

National Rural Health Association Issue Paper

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American Indian and Alaska Native Health Issue Paper

Background and Justification

American Indians and Alaska Natives (AI/ANs) have significantly worse health status compared to the rest of the nation. Approximately 50 percent of AI/ANs reside in rural areas, some on reservations, others in organized communities that are all underserved isolated rural areas where health services are often a conglomerate of overburdened physicians, limited clinical space and resources, underutilized rural hospitals, and burdensome travel distances.

American Indians and Alaska Natives have the highest rates of poverty in America, accompanied by lower education levels, poor housing, and transportation problems. Many of the diseases that are disproportionate in the AI/AN population are preventable and/or treatable. Historic and persistent underfunding of the Indian health care system has resulted in problems with access to care, including primary health care, specialty medical care, long-term care, and emergency services. Suicide and other violent deaths remain a paramount concern for tribal communities. Youth suicide and violent deaths have reached epidemic proportions.

American Indians and Alaska Natives suffer from historic violence that has influenced their lives and is reflected in higher than average rates of suicide, homicide, domestic violence, child abuse and substance abuse.¹ Losing land, culture, and lives through systematic government attempts to assimilate indigenous populations by changed diet, culture, and forced relocation can be linked to today's tribal health challenges. Forcing children into Bureau of Indian Affairs (BIA) boarding schools led to cul-

tural distortion, physical, emotional and sexual abuse, the spread of diseases like tuberculosis, and the ripple effect of loss of parenting skills and communal grief. More recently, exceptionally high numbers of Native children have been placed in non-Indian foster care and other residential placements continuing the unnecessary trauma. These combined experiences continue to result in escalating rates of depression, alcoholism, suicide, and violence in tribal communities.

The National Survey on Drug Use and Health Report illustrates recent studies that show higher rates of substance use among AI/ANs compared with persons from other racial/ethnic groups.² Among AI/AN youth between the ages of 12 and 17, the rates of past month cigarette use, binge drinking, and illicit drug use were higher than those from other racial/ethnic groups.

Further, available data gleaned from the Substance Abuse Mental Health Services Administration (SAMHSA) Treatment Episode Data Set for American Indian and Alaska Natives reports information on admissions to publicly funded substance abuse treatment facilities that clearly shows a substantial increase of admissions for illicit drugs from approximately 9,000 admissions in 1994 to 16,000 admissions in 1999.¹

One of the fastest growing areas of concern is the prevalence and implication of methamphetamine use by AI/ANs. Jan Morley, Assistant U.S. Attorney, informed a gathering of tribal representatives from the 36 states with tribal governments that "methamphetamine has become

an epidemic in our Indian Country. We're losing our children to this drug war, and we need to take our children back."³

Federally recognized tribes in the United States have a special relationship with the federal government. When the AI/AN populations ceded their land to the United States, they were promised, among other things, health care. The federal government's obligation to provide health care to AI/ANs has been further defined through numerous treaties, legislation, and federal court decisions. Despite this legal requirement, AI/AN health-care services continue to be inadequate, complex, and multifaceted; and the health status continues to decline. Most AI/ANs do not have private insurance, relying on the government to fulfill its legal obligations to the AI/ANs. In a report released in July 2004, the U.S. Commission on Civil Rights found the federal government spends about \$5,000 per capita each year on health care for the general U.S. population and \$3,803 on federal prisoners.⁴ In comparison, the federal government spends only \$1,914 per capita on Indian health care, roughly half of what it spends for federal prisoners.

Health disparities between AI/ANs and the majority population in the United States are substantial and persistent. The federal government has attempted to fulfill its promise of health care through the Indian Health Service (IHS). However, funding for these services has never been funded to meet the identified needs. Rather the funding has been limited to 40 to 60 percent of need and insufficient to maintain health status.⁵ Tribally managed health facilities and Urban Indian health clinics are also funded through the IHS and comprise the current IHS, Tribal, and Urban system("I/T/U" system).

