



## Policy and Resource Roundtable:

### Strengthening Mental Health Data & Interventions for Native American Youth

*September 15, 2017*

10:30am - 1:30pm

#### KEY MEETING HIGHLIGHTS

- Suicide is the second leading cause of death for Native American youth between the ages of 10 - 24.
- In order to effectively advocate for improving mental health among Native American youth, we must have more accurate and comprehensive data on tribal communities. Without this data it is extraordinarily difficult to advocate on behalf of tribal communities on Capitol Hill.
- It is imperative that tribal governments retain sovereignty over data being collected on their citizens. It is incumbent upon researchers to consult with tribes when conducting research on their tribal citizens.
- The opioid epidemic has a wide range of mental health implications and far more needs to be done to research and understand the intersection of opioid abuse and mental health.
- There is a very strong need for improved coordination among those entities that are collecting and sharing data including tribal epi-centers, Indian Health Service, SAMHSA, etc.
- Culturally relevant resources and services are necessary to adequately improve mental health outcomes for Native American youth.

#### CENTER FOR NATIVE AMERICAN YOUTH

- Opening remarks by **Senator Dorgan (ret.)**.
  - There is not enough energy or resources being spent on culturally sensitive data collection, coordination, and analysis in tribal communities.
  - The issue of poor data quality and quantity has beset Native American communities for too long, and we cannot wait for any more deaths before being spurred to action.

- We must act collectively to better this problem, and use good data to better the lives of Native American youth and their families. We cannot remain in our silos.

#### NATIVE YOUTH ADVOCATE: **RORY WHEELER, *SENECA NATION OF INDIANS***

- **Highlights:**

- As an Emergency Medical Technician (EMT) having a good data can greatly increase the efficacy and reach of EMT services.
- There is a need to destigmatize mental health issues on the Seneca Nation, and having good data can help convince community members of the seriousness and scope of mental health maladies.
- It is extraordinarily difficult to adequately lobby one's representatives without having accurate data to back it up. One might be able to convince those in the room that mental health is a grave problem that needs serious attention, however, elected officials express the need for data in order to convince their colleagues.
- The opioid epidemic plaguing the country is hitting tribal communities hard, and there are few resources to explain the connections between substance abuse, mental health disorders, and suicide to service providers. As an EMT, Rory witnesses the connections every day, but lacks the tools and data necessary to treat the root causes of his patient's mental and behavioral health problems; and instead, is only able to treat their visible symptoms.

- **Background on Rory:**

- Rory was raised on the Seneca Nation before moving to a nearby border town.
- Rory serves as a youth health fellow for the National Indian Health Board, and played a leadership role in composing their recent resolution on substance abuse in tribal communities.
- Rory also serves as co-Vice President of the National Congress of American Indians Youth Commission.
- Rory is a volunteer EMT for the Seneca Nation and is currently developing a culturally adapted Adverse Childhood Experience survey for his community. He believes there is a great need for community members to be able to understand how their childhood experiences can linger and deteriorate their mental health.
- There is a high risk for EMTs to burnout due to the emotionally taxing nature of the job. Having better data to help guide service providers like EMTs can significantly help lessen the emotional burdens associated with the job.
- The stigma's surrounding mental health can be so bad that EMTs themselves won't seek out mental health services, and can turn to substance abuse in response to their emotionally exhausting job.

- After witnessing so many harrowing situations on the job, Rory nearly quit, believing the job to be too taxing. However, after taking time for himself to seek mental health services and guidance from his elders, Rory was able to return to work and was awarded EMT of the year in 2016.
- It is imperative that EMT and service providers are given the data and resources necessary to help assist those whom they serve.
- **Native Youth Advocacy:**
  - It is imperative to increase the quality and quantity of the collection, coordination, and analysis of data in tribal communities.
  - Without accurate and well analyzed data it is nearly impossible to make your case to government officials who rely on data to advance legislation and appropriate funds.
  - As a Native youth advocate, Rory does his best to use the scant data that exists and his own personal experience as an EMT to advocate on behalf of Native youth and the Seneca Nation.
  - When such little data exists, one must spend precious time trying to explain why these data deficiencies exist, taking away from one's ability to thoroughly explain the need for improved suicide prevention and mental health services in one's community.
  - As a Native youth advocate, Rory believes it is part of his job to explain the need for culturally appropriate services in tribal communities.

