



CENTER FOR NATIVE
AMERICAN YOUTH

AT THE ASPEN INSTITUTE

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Health Innovation & Equity:

*Recommendations from
Native American Youth*

Focus Group Report: A one-year project between the Center for Native American Youth and the Aetna Foundation

Introduction | A Shared Investment

Today, there are 2.1 million Native American youth (under the age of 24) who are stepping into leadership roles to advocate for improved health outcomes, and help raise awareness to community strengths and needs. Health-related issues are often raised as a priority among Native youth, where outcomes in health and wellness represent some of the starkest of disparities and greatest opportunities for investment and positive impact.

Historical trauma, chronically underfunded federal programs, ineffective government laws and policies, and failure to meet trust responsibilities to tribes have all contributed to disproportionately negative health, education, and economic disparities in Indian Country, culminating most egregiously in the fact that Native youth are three to five times more likely to commit suicide than the general population.¹ Though Native youth experience no shortage of challenges to healthy living, they are proving they are among the most resilient in overcoming the hurdles set before them.

“I think we are the future and the voice of our tribal nations. The need for education and healthy minds and bodies is more important than ever.” – Wilton Miwok Rancheria Youth

Founded by former US Senator Byron Dorgan in 2011, the Center for Native American Youth (CNAY) is a national policy program housed at the Aspen Institute. CNAY is dedicated to improving the health, safety, and overall well-being of Native American youth through communication, policy development, and advocacy.

In 2015, CNAY partnered with the Aetna Foundation (Foundation) on a year-long project to engage Native American youth to: (1) better understand current health and wellness priorities; (2) solicit creative ideas from youth to address health disparities; and (3) ensure that health equity for Native youth is a part of the national dialogue. CNAY is a platform for Native American youth to identify and discuss priorities and develop creative solutions, including innovation and technology that helps to bridge health inequities facing Native American people. Thus, the project focused on collecting information about how to better utilize technology and engage youth to address inequities in health and wellness in tribal and urban Indian communities.

Purpose | This report provides qualitative data from focus groups facilitated by CNAY aimed at gathering feedback from Native youth about how to improve health outcomes in Indian Country. In the report, CNAY shares health priorities raised during focus group sessions, as well as ideas and recommendations from Native youth for how innovation and technology can be used to generate solutions to address health disparities.

Native Youth Focus Groups | Throughout 2015, CNAY coordinated and organized 14 focus groups with 230 Native American youth representing more than 70 tribal nations. CNAY staff facilitated the focus groups and recorded qualitative data.

Participants were selected by local programs and schools and represent diverse tribes and geographies – including tribes from the western US region (n=34), Midwestern US region (n=8), southern US region (n=20), and northeastern US region (n=2). Participants were primarily high school (n=128) and college level (n=82) students, with a few middle school students (n=20). Participant information was collected, including name, tribal affiliation, grade level, and contact information. Focus groups followed a basic, informal outline and each lasted approximately one hour. In exchange for participant’s time, CNAY provided resource packets tailored to each region, an invitation to further engage in CNAY’s work, and small gifts (branded bracelets, in pens, brochures, etc.).

14 Focus Groups | 230 Youth | 70+ Tribal Nations

Over the course of the sessions, participants were introduced to the focus group project and examples of health innovation in Indian Country before engaging in an open dialogue to share their unique perspectives, ideas, and recommendations for solutions. CNAY also notified focus group members that a staff member would take detailed notes, which would contribute to a summarized report that respectfully highlights key themes and ideas shared during the Native youth focus groups. Following the focus group, CNAY provided brief summaries with key community stakeholders, as well as a menu of tailored resources for Native youth.