There remains a substantial underenrollment of AI/ANs in the Medicaid, State Children's Health Insurance Program (SCHIP), and Medicare. While the revenues for services provided to AI/ANs who are enrolled in these programs may make it possible to augment services and expand access to health care, there is little information available on the extent to which eligible AI/ANs are enrolled in Medicaid, SCHIP, and Medicare. Information on unique barriers to enrollment that may exist and on effective strategies that might be implemented to facilitate enrollment of AI/ANs into these programs is also limited.

American Indian and Alaska Native Population by Definition⁶

Definition	Who is Included	Estimated number
Tribal definition (BIA estimate)	Enrolled members of federally-recognized tribes	1.8 million
IHS definition (FY 2000-2001)	IHS active user population (AI/AN who live close to I/T facilities and are enrolled members of federally-recognized tribes plus their descendants)	1.59 million
Census definition	Self-identified as only AI/AN	2.48 million
	Self-identified as AI/AN alone or in addition to other racial categories	4.12 million

(Census data: U.S. Census Bureau, 2000)

Federal Duty to Provide Health Services

American Indians and Alaska Natives ceded more than 400 million acres of land in exchange for promises that included commitments to provide health services. The federal delivery of health services and funding of tribal and urban Indian health programs to maintain and improve the health of Indians is required by the federal government's historical and unique legal relationship with the Indian people, as reflected in the constitution, treaties, federal statutes and the course of dealings of the United States.

Very Brief History

1849 - In 1849, the Bureau of Indian Affairs (BIA) was transferred to the Department of the Interior, thus moving the responsibility for Indian relations — including health — from the military to civilian authorities. It was not until 1910, however, that Congress began to appropriate funds to the BIA for Indian health services. Reports of deplorable health and sanitary conditions on Indian reservations led to a nearly 100 percent increase in appropriations for Indian health by 1916. Indian health programs continue to receive annual appropriations from Congress. Today, those appropriations are made primarily to the Indian Health Service (IHS), an agency of the Department of Health and Human Services. Those appropriations still do not meet the identified level of need as identified by numerous IHS studies and documents.

1921 - The most significant Indian welfare law of the early twentieth century was the enactment in 1921 of a permanent authorization of appropriations "for the benefit, care, and assistance of the Indians throughout the United States", 25 U.S.C. § 13. Popularly called the *Snyder Act*, this law authorized the Secretary of the Interior to supervise a variety of actions for the benefit of Indians, including "relief of distress and conservation of health," development of water supplies, and employment of physicians. The Snyder Act remains in force today and serves as an authority for annual appropriations to the Bureau of Indian Affairs and the Indian Health Service.

1934 - Congress authorized the Secretary of the Interior to contract with states and territories for education, medical attention, and other welfare

activities for the "relief of distress" of Indians in the states and territories using federal funds appropriated for this purpose. Popularly known as the Johnson-O'Malley Act, the law was later amended to authorize contracting with colleges, universities, schools, and private corporations. Congress continues to appropriate funds under the Johnson-O'Malley Act authority to the BIA for Indian education programs.

1955 - The responsibility for American Indians and Alaska Natives health care was transferred to the Indian Health Service (IHS), Transfer Act of 1954.

1975 - The Indian Self-Determination and Education Assistance Act (P. L. 93-638) was enacted. It authorized tribes to assume responsibility for BIA and IHS programs.

1976 - The *Indian Health Care Improvement Act (IHCIA)* (P. L. 94-437) was enacted. It included the initial authorization for IHS and tribal health programs to bill Medicare and Medicaid. The IHCIA has been reauthorized four times, most recently in 1992. The act is currently in hiatus, awaiting reauthorization.

1997 - The Balanced Budget Act, State Children's Health Insurance Program (SCHIP), is a regulation issued prohibiting states from imposing "premiums, deductibles, coinsurance, copayments, or any other cost-sharing charges on children who are American Indians or Alaska Natives."

2003 - In the Medicare Prescription Drug, Improvement, and Modernization Act, Congress included Indian-specific provisions to ease participation by IHS, tribal, and urban Indian pharmacies, which are often the only pharmacies available in Indian communities.

The Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638) and its amendments allow tribes and tribal organizations to contract and compact with the federal government to operate the programs that would otherwise be provided by the IHS and other government agencies. In 1976, the IHCIA, (P.L. 94-437), Title V, authorized federal funding for urban Indian clinics. Taken altogether, this is called the "I/T/U" which refers to the services provided directly by the Indian Health Service

("I"), tribally operated programs ("T"), and urban Indian clinics ("U").

The I/T/U distinction is important for understanding the organizational structure and locus of decision-making. Each of the 562 federally recognized tribes may choose how to receive their health services. Some tribes elect to operate their own programs using federal dollars transferred through contracts or compacts. Smaller tribes often form consortia or tribal organizations to operate their programs. Some tribes prefer for the federal government to administer programs directly through the 12 IHS Area Offices and their respective service units and/or clinics. Urban programs are generally organized as local private-non-profit entities governed by a board of directors.

Strategies/Action Steps

There are significant issues that affect the reliability and usefulness of the estimates of AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare. The definition of the AI/AN population is different in different data bases. The 2000 Census data used to generate eligibility estimates includes multiple-race responses that appear to include a significant number of people that may have some AI/AN heritage but who are not members of federally recognized tribes. In addition, some concerns have been expressed about the possibility that the Census disproportionately miscounts the AI/AN population. Data on AI/AN enrollment in Medicaid, SCHIP, and Medicare are based primarily on self-reported primary racial identification or, in some cases, on eligibility worker observational reports. Some evidence suggests that misidentification of race in enrollment data may be a significant problem. The differences in definition and identification of AI/AN race between the eligibility estimates and the enrollment estimates have a substantial impact on the reliability and usefulness of the comparison of these estimates and estimation of the extent to which underenrollment may be present in each program.

The SCHIP has been problematic for tribal governments due to authorizing legislation that negates a tribal government's ability to directly access SCHIP funds. Tribes have attempted to access SCHIP funding through the states and a

cadre of problems have occurred across the country. Some states had progressive Medicaid enhanced programs that seemed to serve urban areas, but their enhanced programs negated tribal ability to access the total federal allotment for each state, thus defaulting on millions of dollars that were inaccessible for respective tribes in those states. This problem could be resolved if tribal governments were not relegated to working through a subordinate of the federal government (a state). Historically, tribes have often had strained working relationships with states that complicate tribal-state communication and negotiation.

An examination of the structure and operation of Indian health programs in the country reveals that Indian health facilities have received adequate ratings in accreditation surveys, however, the system faces significant problems with the retention and recruiting of qualified health service providers, compounded by aging and/or lack of efficient facilities. These factors all contribute to a lack of culturally competent professionals which affects diagnoses or late diagnosis and treatment of diseases.

Behavioral Health Workforce Challenges:

Licensing and accreditation bodies require a credentialed behavioral health workforce. Indian Country has a growing number of master's and doctorate level licensed and credentialed tribal professionals, but not enough to meet the need. Many tribal organizations hire non-Indian professionals who meet the accreditation standards but lack the cultural congruence with the local community. Recruitment and retention of both tribal and non-tribal professionals remains an ongoing challenge. Additionally, the non-Indian professional most often is a product of a mainstream, medical model education that views the role of an expert as the licensed professional. Non-Indian behavioral health clinicians who work for tribal organizations revealed that their early professional work experiences within Indian communities was, in part, a personal journey of "unlearning"—where they slowly realized that the "expert" of tribal behavioral health is the local tribal community, not the "educated" professional.

Evidence-Based Practices:

A new challenge area for tribal behavioral health is the growing institutionalized interest in evidence-based practices. Both state and federal funding sources are now requiring the use of evidence-based practices as part of funding requirements. Tribal behavioral health practitioners are also vigilant about treatment efficacy, but know that treatment efficacy for minority populations is tied to cultural and community knowledge. Clinical trials that produced the approved list of evidence-based practices were normalized on non-tribal populations. Tribal practitioners' concern about the efficacy and cultural fit of evidence-based practices with tribal culture-based populations are valid. Tribal and other minority populations are advocating for equal attention to local practice-based evidence.

