# THE ACCIP HEALTH REPORT:

# THE STATUS OF INDIAN HEALTH CARE PROGRAMS IN CALIFORNIA

A Report by the Advisory Council on California Indian Policy September, 1997

# ACCIP HEALTH TASK FORCE

George Freeman, Chairman

Aileen Bowie-Meyer, Co-Chair

Art Acoya

**James Crouch** 

Leah Exendine

T.J. Harwood

Anthony Largo

David Lent

Benjamin Magante

Peter Masten, Jr.

Dennis Magee

Dianne Parr-Fulbright

Martin Waukazoo

**Dennis Heffington** 

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#### **SUMMARY**

This report is an assessment of the status of Indian health care programs in California. Principal issues identified by tribes, tribal health programs, urban health programs, non-federally recognized tribes, and persons of Indian descent eligible for services from the IHS, are analyzed and presented in significant detail in support of the recommendations included in Section II of the report.

In light of the identified funding deficiencies for California Indian health programs, testimony was provided wherein the issue of "Agency level assessments" on the IHS budget was raised and identified as an area to be studied as a source of funding that should be utilized to meet the unmet need in California. Sections III through VI provide historical background and chronology of events in the history of health services in California and document the tribes' efforts to bring about equity in funding for health care services for the Indian people of California. A summary of testimony presented to the Health Task Force is included in Section V of the report.

#### RECOMMENDATIONS

1. Additional funding required for comprehensive health care services: There are several different standards against which the level of funding necessary to operate a comprehensive health program for California Indians can be measured, including comparisons with other Indian Health Service (IHS) areas, existing IHS Resource Allocation Methodology, local market comparisons, and national expenditure comparisons. Only the local market comparison methodology adjusts adequately for regional differences in the cost of providing health services and is free of political considerations. After surveying the California indemnity insurance market and the more directly analogous Health Maintenance Organization market, it was decided that the most appropriate comparative cost would be \$2,400 per person per year. This figure represents the 1996 cost of providing comprehensive health care services in California.

To calculate the level of additional funding from the Indian Health Service, two additional planning assumptions would have to be made. The first is that the maximum penetration of the census population by the IHS funded health care system is approximately 66%. This percentage is higher than the current penetration rate of 52%, which is somewhat depressed compared to historic rates and reflects the impact of consistent and significant under-funding. The second planning assumption is that 33% of the individual Indians who seek care at IHS funded Tribal Health Programs will be covered by alternative insurance primarily, Medi-Cal, the California Medicaid program. This rate of coverage is higher than the rate on the IHS maintained RPMS data base but compares with rates found by Dr. Trudy Bennett in her 1994 study of Indian Health Care in California and information from a cross section of Tribal Health Programs. Given these planning assumptions, the calculation for additional funding from the Indian Health Service would be as follows:

 $122,004 \times .66 \times .66 \times 2400 - 72,425,848 = 55,122,152$ 

(Service population times the penetration rate, times the rate of uninsured users, times the market cost of comprehensive care, minus the available IHS funding level, equals the level of under-funding for tribal Health programs in California.)

2. The California Contract Health Service Delivery Area (CHSDA): The CHSDA currently consists of 37 rural counties. These counties were first identified administratively by the Indian Health Service as the official IHS service areas and were later codified in statute as part of the Amendments to the Indian Health Care Improvement Act of 1988 (Pub. L. No. 100-713). Currently only two of the 37 CHSDA counties lack federally recognized tribes—Mariposa and Trinity. There are seven additional counties not included in the CHSDA but could join it as a result of the granting of federal recognition to tribes located in these counties. These counties have large Indian populations, significant portions of which are Indians of California.

It is therefore recommended that these counties be brought into the CHSDA as soon as possible and that funding for each of them be added to the IHS program within the area.

Using the same funding formula identified above, the new funding necessary to fully establish a comprehensive health program for the identified Indian population is as follows:

Marin County	population	963	additional cost	\$	978,531
Napa County	population	781	additional cost		816,488
Kern County	population 7,	329	additional cost		,662,029
Merced County	population 1,	680	additional cost	1	,756,339
Stanislaus County	population 4	,363	additional cost		,561,254
Monterey County	population 3	,136	additional cost		,278,488
San Luis Obispo Co.	population 2	,364	additional cost	2	2,471,420

#### TOTAL ADDITIONAL COST

\$21,524,549

- 3. **Contract Health Services:** The Contract Health Service funding shortfall for California is \$8 million dollars, and is included in the global request for comprehensive health services.
- 4. Small Tribes Facilities Program: It is recommended that Congress fund the Small Tribes Facilities Program in order to correct the major deficiencies that exist for tribally operated health programs in California. Approximately \$10 million dollars is required to correct identified deficiencies in tribal health programs and alcohol programs resulting from Deep Look Surveys conducted by the IHS Central Area Office. IHS must be directed to survey all tribal, urban and alcohol programs. Information included in this report shows that only 24 health programs and three alcohol programs are included in the most recent Deep Look Survey, which indicates that approximately \$5,385,061 is required to correct all existing deficiencies. This figure is calculated without the inclusion of information from and deficiencies of four residential alcohol programs, nine tribal health programs and seven urban health programs.
- 5. Construction of Youth Regional Treatment Centers: It is recommended that \$10,000,000 be provided by Congress for construction of two Youth Regional Treatment Centers in California as authorized in Pub. L. No. 94-437 as amended.
- 6. Environmental Health: It is recommended that the IHS work with the Bureau of Indian Affairs (BIA), the Environmental Protection Agency (EPA) and the tribes to address the environmental health issues directly related to the dumping of toxic waste on California Indian reservations. There have been no definitive studies completed to identify the cost of clean up of the most dangerous—Laytonville and Torres Martinez—however, the cost could be in the hundreds of millions of dollars. This is an urgent situation and must be

acted upon without haste.

7. Sanitation facilities funding requirements: It is recommended that \$18,761,000, the underfunded amount in sanitation facilities, be made available. These facilities are significantly underfunded for FY 96. The total project cost was estimated at \$34,926,100, but the actual funding plan was \$16,165,100.

# 8. Urban Indian Health Program recommendations are as follows:

- a. Health care reform legislation must include provisions for Essential Community Provider status, 100 percent cost-based reimbursements, grant subsidies, residency programs, and allocations of capital funds. This status, available to tribally operated programs, should be granted to all current and future Urban Indian Health Programs.
- b. Immediate transitional funding is vitally needed by Urban Indian Health Programs to build the infrastructure necessary to compete in a reformed health care delivery system. Any health care reform legislation must include the infusion of these capital dollars. Immediate technical assistance must be provided in the areas of managed care systems, capitated health care systems, computerization, quality assurance, cost accounting, management information systems, networking, and other related systems needed to move successfully into health care reform.
- c. The present funding level of Urban Indian Health Programs must be increased to be commensurate with the average level of need funded for other IHS programs. Current level of need funded for tribal and IHS-operated programs is approximately 67%, whereas the level of need funded for Urban Indian Health Programs is approximately 22%.
- 9. **Traditional Indian Medicine:** In the area of Traditional Indian Medicine, it is recommended that the IHS, at the headquarters level, collaborate with the Health Care Finance Administration to reform reimbursement regulations to include payment for traditional practitioners.

#### 10. Recommendations regarding the IHS Scholarship Program are as follows:

Amend 25 U.S.C. § 1603 to read:

"Indians" or "Indian," unless otherwise designated, means any person who is a member of an Indian tribe...except that, for the purpose of sections 1612, 1613, and 1613a of this title, such terms shall mean any individual who (1) irrespective of whether he or she lives on or near a reservation, is a member of a tribe, band, or other organized group of Indians, including those tribes, bands, or groups terminated since 1940 and those recognized now

or in the future by the State in which they reside, or who is a descendant, in the first or second degree, of any such member, or (2) is an Eskimo or Aleut or other Alaska Native, or (3) is considered by the Secretary of the Interior to be an Indian for any purpose, or (4) is determined to be an Indian under regulations promulgated by the Secretary.

#### OR

Amend § 1613a to incorporate the broad definition of "Indian" applicable to §§ 1612 and 1613.

In either case, the amendment should be written to apply retroactively and mandate that those who were denied scholarships due to the IHS interpretation of the 1992 amendments should have their alternative loans repaid.

# 11. Data collection and reporting recommendations are as follows:

- a. It is recommended that IHS work with tribes and tribal contractors to evaluate IHS data reporting needs. Are items required in the past necessary in the current healthcare system (e.g. blood quantum)?
- b. It is recommended that IHS work with tribes and tribal contractors to identify an electronic solution to meet the data reporting needs of IHS at headquarters and area office level, as well as the needs of state governments, tribal governments, healthcare providers, insurers (including HMOs, PPOs), accrediting and licensing agencies, local program administrative and financial management, and local programs for other system needs.
- c. It is recommended that IHS work with tribes and tribal contractors in evaluating an electronic medical record as replacement for Resource and Patient Management System (RPMS). The system should be commercially available, interface with other computer systems (e.g. financial and billing), be modifiable by users to meet their specific needs (e.g. tribe of enrollment), be user friendly, contain rigid security systems for protection of the data, and support creation of user-defined reports.
- d. It is recommended that in the interim, the RPMS be revised to define/redefine data dictionary; capture required data to support patient and insurance billing; allow easy modification of data fields to capture data required by states; contain user-friendly report generation capabilities across all modules; accept/import data from other software programs (e.g. reference laboratory results, coding system upgrades); interface with other commercially available software programs; and capture and report quality indicator data.

- e. It is recommended that Congress allocate funds for ongoing staff training in the RPMS. Congress should also allocate funds for video conferencing through partnerships with local community colleges, libraries or health programs and IHS trainers.
- 12. Creation of Statewide Indian Health Advisory Board: Congress should create and fund a state-wide advisory board made up of California Indians, including representatives designated by federally-recognized and unacknowledged California tribes and other eligible Indian population groups, to consult with and advise the IHS in an oversight capacity, regarding health care delivery issues and in updating tribal service contracts.

# I. HISTORY OF HEALTH SERVICES IN CALIFORNIA

A. Recent History of Indian Affairs in California: California Indian Population and Demographics

California is home to the largest American Indian/Alaska Native population in the Nation. According to the 1990 U.S. Census projections for 1995, the California American Indian and Alaskan Native population is 309,238. (Based upon the 1990 U.S. Census and projected according to vital event data for 1983-1992.) [Indian Health Service, Regional Differences 1990-1995.]

There are 104 federally recognized Indian tribes in California with many others seeking federal recognition.

Many of California's tribes are too small to operate or support full-fledged health centers or even health stations (operating less than 40 hours per week). Many of these tribes have joined with other tribes in their geographical area to form health consortiums in order to provide the needed health care services to their members. (See Exhibit 1.)

There are 26 rural tribal health program operating units that administer 54 health facilities, as well as seven urban health care programs. The IHS California Area Office CAO also provides support for seven contract health care/community health representative programs. All of the 42 substance abuse/mental health programs in California are operated by tribes, tribal Organizations/Consortiums, or Indian Organizations and funded by the IHS. [California Area Office Profile, Indian Health Service, 1994-1995; see Exhibit 2.]

To understand the current predicament of California Indians and their health status, one must understand the recent history of Indian Affairs in California. Prior to the implementation in the early 1950's of the Federal policies which were intended to terminate the special status of and services to Indians, the federal government provided health care to the California Indians much the same as it did to Indians elsewhere in the United States. When the era of "termination" was in full swing, California Indians were targeted to be among those chosen to have their relationship with and services from the federal government terminated. As a result, the two hospitals for Indians in California were closed and the federal government withdrew all health care services for the Indian people in California.

The termination policy proved to be a resounding failure. It was repudiated in 1970 and replaced with Self-Determination, which is still the prevailing policy in Indian Affairs. In fact, most of the California Indians whose status as Indians was terminated have been subsequently reinstated through litigation or legislation. At present there are more than 85 Indian reservations in California located in remote and rural areas which for the most part do not have access to comprehensive health care systems.

An issue critical to understanding the current situation is that the state of California

proved totally incapable of taking care of its Indian population due to their location in the remote and rural areas of the state. Studies of the health status of California Indians in the late 1960's showed that their health was the worst of any population group in the state, and that the health care which was available to others in the state was not accessible or available to the Indians. One reason that the state was unable to meet the needs of the Indians was that most doctors in the rural areas would not accept Medi-Cal patients, a problem which persists today and which continues to make the California's state-funded health care inadequate for the Indian people on and near the reservations. As a result, the Indian people began to organize their own health outreach programs, which received a total of \$200,000 from the state and federal government in 1970. This was the beginning of the tribal health care system that exists today.

Today, the tribes maintain full responsibility for the development and operation of their own health care facilities, programs and services pursuant to Pub. L. No. 93-638 Indian Self-Determination Area contracts. None of the tribal facilities and programs currently operating in California originated as facilities previously operated by the IHS, as is the case in most other IHS areas. The California programs were not designed, built, staffed, or equipped using IHS Health Facility Planning criteria. Because of this evolution, California programs, although pioneers of Pub. L. No. 93-638, have always been at a disadvantage due to underfunding. This problem was made worse by the fact that the IHS did not allow for the establishment of a database necessary to allow California programs to fully participate and compete equitably in all IHS-funded programs. Additionally, tribal service areas have evolved reflecting tribal demographic concentrations and political negotiations by the tribes and their health consortiums, not by IHS perceived economies of scale.

Until recently, the IHS CAO did not have data to fully support its reports to the tribes and to Congress. During 1984, IHS began an aggressive program to provide medical information systems for over 500 IHS-supported facilities across the nation. However, in 1986, while data pertaining to the health status of all other IHS programs and areas had their limitations, information about Indians in California was practically nonexistent. This information was relayed to Congress in the 1986 Indian Health Care Report prepared by the Office of Technology Assessment. The Report concluded that "Indians in California experience much the same health problems as Indians in other parts of the country."

