National Indian Health Board

January 9, 2019

Ms. Elyse Greenwald
SAMSHA Desk Officer
Office of Information and Regulatory Affairs
Office of Management and Budget
New Executive Office Building, Room 10102
Washington, DC 20503
Via Email: OIRA_Submission@omb.eop.gov

Re: State Opioid Response (SOR) and Tribal Opioid Response (TOR) Program Data Collection and Performance Measurement—NEW

Dear Ms. Greenwald:

On behalf of the National Indian Health Board (NIHB), I submit these written comments responding to the notice State Opioid Response (SOR) and Tribal Opioid Response (TOR) Program Data Collection and Performance Measurements in response to the Substance Abuse and Mental Health Services Administration (SAMSHA) agency information collection request, dated December 10, 2018.

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 also rely on IHS for delivery of some, or even most, of their health care, the NIHB is their advocate.

Background

American Indian/Alaska Native (AI/AN) communities experience disparities in many health outcomes[1] including overdose deaths.[2] In 2015, AI/ANs had the highest drug overdose death rates

[1] Indian Health Service. *Indian Health Disparities* (2017), https://www.ihs.gov/newsroom/factsheets/disparities/.
[2] Mack KA, Jones CM, Ballesteros MF. *Illicit Drug Use, Illicit Drug Use Disorders, and Drug Overdose Deaths in Metropolitan and Nonmetropolitan Areas - United States*. MMWR Surveill Summ 2017;66(No. SS-19):1–12. DOI: http://dx.doi.org/10.15585/mmwr.ss6619a1.

and the largest percentage increase in the number of deaths over time.[3] For example, Minnesota's overall drug overdose mortality rates for AI/ANs were 64.6 per 100,000 population in 2016 and in Oregon, opioid-related overdose rates for AI/AN were 12.4 per 100,000 population in between 2011-2015.[4] The opioid pain reliever-related overdose death rate for AI/ANs was 22.1 per 100,000 population in 2015[5]. In 2010, the opioid overdose death rate among AI/AN women was 7.3 per 100,000 population, compared with a rate of 5.7 among white women and 4.2 among all U.S. women.[6]

Additionally, national trends documenting this disparity appear to be consistent regionally, by IHS Areas and states where AI/AN-specific data are available. Limited access to specialized health care services contributes to and exacerbates existing disparities in nonfatal and fatal opioid overdose among AI/ANs. Tribal communities are often located far from urban facilities where various specialized health services for opioid addiction treatment are available. In 2014, for example, there were only eight Tribal health facilities with Medication-assisted treatment (MAT)/Office-based Opioid Agonist Treatment (OBOT) services, and six Tribal programs with MAT/OBOT policies and procedures.

The SAMHSA TOR grant program aims to address the opioid crisis in Tribal communities by increasing access to culturally appropriate and evidence-based treatment, including MAT, using one of three medications approved by the Food and Drug Administration (FDA) for the treatment of opioid use disorder (OUD). The intent is to reduce unmet treatment need and opioid overdose-related deaths through prevention, treatment, and rehabilitation for OUD.

General Comments and Recommendations

According to SAMHSA, all funded states/territories and Tribal entities will be required to collect and report client-level data on individuals who are receiving opioid treatment services to ensure TOR program goals and objectives are being met. According to the Request for Information (RFI), client-level data will include information such as: demographic information, services planned/received, mental health/substance use disorder diagnoses, medical status, employment status, substance use, legal status, and psychiatric status/symptoms. Client-level data will be collected at the time of intake, three months post intake, six months post intake, and at discharge.

In order for Tribes to submit client-level data, grantees utilize a GPRA tool to gather client-level data. Within the GPRA tool, there is a link to a tool to reference as an example. However, additional effort is needed on the part of the grantee in order to find this reference tool. It was not clear in the Notice of Funding Opportunity (NOFO) the level of invasive questions being asked which are not immediately relevant to the goal of the TOR, which is to implement systems for treatment of Opioid Use Disorder (OUD) by using one of the three FDA-approved medications.

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[3] *Id*.