Tribal Nations | *Where Native Communities Stand*

The unique legal and political context of tribal nations is critical to understanding the perspectives and recommendations in this report. Currently, 567 sovereign tribal nations have a formal nation-to-nation relationship with the United States government. These tribal governments are legally defined as “federally recognized tribes,” and are located in 35 states throughout the U.S. Today, tribal governments determine their own governance structures, deliver healthcare, run education systems, and pass and enforce laws through police departments and tribal courts.² The most recent Census identified 5.4 million self-identified American Indians and Alaska Natives living in the United States., 2.2 million of which (roughly 41 percent of the population) are under the age of 24 and recognized by CNAY as “youth.”³

“Indian Nations had always been considered as distinct, independent political communities, retaining their original natural rights, as the undisputed possessors of the soil.” - Chief Justice John Marshall, Supreme Court of the United States

In exchange for ceding their lands and other assets, the U.S. government made legal promises through treaties to tribal nations to provide for their education, health and general welfare. These obligations are collectively known as the Federal Trust Responsibility.⁴ This trust responsibility is a legal obligation under which the U.S. government “has charged itself with moral obligations of the highest responsibility and trust” toward Indian tribes (*Seminole Nation v. United States*, 1942). In practice, the U.S. today provides directly – or indirectly through contracts or compacts to tribal governments – federal resources to operate tribal *healthcare*, education, public housing, *public health*, law enforcement, and other social services. Unlike race-based distinctions, this unique legal and political status of tribal nations must be carefully considered when interpreting these stories of innovation and success, as well as opportunities for development. It also has important implications when considering institutions and systems that can serve as barriers, and solutions, to health innovation in Indian Country.

Native Youth Priorities | *Current Health Landscape in Indian Country*

The perspective of Native youth about the health and wellness priorities facing tribal and urban Indian communities is equally important to their political and legal context. Qualitative data from youth focus group sessions, as well as health-related statistics and data, are further explored throughout the report. The CNAY facilitated conversations with more than 200 Native youth, in 14 focus group sessions, representing more than 70 tribes. Native youth shared surprisingly similar and very consistent concerns about the health and wellness of their friends, families, and communities. In addition, youth consistently attributed their health concerns to a lack of healthcare access and other barriers preventing them, and the ones they love, from obtaining positive health care outcomes. During focus groups, CNAY shared examples of health innovation in Indian Country to promote discussion and identify health and wellness strategies from Native youth perspectives. Themes from these conversations are described in detail below to help illustrate the landscape of Indian Country today.

Innovation | Tribes have a demonstrated ability to serve as innovators and leaders in the health field. For rural tribal communities, tribes are taking the lead in telehealth tools to enhance timely consultation, diagnosis, and treatment.⁵ Tribes are also paving the way in public health and oral health care. For example, tribes have established tribal epidemiology centers to manage public health systems, investigate diseases, manage prevention and control programs, and collect and own tribal health data.⁶ Additionally, tribes are leading efforts to address the oral health crisis in Indian Country and the Swinomish Indian Tribal Community became the first tribe in the lower 48 states to employ a dental therapist to provide basic oral health services to tribal members, following the lead of tribes in Alaska who employed that model over 10 years ago.⁷

These innovative approaches, among others, were shared during focus groups as examples to prompt discussions about health and wellness priorities, as well as idea sharing for recommendations and solutions using technology to address health outcomes in Indian Country.

Mental Health | Disparities in the availability of mental health resources and suicide prevention was a consistent and constant priority expressed during the focus groups with Native youth. In 13 out of the 14 focus groups hosted, Native youth emphasized the importance of increasing community support for those struggling with mental health issues. In ten out of the 14 focus groups, youth highlighted the need for improved facilities and additional providers to meet the needs of individuals living with a mental health illness. Uniquely, in more seven separate sessions Native youth stressed the importance of involving community members – particularly tribal elders – in assisting those afflicted by an imbalance in mental health.

→ Suicide is the second leading cause of death among Native youth age 15 to 24 years old. Native teens experience the highest rates of suicide of any population in the United States – at least 3.5 times higher than the national average.⁸ Alaska has the highest rate of suicide in the country, with 23.0 suicides per 100,000 people, compared with 12.9 suicides for every 100,000 people nationally.⁹ Compared with other racial groups, the rate of suicide among young Native men aged 15-24 is up to four times higher; for young Native women of the same age bracket, the suicide rate is up to 11 times higher.¹⁰

“Healthcare in my community is more focused on the physical than the mental – but sometimes poor *mental health* is at the root of the *physical*.” – Native youth focus group participant

Healthy Lifestyles | Diabetes and obesity were highlighted as urgent issues by Native youth in focus group sessions throughout the project. Native youth discussed the harsh negative impacts “food deserts” and “unhealthy eating options” have on their urban and rural communities. In 64 percent of focus groups, it was clear that participants were extremely cognizant of the negative effects fast foods and processed foods on their bodies and overall health. However, they expressed that in many cases alternative healthier foods are not available. Many Native youth participants were disappointed about their unhealthy available eating options, including in their schools. Participants also raised concerns about the lack of safe spaces to participate in sports and other physical activities in their communities. In nine out of 14 focus group sessions Native youth mentioned a desire for more opportunities to participate in interactive, community-based sports activities.

