AMERICAN INDIAN AND ALASKA NATIVE ELIGIBILITY AND ENROLLMENT IN MEDICAID, SCHIP, AND MEDICARE

SUMMARY CASE STUDY REPORT

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DISCLAIMER

The comments and recommendations contained within this report reflect the perceptions and opinions of the interviewees and no attempt was made to either verify the accuracy of these perceptions or to determine the feasibility of the recommendations. Neither the comments nor the recommendations contained within this report necessarily reflect the opinions of the Centers for Medicare & Medicaid Services, the Indian Health Service, individual States, or individual Tribes or Tribal organizations.

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[1] Kathryn Langwell, Project Director, was with Project HOPE when the contract began but is now employed at Westat.

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EXECUTIVE SUMMARY

OVERVIEW OF STUDY

In September 2001, the Centers for Medicare & Medicaid Services (CMS) funded a two-year study to examine barriers to enrollment of American Indians and Alaska Natives (AI/ANs) in Medicaid, State Children's Health Insurance Programs (SCHIP), and Medicare (including the Medicare Savings Programs),[2] and to identify strategies that may be effective in encouraging and facilitating AI/AN enrollment in these programs. The primary objectives of the project – conducted jointly by BearingPoint, Project HOPE's Center for Health Affairs,[3] and Social and Scientific Systems, with assistance from six American Indian consultants and a nine-member Technical Expert Panel (TEP)[4] – were to:

1. Estimate eligibility for, and enrollment of, AI/ANs in the Medicaid, SCHIP, and Medicare programs in 15 selected States.

2. Conduct in-depth case studies in 10 of the 15 States to identify both barriers to enrollment and effective strategies for addressing these barriers in order to increase program enrollment among AI/ANs.

For the case study component of the project, site visits were conducted in 10 States: Alaska, Arizona, Michigan, Minnesota, Montana, North Dakota, Oklahoma, South Dakota, Utah, and Washington. In each State, interviews were conducted with Tribal leaders, Tribal health directors, Indian Health Service (IHS) Area and Service Unit staff, State Medicaid and SCHIP officials, Urban Indian Health Center staff, State/County eligibility and outreach workers, and other organizations and individuals knowledgeable about AI/AN health care and access issues. Draft individual case study reports were prepared for each State following the site visits and follow-up telephone interviews. These draft individual case studies were circulated to key contacts in each Tribe, State Medicaid and SCHIP office, Urban Indian Health Clinic, and other organizations that participated in interviews for review and comment. Comments, including corrections and additions, from interviewees in each State were incorporated into the draft State case studies, which were then sent to CMS for review and comments. The CMS project officer circulated the draft case study reports to additional reviewers within CMS and IHS. This final report contains the Individual Case Studies for the 10 States that reflect input and comments received from all reviewers.

In addition to the final report on Individual Case Studies for Ten States, the project team prepared a Summary Case Study Report that synthesizes and analyzes the information presented

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[2] The Medicare Savings Programs are Federally-mandated programs in which State Medicaid programs must pay some or all of Medicare's premiums, and may also pay Medicare deductibles and coinsurance, for people who have Medicare and limited income and resources. The programs include the Qualified Medicare Beneficiary (QMB), the Specified Low-Income Medicare Beneficiary (SLMB), the Qualifying Individuals-1 (QI-1), and the Qualified Disabled and Working Individuals (QDWIs) programs. Medicare Savings Programs enrollees, together with Medicare beneficiaries who receive their State's full Medicaid benefits, are often referred to as "dual eligibles."

[3] Kathryn Langwell, Project Director, was with Project HOPE when the contract began but is now employed at Westat, Inc.

[4] Appendix A lists TEP members and project consultants who contributed to the study.

in the Individual Case Studies for Ten States, a Data Analysis Report that presents findings from the data compilation and analysis of eligibility and enrollment of AI/ANs in Medicaid, SCHIP, and Medicare, and a Final Report on AI/AN Eligibility and Enrollment in Medicaid, SCHIP, and Medicare.

RESEARCH QUESTIONS AND METHODS

The case study component of the project was designed to obtain information on all barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare and, to the extent possible, to assess the relative importance of each enrollment barrier as indicated by those interviewed during the site visits. An additional goal of the case studies was to solicit suggestions for potential strategies that might be effective in reducing barriers and increasing AI/AN program enrollment. In particular, a comparative case study approach was designed and conducted to address several questions of interest for this study:

- What are the most significant barriers to AI/AN enrollment in each of the public insurance programs?

- How prevalent are the main barriers and how can they best be classified in a way that will help CMS and others to develop initiatives to address them?

- Do barriers differ in important ways by program? Are these differences due to programmatic idiosyncrasies, to differences in historical outreach to AI/ANs among the programs, or to differences in eligible populations (e.g., elderly versus working families)?

- How do barriers differ across Tribes and among urban, rural, and perimeter areas?

- Are some barriers to enrollment unique to AI/ANs and, as such, may require development of new, specifically targeted outreach strategies?

- Are there ways to reduce identified barriers to facilitate increased AI/AN enrollment in these programs? Which entities (Tribes, IHS, States, Federal government) might be best placed to initiate and carry out suggested strategies?

Across the 10 States, information from key informants was gathered in a highly structured method across multiple sites in each State through in-person and follow-up telephone interviews. The project team used the same discussion guide in each State to ensure that each State case study collected common information and that all important project research questions were addressed in the interviews. The individual State case studies were systematically constructed by summarizing each State's interview notes within a project team-developed descriptive framework to organize a case study; the team then identified program barriers and suggested strategies by classifying each into project team-standardized categories, for each State.

