

**Supplemental Document to the National Rural Health Association's
American Indian and Alaska Native Health Policy Paper
February 2016**

STATEMENT OF THE ISSUE

BACKGROUND AND JUSTIFICATION

American Indians and Alaska Natives (AI/AN) are enduring persistent disparities in health services, including high uninsured rates, significant barriers to obtaining health services, and continued decline in health status. AI/AN people have long experienced lower health status when compared with other Americans. Lower life expectancy and disproportionate disease burden exist perhaps because of limited educational opportunities, disproportionate poverty, discrimination in the delivery of health services, and cultural differences. The *Constitution*, treaties, executive orders and laws establish the federal government's responsibility to provide certain rights, protections, and health services to AI/ANs as a government to government relationship.

Members of 567 federally recognized American Indian and Alaska Native Tribes and their descendants are eligible for services provided by the Indian Health Service (IHS). The IHS is a federal agency within the Department of Health and Human Services that provides a health service delivery system specifically for AI/ANs. It is important to understand that IHS health services are not a type of "health insurance". The current health service system is commonly referred to as the IHS, tribes and tribal organizations, and urban Indian programs (ITUs). Tribes may choose to receive health services directly from the IHS or through contracting or compacting agreements (P.L. 93-638), or they may combine these options based on their needs and preferences. This system is funded through discretionary yearly appropriations to the IHS. However, chronic underfunding for IHS and other barriers limit access to services for the population. IHS was established in 1955, and has never been funded at the appropriate level of need for health services. Historically, the range of level of need funding fluctuates between 40 percent to 60 percent. Which can be directly attributed to the continued decline in health status of AI/ANs.

Nationally, the ITU system delivers health services in over 670 IHS and Tribal health service facilities scattered throughout 36 states, mostly in rural and isolated areas. IHS directly operates 31 hospital (service units), 52 health centers (clinics), 2 school health centers (clinics), and 31 health stations (satellite clinics). Tribes and Tribal organizations, through Title I contracting and Title V compacting (P.L. 93-638), operate almost 50 percent of the IHS health system. Tribes operate 15 hospitals, 256 health centers, 9 school health centers, and 282 health stations (including 166 Alaska Native village clinics). The IHS, Tribes and Tribal organizations also operate 11 regional youth substance abuse treatment centers. Additionally, the IHS provides funding for Urban Indian health centers in 34 urban areas throughout the country.¹

Some AI/ANs are not officially enrolled in a federally-recognized tribe, some belong to a state-recognized tribe, and others self-identify as AI/ANs but are not enrolled. Tribal

membership has important implications for access to benefits. Members and descendants of members of federally recognized tribes have broader access to certain federal benefits and services. Specifically, enrolled tribal members have specific provisions in the *Patient Protection and Affordable Care Act (ACA)*.

There has been a major population shift of AI/ANs from rural to metropolitan areas in the last decade. Throughout the 1990s to 2005 approximately 50 percent of AI/ANs listed their primary residence as rural areas, primarily reservations or trust lands. As the economic condition worsened there was a considerable number of AI/ANs that were compelled to leave their homes and relocate to urban areas to find employment. Current available data cites that 22 percent live on reservations and 60 percent live in metropolitan areas.²

The National Congress of American Indians (NCAI), Policy Research Center released a revised Geographic & Demographic Profile of Indian Country³ in 2012 using 2010 Census data. The results are listed below:

POPULATION

A Fast Growing Population

- *In the 2010 Census, 5.2 million people or 1.7 percent of the US population identified as AI/AN alone or in combination with other races, an overall increase of 27 percent from the 2000 Census. The overall US population grew about 9.7 percent between 2000 and 2010.*
- *Total AI/AN alone population is: 2.9 million or about 0.9 percent of the US population.*
- *About 32 percent of AI/AN are under the age of 18, compared to only 24% of the total population who are under the age of 18. The median age for AI/AN on reservations is 26, compared to 37 for the entire nation.*
- *The AI/AN population from birth through age 24 makes up 42 percent of the total AI/AN population; whereas the under 25 population for the United States is only 34 percent of the total population.*

Where AI/AN People Live

- *States with the highest proportion of AI/AN people include: Alaska (19.5%), Oklahoma (12.9%), New Mexico (10.7%), South Dakota (10.1%), Montana (7.9%), North Dakota (6.4%), Arizona (5.5%), Wyoming (3.3%), Washington (3.0%), and Oregon (2.9%).*
- *About two thirds of AI/AN people lived in 10 states: California, Oklahoma, Arizona, New Mexico, Texas, North Carolina, New York, Alaska, Washington, and South Dakota.*
- *The Bureau of Indian Affairs now recognizes 567 federally recognized tribes, with 229 of those tribes and villages located in Alaska; the remaining tribes are located in 34 other states.*
- *In total, tribal governments exercise jurisdiction over lands that would make Indian Country the fourth largest state in the United States if all the lands were combined.*
- *The Navajo Nation is larger than each of the following states: Maryland, Vermont, New Hampshire, Massachusetts, New Jersey, Hawaii, Connecticut, Delaware and Rhode Island.*
- *19 tribal nations are each larger than the state of Rhode Island.*
- *12 tribal nations have a land base larger than the state of Delaware.*

TRIBAL ECONOMIES – STRENGTHS - ASSETS

Native Owned Businesses are Growing

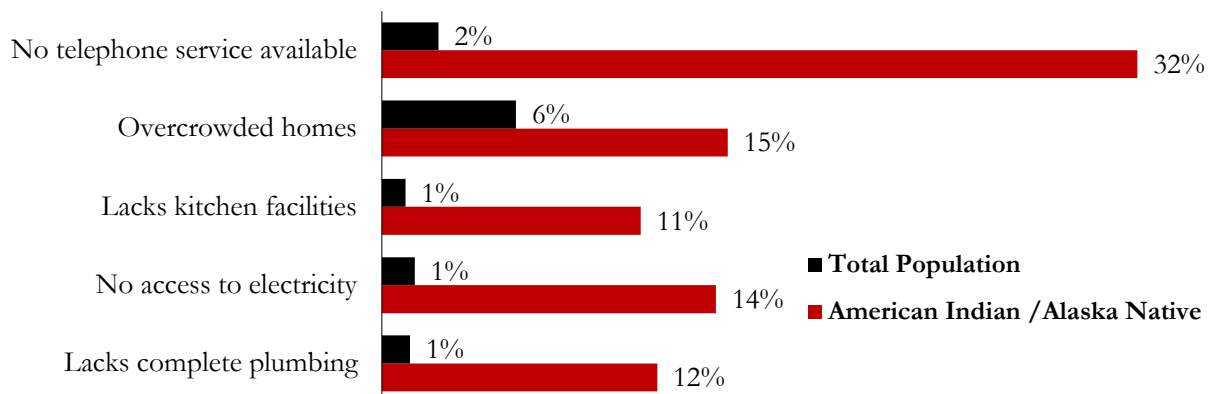
- *The number of American Indian and Alaska Native owned businesses totaled 237,386 in 2007, up 17.9 percent from 2002; total receipts of these businesses were \$34.5 billion, up 28.3 percent from 2002.*
- *However, entrepreneurial parity is still unrealized: the adult AI/AN population represented 1.5 percent of the adult U.S. population in 2009, but AI/AN held only 0.9 percent of all classifiable firms.*
- *AI/AN businesses accounted for 10.0 percent of businesses in Alaska, 6.3 percent in Oklahoma and 5.3 percent in New Mexico.*

