



Chapter II—Listening Councils

A Description of the Listening Councils

Scottsdale, Arizona, October 14, 1998

The Scottsdale Listening Council, was moderated by Anthony Largo, spokesperson for the Santa Rosa Band of Cahuilla Indians in California, and included approximately 32 tribal leaders and other tribal representatives from Southern California, Arizona, Nevada, Utah, Colorado and New Mexico. The meeting began with introductions by each tribal leader and Dr. Trujillo and Deputy Secretary Thurm. Time was provided for tribal leaders wishing to make a statement, first on matters related to health, then on matters related to human services. A significant portion of the discussion focused on the consultation process and how to make it more effective and meaningful with wanting to confirm the steps involved in meaningful consultation and the feedback that they could expect from these Listening Councils. Forty-three individual issues and recommendations were identified during the Scottsdale meeting, most of which were “crosscutting” or national in focus.

Regional/Local Issues: The decrease in Medi-Cal reimbursements in California and the gap in funding it created for tribal and urban Indian health care providers. The allocation of new funds under the IHS Diabetes Initiative, specifically that California Tribes may be receiving an inequitable distribution. The funding needed to replace the Phoenix Indian

Medical Center in Phoenix, Arizona (this facility has been on the IHS facility construction priority list). The need for funding to replace the Fort Defiance Indian Hospital on the Navajo Reservation, and the need for a hospital facility to serve the Tribes in Nevada, who are located too far away from the Phoenix Indian Medical Center to access that facility. The need was expressed for facility construction funding for California Tribes and concerns regarding multigenerational exposure to uranium mining and its related hazardous effects.

Crosscutting Issues: The participants raised concerns about the HHS consultation process and, in particular, the Administration’s commitment to the process. It was recommended that the Secretary establish an “Indian Desk” in the Office of the Secretary. Strong support was voiced for the existing IHS budget formulation and the manner in which it involves tribal consultation throughout. Participants recommended that the self-governance process be made permanent for the IHS, and that contract support cost funding not be allocated on a pro rata basis. It was also recommended that HHS apply the provisions of the Indian Self-Determination and Education Assistance Act (P.L. 93-638), contracting of programs, to all agencies within the Department, not only the IHS.

Concerns were raised about the amount of funding for all IHS programs and services and the process through which funding the IHS allocates, and the lack of support for home- and community-based care for patients with disabilities. The distribution of resources within the IHS system was another concern, and the need to focus more funding and services on alcoholism and substance abuse, the elderly, youth, accident prevention, emergency medical services, complications from chronic diseases, such as diabetes, and the recruitment and retention of qualified Indian health professionals. Concerns were raised about the inadequacy of facilities and infrastructure and, specifically, the need for new or refurbished outpatient and inpatient facilities and sanitary water and updated sewer systems for Indian communities. The Tribal leaders raised the difficulties experienced with reimbursement for services available through Medicare and Medicaid; the need for technical assistance to enable them to more effectively secure reimbursement for eligible patients; assistance in coordinating with state managed care systems and improving third party billing. Additionally, concern was expressed about the impact of the new welfare reform system, Temporary Assistance to Needy Families (TANF) on tribal members. Finally, participants voiced strong concern that the federal government needs to do more to fulfill its trust responsibility by providing the quality and quantity of health care needed by tribes.

Bismarck, North Dakota, December 4, 1998

The Bismarck Listening Council included tribal leaders from Montana, Wyoming, North Dakota, South Dakota, Minnesota, Wisconsin and Iowa. Dr. David Gipp, President of the United Tribes Technical College, served as the moderator for this meeting. Approximately 35 individuals made presentations at the Bismarck meeting.

Regional/Local Issues: Several participants stated that Treaty Tribes were not receiving an equitable distribution of IHS resources and that health status indicators, which reflect severe health problems among the Northern Plains Tribes, such as infant mortality, are not adequately incorporated into allocation decisions. Tribal leaders expressed a fear that the IHS would be required to “means-test” to determine financial eligibility for services at some point in the future. They raised the issue of increasing reliance of the IHS upon revenues from Medicare and Medicaid underscored their concerns about means testing. The leaders questioned the validity of the IHS as a “residual” provider of health care and recommended that it be the “primary” provider of health services for Indian people and be funded appropriately. Tribal leaders recommended that tribes be “treated as states” in determining eligibility for other federal programs and resources beyond the IHS. It was suggested that HHS resources be combined into “block grants” and funded directly to tribal governments. Tribal leaders

expressed concern about the social and financial impact of Indian families returning from urban areas to live on the reservations. Other regional concerns included the lack of adequate funding for the “Healthy Start” program, overall funding for children’s health and the need to develop treatment programs for those using methamphetamine. It was recommended that the IHS conduct a national strategic planning process to better respond to the changing environment and that it consider “regional advocacy” to better focus on the unique health needs in each region.

Crosscutting Issues: Participants focused much of the discussion on the consultation process and the commitment of HHS to follow-up and respond to tribal issues and recommendations. The lack of funding for all aspects of the IHS was highlighted specifically for Contract Health Services (CHS), alcohol prevention, adolescent health, elderly care, nursing home care, diabetes, cancer, the Catastrophic Health Emergency Fund (CHEF), emergency medical services, HIV/AIDS, mental health services and appropriate staffing of health professionals. Like other regions, Bismarck participants were concerned about the lack of funding for new and replacement hospitals and clinics. The issue of traditional Indian healing practices and its relationship to the IHS was also raised.

Other issues included Racism or “anti-Indian sentiment” surrounding Indian reservations and communities. Technical assistance was needed in dealing with states regarding managed care and other reimbursement issues. It was recommended that federal law be amended to make Indian health care an

“entitlement” as opposed to a discretionary program of the government. HHS was asked to support the reauthorization of the Indian Health Care Improvement Act (P.L. 94-437). Concern was raised that the current Medicare program does not adequately support costs associated with nursing home care, including questions regarding eligibility for IHS services and requests that a final rule be established. The impact that depressed reservation economies have on the health status of Indian families should be addressed more holistically. The United States Department of Agriculture Commodity Food Program was identified as one of the problems in making a connection between improved health care and addressing the effects of poverty. The impact of welfare reform on Indian families and their health care was identified as well as environmental issues affecting Indian health status, such as water pollution, bad roads, and lack of transportation services. Finally, participants asked that Congress make a long-term commitment to Indian people and fully fund its treaty obligations to provide health services.

Seattle, Washington, January 21, 1999

The Seattle Listening Council included tribal leaders from Alaska, Washington, Oregon, Idaho and Northern California and was moderated by Julia Davis, a member of the Nez Perce Tribal Executive Committee. Approximately 56 individuals participated in this Listening Council. Each elected tribal official was provided time to make a formal statement or present an issue to the federal representatives.

Regional/Local Issues: Participants raised concerns for the increase in inhalant abuse among Indian youth and the need for treatment services for this population. A recommendation was made that existing federal law be modified so that individual tribes can access funds appropriated for Regional Youth Treatment Centers (RYTC) to address substance abuse issues locally. California tribal leaders recommended that at least two RYTC be allowed in that State to cover the vast territory. A separate recommendation was made to support the operation of the existing RYTC.