# B. Tribal Health Programs in California Prior to the Passage of Pub. L. No. 93-638

Prior to the implementation of the Indian Self-Determination Act, all Indian tribes and consortiums contracting under the Buy Indian Act [25 U.S.C. § 47] were incorporated in the state of California as non-profit corporations with boards of directors governing the program. Today, all of the tribally operated programs are contracted under Pub. L. No. 93-638 with the exception of seven alcohol programs. California tribes have built a health care delivery system in spite of the barriers to access not experienced by most other areas. Prior to *Rincon vs. Harris* [618 F.2d 569 (9th Cir. 1980)], California programs shared in the Hospital and Clinics line item only. All of those programs that were being provided to Indians in other areas by the Secretary were not made

available to tribal health programs in California because of historical and inappropriate allocation methodologies. No California tribal health program has ever been on the IHS Facilities Construction Priority List. We have only accessed the Maintenance and Repair line items in the IHS budget within the last five years. Facility construction and facility lease costs have also been a problem. All health program facilities in California have been built by tribes utilizing donations, Community Development Block Grants and donations from private foundations, or leased from private property owners. When Pub. L. No. 93-638 became law, individual tribes in California were given access to the Pub. L. No. 93-638 contracting mechanism. However, the California Rural Indian Health Board, Inc., a consortium of tribes, was prevented from contracting and only after pursuing legal avenues in Federal Court were the tribes successful in gaining access to the benefits of the Indian Self Determination Act, Pub. L. No. 93-638. Implementation of Pub. L. No. 93-638 has been a problem in California on a continuing basis since the law was passed. The Indian Health Service has not adequately trained and/or directed its staff at the Area Office level to appropriately implement amendments and new provisions in order to facilitate tribal contracting.

#### C. IHS Presence in a Totally Contracted Program Area

There are no IHS inpatient facilities in California. The IHS provides no direct care services in California. It is highly unlikely that IHS will ever be in a position to provide direct services to Indian beneficiaries in California given the current state of the IHS budget and the fact that no IHS operated facility has ever been proposed for construction in California. With the implementation of Amendments to Pub. L. No. 93-638, the downsizing of the Federal government and the redesign of the IHS taking place at this time, it is critical to tribal programs in California that the IHS be prepared to continue to perform those inherently federal functions that are required to maintain the efficient operation of contracted programs and services.

Tribal participation in the identification of those residual functions to be provided by the IHS has been limited, and the CAO has had little interest in negotiation those functions with the tribes. It is the position of some California tribes that in this area we do not need an Area Office with the same set of services as an area with hospitals and service units. In the California Area, we do not have federal employees of the Government providing direct care services to the eligible population requiring federal supervision. There is, however, a tremendous need in the areas of tribal consultation, management systems development, board training, facilities management, systems development, and accreditation preparedness.

Tribes and Tribal Health Programs have expressed a need for training and technical assistance that is not now provided by the CAO. Tribes should be able to identify the areas of training and technical assistance that they need in order to manage their programs in the most efficient ways possible. At this point in time, there needs to be a change in the priority-setting process in order to reflect the requests and priorities of the tribes.

California tribes and Tribal Health Programs have well documented needs and funding

shortfalls that the IHS has not been able to address or resolve for many years. Tribal Health Programs are exercising their rights to contract for those functions provided by the California Area Office and in that process must gain access to Headquarters-level programs and operations. This new era of streamlining government should not mean that tribal programs should have to take a single step backward. Tribes view these changes as an opportunity to maximize their abilities to provide quality health care services.

#### D. <u>Urban Health Programs</u>

For the past 30 years, California has seen steady growth in its urban Indian population. Employment and educational opportunities are incentives to urban Indian migration. A number of factors are responsible for this migration and must be considered, i.e. the General Allotment Act and Assimilation Policies; Indian participation in military service and the defense industry during World Wars I and II; the federal Relocation and Termination Policies (1945-1961); poverty and inadequate funding for reservations (1961 to present); and a general desire by the United States to assimilate Indians into mainstream America. Indian immigrants to urban areas face alienation by a dominant culture that is not sensitive to their many needs. Lacking a culturally-sensitive system of social support, many city environments turned into traps more destructive than the reservations from which many Indians had come. With a growing Indian population, which now exceeds reservation area populations, and with declining resources to support the delivery of health care services, urban Indian health security is at extreme risk.

In a 1994 report prepared by Information and Management Technologies, Inc., titled Indian Health Service, Meta Analysis, Urban Indian Health and Health Care Reform, a number of factors are found to impact urban Indian access to health care, such as culture, accessibility, affordability, and availability. The report states that unlike other migrants to American cities, urban Indians were characteristically different in several respects: 1) their inferior health status; 2) their attitudes toward acculturation: 3) the extent of their economic disadvantage; 4) their pattern of urban community residence; and 5) their mistrust of the dominant culture. First, they carried with them the staggering physical and mental health effects of reservation life. Second, unlike immigrants from other countries who wanted to become Americans, urban Indians were already U.S. citizens and did not wish to stop being "Indian" simply because they had moved to cities. Third, urban Indian migrants were at more of an economic disadvantage than even foreign immigrants. Fourth, Indian migrant families tended to live in areas scattered throughout cities, rather than in urban ghettoes. Unlike English, Irish, German, Jewish, Italian, and Hispanic immigrants who shared a common ethnic culture and wanted to live together, American Indian migrants were from many different tribes and did not form a culturally, linguistically or genetically homogeneous group. Fifth, the history of United States' dealings with Indians had engendered mistrust. The additional stress of urbanization on such a different type of migrant could only make preexisting social and health problems worse.

It is reported that Indians who migrated to the urban areas found themselves in situations of poverty, racism and discrimination much worse than those on the reservation. Social services

agencies were most times culturally insensitive and did little to serve their needs. Urban Indians most often than not sought out other Indian programs and services, or did without. Indian culture was ignored by social services agencies that attempted to address the needs of alcoholism, drug abuse, child abuse, suicide, criminal behavior, runaways, delinquency, school drop-outs, unplanned pregnancies, marital breakdowns, and State guardianship of children. Social instability is evident in the high rate of urban Indian mobility, low income levels and low level of health care services utilization.

As is the case throughout California, comprehensive uniform data on health services utilization for all urban Indians does not exist, although studies have been made of utilization at 34 urban Indian Health programs. Historically, many organizations have gathered data on the use of social and health services by urban Indians. But, without a uniform and national source of utilization data, health research, analysis, and evaluation of urban Indian health conditions and unmet needs has been difficult. Health care utilization data comes from a variety of sources. Generally speaking, available research indicates that the following factors affect utilization of health services by urban Indians: a) culture, b) accessibility, c) affordability, and d) availability.

Cultural Factors: Urban Indians are reluctant to seek help from State, county and municipal social service agencies, were perceived as culturally aggressive and insensitive to them. Urban Indians have reacted negatively to intervention methods chosen by the dominant culture to deal with their problems. Many urban Indians have reacted defensively, by deferring their own utilization of health services until such time that emergency treatment was necessary. But even emergency room treatment can be culturally insensitive, motivating urban Indians to defer followup utilization of health services. This has also been true of their utilization of prevention services. Cultural dissatisfaction with providers, even when medical services have been freely given, can deter health services utilization. Deferral of health services utilization is not limited to medical care, but also includes dental and mental health services. Unsuccessful therapies of the dominant culture have been seen as perpetuating a "revolving" treatment door; prompting researchers to acknowledge the need for more appropriate or alternative therapies. In contrast to the substantial recognition given to other urban ethnic minorities, few health services have been provided to urban Indians because little is known about their health conditions, their unmet needs, or what the effective treatment therapies should be. Urban Indians have been called the "invisible minority" because the dominant culture ignores their health care needs. It is not surprising, therefore, that health services utilization among urban Indians has been lower than that of the general population.

Public health agencies have been known to deny services to urban Indians because they believe that the IHS is the agency responsible for urban Indian health. Other problems with access include the lack of support and knowledge of the Medicaid and Medicare processes, leading to higher emergency room utilization by this population. According to the Meta Analysis Report, assessing unmet needs is another problem affected by inaccessibility. Low levels of utilization produce data on the low consumption of medical and prevention services, but not on the services that are not consumed, i.e., the unmet need. This is an important problem since funding of urban Indian health care programs is predicated on documenting health status and

unmet health needs due to problems of accessibility.

Affordability: The socio-economic profile of urban Indians disposes them to avoid utilization of health services for reasons of cost. Typically, urban Indians have lower levels of education than others, which correlates with higher unemployment, which correlates to lower incomes, which correlates to lack of health insurance coverage, which correlates to the underutilization of health care services, which correlates to poor health. The high cost of obtaining health services has caused many urban Indians to defer medical treatment until emergencies occur. Lack of money is one reason why dental services record more utilization for extractions than tooth fillings. Affordability is also affected by other urban cost factors experienced by Indians. For example, low income urban Indians are likely to report that housing is more of a problem for them than medical care, simply because their most immediate need is to find a place to live. Lack of housing affects mobility, which also correlates to low income and reduced utilization of health services. The fact that urban Indians may have higher incomes in comparison to reservation Indians does not mean that health services utilization is higher for them. In reservation areas housing costs can be cheaper and IHS health care is free. But in higher cost urban areas, health care service costs can include premiums, deductibles and co-payments which combine to reduce utilization. Thus, affordability is an especially difficult problem since urban Indian education, employment and income levels do not support health services utilization.

Availability: Until the passage of the Indian Health Care Improvement Act (Pub. L. No. 94-437) very little health care funding was available to urban Indians. The minimum health care needs of urban Indians had not been addressed. The Act authorized the IHS to allocate funds to establish health clinics by urban American Indian organizations, in order to remedy the problem of health care services utilization. Notwithstanding passage of this law, funds for urban Indian health care services have not kept pace with the urban Indian population's rapid growth.

During the forty-year period of rapid urbanization of Indians, health care services have been largely unavailable. In the last five years, however, funds for urban Indian health care services have increased modestly. Given the size of the population and its fertility, current funding levels are still inadequate. Insufficient funding, increasing population and rising medical cost inflation, have generated fewer, not more health care services. Unavailability of services, nearly level funding, rising population and medical cost inflation have automatically lowered utilization. Urban Indians commonly report low levels of health services utilization due to a lack of resources for available services. Inadequate funding has attributed to the shortage of services in these areas: Medical care, chronic diseases, health professional staff, information and referral systems, dental services, elderly care, pediatric care, alcohol and substance abuse, HIV education and risk assessment, mental health, injury prevention, preventive care, acute care, health promotion and disease prevention, and management and training. Urban Indian program workload data for 1980-1991, indicated that the total number of utilization encounters in 1991 are approximately 3% lower than they were in 1980, according to the American Indian Health Care Association (AIHCA), 1992. (See Exhibit 3.)

<u>Health Status</u>: In the absence of an integrated health care information system, data from limited surveys or from payment system databases are used to support analysis. An accurate and uniform picture of the health status of all urban Indians in California is difficult to create, but a composite picture drawn from the literature and from urban Indian health program surveys is possible.

Morbidity Data: Since 1987 the AIHCA has collected data that has been voluntarily submitted by IHS-funded urban Indian health programs. The Association has found:

Ten Leading Diagnoses: Morbidity data collected from five (5) reporting urban Indian health clinics (with two reporting in California) indicated the top 10 leading diagnoses as: 1) Alcohol Dependency, 2) Health Maintenance, 3) Routine Physical Examination, 4) Prenatal Care, 5) Upper Respiratory Infection, 6) Diabetes, 7) Well Child Care, 8) Acute Otitis Media, 9) Housing or Economic Conditions, and 10) Obesity.

CPT Procedure Code Frequency: CPT procedural code data collected from three urban Indian health clinics disclosed the frequency of procedures to be: 1) Limited Office Visit, 2) Intermediate Office Visit, 3) Minimal Office Visit, 4) Brief Office Visit, 5) Blood Count, 6) Extended Office Visit, 7) Protoporphyn RBC Quantitative, 8) Educational Supplies provided by Physician, 9) Child Immunization (DPT), and 10) Polio virus.

ADA/Dental Code Frequency: ADA Dental Code data collected from four (4) urban Indian clinics identified the top 10 leading dental procedures as: 1) Preventive Planning and Instruction, 2) Intra Oral: Single, 3) Initial Oral Exam, 4) Emergency Oral Exam, 5) Bitewing: Two Films, 6) Sealant: Permanent Molar, 7) Unspecified Treatment, 8) Intra Oral: Additional, 9) Adult Prophylaxis, and 10) Periodic Oral Exam.

[American Indian Health Care Association, Morbidity/Mortality Data and Health Status Information.]

Mortality Data: The American Indian Health Care Association analyzed data tapes from the National Center for Health Statistics for the period 1979-1987, and identified mortality trends among Indians residing within cities. The Association believes that urban Indian mortality rates are understated due to poor reporting of Indian deaths. The Association found:

Heart disease was the leading cause of mortality in urban Indians between 1979-1987. Accidents, cancer and cirrhosis were the other top four causes of urban Indian mortality, while homicide ranked consistently as the fifth leading cause of death.

"...the largest increase in mortality occurred in cancer deaths, which increased by

54.6% from 32.2 to 49.8 deaths per 100,000. Suicide death rates increased by 16% from 11.5 to 13.4 deaths per 100,000. Heart disease mortality increased by 12.6% from 72.8 to 82.0 deaths per 100,000.

"The largest decrease in rates occurred in cirrhosis mortality, which declined by 20.6%, from 46.5 deaths per 100,000 to 36.9 deaths per 100,000 during 1979-1987. Deaths due to accidents decreased by 9.6% from 58.5 deaths per 100,000 in 1979-1981 to 53.2 deaths per 100,000 in 1985-1987. Homicide deaths decreased by 6.9%, from 18.7 to 17.4 deaths per 100,000, but remained the fifth leading cause of death throughout the period.

The understated Indian cause-specific mortality rates were found to be generally lower than all-race rates for most causes of death, with four important exceptions: Accidents, Cirrhosis, Homicide, and Diabetes.

Health Risk Data: The AIHCA has also collected data on behavioral risk factors as part of its on-going project to overcome the lack of national data. The following findings of health risk are from two sources of information: studies conducted by the AIHCA, other urban Indian health studies.