CRIME RATES

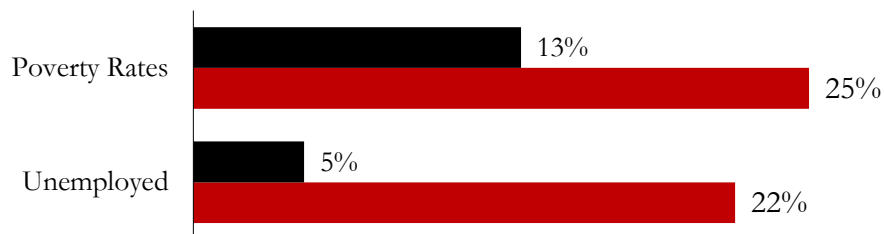
- *The rate of aggravated assault among American Indians and Alaska Natives is roughly twice that of the country as a whole (600.2 per 100,000 versus 323.6 per 100,000).*
- *1 out of 10 American Indians (12 and older) become victims of violent crime annually.*

Additional data from NCAI:

Basic Living Conditions³



Unemployment and Poverty



ANALYSIS OF RELEVANT POLICY AND DATA

MISCLASSIFICATION OF DATA

Misclassification of AI/AN's race in mortality data is an ongoing issue that often is severely undercounted. As the majority of the AI/ANs reside in metropolitan areas, now this misclassification gap is widening. Often AI/ANs choose not to be identified as such due to acts of discrimination, even in 2015. This fact, and the abilities of funeral directors/coroners' to accurately identify race on the death certificate from physical features results in gross misclassification. From a policy standpoint, this makes development of federal policies difficult with inaccurate mortality data for AI/ANs. In recent years there have been attempts made to improve this data through matching Social Security numbers with individuals that have received services at an IHS facility (IHS only serves AI/ANs) with those choosing to use other health providers' services. This is a tedious task, but has unofficially shown results of misclassification ranging from 40 to 80 percent. This is significant, and needs to be considered for policy development. Other methods are being used that matches the all-cause death rate in IHS Contract Health Service Delivery Areas (CHSDA), now referred to as Purchased and Referred Care, (PRC) counties for AI/ANs that do not use IHS.

Misclassification of AI/AN race in mortality data ranged from 6.3% in the Southwest to 35.6% in the Southern Plains.⁴ From 1999 to 2009, the all-cause death rate in CHSDA counties for AI/ANs varied by geographic region and was 46% greater than that for Whites. Analyses for CHSDA counties resulted in higher death rates for AI/ANs than in all counties combined.

Another issue of misclassification is in regard to surveillance. Surveillance data gathering methods do not have the same corrective abilities found in episodic clinic encounters or mortality data sets. Surveillance of notifiable diseases is essential for the prevention and control of infectious diseases. If the race of people who contact any of these high impact diseases is reported inaccurately, there is a high potential for inappropriate actions and even loss of life. Health status assessments for AI/ANs often are hindered by a lack of complete and accurate data regarding race in surveillance systems. Also, surveillance systems often do not have the ability to statistically assess small populations, which is often AI/ANs. It is important with the technology available today, there be new surveillance system designs that accurately captures AI/AN profiles and information to develop accurate and efficient intervention efforts and programs tailored to population.

Additionally, this misclassification has major impacts on policy development, allocation of resources, and the ability to identify health equity issues that are dependent on assets and disparities. An example of misclassification is often found in surveillance data. A cancer surveillance study was conducted by the Centers for Disease Control and Prevention and others published in 2008.⁵ This study revealed that the misclassification of the AI/AN race as non-AI/ANs in central cancer registries ranged from 85 individuals in Alaska (3.4%) to 5297 individuals in the Southern Plains (44.5%). Cancer incidence rates among AI/ANs for all cancers combined were lower than for non-Hispanic Whites, but incidence rates varied by geographic region for AI/ANs. Restricting the rate calculations to Contract Health Service

Delivery Area (CHSDA) counties generally resulted in higher rates than those obtained for all counties combined.

HEALTH DISPARITIES

AI/ANs die at higher rates than other Americans from:

- Tuberculosis – 600% higher
- Vehicle crashes – 229% higher
- Alcoholism – 510% higher
- Diabetes – 189% higher
- Injuries – 152% higher
- Suicide – 62% higher

A 2014 leading causes of death study⁶ found that AI/ANs did not experience the significant decreases in all-cause mortality seen for Whites. From 1999 to 2009 the all-cause death rate in CHSDA counties for AI/ANs was 46% more than that for Whites. Death rates for AI/ANs varied as much as 50% among regions. Except for heart disease and cancer, subsequent ranking of specific causes of death differed considerably between AI/AN and White persons. This article contains the best available data on deaths among AI/ANs between 1990 and 2009. This study used more accurate racial ascertainment in death records, and showed that the disparity in death rates between AI/AN and non-Hispanic White populations in the United States remains large for most causes of death. A concerted, robust public health effort by federal, tribal, state, and local public health agencies, coupled with attention to social and economic disparities, may help narrow the gap.

In a study of tuberculosis (TB) and human immunodeficiency virus (HIV) death rates in the United States have not translated to equal reductions in death rates among AI/ANs compared with Whites that resulted in significant persistence of disparities. Although death rates from HIV in AI/ANs were significantly lower than those in Whites from 1990 to 1998 (4.2 vs 7.0), they were significantly higher than those in Whites from 1999 to 2009 (3.6 vs 2.0).⁷ Death rates from TB in AI/ANs were significantly higher than those in Whites, with a significant disparity during both 1990 to 1998 (3.3 vs 0.3) and 1999 to 2009 (1.5 vs 0.1).⁷

Another 2014 study⁸ found higher relative risks of alcohol-attributable death for AI/ANs compared with Whites for specific groups and leading causes of death, which may point to particular opportunities to reduce these disparities. AI/ANs from the Northern Plains and those aged 25 to 44 years had the highest rate ratios. Among leading causes of death, it was found the highest relative risks were for hypothermia, alcohol poisoning, alcoholic psychosis, alcoholic liver disease, and alcohol dependence. Alcoholic liver disease looms as a significant prevention opportunity for AI/ANs with a high relative risk and is the cause of the most alcohol-attributable deaths. Proven strategies that reduce alcohol consumption and make the environment safer for excessive drinkers should be further implemented in AI/AN communities.