Tribal leaders asked for technical assistance to access federal tobacco control funding; increased funds to serve the large number of urban Indians in California. Participants requested that the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) assist tribes in the development of local Institutional Research Boards (IRB) and provide tribes with the opportunity to approve and review any and all research affecting tribes. The need was expressed to appoint Indian people to the Medicare and Medicaid Advisory Committee through HHS and to require that the Health Resources and Services Administration (HRSA) go through a similar consultation process with tribes. Concerns about the Base Closure Act and whether tribal interests were protected and included in this process was also discussed.

Crosscutting Issues: Participants discussed the HHS consultation process and the steps for follow-up to the Listening Councils. The federal obligation to fulfill Indian treaty rights, its trust responsibility to provide health services, and the requirement that Congress appropriate adequate funds to meet this obligation, was a cornerstone of these discussions. The concern was expressed that funding is not adequate across the board for IHS, in particular full funding for “mandatory increases,” such as medical inflation, payroll increases and population growth should not be taken away from service funds but funded additionally. Increased funding is needed for diabetes, Contract Health Services (CHS), dental care, catastrophic illnesses and accidents, elderly care, adolescent health, alcohol and substance abuse treatment and prevention and staffing.

The lack of funding for facilities construction for outpatient clinics and sanitary water/sewer systems was also identified. The “Joint Venture” program to fund the equipment and staffing of tribally constructed outpatient health clinics was identified as a successful model and recommended to receive more attention and future funding.

Tribal representatives identified the problem of patient travel and geographical access barriers to care and transportation costs as hindering their ability to provide adequate services. Tribal leaders also voiced strong support for the elevation of the Director of the IHS to an Assistant Secretary level. Participants voiced their support for the reauthorization of the IHClA and asked for assistance and

advocacy from the Health Care Financing Administration (HCFA) in educating states about the unique status of tribes. The current Memorandum of Agreement between the IHS and HCFA needs more exposure at the state level and barriers to Medicare/Medicaid reimbursement for tribes must be addressed. Questions were raised about the unwillingness of some states to reimburse tribes retroactively as "Federally Qualified Health Centers" (FQHC), under the IHS/HCFA Memorandum of Agreement. It was recommended that HCFA engage in negotiated rulemaking and meaningful consultation with tribal governments on these and other issues. The tribal leaders voiced strong support that IHS services should be funded as an entitlement; not on a discretionary basis. The issue of "equity" in the allocation of IHS resources was raised, and a recommendation was made that an actuarial approach be adopted in the allocation of funds.

With regard to welfare reform, participants voiced concern that a formal tribal consultation process be initiated for TANF issues. It was recommended that federal support be provided to administer TANF funds for tribes, just as it is provided for states. Questions were raised about the process and funding allocation methodology under the child support enforcement statute and the need for more attention on this issue. More funding is needed for social service programs in tribal communities. Child welfare funds should go directly to tribes and not through states. The ceiling on indirect cost rates allowable to tribal Head Start programs is a problem and should be lifted.

Oklahoma City, Oklahoma, March 9, 1999

The Oklahoma City Listening Council included 104 tribal leaders and Indian organization representatives from Oklahoma, Kansas, Nebraska and Texas. The meeting was facilitated by Ruey Darrow, Chairman of the Fort Sill Apache Tribe in Oklahoma and Wanda Stone, Chairperson for the Kaw Tribe of Oklahoma. Dr. Trujillo provided an overview and expressed HHS's intent to "bring into effect the consultation process" and involvement of tribes with the numerous agencies and programs of the Department. While HHS has an Indian-specific agency and program, (IHS and the Administration for Native Americans (ANA)), there are many more programs and authorities under the Department that impact tribal communities and should be addressed. Deputy Secretary Thurm made a brief presentation regarding his intent to listen to the concerns voiced by tribes and his commitment to provide feedback and follow-up on the major themes that emerge. He also stated that it was his goal to institutionalize this consultation process within HHS, so that it will not be dependent on any one individual but will be an ongoing departmental process.

Regional/Local Issues: A recurring regional theme that emerged at the Oklahoma City Listening Council as well was the issue of “equity” in the distribution of the IHS resources and the belief that Oklahoma was not receiving its fair share based upon a per capita allocation formula. While strong support was voiced for overall increases to the IHS budget, the allocation methodology within the IHS was identified as requiring more attention and fairness. Support was voiced for construction funding for replacement of the Lawton Indian Hospital and for increased funding for maintenance and improvement at that facility. Increased funding at all the Oklahoma Area hospitals was recommended.

A question was raised regarding the potential impacts of planned contracting of the Claremore Hospital under the Indian Self-Determination and Education Assistance Act (P.L. 93-638). It was recommended that additional funds be provided to support a needed inpatient alcohol and drug treatment facility in Western Oklahoma. There were conflicting recommendations expressed regarding the two urban demonstration projects funded in Oklahoma City and Tulsa, with participants suggesting that these programs be made permanent under P.L. 94-437 and others suggesting that only Tulsa should be designated permanent status. A recommendation was also made to extend coverage under the Federal Tort Claims Act and the Office of Management and Budget (OMB) reimbursement rates for Medicare and Medicaid to these two urban demonstration sites.

Crosscutting Issues: A majority of the issues discussed at the Oklahoma City Listening Council were of national and crosscutting significance. Increased funding for existing IHS initiatives was a recurring theme. Tribal leaders also recommended that the IHS develop a system whereby any IHS eligible patient can receive service at any IHS funded facility and that facility will be reimbursed by that patient’s tribal or IHS provider. More funds are needed for diabetes, Community Health Representatives (CHR), environmental health, emergency medical services, pharmacy services, elderly care, dialysis, health scholarships, alcohol and substance abuse treatment and prevention, public health nursing, community health training, and increased funding for dental services.

Like other regions, the tribal leaders at the Oklahoma City meeting expressed their concern that funding is not adequate for the construction of new and replacement inpatient and outpatient facilities. Recommendations were made to lift the moratorium on contracting under P.L. 93-638 and to adequately fund Contract Support Costs and Indirect Costs. Tribal participants asked for a consultation process with HCFA to improve third-party billing for tribes. Reimbursement rates for tribes and urban programs under FQHC are scheduled to decline to only 70% of costs with no plan to cover that gap. It was recommended that the “direct billing” for Medicaid and Medicare be approved for all tribes contracting their own health systems, and not just the tribes participating in a demonstration project. Tribal representatives requested help from HHS to get Medicare coverage for home health care and hospice care for their elderly. Tribal leaders

asked that the HHS Secretary use her authority to waive the budget “caps” for the IHS when preparing the annual budget request. As in other regions, the problem of access due to inadequate transportation services was highlighted.

Other issues included: Support for the elevation of the IHS Director to an Assistant Secretary level. Lift the moratorium on defining eligibility regulations for HHS. Establish an Indian Advisory Committee at HHS. Concern was expressed about welfare reform implementation and whether it can work in the face of high unemployment in Indian country. Concern was expressed regarding funding cuts to the Child Care Bureau; funding needed for construction of Head Start facilities, and access to increased funding and support from other HHS agencies such as NIH and CDC.

