



USET

SOVEREIGNTY PROTECTION FUND

Nashville TN Office
711 Stewarts Ferry Pike, Ste. 100
Nashville TN 37214
P: (615) 872-7900
F: (615) 872-7417

Washington DC Office
400 North Capitol St., Ste. 585
Washington DC 20001
P: (202) 624-3550
F: (202) 393-5218

USET SPF Testimony for the Record of the Senate Committee on Indian Affairs Oversight Hearing, "Native Youth: Promoting Diabetes Prevention through Healthy Living"

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United South and Eastern Tribes Sovereignty Protection Fund (USET SPF) is pleased to provide the Senate Committee on Indian Affairs (SCIA) with testimony for the record of its March 29th oversight hearing, "Native Youth: Promoting Diabetes Prevention Through Healthy Living." USET SPF appreciates the SCIA for making the reauthorization of the Special Diabetes Program for Indians (SDPI) a priority for this Congress. The SDPI program has made inroads in diabetes care and prevention in Indian Country, including in the development of youth education and prevention initiatives. The program must be reauthorized this Fiscal Year.

USET SPF is a non-profit, inter-tribal organization representing 26 federally recognized Tribal Nations from Texas across to Florida and up to Maine.¹ USET SPF is dedicated to enhancing the development of federally recognized Indian Tribal Nations, to improving the capabilities of Tribal governments, and assisting USET SPF Member Tribal Nations in dealing effectively with public policy issues and in serving the broad needs of Indian people. This includes advocating for the full exercise of inherent Tribal sovereignty.

Special Diabetes Program for Indians (SDPI) and Diabetes Prevention Programs

In response to the disproportionately high rate of type 2 diabetes in American Indians and Alaska Native (AI/AN) communities, Congress passed the Balanced Budget Act in 1997 establishing the SDPI as a grant program for the prevention and treatment of diabetes at a funding level of \$30 million per year for five years. After extensive Tribal consultation, the Indian Health Service (IHS) distributed the funding to over 300 IHS, Tribal and Urban AI/AN health programs. In 2001, Congress increased the amount of SDPI funding to \$100 million per year, and then again increased it to \$150 million per year from 2004-2010, which was then extended for an additional 3 years through Fiscal Year (FY) 2013. Since FY 2013, SDPI had been extended in one year increments, however, the most recent extension as a part of the 'Doc Fix' legislation in June of 2015, authorized two additional years at \$150 million/year through September 30, 2017. With SDPI set to expire this year, it is critical that this Congress prioritize its reauthorization.

In the Indian Health Service (IHS) Nashville Area, the prevalence rate of diabetes is 23%, which is 3.6 times higher than the U.S. all races age-adjusted rate of 6.4%. Rates can be even higher in individual USET SPF states, like Louisiana and Mississippi, where prevalence rates for our member Tribal Nations are at 29.5%

¹ USET SPF member Tribal Nations include: Alabama-Coushatta Tribe of Texas (TX), Aroostook Band of Micmac Indians (ME), Catawba Indian Nation (SC), Cayuga Nation (NY), Chitimacha Tribe of Louisiana (LA), Coushatta Tribe of Louisiana (LA), Eastern Band of Cherokee Indians (NC), Houlton Band of Maliseet Indians (ME), Jena Band of Choctaw Indians (LA), Mashantucket Pequot Indian Tribe (CT), Mashpee Wampanoag Tribe (MA), Miccosukee Tribe of Indians of Florida (FL), Mississippi Band of Choctaw Indians (MS), Mohegan Tribe of Indians of Connecticut (CT), Narragansett Indian Tribe (RI), Oneida Indian Nation (NY), Passamaquoddy Tribe at Indian Township (ME), Passamaquoddy Tribe at Pleasant Point (ME), Penobscot Indian Nation (ME), Poarch Band of Creek Indians (AL), Saint Regis Mohawk Tribe (NY), Seminole Tribe of Florida (FL), Seneca Nation of Indians (NY), Shinnecock Indian Nation (NY), Tunica-Biloxi Tribe of Louisiana (LA), and the Wampanoag Tribe of Gay Head (Aquinnah) (MA).

and 36.7%, respectively. Despite the severity of the epidemic, Tribal Nations have implemented successful and culturally relevant diabetes prevention and treatment activities through the SDPI grant program.

USET² has been an SDPI grantee since its inception, and is unique in that it applies for the SDPI grant on behalf of 20 of its member Tribal Nations as the primary grantee. USET then enters into subcontract agreements with participating Tribal Nations for local program implementation. Our member Tribal Nations continue to feel this is the easiest and best grant option for them, as many are small communities with limited staffing and resources to write a grant of this magnitude. USET's administration of grant dollars allows local level staff to focus on the prevention, care, and treatment of diabetes within their communities.