<u>Cardiovascular Risk</u>: Smoking, overweight, lack of exercise, and high blood pressure are risk factors present in many urban Indian communities. The urban Indian smoking rate exceeded the Year 2000 Objective of 200 per 1,000 by 90 percent. The prevalence of overweight in urban Indians is three times the Year 2000 Objectives: no more than 20 percent should be overweight...only 8.84 percent of the sample reported taking medication for high blood pressure, well under the Year 2000 Objective of increasing to at least 90% the proportion of people taking action to control their high blood pressure.

<u>Cholesterol Risk</u>: A significant percentage of urban Indians have moderate to high levels of cholesterol. AIHCA data indicates that a little over one quarter (28%) of the urban Indians sampled showed moderately high cholesterol, with an additional 17% showing high cholesterol levels. Unhealthy urban Indian dietary practices and caloric intakes are at variance with traditional nutrition practices.

<u>Diabetes Risk</u>: Urban Indians show a 4.88 times greater rate of diabetes and nearly half of the families have a history of diabetes. Related problems include a high percentage of overweight individuals, an impoverished lifestyle and poor nutrition and a lack of exercise.

Alcohol Abuse and Injury Risk: High frequency alcohol consumption and failure to use seat belts or adhere to posted speed limits are risk factors for many urban Indian communities, according to the IHS Urban Alcohol and Substance Abuse Program Analysis, 1992. Urban Indian communities have more high frequency heavy drinkers than do rural Indian populations. According to the Journal of Studies on Alcohol, Vol. 45, 1984, urban Indians also show higher

alcohol consumption than other urban ethnic groups or subgroups.

Behavioral/Mental Health Risk: Socioeconomic status directly correlates to the risk of suicide, teenage pregnancy and mental illness. It is reported that a 20-29 year old urban Indian male who is unemployed and a heavy drinker, and who has recently quarreled with his spouse is the highest risk profile for suicide, according to the American Journal of Psychiatry, Vol. 131(1). Urban Indians are at risk for major mental health problems such as alcoholism, anxiety, depression, and maladjustment.

AIDS/STD Risk: Urban Indian males with sexually transmitted diseases are at high risk, as are urban Indian prenatal females. The urban Indian rate of infection is higher than for all races, putting them at high risk for syphilis and gonorrhea. (Public Health Reports, Vol 104.)

### E. IHS Funding Policies

# 1. Historic Funding Policies

Following the withdrawal of services from California as a result of the United States' termination policies of the 1950's and 1960's, limited health services were reestablished in 1970 at the request of nine tribes. In 1970, Department of Health, Education and Welfare Secretary Robert Finch initiated a policy that provided health services to approximately 7,000 California Indians residing on or near 78 Indian reservations and rancherias in predominately rural areas. It was his decision to include California Indians within the IHS program and to provide federal supplementation of health resources. Although the IHS California Field Office was established in 1974, management of the budget was not transferred to Sacramento until FY 1978.

After 10 years of documented inequities in health care services to California Indians, the United States Court of Appeals in *Rincon Band of Mission Indians v. Harris*, 618 F.2d 569 (9th Cir. 1980), ordered the IHS to fulfill its statutory responsibilities to the California Indians by developing criteria aimed at a rational and equitable distribution of all Indian health care funds appropriated by Congress. But although the Congress appropriated \$37 million, the California tribes received only \$13.7 million in additional funding.

Though the IHS was directed by Congress to change its allocation methodologies to correct the deficiencies, the resulting allocation formulas did not increase the funding for California tribes to the level of other IHS service areas. In 1988, the IHS reported in its handbook on the Resource Allocation Methodology (RAM) entitled "Allocation of Resources in the IHS," that development of equitable methods for allocation of funds had occurred over a 15-year period.

In the early 1970s, objective manpower standards were developed and used primarily to establish priorities for staffing and related resources for new and replacement health care facilities. However, these standards were not applied to California programs. In response to the *Rincon* 

decision, IHS was ordered to adopt a rational resource allocation policy that promoted comparable services throughout the country. Only then (in 1981) did IHS develop funding priorities for tribes based upon unmet health care needs. Over a four-year period, these criteria were used to distribute over 32 million dollars appropriated by the Congress for an Equity Health Care Fund. (See Exhibit 4.) After FY 1984, no additional funds for equity were appropriated by Congress; however, IHS continued to reduce funding disparities by setting aside funds from its base appropriation. [Testimony of Barbara E. Karshmer before the House Committee on Interior and Insular Affairs regarding the Indian Health Care Improvement Act, H.R. 3724, March 24, 1992.]

In the mid-1980s, the IHS formed a number of special task groups to further develop IHS resource allocation methods. These methods were used to allocate over 40 million dollars of supplemental funding to IHS areas. In 1986, IHS added health status factors to the allocation methodology. These modifications led to application of a revised methodology, known as ARAM and SURAM, and the distribution of nearly 50 million dollars in FY 1986 and FY 1987. (See Exhibit 5.) All together, IHS has allocated over \$126 million dollars using this criteria since FY 1981. The IHS states in its 1988 report that this process resulted in substantial reductions in the funding disparities among areas. [Allocation of Resources in the IHS, 1988.] But it goes on to state that, because the largest portion of the IHS budget is dedicated to clinical services delivered in hospitals and ambulatory clinics, resource distributions have closely followed the historical distribution of health care facilities. In fact, a substantial portion of the real increases to the IHS program have usually come in the form of funding specifically justified and directed to a new or replacement health facility in which modern comprehensive medical services are planned.

Uneven distributions of fixed health care assets (facilities and manpower) generally lead to uneven access to services. Contract Care funds, however, are not necessarily tied to any geographic location and are used to complement and supplement direct care where the capacity and capability of facilities are limited. Where no IHS facilities exist, the purchased services funded by Contract Care funds may be the only health care provided for Indians. IHS reported (in 1988) that it has proven difficult to redistribute resources in the name of equity because Indian communities come to rely on and expect the continuation of current levels of services. Such problems have been recognized for years within IHS, among tribes and in the courts.

In 1985, IHS established the Operations Analysis Project to develop IHS policy and methods to allocate resources among both IHS areas and service units, rather than rely on allocation quotas specified by the Office of Management and Budget. This workgroup proposed to include redistribution of existing base funding from the best funded areas to the least funded, rewards for productivity and efficiency, emphasis on direct care programs over purchased services, incentives for alternate resource utilization, and consideration of health status indicators in the assessment of need. The two features of this proposal, ARAM and SURAM, called for two distinct allocations utilizing identical data but at different levels of aggregation (service unit data would be aggregated to area level for use in ARAM).

The approach adopted by IHS included using actual workloads and registered users to identify the resources necessary to maintain current levels of services using the Resource Requirement Methodology (RRM) cost standards. The actual workloads were subject to utilization review which could limit the range of acceptable services utilization. IHS assumed in earlier years that low utilization reflected unmet need. High utilization was assumed to reflect over-utilization or a relatively sufficiently funded program. Next, available resources were identified, both IHS and non-IHS (less 10 percent of Medicare and Medicaid), and compared to the RRM need to estimate unfunded or additional need. In addition to the funding status, a health status indicator for the area was introduced, known as Years of Productive Life Lost (YPLL) as a proxy for the health status of Indians in IHS areas. The funding status factor and the health status factor were then combined using a percentage to weigh each factor, to produce the final funding allocation priorities. In 1986 a total of \$20.4 million was allocated by ARAM to the areas. The California Area increase in 1986 from the previous year's allocation was a mere \$869,850.

The application of the criteria in the allocation of Hospitals and Clinics and Contract Care funds from 1981 to 1988 produced marked changes in the base funds of some IHS areas. California area received the most funds in absolute terms, but the relative increase for the California area is even more striking. Such a large relative increase is possible because the base funding of California prior to 1981 was the smallest of all IHS areas. Given the background of the *Rincon* court case it is clear from the 1988 data that substantial progress towards equity was made. In 1995, however, California still has the lowest Level of Need Funded of all IHS areas.

2. Comparative Analysis of IHS Funding in California vs. IHS Funding in Other Areas.

Given that the first Equity Fund Distribution took place in 1987, the same year that the California Field Office was designated an Area Office, and the California Area began to realize significant increases in funding due to the new funding formulas developed by the IHS, it is important to note that in FY 1989 IHS allocations showed that in relation to population, California was still the least funded with a total allowance of \$41,062,870, while Nashville, with half the population, received an allowance of \$39,684,610, and Tucson, with one-quarter the service population as California, received \$21,646,170. Nashville received more than three times of funding and Tucson received more than twice the funding that California received for contract health care, which was approximately 1% (\$2,204,200) of the total contract health care dollars distributed in 1989 (\$202,454,000). California was the only area that did not receive Maintenance and Repair and Health Manpower dollars in the 1989 distribution. (See Exhibit 6 for the IHS 1989 Service Allocations for FY 1989.)

IHS service population figures for 1990 to 1995 show that California is the fifth largest of the twelve IHS areas (See Exhibit 7). However, only two areas received less funding than California in the FY 1990 allocation. In per capita IHS funding levels, including facilities funds and excluding contract support cost funds from 1990 to 1995, California fell behind nine other IHS areas. (See Exhibits 8-11, which document the service population by area and the funding

allocations for all areas and the per user figures for all areas from 1989 to 1995.)

3. The *Rincon* Decision and the Equity Fund—Negative Impacts of IHS Allocation Formulas.

In 1974, the Rincon Band of Mission Indians, whose reservation is located in a remote valley in Northern San Diego County in Southern California, filed a class action suit against the IHS seeking to compel it to provide the same scope and level of health care for California Indians as it provided for Indians elsewhere in the United States. In 1979, the district court entered judgment for the Band, declaring that the IHS's system for allocating funds violated the California Indians' right to equal protection. [Rincon Band of Mission Indians v.Califano, 464 F. Supp. 934 (N.D. Cal. 1979).] The Band had argued that in examining the IHS method of allocation, the "strict scrutiny" standard of constitutional review under the equal protection clause be applied, while IHS argued that application of the more lenient "rational basis" standard was appropriate. The district court found that because the IHS' actions lacked even a rational basis, it need not decide which standard was appropriate. [Id. at 939, fn.5.]

The Ninth Circuit Court of Appeals affirmed the district court's holding, but based its holding on different, non-constitutional grounds. [Rincon Band of Mission Indians v. Harris, 618 F.2d 569 (9th Cir. 1980).] The Court concluded that, because the IHS had breached its statutory responsibilities to the California Indians under the Snyder Act [25 U.S.C.. § 13] to develop distribution criteria that are rationally aimed at an equitable division of its funds, it was unnecessary to decide either the trust responsibility or constitutional questions. [Id. at 575.]

It was not until the *Rincon* case was won and Congress established the "Equity Fund" in FY 1981 that California Indians began to receive an increased, though still inequitable, share of the Indian health care funding appropriated by Congress. Despite the Ninth Circuit's approval of the district court's statement that the IHS has a "continuing obligation... to distribute rationally and equitably all of the available [health] Program funds," [id. at 573,] the IHS continues to allocate less than an equitable share of its funding to California Indians. Under these circumstances, it may prove necessary for California Indians to enforce and clarify the *Rincon* decision by invoking the continuing power of the district court, as affirmed by the Ninth Circuit, to grant supplemental relief.

4. Inadequate Data Collection—IHS Failure to Implement Uniform Reporting in California

It has been nearly 10 years since the Congressional Office of Technology Assessment reported on IHS Data Management issues and the fact that IHS depends on an array of uncoordinated service-specific data systems that have developed over the years in response to particular information needs. None of the IHS data systems has been designed specifically to provide consistent, reliable information for national program management and reporting requirements. IHS' delegation of many management responsibilities to its Area Offices has

contributed to a lack of incentives to establish uniform national data systems. While IHS has recognized the need for national data, its planning efforts to meet those needs are not near to producing results.

Many existing IHS data systems do not generate complete or consistent information for the 12 IHS Areas. Some of the systems are automated, some are not; some systems are automated in certain IHS Areas but not in others. This has created unnecessary complications and expenses in attempting to aggregate data from the different Area systems. Service-specific IHS cost data are virtually nonexistent because facilities and programs operate within an annual budget, but are not otherwise required to account for or report detailed annual operating costs by cost center or unit of service. The IHS funding year for many clinics is different from the fiscal year, creating difficulties in reporting financial information accurately. Uniform use of terms and data definitions has not been addressed or implemented. Definitions for cost centers, units of service, staffing levels, patient load, and location and intensity of service have not been developed or implemented. Recognition of the differences between, and comparisons to, hospital-based services, free-standing ambulatory care clinic services, and ambulatory surgery services are not recognized within the IHS computer program development and analysis systems. Emphasis has been placed on hospital-based information systems with ambulatory care clinics being "tacked" on. There has been little or no recognition of the existence of differences among the 638 triballyoperated facilities.

The Indian Health Care Improvement Act of 1988, Section 602, required the IHS to "establish an automated management information system for the Service," which would include financial management, patient care information, and services-based cost accounting systems for tribes and tribal organizations, by September 30, 1990. [25 U.S.C. § 1662.] The IHS was to reimburse each tribe or tribal organization for "the part of the cost of the operation of a system provided under paragraph (1) which is attributable to the treatment by such Indian tribe or tribal organization of patients of the [IHS]." To date, neither of these mandates have been accomplished. Following an initial push to provide computers to collect patient information, programs have been left on their own to purchase equipment, install the hardware and software, and operate the system. Support and/or training for new packages has, at best, been minimal. Frequently the training amounts to: "The package has been installed, here is the manual." Users are left to their own devices on the implementation of the new packages. Specific clinic needs are not taken into consideration prior to the installation of new packages. No effort has been made to provide the management information systems required by tribal contractors to successfully operate their clinics, such as accounting/financial management and office automation. Contractors remain responsible for the identification of their needs, investigating and researching current vendors, assessing the software capabilities, purchasing both hardware and software, maintaining the systems, providing ongoing training for their staff, and evaluating the outputs of their systems. While some tribal programs were provided with sufficient equipment to meet their needs, most have had to purchase additional equipment on their own. Some tribal organizations have received no funding or equipment from IHS. Budgets have not been enhanced to include the costs of additional personnel required to operate the IHS RPMS, or to purchase equipment

required to add users or new modules within existing clinics, or even to initially purchase equipment and hire computer operators for new clinics. These costs must be borne by the local health organization from either their existing IHS budget or from precious third party funds.