Syracuse, New York, May 21, 1999

The Syracuse Listening Council was a forum for Eastern and Southeastern Tribes located in New York, Maine, Massachusetts, Rhode Island, Connecticut, North Carolina, South Carolina, Mississippi, Alabama, Louisiana, and Florida. Mr. Tim Martin, Executive Director of the United South and Eastern Tribes (USET) moderated the meeting.

Regional/Local Issues: The international border between the United States and Canada creates many difficulties for tribal programs serving families with ties to both countries. Specifically, tribal leaders expressed frustration about the difficulty in making child custody placements or child custody agreements when each parent resides on a different side of the border. They sought HHS assistance in

enlisting the support of the State Department. A concern was raised that the public as well as the state and federal governments have a false perception of the availability of “gaming revenue” to meet tribes’ health and human services needs. Many tribes do not operate gaming enterprises, and most of those that do operate such facilities do not generate the level of funding necessary to meet the significant health and human service needs in tribal communities.

There were concerns about the rise in the number of AI/ANs who smoke and in heart disease due to the lack of adequate prevention initiatives. They expressed the need for more radiology and optometry services, and an increase in substance abuse. Tribal representatives identified the Department of Justice “Drug Courts” as an excellent model of integrating health and law enforcement resources to intervene with addicted individuals. The participants identified a need for more flexibility in HHS programs. Tribal leaders also discussed the concern about Indian burial sites being disturbed and vandalized.

Crosscutting Issues: Tribal leaders were particularly concerned about the specific steps that the HHS would take to document, investigate and respond to each issue and recommendation raised.

Participants expressed the need for “aftercare” services for Indian patients coming home from inpatient alcohol and drug treatment. There is a significant amount of air and water pollution in the northeastern states which adversely impact the health of Indian communities. While this was expressed as a regional issue, it was also a common concern in other areas.

Additional funding for Indian health services was a recurring theme. Tribal leaders recommended a structured HCFA consultation process through which issues relating to Medicaid and Medicare reimbursement rates could be addressed. Participants also requested a standard federal rate for hospital services, similar to the standard Medicare rate, which limits the amount hospitals can charge for services to Medicare patients. Tribes expressed concern that states are not recognizing, cooperating with or serving Indian communities. Participants expressed concern about the allocation of IHS resources and recommended that the “Level of Need Funding” (LNF) formula be reviewed for fairness and improvement. It was also recommended that the overall impact on funding due to contracting and compacting under P.L. 93-638, be reviewed.

The Tribal leaders voiced support for the elevation of the IHS Director to an Assistant Secretary level. Concern was expressed about the lack of adequate data systems to report and monitor the health status of Indian populations. Services provided with IHS dollars to “non-eligible” populations should require additional funds. When the federal government recognizes new tribes, additional funds should be appropriated to support the health needs of that tribe rather than taking it from the existing IHS budget. Tribal leaders expressed their support for the reauthorization of the IHCLA and recommended that Indian health care be made an “entitlement,” not a discretionary program.

Other issues included: TANF implementation and the need for more resources for child care services in Indian communities as well as HHS flexibility with respect to program requirements when dealing with tribal governments. Participants identified the need to provide social services to families returning from other areas to their home reservations. They also expressed their desire for the protection of tribal languages and tribal cultures. Tribal leaders expressed the concern regarding the inadequacy of IHS funding to meet Indian health needs, in particular for diabetes, alcohol and substance abuse, CHS, prevention initiatives, long-term elder care, tobacco control and smoking cessation, cancer and heart disease prevention and treatment, HIV/AIDS, dental care, radiology, optometry, youth education, and construction of tribal health facilities. The need for scholarship assistance to Indian students interested in health professions was also a concern.

In honoring its treaty obligations, included the obligation to provide health services, Tribal leaders emphasized that the federal government, in particular the Office of Management and Budget (OMB), must consult with tribes in making decisions that affect tribal communities.

B. Summary of Crosscutting Issues and Themes that Emerged

In all, tribal leaders and other Indian organization representatives raised 52 distinct crosscutting or national issues and recommendations at the five Listening Councils which are divided into seven categories or themes as follows:

1. Funding and Budget Issues
2. Services and Service Provision
3. Care Providers
4. Facilities, Equipment and Supplies
5. Intergovernmental Relations and Related Issues
6. Infrastructure
7. Data and Research

The majority of individual issues and recommendations raised by tribal leaders (20 out of 52) related to the first category, "Funding and Budget Issues." The next most frequently addressed area (14) was "Intergovernmental Relations and Related Issues." The category "Services and Service Provision" included 8 distinct issues. The remaining categories had fewer than 5 distinct issues in each. The following is a brief discussion of each of the seven major themes.

1. Funding and Budget Issues

This category consolidates a wide array of concerns expressed by tribal leaders, ranging from appropriations for specific IHS programs to reimbursement policies of the Medicaid and Medicare programs. Many of the concerns relate directly to the level of funds appropriated to the IHS to support health services, transportation, sanitation services, construction, CHRs, and nursing. Other issues and concerns relate to policies within the IHS, such as the distribution and allocation of resources among the tribes and areas within the IHS system. Other issues relate to legislative mandates by the Congress, such as the moratorium on contracting under the P.L. 93-638 and related funding for contract support costs. Concerns were also raised regarding the eligibility for services address both IHS policy and congressional mandates. A summary of the funding/budget issues and recommendations is as follows:

Health Services and Transportation: Funding is insufficient for health services and transportation services. Establish a line item for health services. Support appropriation for health services at level of need.

Water and Sewer Systems: Funding is lacking for water and sewer maintenance and repairs and testing of water systems. Appropriately fund maintenance and improvements.

Construction Financing: Funding is lacking to build, expand, replace, and maintain health care facilities. Find innovative financing for tribes to build health care facilities.

Native Healers: Funding is lacking for traditional native healers and practitioners.

Prevention: Funding is lacking for prevention activities. Funding is only enough to address primary care.

CHR/CHN: Community Health Representatives and Clinical Health Nurse Programs are underfunded.

CHS: Contract Health Services are underfunded. Earmark funds for CHS and increase CHS funds.

Targeted Health Needs: Environmental health; Emergency Medical Services (EMS); long-term elderly care; aftercare services; alcohol/substance abuse programs; diabetes programs; prevention, intervention and health education programs and outreach efforts are all underfunded. Appropriate line items for EMS funds, tribal EMS programs, elder care, alcohol prevention and treatment and commit to long-term diabetes initiative.

Contract Support Costs: Administrative and indirect funds for compacting and contracting under P.L. 93-638 are underfunded. Appropriate sufficient funds for administrative costs to tribes.

Equity within IHS: Appropriations are insufficient to keep pace with inflation, growth of Indian population or level of needs. There is inequitable funding for tribes and Areas on per capita allocation.

Inadequate allocation formula: Amend the IHCLA section that authorizes the IHS improvement fund to provide for equity funding.

P.L. 93-638 Contracting: Opposition to moratorium on P.L. 93-638 funding, payment of Contract Support Costs or reallocation of CSC on a pro rata method.

