S. HRG. 106–491, PT. 1

REAUTHORIZE THE INDIAN HEALTH CARE IMPROVEMENT ACT

HEARING

BEFORE THE

COMMITTEE ON INDIAN AFFAIRS UNITED STATES SENATE

ONE HUNDRED SIXTH CONGRESS

SECOND SESSION

ON

PUBLIC LAW 94-437

TO IMPLEMENT THE FEDERAL RESPONSIBILITY FOR THE CARE AND EDUCATION OF THE INDIAN PEOPLE BY IMPROVING THE SERVICES AND FACILITIES OF FEDERAL INDIAN HEALTH PROGRAMS AND ENCOURAGING MAXIMUM PARTICIPATION OF INDIANS IN SUCH PROGRAMS

MARCH 8, 2000
WASHINGTON, DC

PART 1

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REAUTHORIZE THE INDIAN HEALTH CARE IMPROVEMENT ACT

WEDNESDAY, MARCH 8, 2000

U.S. SENATE,
COMMITTEE ON INDIAN AFFAIRS,
Washington, DC.

The committee met, pursuant to notice, at 2:30 p.m. in room 485, Russell Senate Office Building, Hon. Ben Nighthorse Campbell (chairman of the committee) presiding.

Present: Senators Campbell, Conrad, and Dorgan.

STATEMENT OF HON. BEN NIGHTHORSE CAMPBELL, U.S. SENATOR FROM COLORADO, CHAIRMAN COMMITTEE ON INDIAN AFFAIRS

The CHAIRMAN. Good afternoon. If we could be seated, the committee will come to order.

Today, we will begin a series of hearings on draft legislation to reauthorize the Indian Health Care Improvement Act, the cornerstone of Indian health care programs.

The programs operated by the Indian Health Service are vital to the health of American Indians and Native Alaskans. The IHS serves 1.3 million native people. And without these programs, the vast majority of Indian people will be without any health care whatever.

As we have all heard all too often, Native Americans suffer the worst health status of any racial or ethnic group in America, with a diabetes rate that is three times greater than the general population, and a death rate 4.3 times greater than the general population from complications of diabetes.

Diabetes in Native American children is on the rise, and the IHS reports that there is clear evidence that for Indian people the health disparity related to diabetes is increasing.

Native Americans also suffer greater rates of heart disease; in fact, two times higher than the general population. Cancer and alcoholism is six times greater than the U.S. population. Hepatitis is two times as high as the general population, and tuberculosis is five times as high as the general population.

The Indian Health Care Improvement Act, or "the Act" as it is called, was first passed in 1976, and has been reauthorized four times. The purpose of the act is to address and minimize the health care disparities between the Native people and the general population, and to provide a coherent authorization for health programs.

To lay the groundwork for this draft legislation, tribal leaders, health experts, and the IHS formed a steering committee to make the act more flexible and responsive to the needs of Indian people. The draft bill before us is the result of their efforts, and I applaud the steering committee for its work.

It also includes provisions related to health services, health facilities, urban Indians, alcohol and drug abuse, and diabetes, and other matters, in addition to that.

[Text of Public Law 94–437 follows:]

Public Law 94-437
94th Congress

An Act

Sept. 30, 1976
[S. 522]

To implement the Federal responsibility for the care and education of the Indian people by improving the services and facilities of Federal Indian health programs and encouraging maximum participation of Indians in such programs, and for other purposes.

Indian Health Care Improvement Act.
25 USC 1601 note.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Indian Health Care Improvement Act".

FINDINGS

25 USC 1601.

SEC. 2. The Congress finds that—

(a) Federal health services to maintain and improve the health of the Indians are consonant with and required by the Federal Government's historical and unique legal relationship with, and resulting responsibility to, the American Indian people.

(b) A major national goal of the United States is to provide the quantity and quality of health services which will permit the health status of Indians to be raised to the highest possible level and to encourage the maximum participation of Indians in the planning and management of those services.

(c) Federal health services to Indians have resulted in a reduction in the prevalence and incidence of preventable illnesses among, and unnecessary and premature deaths of, Indians.

(d) Despite such services, the unmet health needs of the American Indian people are severe and the health status of the Indians is far below that of the general population of the United States. For example, for Indians compared to all Americans in 1971, the tuberculosis death rate was over four and one-half times greater, the influenza and pneumonia death rate over one and one-half times greater, and the infant death rate approximately 20 per centum greater.

(e) All other Federal services and programs in fulfillment of the Federal responsibility to Indians are jeopardized by the low health status of the American Indian people.

(f) Further improvement in Indian health is imperiled by—

(1) inadequate, outdated, inefficient, and undermanned facilities. For example, only twenty-four of fifty-one Indian Health Service hospitals are accredited by the Joint Commission on Accreditation of Hospitals; only thirty-one meet national fire and safety codes; and fifty-two locations with Indian populations have been identified as requiring either new or replacement health centers and stations, or clinics remodeled for improved or additional service;

(2) shortage of personnel. For example, about one-half of the Service hospitals, four-fifths of the Service hospital outpatient clinics, and one-half of the Service health clinics meet only 80 per centum of staffing standards for their respective services;

(3) insufficient services in such areas as laboratory, hospital inpatient and outpatient, eye care and mental health services, and services available through contracts with private physicians, clinics, and agencies. For example, about 90 per centum of the surgical operations needed for otitis media have not been performed, over 57 per centum of required dental services remain to be provided, and about 98 per centum of hearing aid requirements are unmet;

(4) related support factors. For example, over seven hundred housing units are needed for staff at remote Service facilities;

(5) lack of access of Indians to health services due to remote residences, undeveloped or underdeveloped communication and transportation systems, and difficult, sometimes severe, climate conditions; and

(6) lack of safe water and sanitary waste disposal services. For example, over thirty-seven thousand four hundred existing and forty-eight thousand nine hundred and sixty planned replacement and renovated Indian housing units need new or upgraded water and sanitation facilities.

(g) The Indian people's growth of confidence in Federal Indian health services is revealed by their increasingly heavy use of such services. Progress toward the goal of better Indian health is dependent on this continued growth of confidence. Both such progress and such confidence are dependent on improved Federal Indian health services.

DECLARATION OF POLICY

SEC. 3. The Congress hereby declares that it is the policy of this Nation, in fulfillment of its special responsibilities and legal obligation to the American Indian people, to meet the national goal of providing the highest possible health status to Indians and to provide existing Indian health services with all resources necessary to effect that policy. 25 USC 1602.

DEFINITIONS

SEC. 4. For purposes of this Act— 25 USC 1603.

(a) "Secretary", unless otherwise designated, means the Secretary of Health, Education, and Welfare.

(b) "Service" means the Indian Health Service.

(c) "Indians" or "Indian", unless otherwise designated, means any person who is a member of an Indian tribe, as defined in subsection (d) hereof, except that, for the purpose of sections 102, 103, and 201(c)(5), 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.

(d) "Indian tribe" means any Indian tribe, band, nation, or other organized group or community, including any Alaska Native village or group or regional or village corporation as defined in or established pursuant to the Alaska Native Claims Settlement Act (85 Stat. 688), which is recognized as eligible for the special programs and services provided by the United States to Indians because of their status as Indians. 43 USC 1601 note.

(e) "Tribal organization" means the elected governing body of any Indian tribe or any legally established organization of Indians which is controlled by one or more such bodies or by a board of directors elected or selected by one or more such bodies (or elected by the Indian population to be served by such organization) and which includes the maximum participation of Indians in all phases of its activities.

(f) "Urban Indian" means any individual who resides in an urban center, as defined in subsection (g) hereof, and who meets one or more

of the four criteria in subsection (c) (1) through (4) of this section.

(g) "Urban center" means any community which has a sufficient urban Indian population with unmet health needs to warrant assistance under title V, as determined by the Secretary.

(h) "Urban Indian organization" means a nonprofit corporate body situated in an urban center, composed of urban Indians, and providing for the maximum participation of all interested Indian groups and individuals, which body is capable of legally cooperating with other public and private entities for the purpose of performing the activities described in section 503(a).

TITLE I—INDIAN HEALTH MANPOWER

PURPOSE

25 USC 1611.

SEC. 101. The purpose of this title is to augment the inadequate number of health professionals serving Indians and remove the multiple barriers to the entrance of health professionals into the Service and private practice among Indians.

HEALTH PROFESSIONS RECRUITMENT PROGRAM FOR INDIANS

Grants.
25 USC 1612.

SEC. 102. (a) The Secretary, acting through the Service, shall make grants to public or nonprofit private health or educational entities or Indian tribes or tribal organizations to assist such entities in meeting the costs of—

(1) identifying Indians with a potential for education or training in the health professions and encouraging and assisting them (A) to enroll in schools of medicine, osteopathy, dentistry, veterinary medicine, optometry, podiatry, pharmacy, public health, nursing, or allied health professions; or (B), if they are not qualified to enroll in any such school, to undertake such post-secondary education or training as may be required to qualify them for enrollment;

(2) publicizing existing sources of financial aid available to Indians enrolled in any school referred to in clause (1)(A) of this subsection or who are undertaking training necessary to qualify them to enroll in any such school; or

(3) establishing other programs which the Secretary determines will enhance and facilitate the enrollment of Indians, and the subsequent pursuit and completion by them of courses of study, in any school referred to in clause (1)(A) of this subsection.

Application, submittal and approval.

(b)(1) No grant may be made under this section unless an application therefor has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such manner, and contain such information, as the Secretary shall by regulation prescribe: *Provided*, That the Secretary shall give a preference to applications submitted by Indian tribes or tribal organizations.

Amount and payment.

(2) The amount of any grant under this section shall be determined by the Secretary. Payments pursuant to grants under this section may be made in advance or by way of reimbursement, and at such intervals and on such conditions as the Secretary finds necessary.

Appropriation authorization.

(c) For the purpose of making payments pursuant to grants under this section, there are authorized to be appropriated $900,000 for fiscal year 1978, $1,500,000 for fiscal year 1979, and $1,800,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984 there are authorized to be appropriated for such payments such sums as may be specifically authorized by an Act enacted after this Act.

HEALTH PROFESSIONS PREPARATORY SCHOLARSHIP PROGRAM FOR INDIANS

SEC. 103. (a) The Secretary, acting through the Service, shall make scholarship grants to Indians who—

(1) have successfully completed their high school education or high school equivalency; and

(2) have demonstrated the capability to successfully complete courses of study in schools of medicine, osteopathy, dentistry, veterinary medicine, optometry, podiatry, pharmacy, public health, nursing, or allied health professions.

Scholarship grants, eligibility requirements. 25 USC 1613.

(b) Each scholarship grant made under this section shall be for a period not to exceed two academic years, which years shall be for compensatory preprofessional education of any grantee.

Two-year limitation.

(c) Scholarship grants made under this section may cover costs of tuition, books, transportation, board, and other necessary related expenses.

(d) There are authorized to be appropriated for the purpose of this section: $800,000 for fiscal year 1978, $1,000,000 for fiscal year 1979, and $1,300,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984 there are authorized to be appropriated for the purpose of this section such sums as may be specifically authorized by an Act enacted after this Act.

Appropriation authorization.

HEALTH PROFESSIONS SCHOLARSHIP PROGRAM

SEC. 104. Section 225(i) of the Public Health Service Act (42 U.S.C. 234(i)) is amended (1) by inserting "(1)" after "(i)", and (2) by adding at the end the following:

"(2)(A) In addition to the sums authorized to be appropriated under paragraph (1) to carry out the Program, there are authorized to be appropriated for the fiscal year ending September 30, 1978, $5,450,000; for the fiscal year ending September 30, 1979, $6,300,000; for the fiscal year ending September 30, 1980, $7,200,000; and for fiscal years 1981, 1982, 1983, and 1984 such sums as may be specifically authorized by an Act enacted after the Indian Health Care Improvement Act, to provide scholarships under the Program to provide physicians, osteopaths, dentists, veterinarians, nurses, optometrists, podiatrists, pharmacists, public health personnel, and allied health professionals to provide services to Indians. Such scholarships shall be designated Indian Health Scholarships and shall be made in accordance with this section except as provided in subparagraph (B).

Appropriation authorization.

'(B)(i) The Secretary, acting through the Indian Health Service, shall determine the individuals who receive the Indian Health Scholarships, shall accord priority to applicants who are Indians, and shall determine the distribution of the scholarships on the basis of the relative needs of Indians for additional service in specific health professions.

Distribution.

"(ii) The active duty service obligation prescribed by subsection (e) shall be met by the recipient of an Indian Health Scholarship by service in the Indian Health Service, in a program assisted under title V of the Indian Health Care Improvement Act, or in the private practice of his profession if, as determined by the Secretary in accordance with guidelines promulgated by him, such practice is situated in a physician or other health professional shortage area and addresses the health care needs of a substantial number of Indians.

Active duty service obligation.

Post, p. 1410.

"(C) For purposes of this paragraph, the term 'Indians' has the same meaning given that term by subsection (c) of section 4 of the

"Indians."

Ante, p. 1401. Indian Health Care Improvement Act and includes individuals described in clauses (1) through (4) of that subsection.".

INDIAN HEALTH SERVICE EXTERN PROGRAMS

25 USC 1614.

SEC. 105. (a) Any individual who receives a scholarship grant pursuant to section 104 shall be entitled to employment in the Service during any nonacademic period of the year. Periods of employment pursuant to this subsection shall not be counted in determining the fulfillment of the service obligation incurred as a condition of the scholarship grant.

(b) Any individual enrolled in a school of medicine, osteopathy, dentistry, veterinary medicine, optometry, podiatry, pharmacy, public health, nursing, or allied health professions may be employed by the Service during any nonacademic period of the year. Any such employment shall not exceed one hundred and twenty days during any calendar year.

(c) Any employment pursuant to this section shall be made without regard to any competitive personnel system or agency personnel limitation and to a position which will enable the individual so employed to receive practical experience in the health profession in which he or she is engaged in study. Any individual so employed shall receive payment for his or her services comparable to the salary he or she would receive if he or she were employed in the competitive system. Any individual so employed shall not be counted against any employment ceiling affecting the Service or the Department of Health, Education, and Welfare.

Appropriation authorization.

(d) There are authorized to be appropriated for the purpose of this section: $600,000 for fiscal year 1978, $800,000 for fiscal year 1979, and $1,000,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984 there are authorized to be appropriated for the purpose of this section such sums as may be specifically authorized by an Act enacted after this Act.

CONTINUING EDUCATION ALLOWANCES

25 USC 1615.

SEC. 106. (a) In order to encourage physicians, dentists, and other health professionals to join or continue in the Service and to provide their services in the rural and remote areas where a significant portion of the Indian people resides, the Secretary, acting through the Service, may provide allowances to health professionals employed in the Service to enable them for a period of time each year prescribed by regulation of the Secretary to take leave of their duty stations for professional consultation and refresher training courses.

Appropriation authorization.

(b) There are authorized to be appropriated for the purpose of this section: $100,000 for fiscal year 1978, $200,000 for fiscal year 1979, and $250,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984 there are authorized to be appropriated for the purpose of this section such sums as may be specifically authorized by an Act enacted after this Act.

TITLE II—HEALTH SERVICES

HEALTH SERVICES

25 USC 1621.

SEC. 201. (a) For the purpose of eliminating backlogs in Indian health care services and to supply known, unmet medical, surgical,

dental, optometrical, and other Indian health needs, the Secretary is authorized to expend, through the Service, over the seven-fiscal-year period beginning after the date of the enactment of this Act the amounts authorized to be appropriated by subsection (c). Funds appropriated pursuant to this section for each fiscal year shall not be used to offset or limit the appropriations required by the Service under other Federal laws to continue to serve the health needs of Indians during and subsequent to such seven-fiscal-year period, but shall be in addition to the level of appropriations provided to the Service under this Act and such other Federal laws in the preceding fiscal year plus an amount equal to the amount required to cover pay increases and employee benefits for personnel employed under this Act and such laws and increases in the costs of serving the health needs of Indians under this Act and such laws, which increases are caused by inflation.

Employment during seven-fiscal-year period.

(b) The Secretary, acting through the Service, is authorized to employ persons to implement the provisions of this section during the seven-fiscal-year period in accordance with the schedule provided in subsection (c). Such positions authorized each fiscal year pursuant to this section shall not be considered as offsetting or limiting the personnel required by the Service to serve the health needs of Indians during and subsequent to such seven-fiscal-year period but shall be in addition to the positions authorized in the previous fiscal year.

Appropriation authorization.

(c) The following amounts and positions are authorized, in accordance with the provisions of subsections (a) and (b), for the specific purposes noted:

(1) Patient care (direct and indirect): sums and positions as provided in subsection (e) for fiscal year 1978, $8,500,000 and two hundred and twenty-five positions for fiscal year 1979, and $16,200,000 and three hundred positions for fiscal year 1980.

(2) Field health, excluding dental care (direct and indirect): sums and positions as provided in subsection (e) for fiscal year 1978, $3,350,000 and eighty-five positions for fiscal year 1979, and $5,550,000 and one hundred and thirteen positions for fiscal year 1980.

(3) Dental care (direct and indirect): sums and positions as provided in subsection (e) for fiscal year 1978, $1,500,000 and eighty positions for fiscal year 1979, and $1,500,000 and fifty positions for fiscal year 1980.

(4) Mental health: (A) Community mental health services: sums and positions as provided in subsection (e) for fiscal year 1978, $1,300,000 and thirty positions for fiscal year 1979, and $2,000,000 and thirty positions for fiscal year 1980.

(B) Inpatient mental health services: sums and positions as provided in subsection (e) for fiscal year 1978, $400,000 and fifteen positions for fiscal year 1979, and $600,000 and fifteen positions for fiscal year 1980.

(C) Model dormitory mental health services: sums and positions as provided in subsection (e) for fiscal year 1978, $1,250,000 and fifty positions for fiscal year 1979, and $1,875,000 and fifty positions for fiscal year 1980.

(D) Therapeutic and residential treatment centers: sums and positions as provided in subsection (e) for fiscal year 1978, $300,000 and ten positions for fiscal year 1979, and $400,000 and five positions for fiscal year 1980.

(E) Training of traditional Indian practitioners in mental health: sums as provided in subsection (e) for fiscal year 1978, $150,000 for fiscal year 1979, and $200,000 for fiscal year 1980.

(5) Treatment and control of alcoholism among Indians: $4,000,000 for fiscal year 1978, $9,000,000 for fiscal year 1979, and $9,200,000 for fiscal year 1980.

(6) Maintenance and repair (direct and indirect): sums and positions as provided in subsection (e) for fiscal year 1978, $3,000,000 and twenty positions for fiscal year 1979, and $4,000,000 and thirty positions for fiscal year 1980.

(7) For fiscal years 1981, 1982, 1983, and 1984 there are authorized to be appropriated for the items referred to in the preceding paragraphs such sums as may be specifically authorized by an Act enacted after this Act. For such fiscal years, positions are authorized for such items (other than the items referred to in paragraphs (4)(E) and (5)) as may be specified in an Act enacted after the date of the enactment of this Act.

Research funds.

(d) The Secretary, acting through the Service, shall expend directly or by contract not less than 1 per centum of the funds appropriated under the authorizations in each of the clauses (1) through (5) of subsection (c) for research in each of the areas of Indian health care for which such funds are authorized to be appropriated.

Appropriation authorization.

(e) For fiscal year 1978, the Secretary is authorized to apportion not to exceed a total of $10,025,000 and 425 positions for the programs enumerated in clauses (c) (1) through (4) and (c)(6) of this section.

TITLE III—HEALTH FACILITIES

CONSTRUCTION AND RENOVATION OF SERVICE FACILITIES

25 USC 1631.

SEC. 301. (a) The Secretary, acting through the Service, is authorized to expend over the seven-fiscal-year period beginning after the date of the enactment of this Act the sums authorized by subsection (b) for the construction and renovation of hospitals, health centers, health stations, and other facilities of the Service.

Appropriation authorization.

(b) The following amounts are authorized to be appropriated for purposes of subsection (a):

(1) Hospitals: $67,180,000 for fiscal year 1978, $73,256,000 for fiscal year 1979, and $49,742,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984, there are authorized to be appropriated for hospitals such sums as may be specifically authorized by an Act enacted after this Act.

(2) Health centers and health stations: $6,960,000 for fiscal year 1978, $6,226,000 for fiscal year 1979, and $3,720,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984, there are authorized to be appropriated for health centers and health stations such sums as may be specifically authorized by an Act enacted after this Act.

(3) Staff housing: $1,242,000 for fiscal year 1978, $21,725,000 for fiscal year 1979, and $4,116,000 for fiscal year 1980. For fiscal years 1981, 1982, 1983, and 1984, there are authorized to be appropriated for staff housing such sums as may be specifically authorized by an Act enacted after this Act.

(c) Prior to the expenditure of, or the making of any firm commitment to expend, any funds authorized in subsection (a), the Secretary, acting through the Service shall—

Consultation.

(1) consult with any Indian tribe to be significantly affected by any such expenditure for the purpose of determining and, wherever practicable, honoring tribal preferences concerning the

size, location, type, and other characteristics of any facility on which such expenditure is to be made; and

(2) be assured that, wherever practicable, such facility, not later than one year after its construction or renovation, shall meet the standards of the Joint Committee on Accreditation of Hospitals.

CONSTRUCTION OF SAFE WATER AND SANITARY WASTE DISPOSAL FACILITIES

SEC. 302. (a) During the seven-fiscal-year period beginning after the date of the enactment of this Act, the Secretary is authorized to expend under section 7 of the Act of August 5, 1954 (42 U.S.C. 2004a), the sums authorized under subsection (b) to supply unmet needs for safe water and sanitary waste disposal facilities in existing and new Indian homes and communities. 25 USC 1632.

(b) For expenditures of the Secretary authorized by subsection (a) for facilities in existing Indian homes and communities there are authorized to be appropriated $43,000,000 for fiscal year 1978, $30,000,000 for fiscal year 1979, and $30,000,000 for fiscal year 1980. For expenditures of the Secretary authorized by subsection (a) for facilities in new Indian homes and communities there are authorized to be appropriated such sums as may be necessary for fiscal years 1978, 1979, and 1980. For fiscal years 1981, 1982, 1983, and 1984 for expenditures authorized by subsection (a) there are authorized to be appropriated such sums as may be specifically authorized in an Act enacted after this Act. Appropriation authorization.

(c) Former and currently federally recognized Indian tribes in the State of New York shall be eligible for assistance under this section. New York Indian tribes, eligibility for assistance.

PREFERENCE TO INDIANS AND INDIAN FIRMS

SEC. 303. (a) The Secretary, acting through the Service, may utilize the negotiating authority of the Act of June 25, 1910 (25 U.S.C. 47), to give preference to any Indian or any enterprise, partnership, corporation, or other type of business organization owned and controlled by an Indian or Indians including former or currently federally recognized Indian tribes in the State of New York (hereinafter referred to as an "Indian firm") in the construction and renovation of Service facilities pursuant to section 301 and in the construction of safe water and sanitary waste disposal facilities pursuant to section 302. Such preference may be accorded by the Secretary unless he finds, pursuant to rules and regulations promulgated by him, that the project or function to be contracted for will not be satisfactory or such project or function cannot be properly completed or maintained under the proposed contract. The Secretary, in arriving at his finding, shall consider whether the Indian or Indian firm will be deficient with respect to (1) ownership and control by Indians, (2) equipment, (3) bookkeeping and accounting procedures, (4) substantive knowledge of the project or function to be contracted for, (5) adequately trained personnel, or (6) other necessary components of contract performance. 25 USC 1633.

(b) For the purpose of implementing the provisions of this title, the Secretary shall assure that the rates of pay for personnel engaged in the construction or renovation of facilities constructed or renovated in whole or in part by funds made available pursuant to this title are not less than the prevailing local wage rates for similar work as determined in accordance with the Act of March 3, 1931 (40 U.S.C. 276a-276a-5, known as the Davis-Bacon Act). Construction personnel, pay rates. 40 USC 276a note.

SOBOBA SANITATION FACILITIES

SEC. 304. The Act of December 17, 1970 (84 Stat. 1465), is hereby amended by adding the following new section 9 at the end thereof:

"SEC. 9. Nothing in this Act shall preclude the Soboba Band of Mission Indians and the Soboba Indian Reservation from being provided with sanitation facilities and services under the authority of section 7 of the Act of August 5, 1954 (68 Stat. 674), as amended by the Act of July 31, 1959 (73 Stat. 267).".

42 USC 2004a.

TITLE IV—ACCESS TO HEALTH SERVICES

ELIGIBILITY OF INDIAN HEALTH SERVICE FACILITIES UNDER MEDICARE PROGRAM

SEC. 401. (a) Sections 1814(c) and 1835(d) of the Social Security Act are each amended by striking out "No payment" and inserting in lieu thereof "Subject to section 1880, no payment".

42 USC 1395f, 1395n.

(b) Part C of title XVIII of such Act is amended by adding at the end thereof the following new section:

42 USC 1395x.

"INDIAN HEALTH SERVICE FACILITIES

Hospital or skilled nursing facility, eligibility for payments.
42 USC 1395qq.

"SEC. 1880. (a) A hospital or skilled nursing facility of the Indian Health Service, whether operated by such Service or by an Indian tribe or tribal organization (as those terms are defined in section 4 of the Indian Health Care Improvement Act), shall be eligible for payments under this title, notwithstanding sections 1814(c) and 1835(d), if and for so long as it meets all of the conditions and requirements for such payments which are applicable generally to hospitals or skilled nursing facilities (as the case may be) under this title.

Ineligible hospital or skilled nursing facility, submittal of plan for compliance.

"(b) Notwithstanding subsection (a), a hospital or skilled nursing facility of the Indian Health Service which does not meet all of the conditions and requirements of this title which are applicable generally to hospitals or skilled nursing facilities (as the case may be), but which submits to the Secretary within six months after the date of the enactment of this section an acceptable plan for achieving compliance with such conditions and requirements, shall be deemed to meet such conditions and requirements (and to be eligible for payments under this title), without regard to the extent of its actual compliance with such conditions and requirements, during the first 12 months after the month in which such plan is submitted.

Fund for improvements.

"(c) Notwithstanding any other provision of this title, payments to which any hospital or skilled nursing facility of the Indian Health Service is entitled by reason of this section shall be placed in a special fund to be held by the Secretary and used by him (to such extent or in such amounts as are provided in appropriation Acts) exclusively for the purpose of making any improvements in the hospitals and skilled nursing facilities of such Service which may be necessary to achieve compliance with the applicable conditions and requirements of this title. The preceding sentence shall cease to apply when the Secretary determines and certifies that substantially all of the hospitals and skilled nursing facilities of such Service in the United States are in compliance with such conditions and requirements.

"(d) The annual report of the Secretary which is required by section 701 of the Indian Health Care Improvement Act shall include (along with the matters specified in section 403 of such Act) a detailed

Post, p. 1413.
Post, p. 1410.

statement of the status of the hospitals and skilled nursing facilities of the Service in terms of their compliance with the applicable conditions and requirements of this title and of the progress being made by such hospitals and facilities (under plans submitted under subsection (b) and otherwise) toward the achievement of such compliance.".

(c) Any payments received for services provided to beneficiaries hereunder shall not be considered in determining appropriations for health care and services to Indians. 42 USC 1395qq note.

(d) Nothing herein authorizes the Secretary to provide services to an Indian beneficiary with coverage under title XVIII of the Social Security Act, as amended, in preference to an Indian beneficiary without such coverage. Services to an Indian beneficiary. 42 USC 1395qq note.

SERVICES PROVIDED TO MEDICAID ELIGIBLE INDIANS

SEC. 402. (a) Title XIX of the Social Security Act is amended by adding at the end thereof the following new section: 42 USC 1395.

"INDIAN HEALTH SERVICE FACILITIES

"SEC. 1911. (a) A facility of the Indian Health Service (including a hospital, intermediate care facility, or skilled nursing facility), whether operated by such Service or by an Indian tribe or tribal organization (as those terms are defined in section 4 of the Indian Health Care Improvement Act), shall be eligible for reimbursement for medical assistance provided under a State plan if and for so long as it meets all of the conditions and requirements which are applicable generally to such facilities under this title. Eligibility for reimbursement. 42 USC 1396j. *Ante*, p. 1401.

"(b) Notwithstanding subsection (a), a facility of the Indian Health Service (including a hospital, intermediate care facility, or skilled nursing facility) which does not meet all of the conditions and requirements of this title which are applicable generally to such facility, but which submits to the Secretary within six months after the date of the enactment of this section an acceptable plan for achieving compliance with such conditions and requirements, shall be deemed to meet such conditions and requirements (and to be eligible for reimbursement under this title), without regard to the extent of its actual compliance with such conditions and requirements, during the first twelve months after the month in which such plan is submitted.". Facilities, submittal of plan for compliance. 42 USC 1396j note.

(b) The Secretary is authorized to enter into agreements with the appropriate State agency for the purpose of reimbursing such agency for health care and services provided in Service facilities to Indians who are eligible for medical assistance under title XIX of the Social Security Act, as amended. 42 USC 1396j note. 42 USC 1396.

(c) Notwithstanding any other provision of law, payments to which any facility of the Indian Health Service (including a hospital, intermediate care facility, or skilled nursing facility) is entitled under a State plan approved under title XIX of the Social Security Act by reason of section 1911 of such Act shall be placed in a special fund to be held by the Secretary and used by him (to such extent or in such amounts as are provided in appropriation Acts) exclusively for the purpose of making any improvements in the facilities of such Service which may be necessary to achieve compliance with the applicable conditions and requirements of such title. The preceding sentence shall cease to apply when the Secretary determines and certifies that substantially all of the health facilities of such Service in the United States are in compliance with such conditions and requirements. *Supra*.

42 USC 1396j note.

(d) Any payments received for services provided recipients hereunder shall not be considered in determining appropriations for the provision of health care and services to Indians.

Federal medical assistance percentage. 42 USC 1396d.

(e) Section 1905(b) of the Social Security Act is amended by inserting at the end thereof the following: "Notwithstanding the first sentence of this section, the Federal medical assistance percentage shall be 100 per centum with respect to amounts expended as medical assistance for services which are received through an Indian Health Service facility whether operated by the Indian Health Service or by an Indian tribe or tribal organization (as defined in section 4 of the Indian Health Care Improvement Act).".

Ante, p. 1401.

REPORT

25 USC 1671 note.

SEC. 403. The Secretary shall include in his annual report required by section 701 an accounting on the amount and use of funds made available to the Service pursuant to this title as a result of reimbursements through titles XVIII and XIX of the Social Security Act, as amended.

42 USC 1395, 1396.

TITLE V—HEALTH SERVICES FOR URBAN INDIANS

PURPOSE

25 USC 1651.

SEC. 501. The purpose of this title is to encourage the establishment of programs in urban areas to make health services more accessible to the urban Indian population.

CONTRACTS WITH URBAN INDIAN ORGANIZATIONS

25 USC 1652.

SEC. 502. The Secretary, acting through the Service, shall enter into contracts with urban Indian organizations to assist such organizations to establish and administer, in the urban centers in which such organizations are situated, programs which meet the requirements set forth in sections 503 and 504.

CONTRACT ELIGIBILITY

25 USC 1653.

SEC. 503. (a) The Secretary, acting through the Service, shall place such conditions as he deems necessary to effect the purpose of this title in any contract which he makes with any urban Indian organization pursuant to this title. Such conditions shall include, but are not limited to, requirements that the organization successfully undertake the following activities:

(1) determine the population of urban Indians which are or could be recipients of health referral or care services;

(2) identify all public and private health service resources within the urban center in which the organization is situated which are or may be available to urban Indians;

(3) assist such resources in providing service to such urban Indians;

(4) assist such urban Indians in becoming familiar with and utilizing such resources;

(5) provide basic health education to such urban Indians;

(6) establish and implement manpower training programs to accomplish the referral and education tasks set forth in clauses (3) through (5) of this subsection;

(7) identify gaps between unmet health needs of urban Indians and the resources available to meet such needs;

(8) make recommendations to the Secretary and Federal, State, local, and other resource agencies on methods of improving health service programs to meet the needs of urban Indians; and

(9) where necessary, provide or contract for health care services to urban Indians.

(b) The Secretary, acting through the Service, shall by regulation prescribe the criteria for selecting urban Indian organizations with which to contract pursuant to this title. Such criteria shall, among other factors, take into consideration:

Urban Indian organizations, selection criteria.

(1) the extent of the unmet health care needs of urban Indians in the urban center involved;

(2) the size of the urban Indian population which is to receive assistance;

(3) the relative accessibility which such population has to health care services in such urban center;

(4) the extent, if any, to which the activities set forth in subsection (a) would duplicate any previous or current public or private health services project funded by another source in such urban center;

(5) the appropriateness and likely effectiveness of the activities set forth in subsection (a) in such urban center;

(6) the existence of an urban Indian organization capable of performing the activities set forth in subsection (a) and of entering into a contract with the Secretary pursuant to this title; and

(7) the extent of existing or likely future participation in the activities set forth in subsection (a) by appropriate health and health-related Federal, State, local, and other resource agencies.

OTHER CONTRACT REQUIREMENTS

SEC. 504. (a) Contracts with urban Indian organizations pursuant to this title shall be in accordance with all Federal contracting laws and regulations except that, in the discretion of the Secretary, such contracts may be negotiated without advertising and need not conform to the provisions of the Act of August 24, 1935 (48 Stat. 793), as amended.

25 USC 1654.

49 Stat. 793.

(b) Payments under any contracts pursuant to this title may be made in advance or by way of reimbursement and in such installments and on such conditions as the Secretary deems necessary to carry out the purposes of this title.

40 USC 270a-270d.

(c) Notwithstanding any provision of law to the contrary, the Secretary may, at the request or consent of an urban Indian organization, revise or amend any contract made by him with such organization pursuant to this title as necessary to carry out the purposes of this title: *Provided, however*, That whenever an urban Indian organization requests retrocession of the Secretary for any contract entered into pursuant to this title, such retrocession shall become effective upon a date specified by the Secretary not more than one hundred and twenty days from the date of the request by the organization or at such later date as may be mutually agreed to by the Secretary and the organization.

Contract revision or amendment.

(d) In connection with any contract made pursuant to this title, the Secretary may permit an urban Indian organization to utilize, in carrying out such contract, existing facilities owned by the Federal Government within his jurisdiction under such terms and conditions as may be agreed upon for their use and maintenance.

Government facilities, use.

(e) Contracts with urban Indian organizations and regulations adopted pursuant to this title shall include provisions to assure the fair and uniform provision to urban Indians of services and assistance under such contracts by such organizations.

REPORTS AND RECORDS

Report to Secretary of the Interior.
25 USC 1655.

SEC. 505. For each fiscal year during which an urban Indian organization receives or expends funds pursuant to a contract under this title, such organization shall submit to the Secretary a report including information gathered pursuant to section 503(a) (7) and (8), information on activities conducted by the organization pursuant to the contract, an accounting of the amounts and purposes for which Federal funds were expended, and such other information as the Secretary may request. The reports and records of the urban Indian organization with respect to such contract shall be subject to audit by the Secretary and the Comptroller General of the United States.

Audit.

AUTHORIZATIONS

25 USC 1656.

SEC. 506. There are authorized to be appropriated for the purpose of this title: $5,000,000 for fiscal year 1978, $10,000,000 for fiscal year 1979, and $15,000,000 for fiscal year 1980.

REVIEW OF PROGRAM

Submittal to Congress.
Legislative recommendations.
25 USC 1657.

SEC. 507. Within six months after the end of fiscal year 1979, the Secretary, acting through the Service and with the assistance of the urban Indian organizations which have entered into contracts pursuant to this title, shall review the program established under this title and submit to the Congress his assessment thereof and recommendations for any further legislative efforts he deems necessary to meet the purpose of this title.

RURAL HEALTH PROJECTS

25 USC 1658.

SEC. 508. Not to exceed 1 per centum of the amounts authorized by section 506 shall be available for not to exceed two pilot projects providing outreach services to eligible Indians residing in rural communities near Indian reservations.

TITLE VI—AMERICAN INDIAN SCHOOL OF MEDICINE; FEASIBILITY STUDY

FEASIBILITY STUDY

25 USC 1661.

SEC. 601. The Secretary, in consultation with Indian tribes and appropriate Indian organizations, shall conduct a study to determine the need for, and the feasibility of, establishing a school of medicine to train Indians to provide health services for Indians. Within one year of the date of the enactment of this Act the Secretary shall complete such study and shall report to the Congress findings and recommendations based on such study.

Report to Congress.

TITLE VII—MISCELLANEOUS

REPORTS

SEC. 701. The Secretary shall report annually to the President and the Congress on progress made in effecting the purposes of this Act. Within three months after the end of fiscal year 1979, the Secretary shall review expenditures and progress made under this Act and make recommendations to the Congress concerning any additional authorizations for fiscal years 1981 through 1984 for programs authorized under this Act which he deems appropriate. In the event the Congress enacts legislation authorizing appropriations for programs under this Act for fiscal years 1981 through 1984, within three months after the end of fiscal year 1983, the Secretary shall review programs established or assisted pursuant to this Act and shall submit to the Congress his assessment and recommendations of additional programs or additional assistance necessary to, at a minimum, provide health services to Indians, and insure a health status for Indians, which are at a parity with the health services available to, and the health status, of the general population.

Report to the President and Congress. 25 USC 1671.

Program review, submittal to Congress.

REGULATIONS

SEC. 702. (a)(1) Within six months from the date of enactment of this Act, the Secretary shall, to the extent practicable, consult with national and regional Indian organizations to consider and formulate appropriate rules and regulations to implement the provisions of this Act.

Consultation. 25 USC 1672.

(2) Within eight months from the date of enactment of this Act, the Secretary shall publish proposed rules and regulations in the Federal Register for the purpose of receiving comments from interested parties.

Publication in Federal Register.

(3) Within ten months from the date of enactment of this Act, the Secretary shall promulgate rules and regulations to implement the provisions of this Act.

(b) The Secretary is authorized to revise and amend any rules or regulations promulgated pursuant to this Act: *Provided*, That, prior to any revision of or amendment to such rules or regulations, the Secretary shall, to the extent practicable, consult with appropriate national or regional Indian organizations and shall publish any proposed revision or amendment in the Federal Register not less than sixty days prior to the effective date of such revision or amendment in order to provide adequate notice to, and receive comments from, other interested parties.

Rules or regulations, proposed revision or amendment; publication in Federal Register.

PLAN OF IMPLEMENTATION

SEC. 703. Within two hundred and forty days after enactment of this Act, a plan will be prepared by the Secretary and will be submitted to the Congress. The plan will explain the manner and schedule (including a schedule of appropriation requests), by title and section, by which the Secretary will implement the provisions of this Act.

Submittal to Congress. 25 USC 1673.

LEASES WITH INDIAN TRIBES

25 USC 1674. SEC. 704. Notwithstanding any other provision of law, the Secretary is authorized, in carrying out the purposes of this Act, to enter into leases with Indian tribes for periods not in excess of twenty years.

AVAILABILITY OF FUNDS

25 USC 1675. SEC. 705. The funds appropriated pursuant to this Act shall remain available until expended.

Approved September 30, 1976.

LEGISLATIVE HISTORY:

HOUSE REPORTS: No. 94-1026 pt. I and 94-1026 part IV (Comm. on Interior and Insular Affairs), No. 94-1026 pt. II (Comm. on Ways and Means), and No. 94-1026 pt. III (Comm. on Interstate and Foreign Commerce) all accompanying H.R. 2525.
SENATE REPORT No. 94-133 (Comm. on Interior and Insular Affairs).
CONGRESSIONAL RECORD:
Vol. 121 (1975): May 16, considered and passed Senate.
Vol. 122 (1976): July 30, considered and passed House, amended, in lieu of H.R. 2525.
Sept. 9, Senate concurred in House amendment with an amendment.
Sept. 16, House concurred in Senate amendment.
WEEKLY COMPILATION OF PRESIDENTIAL DOCUMENTS:
Vol. 12, No. 40: Oct. 1, Presidential statement.

The CHAIRMAN. I would note for the audience that Senator Inouye is in another hearing and could not be with us today, although he may drop by, a little bit later.

We will proceed with the first panel made up of one person. For those who have not appeared before this committee, we have a little clock up here. We try and limit the verbal testimony, but all the written testimony is included.

With the exception of the administration testimony, who we give them a little more latitude, other witnesses are asked to watch the clock.

So we will start with Michael Trujillo, the director of the Indian Health Service within the Department of Health and Human Services. Welcome to the committee. Dr. Trujillo, it is nice to see you. If you would like to proceed, we are happy to have you here.

STATEMENT OF MICHAEL TRUJILLO, EXECUTIVE DIRECTOR, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY MICHAEL LINCOLN, DEPUTY DIRECTOR, INDIAN HEALTH SERVICE; CRAIG VANDERWAGEN, M.D., OFFICE OF HEALTH PROGRAMS, INDIAN HEALTH SERVICE; AND GARY HARTZ, OFFICE OF PUBLIC HEALTH, INDIAN HEALTH SERVICE.

Mr. TRUJILLO. Good afternoon, Mr. Chairman, and thank you for the opportunity to be here with others of your committee and staffers, as well as the audience who are present.

We did submit a written statement for the record.

The CHAIRMAN. Without objection, it will be included.

Mr. TRUJILLO. On my far right, accompanying me today is Michael Lincoln, the Deputy Director of our agency, Indian Health Service.

The CHAIRMAN. On your near right.

Mr. TRUJILLO. And further to my right is Dr. Craig Vanderwagen, who is in our Office of Health Programs and who worked extensively in the reauthorization process.

On my left is Gary Hartz, head of our health care programs, who is also involved with sewage, sanitation, and engineering in our field facilities.

This is the first of several anticipated hearings before Congress on the proposed Indian Health Care Improvement Act, Public Law 94–437. The present act is scheduled to expire the end of the fiscal year 2000.

Public Law 94–437 was first enacted in 1976 to address several major items in Indian country—No. 1, long standing deficiencies in Indian health care; No. 2, to increase the number of health professionals serving in Indian communities; No. 3, to authorize services to urban Indian populations; No. 4, to rectify health facility problems; and No. 5, to provide access to Indian patients to other Federal resources such as Medicaid and Medicare.

Since 1976, Public Law 94–437 has been reauthorized four different times, and has had numerous amendments. Together with the Snyder Act of 1921, it provides overall guidance and authority for programs of the Indian Health Service, Indian tribes, and urban programs.

Based on consultation policy and operating procedures of the Indian Health Service, and in concert with the President's Executive order and memorandum regarding the special relationship of tribal governments with the Federal Government, and with the new Department of Health and Human Services consultation policy with Indian tribes, we embarked on a local, regional, and national effort with tribes and urban programs in June 1998, to develop recommendations for the draft bill presented to Congress, the department, the Indian Health Service, by tribes and urban programs. That process is summarized in my witness statement.

I would like to emphasize that this process was most extensive, and many people spent much time and dedicated effort on it. I would especially like to thank the members of the national steering committee, the task group, and those tribal leaders who are here today for all their efforts and their time. Their ability to lead in this process was exemplary.

The Indian Health Service staff and the department staff also devoted much time to this process. I also thank them deeply, especially Michael Mahsetky and Kitty Rogers, who coordinated the effort for our office.

The Indian Health Service and the department are presently reviewing the act and its seven major titles. The secretary, the deputy secretary and I are looking forward to continuing to work and consult with tribes and respective organizations, as the reauthorization process continues.

I especially look forward to working with you, other members of Congress and committees, and with tribal and urban program leadership to assure that together we address the health care needs of American Indians and Alaska Natives in a comprehensive, equitable manner.

We should all be proud to enter this century, this millennium together, so that American Indians, Alaska Native children, and their children can obtain the best health care this nation has to offer, and that the government-to-government relationship of tribes with the Federal Government is duly strengthened.

Thank you, Mr. Chairman. We will respectfully await your questions.

[Prepared statement of Dr. Trujillo appears in appendix.]

The CHAIRMAN. Thank you. I might tell you, from my perspective, Dr. Trujillo, I think you are doing a very fine job. And I certainly appreciate your effort.

You spoke at length about the process that is going on. And maybe it is somewhere in your written testimony, but I wanted to know, you also said it is under review now.

Have you come to any conclusions of any glaring faults with it, or any suggestions you might have, at this point?

Mr. TRUJILLO. Not anything in particular, although we have ongoing discussions within the department and with other agencies within the department, to look at the changes of particular titles.

The CHAIRMAN. And you are involving the tribes in those discussions, too?

Mr. TRUJILLO. That is correct. We also will be working with the tribes and urban programs throughout this year on the whole reauthorization.

The CHAIRMAN. When will you have your review finished?

Mr. TRUJILLO. We hope we will be able to get a more formal process and review done perhaps in the next 2 months.

The CHAIRMAN. Two months? Well, I would remind you, we have a very short year, this year.

Mr. TRUJILLO. Yes; we do.

The CHAIRMAN. I think we only have something like 72 or 74 days, even in session. We are out more than we are in, this year—an election year, as you probably know. So if you could get that to us at your earliest convenience, I think the rest of the committee would really like to move something, as quickly as we could.

Mr. TRUJILLO. Yes; we will. In fact, within the department, we are also going to be meeting on that.

The CHAIRMAN. You mentioned urban Indians. And, of course, this committee hears a lot about the disparity between health service for urban Indians versus reservation-based Indians.

Can you break down the numbers of how many Indians are served by IHS on Indian land, and how many are being served in urban areas?

Mr. TRUJILLO. Well, Mr. Chairman, we have better data, of course, for Indians who are on the reservations, especially those that come to tribal and Indian Health Service facilities, because of the way we have defined a user population base.

For the urban population, it is very difficult to have definitive data on the number of users for those that are living in urban areas. Perhaps Dr. Vanderwagen, do you little bit more to contribute on that?

Mr. VANDERWAGEN. Yes; Senator Campbell, of the 1.3 million users that use our system regularly, about 350,000 of those live in urban environments. But there may be as many as another 500,000 or so, living in urban environments, who are members of federally-recognized tribes, descendants of tribal members, or in State recognized tribes that may not have full access to services.

So we serve some urban folks now through the tribal and IHS facilities. We serve others through the urban program. But there may be as many as another half million or so that do not get counted in our user population.

The CHAIRMAN. How about the comparison of per capita expenditure for health care services for urban Indians versus reservation people?

Mr. VANDERWAGEN. Well, as you know, our expenditures are about $1,300 per capita, for users of the Indian Health Service system. Compared to Medicaid at $3,200 per capita, there is a wide gulf between what is available to Medicaid eligible individuals and Indians.

Now we are not sure exactly what the per capita expenditure would be for urban Indians. But if you look at the segment of our budget that is authorized under title 5, that is a very, very small fraction of the per capita expenditure available to the general Indian population that uses IHS for tribal services.

Mr. TRUJILLO. Mr. Chairman, I would like to also add that a number, of course as you well know, of urban Indians also go between the urban programs or urban sites and go back to the reservations. And also, they receive care at both particular locations.

The CHAIRMAN. Well, one of the things that the committee has heard in the past from Indian people living in urban areas is that sometimes they are not, you might say, very welcome in the local community health services. Because they are often told, you know, if you are Indian and you are enrolled, you already have these health services on your reservation.

Mr. TRUJILLO. That is correct.

The CHAIRMAN. And so some Indian people simply feel they are not welcome in those centers. And, of course, that is wrong, and a violation of the law, too. But I know some of them are not being served, because they just sort of fall through the cracks.

Let me also go on. The draft legislation proposes funding the joint venture program to help expedite building health facilities. What is the success rate for that program, and why is the IHS not pursuing other ways of trying to build health facilities?

Mr. TRUJILLO. I also would like to call on Mr. Gary Hartz to respond a little bit more in detail to this particular question. But the joint venture program has been quite successful. We have had two sites, several tribes involved in this process.

The CHAIRMAN. Two sites?

Mr. TRUJILLO. One is the Warm Springs Confederated Tribes in Oregon, and another is in Oklahoma.

The CHAIRMAN. Where is the one in Oklahoma?

Mr. HARTZ. The Poteau facility.

Mr. TRUJILLO. The Poteau facility in Oklahoma.