The following research projects would provide valuable information for developing Indian health policies and defining needs:

- The current system for determining rural costs is backwards, resulting in data that misrepresents rural needs. To be able to determine what the actual level of need is in Indian health programs, not a formulated adjustment, the following calibrations must be developed to determine actual cost, as currently found in the data centers below:
 1. Allowable costs as determined by tribal governments and CMS
 2. Adjusted costs based on what is actually spent for each patient
 3. Rural-based formulas for costs, not adjusted urban formulas
 4. Rural-based definitions for "weighting" and "standardizing" cofactors for data analysis
 5. Cost analysis based on the public health model of service delivery
- It will be difficult to determine all of these costs mentioned above unless there is a design change of the cost report that is representative of how the business of providing health services needs to be done. It is imperative that this redesign be done and approved by grassroots rural providers. This cost report

design should have tribal consultation and include cost centers that:

1. Are reflective of appropriate productivity levels.
2. Are based on relative values of costs of services provided.
3. Include reimbursable preventative services.
4. Include an allocation of real travel costs to provide services.
5. Include reimbursement for telehealth.
6. Recognize tribally certified health care professionals.
7. Have cost allocations and adjustments based on the public health model.
8. May use flat rates (all inclusive rate) because of the burden of administration of fee for service expenses (i.e. computer programs, additional staff, space).
9. Include additional costs for health education of family members for caring for other family members in their residence, extended stays in hospitals for safety of the patient who does not have or cannot ensure ability for safe transportation (e.g. geography, weather) or be isolated from access to health professionals (i.e. lack of phone service).

Other Areas:

- Matching Medicaid paid claims data with IHS data on active users to better understand the relationship between Medicaid and the Indian health system.
- Using Social Security numbers as identifiers in the two datasets to allow researchers to successfully match many of the individuals who participate in both health systems, but the situation is currently complicated by state ownership of the Medicaid claims data.
- Measuring improvements in quality of care and health outcomes from the provision of Medicaid and Medicare reimbursements to the Indian health system. Changes in acute and chronic illness, prenatal care, and infant mortality could be analyzed with data available from IHS publications or the IHS web site. The IHS epicenters are currently doing work along these lines.

- Forge collaboration between Indian health organizations and research institutions to build capacity for policy and data analysis by AI/ANs (e.g. NIH, CDC).

Recommendations

(Some of the following recommendations were identified from Medicaid Roundtable Discussions, Washington D.C., Summer 2005)

Policymakers are encouraged to “first do no harm” to Indian health programs. To protect Indian health programs the following provisions are recommended for inclusion in any legislation and regulations.

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 (e.g. 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. Specify that AI/AN should be exempt from Medicaid premiums, deductibles, co-payments. (Enrollee cost sharing only shifts those costs to I/T/U programs.)⁷
4. Specifically exempt AI/AN from enrollment waiting lists, estate recovery, and mandatory health plan enrollment.⁷
5. Include language stating that the Indian health system will be fully reimbursed for all covered services provided to eligible AI/ANs. If management of Medicaid services is turned over to the private sector, the I/T/U should be deemed eligible for payment without penalty, as though they were providers under the plan. Language should specifically address requirements for private sector Medicaid contractors to reimburse I/T/U with and without a contractual relationship.⁷
6. State that AI/AN 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 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.
7. In new legislation and regulations, reference existing Indian-specific Medicaid provisions and Indian law that is not part of the Social Security Act, to ensure coordination with current laws and regulations.⁷
8. In new legislation and regulations, reference existing Indian-specific Medicare and SCHIP provisions and Indian law that is not part of the Social Security Act, to ensure coordination with current laws and regulations.
9. If new legislation creates special programs to address health disparities, inequities or access to care, include AI/AN in lists of target groups.⁷
10. Services that are likely to improve AI/AN health, such as community-based diabetes prevention programs, suicide prevention programs should be identified and included in benefit packages.⁷
11. Seek opportunities to improve access to all Medicaid programs for eligible AI/AN by including provisions that address access barriers identified by CMS and its Tribal Technical Advisory Group.⁷
12. Seek opportunities to improve access to all Medicare and SCHIP programs for eligible AI/AN by including provisions that address access barriers identified by CMS and its Tribal Technical Advisory Group.
13. If Medicaid reform proposals include Medicaid Administrative Match (MAM), specify that tribes and tribal organizations are eligible to receive the MAM funding and that states should develop MAM agreements with tribes.⁷
14. Funding should be provided to I/T/U for implementing new programs and regulations.⁷