RESEARCH REPRESENTATIVE: **DR. MARY CWIK, JOHNS HOPKINS CENTER FOR AMERICAN INDIAN HEALTH**– ASSOCIATE DIRECTOR

- **Highlights:**
  - High levels of suicide was not an issue in tribal communities until recently.
  - Although in recent years suicide has grown to be a large scale problem for Native Americans writ large, there are important regional and tribal differences in incidents of suicide.
  - When tribes are empowered to collect data on their own citizens the data is more likely to be sensitively collected and yield more accurate results. A prime example of such data collection is conducted by the White Mountain Apache Tribe.
  - Often, Native Americans are racially misclassified in coroners' reports, police records, and other data sources; meaning, the suicide data we have for Native Americans is inaccurate and likely reflects a lower rate of suicide than what truly exists.

- An alarming new trend is the high rate of young parents committing suicide. Between 2001 and 2006, 5% of Native youth who died from suicide had children; whereas from 2007 to 2012, 60% of female Native youth who died from suicide had children, and 42% of male Native youth who died from suicide had children.
- **Suicide Data in Indian Country**
  - No suicide data exists for tribal communities or Native Americans before 1955.
  - Youth suicide among Native Americans is well above that of any other ethnic or racial peer group.
  - When tribes and tribal communities are able to collect data on their own people, the data being collected is more likely to help serve that community's needs.
  - Mixed method studies that collect both qualitative and quantitative data are highly necessary in order to get an accurate understanding of the issues at hand. This means talking to Native youth and hearing their perspective is crucial when collecting data on youth suicide in tribal communities.
  - According to a recent analysis by the Department of Health and Human Services on Youth Risk Behavior Surveillance System, American Indian/Alaska Native (AI/AN) youth are 51% more likely to have made a plan about how they would attempt suicide than their white counterparts.
  - Additionally, the same study indicates that AI/AN youth 125% more likely to have attempted suicide than their white counterparts.
  - The same study also concluded that AI/AN youth are 169% more likely to attempt suicide that results in an injury, poisoning, or overdose requiring treatment by a doctor or nurse.
  - According to a 2003 study, suicide rates for AI/AN youth is much lower on the east coast, the south-west coast, and in the south, as compared to the northern-midwest, pacific northwest, and the southwestern United States.
  - White Mountain Apache youth between the ages of 15 – 24 have a suicide incidence rate 13x that of the US average, and 2x the average of AI/AN overall.
  - Historical trauma can have lasting effects on Native youth and increase their likelihood of attempting suicide. Extreme trauma can impair one's capacity and capabilities as a parent, which can cause adverse effects for both the parents and their children.
  - Mental illness, depression, and PTSD can be genetically transmitted to secondary and subsequent generations.
- **Critical Risk Factors and Protective Factors:**
  - Having one or more adverse childhood experiences is a critical risk factor for Native youth and their likelihood to attempt suicide. 75% of AI/AN have had two adverse childhood experiences, 2x that of the general population.

- Native youth are at an increased risk of attempting suicide if a close friend or relative has attempted or completed suicide. They are at their highest risk of attempting suicide within six months of their friend or relative's suicide or suicide attempt.
- Native youth are also at a higher risk of committing suicide if they use or abuse substances. 68% of Native youth who died by suicide were drunk or high at the time of their death, and 76% of those who attempted suicide were drunk or high when they attempted. During data collection interviews, Native youth have reported that they only think about suicide or self-harm when they're drunk or high.
- Based on the data available, we know that attending school is a protective factor for Native American youth. Specifically, youth who regularly attend school are less likely to binge use substances.
- Additionally, high family function and connectedness act as protective measures for Native American youth. Talking through one's problems and emotional health can help one's mental health, and lessen one's likelihood of attempting suicide.
- The most powerful protective factor against bingeing is having a strong connection with one's indigenous values and ethnic identity.
- Although we know that these are protective factors, more research needs to be conducted on why they are so effective in deterring substance abuse and suicide. Without further research, we will not be able to use these tools to their fullest potential in saving the lives of Native American youth.