I am very familiar with the Warm Springs site, since I used to be in the Oregon area. They have built an extensive, wonderful facility.

The Indian Health Service now, at the present time, is staffing that facility. We have equiped the facility. We have expanded not only the direct services, but also our public and preventive services. We are working on a collaborative basis with the community programs.

One particular area that I believe the joint venture could be very productive, is in regards to collaborative tribal programs with the Indian Health Service.

The CHAIRMAN. I might mention, when we talk about building health facilities, I visited a couple of them. And the facilities, the ones I have seen that have been built, there are not enough of them, clearly. But they are very nice.

There does seem to be a problem, though, in putting the facilities in the building you need. I was in Lanier, Montana, about 5 or 6 months ago, to look at that new facility they have up there.

And they told me, even with that brand new facility, you still have to go all the way to Crow, which is about a 50-mile drive each way, for dialysis. They have no machines. They certainly have a need for it.

So I would perhaps point out that the problem we do have, when we build new facilities, there does not seem to be something factored in to put the infrastructure and equipment inside the facility.

You know, a big empty building may be called a health clinic. But unless the equipment is in there to actually use, it is still not

going to be of much service to people. So I would just point that out to you.

Mr. TRUJILLO. Yes; that is true. Some of the recent facilities are quite nice. One also has to take a look at when the planning for that particular facility occurred, the staffing, equipment, and change in medical care services also has to be assessed in regards to future planning.

In regards to this particular facility, there is not, I believe, a dialysis program there. However, there is a possibility of contracting with an outside program to have dialysis in that particular unit, which most of our facilities do throughout the Nation, when they do enter into dialysis services.

The CHAIRMAN. So when they contract with an outside unit, they put the machines right in that facility; is that correct?

Mr. TRUJILLO. Some may. Depending upon the availability of space, how many machines and other things are necessary, it may be in that particular facility, or it may be in an adjacent facility, that is either currently there or has been constructed for that particular purpose.

The CHAIRMAN. I understand.

And also, I am sure you heard in my opening statement, I know that the IHS is making great strides and trying very hard. But it still seems like the health status of Indian people continues to go down, or does not get any better, across the board. What do you attribute that to, particularly in areas of diabetes and cancer?

I saw something, I guess it was yesterday. The staff gave me a memo about youngsters, diabetes in youngsters. It is on the incline for Indian kids.

Mr. TRUJILLO. Well, fortunately, years ago, when our Indian people had many diseases that were communicable and infectious, the inroads regarding sewage, sanitation, clean water, waste disposal, immunizations made a drastic impact to decrease the morbidity/mortality rates, as well as in-roads to decrease maternal and child death.

Unfortunately, now we are getting into the arena of chronic diseases and complicated diseases, secondary to changes in lifestyle.

The CHAIRMAN. Well, is diabetes also related to diet?

Mr. TRUJILLO. That is correct. Unfortunately, we are also diagnosing individuals who are sometimes age 5, 6, and 10 years old with diabetes. We have had individuals who have been dialysis who were age 14 or 15.

That is, unfortunately, the complications we are seeing across Indian country. It is now the scourge, I believe, of Indian people, nationwide, much like TB was in the past.

Unfortunately, what we now see is only the tip of the iceberg. We are now diagnosing new individuals with that disease. Unfortunately as we go 5, 10, 15 years from now, we are going to see the impact of the complications of the disease of diabetes, and also the impact upon the families and the communities, all secondary to that.

The CHAIRMAN. One thing I have not seen is a comparative number between diabetes among Indian youngsters and non–Indian youngsters. If you can find some information on that, would you also provide that to the committee?

Mr. TRUJILLO. Yes; we will, Mr. Chairman.

The CHAIRMAN. I appreciate that.

I would like to give my colleague and friend, Senator Conrad from North Dakota, an opportunity for a statement or any questions he would like to ask.

Senator CONRAD. Thank you very much, Mr. Chairman. I appreciate your holding this hearing and, as always, your leadership on these issues. I have always enjoyed our working relationship very much.

Mr. Trujillo, it is good to have you here. I appreciate seeing you, again, and your able staff, as well.

Mr. TRUJILLO. Yes; thank you.

Senator CONRAD. We appreciate your being here for what I think is a very important hearing on the Indian Health Care Improvement Act.

If there is anything clear, it is that we have got a health crisis in Indian country. I am pleased to see Tex Hall, the chairman of Three Affiliated Tribes, is with us. He will be testifying on the next panel. He is here representing the Aberdeen Area Tribal Chairmen's Health Board.

And I say we have got a crisis in health care in Indian country. Everybody on this panel knows it. All of you at the witness table know it. Everybody in the audience knows it.

Just in the Aberdeen area, life expectancy is 10 years less than the national average. And there are many contributing causes—bad water supply, bad housing, bad diet, a situation in which people are badly under-employed and unemployed, in which there is a sense of hopelessness that leads to self-destructive behavior. And I would also put on the list the health care deficit that exists in Indian country.

I have been many times to the reservations in my State. And without exception, the health care provided there is substandard. There is no other way to say it and be honest about it. It is substandard, either because the facilities are lacking; or, where the facilities are not lacking, because the personnel are lacking.

And I am not talking about the individual qualifications of the personnel, as much as I am talking about just not having the personnel, the health care specialties necessary to address the problems that they are confronted with.

So this requires that we take additional steps and take action. If there is ever a case where the Federal Government has responsibility, this is it. We have got 1 million people in this country, who are dependent for their health care services on these systems.

This is a distinctly Federal responsibility, and we are doing a lousy job of it. And I am not blaming you. This is a problem that pre-dated you by a long ways, and it will be here after you are gone.

I salute you for being a very genuine person in trying to improve what you inherited. And I believe you have improved what you have inherited. And I congratulate you and commend you for it.

But I put most of the blame right here in Congress. And I put also substantial blame on all of the administrations who have not paid sufficient attention to this problem, to really make the kind

of progress that we should make. And we have got a moral obligation to make it.

So I hope that this act will help change things. But, you know, it is not going to change things unless we put more resources into the effort. And I know around here it is fashionable to say, oh, no, we can not spend more money.

Well, I tell you, if we do not spend more money, we are not going to get substantially improved results. Anybody who has studied this system knows that is true.

It is also true that we have got to do a better job with the money we do have to spend, because we have not coordinated this effort as well as it could be coordinated.

I, personally, believe that one of the things we could do to improve the situation is to provide training and incentives to increase the number of health care professionals in Indian country.

We are not offering enough incentives for people to be there. And, boy, it is pretty hard to attract top level medical professionals to these communities. Again, if we will just be honest with each other, we know that is true. We have got to provide more of an incentive.

I would ask you, Dr. Trujillo, in your experience, have you concluded that we need to provide more of an incentive to attract medical professionals to these areas?

Mr. TRUJILLO. Yes, Senator Conrad; I believe we do. Having lived in the Aberdeen area for 5 years, I certainly know some of the problems that you and tribes face in regards to the remoteness.

We are also having to be competitive in the health professions arena with the private sector, such as health care corporations, who may offer incentives other than salary, to entice and retain individuals to their programs. We also see that remoteness of sites is another factor, in regards to recruitment and retention of individuals.

The areas we are very concerned about is certainly the dentists, the pharmacists, the sanitarians, and the engineers, who make up the foundation of many of our programs, much less the nurses and the physicians within the clinics.

We have an extremely high rate of vacancies of dentists throughout Indian country, primarily because of location and salary benefits that we are not able to offer as compared to the private sector, and the lack of availability of dentists who are now coming out of dental school. All of those factors contribute to the difficulties that we see in Indian country.

I very much support your statement that we do need to pay more attention to more incentives for health professionals in Indian country.

Senator CONRAD. One thing that I would like to mention if I could, Mr. Chairman, is I do applaud the administration for the increase in health care in this budget. It is badly needed. And I want to commend you for fighting within the administration to get that increase. And I know it is not easy. But this is the biggest increase that I can recall being presented by an administration.

And there is more than money that is required. The chairman has pointed this out. We have also got to be accountable for the dollars that are provided to us, and do a much better job of admin-

istering those dollars. And, Dr. Trujillo, I think you have made serious steps in that regard, and I applaud you for it.

I will end there, Mr. Chairman, and hopefully will have an additional opportunity.

Mr. TRUJILLO. Thank you, Senator. I also would like to add that the secretary and the deputy secretary have also been very supportive of the programs, as well as the ability to have other agencies within the department assure that those resources from those agencies are also applied to Indian people, nationwide.

The CHAIRMAN. Senator Dorgan, did you have any comments or questions for this panel?

Senator DORGAN. Mr. Chairman, I had an opportunity to question Dr. Trujillo just days ago, in the Appropriations Subcommittee on the Interior. So we have already had a discussion.

But I might just say, again, that as I indicated the other day, I believe we have a full-blown emergency in three areas on reservations. And that is health care, housing, and education.

And with respect to health care, I agree with my colleague, Senator Conrad, and with Chairman Campbell, that the proposed increase in funding by the administration is certainly welcome and helpful.

But, in my judgment, this increase does not meet the needs that exist in the Aberdeen region and elsewhere. The needs are crucial. We must, must do something that we are proud of here in deciding that we finally are going to fund Indian health care at sufficient levels to meet our responsibility.

It just remains unforgivable that health care, for some in this country, is still a function of whether someone else has money. It should not be that way.

Those who take their children or their elders to health care facilities on Indian reservations should not be left wondering when and whether good or appropriate treatment will be available to them.

Mr. Trujillo, you are trying to do a tough job. You are trying to meet almost unlimited needs with limited resources. That is a tough job to do. But I applaud you for your efforts. I want to help you and the administration, and I want to help the chairman and others boost this funding so that we can finally be proud of the delivery of health care services on these Indian reservations.

Let me say also that Tex Hall, one of our tribal chairmen in North Dakota, will be testifying later today. And I know that he will talk about the conditions that exist in the Three Affiliated Tribes area.

I have been involved with Chairman Hall's tribe along with Senator Conrad, on dialysis issues and diabetes issues, and so many others. But he will tell us, first hand, how short we are of meeting the needs. And we must, must do better.

Mr. TRUJILLO. Thank you, Senator.

The CHAIRMAN. Are there any further comments?

[No response.]

The CHAIRMAN. Doctor, we appreciate you appearing today. And if you have anything to add, as you get the results of that report, we would appreciate you turning that in.

Mr. TRUJILLO. Thank you, Mr. Chairman.

The CHAIRMAN. We have just one more question.

Senator CONRAD. Dr. Trujillo, as you know, we have had a continuing problem at Mercy Hospital in Devil's Lake with the backlog there.

We have an unusual situation, Mr. Chairman, where we have a hospital that serves the Devil's Lake community.

The CHAIRMAN. Is that the lake that keeps getting deeper?

Senator CONRAD. Yes; it is an incredible situation. This lake has risen 25 vertical feet in the last six years.

And this hospital serves the entire region, including the Spirit Lake Nation. And that hospital is absolutely critical to care in that entire region. And we have had an continuing backlog on the payments there.

Could you get me an update on where we are with respect to that backlog?

Mr. TRUJILLO. Yes; I will forward you an update. I have also asked our staff to make sure that both you and Senator Dorgan's office are informed, on a regular basis, as to the status of the payments of the contract health services bill.

My understanding, at the present time, is that Mercy Hospital has submitted to the Aberdeen area office approximately $150,000 worth of back bills. I believe those payments are now being processed through our fiscal intermediary in Albuquerque.

Most recently, the Lake Region clinic submitted some past bills. They are presently being reviewed by the clinic, as well as the Aberdeen area and Fort Totten service unit staff. That amounts to, I believe, around about $50,000. Based upon the reviews those bills will also be paid in the very near future.

Senator CONRAD. Can I say this, by way of a matter of urgency? Because of the high percentage of people who are eligible at that hospital, and what we have done in terms cutting Medicare, the viability of that entire hospital is now at risk.

Mr. TRUJILLO. Yes.

Senator CONRAD. And this is going to be a significant component to determine whether that hospital survives or not.

Mr. TRUJILLO. Yes.

Senator CONRAD. Now this is not just Kent Conrad talking up here. This is a view of an accounting firm that we have had study the viability of all hospitals in North Dakota.

So we have got a circumstance in which we could lose a hospital that serves that entire community, including the Spirit Lake Nation, if we do not get reimbursement on a more timely basis and unless, frankly, we fix some of what we did in Medicare, to cut back more substantially than was intended.

So I just want to share with you the urgency with which those bills must be paid.

Mr. TRUJILLO. I fully agree with that.

I was just there in July of this past year, at Fort Totten service unit and the Devil's Lake region, there I reviewed the status of the engineering and the rising lake, and conversed with various program staff there. It is of urgency.

The difficulty of reimbursement for all rural facilities has changed, and it has made an impact, especially in South and North Dakota, for example.

Senator CONRAD. Yes.

Mr. TRUJILLO. Dr. Vanderwagen, do you want to add anything?

Mr. VANDERWAGEN. Yes, Senator; one positive here is that last year, the turn around time on bill payment at Fort Totten was about 25 percent over the IHS average. It is now down to 25 percent below the IHS average.

So they have made some significant strides in the billing process and communication with the billing staff at Lake and at Mercy both, to assure that that flows. They are looking at electronic transfer technology as another way to potentially handle that.

The CHAIRMAN. Could I give you my account number on that part of it? [Laughter.]

Senator DORGAN. Might I just ask, Mr. Chairman, what is the IHS average?

Mr. VANDERWAGEN. The IHS average for turn around on these bills, from the time that the service is provided to the time that is paid by the FI, runs about 90 days. But that includes the billing process within the facility itself, and so on.

So it is about a three month turn around, although now the better places are turning these around in about 45 days in our system. So we think that there is a way to go yet.

And with increased use of electronic transfer of this information, we can bring that down to 30 days, from the time the service is provided to the time that the bill gets to us, to the time that it is paid.

The CHAIRMAN. I was reminded by the staff that we have a bill, S. 406, that cuts that time down to 30 days.

Well, we thank you very much for your appearance today. We appreciate it.

Mr. TRUJILLO. Thank you, Mr. Chairman.

The CHAIRMAN. We will now go to the next panel. And that will be Richard Narcia, Lieutenant Governor of the Gila River Indian Community; Rachel Joseph, cochair of the National Steering Committee on the Reauthorization of the Indian Health Care Improvement Act, from Lone Pine, CA; Sally Smith, chairperson of the National Indian Health Board, from Denver; Kay Culbertson, executive director of the Denver Urban Indian Health Center; and Tex Hall, on behalf of the Aberdeen Area Tribal Chairmen's Board, who is also the chairman of the Three Affiliated Tribes at Fort Berthold.

I might say, before we start, that one of the nice things about this committee is that we often get to see old friends. And I see many of my friends, not only from Colorado here, but also Rachel Joseph, who I worked with, my gosh, I guess 25 years ago now, when Rachel was with the California Education Association, and I was teaching school in the program for Indian people. I think that is when we first met.

And so I do not get out there very much, and you do not get back here, but it is just delightful to see you here, Rachel, and all my other friends in the audience, too.

Ms. JOSEPH. Thank you.

The CHAIRMAN. And with that, we will start, as I mentioned, with the Honorable Richard Narcia. I might tell you that from here on out, we will conform to this clock. But all your written testimony will be included in the record. So if you will abbreviate it to about five minutes or so, we would appreciate it.

STATEMENT OF RICHARD NARCIA, LIEUTENANT GOVERNOR, GILA RIVER INDIAN COMMUNITY, ACCOMPANIED BY KAREN WHITE, CHAIRPERSON, HEALTH AND SOCIAL WELFARE STANDING COMMITTEE

Mr. NARCIA. Good afternoon, Chairman Campbell and members of the committee. My name is Richard Narcia. I am Lieutenant Governor of the Gila River Indian Community.

I am accompanied today by Councilwoman Karen White, who is seated behind me. She is chairperson of our Health and Social Welfare Standing Committee.

I am honored to have this opportunity to provide my community's perspective views on the importance of IHS programs to the daily lives of our tribal members and other Native Americans.

We have a young and rapidly growing population that presents with us with a variety of health care challenges. The most serious health challenge we face is an extremely high rate of type 2 diabetes in our population.

Although my written testimony addresses the Indian Health Care Improvement Act in depth, I would like to take this time with you today to discuss the topic of diabetes, because I believe that our community's experience with diabetes clearly illustrates the importance of IHS programs to the every day health and well being of Native Americans.

Native Americans are almost three times more likely to have diabetes than the general population. And when we get it, we are four times more likely to die from it.

The mortality rate, according to IHS, is clearly on the rise. In a troubling development, the prevalence of diabetes has risen as much as 36 percent among Native American children and adolescents.

Our community has the unfortunate distinction of being well known in the medical world for its shockingly high rate of type 2, adult onset diabetes. In fact, according to the World Health Organization, the Pima Indians have the highest known rate of adult diabetes in the world.

Members of this distinguished committee, 80 percent of Pima Indians in our community over age 55 have diabetes. We are 12 times more likely than the general population to die of diabetes. That is 12 times, Mr. Chairman. We are not just talking numbers and statistics, but human lives.

Until recently, our children were not affected by the disease until they reached adulthood. Unfortunately, that is no longer true. Our children are being diagnosed with diabetes in an increasing frequency.

You mentioned earlier, when you questioned Dr. Trujillo, about the children getting diabetes. Today there are 50 Gila River children with type 2 diabetes, the largest cluster of children with type 2 diabetes in the world.

Diabetes is so prevalent in our lives that children do not call this illness by its name, but rather they call it the Pima plague. We call the shoes that diabetic amputees have to wear Pima Nikes.

The dark humor is way of dealing with the fear and frustration that diabetes has brought to our people. The disease and its devastating complications, including kidney disease, limb damage, am-

putation, blindness pose a serious and costly health care challenge to our community.

As a result of our extraordinarily high rate of diabetes, members of our communities have been studied extensively by NIH, which has supported a field research station in Arizona since 1965, to study the Pima Indians.

In fact, the Pima Indians are the most studied people on the planet. We have been studied. We have been weighed. We have been poked, prodded, x-rayed, and screened at a cost to taxpayers of more than $100 million. Nearly 80 percent of our community took part in the NIH research.

Based on the data obtained in its research, NIH has been able to develop new approaches to the treatment of type 1 diabetes, or juvenile diabetes.

The study also identified unhealthy weight and genetics as strong risk factors for type 1 diabetes, and isolated the role of high blood pressure in predicting complications of diabetes, including eye and kidney disease.

The NIH research program, however, failed to focus specifically on improving the treatment and prevention of type 2 diabetes, the type of diabetes that affects my people—the very people that were used to obtain the data.

Regardless of the fact that NIH had several opportunities available in the past 20 years to fund research and prevention efforts for type 2 diabetes programs in our community, NIH chose instead to spend over $150 million to research type 1 diabetes, which is not prevalent in Native American communities.

It took 15 years for NIH to turn some of this cross-over research findings into formal programs on diabetes education among Pimas. The program consisted of only one visiting nurse, who left after 6 years. Not until 1996, 31 years after identifying the type 2 diabetes problem in our community, did NIH launch a nationwide type 2 diabetes prevention study, including Pima volunteers.

We relate this experience not to gain sympathy of the committee, but to describe to you what it has taught us. We have learned that tribal self interest requires that tribes have direct control over intervention and treatment of serious diseases affecting their population, in numbers disproportionate to the rest of the population, such as type 2 diabetes.

The Indian Health Care Improvement Act and the Indian Self-Determination Act, and the program authorized therein, have been and continue to be our critical conduit in obtaining that control.

Our community has not been passive in the fight against the deadly disease of diabetes. We have escalated our diabetes treatment and prevention efforts since taking control of our health care delivery in 1996. However, our community has long been frustrated by the lack of successful intervention in Native American communities to stem the progression of diabetes and its severe complications.

As a result, the community is currently exploring the possibility of establishing a center on community land.

The CHAIRMAN. Governor Narcia, we will move on. And I hope I do not insult you, but I can read it, too.

[Prepared statement of Mr. Narcia appears in appendix.]

The CHAIRMAN. So for the other panelists any written testimony turned in, we are going to read all of that, anyway. But what I really would like to hear from people that are going to testify is your own feelings about things, particularly. And all the extended paperwork, we are going to get it. The staff is going to read every word. And I will, too.

Let us go on with our second person, Rachel Joseph.

STATEMENT OF RACHEL A. JOSEPH, COCHAIR, NATIONAL STEERING COMMITTEE ON THE REAUTHORIZATION OF THE INDIAN HEALTH CARE IMPROVEMENT ACT, ACCOMPANIED BY HENRY CAGEY

Ms. JOSEPH. Good afternoon, Mr. Chairman. I am Rachel Joseph, Cochair of the National Steering Committee on the Reauthorization of the Indian Health Care Improvement Act.

I also serve on the Board of Toiyabe Indian Health Project, a consortium of seven federally recognized tribes and two unacknowledged tribes on the eastern side of Sierra, Central California. I have the privilege of representing California's tribes during this process.

Also with me today is Henry Cagey, who served as my Cochair during the development of this draft bill.

For over 1 year, we participated in this national consultation. We express our appreciate to your committee for cosponsoring the national meeting last July, and to the committee staff, who have been accessible, responsive to our questions, and provided direction, as necessary.

We especially thank Dr. Trujillo and the Indian Health Service for initiating this consultation process. Also, we express our appreciation to tribal governments, tribal programs, urban Indian programs, friends of Indian health, and all those who committed to produce a consensus document, and to those who were willing to negotiate and to compromise, when appropriate, to ensure we met our goal of speaking with one voice.

We commend the IHS for promoting an open and meaningful consultation on the reauthorization, and then having the wisdom to not dictate or put up barriers. Because of this openness, the legislative draft that the National Steering Committee submitted to your committee is tribally produced and, we believe, truly reflects tribal views.

Approximately 1,000 comments were received on the widely circulated initial draft. Every comment we received was processed and a decision made. And in several instances, our draft was revised to address or incorporate the recommendations.

The preamble section of our draft emphasized the trust responsibility of the Federal Government to provide health services and the entitlement of Indian tribes to receive those services.

We state that the Federal Government should raise the health status of Indians to at least the levels set forth in Healthy People, 2010.

Several programs, which have been administered by the Indian Health Service Headquarters, would be centralized, with the funds to be distributed to the IHS area office, which provides for a local priority setting and decision making by the tribes. And we strongly

believe that this would facilitate new and innovative approaches, especially related to facilities' construction, rehabilitation, and renovation.

We consolidated related programs in the same title, which allows for the delivery of comprehensive services for behavioral health, training and facility programs.

The Congress has responded to its special obligations to Indians, in part, by providing direct appropriations to the Indian Health Service, tribal programs, urban Indian health programs and, in part, by authorizing the Indian Health Service.

However, as already stated by committee members, the Indian Health Service system remains under-funded, and there continues to be severe health status deficiencies among our population.

In our draft, major objectives are intended to maximize recovery from third party coverages, included Medicaid, Medicare, and the Child Health Insurance Program, and any new federally-funded program, to ensure that American Indians and Alaskan Natives have access to culturally competent care, provided by the Indian Health Service, tribes and tribal organizations, and urban health programs and, therefore, not assigned, without their approval, to non–Indian managed care plans; and to ensure that when an Indian Health Program provides services, that the full cost of providing the service will be made available.

The National Steering Committee completed a monumental task on time and with broad support across Indian Country. There was overwhelming support for the vast majority of changes described in the Steering Committee's proposed bill, and for the highly participatory consultation process.

We addressed complex and controversial issues, and developed consensus solutions that met the needs of those most concerned. There were areas where there was considerable debate, which exemplifies the complexity and controversy of some issues. A conflict resolution process was approved and used, when necessary.

We believe that this collaborative approach with your committee and the Indian Health Service truly reflects a government-to-government relationship. This consultation process was one of the most rewarding experiences that I have ever been engaged in. I strongly believe that those involved in the process stepped up to the plate in an aggressive, take-control approach, to fulfill what we believed was the major responsibility to Indian Country.

We respectfully offer our assistance to work with you to secure timely passage of this reauthorization, and thank you for the opportunity to present testimony on behalf of the National Steering Committee.

[Prepared statement of Ms. Joseph appears in appendix.]

The CHAIRMAN. Thank you.

Let us go down to the end and talk to Chairman Hall now.

STATEMENT OF TEX HALL, CHAIRMAN, THREE AFFILIATED TRIBES, ON BEHALF OF THE ABERDEEN AREA TRIBAL CHAIRMEN'S HEALTH BOARD

Mr. HALL. Thank you, Mr. Chairman, and also Senator Dorgan and Senator Conrad and their staff that were just here, and your staff, as well, Senator.

First of all, I am chairman of the Three Affiliated Tribes, the Mandan, Hidatsa, and Arikara Nations. I am also the chairman of the Great Plains Region, which includes North Dakota, South Dakota, and Nebraska.

And I also had the privilege to serve on the Steering Committee. And this was a consensus effort, as Rachel had pointed out, Mr. Chairman.

And in the Aberdeen area, we have general support of the bill. And I just want to touch on some of the disparities in the Aberdeen area.

All of us are direct service tribes in the Aberdeen area. And I can appreciate, Senators, all of your comments about the many other issues involved in health care, such as housing and quality drinking water.

Mr. Chairman, we are trying to push the Dakota Water Resources bill, which would include quality drinking water to all of the reservations. In the Aberdeen area, and at least in North Dakota tribes, we are number one in hypertension. And because of poor potable drinking water, we have a high sodium concentrate in our waters. So we have a very poor quality drinking water.

The second point I want to raise is on the issue of housing. We have a huge backlog. We have over 10,000 homes backlogged in the Aberdeen area, including all of my fellows brothers and sisters of the Sioux reservations, of the Chippewa, and also my tribe. So with 10,000 homes, we are all pushing collectively to get the NAHASDA funds leveraged, and to look at economic development.

Mr. Chairman, my tribe, and Sand River Sioux Tribe, are part of the developing of the Native American National Bank. And I just wanted to say that the economic development issue is very critical, as we get back to the issues of health care.

As my colleague, Richard Narcia, had mentioned about diabetes, we, too, in the Aberdeen area are very high in diabetes and in cancer. In diabetes, as was mentioned, it is going lower and lower to the younger ages. And being a former school superintendent of schools on the reservation, I see it first-hand, how it is coming down to a younger age.

And at 43 years of age, Mr. Chairman, I feel fortunate to be alive today. In our particular area, we are even lower than IHS statistics, which is 10 years below the average life expectancy of a U.S. citizen. And we are even 5 years below that in the Aberdeen area.

So many members do not have limbs, and our amputations have gone up; 1 year ago, we averaged 7.5 amputations per year. We are now at 15. So you can see, Mr. Chairman, that those things are vastly going in the negative direction.

One concern, Mr. Chairman, and this goes to one of my major points, is a lack of funding within the Indian Health Service delivery area.

There is a huge lack of funding. So, for example, a woman of any age, and particularly an elderly woman that wants to get a mammogram can not get it, because we are in priority one status, from the start of the fiscal year. And priority one status means you either have to have life-threatening, or a limb has to be threatened to be cut off, to be eligible for a referral for contract health. So in the area of contract health, there is a serious lack of funding.

Also, as Senator Conrad had mentioned, there is a backlog of unpaid bills. I was appreciative of Senator Dorgan asking the question as to how long is the average, and 90 days is what I heard. And we have some that are beyond that.

Yesterday I spoke at a gathering of our elders, Mr. Chairman, and I told them I was going to Washington to testify on the reauthorization of the Indian Health Care Improvement Act. And it grew very silent, because we all know too well that all of our brothers and sisters and relatives die too soon.

But I talked about the consensus of this bill in Indian country. It is the first time I have seen a consensus with this bill, and we are all working towards that effort. And within the timeframes that we had, as a National Steering Committee, we got this done.

Within this short legislative session, as you mentioned, Mr. Campbell, there is tremendous pressure on us to get this done. And I am committing myself and the fellow chairmen and the fellow leaders in health care in my part of the country, in North Dakota, South Dakota, and Nebraska, to work with you, Mr. Chairman, to make sure this is done.

And when I talked about increasing the dollars for contract health in our area, the three affiliated, all the elders—there were 85 of them, Mr. Chairman—they all cheered. I have never seen such motivation on coming to Washington to testify on a bill before Congress. So as we all know, health care affects each and every one of our people, from young to old.

The other point I want to stress is lack of facilities, and you had mentioned that, Mr. Chairman. There is a serious lack of facilities. Dr. Trujillo had mentioned the Joint Venture Program. Again, that is going to go back to funding. How do the tribes obtain funds to build and lease the facility back to Indian Health Service? So that is a key issue.

And, finally, there is lack of ambulatory services, Mr. Chairman. In rural, isolated areas, our reservations in the plains, as you very well know, being a northern Cheyenne, it is so far and few between. We are 70 miles from a hospital.

And so when those services are cut off, the tribe has to find some mechanism, some funding vehicle, to provide that. Because we all know, many of our members lie on a road or fall in a ditch with an accident, and there is no ambulatory to help those.

So, again, we pledge our support for this bill. We look forward to working with you and to helping get this bill passed. Mr. Chairman, thank you for my time today.

The CHAIRMAN. And those northern winters add to the problem, too.

Mr. HALL. Yes; they do.

The CHAIRMAN. Okay, we will go now to Ms. Smith, please.

STATEMENT OF SALLY SMITH, CHAIRMAN, NATIONAL INDIAN HEALTH BOARD

Ms. SMITH. Thank you. Good afternoon, Chairman Campbell and distinguished members of the U.S. Senate, Committee on Indian Affairs.

I am Sally Smith, and I am the newly elected chairman of the National Indian Health Board. I also represent, the Bristol Bay

Area Health Corporation's chairman, with a resolution of 34 villages. I am also the chairman of the Alaska Native Health Board.

I am pleased to be here today to testify on the reauthorization of the Indian Health Care Improvement Act, Public Law 94–437.

The Federal responsibility to provide health services to American Indians and Alaska Natives has grown out of the unique relationship between tribal governments and the United States. This responsibility represents a prepaid entitlement, paid for by the cession of more than 400 million acres of land to United States.

We all share a duty of ensuring that this relationship is not compromised. It is an obligation of the U.S. Government to make certain that comprehensive health care is provided to all American Indians and Alaska Native citizens.

In 1976, when Congress enacted the Indian Health Care Improvement Act, it favorably and forever changed the face of Indian policy. The act is one of the most comprehensive efforts by the Congress to address the health needs and health status of American Indians and Alaska Native populations through a series of initiatives.

It bolstered the Indian Self-Determination Act, which had been enacted the year before. It gave tribes new opportunities to assume responsibility for health programs, in cooperation with the Indian Health Service. At least 45 percent of the budget is currently under an Indian self determination contract or self governance compact.

As we are all aware, at the end of fiscal year 2000, the Indian Health Care Improvement Act is scheduled to expire. Over this past year, the IHS has been engaged in a major consultation effort to bring together tribes, IHS, and urban providers, to make recommendations on a proposed bill for the reauthorization. This culminated in the Indian Health Service convening a National Tribal Steering Committee, with representatives from tribes and national Indian organizations. The National Indian Health Board was involved since the very beginning in drafting the bill.

NIHB strongly endorses the Tribal National Steering Committee draft for reauthorization of the Indian Health Care Improvement Act. This act provides the basic authority for tribal activities.

For instance, in my home region, the Bristol Bay Area Health Corporation contracted the IHS services for the entire 45,000 square mile Bristol Bay region, including the Knackanack Hospital, which had been run by the Indian Health Service.

Since 1994, under the Alaska Tribal Health Compact, our tribal consortium has operated these programs as a self governance demonstration. We have done a first-rate job in improving services to our people.

We know there is concern about the cost of this bill. It is important to recognize that the Indian Health Improvement Act has never been fully funded. We can identify at least 66 provisions in it that were not funded. The Indian Health Care Improvement Act authorizes health programs. It is not an appropriations act.

While we wish all the money we need could be appropriated, we know that it will not. The challenge of obtaining sufficient resources should not interfere with the reauthorization, however.

The act should fully recognize the complexities of the issues faced by IHS and tribes. It should authorize the full range of health pro-

grams needed to improve the health status of American Indians and Alaska Natives. Within the resources available, the IHS and tribes will address the local priorities, to address the most serious problems.

We hope that the proposal set forth by the National Steering Committee will be enacted by the 106th Congress. We know that other congressional priorities may make it impossible. In the event the enactment of this bill is not possible, we recommend that the committee send forward a request to the Interior Appropriations Subcommittee, requesting that the Indian Health Care Improvement Act be extended for one year, beginning October 1, 2000.

If the bill is still under consideration, we request that a hearing be held during the week of August 20, at our annual consumer conference in Billings, MT.

On behalf of the National Indian Health Board, we thank the Senate Indian Affairs Committee for hosting today's hearing. We look forward to working with you after the bill is introduced, and to work out issues that may arise after the administration formally reviews and responds to the bill.

Thank you.

[Prepared statement of Ms. Smith appears in appendix.]

The CHAIRMAN. Thank you.

We will finish with Ms. Culbertson.

STATEMENT OF KAY CULBERTSON, EXECUTIVE DIRECTOR, DENVER URBAN INDIAN HEALTH CENTER

Ms. CULBERTSON. Good afternoon. I would like the record to reflect that I am the executive director of Denver Indian Health and Family Services, as well as the president of the National Council of Urban Indian Health.

Honorable Chairman and committee members, on behalf of the National Council of Urban Indian Health, I would like to express our appreciation for this opportunity to testify before the Senate Committee on Indian Affairs on the Reauthorization of the Indian Health Care Improvement.

Founded in 1998, NCUIH is the only membership organization representing Urban Indian Health Programs. Our programs provide a wide range of services, in health care, from direct services, to outreach in 34 cities, with approximately 332,000 Indian people being served.

NCUIH was an active participant in the activities of the National Steering Committee.

The CHAIRMAN. What was that number you referred to; how many people being served?

Ms. CULBERTSON. 332,000, and this includes the 34 programs, plus the two demonstration projects of Tulsa and Oklahoma City.

NCUIH was an active participant in the activities of the National Steering Committee for the Reauthorization of the Indian Health Care Improvement Act, and strongly supports the National Steering Committee's recommendations for the amendment of the act.

I would like to highlight, in my oral testimony, certain aspects of the National Steering Committee's recommendations that are of particular importance or urban Indians and to the Nation Council of Urban Indian Health.

First, I would like to address the issue of consultation. Every sound relationship must be based on mutual respect and good communication. The National Steering Committee has recommended that the Indian Health Care Improvement Act be amended to require the Department of Health and Human Services and its various divisions to consult with urban Indian organizations to the greatest extent practical, prior to taking any action that might affect urban Indians and urban Indian organizations. This enhanced requirement is very important to us.

As has been dramatically demonstrated with tribes in the area of Indian policymaking, post-consultation with Indian organizations leads to better results, less confusion, and a higher level of cooperation and efficiency on the part of everybody involved; therefore, increasing the services that we provide to our Indian people that live in the cities.

Next, I would like to address the recommendations which will strengthen the financial status of urban Indian health programs, and enable us to expand our services.

Particularly, the National Steering Committee has recommended amendments to provide that urban Indian health organizations have a right of recovery against insurers or other third parties for expenses incurred by the organization while providing services to Indian individuals.

This is particularly important, because we have a lot of people who would rather see our providers than their HMO provider, but have not been able to list us as their primary care providers, because of the extent of our services. So we would like to receive payment for the people that we are providing those services to.

The National Steering Committee has also recommended amendments to the medicaid and the child health programs, which would be the Child Health Insurance Program known as CHIP. This would greatly enhance the ability of urban Indian health organizations to address the health needs of urban Indians.

One amendment would require the 100 percent Federal matching requirement. We would like to see that extended to urban Indian health programs. It would make the states more willing to work with us, and include us in their Medicare and their medicaid programs.

We would also like to see this same match of Federal block grants from the CHIP program that would pay IHS facilities, tribal operated programs, and also urban Indian organizations.

The National Steering Committee has also recommended amending title 5 of the act to allow certain funds which, under current law, can only be used for minor renovations of our facilities. We would like to use those funds for leasing, purchasing, construction, or expansion of our current health facilities.

Some of our facilities are very old that we are in. I know that one in Boston uses skeleton keys to open their doors. They are in an old state mental health institution. It has always been amazing to me that they even have skeleton keys anymore.

The committee also supports establishment of an urban Indian health care revolving loan fund to be used for the same purposes. Both of these changes would enable urban Indian health programs

to establish better facilities and, therefore, better address the particular needs of the urban Indian communities they serve.

The National Steering Committee has also recommended allowing urban Indian health organizations to furnish health care or referral services through satellite clinics. As you know, our populations grow. And they move to different segments of the city.

And if we do not have satellite clinics, it is harder for them to reach us, or to provide those services to them. We would like to have the establishment of satellite clinics, through our existing urban programs, if there is a need.

Finally, I would like to highlight some of the other important program issues. There is an urgent need for women's health needs and Fetal Alcohol Syndrome.

I know that in our clinic, we have had several women that have been diagnosed with breast cancer that do not have access to health insurance, do not qualify for any of the Federal or state programs. And we have had to basically say, you know, if I were you, I would go home, because you can not get those services here, and it is going to cost you an incredible amount of money.

We would also like to see Indian behavioral health treatment programs, specifically for Indian women, that would address the unique needs of Indian women and their children, as well as a Fetal Alcohol Disorders Program.

The National Council of Urban Indian Health is working to enhance our services. We already qualify for the scholarship repayments, as scholarship repayment sites and loan repayments sites. The problem is that the money is not there that we can attract the Indian professionals to our programs.

I would like to thank you on behalf of the National Council of Urban Indian Health for being allowed to testify today, and thank you very much. And Denver was really nice when I left. [Laughter.]

[Prepared statement of Ms. Culbertson appears in appendix.]

The CHAIRMAN. Great, I am looking forward to it, tomorrow. Well, thank you for your testimony. I was jotting down a few questions, comments, and notes, too.

Frankly, I do not know of an Indian family anywhere that has not had diabetes somewhere in the family—a father or a son or a cousin or somebody in the family.

And in my own family, we have had it, too. On my grandmother's side, she had a step brother, who we called Grandpa, in the Indian way, who passed away about 10 years ago in Montana.

And he was a wonderful man. He was active in the culture. He was a sundancer. He was in a Shoshone Society. I never knew him to drink or smoke or anything. He was a very, very straight, careful person.

And, yet, about the last two years I saw him, the complications of diabetes had really taken their toll. You know, it cuts off circulation and leads to gangrene and so on.

They had taken off one of his legs once, and they took off the other leg two times. They could not get it stopped, so they cut it off just below the knee, and then they cut it off just below the hip.

And I went to see him about 2 weeks, I guess, or so before he passed away, or maybe 3 weeks before he passed away. He was in the hospital in Montana.

And it was just amazing the debilitating changes that had overcome him, because of that just terrible experience of those amputations. He was always a very active person. He hunted when he was young. He was a dancer. You know, he was active in all of the tribal things. And I just was so depressed.

And I could still remember, I asked him if there anything I could do for him. And out of all things a person might ask for, he only asked me to go get him some graham crackers. That was the single last thing he wanted.

Well, I mentioned that so you will know that I know what it is like, from a personal standpoint, of having some people in the family that have had diabetes.

You might also know, coming from Colorado, a couple of you, that the University of Colorado has been pursuing a center for diabetes research, at the old Fitzsimmons site. And we are trying to provide the money for that. In fact, we have provided some money, through the university, itself.

And I think they are on the right track. And when they get that done, hopefully, they are going to be able to do an awful lot for Indian people. That research facility will be just for Indian people, as you probably know. And, hopefully, that is going to be open in the next couple of years, when they finish their final move from the University of Colorado.

Let me ask maybe just a couple of questions, first maybe from Richard Narcia. You talked to us about diabetes. It has hit your tribe probably worse than any community in the world, according to what I understand.

Have you taken any efforts that you could share with other tribes, through some kind of a program, that they might learn from, to try to stem the tide of diabetes in your tribe?

Mr. NARCIA. I think the feeling within the communities is that we need to control the programs ourselves. I think our community is frustrated with the western medical technology. We can use that technology, plus incorporate traditional Indian values. I think that would go a long way to helping or to promote the care and intervention for diabetes.

The CHAIRMAN. Well, as I understand it, Gila River has the highest incidence of childhood and adolescent diabetes.

Mr. NARCIA. Yes, sir.

The CHAIRMAN. Do you have anything you attribute that to? It seems to be even much higher than all the other Indian communities.

Mr. NARCIA. Well, I think there are a lot of factors involved in that. I know that the diet, and there is a lot of research or genetic strains, I guess, that are prevalent there in some of the areas with our people. That could be a factor. And then there is just the care and what we are doing with our people, not taking care of themselves, and the processed foods—those types of things.

The CHAIRMAN. Starch foods and so on.

Mr. NARCIA. Yes.

The CHAIRMAN. Let me move on to Rachel, my friend from California. Let me ask you a little bit about the Steering Committee. I was interested if they were going to do a cost analysis of the funding provisions that are proposed.

Ms. JOSEPH. Mr. Chairman, we had much discussion about cost issues related to provisions of the bill. In our final deliberations and approach to, you know, the reauthorization was to approach it just that way.

We felt that our responsibility was to address the authorization or the reauthorization. And those that make the appropriation decisions, you know, will make those decisions, and our responsibility is to work with them.

We also want to point out that in the current bill or the current legislation, there are provisions, as my colleague Sally Smith pointed out, that are not funded. And what we have tried to do is provide a comprehensive approach or a menu, so to speak, which will be selected from. And we would like it to be fully funded, but we recognize the fiscal realities, as well.

The CHAIRMAN. We do not know the cost, either. I understand that CBO still has not come up with an estimate of how much it is going to cost.

But this will be the third year in a row that we have had a surplus. As you probably know, we got rid of the deficit, after a lot of years of belt tightening. And, in fact, we paid down the debt by $158 billion last year, through last year and the first part of this year.

So we are moving into a time in which Federal Government—it looks like we are going to have some extra money for the next 10 or 12 years, I hope. There is no reason why we can not afford a very, very good program.

Let me ask you a couple other things, too. I introduced a bill called S. 1507. It allowed the tribes to consolidate their alcohol and drug abuse programs. They do that with other job training programs and other things now, as you probably know.

Has the Steering Committee taken a look at that, or do you think they would support that?

Ms. JOSEPH. We would support, you know, even incorporating provisions into the reauthorization. We did try to provide, you know, a comprehensive approach and consolidation, as necessary. And anything that would improve upon our bill, we certainly would want to do.

The CHAIRMAN. I am glad you mentioned culturally sensitive care. Because I know, from my own experience, that sometimes people, and particularly the ones that have a very, very strong tradition center, they sometimes are a little skeptical about what they still call, in some areas, white man's medicine.

You have heard that term used, you know. And I know I have met some people that simply will not go to the hospital. They do not trust them, or they do not believe it is in their best interest, from a religious standpoint. And it is a difficult thing to do.

And I know that in your area, there used to be a spiritual lady. She was a Pomo named Mabel McKay. And on several occasions in Sacramento, in the Sacramento General Hospital, she was called in because of people that had very strong traditional beliefs. They did not trust the medicine. They did not trust the doctor's opinion.

And there were many times when she was called in to speak to them or work with them. And I thought that that cultural sensitiv-

ity was very good, and that it was a model that we ought to copy in a lot of hospitals and in a lot of health care programs.

Let me ask you a couple of other things, too. We do have some good ideas, and we have a lot of bad ones here in the Senate, too, as you might have guessed. But we did have a bill that was to elevate the Indian Health Service Director to Assistant Secretary. And as you probably know, that bill did pass the Senate. It is sitting in the House.

Did you, in your deliberations with the committee, consider placing the elevation of that in your draft bill?

Ms. JOSEPH. Yes; we did. We would have placed it in title 6. We strongly support the effort, and were hopeful that that would have been done already, or it would have been in the draft.

The CHAIRMAN. Well, we have a very short year. And we are not sure if we are going to be able to get that through. And if there is any emphasis that you can put on the House side, to try to move it along, I know this committee would appreciate it.

Tex, thank you for your appearance and your very articulate testimony. You have been here a number of times before this committee, and you always do a very good presentation.

Let me ask a couple of things of you. This is not maybe directly related to health, but I guess there is a connection with the lack of housing and the crowded housing that we have. You mentioned that we are going to be short 10,000 homes. Is that on your reservation or in the Aberdeen area or what?

Mr. HALL. The Aberdeen area, Mr. Chairman.

The CHAIRMAN. The Aberdeen area?

Mr. HALL. 1,000 on my reservation.

The CHAIRMAN. 1,000 on your reservation? But some of the northern tribes, as I understand it, have a birthrate in which 25 percent or more of the whole total enrollment is under 16 years old. I mean, you have that fast of a birthrate.

Even if you had that 10,000 homes, would it keep up with the need, do you think?

Mr. HALL. I think that is a low estimate, that the tribes and HUD put together, and the BIA. And I am thinking of the census. You know, we are under counted, what—I hear any where from 25 to 30 percent, Mr. Chairman.

The CHAIRMAN. Yes.

Mr. HALL. Now we take that, and IHS mentioned at point, $3 million. And I hear 2.5 million is our population. There is a huge difference there.

I am projecting in 2010, just as you mentioned, if we are in a backlog now, of 10,000 homes at 2000, what is our backlog and what is our increase in population in 2010. And I really think we need to focus our efforts on doing that. Because housing deals not only with health care, with education, a safe environment.

And Senator Dorgan mentions in one of his talks about one of the ladies of a family. She was a single mom that literally froze to death in a home on the Standing Rock Reservation. It was a dilapidated condition house.

The CHAIRMAN. Yes; well, I have seen those kind of houses, with tar paper on the windows, instead of window panes, or hides nailed

up there, something like that, just to keep the wind out. I have seen that. They are terrible, I know.

You mentioned the census. I might tell you that I think the census, when it gets done next year, is going to really skew the numbers for Indian people. We are making a very big effort to get people to do the census. In fact, we have got people on the reservations going house to house, to try to get a more accurate count of Indian people.

But also, I think we are going to get an increase of the number of Indian people. And I hope that we are going to be able to provide the same percent, at least, of increase in funds that go out to Indian country.

But there is another place I think is going to be skewed. And that is that it seems to be in vogue now to say you are Indian. You probably know that, right? So everybody wants to be some Indian, but nobody wants to be all Indian. The life is too tough. I mean, you have heard that, and I have, too. [Laughter.]

The CHAIRMAN. But I think what is going to happen is, you are going to see a lot of urban numbers of Indians skyrocket, whether they are enrolled or real or not or whatever. Whether it is a conversation piece or what, I will bet you, on the census that comes in, you are going to see huge numbers go up in urban areas.

I do not know what that is going to do, in terms of funding. Maybe it will not put any additional problems on the services that have to be provided, because those people are just using it for a conversation, and might not use the Indian health facility, anyway.

But, in turn, there might be a positive benefit in that there will be additional funding for Indian programs, because of that increased number. But I just mentioned that because I have a hunch, when it is all said and done, there are going to be some really distorted numbers coming back in.

Let me ask you one other thing, too. And that is, as the chairman up there and active with the tribes in your area, what incentives to enter into programs that have been well received by other tribes who have been somewhat reluctant to assume control over their health care programs under self governance?

I know sometimes they are worried that they will lose something. And so they are not real comfortable with taking over self-governance of health care. Is there anything that we can do to encourage them, or help them, or educate them, or do whatever?

Mr. HALL. You know, that is a very good question, Mr. Chairman. I asked that myself a few years back, probably about 5 years ago. And the overwhelming response has always been, until the Federal Government, until the U.S. Government lives up to its trust responsibility and funds us at the level that we need to be, at 100 percent unmet needs level, then we will do that. Then we will take over these programs.

But we will not contract these programs until that funding level is up there. Otherwise, we would be accepting the lack of funding.

The CHAIRMAN. Sure.

Mr. HALL. It is an overwhelming response from all the tribes, Mr. Chairman.

The CHAIRMAN. I understand. Thank you.