For each of the 10 States selected for the case study component of the project, site visits were conducted to:

- Two Tribes or AI/AN Reservations, to meet with Tribal leaders, Tribal health staff, IHS staff, and other local community members knowledgeable about program enrollment issues and processes (e.g., Title VI directors and Senior program directors).5

- An Urban Indian Health Clinic.6

- State Medicaid, SCHIP, and other State Offices, such as State Health Insurance and Assistance Programs (SHIPs) and Elder Affairs Offices, with knowledge of AI/AN issues relevant to enrollment.

Additional appropriate organizations were interviewed when travel arrangements permitted and/or they were interviewed by follow-up telephone contacts (e.g., IHS Area Offices, Indian Health Boards representing multiple Tribes, CMS Regional Office staff, AI/AN referral hospitals, AI/AN epidemiology centers, and AI/AN elder housing facilities). For several site visits, County or State Medicaid and SCHIP eligibility workers were included in group interviews.

In total, more than 300 people participated in interviews conducted in the 10 States, including staff from State Medicaid, SCHIP, and Tribal liaison agencies, 22 Federally Recognized AI/AN Tribes or organizations, 9 Urban Indian Health Clinics, and 10 other organizations involved in AI/AN health and public program enrollment.

KEY FINDINGS

Interviewees identified a number of issues unique to AI/ANs that serve as barriers to enrollment in Medicaid, SCHIP, and Medicare. These include the relationship between the Federal government and Federally Recognized Tribes that may include Federal provision of health care and other services to members of these Tribes, and Tribal sovereignty issues that affects Federal-Tribal-State government-to-government relationships. The historical experiences of Tribes with Federal and State governments appear to have resulted in a degree of mistrust that affects the willingness of some AI/ANs to apply for enrollment in Federal- and State-sponsored health programs. Additionally, in many cases, Tribal leaders and Tribal members perceive that the Federal Trust Responsibility to provide health care to the Tribes means that Tribal members should not need to apply for assistance through Medicaid, SCHIP, or Medicare. Many interviewees also Stated that the fact that IHS services are available for routine primary and preventive care and some degree of specialty care for serious illnesses causes some AI/ANs to question the need to enroll in public programs. However, the IHS operates on an annual budget that has been set at levels that are insufficient to provide adequate services to meet the needs of the AI/AN population. Contract Health Services – services that cannot be provided through IHS and must be referred out to private providers – are particularly a problem for IHS- and Tribally managed health facilities to provide. The available funds for Contract Health Services is often

[5] While the goal was to visit two Tribes/Reservations per State, some variation existed among States. This variation was due either to unique circumstances in the State (e.g., Alaska's large geographic area and many small Native villages) or to recommendations from TEP members who felt that the study would benefit from extending the site visit to include several Tribes/Reservations in specific States.
[6] North Dakota does not have an Urban Indian Health Clinic.

depleted well before the end of the fiscal year and, as a result, AI/AN people may not receive these services at all or may face long delays in obtaining care unless their condition is immediately life-threatening. A number of interviewees suggested that Tribal leaders and Tribal members frequently are not aware of how increased public program enrollment might benefit the entire Tribe by providing additional third-party Medicare, Medicaid, and SCHIP revenues to IHS- and Tribally managed health facilities, thus making more services available to all Tribal members.

In addition to these barriers that are unique to AI/AN populations, other barriers identified by interviewees included: lack of awareness about the existence of the programs (particularly SCHIP and the Medicare Savings Programs); limited knowledge of benefits and eligibility criteria for all of the programs; transportation barriers; language and literacy barriers; complexity of application and redetermination processes; and cultural barriers. Because a high proportion of AI/ANs resides in rural areas on Reservations with high poverty rates and low educational levels, these barriers may be significant deterrents to enrollment.

This study was not able to quantify the magnitude of the impact of specific barriers on enrollment rates. The concentration of the AI/AN population in rural areas does suggest that transportation barriers may be substantial given long travel distances, lack of reliable personal transportation, limited access to public transportation to reach County or State eligibility offices, and the poor conditions of Reservation roads. In addition, outreach, education, and enrollment assistance has been found to be a much greater challenge in remote areas that require outreach/enrollment workers to travel long distances to reach clients and where televisions, radio stations, and newspapers are less available than in urban areas. The large number of different languages spoken by AI/ANs may also be a greater barrier to providing appropriate outreach and education. Many AI/AN languages are spoken languages only, requiring the use of non-written communication modes such as television, radio, and videotapes to effectively reach some people.

Strategies suggested by interviewees to reduce barriers to enrollment and to facilitate higher rates of AI/AN enrollment in Medicaid, SCHIP, and Medicare were strongly focused on increasing culturally-appropriate outreach and education materials and activities, and providing one-to-one assistance with application and redetermination processes. For the most part, these suggestions were coupled with interviewee recommendations that funding for outreach, education, and enrollment assistance activities be given directly to Tribes or to Urban Indian Health Clinics to design and implement such strategies.

A number of interviewees suggested that the government provide funding to Tribes and Urban Indian Health Clinics to develop and implement locally-directed and AI/AN-specific outreach and enrollment assistance programs, either directly or through a requirement that States provide a share of Medicaid and SCHIP administrative match funds to Tribes and urban clinics. Some interviewees suggested that the Federal government establish a Tribal Medicaid option that would permit Tribes to manage their own Medicaid programs and determine eligibility for Tribal

members.[7] Several interviewees from Tribal, State, and Urban Indian Health Clinics also suggested that developing processes to improve Federal-Tribal-State government-to-government relationships would be useful for reducing barriers and facilitating enrollment in these programs.