The IHS implemented patient information system—RPMS—is public domain software, modular in nature, and is based on the Veterans Administration's FileMan software. The software uses M-Technology (MUMPS) as its operating system. The RPMS system allows generation of tracking systems (e.g. diabetic patients, hypertensive patients, immunization status, pap smears, etc.) and problem lists, which help to meet some provider needs. It can generate patient numbers from the registration and visit modules. However, the RPMS system is not user-friendly and requires intensive manual data input. It is an abstracting system that is maintained in addition to the paper medical record. While the system can generate medication lists, this piece of the system was designed to import data from the dispensing pharmacy package. Most of California's clinics are free-standing primary care clinics which have no dispensing pharmacy. In order for these clinics to use the medication list feature, each clinics' staff must spend hours typing the names and strengths of drugs into the computer. The integrity of this typed information is then in question: Was it typed correctly in the first place? Will this typed information be overwritten when there is an upgrade to the visit component of the RPMS system? Many experienced computer users have difficulty using the system.

RPMS is a modular system. Modules include patient registration, patient scheduling, patient care, ambulatory patient care, dental data, case management, contract health care, maternal and child health (immunizations), women's health, chemical dependency management information, mental health/social services, pharmacy, and inpatient systems. There is no synergy between these modules. Each module is its own stand-alone software package, with no central design to move towards a common goal, such as improving the quality of patient care. Developers are given the task of creating a piece of software with no overall supervision or plan for the component's design. Each module uses separate data definitions and patient identifications. Not all modules communicate. For instance, the Patient Care Component, which is designed to store significant information about patient diagnoses and treatments and report it to the clinician, does not receive or send information from/to the Women's Health (pap smear, mammogram), Immunization, or Chemical Dependency modules. RPMS modules are developed for the hospital or hospital-based clinic user, and data needs of free-standing, ambulatory care clinics are infrequently addressed.

System linkages are unnecessarily complicated. Within the same tribal organization, a patient must be registered at each of the clinics/satellites of that organization in order for encounter data from that clinic to be accepted by the IHS RPMS. Within the IHS system, each organization and clinic site are identified by a six (6) digit service unit ID number: the first two digits identify the Area, the next two digits identify the IHS or tribal service unit, and the last two digits identify the specific clinic site. This requires multiple entry or registration data within a clinic system, a waste of personnel time and effort. When registration data changes, it must be updated in each of the registration systems. The accuracy of patient demographic data is

compromised in this non-integrated system. It would be simpler to design a system where the patient registers once and all encounters within the same organization are counted, linked by the first four (4) digits of the service unit ID number.

The quality of data is also not addressed by IHS. In California, clinic staff are given no instructions to monitor data for timeliness and accuracy, nor told how to interpret data entered into the system. Monitoring for accuracy is limited to verifying whether data appears in a given field. This results in data that is incomplete and useless from both management and patient care perspectives.

Office automation systems, such as work processing, spreadsheets, databases, and billing and financial management systems, are incompatible with the MUMPS operating system used in the RPMS. No program has successfully integrated patient data with existing management information or billing systems. Some programs have purchased a billing package written in MUMPS, but this costs nearly twice as much as a comparable off-the-shelf package that operates in the DOS environment. Having this proprietary system modified, even to meet local (e.g. Medicaid) billing needs, is expensive, as each modification is separately charged to each requesting program at the programmer/developer hourly rates. Although this program allows clinics to share data between the patient visit and billing modules, it does not transfer data to the clinic's general ledger accounts, requiring staff to enter the same data twice.

While IHS has a billing/accounts receivable package under development, it was generated, as with most such packages, without tribal contractor input and is designed to meet the needs of IHS hospital-based facilities. The IHS management and reporting systems are significantly different from those of tribal contractors. IHS facilities bill Medicare and Medicaid directly to HCFA at a global rate, and payment is made to Area Offices, not to individual programs. Accounting for payments and balances is less important in the IHS system than in the tribal system, where each account is separately debited and credited. IHS facilities are informed of the total amount of payments credited to the facility, not the individual payments made for individual patients.

Making changes to the IHS RPMS is an inordinately long process. There must be agreement between the Areas before IHS programming staff can be detailed to write the change into the software. This years' long process is too slow for tribal programs, which must be able to account for, and manage, their programs on a daily basis, and report monthly to their governing boards. This untimely response to making changes necessitates creation of "temporary" procedures to accomplish the needed results. Changes which may be specific to tribal programs but not to the majority of IHS facilities are not made. IHS is unable to process changes which may be unique to the state within which a tribal contractor is located. In California, a significant number of tribal health facilities must be licensed by the State of California, as they are not located on tribal land. These clinics must submit an annual report to the state. One of the data reporting requirements for this annual report is an ethnic breakdown of patients seen and services rendered. Licensed clinics are reduced to maintaining manual reports to meet this requirement because in

1992, IHS eliminated all ethnic categories from the RPMS, leaving one ethnic group category for non-Indian clients. Many Indian health clinics, especially satellite clinics, are located in communities in which they are the only healthcare providers. These clinics have chosen to extend services to non-Indian patients on a fee-for-service basis, a situation which is largely ignored by the IHS system. Since non-Indian clients are seen, their numbers must be tracked and reported to the state agency. Tribal organizations also compete for various grant funds to maximize resources available to their Indian patients. These grants frequently require information about the ethnic mix of the organization's clients.

Updates to coding systems are made manually by IHS staff rather than with commercially available tapes or disks which load the information. This practice contributes to inaccuracies within the RPMS. It may also be the more costly alternative. The IHS-produced updates are distributed to Area Offices approximately three to four months after the changes are published. The Area Office then distributes these updates to tribal organizations based on the Area's time schedule. The California Area Office has not implemented a method for assuring that all programs are updated. In April of 1996, two out of nine (22%) California Rural Indian Health Board (CRIHB) clinics had not been provided coding updates from previous years dating back to 1992. The financial impact to the local programs is not known. Five of the other 23 urban and rural clinics in California also have incomplete data, and therefore, compromised information systems. Additionally, the current coding system utilized by IHS allows clinics to edit the "lookup" feature. This can cause incorrect codes to be assigned to diagnoses, thus perpetuating the inaccuracy of data collected by IHS. Consequently, inaccurate information is reported to clinic administration. Appropriate services cannot be provided to, or planned for, clinic patients on the basis of such data. Inaccurate and incomplete coding occurs frequently, as staff are given minimal training in correct coding.

Data reports from the IHS Data Processing Center may take three months to arrive, thus losing their utility for local tribal organizations. Most tribal organizations do not adequately understand data systems and needs, or methods by which submitted data may be rejected by the IHS system. In some modules, incorrect data may not be corrected once accepted into the IHS system. In other modules, data with errors is not counted (e.g. visit data). Correcting this data so that it may be counted requires a specific procedure which many clinics are not aware of. The RPMS Patient Care Component (PCC), which some tribal organizations utilize, has detailed patient diagnostic and treatment information. However, when this data is aggregated for reporting to the IHS Data Processing Center, it is reduced to APC categories, which are not particularly useful for planning, management or reporting purposes. For instance, all ICD-9-CM neoplasm codes (140-239) are truncated to two categories: benign neoplasm and malignant neoplasm; all endocrine problems are reduced to diabetes and other endocrine problems. The APC system allows only 2 diagnostic codes. If more than two codes are specified in the RPMS PCC System or on the manual APC form, only the first two are recorded in the system. These two codes have no indication of their relation to the primary purpose of the patient's visit, another important data item which is not collected by the IHS system. Thus, if a person came to the clinic for a complete physical, and also had diabetes and hypertension, the data maintained in the IHS

system will likely be the diagnoses of diabetes and hypertension since these conditions have a lower ICD-9-CM code than the real purpose of visit (annual physical).

All California Indian health programs submit data to the Area Office, which compiles the data and forwards it to the Data Processing Center in Albuquerque, New Mexico. None of the California area level data is distributed or made available to tribal programs. While the Area employs a full-time statistician, none of the gross statistics, analyses or displays of data are provided routinely to clinics. Because of the unavailability of statewide data, clinic staff are unable to determine whether their patients, diagnoses and services are comparable to those of other Area tribal organizations. They are, therefore, incapable of assessing their systems' performance and deprived of the ability to make improvements in their operations.

Although the Amendments to Pub. L. No. 93-638 allow tribal contractors a choice of voluntarily participating in data reporting, in reality there is little room for "negotiation." In 1990, IHS published its "core data set," which lists those data items which IHS and tribal facilities must collect and report to the IHS Data Processing Center. These data items were published in the regulations with little thought or evaluation as to their utility. The "core data set" was merely a restatement of the data items contained in all existing IHS RPMS modules, data reporting systems, and manual reporting/abstracting systems. No evaluation was performed of the use or utility of each of the specified items, the current necessity of collecting the data item, the frequency with which the data item was used, the overlaps in data items or data definitions, the inconsistencies between data requirements or data definitions, or the alternatives to the current data items.

#### Conclusions:

- a. Software development should be geared around the patient, providing quality data to the provider at the time of his/her encounter with the patient. The system should capture all of the required data to support billing of Medicare, Medicaid, third party insurers, managed care insurers, and patients.
- b. Software should contain user-friendly report generation capabilities to provide management, clinicians and staff required reports, in formats desired upon request of the local RPMS. These report generation capabilities will enhance the quality of management decisions, increase productivity, improve financial management, and improve the quality of patient care.
- c. Commercially available ICD-9-CM and CPT code system updates should be purchased to replace the current IHS staff-intensive, manual data entry process. There should be a move toward commercially available products, with the end product being an electronic patient record system, which will integrate all components of a facility's operations. Only software which meets ANSI and HL7 protocols should be used. Systems should be capable of uploading /accepting

output from outside vendors (e.g. laboratories).

- d. The needs of the IHS data system should be analyzed, from a Headquarters, Area and Service Unit perspective. The Service Unit perspective must be further defined to account for the differences between hospital-based service units, multi-specialty clinic-based service units and small primary care clinic-based service units. The data needs within Areas may be different; these differences need to be allowed. Identification of data needs must entail the definition of the data items so that all Areas are using the same terms the same way. All users will need to be questioned about their use of the data they collect or wish for service units to collect, the frequency with which they use each data item, what they use the data for, whether another piece of data could be used instead, and to justify the continued collection and reporting of each data item they request.
- e. Confidentiality systems within the identified hardware and software should be highly developed.
- f. Commercially available, fully integrated patient management information systems which meet the needs of the IHS system and are capable of producing the majority of data items required should be identified. They should be fully integrated so that all healthcare providers within a clinic or hospital system have access to required data about the patient. Identified products must be easily modifiable to add data items specific to Indian organizations, such as tribe of membership. A list of these products, with an analysis of their strengths and weaknesses should be distributed to all Indian health organizations.
- Indian health organizations should be funded to purchase the necessary hardware g. and software to operate one of the identified programs. The choice of the specific program should be made by the local health organization. The local health organization's base budget should be augmented so that they can purchase the necessary training and technical support for the chosen program and fund staff to maintain the system and input data. Ability to transmit core data items via modem using ANSI and HL7 standards should be part of the IHS Service Unit operations evaluation programs and of Pub. L. No. 93-638 contract performance requirements. Funding for management information systems comes from two different line items within the IHS budget. Both need to be well enough funded to sustain, modify and expand the current information systems. The IHS direct care system receives its funding as part of the Hospitals and Clinics line item. Tribal contractors, however, receive their funding for these expenses through the Contract Support costs line item. Both line items have been consistently underfunded.
- h. California patient, diagnoses and services information should be distributed in

gross and analyzed formats to all Indian health programs at least on a quarterly basis. Monthly reports would be most helpful to those programs involved in managed care contracts and activities. Reports must be timely, utilizing the most current data, and be distributed to programs within 4 weeks of the data's export to the Area Office. (An "Ideal Electronic patient Health Record" sample is attached as Exhibit 12).

# 5. Disparities in Current Funding Levels

The disparity in health care funding levels that exists among the various tribes throughout the United States is a major issue. In order to assist the IHS in implementing the *Rincon* decision, in 1981 the Appropriations Committees established an "Equity Fund" which was intended to be a temporary measure adding supplemental funding to ease the impact of that decision. Those Equity Funds, though intended by Congress to be merely an aid in the redistribution of the budget, and its successor, the Indian Health Care Improvement Fund, which was also for the purpose of bringing up the level of care of the tribes with the least resources, have turned out to be the sole IHS effort at establishing any sort of equitable level of services.

The most important factor to understand in regard to resource allocation is that IHS continues to use the system which it has always used to distribute funds and which the Court found to be illegal in the *Rincon* case. That is, IHS allocates the vast majority of its budget based upon the "program continuity," i.e., funding programs at the same level as they were funded during the prior year. The Court in *Rincon* reviewed this system and held that "[a] system that allocates funds to programs merely because the programs received funds the previous year, regardless of whether the programs are ineffective, unnecessary, or obsolete is not rationally aimed at an equitable division of funds..." [*Rincon*, 618 F.2d at 573.] This practice continues even today, as described by the General Accounting Office (GAO) in its February 1991 report discussed below.

GAO issued a report in 1991 entitled *Indian Health Service -- Funding Based on Historical Patterns, Not Need* [GAO/HRD 91-5, February, 1991.] In that report, GAO determined that IHS distributes funding "based primarily on the level of funding each area received in previous years. This approach takes little account of the number of Indians eligible for or using IHS services in an area, their health status, or the area's particular services needs." [*Id.* at 1.] GAO concluded that "IHS does not attempt to provide the same level of health services in all IHS areas; in fact services vary widely." [*Id.* at 3.] The reason for this appears to be that "each area's base budget is equivalent to its base budget from the previous year and a share of IHS annual funding increases proportional to the area's share of the total base." With this system, underfunded areas are never able to catch up. In fact, between 1980 and 1990, IHS distributed only 2 percent of its total funding -- about \$187 million -- using the needs based method. As a result, needs-based funding has had relatively little effect on the overall funding picture. [*Id.* at 4.]