Sally, Senator Conrad, when he was here, he mentioned that we ought to be offering some kind of incentives to encourage people to retain Indian people in Indian health care professions. Do you have any feeling about what kind of incentives that we could offer, as a committee, or through legislation, to encourage Indian people to go into the health care profession?

Ms. SMITH. Certainly within the act itself, the proposal will offer scholarships—and I am talking about the reauthorization—to a wider set of professions.

When the bill was reauthorized, 8 years ago, the focus was narrowly directed towards family practice, general practitioners and nurses, due to severe shortages. New amendments will enhance continuing education, research opportunities and cultural training programs, which serves to enhance retention.

The bill will also ensure broader availability of retention bonuses and incentive pay. And finally, the ability of tribes to annually determine their local health professional needs, and target scholarship opportunities to fill these priorities serves to enhance health care services effectively. And I speak directly to the bill, as it is being sent forward.

The CHAIRMAN. Okay, I was not aware of that, and I appreciate that.

Explain to me what the words "qualified Indian health care programs"—how does that work, if you can do that briefly. Is there a way of qualifying who should be availed the services?

Ms. SMITH. Well, a qualified Indian health program would use any licensed or certified provider to carry out services within the scope of the provider's practice.

Like States and their health care providers, tribal, IHS, and urban Indian health providers are licensed to provide comparable health services, which would be eligible for reimbursements.

We do not envision a large bureaucracy being created by the QHIP, but we propose a new method for streamlining the reimbursements to IHS and tribal health programs, through the qualified Indian health program designation.

I could further elaborate, if you would like.

The CHAIRMAN. Well, that was okay. That was good, I think.

Ms. SMITH. Okay.

The CHAIRMAN. And last, I was wondering, do you foresee the IHS moving more as a technical service, rather than a direct provider? Because as I understand it, self-governance has really dramatically improved the health care of Indian people when tribes take it over themselves.

Ms. SMITH. At the National Indian Health Board, our studies suggest that tribal governments expect the Indian Health Service to continue to provide direct services to those tribes who chose not to contract or compact under the IHS self-determination or self-governance policies.

We also expect that the IHS functions and activities will promote more activities for training and technical assistance to help tribes acquire and maintain management expertise.

IHS certainly should continue to have an important role in the development of the budget requests to Congress, to provide tribes with necessary financial support.

We firmly believe that IHS should continue to encourage tribes to continue along the path of self-determination and self-governance, and to work with Congress to ensure that contract support costs are available to guarantee the success of tribal health systems.

Many tribal leaders who have participated in our studies would feel more comfortable about their future if there were changes at the Federal level to protect their sovereignty. We look forward to working with the Congress to assure tribes that self-determination contracting and self-governance compacting will not lead to termination. So there indeed is a significant and important role for the Indian Health Service.

The CHAIRMAN. Well, for those tribes that have taken over health care, I understand that not one has turned it back; not one has opted back out. So it must be pretty successful.

Ms. SMITH. Well, I would agree with you that they are indeed successful. But there still remains a role for the IHS in the role of advocacy.

The CHAIRMAN. Yes, sure.

Ms. SMITH. And certainly, the Indian Health Service should be there for those tribes that would elect to.

I am advised to mention to you, I am from Alaska. And as you know, among other things that Alaska has done, we have formed the Alaska Tribal Health Consortium, which has taken over the health services in Alaska.

I currently serve as the chairman of the Joint Operating Board of the Alaska Native Medical Center. And within the Alaska Tribal Health Compact and the Consortium, Alaska indeed should be set forth as a model, if there is ever a success story within Indian country, with assumption of their health services.

The CHAIRMAN. Alaska—I went up there recently with Senator Stevens. Well, it has been about 1 year. It was 42 below in Barrow. [Laughter.]

The CHAIRMAN. You Alaskans are tough.

Ms. SMITH. Please come back. It was only zero, yesterday.

The CHAIRMAN. Is it warmer, now?

Ms. SMITH. Yes; it has warmed up.

The CHAIRMAN. Well, they took us up in a helicopter, to see where Wiley Post had crashed.

Ms. SMITH. Yes.

The CHAIRMAN. And we passed over a man. And there was this beautiful, big white polar bear. I am a little off the subject, here. But it was a magnificent bear. And he saw the helicopter, and he kind of dove into the slush, and got off to the other side and ran off.

And there was a hunter, right over the next hill. We did not realize that the guy was hunting him. He was very unhappy with us. He waived to us. And I took it to be some international sign of unhappiness. [Laughter.]

Ms. SMITH. Please come back and try again.

The CHAIRMAN. Yes; I will.

Ms. SMITH. Thank you.

The CHAIRMAN. We cost him his bear.

Kay, I am sorry I do not know more about the health facilities in Denver. Coming from Colorado, I apologize for that, and I ought to.

But I was interested in your comment when you talked about women that you have had to advise to go home, that had been diagnosed with breast cancer.

Ms. CULBERTSON. Yes.

The CHAIRMAN. Did you do any follow-up at all with those women about did they get adequate services when they went home, or were they cured?

Ms. CULBERTSON. You know, they have not come back, yet. This was just recently. It was about two weeks ago. It just was, boom. We thought, gosh, is there a rash of breast cancer going around, or what is going on?

But we have not heard back from them, yet. And, in fact, we really did not even do an in-take. It was like, you know, you need to get this taken care of. She had let it go for quite some time. And it was like, you need to go home and get this taken care of, or even to a closer reservation.

The CHAIRMAN. Yes.

Ms. CULBERTSON. As you know, Denver, as far as Indian Country goes, we are pretty isolated from the IHS facilities. And so we really wanted her to go home and take care of it, and did not even want to have her fill out the paperwork that we would, if she were going to see a doctor.

The CHAIRMAN. Do you know if other urban Indian centers have also had that problem?

Ms. CULBERTSON. I think that it is common among the outreach and referral programs. And, of course, Denver has just moved into providing primary care. And we only have a clinic 2 days a week, at this point.

And so it is common to the outreach and referral programs, and it is probably common to some of the smaller direct service programs that just provide ambulatory care, and that is it.

The CHAIRMAN. Was it U.S. West that just gave a major grant to the Denver Indian Center?

Ms. CULBERTSON. Yes.

The CHAIRMAN. Will any of that go to health care?

Ms. CULBERTSON. No; what that is, that is linking up the Tribal College in Bismarck with the Indian Center, so that Indian Center in the community can participate in some of their classes.

The CHAIRMAN. And according to your testimony, the urban centers are not currently authorized to conduct diabetes prevention and treatment. What happens to those individuals who have it, who are serve by you?

Ms. CULBERTSON. No; we do provide diabetes prevention and education.

The CHAIRMAN. You do?

Ms. CULBERTSON. We have a portion of the funding that was given from Congress, three years ago. And with our program, we have an outstanding diabetes coordinator that does prevention, diabetes management. Bayer Corporation gave us glucometers so that they can maintain their glucose levels.

She focuses heavy on the traditional diet. Coming from South Dakota, she focuses on a high protein diet for Indian people, and really working with that. And it has been well received in the community. We have started an exercise class with people, and we have worked with the Indian Center to do that.

The CHAIRMAN. Do you give some guidance on diet, too?

Ms. CULBERTSON. Pardon me?

The CHAIRMAN. Do you give some guidance on diet?

Ms. CULBERTSON. Oh, yes, in fact, we have started a weight loss management class with community people. And so we are hoping to expand it a little more. But it is great.

The CHAIRMAN. Let me ask you one last question. On our draft bill, if you were to try to focus on any needed changes, what would you add to it, anything in particular?

Ms. CULBERTSON. I think that I would stress that we would like to see the 100 percent Federal matching percentage extended to the urban programs. It is not that we can not access the scholarship for the loan repayment, but we do not have the funds to attract those people.

And so I think that it is important that we have those funds. Because I was telling Sally, my doctor is going to Alaska. And I was thinking, gosh, you guys keep stealing my people. [Laughter.]

And we just can not compete with the city. We can not compete with Denver General, and we can not compete with IHS. And so it is really hard for us to retain our professionals that come.

The CHAIRMAN. I understand.

Well, I have no further questions. But I think that perhaps some of the other committee members may submit some in writing to you. And if you could answer those for them, I would certainly appreciate it.

I do appreciate you being here. Some of you traveled an awful long way. It is very nice of you to come down. And with that, the record will remain open 2 more weeks, for any additional comments from the panel or anyone in the room. If you would like to add something to the dialog, please turn that in within 2 weeks.

With that, this committee hearing is adjourned. Thank you very much.

[Whereupon, at 4 p.m., the committee was adjourned, to reconvene at the call of the Chair.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF HON. DANIEL K., INOUYE, U.S. SENATOR FROM HAWAII, VICE CHAIRMAN, COMMITTEE ON INDIAN AFFAIRS

On September 30, 1976, in the 94th session of the Congress, the Indian Health Care Improvement Act (IHCIA) was enacted into law as Public Law 94–437. We are here today to receive testimony on a bill to provide for the fifth reauthorization of this 24-year-old act.

First, I would like to commend the Indian Health Service for engaging in an extensive consultation with Indian tribal governments and affected native communities which ultimately led to the formulation of the draft bill we consider today.

I would also like to commend the leadership of Indian country for your hard work and dedication to the development of this measure. This draft legislation is testament to the fact that Indian country can be a powerful force when it speaks with a unified voice.

Over the years this legislation has undergone several changes. I am pleased to see several developments in the areas of Access to Health Services and Health Services for Urban Indians in this draft bill.

Most importantly, I believe, is that the bill provides for the establishment of a National Bipartisan Indian Health Care Entitlement Commission, which would be charged with determining whether Native Americans should receive health care services as an entitlement in the same manner that those who are eligible for social security or medicare participate in those programs as an entitlement.

After all, in exchange for the session of millions of acres of Indian land, the United States has assumed the responsibility for the provision of comprehensive health care services to all American Indian and Alaska Native citizens.

Through each reauthorization, we have worked together to ensure that this Trust responsibility is honored and fully implemented by the Federal Government. I look forward to joining forces with the health care leadership of Indian country as we prepare to introduce this very important legislation.

PREPARED STATEMENT OF MICHAEL TRUJILLO, DIRECTOR, INDIAN HEALTH SERVICE

Good morning, I am Dr. Michael Trujillo, director of the Indian Health Service [IHS]. Today, I am accompanied by Michel Lincoln, deputy director, Gary Hartz, acting director of the Office of Public Health, and Dr. Craig Vanderwagen, director, Division of Clinical and Preventive Services, Office of Public Health. We are pleased to have this opportunity to testify.

The IHS has the responsibility for the delivery of health services to federally recognized American Indian and Alaska Natives through a system of IHS, tribal, and urban [ITU] operated facilities and programs based on treaties, judicial determinations, and acts of Congress. The mission of the agency is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives [AI/AN] to the highest level, in partnership with the population served. The agency goal is to

assure that comprehensive, culturally acceptable personal and public health services are available and accessible to the service population. Our foundation is to uphold the Federal Government's obligation to promote healthy American Indian and Alaska Native people, communities, and cultures and to honor and protect the inherent sovereign rights of tribes.

We are here today to discuss reauthorization of the Indian Health Care Improvement Act [IHCIA] and the recently completed consultation process that reviewed the existing IHCIA in the context of the many changes that have occurred in our country's health care environment since the law was first enacted in 1976.

Two major pieces of legislation are at the core of the Federal Government's responsibility for meeting the health needs of AI/AN: The Snyder Act of 1921 and the Indian Health Care Improvement Act, Public Law 94–437. The Snyder Act authorized regular appropriations for "the relief of distress and conservation of health" of AI/AN. The IHCIA of 1976 was enacted "to implement the Federal responsibility for the care and education of the Indian people by improving the services and facilities of Federal Indian health programs and encouraging maximum participation of Indians in such programs." Like the Snyder Act, the IHCIA provided the authority for the programs of the Federal Government that deliver health services to Indian people, but the IHCIA also provided additional guidance in several areas. The IHCIA contained specific language that addressed the recruitment and retention of a number of health professionals serving Indian communities, focused on health services for Urban Indian people and addressed the construction, replacement, and. repair of health care facilities.

On April 29, 1994, President Clinton issued a memorandum to the heads of executive departments and agencies requiring that a consultation policy be in effect based on the special relationship between sovereign governments, the United States and AI/AN tribal governments. To support this executive memorandum, the IHS established the tribal consultation and participation policy and tribes and urban programs are considered partners with IHS in the delivery of health care to AI/AN. In addition, a provision in the Indian Self-Determination and Educational Assistance Act, Public Law 93–638, states, "Congress . . . recognizes the obligation of the United States to respond to the strong expression of the Indian people for self-determination by assuring maximum Indian participation in the direction of . . . Federal services to Indian communities so as to render those services more responsive to the needs and desires of those communities." Based on this partnership, the IHS has and continues to provide technical assistance to tribes, as they examine the existing IHCIA, and seek consensus on potential changes in a tribal reauthorization bill. The proposed reauthorization bill was submitted to Congress by tribes directly and does not necessarily represent the administration's views or policies.

The first step in the consultation process, held on June 8–9, 1998, was a roundtable discussion with tribal leaders, urban providers, IHS program experts, national Indian health organizations, researchers, and other policymakers. The purpose of the roundtable was to stimulate discussion and develop recommendations regarding the IHCIA. Specific recommendations regarding the manner in which the tribal consultation meetings would be carried out were developed at this roundtable. From these recommendations, the roundtable participants developed a consultation approach that included pursuing consensus on what changes were needed, without consideration of any resource limitations or other budget issues, and concentrating on identifying opportunities for change, identifying area and regional differences ahead of time, promoting a partnership environment for tribes, urban Indians, and the IHS, and establishing a core group to review materials. By not focusing on budget or financial issues, the product of these deliberations included many policies that are not reflected in the President's fiscal year 2001 Budget. Since this draft legislation contains a wide-ranging list of provisions, many of which have significant budget and management implications across Federal agencies, a thorough review and careful consideration are necessary.

Beginning in the fall of 1998, tribal representatives participated in 12 area meetings to begin discussing concerns and recommendations related to the IHCIA. Each of the 12 geographic areas facilitated a consultation process with providers in their areas. These discussions were held over the course of one or several meetings. The expectation was that these area concerns and recommendations would be forwarded to the next step in the consultation process. These area level meetings were completed by January 1999.

Four regional consultation meetings were held across the country from January to April in 1999. These regional meetings were intended to provide a forum for tribal to provide input, to share the recommendations from each area, and to build consensus among participants for a unified position from each regional meeting. From these four meetings a 135-page matrix of recommendations for each of the sections

in the IHCIA as well as proposals for new provisions was developed. Over 900 providers participated in the four regional meetings.

Upon the completion of the four regional meetings, IHS convened a National Steering Committee [NSC] composed of elected tribal representatives and urban health program directors. Many of the members of the steering committee had participated in the area and regional consultation meetings. The NSC developed a draft consensus bill based on the area and regional consultation meetings. The draft bill was mailed to every tribal and urban program in the Nation with a 30-day period for additional comments. The draft bill was then presented at a national meeting in Washington, DC in late July of last year. Attendees at this national meeting included tribal leaders, urban Indian health leaders, congressional members and staff, as well as several administration and departmental officials. The NSC received well over 1,000 written comments. The committee decided to draft actual bill language. This was accomplished between the end of July and October 6 when the NSC submitted the tribal draft to the President, the Secretary of Health and Human Services, to my office, and to each of the authorizing committees in the House and Senate. The House Committee on Resources introduced its version of the new bill, H.R. 3397, on November 16 in language identical to that proposed by the tribes.

The Department is in the process of reviewing the many new provisions proposed in the tribal draft legislation in the context of the President's fiscal year 2001 Budget. At the completion of that thorough review and analysis, the administration will be able to present its position on this tribal bill.

Mr. Chairman, this concludes my statement. Thank you for this opportunity to discuss the Indian Health Care Improvement Act and the consultation process that the ITU utilized in the examination and development of the tribal bill to reauthorization this legislative authority. My staff and I will be happy to answer any questions related to the consultation process and our technical support role. However, we are not prepared to discuss the administration's views on the many new provisions proposed in the tribal draft legislation, as the department is in the process of reviewing that legislation in the context of the President's budget and legislative agenda.

TESTIMONY OF THE GILA RIVER INDIAN COMMUNITY BEFORE THE SENATE COMMITTEE ON INDIAN AFFAIRS

REAUTHORIZATION OF THE INDIAN HEALTH CARE IMPROVEMENT ACT

Washington, D.C.
March 8, 2000

INTRODUCTION

Good morning, Chairman Campbell and Members of the Committee. My name is Richard Narcia and I am the Lieutenant Governor of the Gila River Indian Community. I am honored to have the opportunity to provide my Community's views on the draft bill to reauthorize the Indian Health Care Improvement Act and to give our perspective on the importance of Indian Health Service (IHS) programs to the daily lives of our tribal members and other Native Americans. I am pleased to be accompanied today by Karen White, Chair of our Council's Health and Social Welfare Standing Committee.

Our Community is located in south central Arizona, on the outskirts of Phoenix. We have a young and rapidly growing population that presents us with a variety of health care challenges. The most serious health challenge we face is a tremendously disproportionate rate of Type 2 diabetes in our population, which I will discuss with you in more detail today.

Since Fiscal Year 1996, our Community has provided preventive health and primary care services to our population through Indian Self-Determination contracts with IHS. The IHS program dollars we receive have allowed us to make incredible strides in improving health care by tailoring our services to our specific needs. IHS program dollars are also critical to our goal of moving our Community from the IHS's acute-care model to a prevention and maintenance model better suited to the treatment of diabetes.

INDIAN HEALTH CARE IMPROVEMENT ACT

I will begin first with a few comments on the draft reauthorization bill. I will then share with the Committee the challenge our Community has been facing from diabetes so that the Committee can better understand the importance of Indian Health Care Improvement Act programs to our health and welfare.

Our Community supports the draft reauthorization bill and, specifically, the following provisions:

We strongly support the wording in the draft bill that would change the Act's national goal of improving Indian health from the "highest possible level" to "at least as good as the Nation as a whole." We feel that measuring Indian health in comparison to the national standard is the fairest way to ensure that the Native American community receives the improvements in health care delivery that we deserve. It is more than breathtaking to us that, in this period of unprecedented national prosperity, Native Americans continue to suffer more and longer, and die decades earlier, than most other Americans due to inadequate health care.

With respect to Title I, Health Professions, as a community providing services under an Indian Self-Determination contract with IHS, we want to ensure our health profession staffing needs are given consideration on an equal basis with programs operated by the IHS. There are several sections in the draft bill that specifically provide this directive and the Community would want to see the IHS implement this directive. Section 123 would also designate all programs operated by tribes as Health Profession Shortage Areas. In the past, our Community's inability to receive this designation inhibited our ability to participate in recruitment and retention initiatives. As a result, we strongly support this provision.

With respect to Title II, Health Services, our Community supports the goals of section 201, which would reinstitute the Indian Health Care Improvement Fund. The fund has been used in the past to try and achieve equality among IHS funded programs. Currently, it is estimated that our Community is funded at only 54% of the amount IHS calculates as the Community's full need. It is our hope that the Indian Health Care Improvement Fund will help address our funding deficit, provided that sufficient funds to meet our need are appropriated.

The Community strongly supports the goals of section 204 that would make the model diabetes programs recurring through the year 2012. Our Community has a model program for registry and data collection, but it has evolved only with the dedication of considerable resources. In fulfilling the goals of section 204, we would urge the Congress and the Administration to devote necessary resources to implement this section in a meaningful way. We also support the revision to Section 204 of Title II that adds authority for funding to establish, equip and staff kidney dialysis programs.

With respect to Title III, Health Facilities, our Community supports new financing options, such as the Health Care Facility Loan Fund. The Community is in need of expanding health facilities in other areas of our reservation and we may want to participate in such an initiative. We support the increased ability of IHS to seek out creative ways to meet unmet health facility needs and foster partnerships to build necessary facilities. Given the nearly quarter-of-a-billion dollar backlog in health facility construction need in Indian Country, it only makes sense that the IHS support creative partnerships to build necessary health care facilities.

We also support new Section 317 of Title III that would give IHS the flexibility of using funding from other sources to address health care facility construction needs.

With respect to Title VI, Organizational Improvements, our Community requiring IHS to develop an Automated Management Information System and to provide all contracting tribes an automated management information system. We believe this is vitally important and urge the

Congress and the Administration to fund the provision at an adequate level. We also strongly support the change to Title VI that would elevate the Director of IHS to Assistant Secretary level.

Our Community also supports the intent of Section 813, which would provide authority to tribes and tribal organizations to act as ordering agents under the IHS Prime Vendor contract. In our Community, we have seen our drug costs double since 1995 to approximately $1.6 million annually. From 1998-1999, the total increase in cost for our top 11 drugs was approximately $413,000. In the coming year, we expect the overall cost to increase another 8%. Expanding the authority for tribes to participate in the Prime Vendor Contract will allow some savings in drug costs and, importantly, the administrative costs that currently exist in the IHS system.

As a final matter, the Community supports the establishment of an INMED Program in the Southwest. Section 114 of the Indian Health Care Improvement Act currently provides that at least three grants may be provided to colleges and universities. The Community supports IHS providing a grant to the University of Arizona for the establishment of an INMED program in the Southwest. Currently, there are INMED Programs in Minnesota, North Dakota, and Montana.

Overall, the Community supports the goals of the draft bill that seek to strengthen the delivery of health care in Indian Country. As it is well known, the availability of adequate resources is a primary concern. We are hopeful that as the Committee further develops the draft bill, there will be consideration given to funding issues. We believe our Community can serve as a model for health care delivery in Indian Country and as the Congress seeks to create a Bipartisan Commission on Indian Health Care Entitlement, we would ask that you consider our Community's participation on such a commission.

THE DIABETES CHALLENGE

I would like to turn next to the topic of diabetes. I believe that our Community's experience with diabetes illustrates clearly the importance of IHS programs to the every day health and well-being of Native Americans.

According to IHS, diabetes was the most frequently identified health problem cited during the IHS Area budget formulation workshops for FY 2001. According to IHS, Native Americans are almost three times more likely to have diabetes than the general population and are four times more likely to die from it. The mortality rate, according to IHS, is clearly on the rise. In a troubling development, the prevalence of diabetes has risen as much as 36% among Native American children and adolescents.

GILA RIVER INDIAN COMMUNITY'S EXPERIENCE WITH DIABETES

Our Community has the unfortunate distinction of being well-known in the medical world for its shockingly high rate of Type 2 (adult-onset) diabetes. In fact, the Pima Indians that make up our Community have the highest known rate of diabetes in the world, according to the World Health Organization. Eighty percent of Pimas over age 55 have diabetes and Pimas are 12 times more likely than the general population to die of diabetes. In our Community alone,

over thirty percent of adults over age 35 have diabetes. Until recently, our children were not affected by the disease until they reached adulthood. Unfortunately, that is no longer true. Our children are being diagnosed with diabetes with increasing frequency. Today, there are 50 Gila River children with diabetes, the largest cluster of children with Type 2 in the world.

The disease and its devastating complications, including kidney disease, limb damage, amputations, and blindness, pose a serious and costly health care challenge to our Community and, indeed, the world. The World Health Organization estimates that by 2025, 300 million people will have Type 2 diabetes.

As a result of our extraordinarily high rate of diabetes, members of our Community have been studied extensively by the National Institute of Health (NIH). The NIH National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) has supported a field research station in Arizona since 1965 to study the Pima Indians for causes of diabetes. Our local paper, the *Arizona Republic*, recently ran a series on the diabetes problem within our Community and the NIH research effort, entitled "A People in Peril: Pimas on the Front Lines of an Epidemic." We have included that series of articles in the hearing record as an attachment to our testimony.

As stated by the *Arizona Republic*, "the Pima are the most studied people on the planet. They've been weighed, poked, prodded, X-rayed and screened at a cost to taxpayers of more than $100 million." Nearly 80 percent of our Community, 9,000 people, took part in the research. Based on the data obtained, NIH was able to develop new approaches to the treatment of Type 1 diabetes, juvenile diabetes. The study also identified unhealthy weight and genetics as strong risk factors for Type 1 diabetes and isolated the role of high blood pressure in predicting complications of diabetes, including eye and kidney disease.

Notwithstanding the knowledge gained by the NIH research involving Pimas, after 35 years the rate of diabetes in our population continues to skyrocket out of control. Unfortunately, the NIH research program findings failed to study the treatment and prevention of Type 2 diabetes, the type of diabetes that affects the very people that were used to obtain the precious data.

According to the *Arizona Republic* article, NIH had several opportunities available in the past twenty years to fund research and prevention efforts for Type 2 diabetes programs in our Community, but they chose instead to spend over $150 million to research Type 1 diabetes, which is not prevalent in Native American communities. It took 15 years for NIH to turn some of its cross-over research findings into a formal program on diabetes education among Pimas, after the Tribal Chronic Illness Project was launched in 1980. That program consisted of only one visiting nurse, who left in 1986 to attend medical school. Not until 1996, 31 years after identifying the Type 2 diabetes problem in our Community, did NIH launch a nationwide Type 2 diabetes prevention study including Pima volunteers.

According to the *Arizona Republic*, Dr. Barbara Broussard, Director of the IHS diabetes programs in 1996 and 1997, said that the NIH missed a critical prevention opportunity. She is quoted as saying, "There were small fledgling efforts [by NIH], but it was not enough for the scale of the problem. It was sort of like taking a water hose out there for a forest fire."

We relate this experience not to gain the sympathy of the Committee, but to describe to you what it has taught us. The most important lesson we have learned from this experience is that tribal self-interest requires that tribes have direct control over intervention in, and treatment of, serious diseases affecting their population in numbers disproportionate to the rest of the population, such as Type 2 diabetes. The Indian Health Care Improvement Act and the programs authorized therein have been, and continue to be, our critical conduit to obtaining that control.

THE NEED FOR INCREASED FUNDS TARGETED TOWARD DIABETES

As stated, the Indian Health Care Improvement Act authorizes the health care delivery programs through which tribes receive self-determination contract funds to target the health services most needed by their populations. Since taking over provision of health care services through a Self-Determination contract with IHS, our Community has a higher level of health care than was ever possible through direct IHS service because of our ability to target uses of the program dollars. Clearly, however, we have a long way to go in order to beat diabetes in our Community.

We note that the President's Fiscal Year 2001 budget includes a $3.88 million increase for diabetes programs in the IHS budget. In addition, the IHS budget request includes an annual transfer appropriation of $30 million pursuant to the Balanced Budget Act of 1997 for the Special Diabetes Program for Indians (SDPI). SDPI provides grants to IHS and tribes for the prevention and treatment of diabetes. The SDPI funds have been used as seed money to start over three hundred new tribal diabetes programs. According to IHS, many of these programs, a majority of which are tribally run, are creating innovative, culturally-appropriate strategies to address diabetes.

What tribes are discovering, however, is that they are just beginning to scratch the surface of the diabetes problem in Indian Country. Tribes are reporting to IHS the need for additional trained personnel, support, technical assistance and continued funding beyond the five-year SDPI program term. According to IHS, tribes are just beginning to exert a growing influence in the management of diabetes programs as the number of tribally managed diabetes programs continues to grow steadily. Clearly, IHS must continue to support the initiation and expansion of tribally-run diabetes treatment and prevention programs.

GILA RIVER PLANS FOR INTERVENTION CENTER

Our Community has not been passive in its fight against the deadly disease of diabetes. As one member of our community recently stated, "The story of diabetes on the Gila River Indian Community is about more than alarming statistics and tragic numbers. It's about families and individuals living with and working through a disease that has become a worldwide public health issue." Our Community has escalated its diabetes treatment and prevention efforts since taking control of our health care delivery in 1996 pursuant to an Indian Self-Determination contract with IHS. Our Community already has in place health care services that equal or surpass many other health care delivery systems in the country. We are ready to move to the next level.

The Community has long been frustrated by the lack of successful intervention in our Community to stem the progression of diabetes and its severe complications. As a result, the Community is currently exploring the possibility of establishing a Center on Community land to address the diabetes epidemic raging in our population.

The purpose of the Center would be to develop new diabetes intervention techniques specific to our Community and to train professionals in such techniques. The Center would transfer all control over intervention and treatment to the Community and coordinate with research activity being undertaken by the Community and outside agencies, including NIH.

CONCLUSION

We want to take this opportunity to thank Chairman Campbell and other distinguished Senators on the Committee for their demonstrated concern about the high rate of diabetes in the Native American community. We look forward to continuing to work with the Committee in our effort to win the war against diabetes and other serious health challenges that affect our Native American communities in disproportionate numbers.

We thank the Committee for inviting us to submit our views on the draft reauthorization legislation and to share the importance of IHS health programs to our Community.

I would be happy to answer any questions the Committee may have at this time.

AKIN, GUMP, STRAUSS, HAUER & FELD, L.L.P.
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March 20, 2000

Ms. Eleanor McComber
Senate Committee on Indian Affairs
SH-838 Hart Senate Office Building
Washington, D.C. 20510-6450

Dear Eleanor:

As recently discussed, enclosed is a copy of a series of articles that ran this past fall in the *Arizona Republic* concerning the diabetes epidemic within the Gila River Indian Community population. Please include these articles in the hearing record as an attachment to the testimony of Lieutenant Governor Richard Narcia that was presented at the Committee's March 8, 2000 hearing on the Indian Health Care Improvement Act reauthorization bill.

Thank you for your assistance, and please contact me at (202) 887-4356 if you have any questions.

Best regards,

Katherine Brodie

Katherine D. Brodie

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20 years of research for what? tribe asks

Miscalculations delayed war for control of diabetes

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Oct. 31, 1999

During one of his dialysis treatments, Roy "Rudy" Rhodes cries out in pain as the needles come out of his arm, requiring them to be readjusted.

GILA RIVER RESERVATION - When the nation's most prestigious health research institute uncovered an epidemic of diabetes on this desolate Pima Indian reservation in 1965, researchers realized they had found the perfect living laboratory.

More than a third of the adults over age 35 suffered with the deadly disease. Though fairly isolated, they were just 40 miles from Phoenix, and their

- American Diabetes Association, www.diabetes.org
- NIH's National Institute of Diabetes and Digestive and Kidney Diseases - national diabetes education program, http://ndep.nih.gov
- Centers for Disease Control and Prevention www.cdc.gov/diabetes

'The Republic' team

- Reporter Graciella Sevilla and photographer Mona Reeder

lifestyles, though stable for centuries, were suddenly and dramatically changing.

Rhodes not only has to undergo daily injections of insulin to live with his diabetes, he has to undergo dialysis three times a week, each session lasting three to four hours. Rhodes has lost part of his right leg and half of his left foot. Click here for more photographs.

Today, after 34 years of research by the National Institutes of Health, the Pima are the most studied people on the planet. They've been weighed, poked, prodded, X-rayed and screened at a cost to taxpayers of more than $100 million.

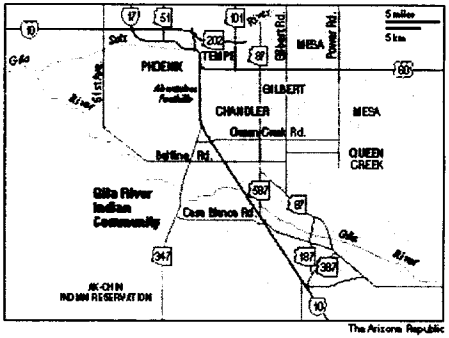
But diabetes still rages out of control. Pimas are 12 times as likely to die of the disease and four times as likely to have limbs amputated because of it.

The number of Pimas over 55 who have diabetes has skyrocketed to 80 percent from 45 percent, and every week, loved ones fill the tribal cemeteries, mourning more victims of "the Pima Plague."

Amputations and blindness are commonplace. Dialysis is a way of life. Even children, who a generation ago were virtually unaffected, are being diagnosed with diabetes with alarming regularity.

Scientists still can't say for certain why diabetes has hit the Pimas so hard, and there are those who fear the 11,500-member tribe is in danger of being wiped out.

And though the National Institutes of Health began testing prevention measures three years ago, the question remains: Did they do enough for the first three decades?



The answer isn't simple, but a six-month investigation by *The Arizona Republic* shows that at best, the war against diabetes was delayed by bad timing and strategic miscalculations. At worst, some Pimas say, they were sacrificed in the name of science.

"Thirty years of research for what?" asks Franklin "Pete" Jackson, a community leader. "What did we get for all of this? We were human guinea pigs. They've just been watching diabetes take its course, but the people here have been hoping for a cure."

NIH officials say they never misled the Pimas or promised them a cure. But dozens of interviews and scores of documents show that the

agency, with its $15.6 billion tax-supported budget, made critical decisions in the late 1970s and early 1980s that set back the fight against diabetes by at least a decade. And now, those choices are coming back to haunt the agency, not only in Arizona but around the world.

A wrong turn

In the early 1980s, the NIH decided put off prevention studies involving the Pimas and focus the bulk of its resources on Type 1 diabetes, even though that form affects less than 10 percent of the people with the disease. Type 1, commonly referred to as juvenile diabetes, affects mostly Anglos. The Pimas suffer from Type 2, or adult-onset, diabetes, which is nearing epidemic proportions among minorities in the United States and in many Third World countries.

While NIH scientists continued to study the origins of Type 2 diabetes among the Pimas, they put off testing methods of prevention until just three years ago. That decision forced the key researcher on the Pima project to go to China to test Type 2 diabetes prevention methods, because the NIH would not fund that experiment among the Pimas.

Dr. Phillip Gorden, a director of the diabetes research branch of the NIH, defends the decision, saying researchers had to seize the scientific opportunity that was available to them at the time. He said that the Type 1 study was more manageable and that new technology had just become available for testing.

Looking back, critics say, that was a serious miscalculation.

Dr. Barbara Broussard, director of the federal Indian Health Services diabetes program in 1996 and 1997, said the NIH missed a critical prevention opportunity.

"There were small fledgling efforts, but it was not enough for the scale of the problem," she said. "It was sort of like taking the water hose out there for the forest fire."

A cure is nowhere in sight, especially not here in the Gila River community. Nowhere in the world is diabetes more widespread or more deadly.

"There's an epidemic happening," Broussard said. "Can you imagine living in a community where one out of every two adults has diabetes . . . and to see children developing this condition?"

Dr. Peter Bennett, chief of the NIH Pima diabetes studies, said his crew's mission has always been to decode and halt the disease. But it took 17 years of basic science to understand enough about it to begin testing prevention. Bennett originally estimated that the research would take no more than 10 years.

Type 1 diabetes

Type 1 diabetes, also called juvenile diabetes, results when the body fails to produce insulin. The onset of the disease can be sudden, and it is fatal unless patients receive insulin daily. It typically affects children, although it can also appear in

When Bennett first came to Gila River, very little was known about what made people more vulnerable to the disease. But tribal members became willing partners, with nearly 80 percent of the population - nearly 9,000 people in all - submitting themselves to exams, donating their blood and sharing their tragic family histories.

They were given glucose tolerance tests, weighed and measured, and had their blood drawn, eyes and kidneys checked and X-rays taken. To chart physical and biological changes showing susceptibility to diabetes, the exams were repeated every two years.

By the 1970s Bennett's staff had figured out that obesity, a lack of exercise and a family history of diabetes are the key risk factors in the disease.

'Just a little seed'

By 1979, the NIH had come up with a plan to translate its research into help for the Pimas, who live on the sprawling, 580-square-mile Gila River Reservation. The agency launched the Tribal Chronic Illness Project in 1980 to help educate Pimas in methods of preventing diabetes and arthritis.

But the NIH budgeted only enough to hire two nurse practitioners, one for arthritis and the other to deal with diabetes. A community awareness program reached only 12 percent of the community's population. Funding ran out in 1986.

Meanwhile, the NIH spent $150 million on the Type 1 project.

Gorden, director of the NIH's National Institute of Diabetes and Digestive and Kidney Diseases, said the Type 1 study helped reduce the suffering of people with that form.

Carried out from 1983 to 1993, the Diabetes Control and Complications Trial showed that intensive control of blood-sugar levels through medication, diet and exercise can slow the onset and advancement of eye, kidney and nerve diseases caused by Type 1 diabetes. The findings were considered a landmark. A United Kingdom study released last fall showed that the lessons from the trial apply to Type 2 patients as well.

But the research didn't begin to extinguish the wildfire of diabetes spreading among the Pimas.

It occurs most commonly among Anglos. An estimated 1 million Americans have this form of diabetes. This disease does not affect the Pimas.

Over time, both forms of the disease can lead to serious and life-threatening complications. If diabetes is not strictly controlled with medication, diet and exercise, the changes begin to develop, typically, after 15 to 20 years.

Type 2 diabetes

Type 2 diabetes, formerly known as adult onset diabetes, occurs when the body develops a resistance to insulin, a hormone that helps convert blood sugar (glucose) to energy.

It is a chronic and deadly illness. It can often be controlled without medication through a lean diet and exercise. These measures can also postpone development of the disease's life-threatening complications.

Type 2 diabetes afflicts more than half of Pima adults and 90 percent of the 16 million Americans with diabetes.

Michael Mawby, the American Diabetes Association's vice president for governmental relations, believes the agency had a moral obligation to do more to help the Pimas.

"As the impact of diabetes was uncovered in the Native American community and in the Pimas in particular, there was a responsibility of the federal government to take more aggressive steps to address the problem, and they haven't done that," Mawby said.

A lack of prevention

Well aware of the impatience of some Pima leaders with how long the studies have gone without a solution to diabetes, Bennett and his crew defend their studies.

"A lot of the way diabetes is treated throughout the country and the world is based on things that we learned with the Pima Indians," said William Knowler, who oversaw the Gila River studies. "These studies have taught us a tremendous amount, but they have not yet taught us how to eliminate the disease. So we still have a way to go."

Outside the Pima community, experts say flatly that they are not impressed by the NIH's approach.

"When the ADA started looking at (medical research) funding for diabetes in 1996, we were stunned by the abysmal state of diabetes research at NIH," said Mawby, the ADA official.

For years, the budget for the diabetes programs run by Indian Health Services hovered at $7 million. That was supposed to cover diabetes care for the Pimas and the other 500-plus Native American groups in the United States.

If funding stood still, diabetes did not. Among many Native American nations, the disease was mushrooming.

"I think everyone was slow to wake up to this evolving epidemic of a disease," said David Nathan, a leading U.S. researcher who participated in the NIH Type 1 study and who now leads the Type 2 prevention trial.

"Quote"

Barbara Broussard

Director of the Indian Health Services diabetes program, 1996-97

QUESTION: Did the National Institutes of Health drop the ball in not pursuing earlier opportunities to study prevention?

ANSWER: "The answer is probably yes, there were opportunities, there was a series of missed opportunities. There were small fledgling efforts (at prevention/treatment), but it was not enough for the scale of the problem. It was sort of like taking the water hose out there for the forest fire."

Q: Did raw science take precedence over people's suffering?

A: "I think that is true. For too many years, diabetes education, teaching people how to manage their diabetes, took a back seat to the funding of biomedical research. At the same time, research for diabetes across the whole spectrum has been too low. Too low by the extent of the disease."

Dr. Kelly Acton

Current head of the Indian Health Services diabetes

program

Q: Has research taken precedence over care for diabetics?

A: "I can see both sides of that argument. The Pima research has led to an incredible gift to the rest of the world in the understanding of Type 2 diabetes. That's how we understand many of the basic mechanisms around it. If you're looking at Indian people, there has been much more money put into research than has been put into the people."

Going to the grave

Today, the same things that undermine the health of many Americans, eating more processed food and exercising less, have resulted in an alarming rate of obesity among the Pimas. It is not unusual for Pima kindergartners to weigh more than 75 pounds or adults to tip the scales at over 300. Scientists think the Pimas may be predisposed to weight gain by "thrifty" genes developed over generations of enduring drought cycles in the desert.

The theory goes that Pimas who survived times of famine were those whose thrifty genes worked to store fat during times of plenty. Now that food is amply available, the thrifty genes serve only to bulk up bodies. Disastrously for the Pimas, obesity is a major risk factor for diabetes.

These days, Bennett's research team is one of dozens around the world scrambling to identify the culprit diabetes genes.

But even as the gene-hunting race heats up, more and more Pimas continue to get diabetes.

Retiring Pima Gov. Mary Thomas, herself a diabetic, dreads the possibility that diabetes will doom her tribe. She wants the Pimas to take responsibility for their own health.

"I shock my people by saying that if we don't get this in check now, we'll become an extinct people 75 years from now," Thomas said.

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Tragedies of diabetes stoke people's fears

Victims are destroyed organ or limb at a time

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Oct. 31, 1999

"There's a fear among some of us," Pima tribal leader Franklin "Pete" Jackson says. "They think that when someone gets diabetes, it's terminal because of what they see surrounding them." That fear is well-grounded as every week, loved ones fill the tribal cemeteries, mourning more victims of "the Pima Plague." Geraldine Brown Terry pays her respects to the family of Violet Jones Brown who died at age 50 of diabetes. The services in Bapchule on the Gila River Indian Reservation began at 7 a.m., which is common in the Sonoran Desert because of the heat. Click here for more photographs.

Inevitable, uncontrollable, inherited and fatal. That's how many Pimas describe diabetes.

Ruby Brown Terry knows why.

Diabetes has ravaged her Pima community. Ruby's family tree is a picture of devastation. Diabetes killed three of her grandparents, her mother, two uncles and an aunt.

Brown Terry watched them suffer before dying as the disease took their sight and destroyed their kidneys. Several relatives lost limbs and were confined to wheelchairs.

Brown Terry, 33, and two of her four siblings live with the disease.

Association, www.diabetes.org
• NIH's National Institute of Diabetes and Digestive and Kidney Diseases - national diabetes education program, http://ndep.nih.gov
• Centers for Disease Control and Prevention www.cdc.gov/diabetes

'The Republic' team
• Reporter Graciella Sevilla and photographer Mona Reeder

And now, her 11-year-old daughter, Cody Lynn, has been diagnosed with the family plague.

"It's scary because she's really young. She's going to have this the rest of her life," Brown Terry says.

Diabetes shapes almost every life on the Gila River Reservation. Those who don't have it are likely taking care of or living with someone who does.

People disabled by the disease -- the amputees, those who've gone blind, those kept alive by kidney dialysis -- are as common on the reservation as the cottonwood trees that once dotted this now barren desert village.

At age 51, Roy "Rudy" Rhodes' body is being slowly destroyed by diabetes, one organ or limb at a time.

In the past eight years, he's been assaulted by three of the disease's worst consequences. He's lost a leg and half a foot to amputations that have put him into a wheelchair. He is going blind. And his kidneys have failed, forcing him to depend on dialysis to survive.

Today, Rhodes is only the shadow of his former self, a robust, 16-year police veteran who stood 5 feet, 8 inches and weighed 280 pounds. But for all the hardship, defeat is not on his agenda.

Rhodes is a familiar figure on the reservation as he wheels himself to the convenience store or church near his apartment.

"You see him going here, you see him going there in that wheelchair. It's something," marvels Michael Locey, one of the tribe's diabetes patient advocates.

Three times per week, Rhodes spends four hours hooked up to a blood-cleansing machine at the dialysis center on the reservation. He watches the technicians carefully as they connect his veins to the acrylic tube that filters his blood.

"I'm just looking at my kidney," he says, laughing at the name he gives the man-made tube that substitutes for his ruined organs.

On this Tuesday, his dialysis session goes from 11 a.m. to 3 p.m. He is one of 18 patients. Among them are several familiar faces.

A couple of chairs away sits his cousin, Robert Rhodes. Down the row is a former police buddy and next to him a former tribal councilman who's a friend of Rudy Rhodes.

Even though he's in good company, dialysis tends to be exhausting.

"Most of the time, I just sleep. If I can sleep all the way through, that's good," he says.

Diabetes was rather rare on the reservation until the 1950s and 1960s. Rhodes is old enough to remember when Pima people lived long

lives, unconcerned by the deadly disease.

"My (maternal) granddad lived to 91, and my other granddad lived to be 89," he says.

Rhodes' paternal grandfather, a wheat farmer, did develop diabetes. But, Rhodes notes, "he was an older man when he was diagnosed."

By contrast, Rhodes was 23 when he learned he was diabetic. Doctors now know that unless diabetes is strictly controlled, the disease often causes life-threatening complications after 15 or 20 years. Now, Rhodes understands that his life will be cut short by the disease.

"I'm a dialysis patient," he says matter-of-factly. "I'm going to go sometime."

Most Pimas know doctors believe diabetes can be controlled through diet and exercise. But there's a huge gap between that ideal and the Pima reality.

Rhodes, for instance, chooses to take what pleasure he can by ignoring the dietary recommendations.

"I don't like to go by the book," he says. "They take all the goodies away."

He managed to give up bananas and tomatoes and cut back on water. But other things are not negotiable.

"They told me watermelon is a no-no. Cantaloupe is a no-no. I still eat them once in a while."

Today, while strapped to the dialysis machine, he gets a special delivery. His nephew drops off a fry-bread popover filled with beans and cheese. Rhodes washes it down with a root beer soda and savors both.

"There's really nothing for me to look forward to. I can't go back to school. I can't go out and get a job," he explains. "But if I eat what I want, I'm happy. And if I die, I die happy."

Diabetes and the deaths it causes are something Tracy Antone, 29, wants to derail.

In a Phoenix National Institutes of Health laboratory, he lies awake on a gurney, his head encased in a plastic hood, a sugar solution oozing into his right arm.

The Pima man's friends, relatives and acquaintances have been dying all around him on the reservation.

Antone, a casino security guard, spends his vacations doing what he can to end the scourge. He volunteers for experiments, donates his blood and has even recruited his brother to the cause.

"I told him we could help find a cure for diabetes," Antone says.

But despite the efforts of scientists and their willing volunteers, no cure is in sight. Instead, the Pimas cope as best they can.

It fell to Ruby Brown Terry and her sister, Eileen, to care for their mother, Violet, during the last two agonizing years of her life. A nurse, Violet Brown developed diabetes in her 20s.

She managed to stay healthy enough to rear six children and work in a nursing home. But by the time she was 48, she had lost a kidney and was forced to begin dialysis.

There were times when Violet would cry and tell her daughters, "I don't want to live like this."

Sometimes, Ruby and Eileen would cry with her.

Violet was only 50 when she died.

Such tragedies are everywhere on Gila River. They stoke the people's worst fears.

"There's a fear among some of us," tribal leader Franklin "Pete" Jackson says. "They think that when someone gets diabetes, it's terminal because of what they see surrounding them.

"They see people diagnosed with diabetes, then they begin taking insulin, then they begin to lose limbs, then they go on dialysis and then to the grave."

Social anthropologist David Kozak says an attitude of surrender is a common emotional response to the rampant devastation. It is the feeling that attempts to prevent diabetes are futile.

Now that Ruby Brown Terry, her husband, Leon, and daughter Cody Lynn are all diabetic, the only one in the household without diabetes is her 8-year-old son, Ryan.

As a mother, Ruby hopes against a bleak family history that her son will be saved, by fate or by science, from the disease her people call "the Pima Plague."

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'Life changed after river stopped'

Traditional diet high in fiber, low in fat a distant memory

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Oct. 31, 1999

Three-year-old LaDania Reid says "ouch" as her mother, Bonita Reid, injects herself with her daily dosage of insulin. Bonita, who was diagnosed with diabetes at age 12, has three daughters and is now on dialysis three times a week. With the highest diabetes rate in the world, the Pima Indians of southern Arizona are discovering that the disease is striking their family and friends at increasingly younger ages. Click here for more photographs.

In Juana Lucero's lifetime, Western culture intruded with a vengeance in the Gila River Indian Community.

It took the fish, the crops and the river that once fed and watered them. It altered the land, swallowed the Indian culture and unleashed the twin scourges of obesity and diabetes that now haunt Lucero's Pima people.

Now 68, Lucero is a nun and schoolteacher. Like many Pima elders, she is also diabetic and a witness to the encroachment of Westernization that bisected Gila River history.

"Life changed after the river stopped," Lucero says.

About 3,000 years ago, it is believed, the Pimas migrated from

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Mexico. Settling in the Gila River Valley, they took the name "O'odham," the River People.