Equity Compared to Other Populations: Funding for Indian population as compared to other U.S. populations is inequitable. Fully involve tribes in the budget process and budget discussions and legislation.

Third Party Revenues: There is inappropriate consideration of third-party collections in budget decisions.

Managed Care: Assess the impact of managed care on tribes and tribal reimbursements.

Demonstration Projects: Provide more funds for demonstration grants on important health issues. It is difficult to implement new approaches to care without adequate or accessible funding.

Service Eligibility and Payment: Services provided to other tribes' members limits or reduces funds to tribes providing the service.

HCFA, Medicaid and Managed Care: Assist tribes in working with HCFA in the area of managed care.

IHS Capitated Restrictions: Support a provision that authorizes IHS to enter into capitation agreements for managed care.

Medicare: Assist freestanding health centers in billing Medicare for outpatient services.

Diabetes Fund Allocation: Change the allocation methodology for diabetes funding.

2. Services and Service Provision

The next major crosscutting theme incorporates issues related to the provision of services.

Traditional Healers: Recognize and support the need and use of traditional American Indian healers. There should be a policy that recognizes the use of traditional American Indian healers and practitioners in mental health.

Expand scope of services provided: Need to improve and provide access to: specialty and inpatient care, behavioral health services, including alcohol/substance abuse programs that include services for children, adolescents and women; diabetes programs; prevention and health education; pre-hospital emergency medical services; hospice and physical therapy programs; long term elderly care; and in home or special transportation for disabled people. IHS should be given authority to license long-term health care units on reservations. Support is needed in obtaining ambulances to provide 24-hour coverage.

Dialysis units: There is a need for dialysis units and to increase the size of existing units.

Access to alternatives: Access to “charity care” is lacking.

Cancer Screening: Increase focus on cancer screening for men.

Holistic Services: Provide holistic services for families, including mental health services.

Medicaid Barriers: Need to address barriers for parents who are not legally married and are unable to enroll their families in Medicaid.

Medicare and Medicaid Outreach: Outreach is needed to develop brochure describing Medicare benefits and provide information on Medicare and Medicaid in plain language.

3. Care Providers

The third crosscutting theme involved improvements or increasing the numbers and types of care providers available to Indian communities. The IHS has available to it programs under Title I of P.L. 94-437 to recruit, train, place and retain qualified health professionals. Despite this resource, tribes voiced concern about the lack of providers in certain fields and the difficulty in retaining providers.

More Providers of Care Needed: Too few health care providers result in high patient care load. IHS must use existing options to encourage careers in IHS and enhance training of American Indians/Alaska Natives (AI/AN) in health professions.

Provider Licensure: Some providers lack appropriate credentials. Assist tribes with licensing of dentists and doctors who are licensed in another state. Assist tribes to access training and continuing education for physicians and staff.

4. Facilities, Equipment and Supplies:

The fourth theme included issues and recommendations regarding facilities, tribal leaders at all five Listening Councils raised equipment and supplies. Many tribes expressed support for their local inpatient or outpatient facility to be replaced or newly constructed. Others expressed concern about the lack of funding for basic upkeep of existing facilities.

Lack of Facilities: There is a lack of facilities for health services, chemical dependency programs, renal dialysis units/clinics, nursing homes, and emergency rooms. Assist tribes to find alternate means for constructing needed facilities and upgrade emergency rooms.

Quality of Facilities: Facilities are unable to meet Joint Commission for the Accreditation of Health Care Organizations (JCAHCO) standards which means tribal facilities cannot compete with non-tribal facilities for patients.

Facility Construction/Replacement Process:

The existing IHS process to identify, prioritize and justify new construction and replacement is time consuming and not working. Facility construction issues affect the number of medical staff, equipment, supplies and auxiliary providers. Delay in new construction also delays funding to bridge the gap between existing services and required services.

Equipment: A need exists for disaster preparedness and disaster response equipment.

5. Intergovernmental Relations and Related Issues:

One theme focused upon at all of the five Listening Councils was the area of tribal consultation, follow-up, and intergovernmental relations. The legal and historic government-to-government relationship is the foundation for these tribal consultation meetings and must not be overlooked. Beyond the process of holding meetings, tribal leaders want assurance that specific follow-up would be undertaken by HHS to address each of the issues raised and institutionalize the consultation process. There were fourteen specific issue areas, and recommendations, identified under this major theme.

Partnerships: Explore new and creative approaches or partnerships for efficient delivery of services for tribes. Encourage collaboration between state and tribal governments. Assist in helping private businesses become partners with tribes.

Input and Advocacy: Establish a HHS Advisory body that includes tribal leaders. Develop a website for AI/AN to make their needs known or respond to issues that affect them. Assure that all tribes are Internet capable. Establish an "Indian Desk" in all HHS agencies to allow better access to resources and technical assistance.

Consultation Follow-Up: Tribal leaders expressed their concern about another consultation process without clear follow up. Establish a plan and timeline for achieving results to the Listening Council meetings.

State Relations: States do not have adequate outreach services in rural areas of the states.

Direct Federal Funding: Tribes need to have access to more than just demonstration projects. HHS should implement a pilot program for direct federal funding to tribes from agencies rather than going through the states. Look beyond the IHS for funding to identify other sources that should be made available to tribes. Initiate and develop tribal specific grants.

Welfare Reform: Address the impact of welfare reform on AI/AN.

Budget Formulation: Provide tribes the opportunity to impact the long term planning for the budget. The budget consultation discussion centers on foregone conclusions, loss of opportunity to influence the outcome. HHS should allow for joint funding of projects to fund services more comprehensively.

Remove Caps on Indirect Rates: Tribes are seeking to raise the cap on funding of indirect costs allowed for Head Start programs which they administer.

Technical Assistance and Information: Assist tribes to maneuver through the federal system by providing contacts in each agency for technical assistance and information dissemination. There are too many obstacles and red tape.

International Border Issues: The international border issues, such as the U.S. and Canada, create many difficulties for tribal programs serving Indian people with ties to both countries. For example, tribes are not able to provide services for children of

divorced parents when one parent resides in the U.S. and the other resides outside the U.S.

Consultation Overload: The agency-level consultation process places a burden on tribes. There should be one workable consultation process.

HHS Key Staff: Fill the permanent positions in the Office of the Secretary, Office of Intergovernmental Affairs.

IHS Director Elevation: Elevate the position of IHS Director to Assistant Secretary.

6. Infrastructure

The deterioration of sanitary water and sewer infrastructure systems was identified at several of the Listening Councils. Tribes have requested assistance to repair these systems and adequately fund operations and maintenance. Training should be provided to tribes to make repairs as needed. Joint efforts are needed to address the impact of contaminated land and water from waste, weed sprays, fertilizers and other pollutants.

7. Data and Research

Two issues were raised in regard to data and research. Those included making community specific health care data more accessible to tribal communities and establishing a national database of companies that can provide assistance to tribal programs such as pharmaceutical companies.