Many interviewees recommended that the States and/or Federalgovernment provide improved training to Tribal, IHS, and Urban Indian Health Clinic staff on Medicaid, SCHIP, and Medicare benefits, eligibility requirements, and application processes as these are often the "front-line" staff that can best provide the one-to-one assistance needed. In addition, many interviewees suggested that simplifying the application process and making redetermination less frequent would be useful strategies. A number of interviewees also suggested that State/County eligibility workers – and Federal employees who work with Medicare, Social Security, and Social Security Disability Income (SSDI) application processes – be given more training on program and eligibility determination issues and on AI/AN history and legal issues that affect eligibility determination. Some interviewees also suggested increased cultural awareness training for State/County eligibility workers.

LIMITATIONS OF THE STUDY AND FEASIBILITY ISSUES

Limitations of this study may affect the validity of the findings and the extent to which they can be generalized to all AI/AN populations in the same or different States. These include:

- Individual interviewees expressed their views and perceptions, based on their own experiences and situations. The project team did not conduct an independent validation of these views and perceptions and, therefore, the interview findings may be based on inaccurate information and/or limited experiences that may not be generalizable.

- Information was obtained in only 10 States and, while these States have large AI/AN populations, the findings may not be generalizable to other States that may have different characteristics and AI/AN populations.

- Detailed information was obtained from only 22 Federally Recognized AI/AN entities or organizations across the 10 States, which does not encompass all Tribes in these States.8 Thus, although the findings may reflect the characteristics and experiences of the Tribes/Reservations interviewed, they may not necessarily extend to other Tribes with different cultures, histories, and experiences that were not interviewed.

- At the time the site visits for this project were conducted, many States were experiencing budget shortfalls that were causing State governments to consider or institute cutbacks in Medicaid and SCHIP program benefits and/or outreach funds. The changes that were being

[7] A logical extension of this suggestion would be to extend the 100 percent Federalmedical assistance percentage (FMAP) match to States for Medicaid services provided to eligible AI/ANs at Urban Indian Health Clinics. This option has been suggested by national AI/AN organizations, which would allow health care funds to "follow" an individual, irrespective of her location (on-Reservation or off-Reservation) and irrespective of provider (IHS facility, Tribally managed facility, or Urban Indian Health Clinic).

[8] Additional information was obtained from a larger number of Tribes through meetings with Indian Health Boards and input from TEP members and project consultants. This information, however, was more general and less detailed in nature than that obtained through visits or follow-up telephone interviews with individual Tribes.

contemplated may have affected the perceptions of Tribal and State interviewees about barriers to enrollment in these programs and strategies to increase AI/AN enrollment. The study findings might well be different if the site visits had been conducted during a period of economic expansion and State budget surpluses.

The extensive number of individuals who participated in the interviews conducted in the 10 States (more than 300 individuals participate in group and individual interviews), and the comprehensive review process for the individual State case study reports undertaken for this project, suggest that this study can provide a basis for developing and testing strategies that may be successful in reducing barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare.

The specific strategies that have been suggested by participants in this study are wide-ranging, from relatively narrow, targeted strategies (e.g., provide more training on program eligibility criteria to State/County eligibility workers) to strategies that would require substantial changes in Federal and State policy (e.g., develop a Tribal Medicaid option). The feasibility of specific strategies has not been assessed in this study. However, it would be necessary to consider feasibility in considering and choosing specific strategies that might be implemented. The most important feasibility considerations are: 1) the cost of the strategy, if extended to all AI/AN populations; and 2) the political issues that would need to be addressed to implement the strategy.

With current Federal, State, and Tribal budget constraints, some strategies might require more resources relative to the benefits obtained than are considered reasonable. Similarly, strategies that would require Congress to act before they could be implemented and/or that would require negotiations between the Federal government, States, and Tribes (such as a Tribal Medicaid option) could take many years to develop and implement. These considerations should be assessed in order to determine whether the strategies identified in this study might be developed and implemented to reduce barriers and increase AI/AN enrollment in the Medicaid, SCHIP, and Medicare programs. Additionally, alternative ways to fund these strategies could be pursued. For example, CMS might consider using Department of Health and Human Services' education and outreach-targeted funds for reducing health care disparities among racial and ethnic minority populations to fund oral translation of educational materials into Native American languages, which are primarily spoken rather than written. Furthermore, ways to reduce strategy development and implementation costs could also be pursued. For example, CMS might consider using existing initiatives involving Tribal colleges and universities to help develop culturally-appropriate educational materials, at lower cost than might be obtainable through marketing firms.

OVERVIEW

OVERVIEW OF STUDY

In September 2001, CMS funded a two-year study to examine the extent to which AI/ANs are enrolling in Medicaid, SCHIP, and Medicare (including the Medicare Savings Programs). These health insurance programs hold the promise of increased access to health care services for low-income families and children, the elderly, and disabled individuals. The primary objectives of the project – conducted jointly by BearingPoint, Project HOPE's Center for Health

Affairs,[9] and Social and Scientific Systems, with assistance from six American Indian consultants and a nine-member TEP – were to:

1. Estimate eligibility for, and enrollment of, AI/ANs in the Medicaid, SCHIP, and Medicare programs in 15 selected States.