→ Native American people in the U.S. have the highest rate of Type 2 diabetes with nearly 16 percent of the population effected¹¹. Type 2 diabetes was once considered to be exclusive to adults, but in less than a decade, diabetes prevalence among Native Americans younger than 35 years of age increased by 46 percent. In contrast, diabetes prevalence among the U.S. general population younger than 45 years of age increased by 14 percent.¹²

Substance Abuse | Although Native youth participants identified a spectrum of challenges in their communities, none seemed to be as difficult to characterize and address as substance abuse. Substance abuse is a challenge Native youth witness throughout their communities. Participants identified substance abuse as an issue that affects their peers, and in some instances, their lives at home. During one focus group, a Native youth shared, “sometimes it’s about lifestyle choices - a parent’s substance abuse can lead to bad choices by their children.” On many occasions, Native youth connected substance abuse with absence of opportunity, and in a handful of roundtables, intergenerational trauma.

→ Alcoholism mortality rates are 514 percent higher for Native American populations than in the U.S. general population.¹³ 22.9 percent of Native youth ages 12 and older report alcohol use, 18.4 percent report binge drinking, and 16.0 percent report substance dependence or abuse. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), Native American teenagers, young people, and middle-aged adults have the highest rates of methamphetamine use and associated trauma in the United States. Additionally, some international drug cartels are increasingly targeting Indian Country as a methamphetamine market.¹⁴

Barriers | *Voices of Native Youth*

When prompted to discuss the barriers that stand in the way of “living a healthy life,” Native youth readily identified a handful of major obstacles, including: absence of healthy eating options, distance to health facilities, unemployment, a deficiency of mental health care resources, and the challenge of extending health promotion initiatives to be inclusive of extended families. These perceived challenges are further described in this section to better understand barriers and to explore innovative approaches to negative health outcomes.

Healthy Eating Options | Participants in many of the focus group sessions emphasized the limited availability of healthy eating options as a major barrier to obtaining positive health outcomes. Fast food industries, convenience stores, and on more than one occasion, “fry bread,”¹⁵ was cited as a barrier to improved health outcomes for Native youth and their respective communities. One youth commented, “On the Navajo Reservation a cucumber cost three dollars and a hamburger only costs one dollar. What kind of decisions do you expect people to make?”

“On the Navajo Reservation a cucumber costs *three dollars* and a hamburger only costs *one dollar*. What kind of decisions do you expect people to make?” – *Native youth focus group participant*

Lack of Access | In seven out of 14 focus group sessions Native youth underscored long waits and the lack of transportation as barriers to improved health outcomes. Difficulty in accessing healthcare, gyms, or markets with fresh produce, was consistently cited by Native youth when discussing challenges to healthy living. Long waiting lists for doctors' appointments combined with a lack of adequate transportation were also cited as making it difficult for youth to get the care that they need. Youth participants highlighted the need for improved and increased local health care resources (adequate funding and improved patient to provider ratio) to help address chronic health and wellness priorities in Indian Country. Lack of transportation also prevents youth from traveling to gyms and markets with healthy food options, which results in youth eating less healthy but more convenient foods and not exercising, according to the youth. These challenges continue to contribute to health disparities across Indian Country.

Unemployment | In five of the focus groups, youth participants highlighted unemployment as a serious barrier to attaining positive health outcomes. Without gainful employment, youth explained they would have to rely on IHS for healthcare, which as noted above, is often underfunded. One youth participant described being afraid of graduating high school because there is "too much time – not enough to do...you get bored, especially after you graduate." Native youth discussed the desire to acquire skills that help prepare them for the job market with access to health insurance.