AI/AN individuals have greater risk of developing and dying of kidney cancers. Incidence rates

have increased faster in AI/AN populations than in Whites. Only a few modifiable risk factors for kidney cancer are known, and these factors cannot fully explain the geographic patterns in kidney cancer incidence and mortality in AI/ANs. Death rates have decreased slightly in Whites but remained stable in AI/AN populations. Racial disparities in kidney cancer are widening.⁹

Herne, Bartholomew, & Weahkee, found death rates from suicide were approximately 50% higher among AI/ ANs (21.2) than Whites (14.2). By region, rates for AI/ANs were highest in Alaska (rates = 65.4 and 19.3, for males and females, respectively) and in the Northern Plains (rates = 41.6 and 11.9 for males and females, respectively). Disparities between AI/AN and White rates were also highest in these regions.¹⁰

Another study found that compared with Whites, the pneumonia and influenza death rate for AI/ANs between 1990-2009 was significantly higher. AI/AN populations in the Alaska, Northern Plains, and Southwest regions had rates more than 2 times higher than those of Whites. The study was not able to determine, because it was difficult to isolate reasons for the continued pneumonia and influenza mortality disparity between AI/AN and White people. The disparities were reported as most likely the result of a complex interaction of factors. These included lower socioeconomic status that was associated with household and environmental factors that increased transmission of infectious diseases. It was also suggested that there was also an increased burden of chronic health conditions and health risk behaviors that might increase infectious disease susceptibility and severity, and barriers to accessing health care that might result in less use of prevention and treatment services.¹¹

Murphy, Pokhrel, Worthington, Billie, Sewell, and Bill found from 2005 to 2009, the unintentional injury (UI) death rate for AI/ANs was 2.4 times higher than for Whites. Death rates for the 3 leading causes of UI death—motor vehicle traffic (MVT) crashes, poisoning, and falls—were 1.4 to 3 times higher among AI/ANs than among Whites. UI death rates were higher among AI/AN males than among females and highest among AI/ANs in Alaska, the Northern Plains, and the Southwest.¹² The results reveal that UIs remain a significant public health problem in AI/AN and White populations. Although data reveal similar trends for both populations, with decreases in MVT death rates and increases in poisoning and fall death rates, AI/ANs continue to have significantly higher rates of UI death overall and by specific causes than Whites

The health equity of AI/ANs and diabetes continues to persist. The following statistics are reported by IHS (Indian Health Service, 2012)¹³:

- There is a 2.3 percent higher likelihood of AI/ANs to have diagnosed diabetes compared with non-Hispanic Whites (16.1% vs. 7.1%; 2009).
- AI/AN youth aged 10-19 have a nine times higher likelihood to have diagnosed type 2 diabetes compared to non-Hispanic Whites (1.74 per 1000 vs. 0.19 per 1000; 2001).
- There was a 110 percent increase in diagnosed diabetes from 1990 to 2009 in AI/AN youth aged 15-19 years (3.24 vs. 6.81 per 1000).
- The death rate to diabetes for AI/ANs compared with the general U.S. population is 1.6 times higher (34.5 vs. 21.8 per 100,000; 2008).
- The incidence rate of kidney failure due to diabetes in AI/ANs compared with the general U.S. population is 1.9 times higher (333.1 vs. 152.9 per million; 2008).
- Results from the Strong Heart Study suggest that the risk for cardiovascular disease

(CVD) in AI/ANs with diabetes may be 3-8 times higher than those with diabetes.

LEGAL JUSTIFICATION

The federal promise to provide Indian health services actually predates the *Constitution*. The initial court case that challenged the federal trust responsibility was: *Cherokee Nation v. Georgia* (1831)¹⁴. Note that the *Treaty of Hopwell* actually preceded the *Constitution* for dealing with the Cherokee Nation. The court ruling further identified tribes with the unique designation of “domestic dependent nations”.

Once the United States became independent, all branches of the federal government acknowledged the nation’s obligation to the tribes and the special trust relationship that exists between the United States and AI/ANs. The federal trust responsibility to AI/ANs is grounded in the *United States Constitution*. While there is no explicit language that established or provides the parameters of that responsibility, the following clauses are considered the basis for trust relationships.

- *Commerce Clause (Article I, Section 8, Clause 3) authorizes Congress to regulate commerce “with foreign Nations, and among the several States, and with Indian Tribes.”*
- *Treaty Clause (Article II, Section 2, Clause 2) grants federal government exclusive authority to make treaties on behalf of the United States.*

The first dealings between the federal government and tribes were undertaken through treaty documents, to establish peace. In actuality large tracts of land were seized, Indian people were removed from their indigenous lands, assimilation was required, and protections were promised including: education, welfare, and health. The most significant Indian health and education law of the early twentieth century was the enactment in 1921 of a permanent authorization of appropriations in the *Snyder Act* (Public Law 67-85, *Snyder Act 25 U.S.C 13*, November 2nd, 1921, Section 13).

The Bureau of Indian Affairs, under the supervision of the Secretary of the Interior, shall direct, supervise, and expend such moneys as Congress may from time to time appropriate, for the benefit, care, and assistance of the Indians throughout the United States for the following purposes:

... General support including education, relief of distress and conservation of health, industrial assistance and advancement and general administration of Indian property.

For extension, improvement, operation, and maintenance of existing Indian irrigation systems and for development of water supplies.

For the employment of inspectors, supervisors, superintendents, clerks, field matrons, farmers, physicians, Indian police, Indian judges, and other employees.

The *Snyder Act* remains in force today and serves as an authority for annual appropriations to the Bureau of Indian Affairs (BIA) and the Indian Health Service.

The *Indian Self-Determination and Education Assistance Act* (P.L. 93-638) was enacted in 1975. This *Act* is the basis for authorizing tribes to assume responsibility for BIA and

IHS programs.

Signed into law on 4 January 1975, this legislation completed a fifteen-year period of policy reform with regard to American Indian tribes. Passage of this law made self-determination, rather than termination, the focus of government action, reversing a thirty-year effort to sever treaty relationships with and obligations to Indian tribes. The disastrous consequences of termination, combined with aggressive Indian activism, had encouraged a reexamination of government policy. During the 1960s, the War on Poverty's Community Action programs, with their philosophy of "maximum feasible participation of the poor," also encouraged a change in direction. Significant too were President Lyndon B. Johnson's 1968 congressional message on Indian affairs entitled "The Forgotten American" and Richard M. Nixon's official repudiation of termination in 1970.

The *Indian Health Care Improvement Act* (IHCIA) (P. L. 94-437) was originally enacted on September 30, 1976. This *Act* was instrumental in setting national policy to improve the health of Indian people; and the initial authorization for the Indian Health Service, Tribes, Urban Indian programs to bill Medicare, Medicaid, and Children's Health Insurance Plan (CHIP). The explicit language of the *Act* further defined the responsibility of the United States to maintain and improve the health of Indians which was needed to augment the intent of previous *Acts* (e.g. *Synder Act*, Public Law 67-85; *Transfer Act*, P.L. 83-568, 1954; *Indian Self-Determination and Education Assistance Act* (P.L. 93-638) by expanding and describing modern health services.

Over the course of the last 34 years reimbursement for Medicare, Medicaid, and more recently Title XXI (CHIP) has helped to acquire and maintain facility accreditations, and improve services. There remain issues with differences of covered reimbursable services (Medicaid, CHIP), which are determined by each state, often without tribal consultation. This particularly impacts AI/ANs who live in areas where the closest ITU may be located in another state, effecting ability of service providers to collect for their services.

In passing the *Patient Protection and Affordable Care Act* (ACA), Congress also reauthorized and made permanent the *Indian Health Care Improvement Act* (IHCIA). Congress reaffirmed the duty of the federal government to AI/ANs by declaring in the ACA that it is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to ensure the highest possible health status for AI/ANs and to provide all resources necessary to effect that policy.

Social Security Act

One issue that has been tested by the states since the mid 1990's is to try to "auto enroll" AI/AN in their respective state Medicaid managed care organizations. States do not have the optional authority to require AI/ANs to enroll in Medicaid managed care organizations (MCOs), unless the MCO is operated by the IHS, a tribe, or an urban Indian health program. State Medicaid programs have broad discretion to determine whether beneficiaries will receive covered services on a fee-for-service basis or through risk-based MCOs. In general, states can require most groups of beneficiaries in urban areas to enroll in risk-based managed care so long as the beneficiary has a choice between at least two MCOs that meet federal standards; in rural areas, states may limit beneficiaries to one MCO, (*Sections 1932(a), 1115 and 1915(b) of the Social Security Act*).