[4] National Indian Health Board. *Indian Specific Data on Opioids and Drug Overdose and Induced Deaths* (December 2018).

[5] Mack KA, Jones CM, Ballesteros MF. *Illicit Drug Use, Illicit Drug Use Disorders, and Drug Overdose Deaths in Metropolitan and Nonmetropolitan Areas - United States*. MMWR Surveill Summ 2017;66(No. SS-19):1–12. DOI: http://dx.doi.org/10.15585/mmwr.ss6619a1.

[6] Warner M, Chen LH, Makuc DM, Anderson RN, Miniño AM. *Drug poisoning deaths in the United States, 1980 - 2008*. Hyattsville, MD: National Center for Health Statistics (2011).

Further, the NOFO stated that it was desirable that grantees achieve an 80% response rate at each interval and it was not clear how that measure was interpreted. For example, some Tribes interpreted this as being the measure of only those clients reaching the milestone rather than *all* clients, regardless of status. This interpretation assumes clients start but not complete a program, which means that those clients would be not be surveyed within subsequent milestones.

Tribal grantees also had a difficult time surmising where in the application reporting requirements were explicitly listed or if SAMSHA would impose alternative requirements after the grants were awarded. For Tribal grantees, although timeframes were clear, it took successive efforts to locate the reference link at all, and additional effort to understand that it was to be used as an interactive tool rather than a supplemental aid.

With respect to client-level reporting data, Tribes feel that the document is invasive when it comes to requests for clients' personal information, thereby distorting the overall effectiveness of the program. Some Tribal members' felt that the requirement to divulge unnecessarily personal information acted as a barrier to their treatment. For instance, some Tribal grantees felt the reporting requirements over-emphasized alcohol-related illness, deterring grantees' reportage of opioid issues, which is the focus of the project. Another concern was the inability to leave an answer to certain invasive questions blank, where the application required a response in order to proceed to the next section. Clients felt genuinely uncomfortable with this process, and forced to provide otherwise confidential personal information. A more fluid, up-to-date question and answer format would be ideal - both for client autonomy in the data collection process, and to fulfill grant protocols. As well, based on practices for Medication Assisted Treatment (MAT) services, some Tribes mentioned that they need to get clients stabilized, which means data is collected "after-the-fact". The application should include a section for users to input the "after-the-fact" data.

The SAMHSA Center for Substance Abuse Treatment (CSAT) anticipates that the time required to collect and report the grantee-level data is approximately 10 minutes per response, and the time required to collect and report the client- level data is approximately 47 minutes per response. CSAT's estimate of the burden associated with the client-level instrument includes an adjustment for data elements that are currently being collected by entities that are likely to be funded by the SOR/TOR grant programs. On-the-ground Tribal evaluators have estimated the burden of client-level data collection to be much higher due to difficulty in locating individuals (lack of phone or permanent address). Provider-level burden to complete these surveys is unrealistic and will take away from direct medical care services in an already over-burdened Indian Health Service/Tribal Health/Urban Indian-health (I/T/U) system.

Moreover, a substantial number of TOR grantees in Indian Country are small Tribal clinics with limited staff capacity to collect extensive information. Grant recipients in Indian Country are grateful for the funding provided in the TOR and SOR opportunities; however, there was no specific funding added for Tribes to include an FTE dedicated to the proposed data collection and reporting requirements. Also, not all TOR Grantees will be developing a MAT program with these grant funds. Tribes are concerned that the creation of a completely new set of measures that leads to additional requirements will deter Tribes from providing MAT treatment services or applying for future SAMHSA TOR grant opportunities.

Conclusion

We thank you for this opportunity to provide comments and recommendations on the GPRA reporting requirements for TOR and SOR grantees. We look forward to further engagement with SAMHSA to meet critical opioid overdose challenges in Tribal communities.

Please contact NIHB's Director of Policy, Devin Delrow, at ddelrow@nihb.org for any additional information.

Sincerely,

Victoria Kitcheyan

Victoria Kitcheyan, Acting Chairperson
National Indian Health Board