C. Actions Taken by HHS since the Listening Councils

Verbatim transcripts from each of the five Listening Councils were made available to tribal leaders for the meeting in which they participated. The 52-crosscutting/national issues were forwarded to the appropriate HHS agency(ies) for response.

A matrix which contains HHS agency responses to these specific issues was developed and reviewed during the National Tribal Consultation Forum. A summary of HHS agency responses has been incorporated into this Final Report. During the National Tribal Consultation Forum, tribal leaders and representatives from other Indian organizations reviewed the detailed responses provided by HHS to each issue. Additional issues were identified at the NTCF and recommendations made to further this dialogue and exchange. These issues can be found in Chapter III.

D. Summary of Responses from HHS Agencies by Major Themes

This section of the Summary Report condenses Agency responses within the seven major themes that emerged at the five regional Listening Councils.

1. Funding and Budget Issues

There were twenty individual issues raised under this category which fall within one of five sub-categories: (a) Appropriation Levels; (b) IHS Allocation Policies; (c) Congressional Mandates; (d) Administration Policies; and (e) Patient Generated Revenues.

(a) Appropriation Levels: Recommendations for increased funding for specific types of services such as transportation, CHRs, water and sewer systems, facility construction, traditional healers, prevention, and CHS received specific responses from the IHS. The Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration (HRSA), the Health Care Financing Administration (HCFA), the Administration on Aging (AOA), the Agency for Healthcare Research and Quality (AHRQ), the Administration for Children and Families (ACF), and the Centers for Disease Control and Prevention (CDC) also commented regarding the appropriations process and its impact on each agency's ability to meet certain health care needs.

IHS formally includes tribal leaders and Indian organizations in the annual budget formulation process, enabling them to identify target funding to meet priority health care needs. It is a comprehensive process in which tribal leadership works to reach consensus on funding priorities. The authority of the Snyder Act (25 U.S.C. 13) provides basic authority for most of the health care services provided by the federal government and those services identified by tribal leaders for increased funding. In meeting the priority needs identified by tribal leaders the primary limitation is the level of funds appropriated by Congress each year, the budget lines associated with the appropriation, and the fact that the IHS is not an entitlement program. The IHS is a discretionary program that depends on an annual appropriation.

Other federal agencies, such as AOA, HRSA, SAMHSA and ACF provide funding for certain types of health care services. Their funding authority is not as broad as that allowed IHS under the Snyder Act, but generally tied to a specific service or target population. These agencies are also subject to annual appropriations.

HCFA responded to these issues as well, providing information about the Medicaid and Medicare programs and the services that are eligible for coverage under each. Unlike discretionary programs, the Medicare and Medicaid programs are entitlement programs and funded differently. HCFA does not submit an annual appropriations request for Medicare benefits, but the benefits are paid on the basis of a permanent, indefinite appropriation authority. Medicaid is a “Federal-State” program in

which both the federal government and the states pay a portion of the cost of the program under current law the federal government is only permitted to make matching payments to states, the District of Columbia, and territories. Changes to federal law would be required to allow similar payments to be made to tribes.

(b) IHS Allocation Policies: There were numerous issues raised regarding the way in which funds appropriated to the IHS are allocated among the twelve IHS areas and the many individual tribes and communities. Issues were raised regarding the “equity” of the current distribution methodology for base funding as well as for special funding, such as the diabetes initiative. Several ongoing efforts by the IHS are targeting the disparity in health resources that exists across Indian country. The extensive consultation with tribes in the budget formulation process allows tribes to target funding to meet priority health care needs. A study is currently underway to examine health-funding parity for Indian people compared to the Federal Employees Health Benefit Plan. This study, known as the Level of Need Funded (LNF) study, uses actuarial methods to estimate the costs of a mainstream benefits plan for Indians. Consultation with Indian tribes is ongoing about the possibility of using LNF study results in new resource allocation formulas to address the inequities within Indian country. Regarding diabetes funding, the IHS established its allocation policy for these funds in consultation with tribal leadership and continues to meet with a Tribal Diabetes Advisory Committee regarding allocation and other concerns.

(c) Congressional Mandates: Several issues were raised that relate specifically to actions taken by Congress that affect the ability of tribes and IHS to provide health services to Indian communities. Those issues include the “moratorium” that Congress placed on further contracting of IHS services under the P.L. 93-638; inadequate funding for CSC associated with administering P.L. 93-638 contracts; use of Medicare and Medicaid revenues to offset the IHS budget; restrictions preventing the IHS from entering into a risk-based capitated plan; and the moratorium on final rules for IHS eligibility. Each of these issues had a significant impact on tribal and Indian communities. The IHS responded to these issues, stating its support and advocacy for full funding of CSC. In FY 2000, the IHS adopted a revised policy on CSC after undergoing an extensive tribal consultation process to ensure equitable distribution of any funding made available for CSC. In addressing the inequity in CSC funding, the IHS policy abandons the historic approach and the maintenance of a “queue list” in favor of a distribution methodology whereby tribes received additional CSC funding proportionate to their overall CSC needs. The IHS continues to support tribes and tribal organizations contracting under P.L. 93-638 and opposes any moratorium. The FY 2000 Consolidated Appropriation Act was signed into law in November 1999, and lifted the previous moratorium on contracting.

Regarding the use of anticipated Medicare/Medicaid revenues to offset the IHS budget, both IHS and HCFE cited the IHCA (P.L. 94-437, Title II, Sec. 207(b)), which explicitly prohibits the IHS from using the amounts generated to offset

the IHS budget. IHS stated that it has done significant work to increase third party collections from Medicaid in recent years and does not believe that these increases have made appropriations requested or provided for IHS smaller than they would otherwise have been. IHS will continue to work with HHS, OMB and the Appropriations Committees in making the most compelling possible case for increased appropriations.

Regarding the other congressional mandates, such as the moratorium on final eligibility rules and restrictions on IHS participation in capitated managed care plans, the IHS responded by citing the specific mandate in Federal law. Lifting the final rule on eligibility will require new law, which is proposed in current drafts reauthorizing the Indian Health Care Improvement Act. Similarly, for the IHS to participate in a capitated managed care plan, federal law would be required to lift restrictions of the Anti-Deficiency Act.

(d) Administration Policies: The most significant funding and budgeting issues raised regarding overall Administration policies is the inequity of funding for Indian health in comparison to other populations and other federally funded health care programs. Tribal leaders are seeking fairness and proportionality in the allocation of all HHS resources to Indian populations. The following HHS agencies responded to this issue: IHS, AOA, HCFE, AHRQ, CDC, HRSA, IGA, and SAMHSA. The IHS has developed a formal consultation process to involve tribal leaders in its budget formulation. The AOA held a Tribal Listening Session in August 8, 2000 to provide tribal leaders the

opportunity to express their concerns, comments and ideas. CDC reports that it will conduct an annual AI/AN Budget Planning and Priorities Meeting and implement its tribal consultation policy. CDC held its first budget consultation in March 2000 and provided a list of Requests for Proposals (RFP) that are currently available to tribes. HRSA plans to hold a budget meeting in 2001 in preparation for FY 2003 budget formulation. IGA and ASMB organize an annual budget consultation for HHS. HCFA participated in the April 10, 2000 budget meeting with tribes and is reviewing tribal budget recommendations. SAMHSA will continue to provide technical assistance workshops to assist potential applicants for discretionary grants, which tribes are eligible to attend.