They tamed the desert by channeling the river through a system of canals that irrigated fields of wheat, cotton, squash, tepary beans, corn and melons.

So abundant were the crops that the Pimas had enough for others. Pima cotton was sought for its fine quality to make textiles at the turn of the century, according to Elinor Pascual, an amateur Pima historian.

There was enough wheat to supply the flour mills in Tempe, says Tribal Gov. Mary Thomas, whose grandfather was a farmer.

Fish from the river, produce from family farms and abundant wild deer, rabbits and quail provided plenty to eat until the early 1930s.

"I don't think they even knew what hunger was here," Pascual says. "The people here would feed anyone who came through - settlers, miners, soldiers."

But in 1929, two years before Lucero and Pascual, also 68, were born, White settlers upstream dammed the river.

Soon, the water stopped running and the land began to die.

Animals and plants that depended on the water became scarce. Now, instead of growing, hunting or gathering their food, the Pimas were forced to buy it.

Hunger led the people to accept government commodities. The handouts introduced the Pimas to processed foods - sugar, cheese, butter and white flour - by the boxload.

"When they started giving commodities, they would just put it by your door if you weren't home," Lucero says. "And if people didn't know what to do with it or they didn't like it, they would just throw it out in the river.

"You'd see syrup for pancakes and orange juice in cans floating out there."

But hunger changes your tastes, and Thomas remembers learning to like the canned meat she and her siblings jokingly called "monkey meat."

"The federal government forced

Eye diseases cause blindness

The Pima Indians suffer substantially more complications from diabetic eye diseases than the U.S. population as a whole.

The most common consequence is diabetic retinopathy, the leading cause of blindness among adults in the United States.

Most people with diabetes will develop some form of retinopathy over time. After 10 to 15 years, the disease damages the blood vessels that supply the retina.

When the condition is not treated early, it can cause vision loss or blindness.

If it's caught in time, doctors can sometimes use lasers to seal damaged blood vessels, preventing them from forming the blood clots that can cause blindness.

Maintaining a healthful diet,

assimilation on us," she says. "You could not eat like an Indian, you had to eat how the federal government told you. We got dependent on commodities, and then welfare followed and it got worse."

After World War II, Western culture invaded rapidly.

controlling blood sugar levels, regular exercise and frequent eye exams are the best ways to prevent diabetic eye damage.

Sources: Blue Cross and Blue Shield; the American Academy of Ophthalmology, the National Eye Institute, American Diabetes Association.

Today, two gleaming casinos are the biggest source of employment for the Pimas. The remaining farmland is leased to commercial growers. The horse-drawn wagons that crisscrossed the reservation when Lucero was a girl have been traded for pickup trucks and utility vehicles.

At the dinner table, cholla cactus buds and black-tailed jackrabbit have been replaced by Hamburger Helper and macaroni and cheese. The traditional diet that was high in fiber and low in fat is a distant memory, like all the activities - walking, horseback riding, farming and hunting - that once kept the Pimas trim.

As the Pimas adopted modern bad-health habits, eating more and moving less, they've come to have the highest rates of obesity and diabetes among any population group in America.

Now, their dramatic story, scientists say, is a tragic case study of a community that was suddenly pushed from subsistance to Westernization.

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China aids diabetes research

Study is model for current trials

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Oct. 31, 1999

By the early 1980s, the scientist in charge of the Pima research studies had a hunch he knew how to slow the surge of diabetes.

Lifestyle changes -- a lean diet and exercise regimen -- might ward off the deadly chronic illness, Dr. Peter Bennett concluded.

He pressed the National Institutes of Health to start a prevention experiment among the Pimas. If Bennett proved his theory, it could be a boon to the Pimas and millions of others around the world at risk of developing Type 2 diabetes.

But officials at NIH headquarters in Bethesda, Md., said no.

At the time, the NIH was spending $150 million on a nationwide, 10-year clinical trial to prevent Type 1 diabetes, a form of the disease that does not touch the Pimas and affects less than 10 percent of the 16 million Americans afflicted with diabetes.

Bennett says he was told privately that all diabetes research funds were tied up in the Type 1 study. He and the Pimas would have to wait.

Dr. Phillip Gorden, who heads the diabetes research arm of the NIH, says money wasn't the deciding factor in pursuing Type 1 studies over Type 2. It was an opportunity to test new technology and the

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critical nature of Type 1 that pushed the NIH to study that form of diabetes first.

"It was really based on severity of disease," Gorden says.

Type 1 diabetes, also known as juvenile diabetes, commonly attacks children. The disease has a sudden onset and patients must take insulin daily to survive.

But Bennett was sure he was onto something. Undaunted, he sought funding and opportunity elsewhere.

He found both in China.

Supported by grants from the World Bank and the Chinese government, he took his study to Da Qing, an industrial city in northern China.

Bennett estimates that it would have cost about $7 million to do the study in the United States. He did it for $300,000 in China. From 1986 to 1992, the doctors at health clinics in Da Qing worked with 530 adults.

The researchers were able to show that both diet and exercise were equally effective in reducing the incidence of diabetes.

But the study in China was considered too small by NIH standards to be conclusive. So, the Chinese research findings could not be translated into medical recommendations for the Pimas and other diabetes patients in the United States.

And there were questions. Did the experiment work because the Chinese are conditioned to accept discipline? Would the same prescribed approach to diet and exercise work in the United States?

In the early 1990s, when the NIH finished its massive Type 1 study, Bennett's idea was dusted off and used as a model for a Type 2 diabetes prevention trial now in progress.

Begun in 1996, the Diabetes Prevention Program is testing the effectiveness of diet, exercise and medication to prevent diabetes. It is the first large-scale clinical trial aimed directly at stopping the disease.

Researchers are working with 4,000 volunteers. More than half the people taking part in the six-year study are from the minority groups hardest hit by the disease -- Hispanics, African-Americans and Asians. Among the volunteers are three dozen Pimas.

Bennett is optimistic that his Chinese results will be confirmed. But he can't help but think that the quest to stop diabetes might be further ahead today had the NIH accepted his study proposal.

Had the funds been made available, he said, a study along the lines of what he did in China could have been started by the NIH as far back as 1985.

Instead, Bennett and the Pimas waited until 1996 for the Diabetes Prevention Program.

"That's where I personally feel the frustration," Bennett says. "We might have been able to do this as much as 10 years earlier."

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Prevention strategies are tested

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Nov. 1, 1999

The National Institutes of Health is finally doing what the Pimas and the scientists studying them have wanted for years: testing prevention strategies for diabetes.

Nationwide, 4,000 volunteers are participating in a clinical trial to determine whether Type 2 diabetes can be avoided or delayed by weight loss and medication.

"If the Diabetes Prevention Program is successful in getting people to lose weight, we think that would eliminate a lot of diabetes," says William C. Knowler, one of the researchers leading the Pima studies.

Due to end in 2002, the six-year study is testing the effectiveness of following a supervised diet and exercise program, both alone and with medication on people with a pre-diabetic condition.

Although genetic decoding of diabetes remains a long-term goal that could lead to prevention breakthroughs, scientists say the prevention project is the best bet for slowing the disease in the near future.

More than half the people participating in the study are from minority groups at high risk for developing diabetes, including Native Americans, Hispanics, African-Americans and Asian or Pacific Island Americans.

Although Type 2 diabetes is one of the most common chronic diseases in the United States, afflicting 16 million people, the

diseases in the United States, afflicting 16 million people, the Diabetes Prevention Program is the first large-scale clinical trial aimed directly at stopping the disease.

But missing from the experiment are a large number of Pimas.

Despite major recruiting efforts by the NIH and financial incentives, fewer than three dozen Pimas from both the Gila River and Salt River reservations in Phoenix have volunteered.

Kristina Morago, a Gila River council member, says that after 34 years as research subjects, many of her people are weary of acting as "guinea pigs" for science.

"People are tired of being studied," she says. "They no longlonger wish to participate in any research."

Peter Bennett, chief of the NIH Pima studies, says he's disappointed but not too surprised by the lack of volunteers.

"When people are being asked to make a commitment for five to six years that involves changing their lives, they think twice about it," he says. "There's only a minority willing to make that commitment."

Even so, researchers are hopeful that the research will provide some definite answers about what combination of diet, exercise and medication works to the growing global diabetes crisis.

- American Diabetes Association, www.diabetes.org
- NIH's National Institute of Diabetes and Digestive and Kidney Diseases - national diabetes education program, http://ndep.nih.gov
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Diabetics' 'Death Row'

Busy reservation dialysis center not for the squeamish

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Nov. 1, 1999

The most feared building on the Gila River Reservation is not a funeral home, but a place many people here think of as the next-to-the-last stop before the grave. It is the dialysis center where the most critically ill diabetics go three times a week for blood cleansings to prolong their lives.

Here, about 100 of the afflicted come to be hooked up to machines that do what their diabetes-wrecked kidneys

Jonathan Milda reaches out for reassurance that everything is OK when the alarm begins beeping on the dialysis machine to which he is hooked. This

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can't -- purge the toxins from their blood. Most of the patients are 40 to 50 years old, but the toll taken on their bodies by the disease makes them look decades older.

was only the second time Milda had been on dialysis. Many people on the reservation refer to the dialysis center as "Death Row" or the last step before the grave. The Pima Indians of southern Arizona have the highest rate of diabetes in the world. Click here for more photographs.

"This is end-stage renal disease," said Corinna King, the charge nurse.

Visitors are allowed at the clinic, but it's not a scene for the weak-kneed. Everywhere one looks, blood is on display.

In pumping machines whirring next to each chair, blood swirls in round, see-through containers that spin like the tapes of a reel-to-reel tape recorder. Patients sit in 18 easy chairs arranged in two semicircles like the seats in a strange beauty parlor. The bright, sterile environment is eerie under the fluorescent lights, which shine starkly on the patients' faces, some darkened by the disease to a unnatural shade that is almost maroon.

Gila River opened its own dialysis center, out of necessity, less than 10 years ago, when it became clear that the diabetes epidemic showed no signs of slowing. Fifty other Pimas go to dialysis clinics off the reservation.

Pimas have more than 20 times the rate of kidney failure of the general U.S. population, according to National Institutes of Health studies. Among the tribe, kidney disease kills more people than any other illness.

As a result, business is booming at the privately owned Renal West clinic on the reservation. Six days a week, the clinic opens its doors at 5 a.m. to receive the first of three daily shifts of patients. They arrive with their pillows, word-puzzle books and, sometimes, a relative to keep them company through the ordeal, which takes 2 1/2 to five hours at a sitting.

In that span, all the blood in their bodies is pumped out, half a pint at a time, and filtered through an artificial kidney. Patients lose 10 to 14 pounds of excess fluids in the process, depending on their body size.

In healthy people, the kidneys filter out waste that builds up in the blood system, preventing excess fluid buildup. But for people with kidney failure, "when they drink, they don't urinate (waste) out," King said.

During dialysis, a person's blood is

Kidney disease among the Pimas

Researchers have found that Pima Indians have over 20 times the rate of kidney failure as the general U.S. population.

Over 90 percent of the Pima cases are caused by diabetes.

And kidney disease is the leading cause of death from disease among Pimas.

The chronic kidnev failure suffered by many Pimas cannot be reversed or cured.

When the kidney's filters are damaged, the remaining ones have to work harder to make up for the loss. As more of the filters are damaged, the kidneys lose their ability to compensate.

When the kidneys decline to only 5 or 10 percent of their original capacity, a person is

siphoned out through an intravenous tube connected to the artificial kidney, an acrylic canister filled with cellulose and acetate fibers that filter out the toxins, excess water and urine.

Patients captive three days per week during dialysis make the best of their confinement. Sitting in the center's gumball-blue recliners, they chat with their neighbors, watch television or just nap, overwhelmed by the exhaustion of having their life's fluid pumped in and out of their bodies.

Michael Locey, one of the tribe's dialysis-patient advocates, remembers being powerfully moved the first time he set foot in a dialysis clinic near the reservation.

diagnosed with end-stage kidney disease.

To stay alive, people with kidney failure must depend on dialysis to filter impurities from their blood, or have a kidney transplant.

Once a person has diabetes, kidney disease may be prevented or slowed by controlling blood sugar levels and blood pressure, and by maintaining healthy weight.

Source: The National Institutes of Health and Fresenius Medical Care North America.

"I walked into the dialysis center in Chandler, and every one of the persons there I knew as a child," he said. "They were the bus driver, a police officer, a schoolteacher, neighbors. It touched me."

Like so many Pimas, Locey has watched relatives endure dialysis.

"My grandmother had dialysis. My stepdad is on dialysis," he said.

Looking at the rows of clinic patients, he ponders his own future.

"I've been diabetic for five years. Eventually, I may be sitting here with them."

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Sister tribe avoids health pitfalls

Traditional life is the difference

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Nov. 2, 1999

Trinidad Rascon Coyote mixes flour as her mother, Dolores Coyote Duarte, tends to a grandchild. They and several extended family members live in a two-room house in Maycoba, Mexico. The Maycoba Pimas are distant cousins of the Pima tribe that lives in Arizona, but the Maycoba lifestyle is more traditional. As a result, obesity and diabetes, which plague the Arizona Pimas, are much less prevalent. Click here for more photographs.

MAYCOBA, Mexico - Here in the bosom of the Sierra Madre in northwestern Mexico, scientists working with the Pima Indians have found proof that diet and intense exercise offer protection from diabetes.

The Pimas who live here come from the same genetic stock as the Pimas who live in central Arizona. Yet while the Gila River community south of Phoenix is being decimated by the "Pima Plague," diabetes has barely touched this Mexican village.

Even on the eve of the new millennium, the Pimas here are following a lifestyle that disappeared from Gila River generations ago.

Television and newspapers do not reach this pine-rimmed valley,

Diabetes Association, www.diabetes.org
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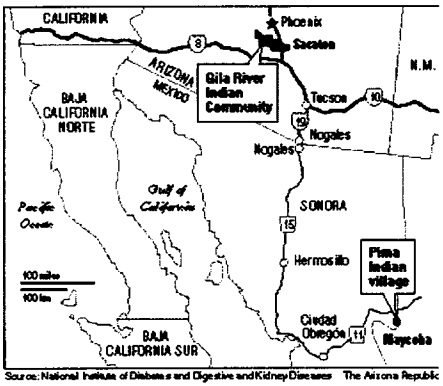
Television and newspapers do not reach this pine-rimmed valley, where the native Pimas have endured ages of rough-hewn living. Grueling labor and subsistence farming so far have shielded the Mexican Pimas from the diabetes that has ravaged their Arizona cousins.

A rural people, the Mexican Pimas tend their fields without machinery, hoeing rows by hand or with a plow and ox. Fires for cooking and warmth are stoked with wood cut from the surrounding forests.

Fewer than one in 15 of the adult Pimas in Maycoba has diabetes. By contrast, one of every two adults on Gila River has the disease. Among those 55 to 65, the rate is 80 percent.

"The lesson shown by the Mexican Pima is that in a population susceptible to diabetes, heavy physical activity and a simple diet have served to protect the people from the disease," says Dr. Mauro Valencia, a Mexican researcher who has studied the Indians in Maycoba.

Scientists comparing the village of Maycoba with the Gila River community believe they have found proof that lifestyle can make a dramatic difference in the battle to prevent diabetes, not only among the Pimas, but in other communities throughout the world.



Source: National Institute of Diabetes and Digestive and Kidney Diseases The Arizona Republic

In Maycoba, the average Pima man spends 29 hours per week at moderate to heavy labor, while the Arizona Pima averages two, according to a study by Mexican and U.S. researchers working for the National Institutes of Health.

"They're not eating much less than the Arizona Pima in terms of calories, but of course they're burning a lot more with all this exercise. There is the secret to why they're so much thinner," says Dr. Peter Bennett, chief of the NIH Pima studies.

Robust activity is a means of survival in Maycoba.

Consider Luz Lao Aguilar's life.

Most days, the 64-year-old grandfather works from dawn to dusk.

The moon is rising over the craggy hillsides when he gets home this crisp fall evening, leading his burro to the two-room wooden cabin he built.

He has finished clearing his fields, bringing home the remains of the late harvest, a burlap sack filled with corn. His wife will strip the cobs of kernels that she grinds into meal used for the stacks of tortillas she makes twice daily.

Lao grows enough corn and beans for his family to eat; but to make ends meet, he has to do more. Tomorrow, he'll be a lumberjack. He's organized a group of Pima men to saw down pine trees. The men plan to collect a truckload of wood they can sell for lumber. In between farming and cutting trees, he earns money by working at the sawmill.

It's a lot of hard work, but typical of the load carried by Pima men here.

Without modern conveniences, women, too, bear heavy burdens for the household.

At 10 a.m. on a weekday, Maria Dolores Coyote Duarte is already five hours into her daily routine.

Having walked to the community store about two miles from her house, the 58-year-old matriarch is going home with a big sack of flour slung over her back. Her daughter, Trinidad Rascon Coyote, 27, walks beside her, carrying a cardboard tray of eggs in one hand and a plastic woven bag full of groceries in the other.

Later, the unflagging grandmother will lead a group of four women from her household on a trek to fetch water.

Chattering and laughing, the women walk about a mile through rolling hills of tall, dry grass to a freshwater spring where each fills two buckets or bottles to be hauled home. Below the source, water flows into small pools where the family bathes. The rocky banks are strewn with ashes from fires used to heat the cold water.

Anthropologists believe the Mexican and Gila River Pimas were once the same tribe, but a group of the Mexican Pimas broke off and migrated north. Historians and anthropologists are unsure how long ago the split took place. Even today, the elders of both groups still speak roughly the same language.

But there are marked differences between the two tribes.

Comparing branches of a Pima family tree

The Gila River Indian Community

Population: 11,550.

Size: 581 square miles.

Location: South of Phoenix, Tempe and Chandler.

Founded: 1859, by an act of Congress.

People: Composed of two tribes, the Pima and the Maricopa.

Median age: 22.7 years.

Origins: Have lived in the Sonoran Desert near the Gila River in southern Arizona for at least 2,000 years.

The Maycoba Pimas are protected not only by their hard labor, but by their food - high-fiber, low-fat meals that help prevent obesity.

"Simple and boring" is how the scientists describe the Mexican Pima diet.

Beans and corn tortillas are eaten at most meals. Several times per week, eggs and potatoes are added. Fruits and vegetables are eaten occasionally, when in season. Chicken or other meat is a rare treat.

A laboratory analysis of the Maycoba diet showed the Pimas there consume about 26 percent fat, while the typical Gila River diet is more than 35 percent fat.

A 1992 study showed the Arizona Pima diet, though unhealthful, was no worse than what the rest of America is eating.

Although it would be difficult to persuade U.S. residents, Pimas or not, to adopt the monotonous diet and hard activities of the Mexican Pimas, researchers think there are lessons to be learned from this traditional tribe.

The Mexican Pimas show that even among people genetically predisposed to diabetes, exercise, combined with eating more fiber and less fat, prevents the weight gain that increases the risk of diabetes.

Making similar changes "may help to reduce the diabetes epidemic that affects many developing countries as well as the underprivileged in industrialized nations," the scientists concluded in the 1994 Maycoba study.

"This doesn't mean that Anglo people in Washington or China should stop working with tractors and go back to using mules, but it's clear that strong exercise is beneficial," says Julian Esparza, a Mexican scientist who is worked closely with the Pima in Maycoba.

History: The Pima are probably descended from the Hohokam, who originated in Mexico. They were called the Pima Indians by exploring Spaniards who first encountered them in the 1600s.

Culture: The Pimas gained a reputation as being strong runners, master weavers and farmers who made the desert bloom by establishing a sophisticated system of irrigation.

Industry: Three industrial parks, housing more than 40 operations, are located on the reservation. The Lone-Butte Industrial Park is considered the most successful Indian industrial park in the nation.

Agriculture: The community's farming corporation produces cotton, wheat, millet, alfalfa, barley, melons, pistachios, olives, citrus and vegetables on 12,000 acres.

Casinos: The community owns two casinos, Wild Horse Pass and Vee Quiva. They employ about 1,500 people, of which about 90 percent are members of the community. Profits from the casinos go to economic development, tribal operations and social services.

Diabetics: About 50 percent of the adult population has diabetes.

Weight: About 95 percent of adult Pimas are overweight.

The Maycoba Pimas

Location: In the Sierra Madres in north-central Mexico, southeast of Hermosillo.Diabetics: Fewer than 1 in 15 adults.

Height: About an inch shorter than Pimas in Arizona.

Weight: On average, 57 pounds lighter than Pimas in Arizona.

Diet: Eat about 10 percent less fat than Arizona's Pimas.

Exercise: Spend an average of 29 hours a week engaging in

moderate to heavy labor.

Sources: The Gila River Indian Community, Scientific American, the National Institute of Diabetes and the National Institutes of Health.

As for changing one's eating habits, researcher Valencia notes that Americans have taken to other healthful trends like eating more fruits and vegetables. People can boost their fiber consumption substantially, he says, simply by adding beans, a staple of the Mexican diet, to more meals.

But even in Maycoba, there are ominous signs of change. The new two-lane "highway" that winds for hour after hour of hairpin curves leads straight to their upland Indian village, where Pepsi-Cola is all the rage.

Since the paved road opened in 1992, the new world has pushed up against the old. Junk treats are delivered regularly, and people are finding the sodas, chips and candy irresistible.

Farther north, along the U.S. border, rising rates of obesity and the diabetes it spurs are being reported in Mexican towns taking up the fast-food and sedentary habits of their American neighbors.

Scientists are now watching Maycoba to see whether the Pimas will likewise be affected by environmental creep.

CONASUPO, a chain of basic-goods grocery stores subsidized by the Mexican government, arrived in Maycoba 15 years ago, bringing snack food, candy and soda. But until the road was paved in 1992, supplies were low and infrequent. Now, Maycoba is on regular delivery routes.

The CONASUPO used most frequently by the Pima is at the lumber mill not far from a Pima elementary school. At recess, children who've scraped together a few coins rush to the tiny wooden store to buy goodies. The chocolate and corn chips are gobbled up with smiles before the teacher calls them back to class.

On weekdays, customer traffic at the CONASUPO hits high gear at the lunch hour.

Men who work at the lumber mill line up along with schoolkids and women who've come to bring lunch to their husbands, brothers or fathers.

Sylvia Perez Rascon, the store manager, and her two boys buzz from counter to window dispensing cool, sweaty glass bottles of Pepsi hand over fist until they run out and begin offering orange or other flavored sodas.

In less than an hour, two 24-bottle crates of sodas are sold. "Some days, I sell up to three crates," Perez says. "It's nothing but soda that sells here at midday.'"

Around the globe, as traditional cultures swallow Western ways, diabetes cases are skyrocketing to epidemic proportions. Like other traditional peoples, the Mexican Pimas are at risk of being absorbed

by the same Westernization that set off the explosion of diabetes among the Arizona tribe.

Still, the Mexican scientists believe occasional junk snacks will not produce the drastic unhealthful changes that came suddenly to Gila River. Researchers believe the Mexican Pimas' timeless ways offer hope for curbing the disease.

"In Maycoba, they are still living off the land," Valencia says. "They continue to live without modern conveniences, without running water, electricity, and without cars they still walk great distances."

"The sodas they drink and the chips they eat won't hurt them because they continue to work hard," Esparza says.

Valencia agrees, observing, "I don't think change will come rapidly because they have no other way to make a living. As long as they maintain the same levels of physical activity, they will be protected."

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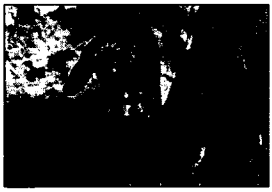

Seeking answers on 'Fifth Floor'

Volunteers give time, bodies in the name of research

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Nov. 2, 1999

Karen James, 42, is a Pima whose family has a history of diabetes. Even though she doesn't have the disease, she has spent three stints as a laboratory volunteer at the Phoenix Indian Hospital, where scientists from the National Institutes of Health are conducting experiments aimed at unlocking the secrets of diabetes. Click here for more photographs.

Inside the drab corridors of the Phoenix Indian Medical Center, Pima volunteers are lending their bodies to science.

Behind one door, Tracy Antone lies awake and still on a hospital bed, his head encased in a plastic hood while a sugar solution oozes intravenously into his right arm. Every five minutes, blood is drawn from his left hand to record his body's reaction.

Down the hall is the DEXA machine that will scan a beam of low-level radiation across Karen James' body to create a computerized picture of her fat-to-muscle ratio.

This is the fifth-floor research ward run by the National Institutes of Health, where Pimas are collaborating with scientists on experiments aimed at decoding the origins of diabetes.

Faced with a worldwide epidemic of the disease, NIH scientists are in

www.diabetes.org
• NIH's National Institute of Diabetes and Digestive and Kidney Diseases - national diabetes education program, http://ndep.nih.gov
• Centers for Disease Control and Prevention www.cdc.gov/diabetes

'The Republic' team
• Reporter Graciella Sevilla and photographer Mona Reeder

a race against time to understand its genetics.

"If we can do that," says Dr. Peter Bennett, chief of the NIH Pima studies, "it will almost certainly open up ways of treating the disease that aren't even imagined yet."

The researchers are optimistic that gene mapping, metabolic experiments and other laboratory studies will lead to a solution. But for now, no one has come up with a method to stop Type 2 diabetes dead in its tracks.

Already, it is overwhelming the Pimas, and new cases are mushrooming among other minority groups. At this point, not even the most optimistic researchers think the coming onslaught of cases can be stopped in the short run.

Still, the possibility of a breakthrough inspired James to come back recently for her third stint on the "Fifth Floor," as the research ward is commonly called by the patients and scientists. James and Antone say they don't mind subjecting themselves to the laboratory. Each has even recruited family members to the cause.

Type 2 diabetes occurs when the body develops a resistance to insulin, a hormone produced by the body that helps convert blood sugar, or glucose, to energy. Type 2 afflicts more than half of Pima adults and 90 percent of the 16 million Americans with diabetes.

Type 1, also known as juvenile diabetes, predominantly affects children in Anglo communities, although it can appear in adults as old as 30 to 35.

As a repeat patient, James isn't fazed by the experiments. She doesn't even mind the muscle biopsy, in which a thin metal tube is poked into her thigh to remove a sliver of tissue.

Like all participants, she is paid for each study she undergoes. The last time, she earned $700 during a week's stay in the lab.

Finding answers

By studying Pima Indian volunteers, researchers have determined that diabetes runs in families, as do insulin resistance and obesity.

Scientists believe that some people also have a gene that makes them more likely to have the kidney disease that occurs in people who have had diabetes a long time. Looking for these genes is a key part of the search being conducted by the National Institutes of Health and the Pimas.

Researchers are working on the genetic puzzle by studying blood drawn from every member of the Pima community who comes into the NIH clinic at Hu Hu Kam Memorial Hospital for an examination.

Blood is checked for healthy levels of blood sugar, cholesterol and other nutrients.

When NIH researchers find a family with one parent who is diabetic and one who is not, they are able to study the genes of both parents and their children in an effort to find genes shared by those who have diabetes.

After finding these genes, scientists hope to break the codes that cause insulin resistance, obesity, diabetes and the kidney disease that results from diabetes.

Source: The National Institutes of Health.

Though diabetes runs in her family and caused her father's death, James, 42, has avoided both the disease and the obesity that often precedes it.

"I brought my sister up once because they wanted to test siblings," she says. "There's a real big difference between my sister and I. She's a lot heavier than I am and . . . she's on the borderline."

By studying both healthy and diabetic family members, scientists hope to find clues to what's behind the differences.

These days, gene hunting has become the primary mission of the Fifth Floor scientists. Finding the genes that cause Type 2 diabetes would set the stage for developing screening tests to identify people most vulnerable to the disease.

"We don't think there is a single gene that causes diabetes, but maybe a combination of genes," says Dr. Richard Pratley, who supervises the research.

More than a thousand people have been studied in the research ward since it opened in 1971.

Recently, researchers charted Tracy Antone's sensitivity to insulin during a six-hour experiment.

Inside the acrylic hood, Antone's head is resting on a small white pillow.

The 29-year-old is using his vacation from his job as a security guard at the Gila River Casino to do his bit for science.

It is his fourth time volunteering on the Fifth Floor. His mother, father and sister have also been research subjects here.

During the test, Antone is instructed to lie perfectly still in order not to disturb the sensitive instruments. He must also stay awake. To get through the ordeal, he opts to watch action movies on videotape.

On the reservation, Pimas over age 5 come in every two years for complete medical exams and blood tests. Over the past 30 years, about 9,000 volunteers have been examined.

Pimas not only have the highest rates of diabetes in the world, but they've provided an ideal population for study.

Gila River, 35 miles south of Phoenix, is a small community of about 11,500 residents. As a people, the Pimas have survived centuries of isolation with relatively little intermarriage with outsiders.

In such a closed society, genetic traits are more clearly defined and easier to track.

But although the Pimas have a unique susceptibility to diabetes, everything that's been learned about the disease from studying them has proved true for diabetic people of all racial and ethnic backgrounds.

Among scientists, there is a consensus that the results of the Pima

genetic studies will help slow the toll of diabetes on all peoples.

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Related links
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• NIH's National Institute of Diabetes and Digestive and Kidney Diseases - national diabetes education program,

Diabetes becoming a global problem

Story by Graciela Sevilla
Photos by Mona Reeder
The Arizona Republic
Nov. 2, 1999

Scientists are sounding the alarm. Across the country and around the world, diabetes is exploding to an epidemic. The surge among the Pimas, they believe, is a preview of the coming global health threat.

"The number of people with diabetes in virtually every country in the world is going to double between 1997 and 2010, from 120 million to 240 million," says Dr. Paul Zimmet, an Australian authority on the disease.

Diabetes targets developing countries and the underprivileged in industrialized nations, people whose lifestyles and diets are changing quickly and for the worse.

"With modernization, diabetes has emerged as a new phenomenon," Zimmet says.

Other researchers agree.

"Third World countries that have adopted Westernized lifestyles suddenly begin to have higher rates of diabetes," says Sharon Brown, who has documented the hard impact of diabetes on minorities.

"This is just going to get worse as more and more people take on our patterns of living, being more sedentary and having a higher-fat diet."

And the boom is coming rapidly.

"There's been a 40 percent increase in diabetes (worldwide) in the last 10 years," Zimmet says.

Across the United States, people with Type 2 diabetes, the form that plagues the Pimas, now number an estimated 16 million.

"The prevalence of diabetes in the U.S. in general is three times today

http://ndep.nih.gov
• Centers for Disease Control and Prevention
www.cdc.gov/diabetes

'The Republic' team
• Reporter Graciella Sevilla and photographer Mona Reeder

what is was in the 1960s," says Peter Bennett, chief of the National Institutes of Health's Pima studies.

Diabetes is also spiraling in countries where rates have been traditionally low.

In less than 10 years, diabetes rates have jumped from 2 to 5 percent in China and 4 to 8 percent in Singapore, for instance.

World Health Organization scientists warned a year ago that the number of diabetics worldwide will reach 300 million by 2025.

In the United States, diabetes is rising fastest among some of the fastest-growing populations -- Hispanics, the aging and African-Americans. Native Americans, led by the Pimas, are hardest-hit.

"Diabetes is affecting more and more people, especially communities of color," says Dr. Brenda Broussard, former director of the Indian Health Service diabetes program. But she adds, "Diabetes is growing as well in White Americans. What's fueling the rise is growing obesity."

Overweight people have a higher risk of developing diabetes. As America fattens up, diabetes is increasingly striking children.

"Across the country you're seeing young children with Type 2 diabetes, what we used to call adult-onset diabetes," Broussard says.

Demographics point to an inevitably snowballing crisis.

"America is becoming heavier and our children are becoming heavier earlier," says Dr. Robert Sherwin, vice president of the American Diabetes Association. "So, as the population ages, gets fatter and as minority populations increase . . . the problem is only going to get worse."

Broussard is blunt about the peril: "In five years, we're not going to cure this or halt the curve because it's not the nature of the epidemic."

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AZ Republic Dec 16 1999

Pimas' spirit missing from series

MY TURN

FRANKLIN PETE JACKSON

The Pima Indians of the Gila River have historically opened their doors to outsiders, welcoming strangers as friends even when situations clearly suggested we might have much more to lose than gain.

Over the past year, we cooperated with reporters from *The Republic* - writer Graciela Sevilla and photographer Mona Rieder - as they explored the effects of diabetes on the Pima Tribe. If there was any reluctance on the part of the community in welcoming reporters covering diabetes, it is with good cause. The Pimas have been the focal point of many print and broadcast reports that have exploited the community and its people in the name of good journalism, public interest and scientific research.

Imagine, then, our sense of frustration at the recent series. "A People in Peril: Pimas on the Front Lines of an Epidemic." There were phrases such as "perfect living laboratory," "victims destroyed organ or limb at a time," "inevitable, uncontrollable, inherited and fatal" and "diabetics," "death row," "paint an ineffective community in a state of utter helplessness."

Photographs of gnarled hands, painful dialysis, funerals and insulin injections sensationalized an important — and, yes, tragic — part of our lives that for generations we have tried to combat in an intelligent, brave and practical manner.

While the series ultimately may serve to educate our neighbors in the thriving suburbs of Phoenix about diabetes, it failed to tell the story of a community living with the disease and its complications. Lost in the reporting is the sense of kinship shared among tribal members — kinship strengthened by the very disease that appears to have taken straight aim at Pimas.

The story of diabetes on the Gila River Indian Community is about more than alarming statistics and tragic numbers. It's about families and individuals living with and working through a disease that has become a worldwide public health issue. For despite the human toll diabetes has exacted, it has not killed the human spirit of our tribe. And it was that spirit of survival, evidenced in so many positive aspects of our daily life, that was sadly missing from the articles.

We would like *The Republic's* readers to know that community leaders and health care providers are actively engaged in health care programming and delivery across the continuum of diabetes intervention. The Gila River Indian Community has in place health care services that equal or surpass many other health care delivery systems across the country. Concentrating on prevention while providing an improved quality of life for individuals living with diabetes is our priority.

We also would like to thank *The Republic* for devoting time, energy and editorial space to a public health epidemic, albeit one that has existed in its back yard for decades. We're quite certain that we will once again open our doors to your news gathering organization when it seeks to report on diabetes in our community. We only hope that future stories portray a human face that is less dire, less tragic, far less passive.

Franklin Pete Jackson is president of the board of directors of the Gila River Health Care Corp. Contributing to this column was Viola Johnson, CEO of the Gila River Health Care Corp. Readers are invited to submit columns of up to 625 words.

TESTIMONY OF RACHEL A. JOSEPH
CO-CHAIR OF THE
NATIONAL STEERING COMMITTEE ON THE
Reauthorization of the Indian
Health Care Improvement Act, P.L. 94-437

Before the United States Senate
Committee on Indian Affairs
March 8, 2000

Good Morning, Mr. Chairman and members of the Committee. My name is Rachel A. Joseph, Co-Chair of the National Steering Committee (NSC) on the Reauthorization of the Indian Health Care Improvement Act (IHCIA). I am here today on behalf of the National Steering Committee to testify in support of the Reathuroization of the Indian Health Care Improvement Act (IHCIA) and joined by Henry Cagey, my Co-Chair during the development of the Tribally-drafted proposed legislation. The IHCIA, first enacted in 1976, is scheduled to expire at the end of fiscal year 2000 (September 30, 2000). The draft bill, which we presented to this Committee, is the most comprehensive to date. And, we believe that it addresses this Nation's policy. Further, it contains the recommendations for modifications and changes that are necessary to improve and enhance the ability of tribal health programs, and urban health programs, and the IHS to provide comprehensive personal and public health services that are available and accessible to all American Indian and Alaska Native people.

I. BACKGROUND

The IHS, an agency in the Department of Health and Human Services, was founded in 1955. Prior to 1955, health services for Indian tribes in the United States were provided by the Bureau of Indian Affairs in the Department of the Interior, which was established in 1849. Some treaties with Indian tribes provided specifically for health services and before 1849, the War Department and philanthropic organizations provided some health care to tribes. The Congress intermittently appropriated funds for Indian health after 1832. By 1880, four hospitals for Indians were operated by the Bureau. In 1908, for the first time, the BIA heath program was placed under the direction of a health care professional. Until 1921, BIA heath services were funded by Congress without any authorizing legislation.

Although Congress expressly authorized the Bureau to expand federal appropriations for the conservation of health in 1921 (the so-called Snyder Act), very little progress was made in addressing Indian health needs from 1921 until 1955. By that time, the poor BIA record had led to a demand for a transfer of Indian health programs to the Public Health Services in the Department of Health, Education and Welfare .

On August 17, 1954, Congress enacted the so-called Transfer Act, which transferred "all functions, responsibilities, authorities, and duties of the Department of the Interior"...relating to the maintenance and operation of hospital and health facilities for Indians and the

conservation of the health of Indians", to the United States Public Health Service. Since the implementation of the Transfer Act in 1955, the Indian Health Service, as part of the U.S. Public Health Service, has achieved very significant improvement in the health status of Indians and Alaska Natives. Also, since 1955 the Indian Health Service has grown in budget and staffing, which enabled it to be more responsive to the health needs of Indians. According to IHS figures, between 1955 and the late 1970s, the three-year average infant mortality rate for Indians was reduced by 74 percent, maternal mortality was reduced by 90 percent, and Indian deaths per thousands from tuberculosis dropped by approximately ninety-one percent.

Nevertheless, in 1976 the Congress found that "the unmet health needs of the American Indian people are severe and the health status of the Indians is far below that of the general population of the United States." Rates of death from tuberculosis, influenza, cirrhosis, and infant death remained well above the national average. The failure of the Indian Health Service to involve Indians in planning and delivering health services was also severely criticized.

Consequently, the Congress enacted the Indian Health Care Improvement Act, "to implement the federal responsibility for the care and education of the Indian people by improving the services and facilities of Federal Indian health programs and encouraging maximum participation of Indians in such programs, and for other purposes". The Act has been the cornerstone for Indian health services developed since it enactment in 1976. The Act has been reauthorized four times, most recently in 1992.

The current authority for the IHCIA expires at the end of fiscal year 2000. The reauthorization of the IHCIA represents an opportunity to address changes in the current health care environment and the impact of these changes on the evolving needs of the I/T/U/ health care delivery systems:

> *"A major national goal of the United States is to provide the quantity and quality of health services which will permit the health status of Indians to be raised to the highest possible level and to encourage the maximum participation of Indians in the planning and delivery of health services." (P.L. 94-437*

As amended in 1988, the Indian Health Care Improvement Act provides detailed directions to the IHS with respect to Indian health manpower, equity in funding Indian health services, alcoholism programs, programs for urban Indians and many other health-related matters. Achievements under the Indian Health Care Improvement Act have been limited by inadequate funding. Nevertheless, the 1976 legislation provided the first detailed statutory guidance to the Indian Health Service as to the particular services and programs which Indians and Alaska Natives are entitled to receive.

The Federal health services to Indian has resulted in a reduction in the prevalence and incidence of illnesses and unnecessary and premature deaths.

Despite such services, the unmet health needs of the American Indian people today remain alarmingly severe, and even continue to decline, and the health status of Indians is far below the health status of the general population of the United States. The disparity to be addressed is formidable. In death rates, for example, Indian people suffer a death rate for diabetes mellitus that is 249 percent higher, a pneumonia and influenza death rate 71 percent greater, a tuberculosis death rate that is 533 percent greater, and a death rate from alcoholism that is 627 percent higher than the rate for all races in the United States.

II. CONSULTATION PROCESS

For almost ten months, tribes have been engaged in a tribally-driven consultation process with the Indian Health Service (IHS) and urban Indian health providers regarding the reauthorization of the Indian Health Care Improvement Act. This process began with the first Area consultation meeting in San Diego, December 1998, with over 100 participants who gathered to develop California Area recommendations for the reauthorization. Subsequent to the San Diego meeting, each Area of the IHS convened meetings of Tribal leaders and urban providers to discuss the reathorization of this important legislation. These discussion were held over the course of one or more meetings with the expectation that these Area concerns and recommendations would be forwarded to the next step in the consultation process. It was agreed , that the goal of the process was to build a consensus on the issues before us and that the draft, which was to be submitted to Congress, would reflect a consensus of the Indian Health Service/Tribes/Urban Programs (I/T/U), to ensure that when we spoke of the reauthorization we would be ***"Speaking with One Voice"***.

Regional Consultation:

From January to April, 1999 four regional meetings were held across the United States. These regional meetings were intended to provide a forum for I/T/U's to provide input, to share the recommendations from each Area, and to build consensus among the participants for a unified position from each region and through-out Indian Country.

National Steering Committee:

Upon completion of the four regional meetings, this IHS Director convened a National Steering Committee to develop a report on national policy issues and IHCIA recommendations. The National Steering Committee is composed of one elected tribal representative and one alternate from each of the twelve Areas, a representative from the Tribal Self-Governance Advisory Committee, the National Indian Health Board, and the National Council on Urban Indian Health. The membership is as follows:

ABERDEEN
*Tex Hall, Chairman
Three Affiliated Tribes Business Council
*Jim Cournoyer (Alternate)
Yankton Sioux Tribe

ALASKA
*H. Sally Smith, Chairperson
Bristol Bay Area Health Corp.
*Larry Ivanoff (Alternate)
Norton Sound Health Corp. Inc.

ALBERQUERQUE
*Rick Vigil, Vice Chairman
All Indian Pueblo Council
*Robert Nakai (Alternate)
Albuquerque Indian Health Board

BEMIDJI
*Eli Hunt, Chairman
Leech Lake Band of Ojibwe
*Sandra Ninham (Alternate)
Oneida Tribal Council

BILLINGS
*Alvin Windy Boy, Council Member
Chippewa Cree Business Committee
*Pearl Hopkins, Council (Alternate)
Ft. Peck Tribal Executive Board

CALIFORNIA
*Rachel A. Joseph, Vice Chairperson
Lone Pine Paiute-Shoshone Reservation
*Jack Musick, Chairman (Alternate)
La Jolla Reservation

NASHVILLE
*Joyce C. Dugan, Principal Chief (Former)
Eastern Band of Cherokee Indians
*Eddie Tullis, Tribal Chairman (Alternate)
Poarch Band of Creek Indians

NAVAJO
*Dr. Taylor McKenzie, Vice-President
Navajo Nation
*Jerry Freedie, Council Delegate (Alternate)
Navajo Nation Council

NATIONAL INDIAN HEALTH BOARD
*Buford Rolin, Chairman

OKLAHOMA
*Merle Boyd, Second Chief
Sac & Fox Nation of Oklahoma
*Mammie Rupnicki, Chairperson (Alternate)
Prairie Band of Potawatomi Nation

PHOENIX
*Arlan Melendez, Chairman
Reno-Sparks Indian Colony
*Merna Lewis, Vice President (Alternate)
Salt River Pima Maricopa Indian Community

PORTLAND
*Julia Davis, Secretary
Nez Perce Tribal Executive Committee
*Pearl Capoeman-Baller, President (Alternate)
Quinault Indian Nation

TRIBAL SELF-GOVERNANCE ADVISORY COMMITTEE PRIMARY
*Henry Cagey, Council
Lummi Nation
*Dennis Smith, Vice Chairman (Alternate)
Duck Valley Shoshone Paiute Tribe

TUCSON
*Edward Manual, Chairman
Tohono O'odham Nation
*Benito Valencia, Chairman (Alternate)
Pasqua Yaqui

URBAN INDIAN HEALTH PROGRAM
*Kay Culbertson, Executive Director
Denver Indian Health & Family Services
*Seh Welch, J.D. (Alternate)
American Indian Health & Services

A 135-page matrix, comparing the recommendations from each of the four regions for every section of the IHCIA, was reviewed by the National Steering Committee to develop a final consensus document. The work was divided into five teams as follows:

(1) Health Services Workgroup for Titles I, II, V, and VII, Chaired by Dr. Taylor McKenzie;
(2) Health Facilities Workgroup for Title III, Chaired by Julia Davis and Robert Nakai;
(3) Health Financing Workgroup for Title IV, Chaired by Buford Rolin;
(4) Miscellaneous Workgroup for Titles VI and VIII, Chaired by Tony Largo; and,
(5) Preamble Workgroup, Chaired by Henry Cagey.

Each group had primary responsibility for the final presentation of recommending setting forth a framework for reauthorization legislation.

It was agreed by the NSC that, specific "draft bill language" would be developed and proposed by the National Steering Committee to minimize any misinterpretation of our position. The NSC maintained an aggressive schedule of meeting as follows:

Rockville, MD	**June 3, 4, 1999**
Gaithersburg, MD	**June 17, 18, 1999**
Rockville, MD	**July 7, 8, 9, 1999**
Reno, NV	**July 13, 14, 1999**
Washington, DC	**July 27, 28, 29, 1999 (National Meeting)**
Salt Lake City, UT	**August 30, September 1, 2, 1999**
Rockville, MD	**September 28, 29, 1999**
Palm Springs, CA	**October 5, 1999**

The National Steering Committee discussed many of the important issues in the full group and others were delegated to individual workgroups. Some of the major issues requiring much discussion by the full group included:

1. **Entitlement:** Whether to seek legislative changes to create an Indian health entitlement was discussed. The issues were referred to a special committee who performed research and provided an overview of the pros and cons of making the delivery of Indian health care an entitlement. It was a consensus that a commission be established to further study and develop reommendations. A key issue is the definition of what an entitlement would be for Indian health.

2. **Urban Programs:** There was much discussion on how urban health programs should be included in the IHCIA. It was agreed by the full NSC that urban health issues should be addressed fully in Title V, and in certain areas in other titles as appropriate (research, consultation and certain financial authorization) where it would be unnecessarily cumbersome to duplicate language in Title V.

3. **Permanent or Term Legislation:** There was considerable discussion about whether to seek permanent legislation or term reauthorization. It was agreed that Congress and Indian Country should revisit the question of Indian health periodically. A term of 12 years is proposed for this reauthorization, to the end of Fiscal Year 2012.

4. **Political Follow-Up:** The NSC discussed and agreed to form a special initiative to work on the passage of reauthorization legislation. The National Steering Committee will continue to function as the link between grass roots concerns and the reauthorization process. A special committee comprised of the two Co-Chairs of the NSC, the alternate Co-Chairs of the NSC, Chairs of the NSC work groups and representatives of the National Indian organizations was established to coordinate efforts to ensure timely passage of the reauthorization legislation.

5. **Tribal-Specific Proposals:** The Steering Committee agreed that tribal specific proposals in the Steering Committee bill would not be included unless the following criteria was met:

   - The provision had national significance with potential for benefit and replication nationwide, but current federal law does not authorize or prohibits implementation or funding;

   - The provision will not adversely affect or diminish funding which is available to other Indian programs or the I/T/U system that it has a right to; and,

   - The provision was reviewed and endorsed at the Area, Regional and National IHCIA consultation levels.

The NSC also recognized that Congress and tribes could work through the legislative process and that the final law could contain tribal-specific proposals.

National Forum:

At the conclusion of all four regional meetings and after the NSC had met four times and developed draft consensus bill language, a national meeting, co-sponsored by this Committee was held here in Washington D.C. This meeting was to provide time for Tribal leaders, urban health representatives, national organizations, federal agencies, and friends of Indian health, to provide feedback on the legislative proposal. Before this meeting, on July 16, 1999, the draft bill language was mailed to over 1200 tribal leaders, tribal health directors, IHS officials, and urban health programs and other health organizations.

The Steering Committee addressed all of the approximately 1000 comments received and incorporated the many comments and changes into the proposed bill to reauthorize the Indian Health Care Improvement Act. A copy of the draft bill was delivered on October 8, 1999 to this Committee, the House Committee on Resources and other appropriate committees with jurisdiction. A copy of our proposed bill was mailed to every tribe and Indian organization.