Current Indian Health System

The current Indian health system remains in despair, despite all the federal promises. AI/ANs continue to live sicker lives and die younger than other Americans. AI/ANs experience significantly higher:

- Mortality rates from alcoholism, suicide, cancer, and influenza deaths
- Ninety percent of AI/AN children suffer from dental caries by the age of eight, compared with 50 percent for the same age in the US all races population
- AI/AN children ages 2 to 5 have an average of six decayed teeth, when children in the US all races population have only one
- According to IHS data, 39 percent of AI/AN women experience intimate partner violence, which is the highest rate of any population group in the United States.

Devastating health risks from historical trauma, poverty and a lack of adequate treatment resources also continue to plague tribal communities.

FUNDING

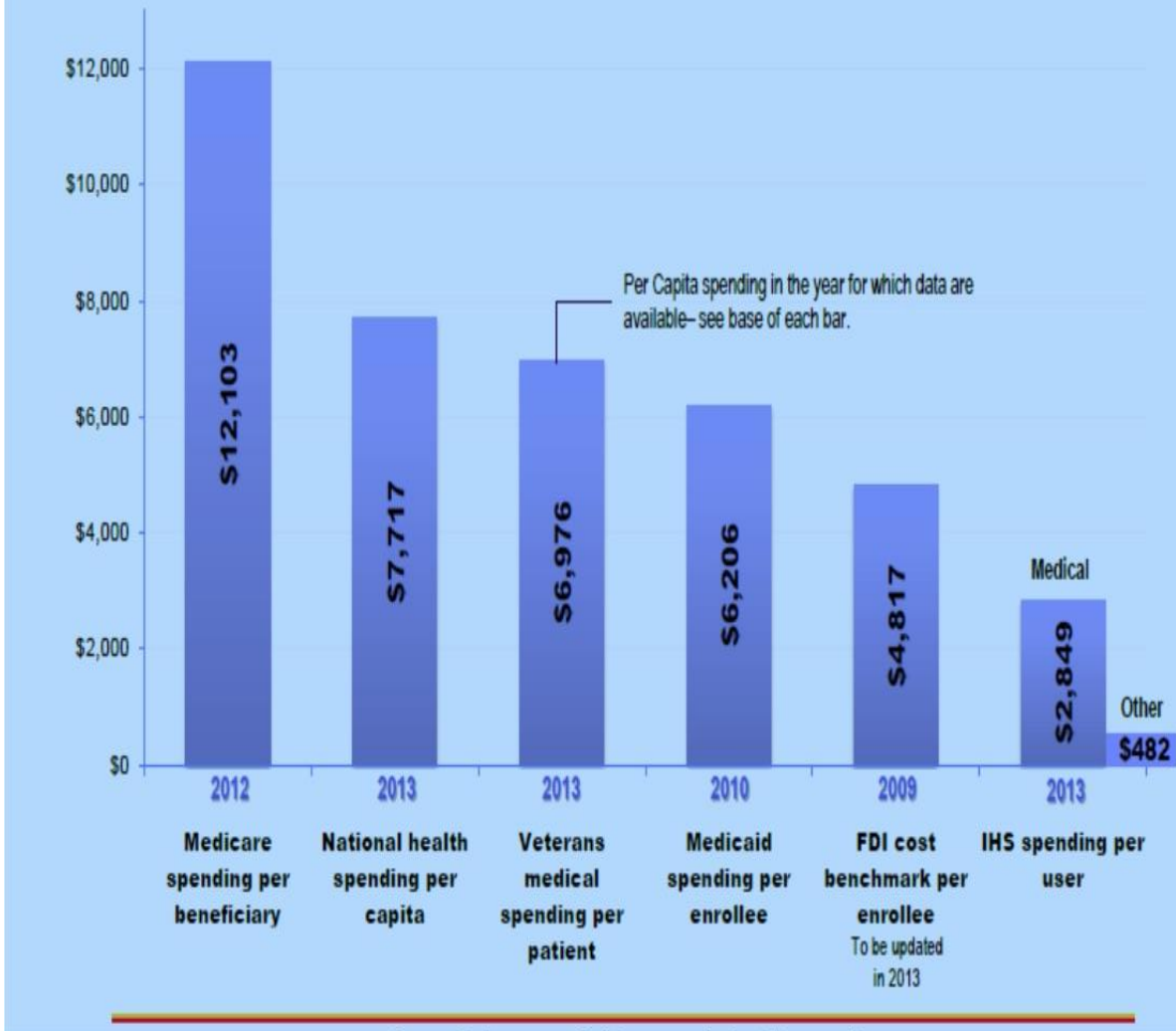
One of the issues identified by the National Indian Health Board (NIHB) Testimony to the Senate Indian Affairs Committee, on January 28, 2015 discussed the Mandatory Appropriations for the Indian Health Service in 2013, the IHS per capita expenditures for patient health services were just \$2,849, compared to \$7,717 per person for health care spending nationally.¹⁵

According to NIHB“ Despite the historic increases that Congress has given to the IHS budget over the last several years, funding discrepancies unambiguously remain. Budgets have not kept up with medical inflation, contract support cost needs, and sequestration cuts. In previous testimony the year before, NIHB testified before the Senate Committee on upcoming budget priorities on March 26, 2014, and noted that for FY 2016 Tribes requested \$5.4 billion for the IHS. Full funding to meet 100 percent of projected need would be \$28.7 billion and is practically achievable in a twelve year phase-in plan. The IHS provided an analysis of 2013 expenditures of other federal spending for health services. Please note the charts below:

2013 IHS Expenditures Per Capita and Other Federal Health Care Expenditures Per Capita¹⁵

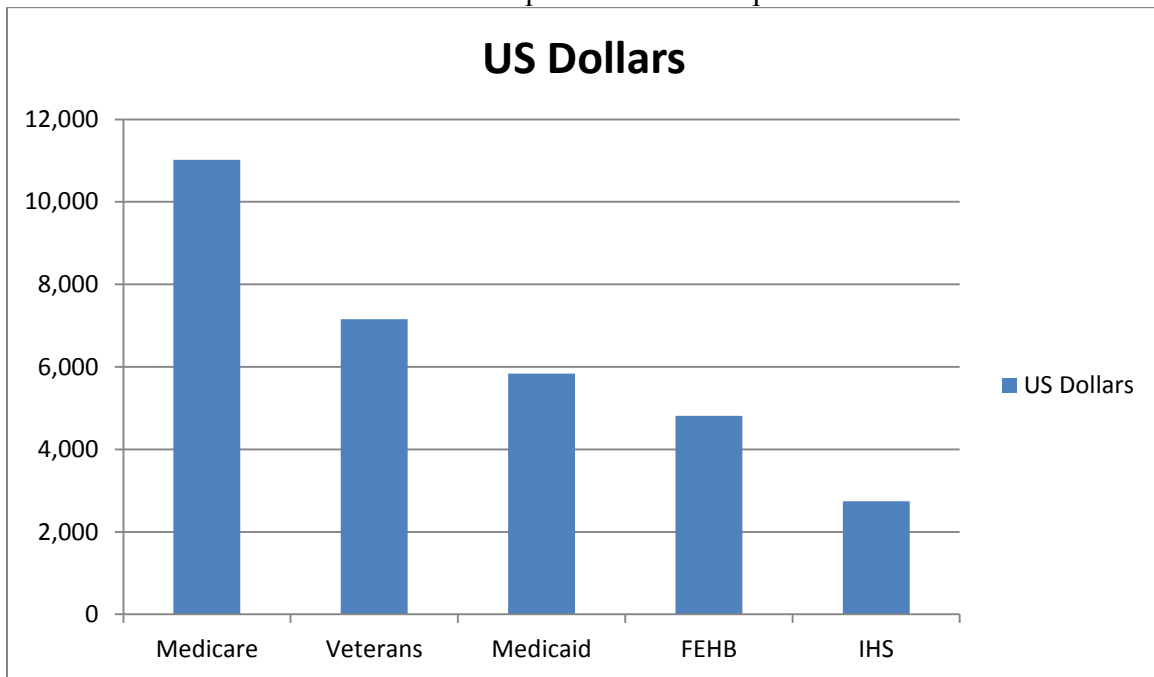


2013 IHS Expenditures Per Capita and Other Federal Health Care Expenditures Per Capita



Please note historical funding discrepancies as further evidence that the per capita payments have not kept up with inflation, please note the chart below to review the disproportionate underfunding of IHS in previous years.

2009 – 2010 Indian Health Expenditures Per Capita as Compared to Other Federal Healthcare Expenditures Per Capita¹⁶



Source: U. S. Department of Health and Human Services, National Tribal Budget Formulation Workgroup (2011). National tribal budget recommendation for the Indian Health Service: Fiscal Year 2013 budget, Washington, DC.

ACCESS

From the reservation and rural AI/AN perspective, there are multiple barriers to access routine health services and tremendous issues for culturally considerate and specialized services. In reality, access to primary care services is often a “choice of one”, and requires an ability to travel (in various modes: land, air, telecommunication) for access to basic professional health services. All reservations have an “automatic designation” of a Health Professional Shortage Area (HPSA), and the entire country, according to the Health Resources Service Administration (HRSA), is designated as a “Mental Health Professional Shortage Area” (with a few metropolitan exceptions). Given these factors, the ability for AI/ANs to access even minimum health services, requires extra planning, support, available reliable transportation (because of distance to and climatic challenges) and availability of a culturally appropriate health providers.

Many times patients will forgo their appointments with specialists because the out of pocket costs are prohibitive including: loss of work time, child/elder care, home heating maintenance (freeze-up for those who only have wood as a heating source), livestock care, and home security issues. Currently, there is little literature available that assesses these expenses. These out of pocket costs create an extra hardship for AI/ANs, who may choose to feed their families and suffer the consequences of postponing their medical appointment until they require extensive and

more costly procedures to save their life. Certainly telemedicine has a role in reducing some of these disparities, but there remains a need for more policies and development of arrangements for technology for use in rural areas.

While in the last decade there has been a major shift of AI/ANs from rural to metropolitan areas, there remains a need for improvements in rural health services as the “new” urban AI/ANs often travel back and forth between their cultural ties, including family, located in rural areas. As the economic conditions continue to offer limited employment in rural areas, this “migration” is expected to continue.

CANCER

One’s geographic location and their potential access and availability of cancer screening services are related. Individuals in areas with higher concentrations of AI/ANs have large gaps in the availability, utilization, and distance to providers when compared to other areas. Despite recommendations for cancer screening for breast and colorectal cancer among the Medicare population, preventive screenings rates are often lower among vulnerable populations such as the small but rapidly growing older American Indian and Alaska Native population.¹⁷ It was also found that counties with higher concentrations of AI/AN individuals had greater disparities in access and utilization of cancer screening services. Even after adjusting for income, education, state of residence, population 65 and older and rurality, areas with higher levels of AI/ANs were more likely to see disparities with regard to health care services related to mammograms ($p < .05$; longer distance, lower screening) and colonoscopies ($p < .05$; longer distance, lower screening).¹⁷

PATIENT PROTECTION AND AFFORDABLE CARE ACT (ACA)

The ACA offers important opportunities to increase health services and insurance coverage for AI/ANs to reduce longstanding disparities. The ACA seeks to reduce the number of uninsured through an expansion of Medicaid and Health Insurance Marketplaces with tax credits to help purchase coverage. According to the Kaiser Family Foundation policy report “Health Coverage and Care for American Indians and Alaska Natives” nine in ten (94%) uninsured American Indians and Alaska Natives have incomes in the range to qualify for these coverage expansions².

This provision has the potential to end “rationed” PRC services. Currently, when an AI/AN needs to have a health procedure that is not provided at an ITU, they must request a referral for such services from public or private service providers. This rationed care environment often results in comments that: “if you need your cataracts removed, or knee replaced, or other “non-life threatening condition” get it done when the new dollars are available at the beginning of the federal fiscal year – or – wait for another year and pray you are high enough in the “list” to receive the referral for service. ACA provides a timely opportunity for AI/ANs to sign up for health insurance, with limited or no cost (94% currently qualify for Medicaid, and or Medicaid expansion selected states) to receive those previously “rationed services” at a provider within their health plan².

However, as the *Act* continues to be implemented, there are issues that substantially affect the ability of AI/ANs to participate. One key caveat is the definition of an “AI/AN”. **The current definition of an AI/AN for Exchanges is “an enrolled member of a federally recognized tribe.” Non-enrolled AI/ANs may apply for a “hardship exemption”. This later group includes beneficiaries of Indian Health Service/Tribal/Urban (I/T/Us) health services. This**

group is often referred to as “IHS beneficiaries or ITU beneficiaries or using the IHS definition” of an Indian. “Non-enrolled” AI/ANs, many of which have historically used ITU services, are now excluded from receiving those services under the “government to government” legal protections.

The “Definitions of Indian” in the ACA, are narrower than those currently used by the IHS, Medicaid and the Children’s Health Insurance Plan (CHIP). This thereby excludes a sizeable population of AI/ANs that the ACA was intended to benefit and protect. Unless the definition of AI/ANs in the ACA is adjusted to match other definitions used by IHS and CMS, many AI/ANs will not be able to receive the special protections and benefits intended for them in the law. Tribal leadership and others are continuing to attempt to amend the ACA to the true definition of an AI/AN, which is to change to the broader IHS definition which has been endorsed nationally by Tribal leadership:

- ... ‘Indian’ means any individual defined at 25 U.S.C. 1603(13), 1603(28), or 1679(a), or who is of Indian descent belonging to the Indian community served by the local facilities and program of the Indian Health Service.
- Currently the only recourse for AI/AN who are not “officially” enrolled with a Tribe is the *hardship exemption* for those with I/T/U eligibility.

Current Legal Interpretation of AI/ANs Participation in the ACA

AI/ANs Enrolled in a Federally Recognized Tribe are:

- Exempt from the annual penalty for being uninsured.
- Exempt from most cost sharing in Exchange plans:
 - Cost sharing = deductible + co-pay
 - Federal government pays cost sharing to plans
 - I/T/Us are eligible to receive these payments
- Able to enroll or change plans monthly.