2. Conduct in-depth case studies in 10 of the 15 States to identify both barriers to enrollment and effective strategies for addressing these barriers in order to increase program enrollment among AI/ANs.

The former component focused on eligibility and enrollment issues in 15 States: Alaska, Arizona, California, Michigan, Minnesota, Montana, North Dakota, New Mexico, New York, Oklahoma, Oregon, South Dakota, Utah, Washington, and Wisconsin. These States were selected for study based on AI/AN population as measured by the 2000 Census, Bureau of Indian Affairs Tribal Enrollment data, Indian Health Service Patient Users data, geographic diversity, diversity of State Medicaid and SCHIP programs, and presence of significant urban Indian populations.[10] Eligibility and enrollment estimates were developed for each of the 15 States using a variety of data sources obtained from the 2000 United States (U.S.) Census, IHS, and CMS. These estimates are provided in a separate report to CMS.[11]

The latter activity collected qualitative data to identify barriers to enrollment in Medicaid, SCHIP, and Medicare, as well as to identify effective strategies to facilitate AI/AN enrollment in these programs. For the case study component of the project, 10 States were selected as a subset of the 15 States for which estimates of eligibility and enrollment were performed. Selection of the 10 States was based on interviews with a number of people (CMS and IHS staff at headquarters and regional offices, Tribal organizations' staff, TEP members, project consultants, and researchers) who were knowledgeable of the study issues. Based on these interviews and other considerations, including geographic diversity and urban AI/AN populations, the States selected for the case studies were: Alaska, Arizona, Michigan, Minnesota, Montana, North Dakota, Oklahoma, South Dakota, Utah, and Washington.

Table 1 displays various estimates of the AI/AN population in each of the 10 case study States. In each State, interviews were conducted with Tribal leaders, Tribal health directors, IHS Area and Service Unit staff, State Medicaid and SCHIP officials, Urban Indian Health Center staff, State/County eligibility and outreach workers, and other organizations and individuals knowledgeable about AI/AN health care access issues. It is this component of the project that is the subject of this report.

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[9] Kathryn Langwell, Project Director, was with Project HOPE when the contract began but is now employed at Westat, Inc.

[10] See *Background, Issues, Data, and Key Informant Interview Findings for Selection of 15 States for CMS Study: American Indian/Alaska Native Eligibility and Enrollment in Medicaid, SCHIP, and Medicare.* Prepared by BearingPoint for the Centers for Medicare & Medicaid Services under Contract no. 500-00-0037 (Task 5, December 12, 2002.

[11] *American Indian and Alaska Native Eligibility and Enrollment in Medicaid, SCHIP, and Medicare, Estimating Eligibility and Enrollment: A Methodological and Data Exploration*. Prepared by BearingPoint for the Centers for Medicare & Medicaid Services under Contract no. 500-00-0037 (Task 5), December 5, 2003.

Table 1: AI/AN Population Estimates for the 10 Case Study States

State	2000 Census AI/AN Only Population	2000 Census AI/AN Only or in Combination with Other Races/Ethnicities	1997 BIA Tribal Enrollment	1997 BIA Total Indian Reservation Service Population	1998 IHS User Population
Alaska	98,043	119,241	114,978	110,825	119,789
Arizona	255,879	292,552	235,795	237,383	257,846
Michigan	58,479	124,412	47,856	25,870	23,652
Minnesota	54,967	81,074	50,908	34,477	33,587
Montana	56,058	66,320	60,282	46,232	59,629
North Dakota	31,329	35,228	48,197	41,888	30,575
Oklahoma	273,230	391,949	541,680	392,672	296,371
South Dakota	62,283	68,281	108,954	91,624	75,452
Utah	29,684	40,445	13,764	13,709	12,743
Washington	93,301	158,940	44,947	84,671	54,035

Sources: 2000 Census data extracted from the U.S. Census Bureau, Census 2000 Summary File 1, various matrices; BIA Tribal Enrollment data extracted from www.bia.gov for total number of members in Federally Recognized Tribes in the State; BIA Total Indian Reservation Service Population data extracted from www.bia.gov for total number of members of Federally Recognized Tribes, living on or near Reservations and eligible to use BIA-funded services; IHS User Population data extracted from www.ihs.gov.

PURPOSE OF REPORT

Individual case study reports prepared for each of the 10 States presented findings from the site visits regarding barriers to enrollment and potential strategies to increase AI/AN enrollment in Medicaid, SCHIP, and Medicare as suggested by Tribal, Federal, State, IHS, and other interviewees. This Summary Case Study Report presents information from the case study reports that were prepared for each individual State.

The next section of the report describes our approach to the design and conduct of the case studies, as well as discusses important limitations of the findings. Subsequent sections present summary findings on barriers to AI/AN enrollment and interviewee-suggested strategies for increasing enrollment, by State, by type of interviewee, and across States. The final section of the report summarizes key findings and discusses the feasibility of the strategies for increasing AI/AN enrollment in Medicaid, SCHIP, and Medicare.

METHODS AND LIMITATIONS

APPROACH

The development of the case study component for the project consisted of several activities:

- A literature review of published documents to identify barriers to enrollment and strategies to increase enrollment in Medicaid, SCHIP, and Medicare.

- Development of criteria for selection of specific States to be included in the case studies, as well as specific criteria for selecting the Tribes within the 10 States that would be studied, with input from the TEP, project consultants, CMS, and IHS.