It is worthy of note that the findings in this report are nearly identical to a 1982 report that CAO prepared after thoroughly reviewing the IHS funding system in the aftermath of the *Rincon* decision and the Equity Fund. In a report to the Chairman of the U.S. Senate Committee on Appropriations, entitled *Indian Health Service Not Yet Distributing Funds Equitably Among Tribes* [GAO/HRD 82-54, July 2, 1982], it stated: Despite the *Rincon* case, IHS has not fundamentally altered the way it distributes the bulk of its health care funds to tribes. It still distributes almost all of its funds based on program continuity. About 96 percent of IHS' \$594 million fiscal year 1981 health services appropriation was allocated based on tribes' and programs' prior year's funding. The major exceptions to this practice were the equity fund, some congressional earmarked funds, and certain mandatory cost increases." [*Id.* at 16.]

Finding that IHS allocated only 1.3 percent of its FY 81 budget through the Equity Fund, GAO stated: "IHS is attempting to achieve equity while maintaining program continuity. The equity fund is distributed based on need, but the bulk of IHS health services appropriations are allocated based on the level of the prior year's funding. While maintaining funding of programs may be desirable to IHS, we believe this practice will not lead to an equitable distribution of funds." [Id. at 15.]

Another critical issue that the GAO addressed in its report was the IHS claim that it had made significant strides in equalizing the relative levels of care that were being delivered through the use of the Equity Fund. This was simply not true. According to the GAO report: "Most of this progress is attributable to IHS' recalculation of tribal requirements for health care services rather than to the distribution of the equity fund." [Id. at 6.] GAO concluded that the IHS has been able to make "progress" in equalizing levels of care by reducing the elements or services which it includes in the benefit package funded, by arbitrarily reducing population figures, by excluding programs from its calculations and by simply manipulating its figures.

Most telling in regard to the failure of the system is the actual funding provided to serve Indians in California. Of the \$37 million appropriated for the Equity Fund between 1981 and 1985, California tribes received only \$13.7 million, despite the fact that throughout these years of funding increases, California continued to have the lowest level of care of any IHS area.

After 1985, IHS began using the Resource Allocation Methodology (RAM) to distribute funds which Congress appropriated for the most underserved tribes; however, in its *Health Services Priority System Report* to Congress, dated January 1990, IHS makes a startling admission, namely: the threshold for distribution of funds through RAM was set at 18% deficiency. [DHHS Justification of Estimates for Appropriations Committees, 1990-1995, 26.] This means that tribes or areas with 82% of the funding they needed were sharing in funding which was intended to go to the tribes with the lowest levels of funding. Thus, because all IHS Areas received 82% or less of the funding they need, IHS simply divided up the funding intended for the lowest funded areas among all the areas of the country, no matter how comparatively well-funded they were. Consequently, of the \$999 million dollars IHS allocated between 1986 and 1988 using the RAM formula, California received only \$4.5 million total. And, as IHS points out

in its Report at page 19, "RAM funding deficiencies were calculated with respect to existing programs and current services and not with respect to new and additional health services required for comparability across areas." Thus, once again California was left behind all other areas because the funding formula IHS used was not designed to allow California Indians to obtain comparable services. (See Exhibits 8-11.)

In 1989, IHS used a new measurement called Level of Need Funded (L.F.). (See Exhibit 13.) According to the same report, L.F. is "based upon improving the quality and scope of health services rather than elevating the volume of services to the ideal levels assumed in the original Health Services Priority System (HSPS). [Id. at 14.] Thus, this formula appears to measure needs against a lower undefined standard rather than against an optimal set of services. Even using this L.F. formula, California ranked at the very bottom in FY 1991 despite IHS being given 10 years of funding to bring those at the lowest levels up to the average levels of care. California area ranked lowest nationwide with approximately 60% L.F., as compared to the average L.F. of 71%. (See Exhibits 14-15.)

As the GAO pointed out in its 1982 report subsequent to the *Rincon* case, "IHS creates the appearance of progress through manipulation of numbers and formulas, not through any real change and refuses to deal with this critical problem of underfunding as mandated by Congress and the Courts for the last fourteen years."

The IHS practice of basing allocations on past workload is unfair for those programs which have not had substantial funding in the past because patients could not receive care if there was no funding to provide the care. Until there is full funding available those facilities will be unable to generate workload data to justify further funding. Without sufficient funding, the program will not be able to provide services and thus workload data will be limited; and conversely, without high workload statistics, the programs will be unable to justify additional funding. Therefore, population figures should be used instead of workload data in those areas that have been chronically underfunded, such as California, until such time as adequate funding is obtained and realistic workload data can be generated. The importance of this issue cannot be overemphasized given the unreliability of the data collection efforts by the IHS in California to date.

#### II. HEALTH FACILITIES

# A. <u>Tribally Constructed and Operated Health Facilities</u>

Unlike most other Areas of IHS, California tribes established and maintain full responsibility for the development and operation of their own health care facilities, programs and services pursuant to Pub. L. No. 93-638 Indian Self-Determination Act contracts. Additionally, no tribal health facility or program in California has ever been designed, built, staffed, equipped, or funded by IHS. No California programs have been transferred from the IHS to the tribes, as is the case in most other IHS areas.

Since the health programs did not descend from previous IHS facilities, IHS lacks the database required to calculate the distribution of Maintenance and Improvement (M&I) funding and to compete in the Health Facility Priority System. At this time IHS has begun a second round of Deep Look Surveys that will encompass all the health program sites in order to establish an information base and collect the data necessary to update the Facilities Engineering Deficiency System. The facilities are not sized or staffed according to IHS standards, and the lack of IHS construction funds has often forced health programs to lease facilities that are substandard according to IHS' own criteria. Limited facilities are available in rural locations, and lack of renovation funding compounds the problem. The lengthy approval process established by the lease Priority System in 1991 and later abandoned further handicapped health programs in acquiring appropriate space.

As a result of Deep Look Surveys done in 1988, IHS identified deficiencies in the amount of \$2,104,420. Subsequent use of the data shows that estimates are only 40-50% of the actual cost of repair, not including the 8-12% cost of professional engineering or architectural services. In addition, the data was found to be incomplete and did not include all sites or facilities occupied by the rural health programs. A IHS Deep Look Survey Report, 1994, includes cost estimates for costs associated with building code or public law deficiencies, which do not generally account for clinics being old or undersized or inappropriate for providing health care. Only 24 health programs and three alcohol programs are included in this survey which indicates that approximately \$5,385,061 is required to correct all existing deficiencies.

The IHS utilizes a multi-tier process for setting priorities for health care facilities construction projects. First, Office of Environmental Health and Engineering (OEHE) solicits proposals from the IHS Areas for major modernization projects, essential staff quarter needs, and urgently needed new or replacement health care facilities. The proposals developed by the Area Offices are evaluated at the headquarters of OEHE and ranked according to relative need. Justification documents are prepared for those ranked highest and, when approved, the projects are placed on the appropriate IHS facilities priority list and funding estimates are included in the five-year IHS Planned Facilities Construction Budget. (See Exhibit 16.) In FY 1990, the IHS revised its Health Facilities Construction Priority System methodology.

Health facilities in California continue to be non-competitive for new facility construction funds through the IHS Health Facilities Priority System. The 1993 amendments to the Indian Health Care Improvement Act provided for funding of small ambulatory health facilities. All existing California facilities qualify for this category of funding. Congress has not funded this category to date.

#### B. <u>Urban Health Facilities</u>

Urban Health Programs in California are operating in facilities that are substandard according to IHS' own criteria for health facilities. Patients are provided care in facilities that are rented, leased and/or purchased from private owners. In most cases, improvements and

renovations are the responsibility of the Health Program. In all cases the Health Program budgets are so underfunded that the necessary improvements and renovations cannot be completed. The majority of facilities are in such disrepair that they would not meet accreditation standards. Results of IHS' most recent Deep Look Survey do not include facility needs of Urban Indian Health Programs.

# C. Barriers to Access—The IHS Facilities Construction Program

Tribally operated programs in California have been locked out of the IHS Facilities Construction Program from the onset. Since 1990, only \$5,496,000 has been allocated to tribal contractors in California for Maintenance and Repair of facilities. According to IHS allocation information from FY 1990 to FY 1995, \$446,996,000 have been allocated to nine of the 12 IHS areas for facilities construction projects. [Regional Differences in Indian Health, 1994.] California, Nashville and Tucson areas have received no allocations whatsoever. The IHS federal construction fund allocation formulas do not support the small tribal facilities constructed or leased by tribes and tribal organizations. Lease and loan costs are funded through program operation funds, further reducing the availability of services.

It is strongly recommended that Congress fund the Small Tribes Facilities Program in order to correct some of the major deficiencies that exist for health programs in California. Justification for this program was provided to Congress in support of the authorizing legislation, and the under-funding continues to increase with each passing year.

# D. <u>Comparative Analysis of California Facilities Construction, Maintenance and Repair Allocations versus Those of Other IHS Areas</u>

The discussion in Section C points out the fact that during Fiscal Years 1990 through 1995, IHS allocated \$446,996,000 to nine IHS areas in Facilities Construction Projects. California, during that same period, received only Maintenance and Repair funds in the amount of \$5,496,000 (See Exhibit 17). Prior to 1990, California was prevented from participating in the Maintenance and Repair allocation by IHS policy and allocation formulas. The results of this ongoing barrier to access is exacerbated year after year with no appropriate process in place to "catch up". As a result, much needed health care dollars are spent on leased, rented or tribally constructed facilities. Again, we ask that Congress review the requests on record submitted by the IHS and tribes, justifying the claims. Figures provided by the IHS CAO indicate that approximately \$10 million dollars are required to correct identified deficiencies in Tribal Health Programs and alcohol programs. IHS must be directed to survey all tribal and urban alcohol programs. Information in the CAO's report indicates that only 24 health programs and three alcohol programs are included in the most recent Deep Look Survey, which indicates that approximately \$5,385,061 is required to correct all existing deficiencies. [p.33.]

#### III. HEALTH STATUS

#### A. Health Status of California Indians

### 1. User Population

The California contracted program covers an estimated 63,000 of California's 216,000 Indians. As mentioned in the previous section regarding data collection, information about Indians in California is practically nonexistent, and what data that is available is extracted from a number of collection systems and is subject to manipulation. The following user population estimates are based on data from the IHS Patient Registration System and published in the IHS' Regional Differences In Indian Health 1994. In this document, the IHS discusses the sources and limitations of data and states that tribally operated programs are registered in the Patient Registration System, which was implemented in 1984, and by now is considered to be fairly complete and accurate. They also state that "it is already known that there is an under-reporting of Indian race on State death certificates in the California, Oklahoma, and Portland Areas." Therefore, the indices based on mortality (i.e., mortality rates, years of productive life lost, and life expectancy at birth) that appear in the 1994 report for these Areas are suspect and should be interpreted with caution. The publication shows IHS-wide mortality-based rates with and without the data for these three Areas. (Patient Registration data for FY 95 is shown in Exhibit 18.)

The IHS California Area user population in FY 1993 is reported to be 62,569. The California user population in 1993 was considerably younger than the national average, with 10.8 percent under age 5, nearly 1.4 times the U.S. All Races percentage of 7.4%. Only 5.9% of the California user population was over age 64 in 1993, compared to 12.6 percent of the U.S. All Races population.

The birth rate for the California service population in 1990-1992 was 22.5 compared to 16.3 for the U.S. All Races population. The infant mortality rate for the IHS service area population in 1990-1992 was 9.4. Again we must note apparent problems in under-reporting of Indian race on death certificates when analyzing infant mortality rates for California. When the three IHS Areas with apparent problems in under-reporting of Indian race on death certificates are excluded (including California) the rate is 11.2. This is 26 percent higher than the U.S. All Races rate of 8.9 for 1991. (Exhibit 19 shows Misclassification of Race By Leading Cause of Death.)

In April 1992, the IHS submitted its Report to Congress on the Indian Health Service With Regard To Health Status and Health Care Needs of American Indians in California (in response to Pub. L. No. 100-713, Section 709). Many important pieces of information about the health status, health care needs and access to care of California Indians were presented in the 91 tables and 48 charts in the report. Five of the most notable findings continue to be major factors in health status. In the five years that have passed since the submission of this report, there has not been a significant growth in funding or program delivery that would indicate changes in health status.

a. By many measures, the health status of California Indians is very similar to that of American Indians and Alaska Natives in the 32 other reservation states.

American Indians and Alaska Natives in the United States (U.S.) are much more likely to die prematurely than persons in the general U.S. population. (See Exhibit 20.) In a disturbingly similar way, deaths occur to California Indians at much younger ages compared with the total California population. In 1986, Indian deaths were more than twice as likely to occur before the age of 45 (28% vs. 13%), or before the age of 25 (11% vs. 5%). Indian men were particularly likely to die before the age of 45 years (33% vs. 18% for all races). From 1989 to 1991, the Years of Productive Life Lost rate (all causes) for the IHS service population was 86.7 [see Exhibit 20, note 1, for an explanation of how Years of Productive Life Lost is calculated.] When the three IHS areas with apparent problems in under-reporting Indian race on death certificates are excluded, the rate is 109.2. This is nearly double the US. All Races rate of 56.2 for 1990. Each of the remaining IHS Areas had a rate greater than the U.S. All Races rate.

Leading causes of death for American Indians in California in 1989-1991 were the similar to the leading causes of death for American Indians nationally. A greater proportion of Indian deaths compared with All Races were caused by accidents and adverse effects, chronic liver disease and cirrhosis, and diabetes mellitus (*See* Exhibits 21-24.)

The proportion of injury related deaths is much higher for American Indians and Alaska Natives in the U.S. (16%) and for California Indians (13%) than for the total population in California (5%). For California Indian boys and men, injury deaths are particularly prominent (16% of all male deaths). Motor vehicle deaths alone accounted for 9% of all deaths to California Indian males in 1986-88.