I/T/U Beneficiaries Not Enrolled In Federally Recognized Tribe also called *IHS Beneficiaries*:

- Eligible for Hardship Exemption – No penalty for being uninsured if granted.
- Not eligible for cost sharing provisions if over 400% FPL.
- Not eligible to enroll in coverage or change coverage monthly.

The ACA does provide recognition of the fact that AI/ANs should not be forced to purchase healthcare that is obligated by the federal government’s trust responsibility. However, Tribal employers (whose employees are often also Tribal members) are subject to the Employer Shared Responsibility Mandate, which states that employers, with 50 or more full-time employees or full time equivalent employees, must offer insurance to their employees or pay a tax penalty.

Applying the employer mandate to Tribal employers directly undercuts the ACA’s Indian-specific protections in three ways. First, it punishes Tribes for assisting AI/AN enrollment in the Marketplaces, despite the multiple ACA provisions designed specifically to encourage such activities. Second, it can disqualify AI/ANs from eligibility for premium tax credits in

Marketplace plans, thus leaving them unaffordable. Third, it ignores the fact that AI/ANs are exempt from the individual mandate and forces Tribal employers to pay for AI/AN insurance plans as a proxy for the individual. None of these outcomes benefit Tribal employers, individual AI/ANs, or the federal government¹⁵.

Additionally, the ACA contains several provisions designed to maximize AI/AN participation in Marketplace plans: for example, Indian-specific cost-sharing protections that help defray the cost of health coverage, special AI/AN enrollment periods, and the ability for Tribes to assist with Marketplace plan premium payments for Tribal members. Many Tribes and Tribal organizations have aggressively sought to facilitate AI/AN enrollment in Marketplace plans in order to take advantage of these protections. However, the employer mandate actively discourages AI/AN Marketplace participation, in direct contradiction to the provisions described above¹⁵.

If a Tribe does offer employer coverage, AI/AN employees will almost certainly be personally responsible for paying premium costs, deductibles, co-payments, and co-insurance. Eligibility for IHS services acts as a natural disincentive for AI/AN enrollment in any insurance plan (employer sponsored or otherwise). Congress incentivized AI/AN Marketplace participation through the availability of premium tax credits. For AI/ANs, various types of Indian-specific income is excluded, thus leaving it comparatively easier for AI/ANs to qualify for subsidies and making many individual Marketplace plans significantly more affordable than employer sponsored coverage for AI/ANs. However, employees are automatically disqualified from tax credit eligibility upon receiving a qualifying offer of coverage from their employer. As a result, even if a Tribal employer provides insurance that is less affordable or a comprehensive plan available through the individual Marketplace, the mere offer of coverage eliminates the ability of AI/ANs to obtain tax credits from the Marketplace¹⁵.

The current call centers have proven to be inadequate at answering questions related to the special benefits and protections available to AI/ANs and have often caused greater confusion and application errors. An actual example of an answer from a call center employee was unbelievable and illegal. A Navigator was attempting to help an AI/AN enroll in a health plan. During this process, the applicant was unable to complete the application because she was unable to locate her tribe from the list provided in the application format. So a call was made to the Call Center. The question to the Call Center employee was “how does this applicant find her tribe from the list on the application form, it was not listed”. The answer was “*well just pick any tribe*”. Well needless to say, this is just one example of inappropriate responses. Other problems exist with state sponsored sites, that do not have provisions to inform the applicant about AI/AN special cost provisions. This has resulted in numerous AI/AN applicants who have not enrolled, because of the inaccurate costs that are quoted to the AI/AN. Further, and very unfortunately, the image of federal broken promises continues to be fueled by these incompetencies.

There are still thousands of exemption applications that have yet to be processed with no discernible reason as to what the problems are. A large portion of those applications that have been processed, have been processed incorrectly and require prompt resolution so that AI/ANs can be issued exemption certificate numbers. These problems have all contributed to low enrollment, as many AI/AN are still confused about the benefits of the ACA and see no reason to sign up. An AI/AN call center would be one solution, since it would be more culturally sensitive and in certain cases, linguistically equipped to answer calls where the caller only speaks their

native language. Tribal leadership has requested this option for over two years, but this proposal has gone unanswered at CMS, despite the fact that the Administration has developed call centers for other minority groups (like native Spanish speakers), who the federal government does not have a special trust responsibility towards. AI/ANs, not only speak languages other than English, but the law applies to them in a completely different way, thereby increasing the need for a native-specific call center¹⁵.

HEALTH WORKFORCE

Access to a long serving quality workforce is one of the significant barriers to achieving high quality health services at ITUs. Remote and rural locations, lower pay, lengthy hiring processes and limited equipment at ITU facilities all effect the ability for providers to be recruited and retained within the ITU system. IHS has an estimated 46% turnover rate for their physicians every year, which leads to significant issues when building trust between patients and physicians and enriching care.

The health service needs of AI/ANs have unique qualifications of providers. Consider the historical actions of colonization, genocide, wars, forced relocation, boarding schools, discrimination, broken treaties and promises, economic conditions, and political injustices upon AI/ANs. These actions have resulted in an entire population that has been traumatized and forced to survive in a “learned dependency” environment. Often this practice environment overwhelms health service professionals, and leads to “early burnout” or limited years of service.

One solution supported by the IHS and Tribes is making IHS scholarships and student loan repayments tax exempt. This would create parity between IHS and other federal health providers such as the National Health Service Corps. The President’s FY 2015 budget recommendation for the IHS supported this approach noting, “The inability to fund 577 applicants who were not currently working for IHS is a significant challenge for the recruitment efforts of the agency.” The Budget request also noted that “IHS, as a rural health care provider, has difficulty recruiting health care professionals”. There are over 1,550 vacancies for health care professionals... across the IHS system”¹⁵.

This is just one small solution to a very complex problem. Possible solutions could include streamlining the federal hiring process (for IHS employees); additional incentives for physicians who stay with IHS or Tribal providers for multiple years, or providing greater flexibility for scholarship and loan reimbursements. It is vital that Congress and the Administration make serious investments in recruiting and retaining medial staff in Indian Country of the health of our people is ever to improve¹⁵.

BEHAVIORAL HEALTH

There are numerous examples in the literature of mental health disparities. Among AI/AN people, there is a wide range of beliefs about illness, healing, and health. The concept of mental illness and beliefs about why and how it develops have many different meanings and interpretations among AI/ANs. Every tribe has their own cultural traditions that was the foundation of how each tribe maintained their own holistic view and well-being of their citizens. Successful behavioral health services has proven that the use of those traditions to ground their healing practices are the most effective. Often physical complaints and psychological concerns are not distinguished and AI/ANs may express emotion distress in ways that are not consistent

with standard diagnostic categories¹⁸.

The ACA offers significant opportunities to begin to ameliorate the impact of mental illness and drug abuse (here after referred to as “Behavioral Health” as a summary term, as found in *Title VII* of the *Indian Health Care Improvement Act*) upon the lives of AI/AN. Behavioral health issues have been profoundly underestimated and culturally undefined in the AI/AN population. Most troubling is the fact that much of the personal and societal burden of behavioral health conditions and issues could be prevented or alleviated if people at-risk for experiencing these conditions had access to and received culturally appropriate prevention and treatment care and services.