- Preparation of a Case Study Design Report that provided detailed objectives of the case study, case study methods, and site visit protocols.

An overview of each of these activities is provided in this section of the report. In addition, it describes limitations of the study that may affect the extent to which the findings may be generalizable to all AI/AN populations.

LITERATURE REVIEW FINDINGS

A substantial body of literature has identified barriers to enrollment of the general U.S. population into Medicaid, SCHIP, and Medicare. In contrast, only limited prior research has addressed barriers to enrollment in these programs for AI/ANs. The literature review included published studies conducted to identify factors that may affect all potentially eligible persons, including the AI/AN population. We also examined published studies that focused on the AI/AN population to identify unique issues that may comprise additional barriers to AI/AN program enrollment.

Barriers to Enrollment in Medicaid, SCHIP and Medicare for AI/ANs

Research to identify barriers to enrollment specific to AI/ANs is limited and is primarily qualitative and anecdotal in nature. Additionally, no rigorously designed qualitative or quantitative studies have been published that identify the magnitude and relative importance of specific barriers to AI/AN enrollment. The available literature, however, suggests that AI/ANs face a number of unique issues that serve as barriers to enrollment in Medicaid, SCHIP, and Medicare.

The Federal government's Trust Responsibility to provide health care for AI/ANs who are members of Federally Recognized Tribes is mentioned in several studies as a barrier to AI/AN enrollment in these programs. That is, because the Federal government has a responsibility to provide health care, many AI/ANs do not feel they should have to enroll in health insurance programs designed for a non-AI/AN only population or pay any out-of-pocket costs for premiums, deductibles, or copayments for these programs. The Federal Trust Responsibility also affects the complexity of the relationship between Tribes and the State governments that are responsible for administering the Medicaid and SCHIP programs. Tribes are quasi-sovereign (or, sovereign dependent) nations geographically located within States, and are to some extent independent of State laws and regulations.

Cultural issues are also cited in several published AI/AN studies and differ, to some extent, from cultural barriers faced by other racial/ethnic groups in the U.S. There are more than 550 Federally Recognized Tribes with unique cultures and languages. Thus, development of culturally appropriate outreach and educational materials and translation of materials into AI/AN native languages would likely require substantial resources. In addition, some AI/ANs may not respond to print media and program materials received by mail, especially if they are not in their native language, do not picture people with whom they can identify, or are text-heavy with little

visual communication elements. The literature strongly suggests that one-to-one interaction and oral communication modes are critical to communicating information to many AI/ANs, as the traditional ways of life are primarily learned through oral tradition.

The geographical isolation of many AI/AN Reservation communities also appears to be a significant factor in accessing health care services. Direct, personal communication is important as an outreach and assistance strategy for many AI/ANs but is much more difficult and costly in rural areas where travel distances between households, communities, and intake facilities are substantial.

In addition to barriers unique to AI/AN populations, the limited available evidence identifies other barriers for AI/ANs. Specifically, lack of awareness of programs and eligibility criteria, concerns about costs, mistrust of government, welfare stigma, limited English fluency and literacy, rural travel distances and lack of transportation, lack of permanent addresses and telephone service, cultural differences, complexity of application processes, and poor customer service at eligibility sites are all identified in the published literature as barriers to enrollment of AI/AN people.[12]

Other Barriers to Enrollment in Medicaid, SCHIP and Medicare[13]

Other major barriers to enrollment for the AI/AN population, and others, that have been identified in the published literature include:

- Lack of awareness that the programs exist, particularly for SCHIP and the Medicare Savings Programs;
- Lack of information on eligibility criteria;
- Inadequate understanding of the programs and their benefits;
- Concerns about potential costs associated with enrollment in these programs (e.g. premiums, cost-sharing requirements, Medicaid eState recovery);
- Lack of transportation or significant difficulties in traveling to enrollment sites, particularly in rural areas;

[12] For discussion of program enrollment barriers specific to AI/ANs, see Robert Wood Johnson Foundation, 2001; Barents, 1999; Forquera, 2001; NICOA, 1999; Kauffman, 1999; Elder Voices, 2001; Klerman, 1999; and Lado et al., 2000.

[13] The discussion in this section is based on Medicaid, SCHIP, and Medicare Savings Programs enrollment barriers previously compiled by BearingPoint in two CD-ROMs under a separate contract with CMS (Contract No. 500-95-0057, T.O. 2): *CMS's Resources for Reaching Out*, an interactive CD-ROM for Medicare Savings Programs, Centers for Medicare & Medicaid Services, Baltimore, MD, October 1999; and *CMS's Resources for Reaching Out*, an interactive CD-ROM for Medicaid and SCHIP Programs, Centers for Medicare & Medicaid Services, Baltimore, MD, February 2000. The compilation of enrollment barriers was based on extensive literature reviews, focus groups, key informant interviews, technical expert panels, surveys, and CMS-sponsored conferences, all focused on barriers to enrollment for individuals and families eligible for these programs. References and other documentation can be found in these two CDs.

- Communication barriers, including limited access to television, radio, the Internet, and telephone, as well as lack of a permanent mailing address,14 that make it difficult to obtain information about programs and eligibility criteria and that make initial enrollment/ redetermination difficult;

- Language barriers for those who do not speak English as their primary language, and limited availability of appropriately translated outreach and educational materials;

- Limited literacy;

- Vision and hearing loss (particularly for elderly people) that renders much printed or audio outreach and application materials inaccessible;

- Cultural differences that require special efforts to explain the programs and provide enrollment assistance;

- Distrust or fear of the government and government-sponsored programs;

- Welfare stigma associated with enrolling in public programs;

- Application and redetermination processes and materials that are cumbersome and confusing and that require extensive documentation; and

- Poor customer service at State or County eligibility offices, including inadequate cultural awareness training for workers, lack of translation services, and long waits for assistance.