TRIBAL REPRESENTATIVE: **DEE SABATTUS, UNITED SOUTH AND EASTERN TRIBES** — DIRECTOR, TRIBAL HEALTH PROGRAM SUPPORT

- **Highlights:**
  - USET's Tribal Epidemiology Center worked with the Johns Hopkins Center for American Indian Health to help them establish their epidemiology center. This is a prime example of a research institution and a tribal organization joining forces to better tribal communities through data collection and health services.
  - USET helps member tribes better understand the needs of their communities and how best to serve them based off of available research.
  - USET is working to destigmatize mental health disorders within their communities, and trying to raise the profile of mental health awareness.
- **Background on USET and USET Programming:**

- The United South and Eastern Tribes, Inc. (USET) is a non-profit inter-tribal organization founded in 1968 to better advocate for the needs of member tribes and their shared interests.
- USET is comprised of 26 federally recognized tribes across 12 states. USET's constituency is highly diverse, with member tribes varying in size, financial stability, and need.
- USET's Tribal Health Program Support has four primary divisions: Dental Support Center; Diabetes Support Center; Tribal Epidemiology Center; and Health Information and Data Portal. These four areas of work help member tribes improve the quality of life for their citizens and provide them with health services.
- Initially, USET knew little about epidemiology and only had a staff of 2 people at their Tribal Epidemiology Center. However, they worked with the Johns Hopkins Center for American Indian Health, who helped them develop their epidemiology center and subsequent programming. Johns Hopkins was a crucial early partner that helped USET create the strong epidemiology center they have today, with a staff of 14.
- Some of the Tribal Epidemiology Center's primary duties are disease surveillance, childhood immunizations, core maternal and child health, and program evaluation. Additionally, USET's Tribal Epidemiology Center is responsible for the development and maintenance of a population health data portal.
- The Tribal Epidemiology Center is also responsible for tribally guided research and providing member tribes with trainings and technical assistance.
- **The Use of Data at USET:**
  - Tribally lead data collection is highly necessary as it provides tribes with an accurate representation of the needs and successes of their communities. USET uses data to better understand their total population through the breakdown of specific populations, including condition specific data. For example, USET uses data to track how many individuals within their member tribes have diabetes, are overweight, or have mental health complications.
  - The Tribal Epidemiology Center spends a great deal of effort compiling and comparing all available data due to the lack of comprehensive data from any single source. Coordinating all of this data proves to be difficult but necessary work when trying to gain a better understanding of what USET member tribes' needs are.
  - USET understands the unparalleled importance of storytelling as part of the data collection process. It is not enough to simply collect numbers when researching

tribal communities, rather, it is necessary to hear directly from those whom they serve to better understand what parts of their programming are successful and why.

- Storytelling is an ancient mode of communication that indigenous peoples have employed for centuries, and should continue using today in furthering their research and data collection efforts.
- Storytelling can help transform data into knowledge, and not simply abstract numbers. For USET, it is crucial to use data to create more awareness on the seriousness of mental health disorders.
- When community members better understand the effects of mental health disorders they can turn such knowledge into *action*.
- There is still a great need to improve available data for mental health disorders affecting Native Americans. Without this data it is not only difficult to properly implement mental health programming, but it is also increasingly difficult to raise the profile of mental health awareness among tribal communities.

FEDERAL GOVERNMENT REPRESENTATIVE: VICTORIA CHAU, **SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION**—ASSOCIATE SCIENTIST, OFFICE OF BEHAVIORAL HEALTH EQUITY.

- **Highlights:**

- Research shows that major depressive episodes and substance abuse can go hand in hand, with the one often exacerbating the other.
- It is very difficult to collect national data on American Indian/Alaska Natives due to their comparatively small size. The Office of Behavioral Health Equity is working to ameliorate this problem, but needs the help of tribal communities and research institutions across the country.
- In order to obtain the most accurate and useful data possible, it is necessary to increase data capacity building for tribes and tribal partners. Research institutions and non-profit organizations have a role to play in bettering the data landscape in tribal communities, but must understand the importance of tribally controlled data.