Through SDPI and its Diabetes Prevention Program (DP, a program piloted as part of the larger SDPI), Tribal Nations have built significant infrastructure to address the health needs of their pre-diabetic and diabetic citizens. This includes diabetes specific health providers, regular testing and monitoring, nutritionists, fitness programs, and patient education. In addition to avoiding the more costly consequences of diabetes, like End Stage Renal Disease and limb amputations, among the diabetic population, Tribal SDPI programs have successfully prevented the disease among at-risk groups. In fact, after steadily increasing over the preceding two decades, between 2000 and 2011, incidence rates of ESRD in AI/AN people with diabetes decreased 43 percent—more than for any other racial group in the U.S.³

In 2004, through the SDPI program, IHS piloted the DP program to implement lifestyle interventions, which were found effective through clinical trials in the National Institutes of Health-led clinical trial on diabetes prevention throughout the federal system. By May 2014, approximately 4,549 high-risk AI/AN participants completed program courses on healthy lifestyle interventions. Among those that completed the program, 87% of participants ate healthy foods once or more per week versus the pre-intervention baseline of 77% and 53% engaged regularly in physical activity compared to 30% pre-intervention. IHS estimates that the incidence rate of diabetes for participants in the SDPI DP was 6.5% compared to the 11% for the NIH Placebo group. The lower rates of diabetes incidence show the efficacy of SDPI DP interventions and the success of diabetes prevention infrastructure in Indian Country.

Challenges with Diabetes Prevention Program Certifications

Although we acknowledge the importance of evidence-based Diabetes Prevention Programs (DPP) through the Centers for Disease Control and Prevention (CDC), we do not believe this is the only approach for Indian Country in administering quality prevention programs. This is because many USET SPF member Tribal Nations do not have the capacity to meet the strict eligibility criteria and program requirements. USET SPF is currently aware of at least one Tribal Nation health program with CDC DPP certification at risk of losing its certification due to on-going challenges with recruitment of patients meeting the eligibility criteria, as well as overly narrow quality and reimbursement indicators. These indicators have unrealistic target thresholds and should be subject to individual targets that better meet the health objectives of a particular program. Additionally, the current criteria omits indicators on behavioral change, which are important for measuring the success of these lifestyle interventions. Indicators should include behavioral change measures related to diet

² USET, or United South and Eastern Tribes, is the 501(c)3 sister organization to USET SPF, which is a 501(c)4. USET provides programmatic and technical support to our 26 member Tribal Nations.

³ IHS SDPI 2014 Report to Congress.

and exercise, which are major factors in diabetes prevention and were proven effective through the SDPI DP pilot. In order for our Tribal Nations to continue programming with CDC DPP certification, these flexibilities are necessary to account for the unique circumstances and challenges of diabetes prevention work in Indian Country.

Similar challenges exist for our smaller member Tribal Nations which operate SDPI programs and may wish to seek CDC DPP certification in the future. Under the current criteria, many USET SPF member Tribal Nations would be precluded from participation due to a lack of capacity, staffing shortages, and small populations of patients meeting patient eligibility criteria. Many of these Nations do not have the staffing bandwidth to undertake the administrative burdens of applying for CDC DPP or American Diabetes Association recognition.

SDPI Advancements

Like other Tribal Nations across the country, USET SPF Tribal Nations suffer disproportionately from a variety of health issues, leading oftentimes to a severely reduced quality of life and life span. AI/ANs suffer from obesity, hypertension, heart disease, and diabetes at rates much higher than the general U.S. population. Data shows that AI/ANs have the highest rates of diabetes in the U.S. and are more than twice as likely as white adults to have diabetes. IHS' SDPI grant program is beginning to turn these statistics around. Recent data shows that through SDPI, USET Tribal Nations have made significant progress. Between 2013 and 2015, USET Tribal Nations increased the percentage of:

- Healthy blood sugar in our diabetes patients from 45% to 49%;
- Normal blood pressure from 60% to 62%; and
- The rate of annual eye exams from 45% to 55% .

Through collaborations, best practices, and prevention initiatives resulting from SDPI, our Tribal Nations are making strides. Nashville Area AI/ANs are living longer with diabetes, with increased access to specialty care and better control of the disease, all due to this essential program.