15. Explicitly require that CMS and states assess impact on tribes and conduct tribal consultation prior to issuing regulations, policies or State Medicaid Plans that affect AI/AN.⁷
16. Congress should direct CMS and states to monitor and report on the implementation of Medicaid changes and their impact on AI/AN access and I/T/U reimbursement. Funding should be provided to CMS for this activity and to improve databases.⁷
17. 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.
18. Retain current types of reimbursement mechanisms for I/T/U so that administrative costs are not increased (All Inclusive Rate).
19. Continue the current 100 percent FMAP for all Medicaid services provided to AI/AN enrollees through I/T facilities and clarify its coverage to extend to medically necessary services referred through I/Ts.
20. States should be prohibited from offering benefit packages to AI/AN Medicaid beneficiaries that are less in amount, duration, or scope than the benefits packages they offer to any other group of Medicaid beneficiaries anywhere in the state.
21. The “most favored nation” rule should apply with respect to all AI/AN Medicaid beneficiaries, regardless of whether they live on or near a reservation.
22. 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.
23. Access to CMS program eligibility should be simplified to improve AI/AN outreach, increase enrollment, and improve eligibility determination. Provide funding to Indian

health programs for conducting outreach and linkage activities. Simplify the application process by reducing required documents, providing “real time” determination, and allowing self-declaration for residency and income. Allow Tribes the option to provide program enrollment and eligibility determination on site.

24. If Medicaid reform includes managed care, Indian programs and AI/AN people must have the following flexibility:
 - Choice - AI/AN individuals should be allowed to choose an Indian health program or a managed care plan, as they prefer (dual citizenship).
 - Default assignment to Indian health program - Individual AI/ANs must NOT be involuntarily assigned to a non-Indian managed care plan when an Indian health program is available.
 - Out-of-Plan Service - Medicaid must require managed care plans or contractors to pay Indian health providers when providing services to AI/AN people who exercise their right to use tribal/IHS programs.
25. All venues for the use and reimbursement of telehealth technologies should be pursued to relieve the disparity of access to all health services (e.g. home, specialists, follow-up treatments).
26. All available disciplines (e.g. health, justice, education, homeland security) from all levels of government, including tribal, state, and federal entities need to collaborate to address the pandemic of methamphetamine use.

In summary, the health delivery system is broken in this country. The attempt in the early 1990s by the Clinton administration to reform “managed care” resulted in “managed finances,” and put the country in such a tail spin it still has not recovered. There needs to be further research done that conclusively determines reimbursement needs to maintain a minimum threshold of services, i.e. inpatient services, emergency services, and mental health services. Typically we find patients 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.

From the reservation patient's perspective, there are multiple barriers to access specialized services. 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 addresses these expenses. These out-of-pocket costs create an extra hardship for our residents, who may choose to feed their families and bear the con-

sequences of postponing their medical appointment until they require extensive costly procedures to save their lives. Certainly, telemedicine will have a role in reducing some of these disparities, but the policies need to be further developed from a rural cost perspective.

The impact on rural America and the Indian people who reside there, has had unfair consequences for: access to services, use of appropriated dollars, provider reimbursement challenges, forced enrollment in managed care organizations, limited cooperation from state Medicaid programs, limited respect for the status of Indian people who are dual citizens, and a general lack of understanding by policy makers of the plights of everyday life in rural America. Rural American Indians and Alaska Natives are literally fighting for their lives.

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