III. KEY PROVISIONS

The NSC draft bill, based on all the input and recommendations which we received, addresses the following major issues:

Preamble

The Preamble Section of the Act, as revised in the NSC proposed bill, includes sections on Findings, Declaration of National Policy, and Definitions. Enhanced emphasis was placed on the trust responsibility of the Federal government to provide health services and the entitlement of Indian tribes to these services. The proposed bill has changed the "Declaration of Health Objectives" to the original "Declaration of National Policy". The NSC proposed bill eliminates the enumeration of 61 distinct objectives and would provide that the Federal government will raise the health status of Indians to the levels set forth in "Healthy People 2010". The new Preamble underscores consultation with Indian people and the importance of the Federal-Tribal relationship. Numerous additions to the Definitions Section were made to conform to changes in later titles. When definitions applied only to one section of the Act, the definition is provided in that section and not in the Definitions Section.

Local Control (Self-Determination)

Several programs which have been administered by IHS headquarters were decentralized, with funds distributed to IHS Area Offices for local priority-setting and decision-making by tribes, and includes decisions about whether further distributions should be made available to individual tribes or service units. This feature has been incorporated in most Title I programs for recruitment and training of health professionals.

Entitlement

The NSC heard from many tribal leaders on the subject of authorizing Indian health as an "entitlement" program. Currently, funding for Indian health is considered a "discretionary" program in the federal budget.

NSC Members and tribal leaders considered the critical issues — e.g. what does entitlement mean: (1) how to effectively set out the basis for an entitlement from a political perspective; (2) how to address the anticipated increased cost of an entitlement program; (3) how an entitlement provision would effect the overall bill; and, (4) how an entitlement program would be designed.

While the NSC agrees that the Federal government has a trust responsibility to provide Indian health services and facilities, it recognizes that there are many unanswered questions regarding what constitutes an entitlement; what criteria should be applied to define the entitlement class; whether the entitlement flows to tribes or individual Indian people; and, what benefits should be included in an entitlement package.

At the recommendation of its Entitlement Subcommittee, the NSC included in Title VIII of the draft bill, a provision that would create a Tribal/Congressional Commission to evaluate entitlement issues and make recommendations to Congress on how Indian health care can be provided on an entitlement basis. The NSC considers this provision to be a starting point and welcomes further comments.

Qualified Indian Health Program (QIHP)

The proposal would create QIHP as a new "provider type" for Medicaid and Medicare reimbursement eligibility. All I/T/Us would qualify [new Sec. 1880A of the Social Security Act].

- There are several payment options from which a QIHP could select, including a full cost recovery method that would include indirect costs (but precluding any over recovery of indirect costs).

- A QIHP could elect to include the following services in its recovery rate: preventive primary care; CHIP services; various immunizations; patient transportation; and, services performed by an employee licensed/certified to perform such services that would be reimbursable if performed by a physician.

Direct Billing/Collections Demonstration

The proposed bill would make permanent and extend to all Tribal health programs the demonstration project for direct billing under Medicaid and Medicare.

Facilities

Title III regarding health facilities underwent several changes in order to provide a broad view of the total unmet facilities needs of Indian tribes and tribal organizations and to develop innovative funding opportunities to meet these needs. The Title was expanded to overcome previous limitations and to give Indian tribes and tribal organizations a greater capacity to meet their various facilities needs, including the use of private sources of credit to address the health facility construction backlog. Facilities-related provisions from other Titles we're re-located here.

Behavioral Health Programs

Title VII in the current law is limited to substance abuse programs. In the draft bill, substance abuse, mental health and social service programs are combined in a new Title VII under te heading of "Behavioral Health Programs". The objective is to integrate these services. Provisions have been added to clarify that programs are subject to contracting and compacting by tribes and tribal organizations. The term "funding" has been used to replace "grant" in order to clarify that Tribes and tribal organizations can utilize contracts, compacts, grants, or any other funding mechanisms, and are not limited to grants.

Development of local and area-wide behavioral health plans are encourage, and the requirement for a National Indian Mental Health Plan is dropped. The section on Youth Treatment Centers has been amended to allow at least one center per Area. New authority is proposed for the establishment of at least one in-patient psychiatric treatment facility per IHS area.

IV. SUMMARY OF TITLES

Title I - Indian Health, Human Resources, and Development

Title I was substantially rewritten to shift priority-setting and decision-making to the local Area levels. Throughout the Title, the listing of distinct disciplines of health professionals was eliminated and replaced with more generic terminology, which includes all health professionals, with only a few exceptions. Special programs were eliminated if these professional disciplines were eligible to receive support under generic programs of this Title. The setting of preparatory and scholarship priorities have been decentralized to the Area Offices based upon Tribal consultation. The administration of scholarship funds is proposed to remain an IHS headquarters function. Language was included to require Title I recipients to fulfill their scholarship job placement requirements in the Areas from which they received their scholarship assistance. Language was also proposed to protect Title I recipients who are already in the "pipeline" for assistance. Eligibility requirements for scholarship and preparatory scholarships were amended so that only persons who are Indian are eligible. Demonstration projects were eliminated in lieu of establishing regular funding for Tribal programs across the board. A new section was proposed, clarifying that all scholarships, loans, and repayment of loans are "non-taxable". Amendments were proposed in this Title to clarify that tribal "matching" requirements for scholarship programs can be from any source, including other federal funds. The training and certification sections for mental health and substance abuse workers were relocated from Title II and Title VII to this Title.

Title II - Health Service

Title II represents a collection of diverse sections addressing issues related to the delivery of health services to Indian populations. This Title continues to address issues of "equity" in the allocation of health resources and attempts to address health care deficiencies. A new section provides a listing of types of services authorized, which were not previously listed. One major change proposed in Title II is the removal of Section 209 "Mental Health Services" from this Title, transferring it to Title VII "Behavioral Health". Throughout most provisions, the term "Indian Tribes and tribal organizations" has been inserted as equal partners with the IHS. A significant change in Section 202, "Catastrophic Health Emergency Fund" (CHEF) is proposed. This change will authorize the IHS to allocate total CHEF funds among the twelve Areas for administration at the Area level. The IHS Area Offices must consult with Tribes in establishing and operating the Area CHEF program. An earlier proposal, considered by the NSC, to set a lower national threshold for Tribes or Areas "dependent" upon Contract Health Services was deleted in favor of this Area-specific approach. An Area-specific allocation methodology must be negotiated with Tribes through a rule-making process. Language was included that prohibits the allocation or assignment of shares of CHEF funds under the provisions of the ISDEAA.

Section 204, "Diabetes Prevention and Treatment", was expanded to establish a national program, not a "model" based program, to provide authority for the continuation of funded diabetes projects. Individually name community "models" were deleted tin the bill, in favor of a national emphasis, with the intent that these programs will continue as a part of a national strategy. Several sections regarding reimbursement and managed care will be shifted to Title IV.

Section 207 was expanded to focus attention on "all cancers" including, but not limited to, mammography screening for breast cancer. Language was added to require that "Epidemiology Centers" be established in each of the twelve IHS Areas. They can be contractible under the ISDEAA, but not divisible. The Comprehensive School Health Education and the Indian Youth Programs were changed to provide funding to Tribal or urban programs throughout the United States.

The Office on Indian Women's Health Care was also changed to a Women's Health Program providing funds for Tribes and tribal organizations, as opposed to an office in the IHS headquarters. In addition, several sections from Title VIII were moved to Title II, including the provision on Nuclear Resource Development and Health Hazards. This Section was changed to Section 215, Environmental and Nuclear Health Hazards, and made applicable nationally to address environmental health hazards that may require ongoing monitoring or study. Section 220 provides for the fair and equitable funding of services operated by the Tribes under funding agreements just like those operated directly by IHS. Section 221 requires that the licensing requirements of staff employed by Tribally operated programs be consistent with

IHS employees. There was an effort to consolidate all the Contract Health Service (CHS) provisions within this Title (sections 216, 217, 218, 219, 222, 223, and 224), which strengthens the prohibition against CHS providers from holding individual Indian patients liable for CHS approved bills.

Title III - Health Facilities

Numerous changes are proposed for Title III to address facility concerns, Section 301 states that Tribal consultation shall be required for any and all facility issues not just facility closures. Recommendations on the accreditation of health care facilities were made "not to be limited only to the Joint Commission for the Accreditation of Health Care Organizations", but instead, open to any nationally recognized accreditation body. Annual reporting on facility requirements should not be limited to the "10 top priority projects", but reflect the true unmet need in Indian Country. A clause was included to provide protection for all projects on the existing priority list.

Language was proposed in Section 302, which will strengthen the relationship between IHS and the U.S. Department of Housing and Urban Development (DHUD), regarding safe water and sanitary disposal, and authorize the use of IHS funds to leverage additional resources. To be consistent with P.L. 86-121, the term "facilities" was used in place of "systems".

Section 305 claries that Tribes, to assist in the expansion, as well as the renovation or modernization of IHS or Tribal health facilities, may use any source of funds. Language was also provided to allow for peer review for small, ambulatory care facilities applications. The Indian Health Care Delivery Demonstration Project was expanded to include facilities such as hospice care, traditional healing, childcare, and other activities. Originally, the NSC attempted to make this section more national in scope and deleted references to the nine individually named Tribal communities. However, the NSC added the list back, pending a final update or status report from the IHS regarding the necessity for listing each project. If it is not necessary, the NSC supports deleting these tribal-specific references in this Title.

The bill seeks to encourage the use of private credit sources for construction of health facilities by requiring that leases of such facilities from Tribes to the IHS be treated as "operating leases" for Federal budget purposes.

Land transfers under Section 308 are authorized for all Federal agencies. A major new provision, Section 310, provides for loans, loan guarantees, a revolving loan fund and a grant program for loan repayment on new health facilities. It also provides that Congress appropriates funds for a Health Care Facilities Loan Fund made available to Tribes and tribal organizations for the construction of health care facilities.

A new section was established for the IHS/Tribal Joint Venture Program , which was originally in Title VIII. The Joint Venture Program now appears as Section 312 and provided for creative, innovative financing by Tribes for the construction of health facilities, in exchange

for the IHS commitment for equipment and staffing. A new Section 314 authorizes the use of "Maintenance and Improvement" funds to be used to replace a facility when it is not economically practical to repair the facility. Section 315, another new section, provides clarification for Tribes operating health care facilities under the ISDEAA. It states that Tribes can set their own rental rates for all occupants of Tribally operated staff living quarters and collect rents directly from Federal employee occupants. Another important new provision to Title III, provides for "Other Funding" to be used for the construction of health care facilities and opens the door for alternative financing options for Tribes and tribal organizations.

This new Section includes a provision to ensure that the use of alternative funding does not jeopardize a Tribe's placement on the priority list referred to in Section 301.

Title IV - Access to Health Service

The provisions in this Title attempt to eliminate barriers which prevent IHS, Tribes, tribal organizations and urban Indian health programs from fully accessing reimbursement from other federal programs, including Medicaid, Medicare, and the Children's Health Insurance Program (CHIP), for which their patients are eligible. By eliminating barriers, it is intended that IHS, Tribes and urban programs take maximum advantage of these other federal funding streams. The severe and longstanding lack of adequate appropriations for the IHS requires that alternative funding streams be accessed to the maximum extent possible consistent with the unique Federal trust responsibility to provide health services to Indians.

The provisions in Title IV of the IHCIA, and the related conforming amendments to the Social Security Act, seek to accomplish three major goals:

- To maximize recovery from all third-party sources, including Medicaid, Medicare, and CHIP, and any new Federal funded health care programs;
- To ensure that Indians have access to culturally competent care provided by the Tribes, tribal organizations or urban Indian organizations, and therefore are not automatically assigned without approval to non-Indian managed care plans; and,
- To ensure that when an Indian health program provides services, the full cost of providing services will be reimbursable.

In order to achieve these goals, specific amendments to the Social Security Act must be enacted. Medicaid and Medicare are amended to provide authorization for the IHS and tribal health programs for cost recovery for all services for which these programs pay. This will eliminate out-of-date limitations to payment for services in certain facilities. The requirement that Medicaid and Medicare payments to tribal health programs be processed through the IHS "special fund" has also been eliminated and IHS is required to send 100% of its Medicaid and

Medicare receipts to the Service Unit that generated the collection. See Sections 401, 402, and 405. To ensure accountability, Section 403 requires all Indian health programs to submit provider enrollment identification to allow the IHS and the Health Care Funding Administration to track payments and reimbursements for services for the purpose of reporting and monitoring.

Several amendments, including Sections 404 and 420, are intended to improve relations between States and Indian health programs and to provide increased flexibility in these historically difficult relationships. Section 408 proposes to authorize Tribes to purchase insurance using IHS funds. Specific new language is provided in Section 410, clarifying that IHS is the "payor of last resort". Section 411 provides corollary authority which authorizes the Indian health system to bill for other federal reimbursements unless explicitly prohibited. A new Section 412 established the "Tuba City Demonstration Project" one of only two new demonstration projects recommended by the NSC in Title IV. This demonstration project authorizes the IHS operated Service Unit in Tuba City to function as a "managed care organization" as part of the Arizona plan. Section 413 authorizes Tribes and tribal organizations to purchase Federal health and life insurance for their employees. In Section 414, specific consultation and negotiated rulemaking procedures are included to address issues with HCF.

Other amendments seek to address related problems faced by the IHS and tribal health programs in their relationship to Medicaid and Medicare and to other health providers accepting payment under contract health. Section 415 requires "most favored" status to be provided to IHS, Tribal or urban Indian organizations when purchasing service. It provides for Indian health system providers to receive the same rates given to other preferred Federal customers, such as Medicare.

A new provider type has been created for the IHS and tribal health programs; the Qualified Indian Health Program (QIHP). It recognizes the unique cultural and programmatic characteristics of Indian health programs and provides for ful cost recovery subject to efficiency measures. This section was carefully crafted to ensure that Indian health programs, to which the United States owes a specific duty, receive the benefits made available to other health providers who meet the needs of specific populations. The draft bill also provides that the 100% Federal Medical Assistance Percentage will be provided to states for CHIP services reimbursed to Indian health programs, as is currently the case with Medicaid, and extends that definition to include referral services paid by the Indian health program. This minimizes artificial and unfair distinctions between india health programs that provide direct services compared to those that must rely on contract health. A new section also authorizes the Secretary of the Department of Health and Human Services (DHHS), to contract directly with Indian Tribes through block grants for the administration of CHIP programs to Indian children within the Tribe's service area. Section 428 will eliminate or "waive" all cost sharing for IHS eligible beneficiaries served by Indian health programs under Medicaid, Medicare, and CHIP. This section also includes language to ensure that Indian people are not subject to estate recovery proceedings or that the impact of estate recovery

is minimized by eliminating trust income, subsistence or traditional income. Similarly, a new section will protect parents who are required to apply for Medicaid as a condition of receiving services for their Indian children from an IHS or tribal health program or under the contract health program, for their children from being obligated to repay Medicaid under a medical child support order. Other new provisions address managed care plans. It ensures that Indian people may not be assigned involuntarily to these plans and that such plans must pay for the services provided by Indian health programs.

Section 430 established the second demonstration included in the Act, the Navajo nation Medicaid Agency" to serve Indian beneficiaries residing within the boundaries of the Navajo Nation, authorizing a direct relationship between the Tribes and the HCF. The NSC elected to promote the Navajo Nation Medicaid Agency as a demonstration effort.

The NSC recognizes that these provisions are ambitious. However, they are critical to ensuring that Indian health programs have fair access to critical Federal funding sources and the opportunity to modernize their programs to address the needs of and fulfill the responsibility of the United States to Indian People.

Title V - Health Services for Urban Indians

This Title covers the majority of provisions for urban Indians. With only a few exceptions, funding authority for urban Indian health was specifically limited to only Title IV and Title V. All other references to urban Indian health found in other titles address issues of consultation, rulemaking, planning or reporting. Title V provided authority for the IHS to fund health service programs serving urban Indian populations. It serves approximately 149,000 urban Indians in 34 different cities throughout the United States. The programs funded under Title V represent a wide range of services, from outreach and referral programs to comprehensive primary care centers. The amendments recommended by the NSC provided minor changes to the existing law and adds new provisions to Title V. The major changes proposed in the bill for Title V include the following:

- To streamline the current law relating to the standard and procedures for contracting and making grants to urban Indian organizations;
- To require the agencies in the DHHS to consult with urban Indians prior to taking actions that would affect them and to establish a negotiated-rulemaking process;
- To expand the Secretary's authority to fund, through grants, loans, or loans guarantees, the construction or renovation of facilities for urban Indian programs;
- To enable urban Indian programs to obtain malpractice coverage under the Federal Tort Claims Act, similar to Tribes and community health centers; and,

- To authorize a demonstration program for residential treatment centers for urban Indian youth with alcohol or substance abuse problems.

Language is proposed to allow urban programs the authority to receive advance, lump-sum payments for IHS contracts or grants under this Title, and to use carry-forward funding from one year to the next. Reporting requirements have been changed from quarterly to semi-annually, and language is proposed to clarify audit requirements. In addition, language is proposed which will allow for funds to be used for facility construction, renovation, expansion, leasing or other purposes. To be consistent, with the redesign of IHS, the department title "IHS Urban Branch" was changed to the "Office of Urban Health". Language was added requiring IHS and the DHHS to consult with urban programs on issues affecting urban Indian populations. A new provision proposes to establish at least two (2) urban Indian youth treatment centers as demonstration programs. The bill proposes similar provisions, as is available to Tribes, for access to federal facilities and suppliers, diabetes prevention and treatment. Section 512 proposes no changes to the Oklahoma City program, but recommends the Tulsa program be made permanent and not subject to the provisions of the ISDEAA. The NSC was notified that consensus had not been achieved among tribes regarding the Oklahoma City program, therefore the NSC did not recommend any changes to existing law regarding this program.

Title VI - Organizational Improvements

Only a few changes are proposed in this title. Future amendments will be considered to incorporate the elevation of the Director of the Indian Health Service to an Assistant Secretary for Indian Health, if legislation currently pending in Congress do not move forward. Unnecessary provisions were deleted in this title if activities had already been completed. New language was proposed authorizing the IHS to enter into contracts, agreements or joint ventures with other federal agencies to enhance information technology.

Title VII - Behavioral Health

Title VII is recommended for major revisions, specifically to integrate Alcohol and Substance Abuse provisions with Mental Health and Social Service authorities. Section 209 from Title II has been moved to the new Title VII. Where appropriate, the terms "Tribes, Tribal organizations and Indian organizations" are referenced in addition to IHS. Provisions that require a "National Plan" were deleted, in lieu of new language establishing a process for locally based behavioral health planning. A broad range of behavioral health services is described under "continuum of care". Several related sections were moved from Title VIII, including sections on Fetal Alcohol Syndrome and Child Sexual Abuse. Demonstration programs were eliminated and replaced with language authorizing programs for Indian Tribes and tribal organizations. The section on Youth Treatment Centers has been amended to allow

for at least one center per Area (including Phoenix and Tucson Areas) and retained authority for two treatment "networks" in California. A new section was proposed in this Title authorizing the establishment of at least one in-patient psychiatric treatment facility for each IHS Area.

These new centers would be funded on a similar basis as the Regional Youth Treatment Centers. All Tribal-specific programs have been deleted in Title VII, except for facilities operated by the Tanana Chiefs Conference and the Southeast Alaska Regional Health Corporation, with the understanding that continued funding is authorized under general provisions of this Title.

Title VIII - Miscellaneous

Ten sections were moved out of Title VIII to more appropriate sections in the IHCIA. All Contract Health Services provisions were moved to Title II. A majority of the "free-standing and severability" provisions were incorporated into Title VIII. A listing of all reporting requirements, contained in the Bill, have been restated in Section 801 of this title. New language was proposed, in regard to negotiated rulemaking procedures in Section 802, requiring the Secretary to initiate these procedures 90 days from the date of enactment. This section also establishes a maximum amount of time for negotiated rules to be printed in the federal register, not later than 270 days after the date of enactment. The authority to promulgate regulations under this Act expires after 18 months from the date of enactment; thus, expecting the rulemaking process. Section 803 requires the Secretary, in consultation with Tribes and urban Indian organizations, to develop a "plan of implementation" for all provisions of this Act. Section 804 continues the prohibition on abortion funding, as it exists in current law. Eligibility of California Indians was covered under Section 805 except that provisions which have already been accomplished, are deleted. Health Services for Ineligible Persons is included in the proposed bill as it appears in current law, with only minor technical changes.

Section 812 amends the Eligibility Moratorium and provides that the Secretary shall continue to provide services in accordance with eligibility criteria in effect on September 15, 1987 until such time as new criteria governing eligibility for services is developed in accordance with negotiated rulemaking provisions in Section 802.

Finally, a major amendment is proposed in Section 816, with the Establishment of a National Bi-Partisan Commission on Indian Health Care Entitlement. The NSC, based upon strong recommendations from the Regional and National consultation meetings, examined the establishment of an entitlement provision for Indian Health Services through the IHCIA reauthorization process. The Committee found that a number of issues related to the establishment of an entitlement provision, and that the need for extensive and representative Tribal consultation required further study.

A Commission was therefore proposed. The Commission will review all relevant data, make recommendations to Congress, establish a "Study Committee", and submit a final report to Congress.

The membership of the Commission will be 25 members, including:

- 10 Members of Congress
- 12 persons appointed by Congress from Tribal nominees (who are members of Tribes)
- 3 persons appointed by the Director of the IHS (who are knowledge about health care services for Indians, including one specifically addressing urban Indian issues).

Meetings require that a quorum of not less than 15 members be present, to conduct business. The Commission will have the power to hire staff, hold hearings, request studies from the General Accounting Office, the Congressional Budget Office and the Chief Actuary of HCFA, detail federal employees, and expend appropriated funds. Two reports are proposed. The first report, "Finding and Recommendations", must be made to the Commission by the Study Committee no later than 12 months from the date all members are appointed. The second, "A report to Congress: On Legislative and Policy Changes," must be made by the Commission to Congress no later than 18 months from the date all members are appointed.

V CONCLUSION:

The decision of the NSC to develop bill language, as opposed to general recommendations, required the actual writing of detailed bill language to be entrusted to a "Drafting Team" composed of the NSC co-chairs, tribal attorneys, and program staff. After each drafting session, the full NSC, at its next regular meeting, reviewed the new draft language.

The National Steering Committee completed a monumental task, on time, and with the broad support of Indian Tribes and communities across the United States. There was overwhelming support for the vast majority of changes described in the NSC Proposed Bill and for the highly participatory consultation process. We addressed complex and controversial issues and developed consensus solutions that met the needs of those most concerned. There were areas where there was considerable debate, which exemplified the complexity and controversy of some issues. A conflict resolution was approved and used when necessary.

This process of consultation was one of the most rewarding experiences I have been engaged in and I strongly believe that those involved "stepped up to the plate" in an aggressive, "take control approach" to fulfill what we believed was a major responsibility to Indian Country.

Thank you for the opportunity to present testimony on behalf of the National Steering Committee.

Final Report

National 437 Steering Committee for the Reauthorization of the Indian Health Care Improvement Act

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I. Executive Summary

In January of 1999, the U.S. Indian Health Service (IHS) began a series of four (4) regional consultation meetings with health care providers from IHS, tribal, and urban Indian programs (I/T/U's) to identify major policy concerns and specific recommendations regarding the upcoming reauthorization of the Indian Health Care Improvement Act (IHCIA). The IHCIA is scheduled to expire at the end of Fiscal Year 2000 (September 30, 2000). First enacted in 1976, the IHCIA provides the most comprehensive Federal statute to date, addressing this Nation's policy and program to improve Indian health care.

Each of the four regional meetings produced specific recommendations that were reached through a consensus process among the I/T/U representatives present. These recommendations were summarized into a single report, providing a description of general recommendations around which there was consensus across the United States, and those topic-areas that lacked consensus.

In June of 1999, the IHS convened a "National 437 Steering Committee" (NSC) to begin to address these recommendations, resolve conflicts, and present a final proposal for the reauthorization of the Indian Health Care Improvement Act. Tribal entities, in each of the 12 IHS Areas, selected two tribal representatives (one representative and one alternate) to be members of the NSC. In addition, representatives from national Indian organizations were identified as members of the NSC. The NSC was, thus, composed of the following:

- 15 Area tribal representatives (1 from each of the 12 Areas)
- 1 National Indian Health Board Representative
- 1 National Council on Urban Indian Health Representative, and
- 1 Self-Governance Advisory Committee Representative

The NSC organized into Working Groups. These Working Groups produced specific draft legislative language that incorporated the spirit of the regional consultation recommendations and reflected a consensus process. On July 16, 1999, the NSC produced a draft bill for the reauthorization of the IHCIA and sent a copy to every tribe and Indian health organization in the United States for review and comment.

On July 28 and 29, 1999, the IHS, the U.S. Senate Committee on Indian Affairs, and the U.S. House of Representatives Committee on Resources convened a National Forum on the Reauthorization of the Indian Health Care Improvement Act (IHCIA) in Washington, D.C. This Forum was provided for representatives of the IHS, tribes, urban Indian health programs, and others concerned about Indian health to provide input and recommendations on the pending reauthorization of the IHCIA and the "Draft Bill" developed by the National Steering Committee.

A thirty-day comment period, expiring on August 16, 1999, was provided for all I/T/U's and other organizations. Over 200 individual submittals were transmitted containing well over 1,000 specific recommendations. Each of these suggestions or concerns were reviewed by the National Steering Committee and work groups in a series of meetings held in Salt Lake City, Rockville, and Portland throughout September 1999. The National Steering Committee released its final Draft Proposed Bill for the Reauthorization of the Indian Health Care Improvement Act on October 6, 1999. Copies were provided to the IHS, the Senate Committee on Indian Affairs, the Senate Finance Committee, the House Resources Committee, the House Commerce Committee, the House Ways and Means Committee, and to the House and Senate Appropriations Committees.

The Proposed Bill reflects, to the maximum extent possible and within the time available, consensus across Indian country on major aspects of Indian health care. Some of the major changes proposed in the NSC Draft Bill include:

- A Stronger Statement on National Indian Health Policy
- Distribution of Scholarship Priority-Setting and Decision-Making to Areas
- Tribal Contracting Authority Clarified or Enhanced for Various Programs
- Expanded Flexibility to Fund Health Care Facility Construction and Replacement
- Elimination of Barriers to Medicaid, Medicare and CHIP Reimbursement for Services
- Continuation and Expansion of Urban Indian Health Resources
- Consolidation of Mental Health and Substance Abuse into a Single Behavioral Health Title
- Establishment of Specific Negotiated Rule-Making Requirements and Limitations
- Reduction in Reporting Requirements
- Establishment of a Commission on Indian Health Entitlement

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"Speaking with One Voice"

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III. Introduction

The IHCIA, Public Law 94-437, was enacted "To implement the federal responsibility for the care and education of the Indian people by improving the services and facilities of Federal Indian health programs and encouraging maximum participation of Indians in such programs, and for other purposes." The Act has been the cornerstone for Indian health services development since its enactment in 1976. The Act has been reauthorized four times, most recently in 1992.

The current authority for the IHCIA expires at the end of fiscal year 2000. The reauthorization of the IHCIA represents an opportunity to address changes in the current health care environment and the impact of these changes on the evolving needs of the I/T/U health care delivery systems. For these reasons, the IHS has initiated a major consultation process, which is based upon Area and Regional consensus recommendations, to produce a national consensus on the major concerns and recommendations for the reauthorization of the IHCIA. This initiative is consistent with the responsibilities of the Department of Health and Human Services (DHHS) that require consultation in the planning and preparation of documents and policy alternatives.

A year prior to this effort, on June 8-9, 1998, the IHS sponsored a Roundtable discussion of tribal leaders, urban providers, national health organizations, researchers, and other policy makers regarding the reauthorization of the IHCIA. Specific recommendations were made during this meeting, including how the IHS should conduct Regional Consultation meetings and the formation of an advisory committee or "Task Group" (later named the National 437 Steering Committee), which could assist the IHS in the analysis and framing of the recommendations received through this process. Specifically, the Roundtable recommended, "...use a core group to review materials for reauthorization..."

In response to these recommendations, the IHS identified a fifteen (15) member Task Group. The group was comprised of one tribal representative from each of the twelve (12) IHS Areas, one urban health representative, one Self-Governance representative, and one representative from the National Indian Health Board. To ensure continuity throughout the process, an alternate accompanied each representative. The National Steering Committee (NSC) conducted its work through several Work Groups that included Health Service; Health Facilities; Health Financing; Miscellaneous Provisions; Preamble; and a special Committee on Entitlement. The NSC selected two Co-Chairs and two alternate Co-Chairs to conduct all meetings. Each Work Group selected one or two chairpersons. Resource staff from the IHS, tribes or urban programs assisted each of the Work Groups.

The IHS contracted with Kauffman and Associates, Inc. (KAI), an Indian-owned firm to provide support for the National Steering Committee and to document the process and

outcome of the NSC efforts. KAI acted as a conduit for information with the National Steering Committee via tele-conferencing, broadcast faxes, e-mail and Federal Express mailings. KAI notified participants of meetings, provided meeting minutes, prepared documents, updated drafts, received feedback and comments, facilitated conflict resolution, and monitored the implementation of NSC directives and other NSC correspondence.

IV. Summary of the Consensus Process

Beginning in January 1999, tribes have been engaged in a consultation process with the Indian Health Service and urban Indian health providers regarding the reauthorization of the Indian Health Care Improvement Act. In June of 1999, the National Steering Committee began to incorporate the recommendations and concerns expressed at these consultation meetings into a proposed bill. The following is a brief summary of the overall consultation process.

Step 1. Area Consultation: IHS, tribal, and urban Indian representatives were invited to participate in a consultation process in their corresponding IHS Area. The expectation was that Area-wide concerns and recommendations would be forwarded to the next step in the consultation process.

Step 2. Regional Consultation: Four (4) regional consultation meetings were held across the United States from January to April 1999. IHS, tribal, and urban Indian representatives from each region were invited to participate. These regional meetings were intended to:

10 Further the consultation process to include all stakeholders in Indian health.
20 To identify and discuss policy issues.
30 Educate participants about each title in the legislation.
40 Share recommendations from each Area.
50 Build consensus on major policy issues of the IHCIA.

From these four meetings, a summary of the I/T/U's recommendations was developed for each of the sections in the IHCIA, as well as proposals for new provisions.

Step 3. National 437 Steering Committee: Upon completion of the four regional meetings, the IHS Director convened a National Steering Committee to assist IHS staff in the final drafting of the report on national policy issues and IHCIA recommendations. The National Steering Committee is composed of one elected tribal representative and one alternate from each of the twelve Areas and representatives from the National Indian Health Board, the National Council on

Urban Indian Health and the Tribal Self-Governance Advisory Committee. The NSC's work was divided into five teams as follows:

(1) Health Services Workgroup for Titles I, II, V, and VII,
Chaired by Dr. Taylor McKenzie, Vice President, Navajo Nation;
(2) Health Facilities Workgroup for Title III,
Chaired by Julia Davis, Secretary, Nez Perce Tribe and Robert Nakai, Albuquerque Indian Health Board;
(3) Health Financing Workgroup for Title IV,
Chaired by Buford Rolin, Poarch Creek, National Indian Health Board;
(4) Miscellaneous Workgroup for Titles VI and VIII,
Chaired by Tony Largo, Health Board Member, Riverside San Bernardino County Indian Health Clinic, and
(5) Preamble Workgroup,
Chaired by Henry Cagey, Lummi Indian Business Council, Self Governance Representative.
Committee members drafted a consensus bill.

Step 4. National Consultation Meeting: The draft bill language, with accompanying comments, was mailed to over 1,200 tribal leaders, tribal health directors, IHS officials, urban Indian health programs, and other Indian health organizations on July 16, 1999. Written, faxed, and e-mail comments were invited and received by the NSC up until August 16, 1999.

The draft bill was also presented at a national forum on July 28-29, 1999 in Washington, D.C. This meeting provided time for tribal leaders, urban Indian health representatives, national Indian organizations, related federal agencies, and others interested in Indian health, to provide feedback on the legislative proposal.

Based on all the input received, the National Steering Committee came up with the final draft legislation to reauthorize the IHCIA. This final version includes the following major points:

1. **Entitlement:** This issue was referred to a special committee that looked at the Pros and Cons. It was decided that our proposed bill would ask for a special Congressional Commission to study the issue of "Indian Health Entitlement".

2. **Social Security Act Amendments:** Much of our proposed Title IV will amend provisions of the Social Security Act to eliminate barriers for Indian patients and providers to access Medicaid, Medicare and the Children's Health Insurance Program.

3. **Urban Programs:** It was agreed by the full NSC that urban health issues should continue to be dealt with under Title V, except in those instances where it is appropriate, such as in Title IV, or in cases of consultation, planning and reporting.

4. **Local Control:** Throughout the proposed bill, provisions were included which will shift resources and decision-making to local tribal levels. One of the most significant changes include the decentralization of Scholarship Program decisions to the Area level, based upon tribal consultation. The Catastrophic Health Emergency Fund (CHEF) was also proposed to be allocated and administered on an Area basis.

5. **Permanent or Term Legislation:** A term of 12 years is proposed for this reauthorization and shall continue through the end of Fiscal Year 2012.

Step 5. Follow-Up Activities: The National Steering Committee plans to continue to function as the link between grass roots concerns and the Congressional reauthorization process. A special committee, called the "Reauthorization Leadership Group," was formed and includes the two Co-Chairs of the NSC, the two alternate Co-Chairs of the NSC, the Chairs of the NSC Workgroups not already represented, and representatives of national Indian organizations.

The Steering Committee delivered their Proposed Bill to Reauthorize the Indian Health Care Improvement Act to Congress on October 6, 1999. Copies were sent to the Senate Committee on Indian Affairs, the House Resources Committee and other appropriate committees with jurisdiction. The National Steering Committee also requested the IHS mail a copy of their proposed bill to every tribe and Indian organization on the IHS database. The text of the proposed bill is currently located on the Indian Health Service web site.

V. Proceedings of the National Steering Committee

The National Steering Committee adopted a grueling schedule, beginning with their first meeting in June 1999 and continuing until their last meeting in October 1999. The ambitious schedule of the NSC reflected their decision to produce a "Draft Bill" by early fall, as opposed to a list of concerns or general statements about the Indian Health Care

Improvement Act. This shift in focus to write detailed bill language required a much more aggressive meeting schedule and the NSC met eight (8) times over four months. The NSC met at the following dates and locations:

- **June 3, 4, 1999 in Rockville MD**
- **June 17, 18, 1999 in Gaithersburg, MD**
- **July 7, 8, 9, 1999 in Rockville, MD**
- **July 13, 14, 1999 in Reno, NV**
- **July 27, 28, 29, 1999, in Washington, DC (National Meeting)**
- **August 30, September 1, and 2, 1999, in Salt Lake City, UT**
- **September 28, 29, 1999, in Rockville, MD**
- **October 5, 1999 in Palm Springs, CA**

In addition to these official meetings of the NSC, several subgroups of the committee held additional working meetings. These included a meeting of the "Drafting Team," which was comprised of a group of attorneys and other individuals assigned by the NSC to draft specific bill language consistent with the decisions of the NSC for each section of the Act. Meetings were also held by a subcommittee of the NSC to plan the National Consultation Forum held at the end of July. Finally, additional sessions were held by an "Entitlement Committee" to draft specific recommendations to the NSC to address questions of entitlement for Indian health in the proposed reauthorization of the Indian Health Care Improvement Act.

A. Organizational Meeting

The first meeting of the NSC was held in Rockville, Maryland near IHS headquarters on June 3-4, 1999. This initial meeting allowed time for participants to share their expectations for the NSC and begin the formation of an organizational structure. During this meeting several key decisions were made. The first critical decision by the NSC was to elect two (2) "Co-Chairs," who were tribal leaders, to convene and chair all meetings of the NSC. Rachel Joseph, Lone Pine Paiute Tribe, and Henry Cagey, Lummi Tribe, were selected as the Co-Chairs. In addition, the NSC selected "Alternate Co-Chairs" to serve in the absence of the official co-chairs. These alternates were Buford Rolin, NIHB Chairperson, and Julia Davis, Nez Perce Tribal Council member. The second major decision reached at this gathering was to produce a complete "Draft Bill," as opposed to a report of general recommendations. This decision required the production of detailed bill language for each of the eight major titles in the existing Act, and the incorporation of new provisions within the existing structure. The next determination was to divide the NSC into Working Groups; each work group was assigned one or several titles of the existing Act. A report-back mechanism was built into the agenda to help the work groups keep on task, improve communications and, to a greater extent, maintain accountability for

the work completed to the NSC. The transferals of Sections from one title to another were often agreed upon in the "report-back" sessions.

B. Working Group Activities

The second meeting held on June 17-18 and the third meeting held on July 7-9 provided time for each of the Working Groups to specifically begin addressing each major title of the Act. It was agreed by the NSC that the Final Report on Regional Recommendations: "Speaking with One Voice," would be used as the guide for each of the Working Groups to begin drafting changes to the IHCIA. The NSC divided the work as follows:

Working Group	Titles	Chairperson(s)
Health Services	I, II, V, and VII	Dr. Taylor McKenzie
Health Facilities	III	Julia Davis, Robert Nakai
Health Financing	IV	Buford Rolin
Miscellaneous	VI, and VIII	Tony Largo
Preamble	Preamble	Henry Cagey
Entitlement Issues	New	Julia Davis

C. Circulation of a Draft Bill

The NSC worked at a "break-neck" pace to produce a draft document which could be mailed to every tribe and Indian organization in the United States, well in advance of the National Consultation Forum. During the NSC meeting of July 13-14, 1999, held in Reno, Nevada, the NSC finalized draft bill language that incorporated the recommendations adopted by the NSC from Regional Recommendations. This document was immediately shipped across Indian Country, with a cover letter, requesting feedback and comments within the next 30 days.

D. National Consultation Forum of July 28, 29, 1999:

On July 28 and 29, 1999, the United States Senate Committee on Indian Affairs, the United States House of Representatives Committee on Resources, the U.S. Indian Health Service, and the National Steering Committee on the 437 Reauthorization, jointly convened a National Forum for tribal leaders, tribal representatives, urban Indian health providers and others concerned about American Indian and Alaska Native health care. The purpose of the meeting was to discuss the upcoming reauthorization of the Indian Health Care Improvement Act (P.L. 94-437 as amended) scheduled to expire at the end of Fiscal Year 2000, and to request feedback on a draft reauthorization bill prepared from comments

received during regional consultation meetings. The goals of the National Forum were identified on the agenda and are listed again below.

Meeting Goals:

1. To provide a forum for and document input from tribes, urban Indian health programs, federal agencies, states, and other interested parties regarding their feedback on the final recommendations generated through the consultation process.
2. To educate and inform federal and state governments, national health related organizations, and the U.S. Congress regarding the outcomes of the national consultation process related to the reauthorization of the Indian Health Care Improvement Act.
3. To create momentum for Indian Country and others supportive of the reauthorization of the Indian Health Care Improvement Act.

This National Forum was the culmination of many months of local, Area, and regional consultation meetings between the IHS, tribal, and urban providers regarding the upcoming reauthorization of the Indian Health Care Improvement Act. The meeting was planned by a committee composed of persons representing the sponsoring groups. It included: Patricia Zell, Paul Moorehead, Marie Howard, Rachel Joseph, Henry Cagey, Buford Rolin, Julia Davis, Seh Welch, Mike Mahsetky, and Kitty Rogers. The National 437 Steering Committee Co-Chairs facilitated the National Forum.

Prior to the National Forum, every tribe, urban program and national Indian organization was mailed a "Draft 437 Reauthorization Bill". This draft bill was developed by a National 437 Steering Committee composed of tribal representatives from each of the 12 IHS Areas, and other representatives from the National Council on Urban Indian Health, the National Indian Health Board, and the Tribal Self-Governance Advisory Committee. The National 437 Steering Committee based its proposed draft bill on the consensus recommendations which emerged from four regional consultation meetings sponsored earlier in the year by the IHS for I/T/U input, discussion and consensus. This draft bill was the central focus of discussion during the National Forum. In addition to the comments received from participants at the National Forum, a thirty-day (30) period to receive written comment was also provided by the National Steering Committee, running from July 16, 1999 to August 16, 1999.

The agenda for the National Forum incorporated liberal time for comments from tribal leaders and others wishing to remark from the floor on proposed amendments to the Indian Health Care Improvement Act. The agenda also included time for formal presentations of the major proposed changes to the Indian Health Care Improvement Act for each of the

eight titles of the existing Act. Time was also allocated for speakers from the U.S. House of Representatives, the U.S. Senate, and the Administration.

Overall, the feedback from participants was very positive regarding the National Forum and the process employed to secure input from tribal and urban leaders and providers of services. This report attempts to briefly summarize the major areas of discussion and recommendations that emerged from this two-day forum. The intent of the National Conference was to collect all comments and concerns, and to provide documentation of both oral and written comments. The NSC used these comments, in addition to the written comments received during the 30-day comment period, to redraft the proposed amendments to the Indian Health Care Improvement Act. The final draft was to be submitted by the National Steering Committee to the U.S. House Resources Committee and the U.S. Senate Committee on Indian Affairs by the end of September 1999. Remarkably, all of the NSC's timelines and projected goals were met — despite limitations of time, distance, and complexity of task. Some of the more remote tribes telephoned KAI to advise us that their local Federal Express service may delay shipment of their Tribe's comments. Many took full advantage of tele-communications, through faxing or e-mailing their comments.

E. Incorporation of Comments, Feedback, and Finalized Bill

The NSC held additional meetings in the beginning of September in Salt Lake City and at end of September in Rockville to make decisions regarding the specific comments and recommendations received on the July 16, 1999 draft bill. These final changes were provided to the Drafting Team to craft the appropriate bill language that was reviewed in October in Palm Springs, California.

VI. Title by Title Summary of Proposed Bill for the Reauthorization of the Indian Health Care Improvement Act

The National Steering Committee approved the final proposed bill language at its meeting on October 5, 1999, in Palm Springs, California. The entire proposed bill is attached to this report. The following is a title-by-title summary.

A. Preamble

The Preamble section of the Act has been revised, including sections on "Findings, Declaration of National Policy, and Definitions." Emphasis has been placed on the trust responsibility of the federal government to provide health services and the entitlement of Indian tribes to these services. The proposed bill has changed the "Declaration of Health Objectives" to the original "Declaration of National Policy." The proposed bill eliminates

the enumeration of 61 distinct objectives. Instead this section provides that the federal government will raise the health status of Indians to the levels set forth in "Healthy People 2010." The new preamble underscores consultation with Indian people, the importance of the federal-tribal relationship, and creating access to health care professionals for Indian populations equal to that of the U.S. as a whole. Numerous additions to the "Definitions Section" were made in conformance with changes in later titles. When definitions applied only to one section of the Act, the definition is provided in that section and not in the "Definitions Section" of the Preamble.

B. Title I - Indian Health, Human Resources, and Development

Title I was substantially rewritten primarily to shift priority setting and decision-making to the local Area levels, where appropriate. Throughout the Title, the listing of distinct disciplines of health professionals was eliminated and replaced with more generic terminology, which will include all health professionals, with only a few exceptions. Special programs were eliminated if these professional disciplines were eligible to receive support under other generic programs of this Title. The setting of preparatory and scholarship priorities have been decentralized to the Area Offices based upon Tribal consultation. The administration of scholarship funds is proposed to remain an IHS Headquarters function. Language was included to require Title I recipients to fulfill their scholarship job placement requirements in the Areas from which they received their scholarship assistance. Language was also proposed to protect Title I recipients who are already in the "pipeline" for assistance. Eligibility requirements for scholarships and preparatory scholarships were amended such that only persons who are Indian are eligible. Demonstration projects were eliminated in lieu of establishing regular funding for Tribal programs across the board. A new section was proposed, clarifying that all scholarships, loans, and repayments of loans are "non-taxable." Amendments were proposed in this title to clarify that tribal "matching" requirements for scholarship programs can be from any source, including other federal funds. The training and certification sections for mental health and substance abuse workers were relocated from Titles II and VII to this Title.

C. Title II - Health Services

Title II represents a collection of diverse sections addressing issues related to the delivery of health services to Indian populations. This title continues to address issues of "equity" in the allocation of health resources and attempts to address health care deficiencies. A new section provides a listing of types of services authorized, which were not previously listed. One major change proposed in Title II is the removal of section 209 "Mental Health Services" from this Title, transferring it to Title VII "Behavioral Health". Throughout most provisions, the term "Indian Tribes and Tribal organizations" has been inserted as equal partners with the IHS. A significant change in Section 202, Catastrophic Health Emergency Fund (CHEF), is proposed. This change will authorize the IHS to allocate

total CHEF funds among the 12 Areas for administration at the Area level. The IHS Area Offices must consult with Tribes in establishing and operating the Area CHEF program. Earlier proposals considered by the NSC to set lower thresholds for Tribes or Areas "dependent" upon Contract Health Services were deleted in favor of this Area-specific approach. An Area-specific allocation methodology must be negotiated with Tribes through a rule-making process. Language was included that prohibits the allocation or assignment of shares of CHEF funds under the provisions of the Indian Self-Determination and Education Assistance Act.

Section 204, Diabetes Prevention and Treatment, was expanded to establish a national program, not a "model" based program, to provide authority for the continuation of funded diabetes projects. Individually named community "models" were deleted in the bill, in favor of a national emphasis, with the intent that these programs will continue as a part of a national strategy. Several sections regarding reimbursements and managed care will be shifted to Title IV. Section 207 was expanded to focus attention on "all cancers," including, but not limited to, mammography screening for breast cancer. Language was added to require that "Epidemiology Centers" be established in each of the 12 IHS Areas, and be contractible under the Indian Self-Determination Act, but not divisible. This also includes those Epidemiology Centers already under contract at the time of enactment. The Comprehensive School Health Education and the Indian Youth Programs were changed to provide funding to Tribal or urban programs throughout the United States. The section on Tuberculosis Prevention and Treatment was changed to expand its focus to all "Communicable and Infectious Diseases," with particular emphasis on certain diseases such as HIV/AIDS. The Office on Indian Women's Health Care was also changed to a women's health program providing funds for Tribes and tribal organizations, as opposed to an office in the IHS Headquarters. In addition, several sections from Title VIII were moved to Title II, including the provision on Nuclear Resource Development and Health Hazards. This section was changed to Section 215, Environmental and Nuclear Health Hazards, and made applicable nationally to address environmental health hazards that may require ongoing monitoring or study. Section 220 provides for the fair and equitable funding of services operated by Tribes under funding agreements just like those operated directly by IHS. Section 221 requires that the licensing requirements of staff employed by Tribally operated programs be consistent with IHS employees. There was an effort to consolidate all the Contract Health Service (CHS) provisions within this title; sections 216, 217, 218, 219, 222, 223, and 224 all address unique aspects of the CHS program. New language was added in Section 224, which strengthens the prohibition against CHS providers from holding individual Indian patients liable for CHS approved bills.

D. Title III - Health Facilities

Numerous changes are proposed for Title III to address facility concerns. Section 301 states that Tribal consultation shall be required for any and all facility issues, not just

facility closures. Recommendations on the accreditation of health care facilities were made to "not to be limited only to the Joint Commission for the Accreditation of Health Care Organizations", but to be open to any nationally recognized accreditation body. Annual reporting on facility requirements should not be limited to the "10 top priority projects", but reflect the true unmet need in Indian country. A clause was included to provide protection for all projects on the existing priority list. Language was proposed in Section 302, which will strengthen the relationship between IHS and the U.S. Department of Housing and Urban Development regarding safe water and sanitary waste disposal, and authorize the use of IHS funds to leverage additional resources. To be consistent with P.L. 86-121, the term "facilities" was used in place of "systems." Language was included which clarifies that the Tribe or Indian family has primary responsibility for funding the maintenance, but that the IHS is authorized to assist in emergencies. Section 303 was amended to provide an exemption from "Davis Bacon" wages for IHS and Tribal construction projects. Section 305 clarifies that Tribes, to assist in the expansion, renovation or modernization of IHS or Tribal health facilities, may use any source of funds. Language was also provided to allow for a peer review panel process for small, ambulatory care facility applications. The Indian Health Care Delivery Demonstration Project was expanded to include facilities such as hospice care, traditional healing, childcare, and other activities. Originally, the NSC attempted to make this section more national in scope and deleted references to the 9 (nine) individually named Tribal communities. However, the NSC added the list back, pending a final update or status report from the IHS regarding the necessity for listing each project. If it is not necessary, the NSC supports deleting these tribal-specific references in this title.