(e) Patient Generated Revenues: There were many issues raised and recommendations made regarding patient generated revenues, primarily regarding Medicare, Medicaid, and managed care systems. The tribes, tribal organizations and urban health providers are becoming more dependent upon their ability to generate revenue through patient visits by billing third-party payers. As states undergo efforts to control health care costs, primarily through the use of managed care organizations to provide services to Medicaid patients, the IHS, tribes and urban providers are affected. Concerns were expressed about decreased Medicaid reimbursements resulting from state's implementation of managed care programs. HCFA has been working with states and tribes to address this issue and to explore alternative payment methodologies for IHS/Tribal/Urban providers. Both Arizona and Oklahoma have already incorporated alternative payment methods

into their Medicaid payment systems. As viable alternative payment approaches are identified, HCFA will share them with tribes and states. HCFA asserts that it will work with states and the tribes through consultation and provision of technical assistance to increase I/T/U access to managed care contracts in an effort to mitigate any negative impact on the provision of health care to AI/ANs.

2. Services and Service Provision

With respect to this category, the tribal leaders generally are seeking a broader scope of services for Indian people, access to traditional and holistic interventions, and better access to alternative coverage for care. The responses from HHS agencies will be discussed in these three general sub-categories.

(a) Traditional and Holistic Care: Tribal leaders and representatives from Indian organizations made several recommendations regarding improved access to and funding of traditional American Indian healing, and access to "holistic" care for Indian families. The agencies responding to these issues included IHS, HRSA, ACF, SAMHSA, and AHRQ. While the Snyder Act provides broad authority for IHS to provide a wide range of health care services, the decision about the extent to which traditional American Indian healing is incorporated into health services is a local one. IHS reports that after lengthy tribal consultation on this issue, there is no consensus among tribes regarding the role of the federal government involving traditional healing. The AHRQ funds a small number of studies on alternative and complementary medicine, some of

which are co-funded by the National Center for Complementary and Alternative Medicine at NIH. SAMHSA is currently administering a three-year discretionary grant program, “the Circles of Care,” targeting tribal communities to improve the service system for children and youth with serious emotional disturbances. One of the program’s objectives is to integrate traditional healing methods indigenous to the communities. Further, tribal grantees in the program are using a holistic approach to integrate services and make them family-based and culturally competent. The Commissioner for the Administration for Native Americans (ANA) has established a traditional Elders’ Circle that has been engaged in discussions concerning traditional healers/practices. Each member of the ANA Elders’ Circle is a traditional healer. HRSA reports on the Navajo Integrated HIV Service Delivery Model Program which will conduct a once a year comprehensive, HIV planning initiative that will define and evaluate the integration of HIV services into existing services currently provided by the IHS and the Bureau of Indian Affairs (BIA).

(b) Scope of Services: The five Listening Councils generated a long list of services that require additional support or an increase in services or development. These included access to specialty care, inpatient care, behavioral health, alcohol/substance abuse programs, health education, long-term care, home- and community-based care, dialysis units, cancer screening for men, 24-hour emergency coverage and other services. Tribes urged IHS to help license providers and facilities in this regard. The major obstacle to addressing the need for an increased scope in services is the lack of adequate appropriations. These issues are addressed in the Funding and Budget section of this report. The

authority for the IHS to meet these added services exists largely under the Snyder Act. HCFA funds dialysis units, but providers must make requests to HCFA or HCFA contractors to become eligible to provide services. The IHS senior clinician in renal disease has been analyzing the data sets of both IHS and HCFA regarding the issues of treatment of end stage renal dialysis (ESRD) and visited many communities to review the issues locally. He will provide his analysis to tribal leadership considering expanding dialysis activities or other approaches to treatment of ESRD. HRSA’s activities and partnership with IHS provides support for American Indian emergency medical services programs throughout the U.S. Support is provided for expert medical direction, training, and other services to more than 100 tribal EMS programs. The IHS has worked with tribes to develop a more comprehensive definition of alcohol services in the draft language for the reauthorization of the Indian Health Care Improvement Act. IHS has worked with the Youth Regional Treatment Centers to evaluate the efficacy of the programs and identify linkages with community aftercare services, and IHS has worked closely with the Department of Justice to improve case finding and treatment programs for juveniles in trouble with the law who may have alcohol related illness. IHS has also placed an Indian alcohol specialist with the Center for Substance Abuse Treatment to advocate for resources targeting Indian Country. For Diabetes, IHS proposed and received increases in the FY 2001 budget to assure recurring funds are available to support the new diabetes activities funded by the BBA of 1999 to assure long-term availability of these programs. IHS has worked with NIH to expand tribal participation in research planning and design targeting Indian Country, and IHS has worked with tribes to

develop the Diabetes Prevention Research Center in New Mexico to assure long-term evaluation of the most effective prevention interventions. For SAMHSA, alcohol and drug abuse funding is provided to AI/AN populations in part through its discretionary programs. For example, tribal populations have been a focus under the Targeted Capacity Expansion program, which has been successfully accessed by tribes in recent years. In the future, Tribal Colleges and Universities administrative grant representatives will be invited to participate in all SAMHSA-sponsored technical assistance workshops relating to enhancing competitiveness for funding of substance abuse and mental health prevention and treatment activities.

(c) Access to Coverage: Issues were raised regarding access to “charity care” programs for Indian populations, barriers to Medicaid and increased outreach for Medicare and Medicaid enrollment. These issues were referred to IHS and HCFA for response. With regard to “charity care,” HCFA responded that a Medicare payment adjustment is provided for hospitals that serve a disproportionate share of low-income patients. The factors considered in determining whether a hospital qualifies for a payment adjustment include the number of beds, the number of patient days, and the hospital’s location. IHS or tribal hospitals that are Medicaid providers may qualify for additional payments above the state plan rate as Disproportionate Share Hospital Payments (DSH) facilities pursuant to Section 1923 of the Act. HCFA will communicate to states that DSH payments are available for IHS and tribal hospitals.

Regarding access to Medicaid coverage, HCFA regulations (42 CFR 435.930) require states to provide Medicaid coverage to all persons who have not been properly determined to be “ineligible” for Medicaid. States must affirmatively explore all categories of eligibility before it acts to terminate Medicaid coverage. HCFA has awarded contracts to provide information to AI/ANs about its major programs, including projects with tribes to develop outreach materials regarding Medicare + Choice and related programs. In addition, HCFA has funded a larger initiative that produced outreach materials for elderly and disabled AI/ANs who may be eligible for Medicare and Medicaid.