The 1989-1991 age-adjusted injury and poisoning mortality rates for the IHS service area population was 120.3 per 100,000, or 159.3 when the three IHS Areas with apparent problems in under-reporting of Indian race on death certificates are excluded. This is more than twice the U.S. All Races rate of 55.1 per 100,000 for 1991. (See Exhibits 25-26.)

IHS reported that there was no diagnostic inpatient data available for the California Area in FY 1992. [Gaps in Basic Health Care Needs in California, Indian Health Service, 1994; see Exhibit 27.]

In 1988, only 22% of the American Indian and Alaska Native hospital discharges were uninsured, compared to 11.9% of All Races. (See Exhibit 28.)

b. The Maternal and child health risk profile for California Indians presents a troubling picture that demands public health action.

Several very important risk factors for adverse outcomes for mothers and babies are disproportionately high for California Indian women. In 1986-1988, 17% of California Indian live births were to women under the age of 20; and 8% of California Indian live births had late (third trimester) or no prenatal care. These risk factors are especially prominent in counties with primarily non-federally recognized Indians.

Although mothers of Indian children compared to all mothers in California were less likely to be uninsured (6% vs. 13%), they were much more likely to rely on Medi-Cal (46% vs. 28%) and much less likely to have private insurance coverage (40% vs. 53%). Geographic availability of Medi-Cal providers and delays in Medi-Cal eligibility determination must be examined for Indian women in California.

While the infant mortality rate for California Indian births in 1984-1986 (10.3 deaths per 1,000 live births) was only slightly higher than the statewide rate (9.3), the post-neonatal death rate for California Indians was alarmingly high (5.1 for Indians vs. 3.4 for the total population). Aggressive efforts are needed to prevent injuries, treat medical conditions and support mothers and infants throughout the first year of life and beyond. (See Exhibits 29-31.)

c. Tobacco and alcohol use are having a devastating impact on the health of California Indians.

According to a study conducted by the University of California at Berkeley, 40% of American Indians in Northern California were found to smoke cigarettes, beginning at an early age. Sioux Indians (a non-California tribe) had the highest smoking rate, followed by California tribes such as the Maidu (46%), Pit River (39%), Pomo (38%), Hupa (37%), and Yurok (32%). [Hodge, 1995.]

A report from the University of California at San Francisco indicated that 42% of deaths among California American Indian women and 37% of deaths among California American Indian men were attributable to smoking. These numbers are very different for women (12%) and men (18%) among other California populations.

Fourteen percent of American Indian males and 2% of American Indian females used smokeless tobacco, compared to 5.2% males and 0.5% females in the general population.

d. Leading Causes of Infant Deaths.

In 1989-1991, 37.1% of all infant deaths in the California Area were caused by sudden infant death syndrome (SIDS). The second leading cause of infant deaths was congenital anomalies (17.1%). (See Exhibit 31.) The mortality rate for SIDS in California for 1990 was

179.8 per 100,000, compared to 103.3 for all races.

### e. Leading Causes of all Deaths.

In 1989-1991, 24.4% of all deaths in the California Area of the IHS were caused by diseases of the heart. This was followed by malignant neoplasms at 14.6%, accidents and adverse effects (14.3%), cerebrovascular diseases (6.0%), and chronic liver disease and cirrhosis (5.0%). (See Exhibit 23.)

The age-adjusted alcoholism mortality rates for California for 1989-1991 was 20.0%, while the rate for U.S. All Races was 7.1%. (See Exhibit 32.) Age-adjusted mortality rates for diabetes mellitus, tuberculosis, gastrointestinal disease, heart and cerebrovascular disease, malignant neoplasms, breast cancer, and cervical cancer were calculated separately by the IHS due to the problems with under-reporting of Indian race on death certificates. However, it is the position of contracted health programs in California that the health status of California Indians is not significantly different from Indians from in other areas. (See Exhibits 33-40.)

### f. Hospital admission rates.

The number of hospital days reported in FY 1992 for California is 4,026. (See Exhibit 41.) Due to problems associated with data collection in California, however, the IHS reports that there was no diagnostic inpatient data available for the California Area in FY 1992. (See Exhibit 27.)

# g. Leading causes of outpatient visits.

For the California Area in FY 1992, 15.0% of all clinical impressions in tribal direct and contract facilities pertained to supplementary classifications, such as well child care, other preventive health services, hospital-medical or surgical follow-up, physical exams, tests only (lab, X-ray, screening), contact/carrier of infectious disease, socio-economic problems, and environmental problems. This was followed by diseases of the respiratory system at 14.2%. (See Exhibit 42.)

2. Indians of California—Non-federally Recognized (Health Status and Health Care Needs of American Indians in California, 1991)

For non-federally recognized California Indians, there are substantial limitations on access to health care services outside the California Tribal Health Programs. They are also poorly insured. One-third of those Indians sampled by the Tribal Health Programs in 1991 reported no health insurance coverage at all, and only 24% reported coverage by private health insurance. Of those non-federally recognized California Indians who have a usual source of care, 60% identified a Tribal Health Program. Alternate sources of care reported by respondents were primarily public programs, such as emergency rooms and county health clinics; 7% of respondents said they did not know what alternate source of care they could use.

When choosing health care, non-federally recognized California Indians place very high value on cultural sensitivity. Among the most important features they seek in health care staff are respect and kindness, and an understanding of American Indian ways.

In California counties where Indians are primarily non-federally recognized, three of the leading causes of hospitalization for Indians in 1988 were not among the leading causes for the total population in those counties, or for Indians statewide. These causes were disorders relating to short gestation and birth weight, cellulitis/abscess and acute bronchitis. Hospitalizations resulting from these causes probably relate to problems with prenatal care access, substance abuse and/or diabetes, and lack of preventive outpatient care, respectively. Access to a wide range of health care services will be needed to begin to combat these problems.

The health status of non-federally recognized California Indians is no better and is in some ways more compromised than that of federally recognized California Indians. Important risk factors for adverse outcomes for mothers and babies are even more prominent among Indian women in counties where Indians are primarily non-federally recognized, or in counties without access to IHS contract clinics. For example, in 1986-1988, 21% of Indian births in counties with no federally recognized tribes were to women under age 20, compared to 17% of Indian births throughout the State. In counties without access to an IHS contract clinic, an extremely high percentage (14%) of Indian births follow delayed prenatal care, compared with 8% of Indian births statewide.

The youthfulness of hospitalized Indians is especially striking among residents in California counties where Indians are primarily non-federally recognized. For example, among Indian residents in these counties, 41% of hospital discharges in 1988 were under age 15, 57% were under age 25, and only 10% were age 65 and over. Over half (51%) of the hospitalizations for Indian males in these counties were for boys under age 15.

Deaths among Indians in California counties where Indians are primarily non-federally recognized were more likely to be caused by heart disease and injuries than deaths among Indians statewide. In the former counties, nearly one-quarter (23%) of deaths among Indian boys and men were caused by injury.

One-third of non-federally recognized California Indians reported at least one unmet health care need during 1990. The most frequently mentioned need was dental care (22%), followed by the need for supplies (19%), such as those for diabetics and prescription medications (18%).

Evidence presented in this report suggests strongly that there are many unmet health care needs for both non-federally recognized and federally recognized California Indians. Health risks for Indian mothers and babies, disease and death caused by tobacco and alcohol use, and the disproportionate occurrence of preventable health problems all deserve aggressive public health action. At present, the health status of non-federally recognized California Indians appears to be

no better than that of federally recognized California Indians. Since Californian Tribal Health Programs are the primary source of health care for non-federally recognized California Indians, and many of these Indians have very limited access to other sources of care, continued access to the tribal programs is essential to maintaining even the current level of health status for this group. Barriers to access must be evaluated in the context of current fiscal conditions and policy trends.

The current fiscal situation implies decreased availability of alternate resources for people who depend on services supported by the IHS. The immediate need to maintain coverage for non-federally recognized California Indians is urgent, but financial coverage alone will not ensure appropriate and acceptable care for the Indian population. Recent expansion of clinical services in California's tribally operated programs has led to a higher level of utilization, indicating both access to services and a desire to obtain them in an Indian-specific environment.

The non-federally recognized California Indians have not had an equal opportunity to participate in the determination of health care priorities and program development processes on the same level as the federally recognized tribes. Appropriations for "new tribes' health assessments" is critical to addressing the needs of this population when reinstatement to recognized status or first time recognition is obtained by the tribes.

In testimonies provided by non-federally recognized members to the Health Task Force throughout the state, numerous testimonies focused upon the problems associated with accessing health services and being denied contract health care services for specialty care because membership in a federally recognized tribe cannot be proven. The solution to this problem rests with Congress and the Department of Interior's Branch of Acknowledgment and Research. Too many California tribes have had petitions for recognition pending for too long. The Shasta Nation, Tolowa Nation, Mariposa Mewuk, and others have had petitions pending for more than ten years. Simplification of the process a few years ago by the Bureau of Indian Affairs accomplished little in the way of eliminating the barriers to recognition.

## B. Access to Primary Health Care Services

# 1. Contract Health Services Funding Shortfalls

Tribes in California are in dire need of Contract Health Services (CHS) funds. Because they have never been served directly by IHS, they do not have any IHS hospitals, and as a result they are unable to provide the care that their patients need because CHS budgets are not sufficient to fund necessary specialty care and inpatient care to supplement and augment the ambulatory care provided. In the California area, the CHS budget is the lowest in the entire IHS system at only \$114 per user, as compared to the national average of \$265 per user. (See Exhibit 43.) In contrast, the Portland Area, the only other Area which like California has no IHS hospitals, receives \$388 per user and the Bemidji Area and the Billings Area, which have similar user populations to California, receive respectively \$16 million and \$28 million for contract care. Yet California receives only \$7,085,200 (FY 1995 allocation). (See Exhibit 44.) There is simply no

rational basis for this extreme disparity which is based solely on a quirk of history.

Eligible Indians in California are suffering without inpatient and specialty care which is available to Indians in other IHS Areas, especially with the escalating cuts in the Medi-Cal budget. Some tribal health programs in California are so short on CHS funds that they were unable to provide any CHS services for a period of two years recently. Through a CRIHB initiative in 1993, a study was undertaken with funding from the Kaiser Foundation Research Institute and the Sierra Health Foundation in support of the California CHS Demonstration Program for inpatient care [p.42.]. This research, done by a nationally recognized accounting firm, shows an \$8,000,000 shortfall. [Milleman and Roberts Actuarial Study, CRIHB, 1993.] The cost projections parallel recently completed IHS Area Office research which found that fully 12% of all deliveries at one California tribal site were not covered by any kind of private or public insurance.

Adding to the funding crisis in the California Area is the State of California's multi-billion dollar budget crisis. The State's budget, based on significantly declining tax revenues, has been balanced by observable reductions in governmental services. These reductions have primarily impacted the level of State-funded county-provided services for the medically indigent. These changes have resulted in a decrease in third party collections and an increase in active user counts. Medicaid-supported specialty services have been targeted for elimination, creating new reductions in the availability of alternative health resources in California. This would have a dramatic impact on the tribally controlled health care system of California.

# 2. Catastrophic Health Emergency Fund

Section 202 of the Indian Health Care Improvement Act established the Catastrophic Health Emergency Fund (CHEF) for the provision of payment of high cost specialty care for eligible beneficiaries. The threshold level to access this fund is \$17,700 in FY 1996 and will be \$18,400 in FY 1997. In an Area that has a history of being vastly underfunded, this threshold is simply much too high. Tribal health programs have such limited health care resources that it is impractical for them to absorb the high cost of Catastrophic Care.

The CHEF status report for FY 1994 indicates that California had only five catastrophic cases, and received a distribution totaling \$99,397. (See Exhibit 45.) The Nashville area, with one-half the service population, submitted 26 cases for a distribution of \$651,921. The Billings area submitted 162 cases for a distribution of \$2,306,181. Billings is an area where inpatient care is available through IHS hospital facilities, whereas in California there is none. According to the CRIHB Contract Health Services Demonstration Program FY 1994 report on CHEF Submissions, 11 cases were submitted with a net eligible total of \$237,806.37. As stated above, only five cases were reimbursed.

An \$8 million increase for the California Area would bring it to a comparable level with tribes elsewhere. (See Exhibit 46 for CRIHB CHS Demonstration Program FY 1994 CHEF Submissions.)

# 3. Managed Care and its Impact Upon Indian Health Programs

The California Indian Task Force on Managed Care made clear its position on managed care in California in a statement to the IHS CAO Area Director, T.J. Harwood, on January 18, 1995. The Task Force made these recommendations on behalf of the Indian Health Programs [California Managed Care Task Force Update, January 18, 1995]:

a. IHS/CAO should make Managed Care a major priority for 1995 and include the following:

IHS should make a clear appointment of CAO staff with full responsibility for California Managed Care health reform. With the multiple needs generated by Fee For Service Demonstration County initiatives, COHS plans; the twelve-county expansion plan, local and mainstream plans, and differing allied health reform models, there is a great need for better information gathering, coordination of communication, impact analysis, and strategic planning that must be addressed.

IHS should set aside funds for quarterly Task Force meetings and critical meetings with the State and Region IX as they arise.

IHS should make managed care Technical Assistance a priority for all the Indian Health programs. This would include CAO assistance as well as funds for consultants; appropriate managed care cost-accounting and data keeping systems; and training to meet the needs of each program.

It is further recommend that "year end" monies be targeted for managed care support and planning.

CAO should assist in the publication of a Managed Care Newsletter on either a quarterly or monthly basis to all the tribes and health programs. To this end, the Task Force has already assigned reporters/recorders for four regions in California.

- b. IHS/CAO should hold concentrated regional training sessions for the tribes, board of directors and health program staff of Managed Care in California. It was readily apparent to the Task Force visitors that the boards and communities are largely unaware of the full meaning and implications of managed care in California. These training sessions should begin as soon as possible.
- c. The Task Force requested a meeting with the IHS and California Department of Health Services to formulate a "blanket" Indian Managed Care policy by the State.
- d. The Task Force has submitted a request to IHS Director for priority funding to assist in Managed Care preparation and efforts by the Task Force and CAO throughout

the coming year.