Existing published studies also note that in addition to barriers to initial enrollment, maintaining enrollment in Medicaid and SCHIP is a significant problem. Many people who enroll are subsequently dropped from these programs because they do not respond or comply with re-enrollment requirements.

Discussion

The literature review identified many issues that may contribute to under-enrollment of the AI/AN population in Medicaid, SCHIP, and Medicare. However, little "hard" evidence exists on which of these barriers, singly or in combination, have the greatest impact on under-enrollment. Similarly, published literature provides little to no quantitative evidence on the effectiveness of specific strategies for increasing enrollment of AI/ANs in these programs. There also has been only limited attention directed to differences among Tribes and between urban and Reservation areas in either the factors that contribute to under-enrollment or in the differences in strategies that may be necessary to increase enrollment in different areas and for different populations.

[14] Since the enactment of the Bureau of Indian Affairs relocation program, AI/ANs have moved between urban settings for employment and their home Reservation or rural communities regularly. This pattern reflects the value that AI/ANs place on their extended families and culture. (Personal communication from Balerma Burgess, IHS, November 28, 2003.)

RESEARCH QUESTIONS AND METHODS

The case study component of the project was designed to obtain information on barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare and, to the extent possible, to assess the relative importance of each enrollment barrier as indicated by those interviewed during the site visits. An additional goal of the case studies was to solicit suggestions for potential strategies to increase AI/AN program enrollment. The study approach was developed to address several questions of interest for this study:

- What are the most significant barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare?

- How prevalent are the primary barriers and how can they best be classified in a way that will help CMS and others to develop initiatives to address them?

- Do barriers differ in important ways by program? Are these differences due to programmatic idiosyncrasies, to differences in historical outreach to AI/ANs among the programs, or to differences in eligible populations (e.g., elderly versus working families)?

- How do barriers differ across Tribes and among urban, rural, and perimeter areas?

- Are some barriers to enrollment unique to AI/ANs and, as such, may require development of new, specifically targeted outreach strategies?

- Are there ways to reduce identified barriers to facilitate increased AI/AN enrollment in these programs? Which entities (Tribes, IHS, States, Federal government) would be best placed to initiate and carry out suggested strategies?

Across the 10 States, information from key informants was gathered in a highly structured method across multiple sites in each State through in-person and follow-up telephone interviews. The project team used the same discussion guide in each State to ensure that each State case study collected common information and that all important project research questions were addressed in the interviews. Next, the cases were systematically constructed by writing each State's case study notes according to a project team-developed descriptive framework to organize a case study; the team then identified program barriers and suggested strategies by classifying each into project team-standardized categories through constructing matrices by category and type of interviewee, for each State; and finally, the team created matrices that summarized and tabulated frequencies of barriers and strategies by type of interviewee. Comparisons across the 10 States then focused on identifying both unique and common themes that emerged from the interviews and differences across type of interviewee, relying on individual case study notes, notes organized by the descriptive framework, and summarized matrices.

Site Visit Methods

For each of the 10 States selected for the case study component of the project, site visits were conducted to:

- Two Tribes or AI/AN Reservations, to meet with Tribal leaders, Tribal health staff, IHS staff, and other local community members knowledgeable about program enrollment issues and processes (e.g., Title VI directors and Senior program directors).[15]

- An Urban Indian Health Clinic.[16]

- State Medicaid, SCHIP, and other State Offices, such as SHIPs and Elder Affairs Offices, with knowledge of AI/AN issues relevant to enrollment.

Additional appropriate organizations were interviewed when travel arrangements permitted and/or they were interviewed by follow-up telephone contacts (e.g., IHS Area Offices, Indian Health Boards representing multiple Tribes, CMS Regional Office staff, AI/AN referral hospitals, AI/AN epidemiology centers, and AI/AN elder housing facilities). For several site visits, County or State Medicaid and SCHIP eligibility workers were included in group interviews. In total, more than 300 people participated in interviews conducted in the 10 States, including staff from State Medicaid, SCHIP, and Tribal liaison agencies, 22 Federally Recognized AI/AN Tribes or organizations, 9 Urban Indian Health Clinics, and 10 other organizations involved in AI/AN health and public program enrollment.

The specific Tribes and Tribal organizations that participated in the site visits were selected with input from the project's TEP, project consultants, and CMS and IHS staff. Ultimately, all but two Tribes/Tribal organizations that were initially contacted agreed to participate in the site visits. Once agreement was obtained, each Tribe/Tribal organization identified a local liaison that worked closely with the site visit team leader to develop a detailed agenda for the site visit.

Prior to conducting the site visits, a wide range of background information was collected and summarized for use by the site visit teams, including:

- Information on individual Tribes, history of governmental relations, language, religion, population demographics, socio-economic status of the Tribe or community, and information on the Tribe's health care system.

- Specific information about the State's Medicaid and SCHIP programs.

- Information on IHS facilities and locations, including Urban Indian Health Clinics.

- Discussions with individual TEP members, IHS staff, and CMS staff to gain their insights and understanding of the selected Tribes and State programs, as well as to obtain their suggestions for additional background materials that would be helpful to review.