3. Care Providers

There were two issues raised regarding care providers. The first dealt with the need for more providers to provide needed care; and the second dealt with the need for IHS to assist in licensure of health providers from other states assigned to tribal health facilities. HRSA, IHS, and SAMHSA addressed these issues. With regard to the need for more care providers, IHS points to the P.L. 94-437 and its following programs: the IHS Scholarship Program (sections 103 and 104), the Loan Repayment Program (section 108), grants to public and nonprofit health and educational entities to provide training (section 102), recruitment activities (section 112), support for nursing schools (section 118), professional scholarship programs (section 120), and section 217, which provides grants to three colleges and universities for psychology recruitment. The IHS continues to pursue salaries

competitive with the private sector to recruit and retain health professionals. SAMHSA provided information about the Office of Minority Health Washington Internships for Native Students program which supports summer internship placements at Tribal Colleges and Universities to train AI/AN students in substance abuse and behavioral health fields. HRSA administers grant programs in the areas of nursing, Allied Health, medicine, dentistry, psychology, and recruitment. With regard to licensure, the IHS responded that it advocates for licensure of all health care providers. Licensure is between the state of jurisdiction, the employing tribe or tribal organization, and the individual provider.

4. Facilities, Equipment and Supplies

Four distinct issues came within this category. The first issue was the general lack of health care facilities, including clinics, nursing homes, chemical dependency units, renal dialysis units and emergency rooms. Another issue addressed the ability of IHS and tribal facilities to meet Joint Commission on Accreditation of Health Care Organizations (JCAHCO) standards. The third issue concerned dissatisfaction with the current IHS facility construction priority system and the need to examine alternative financing options. The final issue in this category addressed the need for disaster preparedness equipment.

The agencies that responded to these concerns include IHS, HCFA, HRSA, AOA, and SAMHSA. SAMHSA reported that although it is authorized to fund services for treatment, these funds may not be used for construction of facilities for such programs, although rental and other facility

overhead costs may be reimbursable expenses. Regarding alternative financing options, the IHS referenced a roundtable held to address this issue. A document, "Report of Roundtable Discussion and Analysis of Future Options for Indian Health Care Facility Funding," was disseminated to all tribes. Utilizing Medicare and Medicaid revenues, the IHS and tribes are addressing renovation and expansion projects including upgrade of emergency rooms and other facilities. As replacement projects are being processed in the IHS Health Facilities Construction Priority System, upgraded emergency rooms are being considered.

HCFA responded that the accreditation requirements are described in 42 CFR 488.4 to 488.11 for accrediting organizations, such as JCAHCO. The Survey and Certification Group in HCFA's Center for Medicaid and State Operations proposes a two-tiered approach to the issue of how tribally-owned facilities that lack sufficient capital could become accredited. HCFA proposes to ask JCAHCO to allow the accreditation fees for tribally owned facilities to be waived or offered at a reduced rate, or at least be included under the same rate setting as the IHS.

Since 1980, IHS has supported postgraduate training in institutional environmental health to ensure that a cadre of highly trained specialists are trained to enable IHS and tribal health care facilities to meet all applicable regulatory guidelines and standards. Currently, seven of the IHS areas have full time Institutional Environmental Health Specialists on staff to address JCAHCO and other regulatory issues. HCFA is establishing a workgroup to determine possible changes in surveying tribal facilities.

Regarding the dissatisfaction with the IHS Health Facilities Construction Priority System Methodology, the IHS responded that extensive consultation regarding the reauthorization of the P.L. 94-437 has occurred. IHS anticipates that further tribal consultation will lead to beneficial changes to this system.

The OPHS responded to the issue of disaster preparedness equipment. During Presidential declared disasters or major emergencies, health and medical response assets, with appropriate medical equipment, is furnished through Emergency Support Function #8 (Health and Medical Services) of the Federal Response Plan, by activation and use of the National Disaster Medical System. The IHS seeks funds to provide one time funding to tribes and tribal organizations to purchase emergency response equipment. Since 1990, approximately \$2 million has been provided to tribes and tribal organizations to fund injury prevention projects, and to purchase EMS equipment.

5. Intergovernmental Relations and Related Issues

With respect to intergovernmental relations, the tribes' issues can be divided into three subcategories: (a) structure and process; (b) new initiatives; and (c) changes in law.

(a) Structure and Process: It was recommended that the HHS establish an advisory body that includes tribal leaders and establishes "Indian Desks" at all the HHS agencies to provide better access to programs and enhance communication.

Tribes also wanted to know the specific actions HHS planned to undertake to document, investigate, and respond to each of the issues raised during the Listening Councils, as well as at future tribal consultations. Some participants voiced concern about "consultation overload," and suggested that HHS employ one system or process for providing input. It was recommended that "key staff" be identified in each agency of HHS and the Office of Intergovernmental Affairs in the Office of the Secretary (IGA) coordinate all tribal issues. HHS will examine the proposal of establishing a departmental advisory body that includes tribal leaders. Another possible approach to consider is to expand the HHS Inter-Agency Tribal Consultation Workgroup (which is co-chaired by the Directors of the IHS and the IGA) to include tribal representatives.

IGA, which is the HHS liaison to state, local, and tribal governments, is the lead office for tribal consultation. IGA, along with the Office of the Assistant Secretary for Management and Budget, annually convenes a meeting of tribal leaders and Indian organization representatives to discuss with HHS leadership tribal appropriation needs and priorities for the following budget cycles. All HHS agencies responded to the budget consultation issue by underscoring their intent to either continue or to initiate an annual tribal budget consultation process. In addition, all HHS agencies have formulated consultation plans which are being reviewed by the tribes. Most of the agencies have scheduled tribal consultation sessions to formalize this process.

(b) New Initiatives: Tribal leaders suggested new or expanded initiatives beyond the Department and involving other entities, such as HHS/tribal partnerships and other means of collaboration between the tribes, the states, the private sector and HHS. Interdepartmental coordination will be needed to assist tribes in addressing issues related to international borders, such as drug trafficking and child custody issues. IHS responded that a sub-group of the HHS Interagency Tribal Consultation Workgroup could be charged to meet with tribal leaders and/or their representatives to discuss the issue of partnering with private entities, and to call upon state government officials to explore enhanced collaboration.

ACF identified numerous situations and programs involving partnership with Indian communities and states, in particular related to welfare reform, TANF and child support enforcement. The Office of Child Support Enforcement (OCSE) will be providing direct federal funding to AI/AN under Section 455(f) of the Social Security Act to operate their own Tribal Child Support Enforcement Act upon publication of a final rule.

HCFA identified numerous instances of collaboration between HCFA, tribes and the states and voiced its commitment to continue working to develop these partnerships to improve the delivery of services to AI/AN beneficiaries under Medicare, Medicaid and SCHIP.

CDC is proposing to engage the Council of State and Territorial Epidemiologists (CSTE) in the planning and development of surveillance systems for AI/AN communities, including urban Indian

populations, and to encourage tribal government participation in the CSTE. IGA, along with all HHS agencies, will work with the national intergovernmental organizations, such as the National Conference of State Legislatures, the National Governors Association, National Association of Counties, and the U.S. Conference of Mayors to formulate tribal/state partnerships and opportunities for collaboration.

In FY 2000, SAMHSA issued a priority initiative for Community Action Grant for Service Systems Change for American Indian Alaska Native Youth. This grant offering was part of an interagency effort to provide tribes with easy-to-access assistance in developing innovative strategies that focus on the mental health, behavioral, substance abuse, and community safety needs of American Indian young people and their families through a coordinated Federal process. Federal partners in the initiative were the Indian Health Service and the Departments of Justice, Education, and the Interior.