As a result, AI/ANs face significant access barriers for effective behavioral health prevention and treatment care and services. Access to and the availability of behavioral health professionals, such as psychiatrists, psychologists, drug counselors, and social workers are seriously lacking. Poverty, geographic location, and cultural differences further limit the amount and quality of services available. Research confirms that limited insurance coverage, scarce availability of services, excessive travel distances, weather hazards, increased personal monetary costs, and stigma related to behavioral health needs additionally contribute to poor access. Finally, for those who do receive treatment, many find that the care provided is not intensive enough, not long enough, and/or lacking in important follow-up health and social services.

The ACA has specific language for government to government relations for tribes and tribal organizations, urban Indian programs, and the Indian Health Service. Additionally, there are public sector sections that would be available, often working with a state, but also directly with federal departments. There are specific provisions that specifically name tribes: Sections 3502, 4001, 4201, 4202, 5101, 5405, 5507, and 10306; and one (1) Section 5507 that names urban Indian programs.

The behavioral health features of the ACA are numerous and complex. There are a variety of different opportunities that can impact or begin to impact the tremendous needs of Indian Country. The American Psychiatric Association lists the following AI/AN barriers to services¹⁸:

- Economic barriers (cost, lack of insurance)
- Lack of awareness about mental health issues and services
- Stigma associated with mental illness
- Lack of education and pervasive poverty
- Lack of culturally appropriate services
- Mistrust, with which many AI/ANs relate to their health care providers
- Continuing lack of accurate data and research on AI/ANs
- Lack of appropriate intervention strategies (including integration of mental health and primary health care services)
- Mental health professional shortages and high turnover
- Availability of mental health services in rural, isolated locations

Public Health Model Adoption

In Indian Country, public health support is virtually non-existent. While much of the U.S. population has access to government-sponsored, accredited health departments, behavioral health facilities, or alcohol and substance abuse treatment facilities, these facilities are rare in Indian Country. Combine this with high rates of poverty, widespread historical trauma, and adverse childhood experiences, and the problems seem insurmountable¹⁵.

In regards to the ACA's trend to start practicing health services using the public health model, consider changing health services to meet the needs of AI/ANs by targeting funding and investments in public health infrastructure to fight some of the immense disparities. Public health is the science of protecting and improving the health of communities through education, promotion of healthy lifestyles, and research for disease and injury prevention. Perhaps the most difficult of developing public health assets is the definition of "community". One would be hard pressed to find ANY two "communities" with exactly the same culture, sub-cultures, economic structure, leadership, health issues, assets, resiliency, and factors that bind a group of residents to function and be responsive to the wellness of others. Often policy developers consider their own definition of a "community" without consideration or knowledge of historical human groupings. Additionally, there is often an assumption by policy makers that a given geographic rural area or "town" is a single "community". These assumptions often preclude actual groups of citizens i.e. "communities", the freedom to be recognized as such, and results in a forced definition of community. Policy makers need to understand, that it is not unusual for rural geographic areas, with small populations, to have more than one "actual community". Following are some guidelines to determine a community structure (there may be more than one structure in any geographic area) that could benefit from using a public health model to meet the needs of their respective citizenry.

1. Identify and address health equity from a population-based, whole group aggregate perspective to determine health status, spotlighting specific groups when indicators of health disparities are noted.
2. Support culturally relevant health promotion and prevention that is community-determined; and culturally relevant strategies that enhance, promote, and improve the health status of AI/AN communities.
3. Support communities to identify as communities that can support their own cohesiveness, identify their strengths and assets, and develop their own strategies based in cultural beliefs and practices to enhance health and overall well-being of their population.
4. Ensure that the health of vulnerable populations within a community are identified and addressed to support the "greater good" because of the affects they have on any community. Communities need to accept this as a responsibility. This promotes a comprehensive potential for improved quality of life, increased energy and resources to create stronger families and communities.
5. Work with, connect, and support local communities and their leaders to identify, take responsibility for, and address racial/ethnic assets and health disparities, and to identify and publicize these assets and health disparities among their members, together developing strategies to address the disparities and reinforce assets.
6. Start a process to collect reliable data on the health status of respective communities. Currently, small rural communities have very limited comprehensive data and often data that is collected is invalid as it is not culturally sensitive (includes races, ethnicity, sub-cultures e.g. rural farming, rural wilderness etc.). Actions can be developed to prevent

poor health outcomes by: appropriately identifying, collecting, and reporting cultural specific data; identifying where data are lacking and developing appropriate tools to collect those data; and by linking poor health status indicators to social conditions and influences, as well as personal behaviors and genetics.

RECOMMENDATIONS FOR NRHA POLICY POSITIONS

Policymakers are encouraged to “first do no harm” to AI/AN health programs. To protect Indian health programs the following provisions were recommended for inclusion in any legislation and regulations. Please note that the first nine are continued from the 2006 Issue Paper.

1. Include “tribes,” “tribal organizations,” and “tribal” when listing governmental entities. Without specific wording, Centers for Medicare and Medicaid Services (CMS) may not give tribes the same consideration as other governments. It is vitally important because this recommendation is not followed, history has proven over and over again that the government to government relationship is compromised. The appropriate language for policies is: federal, state, tribal, and local governments.
2. As appropriate, include specific wording acknowledging the I/T/U as a special type of provider essential for AI/AN access to Medicaid, Medicare, and SCHIP programs. The wording of such an acknowledgement is necessary based on the legal classification of AI/ANs as dual citizens. (It is important to understand that dual citizens have the choice of using Indian specific and/or public sector programs/services.)
3. State that AI/ANs are entitled to health care on the basis of their enrollment in federally recognized tribes and/or descendants of enrolled members of tribes. Explicitly recognize the special relationship AI/ANs have with the federal government as a political group to establish policies that demonstrate recognition of the government-to-government relationship that AI/ANs have that is not a classification as a “minority group” or a racial group.
4. If new legislation creates special programs to address health disparities, inequities or access to care, include AI/ANs in lists of target groups.
5. Funding should be provided to I/T/Us for implementing new programs and regulations.
6. Explicitly require that CMS (as noted in the **Legal Justification Section**) and states assess impact on tribes and conduct meaningful tribal consultation prior to issuing regulations, policies or State Medicaid Plans that affect AI/AN.
7. Explicitly require that CMS assess proposed legislative and regulatory changes that impact tribes and conduct meaningful tribal consultation prior to submitting legislative changes, issuing new regulations, and policies that affect AI/ANs. Numerous Executive Orders from four administrations have supported this. However, there remain some state waiver requests that have been approved by CMS without the required meaningful tribal consultation.
8. Traditional practices and customs must be respected. Respect for cultural beliefs requires blending of traditional practices with a modern medical model and emphasizing public health and community outreach. The CMS should include

- access to traditional medicine as part of the services available to AI/AN people and fully recognize traditional medicine as an integral component of the Indian health care delivery system.
9. All venues for the use and reimbursement of tele-health technologies should be pursued to relieve the disparity of access to all health services (e.g. home, specialists, follow-up treatments). Including building new collaborations with the Veterans Affairs for tele-health and reimbursement.