In November of 1995, the Managed Care Task Force met with the State Department of Health Services and representatives of the State Indian Health Program and came to agreement on State regulations governing Medi-Cal and Managed Care with specific language included to ensure that Indian programs in California are able to participate in the Managed Care transition. (See Exhibit 47.)

#### 4. Retention and Recruitment Issues

# a. The IHS Scholarship Program

A principal means of recruiting physicians to work at the IHS and other organizations involved in providing health care to Indian people is the Recruitment and Scholarship programs of the Indian Health Care Improvement Act (IHCIA). The IHS offers grants to Indian tribes and other organizations to enable those groups to identify Indians with a potential for education or training in the health professions and to assist those individuals with their education. [25 U.S.C. § 1612.] In addition, the IHS offers scholarships to individuals for pre-graduate and pre-professional work [25 U.S.C. § 1613] and for medical school or other health profession training [25 U.S.C. § 1613a]. In FY 1994, 744 scholarships were awarded under §§ 1613-1613a. [Federal Register Notice, Vol.60 No. 4/Friday January 6, 1995, page 2133, IHS List of Recipients of Indian Health Scholarships Under the IHS Scholarship Program.] Only seven of those recipients were members of California tribes.

The number of Indian scholarship recipients in California is a disgrace, and is a clear reflection of the IHS CAO's inability to effectively and efficiently carry out the scholarship program. As long as the scholarship has existed, there has been no single point of contact within the CAO for information and assistance with the application process, and it appears that the responsibility for the scholarship program is an "additional duty" assigned to various positions at the area office. It is extremely difficult to process an application given the short-turn around time allowed by the IHS for preparation. It has been the experience of CRIHB that it is absolutely necessary to assign CRIHB staff to assist the IHS CAO with the physical packaging and mailing of applications. More often than not, the staff responsible have neither an interest in, nor any significant knowledge of, the scholarship program, therefore further impeding the process.

Moreover, due to the special status problems of California Indians, many have recently been categorically excluded from receiving Health Professions Scholarships. Many California Indians, regardless of their tribes' political status, have always been eligible to receive health services from the IHS and were previously eligible for all scholarships offered through the IHCIA. A recent change in § 1613a, however, has jeopardized the full participation of California Indians in this important scholarship program.

Before the 1992 amendments, the same definition of "Indian" applied to all of the

education provisions of the IHCIA. This definition, which still applies to the Recruitment and Preparatory Scholarship Programs, is very broad. In addition to members of federally recognized tribes, that definition includes: members of terminated tribes; members of tribes recognized by the State in which they reside; descendants of federally recognized, terminated, and state-recognized tribes; Alaska Natives; persons considered to be an Indian for any purpose by the Secretary of the Interior; and persons determined to be an Indian under regulations promulgated by the Secretary. [25 U.S.C. § 1603.] Section 1613a formerly incorporated the broad definition of Indian applicable to the other scholarship provisions: "For purposes of this section, the term 'Indian' has the same meaning given that term by subsection (c) of section 4 [§ 1603] of this Act, including all individuals described in clauses (1) through (4) of that subsection." This separate definition was deleted by the 1992 amendments. Based on this deletion, the IHS currently takes the position that Health Professions Scholarships are available only to members of federally recognized tribes.

Previously, the Preparatory scholarships and the Health Professions Scholarships were administered as if they were one. In other words, any recipient of a Preparatory scholarship was ensured of receiving a Health Professions Scholarship, as long as he or she maintained good standing at an accredited institution and was ultimately admitted to a professional school. As a result of the IHS' current interpretation of § 1613a, however, some California Indians may be recruited for medical study pursuant to the scholarship Recruitment Program [25 U.S.C. § 1612], or may receive a Preparatory Scholarship for pre-medical studies [25 U.S.C. § 1613], only to be denied a Health Professions Scholarship upon enrolling in medical school. This has in fact happened to at least one California Indian who began undergraduate studies with IHS grants and the expectation that he would receive support through medical school. After achieving a 4.0 average in a pre-medical program, and being admitted to Stanford Medical School, he has now been denied a Health Professions Scholarship.

The IHS' position is inconsistent with their traditional treatment of California Indians. Historically, Congress has treated California Indians as a group entitled to benefits. This is especially true of health services provided by the IHS. Thus, while the BIA provides many services only to federally-recognized tribes and their members, this has never been the case with health care and other services provided by the IHS. As Senator Cranston explained during the debates on the IHCIA.

The California Indian population is unique in this country and must be understood in historical context... [A]Ithough they were eventually recognized in Federal law as individual "Indians of California," many California Indians are not members of federally recognized tribes...[F]airness required the development of policies...providing specifically for California Indian's [sic] eligibility for [IHS] care.

[134 Cong. Rec. S13565 (daily ed. Sept. 28, 1988) (quoted in *Malone v. Bureau of Indian Affairs*, 38 F.3d 433, 438 (9th Cir. 1994).]

As a result of their unique history and relationship with the federal government, many California Indians who are not members of federally recognized tribes are "eligible for health services provided by the Service" pursuant to § 809 of the IHCIA [25 U.S.C. § 1679]. The definition of California Indians includes members of federally recognized tribes, descendants of Indians who resided in California on June 1, 1852, Indians who hold trust interests in lands held by the United States in trust in California, and Indians listed on the plans for distribution of the assets of California rancherias and reservations under the Act of August 18, 1958 and their descendants. California Indians, as defined in § 1679, are arguably eligible for all of the benefits provided under the IHCIA, including Health Professions Scholarships. The IHS, however, refuses to so construe the statute, despite the fact that their position is unsupported by the legislative history of the amendments.

Despite the deletion of the former § 1613a(c), there is no evidence that Congress actually intended to narrow the eligibility requirements for Health Professions Scholarships. Neither the reports by the House and Senate Committees that reviewed the proposed amendments, nor the Congressional Record contain any discussion of the change in the definition of Indian for purposes of the Health Professions Scholarships. In fact, the possibility that eligibility for Health Professions Scholarships was being narrowed was literally never mentioned in any of the reports or hearings. The former § 1613a(c), by its own terms, seemed to simply repeat the definition of "Indian" that applied to the entire act. Thus, it is likely that it was deleted due to the perception that it was a superfluous provision.

Given the total absence of discussion on the amendment, it seems highly unlikely that it was understood to limit eligibility in a way that contradicted the purposes of the IHCIA.

"[T]he purpose of Title I is to increase the number of Indians entering the health professions and to assure an adequate supply of health professionals to provide primary health care to Indian people." [S. Rept. 102-392 at 46. See also 25 U.S.C. § 1602(c) ("It is the intent of Congress that the Nation increase the proportion of all degrees in the health professions and allied and associated health profession fields awarded to Indians to 0.6 percent.")] Of course, many people are Indian in a cultural and ethnic sense, yet are not members of federally recognized tribes. Congress found that "health care provided by people of one's own culture is the most appropriate, and results in better utilization of health care services." [S. Rept. 102-392 at 7.] This finding indicates that when Congress spoke of "increasing the number of Indians entering the health professions," it was using a cultural/ethnic definition of "Indian," rather than a political definition.

Moreover, the Health Professions Scholarship provision, when read *in para materia* with 25 U.S.C. § 1679(b) of the IHCIA, includes California Indians. As noted above, a broad range of California Indians are eligible for health services pursuant to § 1679 of the IHCIA. Thus, for purposes of the IHCIA, California Indians constitute an "organized group or community... which is recognized as eligible for the special programs and services provided by the United States to Indians because of their status as Indians," and should be eligible for Health Professions

Scholarships pursuant to 25 U.S.C. § 1603(c). The IHS' narrow construction of the IHCIA conflicts with "that 'eminently sound and vital canon,' that 'statutes passed for the benefit of dependent Indian tribes...are to be liberally construed, doubtful expressions being resolved in favor of the Indians." [(Citations omitted) Bryan v. Itasca County, 426 U.S. 373, 392 (1976).]

Because there is no evidence that Congress intended to narrow the eligibility requirements for Health Professions Scholarships, the IHS should consider California Indians, as defined in 25 U.S.C. § 1679, to be eligible for these scholarships. The IHS, however, refuses to do so. Thus, Congress should amend the statute to clarify the eligibility of California Indians.

IHS scholarship payback is another issue that requires attention because of the treatment of scholarship recipients by Area and Headquarters staff. It has been the experience of a significant number of scholarship recipients that the IHS at all levels does not facilitate the process required to fulfill the payback. It has come to our attention that recipients who have documented their "eligible employment" have been reported to the IRS and to credit agencies as out of compliance with their payback agreements. This treatment of Indian scholarship recipients is intolerable and must stop immediately. Indian programs have always experienced, and will continue to experience for years to come, a shortage of employable Indian health professionals. It is difficult enough to attract qualified health care providers and administrators without the added burden of dealing with a program that does not operate efficiently and professionally.

# b. Long Term Training Barriers

Indian Health Programs operated by tribes and Urban organizations have never enjoyed access to Long Term Training Programs on the same basis as the IHS operated programs. It has been the experience of CRIHB to have its manpower and training needs documented and included in Area requests for training dollars, but when the allocations are made none of the training dollars come to the contractors.

# c. Physician Recruitment and Special Pay Issues

Recruitment and retention of well-trained physicians at several isolated, rural clinics remains difficult. A number of factors can be attributed to the difficulty in recruitment and retention, including the rural geographical location of the clinics, access to clinical support, non-competitive salary and benefits, working conditions, and job dissatisfaction. Although conditions at Indian health clinics have improved tremendously over the years, the advent of health care reform/managed care and the demand on well-trained primary care providers is having a predictable impact on the shrinking pool of qualified practitioners interested in working in tribal health programs.

The lack of consistent clinical support adds to the frustration of physicians and contributes to job dissatisfaction. Examples would range from the lack of access to medical consultation, to under-staffing. Ways to improve this situation would include on-line medical teleconferencing,

on-line computer medical consultation, well-trained nursing support, and adequate staffing, in addition to the continuing medical education of physicians and medical staff, all of which are virtually out of the reach of tribally operated health centers in California due to the inconsistent funding priorities and processes referenced throughout this report. Many of the improvements mentioned are thought to be standard operating practices in the medical community in this day and age—that there is discrimination in funding for tribal communities seems obvious to even an unskilled observer.

- 5. Youth Regional Treatment Center(s)
  - a. Alcohol and Substance Abuse Prevalence

The age adjusted mortality rate for calendar years 1989-1991 for the IHS service population was 37.6%. When the three IHS areas with apparent problems of under-reporting Indian race on death certificates are excluded, the rate is 51.8%. This is 630% higher than the U.S. All Races rate of 7.1% for 1990. (See Exhibit 32.) A high percentage of clinical visits, mental health problems, deaths from accidents, and homicides are alcohol related. The 35 clinic-based alcohol/substance abuse programs provide outpatient counseling services only.

b. History of IHS/CAO Pub. L. No. 99-570 Implementation Activities

In 1986, Congress passed the Anti-Drug Abuse Act of 1986. Part VI of Subtitle C entitled, "Indian Alcohol and Substance Abuse Treatment and Rehabilitation Act" has been amended several times and currently provides that:

- (a) DETOXIFICATION AND REHABILITATION--The Secretary shall develop and implement a program for acute detoxification and treatment for Indian youth who are alcohol and substance abuse users. The program shall include regional treatment centers designed to include detoxification and rehabilitation for both sexes on a referral basis. These regional centers shall be integrated with the intake and rehabilitation programs based in the referring Indian community.

  (b) TREATMENT CENTERS OR FACILITIES--(1) The Secretary shall construct, renovate, or, as necessary, purchase, and appropriately staff and operate, a youth regional treatment center in
- secretary shall construct, renovate, or, as necessary, purchase, and appropriately staff and operate, a youth regional treatment center in each area under the jurisdiction of an area office. For the purposes of this subsection, the area offices of the Service in Tucson and Phoenix, Arizona, shall be considered one area office and the area office in California shall be considered two area offices, one whose jurisdiction shall be considered to encompass the northern area of the State of California, and one office whose jurisdiction shall be considered to encompass the remainder of the State of California.

Section 704(d) provides for a community-based rehabilitation and follow-up treatment separate and distinct from the inpatient detoxification services provided by the regional treatment center.

The California Area Office did not carry out the mandate from Congress and establish a youth treatment center in California. When the legislation was amended to provide for two treatment facilities in California, the first program was still nonexistent. Instead, IHS chose to distribute the treatment center dollars to the tribally operated programs where alcohol, substance abuse and mental health program staff made referrals and placed youth for treatment in facilities located in the states of Arizona, Utah, Wyoming, Oregon, and Washington, at rates ranging from \$165 to \$365 per day. Funding was distributed based on a formula that provided large sums to large programs and small sums to small programs. At an average cost of \$200 per day to treat one youth for 180 days (totaling \$36,000), most programs could only afford to treat two or three youth in a year.

Tribes advocated heatedly for Youth Regional Treatment Center construction dollars before the IHS at the Area and Headquarters levels, and before Congress, but with no success, although the proposed options were considered acceptable by the IHS. Then, in 1994, the IHS advertised a commercial bid for the operation of a youth treatment center in California. A contract was awarded to a non-Indian licensed group home, the Kingsview Center. The contractor proposed to establish a Native American component in its existing operation. Although 88 youth were referred and treated at this program (58 were treated at other facilities), the tribes and tribal health programs were not satisfied with the level of service and treatment provided to the Indian youth. Cultural appropriateness and sensitivity were areas of grave concern. The participation of Indian staff in the program was also an area of consternation. The resolution of the documented concerns by Kingsview and the IHS California Area Office were deemed unsatisfactory to tribes and tribally operated programs. [Regional Treatment Center Update: Kingsview Mental Health System, IHS CAO, October, 1994.]

At the request of the tribes, the Kingsview contract was not renewed at the end of the year contract and the money was again distributed to individual tribally operated programs.