New sections were added to Title III for operating leases in order of scoring under the Budget Enforcement Act. Land transfers under Section 308 are authorized for all federal agencies. A major new provision, Section 310, provides for Loans, Loan Guarantees, a Revolving Loan Fund and a grant program for Loan Repayment on new health facilities. It also provides that Congress appropriate funds for a Health Care Facilities Loan Fund, made available to Tribes and Tribal organizations for the construction of health care facilities. A new section was established for the IHS/Tribal Joint Venture Program, which was originally in Title VIII. The Joint Venture Program now appears as Section 312 and provides for creative, innovative financing by Tribes for the construction of health facilities, in exchange for IHS commitment for equipment and staffing. Another section from Title VIII was transferred to Title III, addressing location of facilities on Indian reservations and Alaska Native lands. A new Section 314 authorizes the use of "Maintenance and Improvement" funds to be used to replace a facility when it is not economically practical to repair the facility. Section 315, another new section, provides clarification for Tribes operating health care facilities under the Indian Self-Determination and Education Assistance Act. It states that Tribes can set their own rental rates for all occupants of Tribally operated staff living quarters and collect rents directly from federal employee occupants. Another important new provision to Title III, provides for "Other

Funding" to be used for the construction of health care facilities and opens the door for alternative financing options for Tribes and Tribal organizations. This new section includes a provision to ensure that the use of alternative funding does not jeopardize a Tribe's placement on the priority list referenced to in Section 301.

E. Title IV - Access to Health Services

The provisions in this Title attempt to eliminate barriers which prevent IHS, Tribes, Tribal organizations and urban Indian health programs from accessing reimbursement from other federal programs, including Medicaid, Medicare, and the Children's Health Insurance Program (CHIP), for which their patients are eligible. By eliminating barriers, it is intended for IHS, Tribes and urban programs to take maximum advantage of these other federal funding streams. The severe and longstanding lack of adequate appropriations for the IHS requires that alternative funding streams be accessed to the maximum extent possible, without infringement upon the unique federal trust responsibility to provide health services to Indians. The provisions in Title IV seeks to accomplish three major goals:

- To maximize recovery from all third-party coverage, including Medicaid, Medicare, and CHIP and any new federally funded health care programs;
- To ensure that Indians have access to culturally competent care provided by the Tribes, Tribal organizations or urban Indian organizations, and therefore are not automatically assigned without approval to non-Indian managed care plans; and
- To ensure that when an Indian health program provides services, the full cost of providing the service will be made available.

In order to achieve these goals, specific amendments to the Social Security Act must be enacted. The sections of the proposed bill amending the Social Security Act have been consolidated for easier review at the end of this Title. Sections amending the IHCIA are stated at the beginning. Major amendments to the IHCIA include eliminating the application of the "special fund" for Medicaid, Medicare or other reimbursements for programs operated by Indian Tribes or Tribal organizations under the Indian Self-Determination Act. These programs may receive their reimbursements directly. Amendments also require 100% (rather than 80%) of the reimbursements received by the IHS to be sent to the Service Unit, which generated the collection. The bill proposes that Indian health programs submit provider enrollment identification to allow the IHS and the Health Care Funding Administration to track payments and reimbursements for services for the purpose of reporting and monitoring. An amendment was provided which allows for the IHS to bill Tribal self-insurance programs only under certain, limited conditions including specific written approval of the Tribal governing body. Amendments in this title are also proposed to authorize Tribes to purchase insurance using IHS funds. Specific new language is provided in Section 410, clarifying that IHS is the "payor of last resort," unless

federal law "explicitly" provides otherwise. This section is followed by Section 411 authorizing the Indian health system to bill for other federal reimbursements unless explicitly prohibited. A new Section 412 establishes the "Tuba City Demonstration Project," one of only two new demonstration projects recommended by the NSC in Title IV. Section 412 authorizes the IHS operated Service Unit to function as a "managed care organization" as a part of the Arizona plan. Finally, the proposed bill authorizes Tribes and Tribal organizations to purchase federal health and life insurance for their employees. Specific negotiated rulemaking procedures are included in this Title.

Amendments to the Social Security Act include amendments to Title 18, Medicare, providing for a "most favored" status to be provided to IHS, Tribal or urban Indian organizations when purchasing services. It provides for Indian health system providers to receive the same rates given to other preferred federal customers, such as Medicare. The proposed draft bill will make all Indian health programs eligible providers for Medicare reimbursement for all services which Medicare otherwise pays.

Improved access to Title XXI of the Social Security Act and CHIP resources was incorporated into the revised Title IV. A new provider type is proposed, called the "Qualified Indian Health Program" (QIHP), which provides for cost-based reimbursement for qualifying Indian health programs. An exemption from certain provisions of the Emergency Medical Treatment and Active Labor Act (EMTALA) is proposed. The draft bill also provides that the 100% Federal Medical Assistance Percentage will be provided to states for CHIP services reimbursed to Indian health programs, as is currently the case with Medicaid, and extends that definition to include referral services paid by the Indian health program. A new section also authorizes the Secretary of the Department of Health and Human Services to contract directly with Indian Tribes through block grants for the administration of CHIP programs to Indian children within the Tribal service area. The proposed draft bill also includes language requiring "meaningful consultation" between HCFA, the states, and Indian health programs. Section 428 proposes to eliminate or "waive" all cost sharing for IHS eligible beneficiaries served by Indian health programs under Medicaid, Medicare, and CHIP. This section also includes language to ensure that Indian people are not subject to estate recovery proceedings or that the impact of estate recovery is minimized by eliminating trust income, subsistence or traditional income. This section also includes a "place holder" for more precise language to amend current spend-down provisions in the Medicaid program. Finally, this section includes new language to prevent state Medicaid and CHIP programs from seeking to recover from parents the cost of payments made to an Indian health program for services to their children.

A new Section 429 ensures that "managed care organizations" (MCO) will pay Indian health programs for services provided to Indian patients and MCO enrollees, and provides a mechanism for MCO's to contract with Tribes. This section prohibits automatic enrollment of Indian beneficiaries into MCO's, and authorizes the establishment of Indian

MCO's. Section 430 establishes the "Navajo Nation Medicaid Agency" to serve Indian beneficiaries residing within the boundaries of the Navajo Nation, authorizing a direct billing relationship between the tribe and the HCFA. The NSC elected to promote the Navajo Nation Medicaid Agency as a demonstration effort, prior to pushing for direct billing authorization for all Indian Tribes across the United States.

New provisions require the establishment of Indian Advisory Committees within HCFA, including a National Indian Technical Advisory Group to provide "meaningful" participation of Tribes at the national and state levels, and an Indian Medicaid Advisory Committee in each state, where appropriate.

F. Title V - Health Services for Urban Indians

This title covers the majority of provisions for urban Indians. With only a few exceptions, funding authority for urban Indian health was specifically limited to only Title IV and Title V. All other references to urban Indian health found in other titles address issues of consultation, rulemaking, planning or reporting only. Title V provided authority for the IHS to fund health service programs serving urban Indian populations. It serves approximately 149,000 urban Indians in 34 different cities throughout the United States. The programs funded under Title V represent a wide range of services, from outreach and referral programs to comprehensive primary care centers. The amendments recommended by the NSC provides minor changes to the existing law and adds new provisions to Title V. The major changes proposed in the bill for Title V include the following:

- To streamline the current law relating to the standards and procedures for contracting and making grants to urban Indian organizations;
- To require the agencies in the DHHS to consult with urban Indians prior to taking actions that would affect them and to establish a negotiated rulemaking process;
- To expand the Secretary's authority to fund, through grants, loans, or loan guarantees, the construction or renovation of facilities for urban Indian programs;
- To enable urban Indian programs to obtain malpractice coverage under the Federal Tort Claims Act, similar to Tribes and community health centers; and
- To authorize a demonstration program for residential treatment centers for urban Indian youth with alcohol or substance abuse problems.

Language is proposed to allow urban programs the authority to receive advance, lump-sum payments for IHS contracts or grants under this Title, and to use carry-forward funding from one year to the next. Reporting changed from quarterly to semi-annually, and language is offered to clarify audit requirements. Language is proposed which will allow for funds to be used for facility construction, renovation, expansion, leasing or other purposes. To be consistent with the redesign of IHS, the department title "IHS Urban Branch" was changed to the "Office of Urban Health". Language was added requiring the

IHS and the DHHS to consult with urban programs on issues affecting urban Indian populations. Language was also included to extend staff coverage to urban programs under the Federal Tort Claims Act. A new provision proposes to establish at least two (2) urban Indian youth treatment centers as demonstration programs. The bill proposes similar provisions, as is available to Tribes, for access to federal facilities and suppliers, diabetes prevention and treatment. Section 512 proposes no changes to the Oklahoma City program, but recommends the Tulsa program be made permanent and not subject to the provisions of the Indian Self-Determination Act. The NSC was notified that consensus had not been achieved among tribes regarding the Oklahoma City program, therefore the committee did not recommend any changes to existing law regarding this program.

G. Title VI - Organizational Improvements

Only a few changes are proposed in this title. Future amendments will be considered to incorporate the elevation of the Director of the IHS to an Assistant Secretary, if bills currently pending in Congress do not move forward. Unnecessary provisions were deleted in this title if activities had already been completed. New language was proposed authorizing the IHS to enter into contracts, agreements or joint ventures with other federal agencies.

H. Title VII - Behavioral Health

Title VII is recommended for major revisions, specifically to integrate Alcohol and Substance Abuse provisions with Mental Health and Social Service authorities. Section 209 from Title II has been moved to the new Title VII. Where appropriate, the terms "Tribes, Tribal organizations and Indian organizations" are referenced in addition to IHS. Provisions that require a "National Plan" were deleted, in lieu of new language establishing a process for locally based behavioral health planning. A broad range of behavioral health services is described under "continuum of care". Several related sections were moved from Title VIII, including sections on Fetal Alcohol Syndrome and Child Sexual Abuse. Demonstration programs were eliminated and replaced with language authorizing programs for Indian Tribes and Tribal organizations. The section on Youth Treatment Centers has been amended to allow for at least one center per Area (including Phoenix and Tucson Areas) and retained authority for two centers or treatment "networks" in California. A new section was proposed in this Title authorizing the establishment of at least one inpatient psychiatric treatment facility for each IHS Area. These new centers would be funded on a similar basis as the Regional Youth Treatment Centers. All Tribal-specific programs have been deleted in Title VII, except for the Tanana Chiefs Conference and the Southeast Alaska Regional Health Corporation, with the assumption that continued funding is authorized under general provisions of this Title.

I. Title VIII - Miscellaneous

Ten sections were moved out of Title VIII to more appropriate sections in the IHCIA. All CHS provisions were moved to Title II. A majority of the "free-standing and severability" provisions were incorporated into Title VIII. A listing of all reporting requirements, contained in the Bill, have been restated in Section 801 of this title. New language was proposed, in regard to negotiated rulemaking procedures in Section 802, requiring the Secretary to initiate these procedures 90 days from the date of enactment. This section also establishes a maximum amount of time for negotiated rules to be printed in the federal register, not later than 270 days after the date of enactment. The authority to promulgate regulations under this Act expires after 18 months from the date of enactment, forcing an expedited rulemaking process. Section 803 requires the Secretary, in consultation with Tribes and urban Indian organizations, to develop a "plan of implementation" for all provisions of this Act. Section 804 continues the prohibition on abortion funding, as it exists in current law. Eligibility of California Indians was covered under Section 805 except that provisions, which have already been accomplished, are deleted. Health Services for Ineligible Persons is included in the proposed bill as it appears in current law, with only minor technical changes.

Section 812 amends the Eligibility Moratorium and provides that the Secretary shall continue to provide services in accordance with eligibility criteria in effect on September 15, 1987 until such time as new criteria governing eligibility for services is developed in accordance with the negotiated rulemaking provisions in Section 802.

Finally, a major amendment is proposed in Section 816, with the Establishment of a National Bi-Partisan Commission on Indian Health Care Entitlement. The NSC, based upon strong recommendations from the Regional and National consultation meetings, examined the establishment of an entitlement provision for Indian health services through the IHCIA reauthorization process. The Committee found that a number of issues related to the establishment of an entitlement provision, and that the need for extensive and representative Tribal consultation required further study. A Commission was therefore proposed. The Commission will review all relevant data, make recommendations to Congress, establish a "Study Committee", and submit a final report to Congress. The membership of the Commission will be 25 members, including:

- 10 members of Congress,
- 12 persons appointed by Congress from Tribal nominees (who are members of Tribes), and
- 3 persons appointed by the Director of the IHS (who are knowledgeable about health care services for Indians, including one specifically addressing urban Indian issues).

Meetings require that a quorum of not less than 15 members be present, and that not less than 9 of those members be Indian, to conduct business. The Commission will have the power to hire staff, hold hearings, request studies from the General Accounting Office, the Congressional Budget Office and the Chief Actuary of HCFA, detail federal employees, and expend appropriated funds. Two reports are proposed. The first report, "Findings and Recommendations", must be made to the Commission by the Study Committee no later than 12 months from the date all members are appointed. The second, "A Report to Congress: On Legislative and Policy Changes", must be made by the Commission to Congress no later than 18 months from the date all members are appointed.

VII. Conclusions

The National Steering Committee completed a monumental task, on time and with the broad support of Indian communities across the United States. There was overwhelming support for the vast majority of changes described in the NSC Proposed Bill to reauthorize the IHCIA and for the highly participatory consultation process employed. In some cases, the NSC tackled complex and controversial issues and developed consensus solutions that met the needs of those most concerned. There were other areas where there was considerable debate which exemplified the complexity and controversy of some issues. The NSC took the position that the legislative process would provide additional opportunities to further examine these issues.

The hearings that are expected to occur during the Congressional reauthorization process will provide the IHS, tribes and urban programs, as well as others concerned about Indian health, the opportunity to raise additional issues and make improvements on the NSC proposed language. Indeed, the NSC and the IHS advised tribes and urban providers that the upcoming Congressional legislative process will provide an opportunity to discuss any additonal issues not fully addressed during the consultation process.

The decision of the NSC to develop bill language, as opposed to general recommendations, required the actual writing of detailed bill language to be entrusted to a "Drafting Team" composed of the NSC co-chairs, tribal attorneys, IHS attorneys and program staff. After each drafting session, the full NSC, at its next regular meeting, reviewed the new draft language. These reviews occurred within a limited amount of time and centered primarily on major changes to the draft. The Drafting Team reviewed each line of the proposed bill on numerous occasions, but each member worked on different titles and the consolidated draft may have some numbering, formatting or technical errors. A "commentary" section is provided to assist readers of the proposed bill to better understand the intent of the new language.

"Speaking with One Voice"

The progression to consolidate Area, and then regional recommendations into a National draft Bill required compromise and consolidation. For example, a recommendation that may have been supported by one Area, but not other Areas, may have been eliminated, reworded or expanded to become applicable or appropriate for all Areas. The NSC adopted the position to generally reject tribal-specific or program-specific provisions that did not have a broader benefit for Indian country.

Overall, the consultation process used to develop the NSC's Proposed Bill to Reauthorize the Indian Health Care Improvement Act received strong support and endorsement by Indian country. The document reflects hours of committee members time and the support from their tribes or organizations to allow them time to participate in this process.

To the greatest extent possible, it was the goal of the NSC to present a draft bill which reflected the consensus of Indian country. This proposed bill, more than previous reauthorizations or amendments to the Indian Health Care Improvement Act since it was enacted in 1976, truly represents Indian country. The NSC draft bill contains the recommendations for modifications needed in this cornerstone authority to reflect the changes in the health care environment. These modifications and changes are necessary to improve and enhance the ability of tribal health programs, urban health programs, and the IHS to provide comprehensive personal and public health services that are available and accessible to all American Indian and Alaska Native people.

The theme of this consultation was "Speaking With One Voice" reflecting the goal of working toward consensus. On a national level every tribe in the U.S. was kept informed and given opportunities to participate in this consultation process. Based on this extensive consultation, it is hoped that the changes and modifications called for in this draft bill will be the basis for future legislative action related to the Indian Health Care Improvement Act.

National Forum (437) Meeting Questions and Answers July 28 and 29 edited

The following are the notes from the National Forum of July 28 and July 29 taken during the Question and Answer sessions that followed the section by section presentations. In most cases questions were recorded without response with the understanding that all questions would be taken up by the full committee.

Day 1 AM. Title III, Facilities
Day 1 AM Titles I, II,
Day 1 PM Titles V, and VII
Day 2 AM Michael Hash presentation followed by Title IV
Day 2 PM Titles VI and VIII

Questions: Facilities title III
July 28 AM session

Section	Name, Tribe/ Organization	Comment
310	Rod Smith	Broaden definition of facilities
301	Alida Montiel	What is nomination process?
301	Jacob Lonetree	What will happen to facilities on the list?
306	Jim Crouch	Add authority for repayment of loans Raise threshold size above 2000
	Lydia Southerland	When will entitlement be
301	Byron White, Rosebud Sioux	Some Title I tribes have worked for years to get on the top of the list
301	Michael Jackson Sr	Don't strike list
	Brian Eagleman	Need Construction standards with default be jurisdiction by the tribe
	Donna Begay	Tribes need operational flexibility to be Effective and efficient
	Edwin Martinez, Sr. Laguna Pueblo, former Governor	Maintenance and improvement increase needed.
301	Paul Sherry, Alaska	Good work Should state clearly that top 10 will remain Should do for health facilities what we do for sanitation Need to sort out what is a fair priority system for construction
301	Ervin Chavez	Keep top ten, give Congress true need

National Forum (437) Meeting Questions and Answers July 28 and 29 edited

		May be more projects with joint venture authority This will impact any priority system, How do they relate, need to look at that Land transfer, hopeful change will make it easier. Annual reporting on health facilities need will be difficult given amount of work required.---may spend all our time on this versus current five year basis. Need will increase
	Julia Davis	Jt. Venture will not supplant priority list, its another tool for tribes to bridge gap between need and funds.
	Bill Old Chief, Chairman, Blackfeet	Concern that staffing not provided when new facilities built. For tribe expenses related to using other facilities. Health needs, like diabetes, impact facilities need. Concern to find common ground, not compete-
312	Bob Newcombe, Navajo	Non service funds-any definition yet? e.g., are third party reimbursements non-service funds? Rachel responded that definitions will be taken up after comments are received
	Vernon James, San Carlos Apache Tribe	Entitlement should be pursued more aggressively. Would like to work on this. Timetable needed to deal with this.
	Bob Nakai/Julia Davis	Support for entitlement, continued work. Relationship to Treaties and support of Supreme Court statements on Treaty rights.
308	Rosemary Landis, NARA	Authorized no later than 90 days to transfer land. Chemawa has never been transferred yet. Keep Chemawa in until transferred
	Jackie Myers,437 Recipient	Keep govt-to-govt relationship intact
	Marie D. Talieje, Peach Springs	Concern about increasing minimum user pop for facility construction. Would be detrimental to small tribes. Small rural tribal communities have needs, ie, diabetes. Modular buildings will not last long.
	Dennis Smith, Sr.. Duck Valley, NV	Thank National Steering Committee on Reauthorization of the Indian Health Care Improvement Act. Recommends a committee of Tribal Area reps to work on "entitlement". Do this today. Decide during this meeting which direction we go on entitlement.
	Henry Cagey, Co-Chair	Entitlement paper in packet. Recommends tribes "take closer look" at entitlement. Is this the solution or not? Need=$15 B. Would entitlement restrict tribal sovereignty? Would it lock in amounts? This needs

		further study. That's what steering committee recommended.
	Julia Davis	Volunteer to get list of names willing to work on Study Committee on Entitlement.
	Alvino Lucero, Governor, Isleta Pueblo	Does not agree with lease back to IHS for 20 yrs. The debt needs to be amortized, and lease back makes that difficult. The Joint Venture funding ($15M) is not enough. Diabetes affecting every tribe. All clinics should have dialysis equipment.-change diet. On Entitlement -support this-agree with Sen. Inoyue that it is paid for. Question on estimating population for urban Indians-funding should follow them Opposes transfer of personnel from Albo to Rockville, believe we need personnel close to the people they serve.
	Patricia Martin, council member, Yakama Nation	Support entitlement, Partnerships yes, we need other agencies here, HHS, BIA, HUD--all those agencies we go to for funding-it is so fragmented now- Safe Water and Sanitary Facilities, commend you for listening to us at regional meetings.--Example of sanction for paperwork oversight, bureaucratic inflexibility--There is a need for training and training in the West, not all back East (HUD example NAHASDA) Self-determination hard for federal agencies
303		Exemption from Davis Bacon needs to mention throughout
307		Hospice... make sure we pay attention to "elder care facilities"
	Norma Peone, Coeur d'Alene Tribe, Vice Chair	Until Indian Health Service provides for needs on reservations expansion beyond reservations difficult We do serve needs of urban Indians. Tribes are not against the needs of Urban Indians. We need to be careful what we say on this.
	Fred Hubbard, White Mountain Apache	Concern on preamble, section C, priority setting separate from national objectives could be problematic
302		Loans Utility authorities had a bad experience, Add necessary sewer and water dollars included in these

		authority's agreements.

Rachel: Arizona CHS will be addressed in Title II.

Henry Gagey on preamble question of Vice Chair Hubbard, preamble reflects view that priorities should be set by tribe.

Questions: Workgroup 1, Titles I, II, V, VII

Section	Commenter	Comments
	Fred Hubbard, White Mountain Apache	What happens to current programs (example of home/community based care that are newly included in the Act? If they are non- 638 programs can they be included in pay back?
705	Joe Bulfer, Southern California Indian Health Council	YTC, Funding is not recurring-so this is incorrect, specific language is needed for Youth Treatment Centers YTCs "now d 4 a" Funding issue has not been addressed, we've looked for a separate line item funding. We'd like it in new Act. See written comments This is not in conflict with 'network' in CA.
404 Title IV	Joe Bulfer	TANF programs need some language to allow tribes and tribal organizations to determine eligibility for TANF and Medicaid, CHIP. See written.
	Emmet Francis Navajo, from Mayor's office City of Albuquerque	Make sure urban Indians are included in all references to Indian organizations in the Act. Example of loss of dental clinic SIPL Health clinic in jeopardy too. Written comments to follow.
213	Marie D. Talieje, Hualapi	I don't see programs specifically for men
103	Tony McNevin, College of Podiatric Medicine	Comment on diabetes, ambutations, Recrutiment, Indian youth need access to training, role models,
201, 204		Don't neglect podiatric care

		Health Profession residents provide important care, Recent Medicare reimbursements changes for residents threaten services provide in your programs, Need quarters for residents.
	Rudy Clark, Hualapi, Urban Indian	Referenced meeting with department heads (reinventing government) We, as tribes, need to address needs rather than agencies Other funding sources too-referenced Community Development Block Grants Be pro-active Appropriations comments.
204	Lorraine Valdez	Staff at IHS HQ diabetes Have diabetes control officers been crossed out? They are now area diabetes consultants, conducting surveillance, training, Referenced BBA diabetes funding($30 million for 5 years) Consider reinstating area diabetes consultants.
201 sub 2, a	Jim Crouch CRIHB	I would like to add actuarially sound basis to this subsection.
706	Alida Montiel, ITC Arizona	Need more emphasis on traditional healing in mental health programs as part of the team.
	Alma Young, Fort Belknap, Mt	Water issues in Montana, gold mining pollution Gros Ventre and Assiniboine tribes also oppose cyanide leach mining. Call on Indian Health Service to monitor water quality, conduct epidemiological study. See written comments. Appropriations comments.
	Donna Begay, Sacramento, CA Urban Indian Health Program	We need a national information system We need information to share lessons learned
	Melvina Molatare, Blackfeet Tribe	Indian Women Treatment How do you trace whether authorization results in funding.
	Beverly Wright, Tribe located on Martha's Vineyard (Gays	Entitlement volunteer. CHS is paid at 100% of charges, Recommend mandatory Medicare rates for Indian health programs this would double purchasing power.

	Head, MA)	
105 (3) c?	Dr. Yvette Robidaux, AAIP American Indian Physicians ,President American Health Program, U of Arizona	Oppose Payback requirement in area, change language to, 'if possible.' Support the idea, but this is not always possible.
		Diabetes control officers still needed.
	Mickey Percy, CEO Chicksaw Nation	Issue on urban demonstration projects in Oklahoma, there is no consensus in OK on this. Support having two urban programs becoming permanent, but oppose 638 exemption. Wants tribal option to compact or contract in the future. Dr. MacKenzie, She, noted that National Steering looks to Oklahoma for resolution.
512	Melanie Knight, Navajo Cherokee Nation	Also noted support for urban programs in OK (Tulsa, OK City), Government to Government relationship essential to resolution, supports 638 option for tribes.
	Dave Baldridge, NICOA National Indian Council on Aging	Diabetes, and other health issues do affect elders. Support Lorraine, and Yvette Robideaux, on importance of area coordinators for diabetes. Commend attention to elders, long term and home and community based care.
	Nicole Guardaipe	Supports local level administration of scholarships, selection of recipients. Preamble: Supports premise of tribal governments and historical obligation, based on Trust responsibility.
	Jerry Waukau, (Walker) WI	Tribal colleges support, each Area is different. Supports more use of technology, more flexibility, distance learning.
209		Epi Centers. Must show where money is going. Provide good data on chronic diseases. Fully fund epi cnt.
	Dennis Nissim-Sabat, American Psychological Association	Commend keeping Indians into Psych. In the Act. And attention to Mental Health. Should add a section on developing a "suicide prevention coordination center"
204	Carmelita Skeeter	Does not support closing "model diabetes centers" run by IHS, such as Claremore. Also concerned about closing Indian Women's Health Office. Supports language developed by urban Indians on Section 512 and has written support of Creek Nation.
	Brian Eagle Man, Chippewa Cree	Support for Public Schools with high Indian enrollment

	Jeff Zang with Congressman Martinez of California	Consider involving Indian staff working on "the hill" to help Indian Health Care Improvement Act. Hold meetings in Washington, DC. Write you Congressman, keep an eye on the hill on multiple issues.
	Rudy Clark,	Open door efforts with Legislative Offices. Watch the bill to make sure no other language is inserted.
306(c) 204	Dr. S.S. Batwa	Funds should go directly to Area Offices based on # of users. Change paragraph. Sec 204: Diabetes is also a mental health problem, not just medical. Give medical staff mental health training.
807	Rachel Bigknife, recipient of scholarship	Eligibility language should be changed to provide services to Indians wherever they live before providing services to non-Indians.
512	Perry Beaver	Support permanent demonstration project. Tulsa clinic is unique with multiple tribes with jurisdiction in that area. What is something goes "wrong". We request oversight or some language, in case demo projects does not meet standards or something goes wrong, that we could take out our funds with concurrence other tribes.
512	Terry Hunter	OKC serves many tribes. In OK we have not reached consensus on Section 512, but working on it
204	Terry Hunter	Support restoration of Area diabetes coordinators
209	Colleen F. Cawston. Chairperson, of Confederated Tribes of Colville	Epi Centers. Concerned about proposed changes. Deletion of (unclear) will hinder diabetes effort. Contractability should be with the concurrence of all other affected tribes in the area.

Questions: 4:00 PM DAY 1 (July 28)

Section	Commenter	Comments
105	Joe Bulfer CA	Opposition to deleting 105 (c) requiring payback in own area for scholarship recipients
Title 3,	Joe Moran, council member, Salish and Kootenai Tribes	Add provisions to make it more flexible as we did on 301(2)
		CHS language should be provided to committtee
Title V	M. Lande	Men's Health- Support specific references
	Robert Shakezey	Disability issues, cannot forget them in reauthorization
	Patricia Martin, Yakama	
210		School health activities, make consistent with school wide goals
702		MOA with D of Interior recommend expansion of agreement and include department of Education
302		Sanitation Deficiency listing Our SDS system shows a major backlog, have we thoroughly examined this? Tribes need to look/organize as we look at that listing.
	Rudy Clark	Commented on advocacy, working with congressional aides, possible tribal leader letter
	Marie D. Talieje, Hualapi	Need to end reliance on Indian Health Service
	Tex Hall, Chair, Three Affiliated Tribes, National Steering Committee member	We need to emphasize the trust responsibility and treaty obligation of the federal government. Support for entitlement status in the Act. Go for it now.

		Yes we need to be united, tribal, direct service, urban Equal access no matter where you come from. Speaking with one voice is important. In facilities, we need to support effort for those tribes that can't get on that list, (noted the smaller tribes).
302	Hatch	Sanitation, solid waste disposal, Clean water act, utility Has increased costs three fold (119%). Act needs to address issue of contracts with local utilities. Address difficulty tribes have operating their own utilities.
	Trudi Zopah White Mountain Apache	We need to pull together — tribal, Indian Health Service and urban. Let's get going.
	Bill Wallace, Gros Ventre, Montana	Appropriations comments, Poor socio-economic indicators, See written comments. Comments on trust responsibility
	Edward T. Begay, Speaker, Navajo Nation Council	Commend drive for speaking with one voice, Participated in Area and regional meetings, Noted congressional attention to reauthorization Use voting power to influence Congress Noted new Executive order is coming on government to government relationship and tribes always need to emphasize the importance of honoring this relationship.

	Priscilla Antone, Gila River	Hospital has not received its start up costs — 6 years after contracting Wants support in fight to receive contract support cost start up costs.
	Paul Sherry Alaska Consortium	Substance Abuse needs for American Indian and Alaska Native youth need to be addressed. Introduced youth from Alaska.
	Morris Reed	Look at smaller agencies , make sure small programs get attention too.
216	Frank Ross	California counties, please recognize the needs of non-recognized tribes in CA to receive services including CHS.

Questions: DAY 2

Michael Hash address was followed by Questions. This Appears first.

Section	Commenter	Comments
AM	Yvette	Question on scoring the proposals. The cost of our proposals will be key and we don't want unreasonable/unfair cost estimates.
	Michael Hash	Health Care Financing Administration agrees that to the extent that American Indians and Alaska Natives are currently eligible they should not be scored as a new cost paid or offset. Reimbursements that are greater than what would otherwise occur would raise the issue of scoring. I am hopeful that will be fairly addressed. For Health Care Financing Administration the important thing is to structure the delivery system so current eligibles receive services.
		We will work with CBO on determining costs of differing /appropriate differences in how we structure delivery systems.
		Yes budgetary scoring will be raised.
		No dispute that current eligibles should be served and they do not represent new costs for purposes of scoring.
	Jim Crouch	It was a positive meeting at Health Care Financing Administration on July 26. Navajo project very positive, appropriate.
		Health care is driven by health data. In California Health Care Financing Administration does not control the data about American Indians and Alaska Natives participation in California. If we had our own Medicaid agency status we would have better data to help with things like disease burden. Again it was a positive meeting with Health Care Financing Administration in Baltimore on July 28.
	Hash	Yes data important, Risk adjustment important and this gets at the heart of the need for information on the people that you are covering.

		If there is high incidence as there is in Indian country. The allocation of resources should reflect this.
	Hash	Yes it was positive, there are opportunities.
	Jim Crouch	The Level Of Need Funding Workgroup has worked on this and it demonstrates that disease burden increases cost 15 %.
	Alida Montiel	Concern about not adding resources. CHIP in AZ is not a Medicaid expansion it is a title XXI stand alone. Extension of Medicaid to 100% of the poverty level needed. Who do we need to talk to about who is tracking the Indian Health Care Improvement Act We don't want to have big surprises. What working relationship will continue?
	Mr. Hash	Steering committee with Indian Health Service and Health Care Financing Administration And will discuss recommendations from the draft act. We will continue working with you.
		As an administration we are only one voice, critical one. You need to advocate in the Congress as well, of course. Need to develop consensus. We want to be supportive. Will focus on it in August.
	Julia Davis	Thank you for coming. Tribal consultation is very important to us. I have not seen a good effort to improve consultation. They need to bring tribal leaders to the table. Estate recovery an important issue that we want the Health Care Financing Administration help on. I hope we are showing up at the right places. We want to be a visible presence. We want feed back. Estate recovery does present hardships. We need to take a careful look at the policy. Unintended consequences. We need to look carefully at lands being appropriated for nursing home costs. Ultimate solution will require congress' involvement.

		We can be advocates for other obligations.
	Julia Davis	Glad to set up a meeting with Health Care Financing Administration.
	Taylor MacKenzie, Navajo	Comment on trials and tribulations of working with states. Navajo would like a direct relationship with Health Care Financing Administration.
	Michael Hash, Health Care Financing Administration	We are reviewing the tri-state Medicaid proposal. The law does make the states a partner in this relationship. We understand your position for a direct relationship. I t will be a decision involving the Congress and the executive branch. We need to continue to refine proposal. We need to work on having better relationship with states. We have oversight role here. Federal law needs to be carrying out enforcement and oversight with states. If we are not diligent enough, let us know if states are not filling this obligation.
	Yankton Sioux Tribes SD	We have worked with state on an innovative proposal that has gotten lost in the bureaucracy. Case management for substance abuse women. It seems to have gotten lost in the Baltimore office. HCFA and the State insisted we worked with Indian Health Service --we worked that out. How do we keep these from getting lost?
	Mr. Hash	I will look into how this got lost. Your model is something we can all support. I can find out about it.
	Jerry Walker Menominee Tribe, Wisconsin	Badger Care, Copayments for those over 150% poverty guideline. A decision needs to be made on copays. Cost sharing. There is a role for you here. Indian people are not being served.

	Mr. Hash	Cost sharing will be addressed early this fall when we publish CHIP regulations.
	Edward Begay, Speaker Navajo Nation	Executive Order We are now in the arena of government to government relationship. Consultation is not handing out papers, but being across the table working with us. We want to be on the same playing field as the states.
		For program funding or policy decision it is crucial that you follow the President's executive order to work with us.
	Mr. Hash	Couldn't have said it better. This is our approach to working on a government to government relationship. You are right on point.
		Thank you again. Again Health Care Financing Administration wants to reach all eligibles.
Section	Commenter	Comment
408 (f)	Bob Newcombe, Alamo School Board	New phrase attached to old provision, "unless tribe authorized.." Wants to see old provision stay. Or add another phrase, between writing and such, "by resolution of such tribal governing body". Nobody in a tribe just by writing a letter should be able to open up self-insurance. (see written comment)
		What would be difference between 405 and 1911(c) dealing with direct billing? Response was there are no differences. Indian Health Care Improvement Act must also amend Social Security Act to be effective. (there will be even more cross references)
		What's difference between FQHC and QIHP? Trying to protect FQHC status, QIHP would give greater power to package of services (larger) and 100% of actual costs no reasonable costs.
404	Bobo Dean, counsel for several tribes	Clarification on SEC agreement with I/T/U's? Doesn't mean IHS does it.
	Anthony Hunter, American Indian Community House, NYC	This is excellent product from consultation process. Thanks to this Workgroup. Everything is addressed! -- Declaration of National Policy: should mention role of I/T/U to help the people, and be advocates, should cover monitoring care to Indians when provided by other systems, MCO's, VA, etc. This new bill clears the path for smaller T/U's. (see written comments for Preamble)
406	Everette Eno, Trenton Service Area	Does this address recipient liability? Alternate resource is Medicaid, but it also includes "recipient liability" or premium. It puts burden on patients. Can this be addressed? This section eliminates recipient copays, premiums, and contribution to

		costs of care. Comment on Entitlement: There are those that feel health care is a "hand out". To Indians it is an entitlement. We should support entitlement.
	Norma Peone, Coeur d 'Alene Tribe	NW Portland area has problem with Medicaid paternity issues. IHS requires alternate resource, but state Medicaid agency will go after parent. This shouldn't happen. Thanks to Ed Fox! Whole section important to Portland Area.
414	Alida Montiel, ITCA Intertribal council of Arizona.	Thanks to Phoenix and Tucson area consultation participants, specifically T'O. Regarding Tuba City, why would tribe want to be reimbursed on capitated basis when we have other options? Have been working hard to apply encounter rate or cost-based for I/T/U's. Response: AZ has been advocating capitated basis, asking for demo sites, Navajo Nation and Tuba volunteered to participate. Just a demo, and will produce results to assess if it is good or not good for Indian country.
	Alida Montiel	Crediting of Reimbursements doesn't include urbans. Section 417 covers urbans for all sections in Title IV. Just need to clean up language.
	Edward Begay, Speaker, Navajo Nation	Thanked those who contributed. See Written comments
		This document needs to be a tribal document. Material considered at regional meetings should be reflected in the document. Health care for Indian people should be an entitlement. Managed Care will not go away soon. Need to test managed care principles, Tuba City a type of tribal initiative that should be supported. We believe in maximum recovery of Medicare and Medicaid and CHIP. Support for proposed Navajo Medicaid agency. Feasibility study for the universal health insurance card (check name). Support a core set of health services be available for all American Indians and Alaska Natives.
		Current draft of proposed amendment does significantly improve opportunities for Indian people. Propose introduction to the Congress.
Entitle-ment	Michael Jackson, AZ	Supports entitlement as a right.

Entitle-ment	Buford Rolin	We do want to hear from tribal leaders, not our intent to oppose, but to take a good look at entitlement status.
Entitle-ment	Dennis Smith, Duck Valley, Shoshoni-Paiute	Will the entitlement group have national recognition? I recommend NCAI or National Indian Health Board. Let's figure this out.
	Buford Rolin	We have list of volunteers. Get on list that Julia has.
406 (a), (b)	Siu Wong	Indian Health Service Albuquerque, Area Why does this only apply to I/T/U? Response: in fact it does go beyond this-covers referrals.

Questions: DAY 2

TITLE 6 and 8

Section	Commenter	Comments
	Tony Largo	Noted importance of Negotiated Rulemaking process-This is in Title VIII look it over.
	Yvette Joseph, National Indian Health Board.	Negotiated Rulemaking process is important feature.
		Eligibility issue (given limited funding) may require neg-reg process in the future.
		Reporting, one central location for information recommended
	First name?.. Stiffarm, Denver, Indian Liaison Ft. Peck	Came to listen, visit with relatives/friends and talk, importance of 'one voice' Importance of listening to those who do live off-reservation.
	Former council member	Understands the importance of the government to government relationship.
		Attempts by some to divide. Those not living on reservation are a resource for tribes.

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Statement of H. Sally Smith
Chairperson
National Indian Health Board
On the
Reauthorization of the Indian Health Care Improvement Act
March 8, 2000

Good Morning, Chairman Ben Nighthorse Campbell, Vice-Chairman Daniel Inouye, and distinguished members of the United States Senate Committee on Indian Affairs. I am H. Sally Smith, Chair of National Indian Health Board (NIHB). I also have the honor of serving as Chair of the Alaska Native Health Board, Chair for the Bristol Bay Area Health Consortium and Treasurer for the Alaska Native Health Consortium. Locally, I serve as the Member Chief – Secretary and Tribal Judge of the Native Village of Dillingham. Nationally, I also serve on the Tribal Self-Governance Advisory Committee, on the Tribal Leaders Diabetes Committee and on the National Steering Committee on Reauthorization of the Indian Health Care Improvement Act (P.L. 94-437).

I am pleased to be here today to testify on pending reauthorization of Public Law 94-437, the Indian Health Care Improvement Act (IHCIA).

The NIHB serves all 558 Tribal Governments in advocating for the improvement of health care delivery. Our Board Members represent each of the twelve Areas of the Indian Health Service (IHS) and are generally elected at-large by their respective Tribal Governmental Officials within their regional area. We have the duty to ensure that the solemn treaty commitments made to our ancestors are upheld in all matters related to health and human services.

Trust Obligation of the United States

The federal responsibility to provide health services to American Indians and Alaska Natives has grown out of the unique relationship between Tribal Governments and the United States. This government to government relationship arises from Article I, section 8, clause 3 of the United States Constitution, which gives specific authority for federal supervision of Indians. Over the course of 200 hundred years, the unique federal/tribal relationship has been underscored by Treaties, Statutes, Executive Orders, and U.S. Supreme Court decisions.

For American Indian and Alaska Native people, the federal responsibility to provide health services represents a "pre-paid" entitlement, paid for by the cession of over 400 million acres of land to the United States. In many of the treaties which were negotiated between Tribes and the U.S. government, specific provisions for basic health care, such as the services of a physician and the construction and maintenance of hospitals and schools were included. The Snyder Act of 1921, provides the broad authority for Congress to appropriate funds for the, "relief of distress and the conservation of health", among American Indian populations throughout the U.S. This permanent authority is recognized as the foundation for numerous federal programs, including Indian health care. In 1954, the Transfer Act transferred the responsibilities for health care from the Secretary of Interior to the Secretary of Health, Education and Welfare which brought a much needed public health focus towards restoring health among American Indians and Alaska Natives.

Let me begin by stating it is the consensus of the members of our board that we have a duty to ensure that the special Trust Responsibility, acknowledged and adhered to by the federal government in its relationship with the tribal nations, continues. It is an obligation of the United States Government to make certain that comprehensive health care is provided all American Indian and Alaska Native citizens.

In 1976 when Congress enacted the Indian Health Care Improvement Act, it favorably and forever changed the face of Indian policy. The Act is one of the most comprehensive efforts by Congress to address the health needs and health status of American Indian and Alaska Native populations through a series of initiatives. Its intent was to address long-standing deficiencies in Indian health care; to increase the number of health professionals serving Indian communities; to authorize services to urban Indian populations; to rectify health facility problems; and to provide access for Indian patients to other federal health resources such as Medicaid and Medicare. The IHCIA provided comprehensive directives to the federal government with regard to Indian health, and with the Snyder Act provided overall guidance and authority for the programs of the IHS.

Since its enactment 24 years ago, IHCIA has been amended numerous times and reauthorized four different times by Congress. Although improvements to the health status of American Indians and Alaska Natives have been accomplished, Indian health continues to lag behind all other groups in the United States. In addition, federal appropriations for Indian health have been shrinking relative to inflation, making it more difficult to provide health care to American Indians/Alaska Natives (AI/AN), including IHS, Tribes and urban Indian health organizations. Other trends, such as managed care and its relationship to Medicare and Medicaid programs, have strained budgets for these health programs even further.

Development of a Tribal Proposal

As we are all aware, at the end of Fiscal Year 2000, the IHCIA is scheduled to expire. Over this past year the Indian Health Service, (IHS) sponsored a major consultation and drafting effort to bring together tribes, IHS and urban providers to make recommendations in drafting a proposed bill for reauthorization. This was accomplished by the IHS convening a National Steering Committee (NSC) with representatives from Tribes and national Indian organizations.

Over the course of five months, the NSC drafted specific proposed legislation, which was based upon the consensus recommendations developed at four regional consultation meetings held earlier in the year. A copy of the first draft was mailed to every tribe and every urban program on July 16th of last year, soliciting written comments. More than a thousand written comments were returned to the National Steering Committee and carefully considered as the final proposal was drafted. The final bill language was reviewed by the Steering Committee on October 5, 1999 during the National Congress of American Indians Convention in Palm Springs, and was adopted by consensus. NIHB was involved from the very beginning with the National Steering Committee and strongly endorses the final draft reauthorizing the Indian Health Care Improvement Act. Suffice to say, P.L. 94-437 and its subsequent amendments was undoubtedly one of the most important laws affecting the health of American Indians and Alaska Natives. I hope we will continue to build on that progress by finding new ways to improve the health of our tribal populations.

Summary of the draft bill:

Title I – Indian Health Manpower:

Purpose: To increase the number of Indians entering the health professions.

Proposed Change: Use of generic terminology to include all health professions rather than a specific discipline.

Comment: In the early 1970's there were very few identifiable AI/AN health professionals. For example, in 1972 there were 75 AI/AN medical doctors but today, that number has more than quadrupled because of the Indian Health Care Improvement Act. Over 90 percent of all AI/AN health professionals who graduated under scholarship programs authorized by the IHCIA are serving villages in Alaska, on reservations in the lower 48 or addressing the needs of tribal populations in urban areas.

Proportionately, we still have fewer AI/AN health professionals than our population demands. Also, despite our advancement in recruitment, retention

and placement a new dimension has been added to the equation, one which came about because of the increased number of AI/AN health professionals working with our tribal populations. As our knowledge broadened, we became increasingly aware of disease patterns revealing variations that were influenced by socioeconomic status, tribal genetics and culture. Unless we can continue to build a cadre of health professionals who can utilize the health sciences to understand the differing incidence of disease, the affects of these diseases, and tribal response to treatment, the gap limiting the health status of our tribal populations will continue to widen, further lowering the quality of life for AI/AN's.

Title II – Health Services:

Purpose: To expend funds which are appropriated to eliminate health deficiencies and resources in all Indian tribes.

Proposed Change: Reflects the increased assumption by Tribes of health programs and the changes in health care delivery since the last reauthorization and moves Section 209 Mental Health Services to Title VII, Behavioral Health.

Comment: Far too many of our tribal members continue to die before the age of 40. Diabetes, heart disease, cancer, high cholesterol, chronic liver disease, severe obesity, smoking and inactivity are all health problems AI/ANs suffer more from than the general population. These health problems were not part of our way of life generations ago. Today, across Indian Country, there is a continuing effort to blend Western knowledge with traditional knowledge, thereby providing a delivery of health services acquired through knowledge gained from the best of both worlds.

Since the enactment of P.L. 94-437 the health status of AI/AN's has improved through a concentrated effort by federal agencies and tribal governments to address issues related to the delivery of health services. With the inclusion of language added to many sections of this Title requiring consultation, tribes and tribal organizations are assured of their ability to carry out a broad range of health programs. However, we have yet to reach a level equal to that of the general population. We cannot rest until our tribal elders, many of whom were forcibly removed as children and placed in off-reservation boarding schools, are assured of access to long-term care within their homelands. Not until we can provide home and community based services to our terminally ill tribal members, can we rest. And, not until we can exercise our right of self-determination to effectively eliminate backlogs in health care services to all American Indians and Alaska Natives can we rest.

Title III – Health Facilities:

Purpose: To provide construction and renovation of health facilities.

Proposed Change: Provide a comprehensive view of unmet facilities needs to President and Congress for development of funding opportunities to meet needs.

Comments: The IHS implements construction projects under the authority of the Snyder Act of 1921. Over the years annual appropriations from Congress for facilities construction has varied. For example, it has fluctuated from $32 million in FY 1984, dropping to only $14 million in FY 1989, and up as high as $134 million in FY 1993. In 1994, the IHS conducted a thorough assessment of facility replacements and modernization for purposes of bringing all facilities up to levels competitive with the private sector. In the 1994 analysis, the estimated total need was $3.2 billion. Unfortunately, at the pace Congress appropriates new construction funding it will take over 70 years before all the projects on the current priority list are constructed. The NIHB supports changes to this Title that will help eliminate barriers and create innovative opportunities for construction of new and replacement health care facilities in Indian Country.

Title IV – Access:

Purpose: To address treatment of payments from third party collections.

Proposed Change: Most references to facilities replaced with programs to allow for reimbursements outside of a facility.

Comment: Many of Indian people do not have access to health care. We are well aware that the per capita expenditure for an Indian person was $1,430 as compared to $3,369 for a Medicaid beneficiary and $5,458 for a Veterans' Administration beneficiary. As you can well observe, Indian people in the Indian Health Service programs are not being served under the Nation's first prepaid health plan at a level which even meets one-third of what is available to a Medicaid and one-fifth of what is available to Veterans' Administration beneficiaries. Even though many Indian people are eligible to participate in Medicaid and Medicare, there are many barriers which limit their participation. Tribal and IHS health programs do not have equal access to these programs due to technical legislative impediments. At the same time, new Medicaid managed care efforts are largely controlled by State governments and managed care providers who will do their best to count Indian patients as a part of their plan, but will not make reasonable reimbursements to Indian health programs. And while improvements have been made to increase reimbursement rates within Indian health programs, the net gains in collections simply do not equal the disparity inherent in the IHS Budget.