RECOMMENDATIONS (NEW)

1. Suicide is catastrophic in Indian Country. Last year (Feb. 2015), there was a state of emergency declared on the Pine Ridge Reservation. It was reported there were five (5) suicides in one month. There needs to be a coordinated, multidisciplinary effort involving federal, state, tribal, and local health officials to address this important public health issue.
2. The AI/AN populations continues to experience much higher death rates than Whites. Patterns of mortality are strongly influenced by the high incidence of diabetes, smoking prevalence, problem drinking, and social determinants. Much of the observed excess mortality can be addressed through known public health interventions.
3. Improve race classification among AI/ANs and decedents to strengthen AI/AN accurate mortality data, and analyze deaths by geographic region to aid in planning, implementation, and evaluation of efforts to reduce health disparities in this population.
4. There needs to be emphasis placed on improving accuracy of all AI/AN health data. Proven methods of matching AI/AN social security numbers with health services provided at non-ITUs would have significant benefits for all health policy development. The only delimitation of this policy suggestion is the fact that it would only identify AI/ANs that have used an ITU service sometime in their lifetime, including IHS's CHSDAs now referred to as Purchased and Referred Care (PRC). Improvements in AI/AN accurate data is essential for effective and efficient health policy development.
5. Improvements in education and awareness of cancer screening benefits continue to be needed in rural areas. There needs to be better access to specialists to prevent unnecessary morbidity and premature death as the entire rural population tends to be over represented by the baby-boom generation turning 65 years of age.
6. There needs to be an improved cancer surveillance data policy adjustment for AI/AN communities. This adjustment is a critical need for accurate planning, implementation, and evaluation of more effective cancer controls and would have an impact on reducing all cancer health disparities in the AI/AN population.
7. Because of the more rapid increase of kidney cancer incidence in AI/ANs and the less favorable mortality trend compared with Whites, additional studies are needed to explain the differences in incidence and mortality that would reduce and eliminate racial disparities for this disease. Continued monitoring of kidney cancer patterns through surveillance is warranted to track progress in eliminating racial disparity in kidney cancer. Given the high prevalence of obesity, smoking, and hypertension,

more public health interventions are needed including healthy diet and physical activity promotion, tobacco cessation, and early detection and control of hypertension.

8. It is well known that diabetes can affect many parts of the body and is associated with serious complications, such as heart disease and stroke, blindness, kidney failure, and lower-limb amputation. Some complications, especially microvascular (e.g., eye, kidney, and nerve) disease, can be reduced with good glucose control. While current programs in the AI/AN health service system have exemplary programs that have impressive results compared to the public sector, there remains an urgent need for continued persistence for prevention. New innovative approaches are needed for early detection and treatment of complications which can prevent development and progression of this devastating condition for AI/ANs.
9. Proven strategies that reduce alcohol consumption should be considered dependent upon community recommendation and acceptance. These may include: accepted cultural interventions, early age education, drug courts, increasing alcohol taxes, increased law enforcement. The intervention must be accepted and endorsed by the respective community for best results.
10. Continuing efforts to improve pneumococcal conjugate vaccine coverage among AI/AN children, and increased awareness of the importance of early antiviral treatment of influenza among providers and AI/AN communities, is needed. Continuing to strengthen on-going surveillance efforts to better identify the disease burden among AI/AN people at local and regional levels is essential to increase public health action to address disparities. Although progress has been made in reducing pneumonia and influenza mortality, disparities between AI/ANs and Whites persist. Strategies to improve vaccination coverage and address risk factors that contribute to pneumonia and influenza mortality are needed.
11. The decrease in death rates from HIV and TB was greater among Whites, but death rates remained significantly higher among AI/AN individuals. Public health interventions need to be prioritized to reduce the HIV and TB mortality in AI/AN populations.
12. AI/ANs had consistently higher unintentional accident death rates than did Whites. This disparity in overall rates coupled with recent increases in unintentional poisoning deaths requires that injury prevention be a major priority for improving health and preventing death among AI/AN populations.
13. The American Psychiatric Association, (2014) recommends the following responses and approaches to address the barriers to mental health services for AI/ANs:
 - Increase awareness of mental health and chronic disease connections, e.g. diabetes
 - Conduct stigma awareness training with gatekeepers
 - Educate providers about unique mental health issues
 - Increase presence of AI/ANs in research (as researchers and subjects)
 - Advocate for policies that promote social justice, equity, and equality
 - Increase comprehensive, (including mental health and substance use disorders), affordable, health insurance coverage for all

- Focus on prevention, early intervention
 - Develop systems that endorse the integration of traditional healing and spiritual practices
 - Increase use of technologies (e.g. telepsychiatry) to better serve remote populations
 - Increase person-centered services and respect for the role of the family
14. There are still thousands of ACA hardship exemption applications that have yet to be processed, including those that have been processed incorrectly. These problems have all contributed to low enrollment, as many AI/AN are still confused about the benefits of the ACA and see no reason to sign up. As there seems to be no acute solution for the near future, there is one way to dramatically improve AI/AN enrollment. There needs to be an establishment of an AI/AN call center that would be more culturally sensitive, know the special AI/AN provisions, and in certain cases be linguistically equipped to answer calls where the caller only speaks their native language.
15. At this time the ACA impact for AI/ANs is unclear, but there is potential for innovative, far reaching treatment and prevention programs, an emergency demonstration project, education and trainings, school based centers, leadership development, work force development, research, data base development, loan repayment, and reimbursement improvement for behavioral health services. Every opportunity from the ACA needs to be supported by all policy developers.

CONCLUSIONS/SUMMARY

The health delivery system remains critically challenging for all rural Americans. This challenge is basic, but there needs to be policy, support, and advocacy to maintain at the very least, a minimum threshold of services. This minimum is being challenged from the ACA and resulting policy. The closing and potential closing of more Critical Access Hospitals is a prime example. The lack of access for rural residents to basic emergency services, primary and mental health services, and reasonable local inpatient services will cost lives.

We still live in an environment where rural residents (especially elders) feel an urgency to move to “town” when they retire so they will have access to health services. It is unfortunate in our great country that elders feel the necessity to literally move from their lifelong residence in order to access health services. Further, those who cannot afford to relocate simply go without services. Now, the likely potential for access to health services in “small towns” is slowly being eliminated. Every rural clinic and Critical Access Hospital that closes negates even this option for access to services. If this trend continues, all of our rural residents will be disproportionately negatively affected to access basic primary care services. Action needs to be taken in concert with NRHA to advocate for continued access to services in rural areas.

History and current health statistics remain especially alarming for AI/ANs. Addressing health equity continues to be a complex undertaking for the 567 federally recognized tribes, with varied cultures, infrastructures, and environments. There continues to be barriers, including poverty, alcohol use, unintentional injuries and deaths, and complexity of tribal structures and jurisdictions. There needs to be improved methods and processes developed to improve the accuracy of data for smaller population groups.

When Congress passed the ACA, it also permanently reauthorized the *Indian Health Care Improvement Act* (IHCA). The IHCA provides new authorities for AI/AN health services, however, additional actions are needed to fully implement the ACA. Specifically, more needs to be done on behalf of the IHS and Congress to take advantage of these new authorities that have the potential to start to reduce the health inequities for AI/ANs. The battle for IHCA renewal was over ten years in the making. When this historic law was signed, Indian Country was elated by the promise of a new and more efficient health service delivery system for AI/AN people. However, four years later many of the provisions of the ACA remain unfunded or not implemented, and in many ways, represent yet another broken promise for AI/ANs.

It is incredibly painful to continue to report that the health system is broken in this country. There remains substantial differences of health equity for AI/ANs and a critical need for continued advocacy from NRHA. The relationship between NRHA and AI/AN policy support has been extremely beneficial. As rural AI/ANs continue to literally fight for their lives, advocacy and collaboration from NRHA is a key asset in these efforts.

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