank you for the opportunity to provide comment and our recommendations on the SDPI programs. If you should have any questions about our recommendations, please contact Jim Roberts, Policy Analyst, at (503) 228-4185 or email at jroberts@npaihb.org.

Sincerely,

Andy Joseph, Jr., NPAIHB Chair
Colville Tribal Council Member

cc: Portland Area Tribal Chairs
Portland Area Tribal Health Directors
Portland Area SDPI grantees
Dean Seyler, IHS-PAO Area Director
Donnie Lee, IHS-PAO Diabetes Consultant
Kerri Lopez, NPAIHB Diabetes Proj

GEORGE R. NETHERCUTT, JR.
5TH DISTRICT, WASHINGTON

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Congress of the United States
House of Representatives
Washington, DC 20515–4705

223 CANNON HOUSE OFFICE BUILDING
WASHINGTON, DC 20515
(202) 225–2006

920 WEST RIVERSIDE, SUITE 594
SPOKANE, WA 99201
(509) 353–2374

9209 EAST MISSION AVENUE, SUITE B
SPOKANE, WA 99206
(509) 924-7775

[illegible] SOUTH PALOUSE
WASHTUCNA, WA 99362
(509) [illegible]-9358

555 SOUTH MAIN STREET, SUITE C
COLFAX, WA 99114
(509) 397-3481

www.house.gov/nethercutt (web)
www.house.gov/nethercutt/contact (e-mail)

February 10, 2003

The Honorable Charles W. Grim
Interim Director
Indian Health Service
The Reyes Building
801 Thompson Avenue, Ste. 400
Rockville, MD 20852-1627

Dear Dr. Grim:

Congratulations on conducting successful diabetes programs during the first five years of the Special Diabetes Program for Indians. When I worked with others in Congress to establish this program, our goal was to address the tremendous need for diabetes treatment throughout Indian County and to begin prevention activities. I am proud that these initial goals have been largely met.

It is very troubling to me that we have not yet begun to slow the increasing rate of diabetes among American Indians and Alaska Natives. For this reason, I fought hard last year not only to continue the Special Diabetes Program, but also to increase the funding so that we may target the areas of greatest need. I discussed this need not only with my colleagues, but also with Secretary Thompson and the White House. Another generation of Native children must not be permitted to develop diabetes at even greater rates than today!

I am writing this letter to address the Congressional intent of the additional funds that will be made available through the Special Diabetes Program for fiscal years 2004-2008. I am aware that many tribes and organizations have established effective diabetes programs. These programs should not be dismantled or reduced in funding. Therefore, I urge you to ensure that existing effective programs continue to operate at their current levels of funding. As with all federal funding provided for very specific initiatives such as this program, any tribes or organizations that are having difficulty meeting the diabetes objectives outlined in the legislative history accompanying the funding, should be assisted by IHS to use the money as designed, or else improper or ineffective programs should be terminated.

The increase in funding that will become available beginning in fiscal year 2004 should be used to target specific interventions in a competitive manner throughout the Indian health system. This will both treat the greatest need, and encourage the best treatment and prevention activities throughout our system.

First, IHS must strengthen its national clinical data system so that data from programs may be tracked comprehensively and outcomes reported with confidence. While IHS has made strides over the past five years, more needs to be done. IHS should be able to answer questions of program effectiveness and outcomes based on solid, statistically accurate and timely data. Good data is essential to measuring program effectiveness and ultimately the success of the diabetes effort in Indian communities. In order to ensure a solid course for future program efforts and for me to convince my colleagues that the funding is being spent well, we need to know what works and what does not work with various program strategies, and revise our approaches accordingly.

Second, IHS should use the additional funds to support key activities for people with diabetes and for people who are at risk for diabetes. To that end, these funds should be used for two targeted activities conducted through competitive grant mechanisms as follows: 1) IHS should design a competitive grant program to address the most compelling diabetes complication(s) in American Indians and Alaska Natives and 2) IHS should design a competitive grant program to address primary prevention of diabetes in American Indians and Alaska Natives that uses the latest scientific findings on this subject. These competitively awarded projects should demonstrate new approaches to dealing with diabetes and related health complications.

I look forward to working closely with you to ensure the success of this critically important program.

Cordially,

George R. Nethercutt, Jr.

GEORGE R. NETHERCUTT, JR.
Representative in Congress

GRN/kvp