Dearth of Mental Health Resources | In nine out of the 14 focus groups, participants highlighted the need for additional mental health care facilities and professionals dedicated to helping individuals affected by a mental health illness. Focus group participants see mental health and other behavioral health issues as significant barriers to their well-being and that of their peers, noting that suicide and substance abuse are common in their communities. Although both issues persist and have for some time, Native youth feel as though there are not enough resources in their communities to address them in a way that will have a meaningful impact. Focus group participants expressed that a lack of trained professionals in the communities – and at the schools in particular – leave youth without someone to turn to when they are struggling with thoughts of suicide or when they're abusing drugs and alcohol.

Native youth participants were concerned about the lack of support for individuals struggling with mental health issues. In particular, in more than five sessions Native youth stressed the importance of involving the larger community – particularly tribal elders and extended family – in assisting those afflicted by mental health issues. One youth participant emphasized a desire to see "everyone working together as a whole – not just some people – but the whole community."

Health + Technology | *Native Youth Ideas for Solutions*

During focus group conversations, Native youth proposed solutions to address health and wellness barriers – with an emphasis on the use of technology as a medium to promote health and well-being in Indian Country. Focus group participants were encouraged to "think outside the box" and get creative with their suggestions. Themes, ideas, and recommendations captured from focus group sessions with Native youth are further explored in this section.

Research | Lack of Native American-focused research in healthcare and technology emerged frequently during focus group sessions. Participants explained that tribal communities are often excluded from research because of small sample size and lack of trust between tribal communities and non-tribal researchers. Youth participants noted that the lack of research specific to tribal communities ultimately stifles the ability to treat – and prevent – the diseases that do the most harm. Participants noted that studies and research that are community-driven, -owned and -led, could encourage tribes to partner with outside entities and increase research participation of tribal members.

For example, one participant wanted to explore innovative research techniques that address mental health and well-being and went on to discuss biofeedback therapy and how it can be tailored to meet cultural needs, promote relaxation and relieve a number of conditions that are related to stress. Recognizing that there are successful models already in existence, youth recommended and encouraged the use of innovative approaches that are culturally sensitive and adaptable to tribal communities.

Access to Healthy Foods | Unhealthy diets, largely caused by a lack of access to healthy foods and nutrition education, were often cited by focus group participants as barriers to positive health outcomes. Focus group participants talked about food deserts, lack of transportation, and the need for healthier foods for school lunch programs. To help combat those access issues, youth recommended utilizing community gardens to grow fruits and vegetables for use in school cafeterias. Participants also recommended using mobile grocery stores that would travel throughout communities and provide healthy options when fresh produce is difficult to access. They also talked about acquiring and using traditional foods knowledge to grow healthy foods while simultaneously promoting cultural engagement and preservation – a protective factor identified in tribal and urban Indian communities.

Electronic Health Records | During focus groups, participants often raised the issue of long waiting lines at local clinics and hospitals, which many said were caused by lack of providers, and inefficient and slow systems in place. One focus group member recommended that all clinics and hospitals use electronic health records to expedite and improve the process for patients who need to share or transfer health records. Participants went on to say that physicians and other health professionals in Indian Country should be able to access a full, up-to-date health records for each patient, thus enabling them to better diagnose and treat illnesses. The participant suggested that this would ultimately create a faster and more efficient health care delivery system that provides better care for Native patients. However, participants noted challenges with lack of broadband in Indian Country, which continues to slow or hinder technological advancements in tribal communities.



Utilizing Social Media | A brief literature review was conducted in the early stages of the project, and research out of Portland State University conducted a study with results stating that 87 percent of Native youth utilize social networking sites such as Facebook.¹⁶ This data reflects the feedback CNAY received from Native youth participants in roundtable discussions focused on health innovation through social media.

Frequently, focus group participants recommended that health-related programs utilize popular social media platforms (Snapchat, Facebook, Twitter, Instagram, etc.) to communicate programming, events, and opportunities to the community and engage Native youth.

In addition to using social media platforms, participants suggested using various multimedia to reach and exchange resources among Native youth. These ideas include: creating interactive videos and online resource portals, developing mobile-friendly websites, and using audio broadcasts and text message alerts to share health and wellness-related information and tools. Several participants advocated for youth-led outreach efforts, with one participant suggesting youth engagement strategies aimed at designating social media youth ambassadors to help raise awareness within their communities of health-related services, resources and opportunities with their peers.