For example, the Passamaquoddy Tribe of Maine (USET SDPI sub contractor) is working in partnership with the University of Maine's Cooperative Extension Program and the Pleasant Point Health Center SDPI Program collaborated on two community programs, the first being a 4-week program called Dining with Diabetes Down East. The program was adapted to include information specific to the Passamaquoddy community, culturally specific foods, and some use of the Passamaquoddy language. Each session included a presentation, cooking demonstrations, and facilitated discussion. An overview of the Diabetes "ABCs" (A1C, Blood Pressure and Cholesterol) was presented during the first session and the other sessions covered other aspects of diabetes prevention. The program gave many participants a new outlook on traditional foods and culture within their communities, while developing healthy habits for long-term prevention.

The second program was teaching the Diabetes Education in Tribal Schools (DETS) curriculum to pre-school, kindergarten, first, and second grade students from October 2015 – March 2016. The children and teachers learned about more and less healthy foods and activities; and about diabetes. One of the last classes involved bringing in a community member with diabetes so that the students could ask them questions about the disease. The success of the program is due to the collaborative effort between the teachers, students, Pleasant Point Health Center SDPI program and the University of Maine Cooperative Extension. These collaborations are only some of the impacts that SDPI has had on Tribal communities, including youth.

Because there is Strength in Unity

Native Youth: Obesity and Diabetes Rates

The impacts of obesity and diabetes on Native youth are troubling. In the IHS Nashville Area, Tribal Nations have been able to maintain the low rates of diabetes for youth under 20 years of age (accounting for less than 1% of the total diabetes population) within our communities. However, many USET SPF Tribal Nation battle high youth obesity rates, with over half of the youth between the ages of 2 and 5 years falling into the obese body mass index ranges. Some initiatives that USET SPF Tribal Nations are utilizing through SDPI to decrease these rates are:

- Teaching the DETS curriculum in schools or after school programs;
- Making healthy food choices available and fun/interesting to Native youth;
- Learning about traditional Tribal Nation foods and incorporating them into diets;
- Providing healthier foods in vending machines;
- Providing healthy cooking and/or snack preparation classes for kids; and
- Limiting fast food meals for kids and providing quick, easy, healthy options for families on the go.

SDPI plays an important role in ensuring USET SPF Tribal Nations are able to reduce high rates of obesity among our youth. These types of interventions reduce the incidence of risk factors for diabetes, such as obesity, providing long-term health benefits.

Access to Healthy Food and Fresh Vegetables

Tribal Nations are located in some of the most rural and impoverished communities, lacking overall access to health care and healthy food options. Limited access to healthier foods, such as fresh vegetables, is often times a barrier to maintaining a healthy diet. USET SPF member Tribal Nations vary in their ability access to healthier food options, but through SDPI, all are utilizing methods to increase traditional foods and healthier options available to Tribal communities. SDPI has allowed for community and school gardens, providing access to healthier and fresh foods, while encouraging physical activity. Tribal Nations are incorporating traditional foods and language into these gardens as a means to maintaining community and youth cultural knowledge and the foods our ancestors consumed.

Reauthorize SDPI

Despite its documented success, funding for SDPI has been flat since 2004, even as inflation and medical costs rise. Tribal Nations and Congress have made significant investments in preventing and managing diabetes. In order to continue making progress in the fight against the disease in Indian Country, SDPI must be reauthorized this Fiscal Year to avoid the loss of Tribal programs, prevention, and progress. Any lapse in reauthorization will cause the costs of diabetes and its complications to increase again for Tribal communities, and precious jobs created by this program will cease. USET SPF is urging Congress to reauthorize the SDPI for multiple years at no less \$150 million/year, with incremental increases each year based on medical inflation rates. Congress must not allow this successful investment to lapse, just as its effects are being realized in the form of strong data and widespread lifestyle changes. Timely reauthorization will ensure that Tribal Nations can continue the fight against this epidemic without interruption.

Conclusion

USET SPF appreciates the opportunity to provide comments following the SCIA hearing on Native Youth:

Because there is Strength in Unity

Promoting Diabetes Prevention through Healthy Living. Over the past 19 years, Indian Country has been leading the fight against the diabetes epidemic, and assisting patients and communities affected by the disease. Congress and IHS, along with Tribal Nations, recognize the importance and effectiveness of SDPI interventions in improving and maintaining the health of Tribal communities. USET SPF urges this Congress to reauthorize SDPI before it expires on September 30, 2017, and looks forward to working with the Committee on advancing this vital legislation.

Should you have any questions or require additional information, please do not hesitate to contact Ms. Liz Malerba, USET SPF Director of Policy and Legislative Affairs, at (202) 624-3550 or by e-mail at lmalerba@usetinc.org.