HRSA's Healthy Start initiative has provided approximately five million dollars to three tribal governments.

(c) Changes in the Law: Several of the recommendations made during the Listening Councils involving intergovernmental relations would require new legislation or changes to existing law. One of the most frequently mentioned change, is the elevation of the IHS Director position to an Assistant Secretary. There have been several bills introduced in the Congress to achieve this change. The Secretary of HHS supports the elevation.

Tribes have also asked that the cap on indirect rates for Head Start be lifted and tribes be allowed to charge a more realistic rate. ACF responded that the law sets limits on costs of development and administration of Head Start and Early Head Start programs. An administrative waiver is available to exceed the 15% threshold only for a specific time period not to exceed 12 months.

6. Infrastructure

Tribal leaders expressed concern about the deterioration of water and sewer infrastructures in Indian communities. Assistance is requested to repair and replace these systems, including adequate funding for ongoing maintenance and improvement.

Training is recommended for tribal communities to conduct their own repairs of these systems rather than depend upon other resources. A joint effort to address the impact of contaminated lands and water from waste, chemical sprays and fertilizers is recommended. The IHS was the only agency to respond to this issue. The IHS, under the authority of the Snyder Act, the IHCLA, The Indian Sanitation Facilities Act, and the Indian Self-Determination and Education Assistance Act provides technical assistance to tribes on environmental health issues and authorizes tribes to operate certain environmental health programs. The IHS provides funds to upgrade service to existing Indian homes. Projects to upgrade existing community facilities are funded based on each IHS Area's priority system. The projects are scored on the priority system based on health risk, capital cost, deficiency level, and tribal priority. The IHS plans to upgrade services to 9,300 previously served homes in FY 2000 and 9,660 previously served homes in FY 2001. The IHS

budget includes \$1,000,000 annually for training personnel from tribal operation and maintenance organizations. The IHS will continue to update the sanitation facilities priority system annually and consult with tribes on their sanitation facilities needs and priorities.

Concerns regarding contaminated lands and water in Indian communities have also been referred to the Environmental Protection Agency (EPA). Additional follow-up may be needed on issues, such as this one, which require the coordination of other departments.

7. Data and Research

Data systems currently available to IHS and tribal health systems should do more than simply generate billing or patient encounter information. Tribal leaders are interested in user-friendly data systems that can provide community-specific health care data and track health status of the patient population. The utility of the data systems for local planning and priority setting should be assessed and corrected, if needed. In addition to local data systems, the tribal leaders asked that the Federal government assist in establishing a national database of pharmaceutical and other companies that provide assistance to tribal health efforts.

All HHS agencies were asked to respond to the issue of local, community-specific data systems. The IHS response included background on section 602 of P.L. 94-437 which establishes an "Automated Management Information System" to be established by IHS. This system has evolved into today's "IHS Resource and Patient Management System"

(RPMS) that collects both clinical and administrative data. Data is generated at the local level and forwarded to the Area, which in turn sends it to the IHS National Data Repository in Albuquerque where it is aggregated for national purposes. This aggregated data is used primarily for statistical analysis and reporting to Congress. IHS reports that the RPMS already can provide local data requested by tribes, except for a possible lack in staffing to extract data or insufficient training at the local levels. Tribes may not be aware of the reports that can be generated locally.

The Division of Information Resources (DIR) Information Technology Support Center in Albuquerque has provided a series of RPMS training sessions and a national Help Desk for local customers. The IHS also makes information available through the National Data Repository, the Internet, and Epidemiology Centers (Epi). Several of the four Epi Centers have developed innovative strategies to monitor the health status of tribes and use sophisticated record linkage computer software to correct existing state data sets for racial misclassification. These Epi Centers provide immediate data feedback for self-governed tribal health programs to plan and decide the most efficient and effective health care services for their people.

The AOA, through the National Resource Center on American Indian Elders at the University of North Dakota, has developed a computerized needs assessment tool for tribes to use at their discretion. HCFA responded that the IHS and HCFA have formed a steering committee to address key issues of mutual concern, and is working to establish a data subcommittee to address these issues.

The CDC is working with the IHS to assist tribal governments in developing health data systems that have practical public health applications, such as improved disease surveillance. Pursuant to making community specific data available, CDC's National Center for Health Statistics (NCHS) has proposed two new surveys: (1) Defined Population Health and Nutrition Examination Survey (DP-HANES) to provide flexible and timely access to high quality examination and laboratory data for a range of defined populations that cannot be addressed using the standard NHANES framework. Most of the sub-populations suited to this system are not sufficiently large and/or sufficiently geographically dispersed to allow efficient data collection using a national sampling frame; (2) State and Local Area Integrated Telephone Survey (SLAITS) to track and monitor questions already existing on NCHS National Health Interview Survey (NHIS), which assesses health status, health insurance, access to care, and health risk factors and behaviors. CDC also periodically publishes Mortality and Morbidity Weekly Report articles addressing public health issues of importance to AI/AN communities.

HRSA responded that the Office of Minority Health/Office of the Secretary is currently finalizing the Joint Report of the HHS Data Council Working Group on Racial and Ethnic Data and the Data Work Group of the HHS Initiative to eliminate Racial and Ethnic Disparities in Health. IGA will continue to work through the Inter-Agency Tribal Consultation Workgroup to institutionalize the Department's Consultation Policy and address issues such as this. SAMHSA reported that Centers for Substance Abuse Prevention (CSAP) is funding a feasibility study to develop local infrastructure necessary to collect data in AI/AN communities.

This data was collected in two communities and will give tribes a more accurate snapshot of the incidence and prevalence of substance abuse-related violence, especially domestic violence. CSAP is also engaged in the task of developing culturally appropriate measures for substance abuse prevention problems and efficacy in their unique prevention programs, through the "Cultural Core Measures Initiative."

Finally, AHRQ responded that it has discussed incorporating IHS data into the Health Cost and Utilization Project (HCUP), a Federal-State-Industry partnership to build a standardized, multi-state, longitudinal data system. Presently, HCUP includes inpatient data and is managed by AHRQ. AHRQ has also discussed doing an oversampling of Indians in the Medical Expenditure Panel Survey (MEPS) with the IHS in order to be able to produce data for AI/AN. MEPS is a nationally representative survey of health care use, expenditures, sources of payment, and insurance coverage for the U.S. civilian non-institutionalized population, as well as a national survey of nursing homes and their residents. MEPS is co-sponsored by the AHRQ and the NCHS. Oversampling would produce national, not community-specific data, and would be very costly.

With regard to the request by tribal leaders to develop a national database of pharmaceutical and other companies that provide assistance to tribes, the IHS responded that a national database of patient assistance for prescription drugs has been established by the Pharmaceutical Research and Manufacturers of America. A complete directory of pharmaceutical companies offering these services can be found on the Internet at www.phrma.org/patients. HCFA has provided similar lists to the IHS and will furnish source lists of pharmaceutical companies having drug assistance programs.