- **National Research:**

- The National Survey on Drug Use and Health (NSDUH) is one of the largest national studies on behavioral health.

- According to the 2016 NSDUH, 17,000 American Indian youth between the ages of 12 – 17 reported using specialty mental health services, which amounts to 11.9% of the total AI/AN youth surveyed.
- According to the same 2016 study, 11.5% of AI/AN youth between the ages of 12 – 17 experienced a major depressive episode in the past year. This means that over a period of at least 2 weeks, they experienced a depressed mood or loss of interest or pleasure in daily activities and had a majority of specified depression symptoms.
- The same NSDUH study shows that 2.5% of AI/AN youth between the ages of 12 – 17 had cooccurring substance abuse disorders and major depressive episodes.
- According to available data, suicide is the second leading cause of death for AI/AN youth between the ages of 10 – 24, with the primary mode of suicide being suffocation.
- **Issues in Collecting Data:**
  - AI/AN are not always included in data collection, and when they are included they represent a small sample size, leading to issues of accuracy and confidentiality.
  - Additionally, it is rare that data on AI/AN can be disaggregated based on tribal affiliation. Even if researchers collected the tribal affiliation of those in their studies, there is an issue of data sovereignty and ensuring that tribes have control over the information being collected on their people.
  - In order to better understand the differing needs of AI/AN throughout the country, it is necessary to disaggregate data based off of urban area, counties, and states.
  - There is a great need to increase data capacity building for tribes and tribal partners.

## OPEN DISCUSSION

- **How does one access tribally controlled data?**
  - If one wishes to gain access to tribally controlled data they must reach out to the tribe directly requesting the data, explaining how it will be used and why. It is imperative that tribal nations retain sovereignty over the data being collected on their citizens, and researchers must consult with tribe and tribal organizations when collecting, coordinating, and analyzing data on tribal communities.
  - If one wants to disaggregate data on AI/AN by tribal affiliation, one must first get permission to do so from the tribes themselves.
  - The National Institutes of Health is currently preparing a best practices resource guide for those conducting research on AI/AN peoples.



- **Culturally Informed Approaches**
  - If we are to properly address Native American youth suicide we must do so with comprehensive wraparound services that are rooted in culturally informed programming. Native youth deserve services tailored to their tribal background, and should be afforded the ability to have traditional forms of healing like ceremony and sweats.
  - Rory, like many Native American youth, has faced racism and discrimination because of his Native American identity. His culture and ways of being have been denigrated while spending time with his peers in and out of school. Rory believes that these traumatic experiences should be considered Adverse Childhood Experiences. This, he believes, will help service providers identify at risk youth, who they can then help through culturally informed program services.
  - Research indicates that connection to culture and one's ethnic identity can serve as protective factors for Native American youth.
- **Collecting Data on Urban Native Youth**
  - Oftentimes, Native Americans living in urban areas are left out of the conversation surround data collection. Tribes are often largely focused on collecting data on those living on their reservation, while state and county authorities often collect inaccurate data on AI/AN.
  - We must put pressure on state and local authorities to collect more accurate data on AI/AN peoples. AI/AN are often misclassified as belonging to another race or ethnicity, and measures should be taken to curb this unsettling trend.
  - Urban Native communities are growing more invisible and there is minimal funding for urban Indian programming, leaving them further behind.
  - Even when conducting research in urban areas, it is important to get permission from tribal authorities to collect and publish data on their citizens.
- **Other Resources and Projects**
  - [Steps for Conducting Research and Evaluation in Native Communities](#)
  - [Indian Health Service's Zero Suicide Initiative](#)
  - [AI/AN Behavioral Health Briefing Book](#)
  - [USET Tribal Epidemiology Center](#)
  - [Johns Hopkins Center for American Indian Health](#)
  - [SAMHSA Tribal Affairs](#)
  - [National Network to Eliminate Disparities in Mental Health](#)
  - [AI/AN National Behavioral Health Strategic Plan 2011-2015](#)
  - [National Indian Health Board's Behavioral Health program](#)
  - [Indian Health Service's Division of Behavioral Health](#)
  - [Report Shows Dramatic Increase in Suicide Rates in Indian Country](#)