The IHS response to individual tribes and/or consortium of tribes proposing to establish and operate a youth treatment center with dollars distributed through the "tribal shares" formula is unacceptable. The IHS has let it be known to California tribes that their position on this issue is that IHS would be violating § 704 of the Indian Health Care Improvement Act if it divided funding for Youth Regional Treatment Centers into tribal shares, since the IHS would be preventing its ability to operate and staff a regional youth treatment center that provides detoxification and rehabilitation on a referral basis. It is the position of a majority of tribes in the California Area that IHS has always been in violation of § 704 of the Act and is in fact distributing treatment dollars based upon tribal shares at the time of this writing. It is also the position of a majority of the tribes (those that caused IHS to discontinue the contract with Kingsview) that Pub. L. No. 93-638 contains language that specifically includes those contractible services

intended to be provided under the Indian Alcohol and Substance Abuse Prevention and Treatment Act of 1986. [Pub. L. No. 99-570.]

c. Adverse Impact of IHS Policy on Youth Regional Treatment Center Contracting Issues in California

Indian children are dying as a result of alcohol and drug abuse and the violence, injuries, suicides and illnesses associated with alcohol and drugs, while the IHS continues to review and make comment on the PJD and Program Operations Requirements documents before submission to IHS Headquarters for further review and comment.

For the IHS service population, accidental death, accidental alcohol related death, and suicide death rates are 96% higher than that of U.S. All Races rates. At each and every public hearing held by the Advisory Council on California Indian Policy, concerns were expressed and requests for support and assistance were very strongly communicated regarding the need for youth treatment facilities in California.

Funding is required to construct two treatment facilities for youth treatment in California at a cost of approximately \$5,000,000 per facility. It is the belief of a majority of the tribes and tribal health programs in California that Congress and the IHS have the flexibility and the authority to cut through the bureaucratic "red tape" and other existing barriers, to arrive at an appropriate method of providing the necessary funds to meet this long outstanding need in California, of which both Congress and IHS have been appraised for more than 10ears.

#### 6. Sanitation and Environmental Health Issues

The majority of Rural and Urban Health Programs do not operate environmental health programs. Less than one-third of the Health Programs are fully staffed and able to provide the necessary services.

Solid waste is a major problem for a large number of reservations and rancherias in California. Training, technical assistance and funding are required to put into place adequate solid waste disposal locations on tribal lands. In its Facility Data System, the IHS has identified approximately 30 unapproved solid waste disposal locations on California tribal lands. Given the funding, staffing and planning limitations within the CAO, only 10 tribes were identified to receive solid waste management program development assistance in FY 94. At this rate it would take at least 10 years to establish solid waste management programs for all California tribes.

Sanitation Facilities Deficiency Data taken from the IHS Area summary for FY 1996 is as follows:

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Total Project Cost: Total Data Base \$34,926,100  Current Agency Funding Plan 16,165,100  Estimated No. of Homes Without Potable Water: 140  Estimated No. of Homes In Communities At UNIT Deficiency  Levels 4&5 233  Estimated No. of Homes Eligible for Assistance 5,266					
<b>Deficiency Level Information</b>					
Deficiency Level	<u>1</u>	2	<u>3</u>	<u>4</u>	<u>5</u>
Homes				213	20
% Eligible Homes			43.6%	4.0%	.4%
No. Projects	3	30	67	8 ·	4
Estimated Cost:					
Total Data Base	\$70,000	\$9,312,000	\$21,670,000	\$3,398,100	\$476,000
Current Agency	,				
Funding Plan	0	\$8,412,000	\$6,116,000	\$1,198,100	\$439,000
J					
Home Deficiency Information					
Type of Service	<u>Water</u>	<u>Sewer</u>	Solid Waste		<u>0&amp;M</u>
Homes	3,842	1,403	5,229		N/A
% Eligible Homes	73.0%	26.6%	99.3%		N/A
Estimated Cost					
Total Data Base	\$14,468,600	\$2,096,500	\$18,137,500		\$233,500
Current Agency					
Funding Plan	\$10,828,100	\$2,071,500	\$3,079,000		\$186,500

While the total project cost for FY 96 was estimated at \$34,926,100, the actual funding was \$16,165,100, leaving an unfunded amount of \$18,761,100.

It is recommended that the IHS work with the BIA, EPA and the tribes to address the environmental health issues directly related to the dumping of toxic waste on California Indian Reservation lands. There have been no definitive studies completed to assess and reveal the damage to the local environment and the effects of the contamination to the health of the inhabitants of those areas. Likewise, no cost estimates available identify the cost of clean-up of the most dangerous dump sites—Laytonville Rancheria and Torres Martinez Reservation. That cost could be in the hundreds of millions of dollars. This is an urgent situation and must be emphasized. The tribes need support and assistance from the regulatory agencies to ensure that dumping is halted and prevented from happening in the future.

# IV. THE GOVERNMENT TO GOVERNMENT RELATIONSHIP AND TRIBAL CONSULTATION

# A. The IHS-Tribal Relationship in California

#### 1. Tribal Consultation

Tribal leaders in California have been very active in the consultation process with the

Federal Government for more than four decades with varying levels of success in the areas of Termination, Land Claims, Water Rights, Civil Rights, Education, and Child Welfare. In the late 1960s, tribes began consulting with Congress on health and funding issues. The tribes' relationship with the IHS in California began in 1969 with the establishment of the IHS Sacramento Field Office, where a staff of two was responsible for overseeing the implementation of the single IHS contract operating in California, and for providing technical assistance to CRIHB on a limited basis. It was not until the *Rincon* law suit that the CAO began to grow by leaps and bounds. By 1994, the CAO staff numbered more than 100 full-time employees charged with monitoring the contracted programs being administered by the tribes.

In 1992, the CAO was compelled to establish an advisory group to "help run the Area Office". From that point in time until the present, the CAO has struggled to implement and follow a tribal consultation process in accordance with the wishes of the tribes. The process adopted by the CAO in 1994 is yet to be implemented, although the tribes have voiced their concerns about some serious issues and activities being carried out by the IHS, which affect all tribal health programs. The CAO totally botched initial efforts to establish a CAO Design Team which could have had an opportunity to provide input into the national IHS Design Team Report, published by the IHS Director. The report was completed prior to the time the California Design Team could appropriately organize a first meeting.

Tribally-operated health programs would benefit greatly if the appropriate Secretaries would emphasize and support the provisions of the Indian Self-Determination Act (ISDA) at each level of the Agency, and put in place a policy that would ensure that the leaders, starting at the highest levels, are educated about the ISDA and the meaning of tribal sovereignty. The delegations of authority should include mandates for tribal consultation and problem-solving to facilitate tribal contracting. Tribes are in need of an IHS partnership that seeks solutions and promotes the goals of the tribes at all levels and at all times. For too long, California has experienced flagrant abuses of authority that have only served to circumvent tribal consultation and prevent unity among the tribes. The proof is in the ongoing funding shortfalls and unmet needs of the California programs and in the inconsistent policy implementation.

# 2. Title I Contracting

With the passage of the 1994 amendments to the Indian Self-Determination Act, tribes in California looked forward to the implementation of the new provisions and the opportunity to take advantage of the increased control and flexibility in the contracting process. The lack of knowledge on the part of the CAO staff and their unwillingness to take a proactive role in the transition to the streamlined process outlined in the amendments has caused tremendous of problems for numerous contractors. The process utilized by the CAO to define inherently federal functions in order at a residual funding level required to carry out those functions, and to determine tribal shares for all tribes in the California Area, is now the subject of great concern for numerous tribal contractors. For Title I contractors, the initial residual amount was determined to be \$1.7 million in May of 1995. Tribal shares were distributed based upon that calculation and

contracts awarded. In October of the same year, the residual was increased because, according to the budget experts ("we made a mistake"), resulting in a \$2.54 million residual and decreased tribal shares. It has been reported in public forums and discussions with tribal leaders that the residual may continue to change. This creates the threat of several legal challenges because those contractors who signed initial contracts based upon a \$1.7 million residual have contract language protecting their tribal shares awarded based upon the residual amount. The tribal shares distribution formula made following the revised residual amounts will affect the Annual Funding Agreements in subsequent years. No agreement on proposed tribal solutions has been reached to date.

# 3. Title III Compacting

The Hoopa Tribe of California is the only tribe engaged in Title III compacting at the time of this writing. In testimony provided by the Hoopa Tribe, members point to the origin of the United States' legal obligations to Indian tribes stemming from treaties and agreements which contain the fundamental commitments that generate federal trust responsibilities, annual appropriations and the requirements of prudent management of tribal assets, health care and a host of other matters in which the United States acts as the trustee to Indian tribes. In the Hoopa Tribe's testimony before the ACCIP, one member stated that:

the administration of federal policy has undergone tremendous change, partly due to tribal leadership and leadership direction. With the enactment of the amendments to the Self-Determination Act over the past two decades, we now have reached a point where the tribal self-governance and self-determination once again has become a common term in designing and implementing Indian affairs policy and service programs. There remains much work left to do to eliminate the unnecessary federal rules, regulations and policies that obstruct the efforts of tribal governments to develop a true government-to-government relationship. The principles of self-governance are consistent with those of health care reform and reinvention of the federal government. The principles of self-governance are designed around the concept of allowing flexibility in designing services, establishing tribal quality control measures, and appropriate funds to improve the quality and quantity of services to our Indian people. Tribes are committed to accomplishing the goal of regaining their rightful role as independent, selfsustaining sovereign nations, communicating respectfully as governments with the United States to control our own destinies.

#### V. SUMMARY OF PUBLIC HEARING TESTIMONY TO THE ACCIP

The following summary is comprised of issues, concerns, recommendations, and comments presented to the Advisory Council and Health Committee in 10 public hearings conducted over a 12 month period from July 1994 through July 1995, and held in the following locations: Sacramento, Redding, San Diego, Fresno, Bakersfield, Ukiah, Eureka, Hoopa, and

Bishop. Major health issues presented in testimony provided by tribal leaders to the Health Committee are summarized as in the following paragraphs. Excerpts from the hearing records are summarized in Exhibit 47.

Eligibility for health services: At each and every public hearing the problems facing California Indians who are not members of federally recognized tribes and the eligibility for Contract Health Services was raised. Service area boundaries cause eligibility problems in that California Indian people residing outside the 21-county Contract Health Service Delivery Area (CHSDA) are not eligible when members of the same family residing 10 miles away are. The position taken by the presenters is one that calls for equal treatment of all tribes regardless of where they live in California. A recommendation to expand the CHSDA and the increased funding requirements for the service population in the expanded counties is included in the Recommendations section.

IHS funding shortfalls: Tribal leaders and tribal health directors testified at length and provided written position papers and documentation to support their funding issues. In light of the identified funding deficiencies for California Indian health programs, testimony was provided wherein the issue of "Agency level assessments" on the IHS budget was raised and identified as an area to be studied as a source of funding that should be utilized to meet the unmet need in California. Emphasis is placed on detoxification and aftercare programs for youth, including urban youth, environmental health services, and facility construction and repair requirements.

Environmental protection: In northern and southern California serious concerns were voiced about the fact that the IHS does not have appropriate methods for testing (of the blood) for chromium poisoning, nor are they able to ensure protection from airborne pathogens in areas where toxic human waste contamination is blowing through the air that people are breathing on a daily basis. In these areas (i.e. Torres Martinez, Cahuilla and Soboba Reservations, and the Laytonville Rancheria) the children are sick and cannot play outside. Family homes are almost on top of the dump sites and federal agencies do little or nothing to stop the dumping at these illegal facilities which are causing such severe health problems for making entire tribes. Contaminated soil at Soboba contains 10 times the amount of lead that allowed by State regulations. The IHS must do all in its power to address these issues and work with its counterparts at the federal level to initiate a clean-up of these toxic waste dumps. Water contamination is another major problem documented by numerous tribes with the IHS and other federal agencies to no avail. Testimony provided indicates that the IHS and other federal agencies are not perceived as taking these dire health conditions seriously. Cancer clusters in Indian country, specifically Humboldt County, are very real causes of concern, documented by a university study, yet the national Forest Service chooses to study some other area of the State. Tribal leaders do not want their people to continue dying before appropriate agencies decide to pay attention to the effects of pesticide spraying.

Adult and youth treatment centers: Testimony was presented at all hearings regarding the need for the construction of two youth regional treatment facilities in California in accordance with Pub. L. No. 99-570. Alcohol and substance abuse problems were emphasized by tribal

leaders, family members and counselors who stressed the frustration faced in efforts to find appropriate residential treatment facilities for young clients. Tribal representatives point to the IHS and its failure to implement the youth regional treatment center program intended for California. Aftercare and mental health programs were highlighted as severely underfunded. The need for funding in support of adult treatment was also stressed in the hearings.

Traditional Indian medicine: Throughout the hearing transcripts there are references to the importance of preserving the cultural and spiritual heritage of tribal people in finding solutions to the problems presented. That the "government agencies must listen to the Indian people and the tribes" is a recurring theme. The fact that traditional Indian medicine is not respected on the same level as western medicine is also mentioned. Indian patients should have access to traditional medicine on the same basis as western medicine. Clinically trained providers must be willing to consult with traditional Indian medicine practitioners early in a patient's treatment and not at the end, when all hope is lost and the traditional medicine practitioner is called in only to provide the last rights. Non-Indian practitioners and professionals in the IHS system must be provided orientation and training in cultural sensitivity and appropriateness and must be willing to work collaboratively with traditional Indian medicine practitioners at the local level.

Urban health programs: Testimony was provided regarding the poverty level of most urban Indian families, employed in unskilled jobs that provide low pay and no health coverage. With no contract health services available to the urban service population, the advent of a serious illness in these families is particularly devastating and wipes out the family finances, causing extreme hardship and suffering for all family members. Access to youth regional treatment center facility programs pursuant to Pub. L. No. 99-570 is of great concern to urban health programs. Urban youth have been prevented from entering treatment because they cannot access the youth treatment dollars allocated to tribal programs. Youth alcohol and substance abuse treatment and aftercare is a major problem in the urban areas and must be addressed.