Even when Indian people secure care in IHS or tribal programs, they may not have access to a full range of health care services that insured people or non-IHS clients enjoy. Senators, as you are aware being an AI/AN does not mean one enjoys full health coverage, as many Americans tend to think. IHS clinics are typically wrought with long waiting times, crowded clinic conditions, and minimal time to see the provider. Many IHS facilities do not have the technology enjoyed by others. The IHS system remains underfunded, even though there continues to be severe health status deficiencies among our tribal populations. The NIHB supports removing limitations on the IHS, Tribes and tribal organizations to bill Medicare, Medicaid and Child Health Insurance Programs so that Indian health programs can take maximum advantage of this funding stream.

Title V – Health Services for Urban Indians:

Purpose: To establish accessible health services to urban Indians.

Proposed Change: Provides urban Indian programs with protections and access comparable to those available to other Indian health programs without compromising tribal sovereignty.

Comment: For the record, I believe it is important to reiterate the moral and legal responsibilities to AI/ANs, in which the U.S. government appropriates funds for the Indian health care system complementing a partnership of federal, tribal, and urban Indian operated health care programs. Despite these moral and legal principles, AI/AN's have long experienced health problems disproportionately compared with other Americans. Whether they are reservation or urban, their life expectancy is less than other Americans, they die at higher rates than other Americans and their lingering health disparities are shocking. It is no wonder that when provided an opportunity to recover their position of self-sufficiency they migrated to America's cities with the hope for a better quality of life.

The migration which began after World War II was promoted by the Bureau of Indian Affairs which advocated the "Relocation Program" to tribal populations. It is estimated that over 160,000 of our tribal members were relocated to urban areas between 1950 and 1960. In light of our strong tribal kinship systems, we must never forget the hardship our family members suffered as they found themselves in cities where little support, if at all, was provided them. Although life on the reservation and in the villages was also difficult, we continued to be closely related socially and culturally as families, within our respective tribal units. None of that has changed.

Studies on urban Indian populations reveal a serious lack of adequate health care. Under the IHCIA, Title V specifically authorizes health outreach and referral and the delivery of services to Indian people in urban areas. The NIHB

supports the draft language within Title V, which represents a wide array of health care opportunities for urban Indian centers. These include requiring the Department of Health and Human Services to set up procedures for consultation with urban Indians on issues affecting the AI/AN people they serve and to allow for urban Indian programs to obtain malpractice coverage under the Federal Tort Claims Act.

Title VI – Organizational Improvements:

Purpose: To establish IHS as an agency of the PHS.

Proposed Change: Possible language to include the elevation of the Director of IHS.
Comment: For the last three years, the NIHB joined forces with the Tribal Self-Governance Advisory Committee and the National Council Urban Indian Health to request special legislation to elevate the Director of the Indian Health Service to Assistant Secretary for Indian Health within the Department of Health and Human Services. We appreciate passage of S. 299 and hope the House will soon take action on their companion measure. If they do not, we believe elevation should be added to the reauthorization bill.

Title VII – Behavioral Health:

Purpose: To outline responsibilities of IHS pursuant to section 4205 of the Indian Alcohol and Substance Abuse Prevention and Treatment Act of 1986.

Proposed Change: The aim is to integrate substance abuse, mental health and social services into holistic Behavioral Health programs.

Comments: Statistics reflect the effects of cultural oppression, racism, loss of traditions, boarding schools, and its impact on family and parenting, alcoholism and substance abuse, and internal violence as major contributions to sustained, multi-generational behavioral problems in our American Indian and Alaska Native communities. The NIHB supports integrating programs which are nurturing, fulfilling, accountable, and responsible in their ability to offer significant insight and opportunity for wellness and balance in our tribal communities. Tribal communities are taking a leadership role in addressing the myriad of needs associated with behavioral health problems, therefore the ability to contract and compact will offer greater coordination of resources to achieve the goal of tribal wellness.

Title VIII – Miscellaneous:

Purpose: To address various topics.

Proposed Change: Establishment of an Entitlement Commission, and enacts provisions for negotiated rule making and various other improvements.

Major Concerns

The National Indian Health Board recognizes that the complexity associated with Indian health care, as with non-Indian systems, is significant and far reaching. Each of our Board Members have been engaged in extensive dialog within their respective Areas with Tribal Leadership, tribal health directors and health care providers. Once a Senate bill is introduced, we expect each of the respective Area Health Boards and Intertribal organizations will consider their position and will offer resolutions of endorsement and opposition later this Spring. Since nine of our Board Members were a part of the National Steering Committee responsible for drafting the bill, we will likely support the enactment dependent on the views of each Area. At this point, we want to emphasize the following points.

Maximizing Local Tribal Control

Twenty-five years ago, two important public laws changed the delivery of health care in Indian Country. The Indian Self-Determination and Education Assistance Act of 1975 (ISDEAA), and the 1988 and 1994 Amendments to the Act, as well as the Indian Health Care Improvement Act of 1976, gave new opportunities and responsibilities to the Indian Tribes and tribal organizations in the management of health care services. Self-Determination and Self-Governance provided for in Title III of the ISDEAA today is having a significant impact on the way Federal health services are provided in Indian communities. The IHS reports that at least 45 percent of the budget is currently under an Indian Self-Determination contract or Self-Governance compact. In our study, *"Tribal Perspectives on Indian Self-Determination and Self-Governance in Health Care Management"*, we found that of the 210 tribes surveyed, 75 percent were already contracting some IHS program and within the next five years 94 percent planned to be under a contract or compact with the IHS. Tribes involved in this study report improved quality of care and better health systems after contracting and compacting.

The policy of Self-Determination and Self-Governance is having a profound impact on health care in Indian Country. Utilizing the insights from their experience in managing their health care services, Tribal Governments are

working to ensure that new policies and the budget authority contained within the annual budget justification document is responsive to their health needs.

In order to ensure that the Indian Health Care Improvement Act is responsive to the growth of Indian Self-Determination Contracts or Self-Governance Compacts, we strongly support the policy changes contained in the Tribal proposal.

Promoting Innovation, Flexibility and Creative Financing in Facility Construction

At present the Indian Health Service does not provide Congress with information on the full health facilities needs in Indian Country although the absence of adequate health facilities is well known to be one of the primary obstacles to health services improvement. We strongly support the requirement in the bill which requires that IHS provide this information to Congress annually. In addition, we urge enactment of the innovative approaches to increase the resources available for health facility construction, renovation and expansion contained in Title III.

Need for Entitlement Designation

The bill addresses the issue of the right of American Indians and Alaska Natives to receive services provided for in the Act and in many Treaties. By establishing an Entitlement Commission including Congressional and Tribal Representatives to study the questions which need to be resolved in defining an entitlement, we expect: (1) to clarify just what types of services are included; (2) to whom does the entitlement serve (individual Indians or Tribes); and (3) how is the entitlement to be funded.

Authorization for Appropriations and Balanced Budget Act Concerns

When the Senate Committee on Indian Affairs held it's briefing on the proposed amendments to the Indian Health Care Improvement Act on February 17, 2000, a question was posed about the potential cost of the entire bill. It was noted that new amendments would be subject to Appropriations caps and since the bill would still be considered as discretionary and not necessarily an entitlement measure, the pay-as-you-go rules would not be applicable. The National Indian Health Board is just anxious as the Senate Committee to review the Congressional Budget Office estimate so that we can ascertain the costs of this draft bill.

In anticipation of the cost estimate, the National Steering Committee on P.L. 94-437 requested a section-by-section analysis of the existing authorization bill which displays authorizations as compared to appropriations. It should be noted that the existing law contains 120 provisions, of which 93 would be

regarded as actual authorizations for appropriations. At least 27 provisions are to be considered "not applicable" in terms of directed appropriations. Some provisions indicate a certain level of authorizations ""not more than" a certain amount or "not less than" a certain authorization amount. And many provisions authorize "such sums as are necessary". **We raise this point because we want to be perfectly clear in noting that only 27 of the 93 funding authorities are indeed funded with appropriations in the existing law.**

In FY 2000, the 27 provisions which are actually funded in the Indian Health Care Improvement Act amounts to $382.4 million. There are 66 provisions which constitute "unfunded mandates" in the existing law. The anticipated cost for these 66 provisions is not available, however, the establishment of these authorities in 1992 did not complicate enactment of the reauthorization bill.

It is anticipated that certain provisions contained within Title IV of the legislative proposal will have limited budgetary impact affecting Medicare, Medicaid and State Child Health Insurance Programs. However, we want to make it very clear that much of the scoring associated with these provisions is already counted for within the existing entitlement spending authorized for under these Social Security Act programs. The provisions we seek merely enhance the access potential for American Indians and Alaska Natives who qualify for these programs and are counted for within the current offsets contained in these Social Security Act programs. The benefits they provide are consistent with those given to other special providers and recognize the unique relations between the United States and Tribes. The costs for implementing the Title IV programs are insignificant in the overall budget for Medicare and Medicaid and in many cases are already present in the program. We look forward to studying the CBO estimate to consider the cost implications of these amendments.

Interim Extension to Maintain Authorization

We are very aware that this year is a Presidential election year and it is understood that very few authorization bills will be able to successfully weave their way thru the legislative process. Tribal Governments are still optimistic that the proposal sent forth by the National Steering Committee on P.L. 94-437 will be enacted within the 106th Congress. And yet it is understood that the comprehensive aspects of this legislative proposal may require extensive discussion by the Committee's Members. Once the bill is introduced, we respectfully recommend that a reasonable timeframe for hearing consideration be specified within the Sponsor's Introductory Statement so that Tribal Governments can plan for potential field hearings if requested by Members of the Committee. We believe it is reasonable to limit the number of hearings since the draft bill was the subject of extensive discussion by Tribal Governments during the ten months of its development.

In the event that enactment of this bill is not possible, we recommend that the Committee send forward a request to the Interior Appropriations Subcommittee requesting that the Indian Health Care Improvement Act be extended for a period of one year beginning October 1, 2000. This extension will ensure that existing authorizations for appropriations are continued while the bill is under consideration.

Request for Field Hearing

In the event that the Senate bill is not reported out of the Committee by August 21, 2000, the National Indian Health Board respectfully requests that a field hearing be held during our Annual Consumer Conference this summer. The 18th Annual Consumer Conference will be held in Billings, Montana, during the week of August 20 to 25th, 2000. The eight tribes who comprise the Montana – Wyoming Area Indian Health Board will be serving as our hosts this year and would be certainly welcome the Senate Committee on Indian Affairs to this event.

Conclusion

On behalf of the National Indian Health Board, we thank the Senate Indian Affairs Committee for hosting today's hearing on the Indian Health Care Reauthorization proposal.

As Chairperson of the NIHB, I pledge our organization will help educate the Senate Finance Committee, House Resources Committee, House Commerce Committee, House Ways and Means, and House Government Reform Committee on how important reauthorization is to the health needs of American Indians and Alaska Natives.

I call upon my Indian friends to work together with the distinguished Chairman of the Senate Committee to uphold the Treaty commitments of our ancestors to ensure that our health care fully meets our needs. Indian health care is a right and reauthorization is vital to the health of our people. Thank you!

Testimony of

Kay Culbertson, President
National Council of Urban Indian Health

Before the
Senate Committee on Indian Affairs

On The Reauthorization of
The Indian Health Care Improvement Act

March 8, 2000

I. INTRODUCTION

Honorable Chairman and Committee Members, on behalf of the National Council of Urban Indian Health and its 34 member programs, I would like to express our appreciation for this opportunity to testify before your Committee on the reauthorization of the Indian Health Care Improvement Act (IHCIA).

Founded in 1998, NCUIH is the only membership organization of urban Indian health programs. Of the 60% of Native Americans and Alaskan Natives who live off-reservation, slightly over half live in urban areas. NCUIH seeks, through education, training and advocacy, to meet the unique health care needs of this urban Indian population. NCUIH members provide a wide range of health care and referral services in 34 cities, actively serving a population of 332,000 urban Indians.

II. NATIONAL STEERING COMMITTEE RECOMMENDATIONS

NCUIH strongly supports the recommendations of the National Steering Committee for the Reauthorization of the Indian Health Care Improvement Act. NCUIH, on behalf of the urban Indian health care organizations, was an active participant in the activities of the National Steering Committee in developing the recommendations. This initiative brought together the Indian Health Service, the Tribes, and the urban Indians in a united effort to develop sensible and effective amendments to the IHCIA, as well as certain other Federal laws which affect the provision of health care services to Indian populations (such as the entitlement programs Medicaid and Medicare, as well as the Federal Tort Claims Act). The parties recommendations are incorporated in H.R. 3397. NCUIH fully supports these recommendations.

This testimony addresses those recommendations which directly relate to urban Indians and urban Indian organizations. NCUIH asks that the Senate Committee on Indian Affairs' fully support the entire set of recommendation made by the National Steering Committee.

III. TITLE V - HEALTH SERVICES FOR URBAN INDIANS

Title V of IHCIA is concerned with the delivery of health care and referral services to urban Indians. NCUIH supports retaining most of the Title V provisions in the current law, with certain modifications as described below.

- **Accreditation and Site Visits**. NCUIH supports lifting the requirement that the IHS make annual site visits to each grantee or contractor where that grantee or contractor has been accredited by a private independent accrediting body recognized by the Secretary of Health and Human Services for Medicare purposes. Such visits are unnecessary where accreditation has been granted.

- **Lump Sump Payments**. NCUIH supports authorizing the IHS to make payments under grants or contracts on a lump-sum basis at the beginning of a funding period. This substantially enhances the ability of grantees and contractors to implement efficient financial operations.

- **Multiple urban centers under one organization**. NCUIH supports allowing an urban Indian organization to furnish health care or referral services to urban Indians through satellite clinic sites. This amendment would enable urban Indian programs, with hard-won expertise, to serve in a cost-effective more urban Indians while also providing flexibility to address the ever changing urban Indian communities

NCUIH also supports certain significant expansions to Title V:

- **Expansion of uses for Renovation Grants**. Currently, the IHS is authorized to make funds available to Title V grantees or contractors for minor renovations. NCUIH supports amending Title V to also permit these grant funds to be used for leasing, purchasing, constructing or expansion of facilities. This amendment would greatly expand the ability of the grantees or contractors to tailor the use of the funds to their most pressing needs, thus allowing them to better serve their patient population.

- **Establishment of an Urban Indian Health Care Revolving Loan Fund**. The proposed amendments would establish a revolving loan fund to be used for the same purposes as the renovation/construction funds described immediately above. This would be a self-sustaining funding mechanism which would better enable the urban programs to address facility needs and to do so in cost-effective manner.

- **Extended Federal Authorization Period**. The Steering Committee recommends, and NCUIH supports, that Title V programs be authorized to receive "such sums as may be necessary" for each fiscal year through 2012. This would allow Congress the

maximum degree of flexibility to address the needs of a growing population of urban Indians while also assuring authorization for funding for an extended period, bringing greater funding stability to these programs.

The proposed amendments would also add a number of new provisions to Title V which NCUIH fully supports:

- **Increased Consultation.** The Secretary of Health and Human Services would be required to ensure that the IHS, Health Care Financing Administration (HCFA) and other divisions of the Department of Health and Human Services consult with urban Indian organizations to the greatest extent practicable prior to taking "any action" that may affect urban Indians or urban Indian health organizations. For this purpose "any action" would include HCFA approval of federal matching funds to state Medicaid programs to extent to urban Indian health programs. As has been dramatically demonstrated in other areas of Indian policy-making, close consultation with Indian organizations leads to better results, less confusion, and a higher level of cooperation and efficiency on the part of everyone involved. See related discussion at Part V, below.

- **Federal Tort Claims Act Coverage.** Urban Indian organizations receiving grants or entering into contracts with the IHS should be covered under the Federal Tort Claims Act for any medical malpractice or other personal injury claims filed on or after October 1, 1999. This would appropriately grant the urban Indian organizations coverage enjoyed by other Indian organizations which receive federal funding. Elimination of the high cost of malpractice insurance would lessen a major barrier to outreach and referral programs in their efforts to become direct medical service providers.

- **Urban Youth Treatment Centers.** The IHS would be directed to fund the construction and operation of at least two residential treatment centers in each state in which there reside urban Indian youth in need and where there is also a shortage of culturally competent residential treatment services. NCUIH believes that it is critically important to "catch them young." Indian youth face many challenges in the urban environment. They respond most effectively to programs which are culturally sensitive to Indians.

- **Use of Federal Government Facilities.** The Secretary of Health and Human Services would be (1) directed to permit urban

Indian organizations receiving assistance under Title V to use facilities or equipment owned by the Federal government within the Secretary's jurisdiction; and (2) authorized to donate excess property of the IHS or the GSA to such organizations. This is consistent with rights held by other Indian entities and has the potential to greatly expand the capabilities and resources of urban Indian organizations.

- **Grants for Diabetes Prevention, Treatment, and Control.** Diabetes is at epidemic levels among the Indian population, no matter whether they are located on-reservation or in urban areas. NCUIH supports an amendment that would authorize the IHS to make grants to urban Indian organizations under Title V to provide services for the prevention, treatment, and control of diabetes among urban Indians.

- **Community Health Representatives.** CHR's have been very effective in promoting health care and health consciousness among the Indian population. NCUIH supports authorizing the IHS to contract with, or make grants to, urban Indian organizations under Title V for the use of Indians trained as Community Health Representatives in the provision of health care, health promotion, and disease prevention services to urban Indians.

- **Regulations.** If the IHS promulgates regulations to implement these new amendments, it would have to use negotiated rulemaking procedures, including a committee with representatives of urban Indian organizations from each IHS service area constituting a majority of the members, to develop those regulations.

IV. OTHER TITLES IN THE IHCIA

Urban Indians and urban Indian organizations are affected by provisions in other titles of the Indian Health Care Improvement Act. Set forth below are key proposed amendments, again adopted by the National Steering Committee and fully supported by NCUIH:

A. Title I

- **Health Professionals Serving at Urban Indian Centers.** Under the Steering Committee's amendments, urban Indian health programs would be among the practice sites where active duty service obligations could be met by recipients of Indian Health Scholarships, by health professionals participating in

the IHS loan repayment program, and by nurses, nurse midwives, or nurse practitioners participating in the Indians into Nursing Program. In addition, health professionals employed by urban Indian organizations could qualify for retention bonuses. By opening up the Urban Indian organizations to these professionals, the quality and number of medical professionals available to the urban Indian organizations would increase. There also may be an increased interest by health professionals to participate in these IHS programs if they know they may have an opportunity to serve Indian people in an urban location.

B. Title II

- **Studies, School Programs and Treatment Models.** Under the Steering Committees amendments, Title V urban Indian organizations would be eligible to receive funding to conduct epidemiological studies, to develop comprehensive school health education programs, and to develop treatment models for Indian women. Urban Indian needs and issues are not always the same as those for reservation Indians. Studies of this population are critical to serving its needs and, additionally, may prove valuable in providing new insights which would benefit the entire Indian population.

C. Title IV.

- **Establishment of Qualified Indian Health Programs.** NCUIH fully supports the establishment of Qualified Indian Health Programs. Such programs will allow urban Indian organizations to partner better with Indian Health Service facilities and tribal health programs.

- **Recovery and/or Reimbursements of Expenses.** Under the Steering Committee's amendments, urban Indian organizations would, among other things, have:

  -- a right of recovery against insurers or any other third parties for expenses incurred by the organization in furnishing services to an individual covered by the insurer or other third party; such a right, common for other health care providers, would greatly expand the range of cost-effective and culturally sensitive health care services that the urban Indian organizations could provide.

-- a right of recovery against managed care plans, including those participating in Medicaid, for the expenses of delivering care to enrollees of the plans; again, as with the right of recovery against insurers and other third parties described above, such a right, common for other health care providers, would greatly expand the range of cost-effective and culturally sensitive health care services that the urban Indian organizations could provide.

-- the right to retain reimbursements that the organization receives or recovers from private or public payers for delivering services (for the same reason set forth in the two immediately proceeding paragraphs); and

- **Employee Access to Federal Health and Life Insurance.** The urban Indian organizations would also gain the authority to use funds received from the IHS to purchase federal employee health and life insurance coverage for their own employees. This would enable the urban Indian organizations to provide more cost-effective and comprehensive health care coverage to their own employees. Extension of these benefits would assist with recruiting and retaining employees and would help bridge the gap created by the lower salaries that urban Indian health programs, as non-profits, are able to pay.

D. Title VII

- **Behavioral Health Treatment for Indian Women and Fetal Alcohol Disorder Programs.** Under the Steering Committee's amendments, the IHS would have to set aside for urban Indian organizations (1) 20 percent of any amounts appropriated to develop and implement behavioral health treatment programs for Indian women; and (2) 10 percent of any amounts appropriated to establish and operate fetal alcohol disorders programs. The special health needs of Indian women, as well as the serious problem of fetal alcohol disorder, are as common among the urban Indian population as the reservation population. These amendments will give the urban Indian organizations the funding they need to combat these problems.

V. IMPLEMENTATION OF IHCIA AMENDMENTS

As noted above, the Steering Committee's amendments to Title V would require the IHS, HCFA, and other divisions of the Department of Health and Human Services to consult with urban Indian organizations before taking any actions that might affect urban Indians, and would also require the use of negotiated rulemaking in developing any regulations to implement Title V. Title VII of the Act contains two parallel provisions that address consultation and rulemaking issues with respect to all of the Titles in the Act:

- **Regulations.** The Secretary would be required to initiate negotiated rulemaking procedures to promulgate regulations necessary to carry out the amendments. A majority of members of the negotiated rulemaking committee would be representatives of tribes, tribal organizations, and urban Indian organizations from each service area.

- **Plan of Implementation.** The Secretary would be required to prepare, in consultation with tribes, tribal organizations, and urban Indian organizations, and to submit to Congress a plan for implementation of any amendments adopted within 240 days of enactment.

VI. ENTITLEMENT COMMISSION

The Steering Committee has proposed an amendment to the Act that would establish a National Bipartisan Indian Health Care Entitlement Commission. The purpose of the Commission would be to make recommendations to the Congress to implement a policy that would establish a health care system for Indians based on delivery of health services as an entitlement. The Commission would be composed of 25 members, at least one of whom would have to be a nominee of an IHS-funded urban Indian Health program. The Commission's report would be due 18 months after appointment of all members.

VII. PROVISIONS AMENDING OTHER LAWS

A number of the Steering Committee's recommendations would affect Federal laws other than the Indian Health Care Improvement Act, such as the entitlement programs Medicaid and Medicare. In some cases, the Steering Committee has proposed to incorporate these amendments into the Indian Health Care Improvement Act itself; for example, the new section 515 of Title V which would extend Federal Tort Claims Act coverage to

urban Indian organizations and their employees, is in effect an amendment to the Federal Tort Claims Act, but it is drafted as a provision of Title V.

With respect to urban Indian organizations, the two most important Medicaid and CHIP amendments (both of which are drafted into the Medicaid and CHIP statutes rather than the Indian Health Care Improvement Act) are:

- **100 Percent Medicaid Matching Rate.** The Federal government would be required to match 100 percent of the payments that state Medicaid agencies make to urban Indian organizations for furnishing services to Medicaid beneficiaries; this would eliminate any state contribution for these services.

- **100 Percent CHIP Matching Rate.** From their annual block grant allotments under the State Child Health Insurance Program (CHIP), States could draw down Federal funds to cover 100 percent of the amounts they spend to pay IHS facilities, tribally operated programs, and urban Indian organizations assisted by grants or contracts under Title V.

VIII. ITEMS TO BE RESOLVED

Although NCUIH fully supports the National Steering Committee recommendations, the National Steering Committee did not come to a final consensus on whether both the Oklahoma City Clinic and Tulsa Clinic demonstration projects should be made permanent and should meet the definition of an urban Indian organization under Section 512 of IHCIA. NCUIH supports such an action. NCUIH does not, at this, time have a position on changing the definition of "urban Indian" in the Act.

IX. CONCLUSION

NCUIH thanks the Committee for this opportunity to provide testimony on the reauthorization of the Indian Health Care Improvement Act. This legislation will have far-reaching consequences for the health care of American Indians, including urban Indians. NCUIH urges the Committee to support the proposed amendments to IHCIA developed by the National Steering Committee. They provide an essential basis for improving the health care of America's native peoples.

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Bristol Bay Area Health Corporation is a tribal organization representing 34 villages in Southwest Alaska:

Aleknagik
Chignik Bay
Chignik Lagoon
Chignik Lake
Clark's Point
Dillingham
Egegik
Ekuk
Ekwok
Goodnews Bay
Igiugig
Iliamna
Ivanof Bay
Kanatak
King Salmon
Kokhanok
Koliganek
Levelock
Manokotak
Naknek
New Stuyahok
Newhalen
Nondalton
Olsonville
Pedro Bay
Perryville
Pilot Point
Platinum
Port Heiden
Portage Creek
South Naknek
Togiak
Twin Hills
Ugashik

To promote health with competence, a caring attitude & cultural sensitivity

Statement of Robert J. Clark
Chief Executive Officer
Bristol Bay Area Health Corporation

On The

Reauthorization of the Indian Health Care Improvement Act

March 8, 2000

Mr. Chairman, my name is Robert Clark. I am the Chief Executive Officer of the Bristol Bay Area Health Corporation, a tribal consortium of thirty-four Alaska Native tribes which administers health programs, including the Kanakanak Hospital, funded by the Indian Health Service in the 46,000 square mile Bristol Bay region in Alaska. We have operated the hospital and most community health programs in the region since 1980 when we contracted with IHS under the Indian Self-Determination Act. In 1994 we joined with other tribes and tribal consortia in Alaska in negotiating the trail-blazing Alaska Tribal Health Compact, under which most IHS-funded health programs in Alaska are tribally administered under the IHS self-governance demonstration project (Title III of the ISDEAA).

We strongly support the reauthorization of the Indian Health Care Improvement Act as provided in the

draft bill prepared and submitted to the Congress by the National Steering Committee

representing tribes throughout the United States. We support the statement made in support of the bill to your Committee by Rachel Joseph, Co-Chair of the National Steering Committee, and by H. Sally Smith, Chairperson of the National Indian Health Board. We will add a few comments summarizing areas of the bill which are of specific concern to us in the Bristol Bay region.

First, I should say that BBAHC representatives participated actively in consultation meetings held in Alaska which developed an "Alaska draft" of the bill. This draft was later submitted at regional and national meetings conducted by the National Steering Committee. The final draft bill addresses the concerns covered in the Alaska draft and includes many of its provisions. BBAHC's officers and counsel participated actively in the development of the final Steering Committee product. We will highlight our major concerns about reauthorization title by title.

Title I

We strongly support the new provisions proposed in Title I to encourage the recruitment of Indians and Alaska Natives in the health professions. In particular we support the decentralization of the administration of scholarship, recruitment and training programs so that tribal input will have greater bearing on the allocation of scarce resources for such activities. We support

the preference in health training for tribally-controlled community colleges, the extension of extern opportunities to high school students, the authorization of three-year demonstration projects and the establishment of the loan repayment recovery fund.

We also support the ban on taxing scholarships awarded under Title I. Taxation of these scholarship grants undermines the purpose for which the program was established by diminishing the amount available to the student. We also support the elimination of specific allocations to particular health professions in the statute. Finally, we support the requirement for training in cultural sensitivity for health professionals employed by the Indian Health Service.

Title II

The revisions in Title II relating to health services are also geared to an emphasis on greater tribal involvement. Changes in the statute would encourage tribal contracting of the programs provided for in this title and would require negotiated rulemaking with tribal representation to issue regulations applicable to several programs. We support the addition of "long term care" to the programs for which IHS is expressly authorized to provide financial support.

We strongly support the strengthening of the IHS effort against diabetes, including express authorization for dialysis programs. The development of the allocation methodology for

Catastrophic Health Care funding by negotiating rulemaking provides for tribal input in this critical area. The strengthening of authority for hospice care and home and community based services is also well received in Alaska.

Title II contains many other provisions which are designed to eliminate current impediments to the provision of effective health care to Alaska Native and Indian communities. The provision permitting health care professionals licensed in any State to serve in a tribally operated, IHS-funded program would bring consistency with the present rule for IHS health professional employees. This title also clarifies that providers under the Contract Health Care Program may not seek payment from an Alaska Native or Indian patient if the IHS is slow in making payment to the provider. The expansion of the comprehensive school health education program to off-reservation Indian children will benefit Alaska Natives. Report language should make clear that these grants, although made to tribes and tribal organizations, would be operated in the public schools of the State of Alaska.

Title III

The absence of modern and even minimally adequate health care facilities in many Alaska Native communities remains a serious impediment to effective health care in Alaska. Although some Alaska Natives have benefited in recent years from IHS health facility constructions, many other communities remain on the IHS construction priority waiting list, some not yet even identified in the annual budget requests to Congress.

We support the revisions in Title III intended to scope out the extent of the health facility deficiency in Indian country and to introduce new innovative approaches to health facility construction in addition to the existing IHS construction priority system. While we support review and revision of the present system with tribal input, we are gratified that tribal projects that have completed Phases I and II of the IHS system will not lose their priority position. Some of these projects represent direly needed new facilities in Alaska communities which have been waiting many years on the priority list.

We support the elimination of Davis-Bacon rates in health facility construction, which will allow more facilities to be built at the same cost. The health facility crisis in the Indian country justifies this step.

Title IV

The innovative approaches designed to maximize the funding available to address Alaska Native and Indian health care needs contained in Title IV should be enacted. Some of these, such as the revisions in the Medicare and Medicaid programs intended to eliminate inconsistencies and discrimination in the treatment of Indian patients, may seem complex at first sight. However, they are worth careful Congressional attention and approval as they seek to maximize the funding stream available to achieve the goals of the Act, especially the goal to "assure the highest possible

health status for Indians [including Alaska Natives] and to provide all resources necessary to effect that policy."

Title V

We will not comment in detail on the provisions relating to urban Indians. We support the position taken by the Alaska caucus on IHCIA to support improved health services for Indians living in urban locations provided they are not made at the expense of Indians and Alaska Natives in remote, rural reservations and communities. The needs in these areas should continue to be the first priority for the Indian Health Service. Without the IHS-funded programs, many rural areas of the United States, including, in particular, most of Alaska, would lack any effective health care system.

Title VI

We have long supported the elevation of the IHS Director to the position of Assistant Secretary. We recommend that this provision, consistent with S. 299 which has already passed the Senate, be included in the IHCIA reauthorization bill when it is introduced in the Senate so that it will be assured of being addressed by the House one way or the other. It is our understanding that the present position of the IHS Director in the Health and Human Services structure diminishes the authority of IHS and therefore limits the consideration given to the needs of Indian programs in the budget formulation process in that Department.

Title VII

Substance abuse is a major concern in Alaska, and we strongly advocate the redirection of effort on this problem which would result from the provisions of Title VII of the draft bill. We supported the coordinated approach advocated by the bill, including all programs addressing the substance abuse problem, and we also support the emphasis on the development of local, tribal and Area wide plans. In particular, the cooperation between Interior and HHS should be strengthened as proposed by the bill, and both BIA and IHS should be required to cooperate with tribal governmental anti-substance abuse efforts.

The broadening of programs under this title to include all "behavioral health," as opposed to just substance abuse, makes sense. We support the retention of the present legal requirement for a youth treatment facilities operated by the Tanana Chiefs Conference and the Southeast Alaska Regional Health Consortium. We approve the requirement that women's and children's substance abuse programs address spiritual needs and the inclusion of traditional health care in the adolescent health program. Both HHS and Interior should be required to consult with tribes and Indians and Alaska Natives on annually renewable memoranda of agreement between the two departments.

Finally, we support the establishment of new programs in each Area to address child sexual abuse, including treatment for both the victims and perpetrators of such abuse.

Title VIII

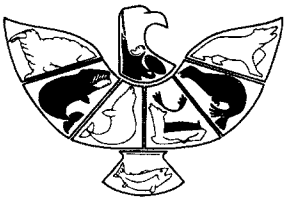
This title contains a number of highly desirable miscellaneous provisions that would increase the effectiveness of the Indian health program. These include: a negotiated rulemaking process to assure tribal involvement in the development of regulations in several key areas; continuation of the moratorium on implementing new eligibility rules until such rules are developed through negotiated rulemaking; assurance that NLRB jurisdiction does not apply to tribes and tribal organizations operating health programs in Alaska (which is consistent both with the inapplicability of such jurisdiction over IHS and over on-reservation tribal activities as upheld by the courts); and access for tribally operated, IHS-funded health programs to the "VA prime vendor list" by providing the same treatment for such tribally operated programs as is presently applicable to IHS operated programs.

Entitlement Commission

While we agree with many Indians and Alaska Natives that the United States does indeed have an obligation to provide health care to Indians both because of treaties and because of the obligations undertaken in the IHCIA, we recognize that the defining of the scope of an Indian and Alaska Native entitlement to health care is complex. We commend the National Steering Committee for proposing a national bipartisan commission including both Congressional and tribal representatives to recommend to the Congress "a policy that would establish a health care system for

Indians based on health services as an entitlement." The Commission would also determine the implications of such a system for the existing IHS health care delivery system and the sovereign status of Indian tribes.

We appreciate the opportunity to provide your Committee with our views on this important legislative proposal. We request that field hearings be held to give Indians and Alaska Natives an opportunity to express their views, including at least one such hearing in Alaska.



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Statement of Cynthia J. Navarrette, President / CEO of the Alaska Native Health Board on the Reauthorization of the Indian Health Care Improvement Act

March 8, 2000

Mr. Chairman, my name is Cynthia J. Navarrette. I am the president and CEO of the Alaska Native Health Board (ANHB). ANHB is a statewide non-profit corporation that was established more than 30 years ago for the purpose of "promoting the spiritual, physical, mental, social and cultural well-being and pride of Alaska Native people." The members of the Board of Directors of ANHB include Alaska Native regional and village health providers from across Alaska. In many cases, these organizations are the only health care providers for their region, serving both Alaska Natives and non-Natives who would otherwise have virtually no access to health care services.

ANHB strongly supports the reauthorization of the Indian Health Care Improvement Act (IHCIA). The IHCIA, first enacted in 1976 and reauthorized four times since, is designed to raise the health status of Native people and is a vital element in the fulfillment of the United States' trust responsibility – in this case, for health care – for Alaska Native and other Native people.

On November 16, 1999, Representative Don Young, Representative George Miller, and others introduced H.R. 3397, legislation to reauthorize the Indian Health Care Improvement Act. Your hearing today is considering an identical bill to be introduced into the United States Senate. This bill is the product of a tribally-led consultation and drafting process, a process in which ANHB and other tribes and tribal organizations in Alaska were extremely active. ANHB President H. Sally Smith was the Alaska representative on the IHCIA Steering Committee. The Indian Health Service and the Health Care Financing Administration provided invaluable technical assistance during this process.

The Indian Health Care Improvement Act, along with the Indian Self-Determination and Education Assistance Act (ISDEAA) which authorizes tribes and tribal organizations to design and administer health programs, form the statutory foundation of the health delivery system for Native people in Alaska. Increased access to third party reimbursements – Medicaid, Medicare, CHIP – is also needed to make the health care foundation stronger, and H.R. 3397 addresses this matter.

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YUKON-KUSKOKWIM HEALTH CORPORATION
NORTH SLOPE BOROUGH

We need a three-legged stool on which to build our health care system – services and facilities authorizations through the IHCIA, federal appropriations to fund the tribal delivery system through the ISDEAA, and full access to Medicare, Medicaid, and CHIP reimbursements.

Just as the Indian Health Care Improvement Act has changed over time to reflect urgent needs – substance abuse, mental health, health professional education and recruitment, diabetes, sanitation, catastrophic health costs -- the pending reauthorization bill reflects current tribal experiences and views on health care.

We realize the legislation will undergo changes during the Congressional reauthorization process – and we will likely have amendments of our own to propose – but want to retain provisions which support the philosophical underpinnings of the bill.

H.R. 3397 has eight titles, in some cases is highly technical, and is 305 pages in length. We bring to your attention, however, key thematic elements of the bill:

Local Control/De-centralization. Throughout the bill there is an effort to make as many programs as possible available for tribal administration through the Indian Self-Determination and Education Assistance Act. This was accomplished by changing the term "grant" in the current law to "funding agreements" to assure that funding could be transferred to tribes through ISDEA contracts and compacts.

The bill would also de-centralize some programs currently administered by IHS headquarters, i.e. scholarship programs, by providing the funding to IHS Area offices for local priority-setting and decision-making by tribes. It would authorize the Secretary to provide CHIP funding directly to tribes/tribal organizations to serve Indian children in their service areas.

Facilities Innovation. The bill is designed to offer innovative opportunities to tribes and tribal organizations in meeting their various facility needs. The current approach an IHS priority list for construction funding through the appropriations process will never meet the construction backlog. Among the many facility-related provisions in the bill are ones which would allow leases to be used as a financing vehicle for health facility construction, establishment of a revolving loan program for direct loans and loan guarantees for construction, authorization of IHS/tribal joint venture projects where the tribe would supply the facility while IHS (under a no-cost lease) would provide staffing and equipment.

Improved Access. The legislation proposes many amendments to the Medicare, Medicaid and CHIP programs in an effort to both increase tribal access to third party payments and to remove existing barriers to accessing reimbursement from these or any new federal health programs.

Examples of proposals to increase access to reimbursements from the above-mentioned programs are:

• Replacement of the facility-based focus for collecting reimbursement from Medicare and Medicaid with a program-based focus. This would allow collection for services provided outside a facility, such as in home or community settings.

• Elimination of co-payments or cost-sharing for IHS beneficiaries under Medicaid, Medicare, and CHIP.

• A requirement that all Indian health care providers receive the same rates as given to other preferred federal customers for purchase of services.

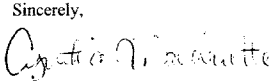
• Authorization for tribes and tribal organizations who administer IHS-owned facilities to bypass IHS when billing for Medicare and Medicaid reimbursements. A 7-year demonstration program by four tribal health care providers, including two in Alaska, showed that tribes were increasing their M& M collections because they did a better job than IHS of billing and collecting reimbursements.

ANHB urges your support for legislation to reauthorize the Indian Health Care Improvement Act consistent with the goals and principles in H.R. 3397. Where appropriate, we urge that some provisions in the bill be considered on their own and enacted into law this year:

- Elevation of the position of the IHS Director
- Authority for tribes which administer IHS facilities to bill directly for Medicare and Medicaid
- Authority for IHS clinics to receive payment for Medicare Part B (doctor) services

Thank you for the opportunity to present the views of the Alaska Native Health Board on this important legislative proposal.

Sincerely,



Cynthia J. Navarrette
President / CEO

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March 15, 2000

The Honorable Ben Nighthorse Campbell
United States Senate
SR-380 Russell Senate Office Building
Washington, DC 20510-0605

Dear Senator Nighthorse Campbell,

As the chair of the Alaska Native Health Board, I would like to present the attached written testimony to you and urge you to support the priorities as indicated by all Tribal Health Organizations of Alaska. If you have questions after reading the testimony, or would like to follow up with comments, please contact Cynthia J. Navarrette, President/CEO, at the Alaska Native Health Board via the numbers provided on this letterhead or contact us by email: Cnavarrette@anhb.org and hsmith@bbahc.alaska.ihs.gov.

We are also enclosing an extra copy of our Federal Priorities as voted on by all Tribal Health Organizations in November 1999. Your office may have received a copy of this booklet earlier this month as well. We appreciate the support you have continually given to indigenous health issues.

If there is any issue you believe ANHB can assist your office with, please don't hesitate to contact us by the means listed above. I also invite you and your staff to visit our website @ www.anhb.org.

Sincerely,

H. Sally Smith

H. Sally Smith
Chair

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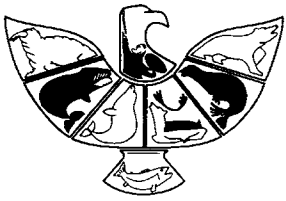

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Statement of the Alaska Native Health Board
H. Sally Smith, Chair

On FY 2001 Indian Health Service Appropriations
Submitted to the Senate Interior Appropriations Subcommittee

March, 2000

The Alaska Native Health Board (ANHB) submits this statement on the Administration's proposed FY 2001 Indian Health Service budget. In summary, our recommendations are that the IHS budget be increased over the FY 2000 level in order to address the following health priorities:

- *$60 million for inflation*
- *$1.2 million increase for the Alaska Village Built Clinic Lease Program for a total of $5 million*
- *Support at a minimum the Administration's proposed $41 million increase in Contract Health Services to help address patient and family housing needs in Alaska and to reduce deferred health services*
- *Support at a minimum the Administration's proposed $40 million increase for Contract Support Costs, but distribute the increase consistent with the January 20, 2000 Circular signed by IHS Director Trujillo.*
- *Fund design and construction of health centers at St. Paul and Metlakatla*
- *Increase funding for diabetes*
- *Increase funding for access to dental care*
- *Support at a minimum the Administration's proposed $6 million increase (for a total of $18 million) for the Community Health Emergency Fund, in part to assist with emergency patient travel costs in Alaska.*

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Because the length of appropriations testimony is limited to four pages, we refer you to our Federal Legislative Priorities booklet of February 4, 2000 which describes in more detail our legislative and appropriations recommendations.

Built-in Costs (Inflation). While the proposed budget includes funding for required pay cost increases, no funding is provided for inflation. IHS indicates that approximately $60 million is needed to cover the cost of inflation, and we urge Congress to provide funds for this purpose. Tribal and IHS health care providers annually see the value of their program dollars diminish because they must absorb substantial portions of built-in costs. The proposed FY 2001 program increases are in part off-set by the lack of funding to cover medical and non-medical inflation.

Village-Built Clinics. Village Built Clinics and the Community Health Aide/Practitioners who staff them are the source of all health care in rural Alaska. Community Health Aide/Practitioners serve 169 villages with populations ranging from 50 to 1,500.

The $1.2 million increase we request (for a total of $4.9 million) consists of $965,000 for inflationary costs and to mitigate the fact that the lease income from the facilities is in many cases lower than reasonable local rates. The remaining $278,000 is requested for eight additional leases for village-built clinics.

Contract Health Care: Deferred Services; Patient and Family Housing. The Administration requested a $41 million increase in Contract Health Care for a total of $447 million. While this may seem like a large increase, the need in Alaska and elsewhere exceeds by far the budget request. In Alaska, we have a serious problem with deferred services and with covering the cost of patient and family housing due to inadequate contract health care funding.

In Alaska alone, there were 9,416 deferred health services in FY 1999 due to inadequate IHS contract health care funding.

And the housing needs of patients, escorts, and family members who must travel away from home for medical care services are uniquely pressing in Alaska, where services are frequently sought hundreds of miles away in areas where hotels and other public lodging may be scarce or prohibitively expensive.

In Anchorage, this need is partially met through the availability of Quyana house, a patient hostel connected to the Alaska Native Medical Center. Quyana House has 50 rooms and 108 beds and is almost always filled to capacity. Patients must seek off-campus housing in hotels or with family and friends. In the long term we hope that funding, possibly through HUD, can be obtained to build more housing on the ANMC campus, but in the interim we need additional funds through Contact Health Services to assist in the provision of patient and family housing in Anchorage, Sitka, Dillingham, Barrow, Kotzebue, Nome, Kodiak, and Bethel.

Contract Support Costs. We support the Administration's proposed $40 million increase (for a total of $268 million) for Contract Support Costs. But we disagree with the proposed bill language, which would apply the entire increase to new and expanded programs, with any unused funds being distributed to ongoing contracts.

We believe the funds should be distributed consistent with the IHS contract support circular which was signed by IHS Director Trujillo on January 20, 2000 which provides one pool of funding for new contracts and another for ongoing contracts. And we would continue to oppose a pro-rata distribution of contract support funds, an idea which was considered last year by the Appropriations Committees.

St. Paul and Metlakatla Clinics. ANHB urges Congress to appropriate FY 2001 funding for the St. Paul and the Metlakatla health centers so that the communities can finally begin the construction process for these desperately needed health facilities. The St. Paul and the Metlakatla Indian Community health centers and associated staff quarters are next on the IHS priority list to receive funding (assuming that Congress funds the design of the Pawnee clinic as requested by the Administration). St. Paul and Metlakatla are both island communities who are the sole source providers of health care for Native and non-Native populations.

-- St. Paul Health Center. The Pribilof Island of St. Paul is the northern most island in the Aleutian chain. It is located in the Bering Sea, 800 miles from Anchorage, and is arguably one of the most isolated communities in the nation. The current health facility at St. Paul was built in 1929 -- the oldest facility in the IHS system. The present clinic has many documented physical and environmental deficiencies and is much too small to adequately serve the Native and non-Native population. While the clinic serves the approximately 900 permanent residents of St. Paul Island, it also is the sole source provider of health services to 3,000 fishermen during fishing and crabbing seasons and to tourists who come to see the sea birds. Accident rates on St. Paul are very high, attributable to both the harsh environment and the high risk of the fishing occupation. Medical emergencies among fishermen is a daily experience.

-- Metlakatla Indian Community Health Center. The Metlakatla Indian Community of the Annette Islands Reserve has a population of over 1,500 and a land base of 87,000 acres in southeast Alaska. Health services are housed in four modular units that were built in the 1970's. The facilities are set on pilings and are connected by open, elevated, wooden walkways. Over time the buildings have settled unevenly, posing an unsafe environment for people seeking health services (18,000+ visits per year). The buildings continue to deteriorate. In the past few years the walls continued to drop or resettle, causing expensive emergency repairs and in some cases, evacuation of rooms. And the facilities are overcrowded and the utility systems inadequate to support the modernization of medical equipment.

Diabetes. The Administration requested a $3.88 million increase for diabetes, but given the incidence of diabetes throughout Indian country we urge Congress to provide an increase larger than the amount requested.

According to a recent report released by the National Indian Council on Aging, there is an emerging epidemic of diabetes among Alaska Natives, who until recently had registered relatively low rates of the disease. While the rate of diabetes in the Anchorage Service Unit is relatively normal, in some areas of Alaska, the prevalence of diabetes is almost four times higher than the prevalence of the disease across all races in the U.S. In areas that have traditionally had very little diabetes, such as the Y-K Delta and Norton Sound, the rate of increase is alarmingly rapid--over 150% in twelve years.

Dental Care. We urge Congress to at least double the IHS funding for dental care services and education. We urge the development of a system for training Community Dental Health Aide Practitioners to provide some types of dental services in villages. And we recommend that dental hygienists be trained so that their duties can be expanded (e.g, traumatic restoration of teeth). We need additional incentives (e.g, through the IHS loan repayment program and retention bonuses) so that we can recruit and retain more dentists in Alaska.

Access to dental services for Alaska Natives, which historically has been limited, has now reached crisis proportions. In almost all Alaska Native dental programs, the available care is tightly rationed. Most dental programs in Alaska have unreasonably long waiting times for appointments, up to a year for many services. Some programs have stopped making new patient appointments altogether as they are barely keeping up with basic preventive care for children and treatment already in progress for adults.

Patients with toothaches, living in villages, sometimes suffer for months while waiting for the next itinerant dental visit. In some cases, these patients spend hundreds of dollars traveling to an already overcrowded dental clinic hundreds of miles away.

Children with rampant dental decay often go untreated because of lack of access to dental care. It is not uncommon to see children with 12 out of their 20 baby teeth severely decayed. The rate of decay among children in Alaska is 2-1/2 times the national rate. And rates of oral cancer among Alaska Natives are higher than in any other IHS area. Oral cancers are often detectable through routine oral exam and biopsy. These cancers generally appear in adults, the segment of the Alaska Native population with the least access to dental care.

Travel Subsidy for Patients. ANHB recommends that an additional $10 million be added on a recurring basis to the IHS Hospitals and Clinics budget for patient travel in Alaska. Additionally, we support the Administration's proposed $6 million increase for the Comprehensive Health Emergency Fund, some of which can assist with the costs of emergency medical travel in Alaska.

Due to Alaska's unique geography and the lack of a developed road system in most of the state, access to care is a critical issue facing Alaska Natives. While the Community Health Aide/Practitioner Program and physicians assistants ensure basic health care at the village level, many diagnostic services and treatment procedures are not feasible in village clinics. The majority of rural Alaska Natives who need a physician's care must travel by air to receive these services from regional hospitals. When rural regional hospitals are not staffed or equipped to provide specialized diagnostic or treatment services, Alaska Natives must travel further by air to the Alaska Native Medical Center in Anchorage.