A major theme for innovative solutions involved the need for online platforms to utilize up-to-date calendars with national, state, and local community events, programs, and opportunities in which youth can get involved. Again, youth recognize the strength of social media as an avenue in which they could create and share health promotion ideas with other Native youth from across the country. Native youth value social media tools as an effective means to connect communities – specifically on issues surrounding health and wellness.

Smart Phone Applications | During many focus group sessions, Native youth participants discussed a broad array of mobile applications they believed would help address health disparities and promote wellness and nutrition in their communities. From expanding physical activity through the use of mobile apps like Nike Plus – a physical activity tracker that could be used in community-wide competitions that get people moving together– to a Native-tailored web-platform to create and celebrate a Native American Heritage Month Snapchat Story that highlights the ways in which indigenous communities across the country incorporate health and wellness into their daily lives, youth are eager to find creative solutions to the health challenges their peers and families face. One Native youth recommended the development of a dynamic smart phone application that would demonstrate culturally-appropriate exercises while simultaneously connecting Native youth with other youth, so they can encourage one another, or even meet up to exercise together. In this way, Native youth are seeking ways to build upon popular technologies to meet the health and wellness needs of their tribal and urban Indian communities.

Specific to mental health, focus group participants recommended creating an application that helps youth recognize the signs of suicide ideation, so that they can recognize when a peer may be having thoughts of suicide, and users can locate local resources and hotlines to share using the mobile application. Another idea was the development of an application that provides information about traditional tribal foods and recipes, which could include organizing foods and recipes by region and tribe. Some participants suggested having the application automatically send a new recipe each week for users to try, and/or trips and “do it yourself” approaches to growing individual or community gardens focused on indigenous harvesting.

Conclusion | *Elevating Native Youth Perspectives*

Too often, when poor outcomes are driven by systemic failures and challenges, they can seem intractable. This is especially true for healthcare in tribal communities. This partnership with the Aetna Foundation took a different approach and leveraged the insightful perspectives of Native youth leaders to innovate, think outside-the-box, and identify new opportunities for improved health outcomes. Additionally, the ideas and recommendations in this report stress the importance of youth engagement—a critical component for success—and one where innovation and technology have an important role to play for Native youth across the country.

Youth participants provided feedback on current approaches that are making an impact on health



outcomes in Indian Country, with an emphasis on addressing prevalent health concerns such as: mental health, diabetes, obesity, oral health, and substance abuse. To help identify opportunities for further health-focused innovations, focus group participants also shared barriers to positive health outcomes that should be considered when developing solutions. These include: a lack of access to healthy foods and food deserts; healthcare inequities and lack of access to health care due to transportation and broadband; a dearth of mental health

resources available; and widespread unemployment, which restricts access to health care, increases stress, and decreases self-worth.

As a direct result of this project, Native American youth who participated in the 14 focus group sessions recommend:

- **An increase in Native American-focused research** in healthcare and technology in partnership with tribal and urban Indian communities;
- Creating opportunities and partnerships to **promote food sovereignty, such as developing and sustaining community gardens** that integrate traditional foods knowledge, and developing healthy foods curricula;
- **A full integration of electronic health records** in clinics and hospitals serving Native American communities;
- **Creating a national and local resource platform** that provides up-to-date resources and information about meetings, events, and opportunities for Native youth to engage and develop leadership skills; and
- **Developing Native youth-specific applications for smart phones** that encourage positive health outcomes through healthy eating and traditional foods, and promote physical activity.

In addition to these recommendations from youth, CNAY observed a need to enhance, promote, and extend resources related to STEM fields (science, technology, engineering, and mathematics) to Native American youth. Ideas shared by focus group participants primarily focused on existing health-related resources and mobile applications. Youth participants did share interest in training opportunities, internships, summer camps, conferences, and hands-on learning that would help inspire STEM-related studies and career pipelines. CNAY believes that STEM-exposure opportunities like these would help inspire further innovative and out-of-the box thinking about technology and health innovation. Further development of STEM opportunities for Native youth is an area in need of strategic focus and attention on a national, state, and tribal level.

Please contact CNAY at the information provided below to learn more about the project and/or the partnership with the Aetna Foundation.



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