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[15] While the goal was to visit two Tribes/Reservations per State, some variation existed among States. This variation was due either to unique circumstances in the State (e.g., Alaska's large geographic area and many small Tribal villages) or to recommendations from TEP members who felt that the study would benefit from extending the site visit to include several Tribes/Reservations in specific States.

[16] North Dakota does not have an Urban Indian Health Clinic.

A three-person team, consisting of two project staff members and a project consultant, conducted each site visit. Three days was originally planned for each site visit, but several States (such as Alaska and Arizona) required four to five days to complete due to travel distances and other logistical problems. A list of the case study States, Tribes, Urban Indian Health Clinics, and other organizations that were visited by the site visit team is included in Appendix B. Appendix C contains the site visit interview guide used to conduct the discussions.

Analysis Approach

Once each site visit was completed, site visit team members individually summarized the barriers identified and strategies suggested by interviewees from each Tribe/Reservation, State offices, Urban Indian Health Clinics, and other organizations visited or interviewed through follow-up telephone contacts. The site visit team then reviewed and finalized the individual summaries. A Case Study Report was prepared for each State that included background information and individual summaries for each Tribe, Urban Indian Health Clinic, State offices, and other organizations interviewed. A common format was developed for the State Case Study Reports to facilitate comparisons and analysis across States.

Drafts of the State Case Study Reports were sent to Tribal liaisons, IHS Area and Service Unit staff, State staff contacts, and interviewees from Urban Indian Health Clinics and other organizations, for review and comments. In addition, project consultants and CMS and IHS staff reviewed and provided comments on all of these Reports. Revisions to the State Case Study Reports were made based on reviewers' comments and suggestions. The final versions of the individual State Case Study Reports provided the base information from which this Summary Case Study Report was developed.

For each identified barrier and strategy, tables were constructed showing: 1) the number and percent of States where the specific barrier or strategy was identified; and 2) the percent of Tribal, State, Urban, and Other organizations that cited each specific barrier or strategy. Data in these tables were used to assess the "importance" of each barrier or strategy, as measured by the number of States and the frequency with which representatives from each key informant category cited it. In addition, the data permitted examination of differences among key informant categories in the frequency of specific barriers and strategies reported.

LIMITATIONS OF CASE STUDY

The case study component of this study was developed to obtain information on barriers to enrollment in Medicaid, SCHIP, and Medicare and to seek suggestions for strategies to facilitate AI/AN enrollment in these programs from Tribal representatives, State officials, health providers that serve AI/AN populations, and other knowledgeable people. In the 10 case study States, interviews were conducted with more than 300 individuals. In addition, the process of submitting drafts of State Case Study Reports to interviewees, project consultants, and to knowledgeable CMS and IHS staff for review and comment provided additional input and verification of information that was incorporated into the State Case Study Reports.

Despite the large number of interviews that were conducted and the extensive review process, this study has intrinsic limitations that may affect the validity of the findings and the

extent to which they can be generalized to all AI/AN populations in the same or different States. These limitations include:

- Individual interviewees expressed their personal views and perceptions, based on their own experiences and situations. The project team did not conduct an independent validation of the interviewees' perceptions. Therefore, findings from the case studies should be interpreted as anecdotal information that may not be generalizable to the larger AI/AN population.

- Information was obtained in 10 States that have large AI/AN populations. However, the findings of the individual State case studies may not be generalizable to other States with different characteristics and AI/AN populations.

- Detailed information was obtained from only 22 Federally Recognized AI/AN entities or organizations.17 Thus, although the findings may reflect the characteristics and experiences of the Tribes/Reservations interviewed, they may not necessarily extend to other Tribes with different cultures, histories, and experiences that were not interviewed.

- At the time the site visits for this project were conducted, many States were experiencing budget shortfalls that were causing State governments to consider cutbacks in Medicaid and SCHIP program benefits and/or outreach funds. The changes that were being contemplated may have affected the perceptions of Tribal and State interviewees about barriers to enrollment in these programs and strategies to increase AI/AN enrollment. The study findings might well be different if the site visits had been conducted during a period of economic expansion and State budget surpluses.

Although it is important to recognize the limitations of this study, it still provides useful information that can provide a basis for developing and testing strategies that may be successful in reducing barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare.

FINDINGS: BARRIERS TO AI/AN ENROLLMENT IN MEDICAID, SCHIP AND MEDICARE

INTRODUCTION

Barriers to AI/AN enrollment identified by interviewees were grouped into five broad categories:

1. Barriers related to Individual Tribal Members.
2. Barriers related to Tribal Leadership.
3. Barriers related to IHS Programs.
4. Barriers related to State Medicaid and SCHIP Programs.
5. Barriers related to Federal Programs.

[17] Additional information was obtained from a larger number of Tribes through meetings with Indian Health Boards and input from TEP members and project consultants. This information, however, was more general and less detailed in nature than that obtained through visits or follow-up telephone interviews with individual Tribes.

The most often cited barriers fit within these categories, although a few were applicable to more than one category (for example, concerns about cost-sharing applied to Individual Tribal Members and to State Medicaid and SCHIP and Federal Programs). Most identified barriers were common to Medicaid, SCHIP, and Medicare, although respondents mentioned some barriers specific to Medicare.