Citizens in other parts of the United States access health care through federal or state subsidized highway systems. We need comparable consideration in funding of access to health care in Alaska.

Alaska Native Health Board

4201 Tudor Centre Dr., Suite 105
Anchorage, Alaska 99508

Phone: (907) 562-6006
FAX: (907) 563-2001

February 4, 2000

Dear Legislator,

The Alaska Native Health Board (ANHB) is a statewide non-profit corporation that was established more than 30 years ago for the purpose of "promoting the spiritual, physical, mental, social and cultural well-being and pride of Alaska Native people." The members of the Board of Directors of ANHB include Alaska Native regional and village health providers from across Alaska. In many cases, these individuals are the only health care providers for their region, serving both Alaska Natives and non-Natives who would otherwise have virtually no access to health care services.

The Board appreciates this annual opportunity to advise you regarding the most pressing needs that we have identified in our work. These priorities have emerged based on our day-to-day, on the ground experience of the challenges and roadblocks that exist in providing health care for Alaska Natives. Through your work in Washington you are in a position to have a direct, positive effect on these conditions.

In the materials that follow, we identify briefly many important initiatives that need your support. We know that political realities may mitigate what can be accomplished in the coming year, but the pressing needs exist nonetheless. Your support for these programs today is key to assuring that in time each one of these critical needs are ultimately addressed.

We expect to offer testimony before congressional committees on a number of Appropriations and health bills related to these priorities over the coming year. We look forward to working with you during this Congress and the years to come in ongoing efforts to improve the health of Alaska Natives. For further information on any materials included in this publication, please contact our CEO, Cynthia Navarrette.

Sincerely,

H. Sally Smith

H. Sally Smith
Chair

ALEUTIAN/PRIBILOF ISLANDS ASSOCIATION
ARCTIC SLOPE NATIVE ASSOCIATION
BRISTOL BAY AREA HEALTH CORPORATION
CHUGACHMIUT
COPPER RIVER NATIVE ASSOCIATION
EASTERN ALEUTIAN TRIBES
KETCHIKAN INDIAN COMMUNITY
VALDEZ NATIVE TRIBE

MANILAQ ASSOCIATION
METLAKATLA INDIAN COMMUNITY
MT. SANFORD TRIBAL CONSORTIUM
NATIVE VILLAGE OF EKLUTNA
NATIVE VILLAGE OF TYONEK
NINILCHIK TRADITIONAL COUNCIL
KODIAK AREA NATIVE ASSOCIATION

NORTON SOUND HEALTH CORPORATION
SELDOVIA VILLAGE TRIBE
SOUTHCENTRAL FOUNDATION
SOUTHEAST ALASKA REGIONAL HEALTH CONSORTIUM
TANANA CHIEFS CONFERENCE
YUKON-KUSKOKWIM HEALTH CORPORATION
NORTH SLOPE BOROUGH

I. FACILITIES

A. Village Built Clinic Lease Program

ANHB urges an IHS appropriation of $5 million to account for inflation in operating costs for village built clinics in Alaska.

Village Built Clinics and the Community Health Aide/Practitioners who staff them are the source of all health care in rural Alaskan villages. They comprise the first line of defense for the health of rural Alaskans. Currently, Community Health Aides and Community Health Practitioners serve 169 villages with populations ranging from 50 to 1,500.

Funding for these clinics is currently provided through a lease agreement with the owners of the facilities, usually local city governments or tribal governments. Since 1989 when this system was established, operating costs have greatly increased. Many clinics now receive lease amounts that are considerably lower than reasonable local rates. Inadequate facilities operations and maintenance negatively affect health care delivery.

Between 1989 and 2000 the Consumer Price Index has increased by approximately 32.3 percent. A $965,216 increase in funding is required to reflect inflation in operating expenses for these 169 clinics in FY 2001.

In addition to current leases, there are eight (8) rural Alaska communities that will need new lease funding within the next year. These communities are working diligently to get facilities constructed or renovated that are safe and meet local codes. At this point, no funding is available to fund these clinics. $278,000 is required to fund these issues on a recurring basis.

Summary of Requirements: Alaska Village Built Clinic Lease Program

FY2000 Advise of Allowance (current)	**$3,729,592**
Increase required for CPI inflation	**+$965,216**
Increase required for 8 new clinics	**+$278,000**
Total Increase required	**+1,243,216**
FY2001 Appropriation Requested	**$4,972,808**

B. Patient and Family Housing Needs

ANHB urges Congress to increase funding for the Indian Health Service (IHS) Contract Health Services as a means to support critical patient and family housing needs in Alaska.

The housing needs of patients, escorts, and family members who must travel away from home for medical care services are uniquely pressing in Alaska, where services are frequently sought hundreds of miles away in areas where hotels and other public lodging may be scare or prohibitively expensive.

In Anchorage this need is partially met through the availability of the Quyana House, a patient hostel connected to the new Alaska Native Medical Center. The Quyana House has 50 rooms and 108 beds, and is nearly always filled to capacity. On a regular basis patients must seek off-campus housing in hotels (at their own expense) or with family and friends; in some cases Medicaid resources allow for patient housing off-campus in contract facilities or hotels.

Such arrangements are expensive, require additional transportation expenditures and are not conducive to providing timely access to medical appointments. The situation is especially severe for special needs children and the elderly.

To address this problem, additional patient/family housing is needed on the Alaska Native Health Campus adjacent to the Alaska Native Medical Center. This has been identified as a required component of the long-range campus facility plan. The Alaska Native Tribal Health Consortium will be evaluating various potential funding sources, including the Native American Housing and Self-Determination Assistance Act (NAHSDA) resources, to support such development.

In the interim, Congressional support for increases in the Indian Health Service Contract Health Services appropriation will allow these pressing patient and family housing needs to be better met in Anchorage.

Similar needs exist in the communities of Sitka, Dillingham, Barrow, Kotzebue, Nome, Kodiak, and Bethel, where patients travelling for services at tribally-operated hospitals require similar assistance.

C. Sub-Regional Health Clinic Construction

ANHB urges Congress to appropriate FY 2001 funding for the St. Paul and the Metlakatla health centers -- at a minimum $2.5 million for planning and design for each health center -- so that the communities can finally begin the construction process for these desperately needed health facilities.

The St. Paul and the Metlakatla Indian Community health centers and associated staff quarters are next on the IHS priority list to receive funding (assuming Congress funds the design of the Pawnee clinic as requested by the Administration). These are both island communities who are the sole source providers of health care for Native and non-Native populations.

St. Paul Health Center. The Pribilof Island of St. Paul is the northern most island in the Aleutian chain. It is located in the Bering Sea, 800 miles from Anchorage, and is arguably one of the most isolated communities in the nation.

The current health facility at St. Paul was built in 1929 -- the oldest facility in the IHS system. In 1970, a small addition was added by IHS. The St. Paul Health Center is administered by the Aleutian-Pribilof Islands Association under a Self-Determination compact.

The present clinic has many documented physical and environmental deficiencies and is much too small to adequately serve the Native and non-Native population. While the clinic serves the approximately 900 permanent residents of St. Paul Island, it also is the sole source provider of health services to 3,000 fishermen during fishing and crabbing seasons. Accident rates on St. Paul are very high, attributable to both the harsh environment and the high risk of the fishing occupation. Medical emergencies among fishermen is a daily experience.

There is a growing tourist industry on St. Paul Island; currently 1,000 tourists annually visit the Island to see returning fur seals and sea birds.

The health clinic is not handicapped-accessible, and hallways and doors are very narrow. There are only two examination rooms, and it is extremely difficult to make space for two or more people to simultaneously work on one patient. Due to lack of examination space, treatment of patients must also be provided in hallways and in the x-ray room. There is little privacy for patients, and patient confidentiality is difficult. In 1998, the clinic served 6,200 patients.

In addition to the daily challenge of treating accident-related trauma, the clinic services a Native population which has the highest rates of diabetes and cardio-vascular disease in Alaska. Deaths from suicides and accidents among St. Paul Native residents are several times the national average.

Metlakatla Indian Community Health Center. The Metlakatla Indian Community, Annette Islands Reserve, is the only existing statutory Indian reservation in Alaska. The Community's population is over 1,500 and has a land base of 87,000 acres in southeast Alaska. The Community provides essential health services through the Annette Islands Service Unit Health Center under an Indian Self-Determination and Education Assistance Act contract. The Health Center is the sole source of health care as there are no private providers on the Island. Inpatient or hospital services must be obtained off-island through Ketchikan General Hospital, Southeast Alaska Regional Health Corporation/Mt. Edgcumbe Hospital in Sitka, or the Alaska Native Medical Center in Anchorage. In winter months, travel between Metlakatla and Ketchikan and other destinations is often cut off by heavy winds and storms.

The Metlakatla Indian Community has been pursuing funds for many years for the replacement of its health facility. At present, clinic services are housed in four modular units which were built in the 1970's. The facilities are set on pilings and are connected by open, elevated, wooden walkways. Over time the buildings have settled unevenly, posing an unsafe environment for people seeking health services (18,000+ visits per year). The building continues to re-settle, particularly when freezing and thawing occurs, resulting in cracked walls and other damage. There is an ongoing, and losing, effort to do emergency repairs. Additionally, the facilities are overcrowded and the utility systems inadequate to support the modernization or updating of medical equipment.

The Metlakatla Indian Community is in desperate need of a new health facility. According to a 1995 comprehensive assessment of the present facilities, the total cost for repairs necessary to achieve compliance with current fire, mechanical, electrical and life safety codes, as well the Uniform Building Code and the Americans with Disabilities Act guidelines exceeds $1 million. The proposed replacement facility would be sufficient to house the current outpatient clinic services, including dental, pharmacy, laboratory, and emergency services. It would also provide additional space for community health programs the Community is currently unable to provide due to space limitations, such as community health nursing, environmental health, social services and health education.

The Community's program justification document for construction of a replacement health center was approved by IHS and included in the Health Care Facilities Construction priority list for design and construction funding in FY 1997. Thus far, no funds have been appropriated for it. However, there are only two projects ahead of Metlakatla on the IHS national priority list which have not received planning and design funding. We urge Congress to fund enough P&D in the FY 2001 IHS budget to allow work on the Metlakatla health center to commence.

II. CLINICAL SERVICES

A. Diabetes

We encourage Congress to increase fudning for prevention education, early screening and ongoing diabetes care to address the alarming increase in diabetes cases among Alaska Natives.

According to a recent report released by the National Indian Council on Aging, there is an emerging epidemic of diabetes among Alaska Natives, who until recently had registered relatively low rates of the disease. While the rate of diabetes in the Anchorage Service Unit is relatively normal, in some areas of Alaska, the prevalence of diabetes is almost four times higher than the prevalence of the disease across all races in the U.S. In areas that have traditionally had very little diabetes, such as the Y-K Delta and Norton Sound, the rate of increase is alarmingly rapid--over 150% in twelve years.

While some of this increase can be attributed to better screening for the disease, experts point to rapid changes in lifestyle, including less hunting and fishing and more reliance on store-bought than subsistence foods, contributing to rates of obesity and associated diseases among Alaska Natives.

Prevention education is critical in addressing these troubling increases. Early screening is important as well, since diabetes that is diagnosed early can be easier to control with lifestyle changes. Finally, given the realities of increased incidence of this long-term disease among Alaska Natives today, systems of care must be in place to enable clinics to handle increased need for diabetes care in the coming years.

B. Dental Care

The Alaska Native Health Board recommends that Congress support tribes and the IHS in truly addressing the crisis in dental health care among Native peoples in Alaska and elsewhere. Increased funding is urgently needed not only for more dentists, but for training which will allow more dental services to be offered in Alaska villages. And we support efforts to encourage healthy lifestyles as key to the promotion of good dental health.

Access to dental services for Alaska Natives, which historically has been limited, has now reached crisis proportions. In almost all Alaska Native Dental programs, the available care is tightly rationed. The problem continues to worsen each year.

The Indian Health Service reports that less than 20 percent of eligible American Indians/Alaska Natives had access to dental services in FY 1998. This compares to the early 1990s, when 33 percent of Native people nationally had access to dental services.

Most dental programs in Alaska have unreasonably long waiting times for appointments, up to a year for many services. Some programs have stopped making new patient appointments altogether as they are barely keeping up with basic preventive care for children and treatment already in progress for adults.

Patients with toothaches, living in villages, sometimes suffer for months while waiting for the next itinerant dental visit. In some cases, these patients spend hundreds of dollars traveling to an already overcrowded dental clinic hundreds of miles away.

Children with rampant dental decay often go untreated because of lack of access to dental care. It is not uncommon to see children with 12 out of their 20 baby teeth severely decayed. The rate of decay rate among children in Alaska is 2-1/2 times the national rate.

The increasing population of Alaska Natives with Diabetes often don't receive treatment of periodontal problems associated with their disease. Diabetic patients with broken or ill fitting dentures find it difficult to obtain repair of dentures so they can maintain an adequate diet. If services considered "higher level" care (such as dentures) are available at all, the patient must pay a portion of the cost.

Rates of oral cancer among Alaska Natives are higher than in any other IHS area. Oral cancers are often detectable through routine oral exam and biopsy. These cancers generally appear in adults, the segment of the Alaska Native population with the least access to dental care.

There are a variety of reasons for this crisis in access to dental services including:

- Escalating costs and complexities of providing dental care
- Increased treatment needs due to the increasing number of high maintenance teeth in adults
- Difficulties in the recruitment of professional staff
- Inadequate funding of dental programs for Alaska Natives
- Change in eating habits of Alaska Natives – from a traditional diet to a diet high in simple sugars
- The increase in Native population – a 60% increase since 1970

ANHB recommends an array of responses to address the dental crisis among Native peoples including:

- Development of a system for training Community Dental Health Aide Practitioners to provide some types of dental services in villages.
- Train dental hygienists in expanded duties and techniques such as a traumatic restoration of teeth.
- Encourage healthy lifestyles that include an emphasis on oral health and healthy eating habits, including advocating for a return to or maintenance of subsistence diets.
- Increase the IHS dental budget in FY 2001 from it current $80 million level (only 3.3% of the IHS budget) to an amount at least equal to the percent of health expenditures nationally for dental care (6 percent).
- Increase incentives for dentists and other dental health professionals to work in tribal areas.
- Currently, only 10-12 dentists per year are able to participate in the IHS loan repayment program nationally. We recommend an expanded IHS loan repayment program in order to accommodate an increased number of dentists and other health professionals serving in tribal and IHS health programs.
- Support other efforts to increase dental care among Alaska Natives, such as the proposal in S. 901, the Children's Dental Health Improvement Act, introduced by Senator Bingaman (D-NM) which would authorize retention bonuses for IHS dental officers committing to an additional two to four years of service after completion of any other active duty service commitment.

C. HIV/AIDS

1. *ANHB requests concerted federal efforts to improve HIV and AIDS surveillance, access to AIDS drugs, coverage of Native Americans under the Ryan White Care Act.*

2. *The Alaska Native Health Board AIDS Project urges that at least $700,000 of funds be available to AN/AI proposals for HIV/AIDS Prevention projects under CDC Announcement 00003.*

ANHB requests concerted federal efforts to improve HIV and AIDS surveillance, access to AIDS drugs, coverage of Native Americans under the Ryan White Care Act.

While great progress has been made in the care of individuals living with AIDS over the past 20 years, the epidemic is far from over. Based on the most recent available data from the Centers for Disease Control, Alaska ranks fourth-highest in numbers of reported Native American AIDS cases. Native Alaskans face a number of unique hurdles in access to care and in documentation of HIV and AIDS. Native Americans as a whole need to be better served by Ryan White and other federal programs.

Improved Disease Surveillance. Tracking the appearance of infectious diseases is critical to targeting resources and preventing further proliferation. New drugs that are slowing the progression from HIV infection to AIDS in many individuals increase the importance of documenting and reporting instances of HIV as well as AIDS.

A recent nationwide survey of IHS service units and tribal health departments conducted by the National Native American Aids Prevention Center (NAAPC) and others showed that the majority of the 94 tribes responding do not report infectious diseases to the Center for Disease Control and the Indian Health Service. An even higher number of IHS service units reported that they do not collect information on infectious diseases. Federal agencies, Congress, and Native American communities should work together to assure that this critical information is collected and addressed, and that Native Alaskans are not overlooked in this effort.

Ensuring Availability of and Access to AIDS Drugs. The cost of providing highly active anti-retroviral therapy (HAART) for individuals living with HIV is approximately $12,000-$13,000 per year for drugs alone. Such costs are entirely prohibitive for most Native Americans with HIV/AIDS and represent a very serious burden on tribal and urban health budgets.

Congress recognized the burden of these costs on states and responded by passing the AIDS Drug Assistance Program (ADAP) to assist state health departments in underwriting the cost of the drugs, especially for those people dependent upon Medicaid and Medicare. Congress did not consider the burden of cost on the Indian Health Service. We believe Congress should add the Indian health care system into the ADAP program.

Ensuring Native American Coverage in the Reauthorization of the Ryan White Care Act. Under the current Ryan White Care Act, the needs of Native America are covered only through a section of the Act called "Special Projects of National Significance," or SPNS. This section of the Act is designed to evaluate demonstration projects, not to serve ongoing needs, as in Titles I (for especially impacted cities) and Title II (a formula grant for states). Since 1990, SPNS has been the primary source of funds for Native American-specific care programs. The Act expires on September 30, 2000, and the upcoming reauthorization effort represents an important opportunity to secure ongoing support for the needs of Native Americans with HIV/AIDS under the Act. American Indian and Alaska Native tribes and tribal organizations should be directly involved in any effort to develop policies that will impact access to care and other services for Native People with HIV/AIDS.

The Alaska Native Health Board AIDS Project urges that at least $700,000 of funds be available to AN/AI proposals for HIV/AIDS Prevention projects under CDC Announcement 00003.

In FY99, about $700,000 was available under the extension of the CDC's NRMO (National/Regional Minority Organization) Program. By reducing the availability of funds by more than half ($225,000) to AN/AI HIV/AIDS prevention project, activities by the ANHB AIDS Project will be severely reduced.

The Alaska Native Health Board AIDS Project has been working under a subcontract with the National Native American AIDS Prevention Project (NNAAPC) for the past six years. CDC based this proposed level of funding on number of Native AIDS cases. This is especially troubling since CDC fails to take into account evidence of HIV risk required by good public health practice (STDs, substance abuse and other indicators of risk).

This funding cut will severely impact the Alaska Native Health Board HIV/AIDS Project. Under the subcontract agreement with NNAAPC, the AIDS Project Manager has been able to provide technical assistance for improving HIV/AIDS prevention projects in Native country, advocate for special initiatives in Native country, identifying and advocating for fair funding policy issues, providing technical assistance with the Alaska State HIV Prevention Community Planning Group, HIV/AIDS care and treatment issues and direct HIV/AIDS prevention education/training services.

Without continued and increased funding that is at an appropriate level to provide HIV/AIDS prevention services, the ANHB AIDS Project could lose 1.0 FTE.

The Alaska Native Health Board AIDS Project believes that the Centers for Disease Control must direct funds to Native American HIV/AIDS programs on a level of need based on HIV cases (and not AIDS cases) AND take into account other sound public health indicators which indicate a high risk for the spread of HIV in Native country. The continued thinking that we won't see acceptable levels of funding for Native programs until there are enough Native people who are infected with HIV is not justification at all.

D. Hepatitis C

ANHB asks Congress to fully fund Hepatitis C prevention and treatment for Alaska Natives.

Hepatitis C is a leading cause of liver disease in the United States. Since 1990, 1000 persons receiving care in the Alaska Native Healthcare system (Alaska Native Medical Center (AMNC) and outlying service units) have tested positive for Hepatitis C. To date, approximately 600 of these individuals have been evaluated by the ANMC Viral Hepatitis C Program and have enrolled in the Alaska Long-term Outcomes study.

Data from the Third National Health and Nutrition Examination Survey (NHANES III) conducted during 1988-1994 indicated that an estimated 1.8% of Americans have been infected with the hepatitis C virus.

The ANMC Viral Hepatitis C Program anticipates that as many as 1000 additional Alaska Natives may be infected in our population but remain undiagnosed due to the insidious nature of this disease. 75% of individuals infected with hepatitis C develop a chronic infection. These infected individuals may not be aware of their infection because most are not clinically ill. These individuals serve as a source of transmission to others and are also at risk for chronic liver disease.

Chronic hepatitis C varies greatly in its course and outcome. Chronic hepatitis C can cause cirrhosis, liver failure, and liver cancer. Liver failure from chronic hepatitis C is one of the most common reasons for liver transplants in the United States.

All infected patients should eventually be treated to halt the progression of disease, prevent hepatocellular carcinoma, and decrease the need for liver transplantation. Treatment of these patients also aids in reducing transmission of the virus. Conservatively, 20% of these patients may develop end-stage liver disease or hepatocellular carcinoma if they remain untreated.

The projected treatment cost for medications alone with the recommended combination Interferon / Ribavirin therapy ranges between $8-15,000 per patient depending on the individual's genotype. Indirect costs of this treatment include a diagnostic workup, extensive laboratory testing, and follow-up visits could add between $10-15,000 per patient.

III. ENVIRONMENT

A. Rural Alaska Sanitation Coalition

According to reports from the U.S Department of Agriculture and the Congressional Office of Technology Assessment, nearly 50% of Alaska Native rural households still do not have adequate running water and sewer services. Of 192 Alaska villages, 89 do not have water piped or trucked into homes, and water must be physically carried from a central location. Human waste disposal methods such as "honey buckets", pit toilets, and outhouses must be used in these communities, affecting an estimated 20,000 of residents of Alaska. Villages using some form of the honey bucket system come in frequent contact with human waste, which leads in turn to a high risk for outbreak of diseases that are linked to poor sanitation such as hepatitis A, hepatitis B, meningitis, giardia, and impetigo.

The Indian Health Service (IHS) estimates that it would cost $960 million to meet all of the current sanitation needs of Alaska Native villages. However, the IHS has determined that it would cost only $198 million to fund "feasible projects", those determined to be both economically and technically viable, desired by the village, and serving a clear improvement of sanitation.

We applaud recent federal increases for water and sewer system construction. However, resources to support technical, financial, and managerial capacity necessary to operate the systems on an ongoing basis have not been proportionately increased. Many of the villages with water sanitation projects in place or under construction lack the financial resources to ensure their long-term operation and maintenance. With a limited economic base to pay for user fees, higher costs of shipping and transportation to contend with, and harsh climates and geology, among other mitigating factors, support for operation and maintenance is a vital component to assuring long-term success of sanitation projects in the villages.

We ask for full funding to undertake feasible sanitation projects in Alaska, as well as adequate funding and technical support for ongoing operation and maintenance needs.

B. Solid Waste Management

Most of Alaska's rural communities have open dumps. Problems with blowing and travelling garbage, birds and bears, indiscriminate dumping, human waste being disposed of in garbage sites, hazardous wastes mixed in with other wastes and improperly handled, capacity problems, and fire hazards are the norm for most villages.

Much of the current funding for solid waste management is available only in competition with water and sewer system needs. We ask that increased and designated funding for landfill and dump construction and solid waste management be included in the FY 2001 budget. We also ask that legislation be advanced to reduce the amount of waste going into communities, through efforts such as packaging reduction for commercial products.

C. Environmental Contaminants Research

The impact of persistent contaminants on the environment and human health has emerged as an extremely important issue among Alaska Natives. Traditional foods make up about 40 percent of the Alaska Native diet. In many rural "bush" communities over 90 percent of the Native diet is from traditional foods. Reports of high levels of persistent contaminants in the food chain and traditional foods are especially alarming. Many Alaska Natives equate rising cancer rates and other health problems to persistent contaminants such as pesticides, PCBs and radionuclides in traditional foods.

To date, efforts to address the source and impacts of contaminants in Alaska have failed to meet the existing needs and concerns of Alaska Natives.

We support an "Alaska Contaminants Program" (ACP) consisting of agencies, Native organizations and other interested groups such as commercial fisheries working in partnership to coordinate research and programs dealing with persistent contaminants in and around Alaska. As envisioned, the ACP would be modeled after the Canadian Northern Contaminants Program which was established in 1991 in response to similar concerns about elevated levels of contaminants in the environment and especially traditional foods of northern aboriginal peoples. Since then it has emerged as the model program for responding to the needs of indigenous peoples as well as meeting international commitments of the eight nation Arctic Council and the Arctic Monitoring and Assessment Program.

Like the NCP, the ACP would administer competitive research grants that would focus on sources, pathways, behavior and effects of contaminants on the environment and human health.

It would also serve as an information resource on Alaska contaminant issues. Lastly it could serve to coordinate research and treaty initiatives to define and reduce sources of contaminants which reach Alaska from other nations.

An Ad Hoc Committee composed of representatives from state and federal agencies and Native organizations was formed in November 1999 to develop the initiative. The current focus of the group is to solicit broad input from across Alaska that can be used to establish goals and a vision for an Alaska Contaminants Program.

We ask your support for this program as it develops.

IV. OTHER HEALTH SERVICES

A. Travel Subsidy for Patients

ANHB recommends that an additional $10 million be added on a recurring basis to the IHS budget for patient travel in Alaska and that funding for the Comprehensive Health Emergency Fund be increased to better meet the costs of emergency medical travel.

Due to Alaska's unique geography and the lack of a developed road system in most of the state, access to care is a critical issue facing Alaska Natives. While the Community Health Aide/Practitioner Program and physicians assistants ensure basic health care at the village level, many diagnostic services and treatment procedures are not feasible in village clinics. The majority of rural Alaska Natives who need a physician's care must travel by air to receive these services from regional hospitals. When rural regional hospitals are not staffed or equipped to provide specialized diagnostic or treatment services, Alaska Natives must travel further by air to the Alaska Native Medical Center in Anchorage.

Citizens in other parts of the United States access health care through federal or state subsidized highway systems. We need comparable consideration in funding of access to health care in Alaska. Outside of Alaska, funding for patient travel is generally not a significant part of the operating budget for health care facilities because they are connected by a road system. But in Alaska, transportation must be considered an integral part of the health care delivery system.

The report ACCESS TO CARE: CRISIS FOR ALASKA NATIVES (January, 1991) revealed that inadequate patient travel funding has caused approximately 40 percent of all patients who need to travel for medical care to defer treatment or diagnostic services because they lack money for air fare and lodging. Such delays often result in more expensive remedial treatment or, more tragically, premature loss of life.

Both patients and regional health care providers contribute what they can to payment of medical travel. The above-mentioned report found that 50 percent of Native people in Alaska paid all or part of their own medical travel expenses. But a single medical trip, including room and board, may equal 50 percent of a family's annual income for those whose income falls below the poverty level (the majority of Native village residents). Over the past nine years Alaska Native tribal health agencies and Medicaid program officials have increased their support for patient travel, but the deficit situation remains serious and significant.

Regional health care providers have had to absorb tremendous shortfalls in their patient travel budgets. For instance, Kodiak Area Native Association budgeted $69,000 in FY 1998 for patient travel. Their shortfall, however, was $30,200, 44% of their patient travel budget. That same year, Annette Islands Service Unit (Metlakatla) spent $182,890 for patient travel, resulting in a shortfall of $71,000. Meanwhile, Tanana Chiefs Conference Health Services expended $846,000 for patient travel. The cost of one Medivac trip from St. Paul Island to Anchorage is approximately $6,000.

The issue of patient travel has impacted the new Alaska Native Medical Center (ANMC). There has understandably been a significant increase in patient use of the facility now that a wide range of high quality health care services are available. In November, 1998 ANMC had to limit patient travel support because of increased patient volumes and associated patient travel costs. For nearly a year ANMC was not able to fund outpatient and escort housing outside of the Quyana House in Anchorage, a place with 50 rooms which cannot possible house all those in need.

Alaska Natives have been requesting consideration of this serious health care need by the Administration and the Congress for nearly ten years. Increasing patient travel support will result in significantly improved health services and a higher level of health status for Native Alaskans.

B. Contract Health Care Increase

The IHS contract health services program provides funding to purchase health services which cannot be provided in the IHS direct care system. ANHB requests increases in IHS funding which will significantly decrease the backlog of deferred medical services.

In FY 1998 the IHS deferred payment authorization for 80,398 recommended cases nationally due to lack of funding. These are cases where people were denied medical services which they needed and which were approved, but which were denied based on a rationed system of health care.

In Alaska, the small IHS and tribal health facilities are unable to provide many required health services, and in those cases health care must be purchased from another provider. Sometimes this means utilizing the services of another hospital in the region; other times it will require flying patients to other locations such as Seattle. Or, it might entail bringing a specialist to the Alaska Native Medical Center in Anchorage. In FY 1999, the IHS allocated $41 million for Contract Health Services in the Alaska area. An amount estimated to be $10 million short of the need in our State.

The Alaska Native Health Board is encouraged by the $24 million program increase for IHS contact health services provided in FY 2000 and supports FY 2001 federal appropriations which would end the backlog of deferred cases, and which would provide for the IHS medical inflation rate (5.27 percent) which is higher than the private sector rate (2.8 percent).

C. Health Care Training & Recruiting

ANHB asks Congress to support educational opportunities for youth that will enable more Alaska Natives to pursue careers in the health care professions.

Recruiting and retaining rural residents for management and professional positions in the health care field proves difficult and costly both in terms of expense for recruiting and delays in access to health care. It is especially difficult in rural areas, where the lack of both rural non-Native and rural/urban Alaska Native/American Indian health professionals is evident. Further, rural health programs face a high turnover of health professionals from out of state. This is a chronic statewide demand for qualified Alaska Natives who are trained and prepared for careers in the health care field, as rural administrators, nurses, physicians, technicians, pharmacists, dentists, mid-level practitioners, and engineers, etc.

This shortage is fueled by gaps in secondary education that may make it difficult for rural students to proceed to post secondary studies in the health care area. These gaps include a failure to academically prepare high school students for college. In some rural areas, college preparatory courses are not available. Information, encouragement and academic support is needed to turn this situation around.

ANHB urges the development and support of programs designed to fill gaps in secondary education and prepare rural Alaskan youth for post secondary education and careers as health professionals.

ANHB urges support for existing heath care training programs at the University of Alaska Anchorage and Fairbanks through sustained and increased funding.

ANHB urges the development of additional programs for mentoring of students interested in the health professions (middle school through graduate education) with the funding of meaningful internship experiences and financial aid in the form of scholarships.

V. LEGISLATIVE / REGULATORY

A. Self Governance Legislation

ANHB supports enactment of legislation to improve and make permanent the authority for tribes and tribal organizations to administer health programs through self-governance agreements. Two such bills are pending in Congress — H.R. 1167 and S. 979. These bills are often referred to as "Title V" legislation because they would create a new Title V in the Indian Self-Determination and Education Assistance Act.

Alaskan Tribes and tribal organizations have for the past 20 years been at the forefront of tribal self-determination efforts to assume responsibilities from the Indian Health Service to deliver health care to eligible American Indians and Alaska Natives.

In 1994, a number of tribes and tribal organizations sought to further expand the scope of the programs and responsibilities that they could assume from the IHS by participating in the Tribal Self-Governance Demonstration Project. That year, thirteen tribes and tribal organizations negotiated and signed the Alaska Tribal Health Compact (ATHC). Since 1994, virtually every other tribe and tribal organization that provides health care services in Alaska have become co-signers of the ATHC. In FY 2000, the ATHC had 20 co-signers under which a total of over 217 federally recognized tribes in Alaska receive the great majority of the health care services provided to Alaska Native and American Indian beneficiaries in the state. Today, over 98 percent of the IHS programs in Alaska, including the Alaska Native Medical Center in Anchorage, are operated under the ATHC.

The ATHC and the Self-Governance Program in Alaska has, by all accounts, been a tremendous success. As a result of self-governance, tribes and tribal organizations have assumed more responsibilities and funds from the IHS than at any time previously. Furthermore, as a result of legal authorities contained in Title III of the Indian Self-Determination and Education Assistance Act, tribes and tribal organizations have greatly enhanced tribal control over health programs and freed themselves from overly bureaucratic oversight of their program management.

One potential risk of the Self-Governance Program at the present time is that its statutory authority is temporary.
Accordingly, it is critical that self-governance becomes a permanent program within the DHHS to ensure that the great strides that have been accomplished in Alaska under the ATHC are not compromised.

For the past four years, a nationwide tribal effort has been underway to develop and seek Congressional approval for legislation that will make the Self-Governance Program permanent. The effort has involved extensive consultation with tribes throughout the country as well as with representatives from DHHS and IHS. These efforts have culminated in bills being introduced in the House (H.R. 1167) and the Senate (S. 979). During the last session the House passed its version of the bill. The Senate, however, was never given an opportunity to vote on it due to a hold by Senator Gorton (R-WA) placed in the Senate Committee on Indian Affairs.

The tribal leaders participating in this effort, including H. Sally Smith, Chairman of the Alaska Native Health Board, are optimistic that Senator Gorton's concerns can be resolved during this upcoming session, freeing the bill to proceed through Congress to an expected Presidential signature.

Because of the importance of this bill to all tribes and tribal organizations in Alaska, this bill is one of ANHB's top legislative priorities during the upcoming legislative session.

B. Indian Health Care Improvement Act Reauthorization

ANHB strongly supports the reauthorization of the Indian Health Care Improvement Act (IHCIA). The IHCIA, first enacted in 1976 and reauthorized four times since, is designed to raise the health status of Native people and is a vital element in the fulfillment of the United States' trust responsibility — in this case, for health care — for Alaska Native and other Native people.

On November 16, 1999, Representative Don Young, Representative George Miller, and others introduced H.R. 3397, legislation to reauthorize the Indian Health Care Improvement Act. The bill they introduced is the product of a tribally-led consultation and drafting process, a process in which ANHB and other tribes and tribal organizations in Alaska were extremely active. ANHB President H. Sally Smith was the Alaska representative on the IHCIA Steering Committee. The Indian Health Service and the Health Care Financing Administration provided invaluable technical assistance during this process.

The Indian Health Care Improvement Act, along with the Indian Self-Determination and Education Assistance Act (ISDEAA) which authorizes tribes and tribal organizations to design and administer health programs, form the statutory foundation of the health delivery system for Native people in Alaska. Increased access to third party reimbursements — Medicaid, Medicare, CHIP — is also needed to make the health care foundation stronger, and H.R. 3397 addresses this matter.

We need a three-legged stool on which to build our health care system – services and facilities authorizations through the IHCIA, federal appropriations to fund the tribal delivery system through the ISDEAA, and full access to Medicare, Medicaid, and CHIP reimbursements.

Just as the Indian Health Care Improvement Act has changed over time to reflect urgent needs — substance abuse, mental health, health professional education and recruitment, diabetes, sanitation, catastrophic health costs -- the pending reauthorization bill reflects current tribal experiences and views on health care.

We realize the legislation will undergo changes during the Congressional reauthorization process — and we will likely have amendments of our own to propose — but want to retain provisions which support the philosophical underpinnings of the bill.

H.R. 3397 has eight titles, in some cases is highly technical, and is 305 pages in length. We bring to your attention, however, key thematic elements of the bill:

Local Control/De-centralization. Throughout the bill there is an effort to make as many programs as possible available for tribal administration through the Indian Self-Determination and Education Assistance Act. This was accomplished by changing the term "grant" in the current law to "funding agreements" to assure that funding could be transferred to tribes through ISDEA contracts and compacts.

The bill would also de-centralize some programs currently administered by IHS headquarters, i.e. scholarship programs, by providing the funding to IHS Area offices for local priority-setting and decision-making by tribes. It would authorize the Secretary to provide CHIP funding directly to tribes/tribal organizations to serve Indian children in their service areas.

Facilities Innovation. The bill is designed to offer innovative opportunities to tribes and tribal organizations in meeting their various facility needs. The current approach an IHS priority list for construction funding through the appropriations process will never meet the construction backlog.
Among the many facility-related provisions in the bill are ones which would allow leases to be used as a financing vehicle for health facility construction, establishment of a revolving loan program for direct loans and loan guarantees for construction, authorization of IHS/tribal joint venture projects where the tribe would supply the facility while IHS (under a no-cost lease) would provide staffing and equipment.

Improved Access. The legislation proposes many amendments to the Medicare, Medicaid and CHIP programs in an effort to both increase tribal access to third party payments and to remove existing barriers to accessing reimbursement from these or any new federal health programs.

Examples of proposals to increase access to reimbursements from the above-mentioned programs are:

- Replacement of the facility-based focus for collecting reimbursement from Medicare and Medicaid with a program-based focus. This would allow collection for services provided outside a facility, such as in home or community settings.

- Elimination of co-payments or cost-sharing for IHS beneficiaries under Medicaid, Medicare, and CHIP.

- A requirement that all Indian health care providers receive the same rates as given to other preferred federal customers for purchase of services.

- Authorization for tribes and tribal organizations who administer IHS-owned facilities to bypass IHS when billing for Medicare and Medicaid reimbursements. A 7-year demonstration program by four tribal health care providers, including two in Alaska, showed that tribes were increasing their M& M collections because they did a better job than IHS of billing and collecting reimbursements.

ANHB urges your support for legislation to reauthorize the Indian Health Care Improvement Act consistent with the goals and principles in H.R. 3397. Where appropriate, we urge that some provisions in the bill be considered on their own and enacted into law this year:

- Elevation of the position of the IHS Director

- Authority for tribes which administer IHS facilities to bill directly for Medicare and Medicaid

- Authority for IHS clinics to receive payment for Medicare Part B (doctor) services

C. Medicare Coverage for Prescription Drugs

ANHB supports legislative efforts to expand Medicare coverage for prescription drugs, and is encouraged by the bipartisan interest has emerged on this issue. We also support tribal health care provider access to the VA Prime Vendor Program as a means of getting lower purchasing costs for pharmaceuticals.

The federal government reports that thirty nine million Medicare recipients have no drug coverage, and most others must buy expensive supplemental insurance policies to help cover the cost of medicine. When the Medicare program was established, it was not known that the price of prescription drugs would become a central health care cost. It is time to bring the Medicare program into line with reality.

Ideas regarding how to approach prescription drug coverage vary widely, and as of this writing, some proposals are not yet finalized. Last year the President proposed to expand the Medicare program to provide limited coverage, in return for a monthly fee, for the costs of prescription drugs for all Medicare recipients. Others propose a limited coverage for prescription drugs according to financial need. or a combination of tax deductions and block grants to states.

ANHB will closely follow legislative developments on prescription drug coverage, and will support proposals which will lessen the burden of the cost of prescription drugs for Native peoples.

ANHB also support the provision in H.R. 3397, the Indian Health Care Improvement Act Reauthorization, which would allow tribes and tribal organizations to get lower purchasing costs for pharmaceuticals by accessing the Veterans Administration Prime Vendor program. The proposal would deem Indian Self-Determination contractors an executive agency and part of the IHS for purposes of this program.

D. FDA Regulation of Tobacco Products

Congress should support efforts by the Food and Drug Administration (FDA) to regulate tobacco as a dangerous and deadly product that kills approximately half a million Americans each year. Current and former smokers in the US generate over $500 billion in excess health care costs over the course of their lives. All of these deaths and expenses are 100% preventable.

Rates of tobacco use and tobacco-caused disease are especially high among Alaska Natives. Alaska Natives suffer 23.2% of smoking related deaths, although Natives comprise only 16.5% of the state's population. Over 40% of Alaska Natives use tobacco.

On August 28, 1996, President Clinton approved the U.S. Food and Drug Administration's (FDA) effort to regulate tobacco products and its related Tobacco Rule, which the FDA had developed to reduce teenage tobacco consumption through a comprehensive range of initiatives. These include:

Nationwide Minimum Age and Photo Identification Requirement. Among other things, the FDA Rule established 18 as the nationwide minimum age for purchasing tobacco products, and required retailers to check photo identification of anyone buying tobacco products who appears younger than 27.

Reducing Easy Access by Children. To make it more difficult for kids to obtain tobacco products illegally, the FDA Rule also bans vending machine sales and self-service displays; except in places where minors are not allowed, such as certain bars and nightclubs; prohibits the sale of single or loose cigarettes (requires packages to contain at least 20); and prohibits free giveaways of cigarettes or smokeless (chew) tobacco products.

Restricting Tobacco Company Marketing to Children. The FDA rule also bans all outdoor advertising within 1,000 feet of schools and playgrounds; limits all remaining outdoor and point-of-sale tobacco advertising to black-and-white text only, except inside facilities that minors are not allowed to enter; limits advertising in publications with significant youth readership (those with either 15 percent or 2 million readers under 18 years of age) to black and white print only; prohibits tobacco company sales or giveaways of non-tobacco merchandise or products -- such as caps, jackets, or gym bags -- that carry cigarette or smokeless tobacco brand names or logos; prohibits the tobacco companies from giving away non-tobacco items -- such as key chains, lighters, or music CDs -- in exchange for the purchase of cigarettes or smokeless tobacco; prohibits tobacco company brand-name sponsorships of sporting or entertainment events, or of individual teams or entries (while still permitting sponsorships in the companies' corporate names).

The tobacco companies immediately filed lawsuits to challenge FDA's authority. On April 25, 1997, District Court Judge William L. Osteen upheld the FDA's legal authority to regulate cigarettes and smokeless tobacco products as "drugs" and "devices" under the Food, Drug, and Cosmetic Act, as well as its specific authority to issue the FDA Rule's youth access provisions. But the Judge also ruled that the FDA did not have statutory authority for the proposed advertising and promotional restrictions.

The tobacco companies appealed Judge Osteen's ruling that FDA has statutory authority over tobacco products to the U.S.

This lawsuit is now before the U.S. Supreme Court.

If the Supreme Court finds that the FDA does not have clear existing authority to regulate tobacco products, Congress should move quickly to provide that authority.

The U.S. Food and Drug Administration (FDA) is the only government agency that can provide comprehensive oversight of all aspects of tobacco products and the tobacco industries efforts to advertise and promote these products.

With established jurisdiction over tobacco, the FDA could make sure that the tobacco companies do not manipulate the nicotine levels in their products or add any new, dangerous, ingredients. Similarly, the FDA could ensure that the tobacco companies do not change the character, packaging, or marketing of their products to make them more appealing to kids. This kind of comprehensive and continuous oversight of tobacco industry practices is essential to protect children's health.

The FDA is *required*, under the legislation which created it, to regulate products which are intended to affect "the structure and function of the body." Internal documents show that major tobacco companies have researched and understood the effects of nicotine and have deliberately designed their products to have these effects. Consider the following excerpts:

> *"In a sense, the tobacco industry may be thought of as being a specialized, highly ritualized, and stylized segment of the pharmaceutical industry. Tobacco products uniquely contain and deliver nicotine, a potential drug with a variety of physiological effects."* [1]

> *"The cigarette should be conceived not as a product but as a package. The product is nicotine.... Think of the cigarette as a dispenser for a dose unit of nicotine....Think of a puff of smoke as the vehicle of nicotine."* [2]

Establishing FDA authority over tobacco products would not subject the tobacco industry to more intensive governmental scrutiny than other products but would simply apply the same kind of regulatory oversight to tobacco products that already applies to all other legal products consumed by U.S. consumers.

Many of the harmful chemicals in tobacco smoke are strictly regulated as toxic chemicals -- for example, pesticides sprayed on tobacco leaf -- but because they are in tobacco smoke from cigarettes, the tobacco industry argues that they are not subject to the FDA's jurisdiction.

We urge Congress to give the Food and Drug Administration (FDA) the regulatory authority needed to regulate tobacco and protect the public health.

[1] RJR executive Claude Teague, Jr., "RJR Confidential Research Planning Memorandum on the Nature of Nicotine and the Crucial Role of Nicotine Therein," also quoted in The New York Times, July 26, 1995.

[2] Philip Morris researcher William Dunn as quoted in a 1972 Philip Morris document and The New York Times, April 4, 1994.

E. Increasing the Federal Tobacco Tax

ANHB supports efforts to increase the Federal tobacco tax to further reduce smoking.

Increasing the price of tobacco products is recognized as one of the single most effective public health strategies to reduce the use of tobacco products. Numerous economic studies in peer-reviewed journals have documented the impact of cigarette tax increases and other price hikes on both adult and underage smoking.

The 1999 World Bank report *Curbing The Tobacco Epidemic: Governments and the Economics of Tobacco Control* carefully evaluated existing research and data, worldwide, and concluded that "the most effective way to deter children from taking up smoking is to increase taxes on tobacco."

In its 1998 report, *Taking Action to Reduce Tobacco Use*, the National Academy of Sciences' Institute of Medicine concluded that "the single most direct and reliable method for reducing consumption is to increase the price of tobacco products, thus encouraging the cessation and reducing the level of initiation of tobacco use."

The Maxwell Report USA, regularly published in the tobacco industry trade journal *Tobacco Reporter*, concluded in May 1998 that "a 100 percent increase in cigarette prices could cause a 30 to 40 percent decline in [cigarette] consumption."

A National Cancer Institute Expert Panel reported in 1993 that "a substantial increase in tobacco excise taxes may be the single most effective measure for decreasing tobacco consumption," and "an excise tax reduces consumption by children and teenagers at least as much as it reduces consumption by adults."

The general consensus within the research community is that every 10 percent increase in the real price of cigarettes will reduce overall cigarette consumption by approximately 3-5% and reduce the number of kids who smoke by about 7%. This indicates that raising the federal cigarette tax to produce a 10 percent increase in cigarette prices would reduce the number of current youth smokers by more than 300,000.

Higher taxes on smokeless tobacco also reduces use of this tobacco product, particularly among young males.

Research has also shown that kids do not smoke more marijuana if they reduce their cigarette smoking. In fact, cigarette price increases not only reduce youth smoking but also reduce both the number of kids who smoke marijuana and the amount of marijuana consumed by continuing regular users.

Wall Street tobacco industry analysts have long recognized the powerful role increased cigarette taxes and rising cigarette prices play in reducing U.S. smoking levels. A December 1998 "Sensitivity Analysis on Cigarette Price Elasticity" by Credit Suisse First Boston Corporation, for example, settled on a "conservative" estimate that cigarette consumption will decline by four percent for every 10 percent increase in price.

In its August 1999 Report to the Securities Exchange Commission, Philip Morris stated that "increases in excise and similar taxes have had an adverse impact on sales of cigarettes."

The tobacco industry's own internal documents, disclosed in the tobacco lawsuits, also show that raising cigarette taxes is one of the most effective ways to prevent and reduce smoking among youth.

For example:

> *"It is clear that price has a pronounced effect on the smoking prevalence of teenagers, and that the goals of reducing teenage smoking and balancing the budget would both be served by increasing the Federal excise tax on cigarettes."*[1]

> *"If prices were 10% higher, 12-17 incidence [the percentage of kids who smoke] would be 11.9% lower."*[2]

The cigarette companies try to argue that cigarette tax increases are regressive taxes that fall disproportionately hard on those with lower incomes. This argument turns reality upside down. The fact that smoking rates are highest among low-income groups means that those groups currently suffer the most from smoking and will benefit disproportionately from any effective new measures to reduce smoking, including increased federal cigarette taxes.

Because low-income Americans are also the most sensitive to cigarette price increases, increasing federal cigarette taxes will work even more effectively in low-income communities to prompt smokers to quit and stop kids from ever starting to smoke in the first place. Low-income communities will not be the victims of a federal cigarette tax increase but its biggest beneficiaries.

Rates of tobacco use and tobacco-caused disease are especially high among Alaska Natives. Alaska Natives suffer 23.2% of smoking related deaths, although Natives comprise only 16.5% of the state's population. Over 40% of Alaska Natives use tobacco.

As part of a comprehensive effort to reduce tobacco-caused disease and death among Alaska Natives, Congress should act to substantially increase the federal tax on tobacco products. While such an action will not erase the problem of lung cancer, heart disease and other deaths resulting from smoking, it is an important part of an overall strategy for reducing use of this dangerous drug.

[1] Philip Morris Research Executive Myron Johnston, "Teenage Smoking and the Federal Excise Tax on Cigarettes" (September 17, 1981)

[2] R.J. Reynolds Executive D. S. Burrows, "Estimated Change In Industry Trend Following Federal Excise Tax Increase" (September 20, 1982)

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