Barrier categories were first examined by individual State to identify differences in issues raised across States. Table 2 presents this information, with a circle indicating that one or more interviewees in a specific State identified the indicated barrier as an issue. Table 2 combines Medicaid, SCHIP, and Medicare barriers. In addition to examining the barriers identified by category and State, responses were grouped by Tribe, Urban Indian Health Centers, State officials, and Other organizations and frequencies of individual responses were calculated for each barrier category. These frequencies permit comparisons among respondent groups to identify differences in perceptions that a specific barrier was an issue. Table 3 presents findings for Medicaid and SCHIP and Table 4 provides findings for Medicare.

It is important in reviewing these findings to consider that the information reported reflects perceptions of the individuals interviewed. Independent verification of these perceptions by the study team was not possible. Consequently, the results must be viewed as anecdotal rather than as statistically representative of the perceptions of the broader AI/AN population.

BARRIERS BY STATE

As an initial step in assessing the importance of barriers that were identified by interviewees, the information collected was organized by State to examine the extent to which individual barriers were reported across States. Table 2 presents information on whether a specific barrier was reported as an issue by any interviewee in the State. The information in Table 2 does not reflect the frequency with which a specific barrier was identified by interviewees, but rather shows that the barrier was mentioned by at least one individual in interviews conducted in the State.

Table 2: Reported Barriers to AI/AN Enrollment in Medicaid, SCHIP, Medicare and the Medicare Savings Programs, by State

Barriers (Percent of States Reporting Barrier)	AK	AZ	MI	MN	MT	ND	OK	SD	UT	WA
Barriers Related to Individual Tribal Members										
Transportation (100%)	●	●	●	●	●	●	●	●	●	●
Financial (100%)	●	●	●	●	●	●	●	●	●	●
Lack of awareness/knowledge (90%)		●	●	●	●	●	●	●	●	●
Language/literacy (90%)	●	●	●	●	●		●	●	●	●
Belief in Federal Trust Responsibility (80%)		●	●	●	●		●	●	●	●
Mistrust of government (70%)		●	●	●			●	●	●	●
Cultural (70%)			●	●	●		●	●	●	●
Welfare stigma (60%)		●	●	●			●	●		●

Limited access to communication devices (50%)	●	●		●			●			●
Barriers Related to Tribal Leadership										
Lack of awareness/knowledge (50%)		●		●			●		●	●
Inadequate Tribal infrastructure/resources (50%)		●		●		●		●		●
Federal Trust Responsibility will be reduced (40%)		●				●		●		●
Barriers Related to IHS Programs										
Inadequate outreach/enrollment assistance (100%)	●	●	●	●	●	●	●	●	●	●
Lack of coordination/data sharing w/State (80%)		●	●		●	●	●	●	●	●
Inadequate I/T/U staff training (70%)		●	●	●	●		●	●		●
Barriers Related to State Medicaid and SCHIP Programs										
Lack of outreach/education activities (100%)	●	●	●	●	●	●	●	●	●	●
Complex application/redetermination processes (90%)	●	●	●	●		●	●	●	●	●
Inadequate training of eligibility workers (80%)		●	●		●	●	●	●	●	●
Cultural competency issues (70%)		●	●	●			●	●	●	●
State budget (60%)		●		●	●		●	●		●
Imposition of program fees/cost-sharing (50%)	●	●		●		●			●	
Medicaid managed care (50%)		●	●			●	●			●
State-to-State border issues (40%)		●		●			●			●
Barriers Related to Federal Programs										
Imposition of Medicare premiums/cost-sharing (100%)	●	●	●	●	●	●	●	●	●	●
Complex application processes (SSDI)) (60%)	●	●				●	●	●	●	
Complex Federal-State-Tribal relations (50%)		●		●			●		●	●
Lack of outreach/education activities (50%)	●					●	●	●		●
Lack of coordination among Federal agencies (40%)	●					●		●		●
Cultural competency issues (20%)		●								●

Barriers Related to Individual Tribal Members

Two barriers related to individual Tribal members' circumstances were reported by interviewees in all 10 States: 1) transportation barriers and 2) financial barriers. Transportation barriers to enrollment in Medicaid, SCHIP, and Medicare reflect the rural/frontier geography of most Reservations and the need to travel long distances to eligibility offices, as well as the lack of reliable transportation options and public transportation services. In urban settings, public transportation may be available but may require long travel time and be costly relative to incomes of eligible people.

Financial barriers to enrollment include premiums and cost-sharing requirements that are associated primarily with Medicare Part B enrollment. Several interviewees also mentioned

SCHIP premiums and cost-sharing requirements. AI/AN SCHIP enrollees are exempt from these requirements; however, interviewees said that many people are unaware of this exemption and are deterred from enrolling because they believe they would have to pay these costs. The issue of lack of knowledge and understanding of programs is discussed later in this report. In addition, financial barriers to enrollment include concerns about Medicaid estate recovery and fears among AI/AN eligible people that if they enroll in Medicaid or the Medicare Savings Programs, the State will confiscate their assets. Concerns about premiums and cost-sharing requirements are an issue for AI/AN eligible people because the IHS provides services at no cost to members of Federally Recognized Tribes that reside on or near Reservations with IHS facilities.[18] As a result, some AI/AN eligible people are reluctant to pay premiums for Medicare Part B when many of these services can be obtained through IHS at no cost.

Other barriers to enrollment related to individual Tribal member circumstances that were identified in a majority of States include:

- Lack of awareness or knowledge of programs, eligibility criteria, and benefits. This issue was mentioned in 9 of 10 States as a barrier to AI/AN enrollment. Interviewees stated that some AI/AN eligible people do not know about Medicaid, SCHIP, and Medicare and, if they are aware, do not know that they may be eligible to enroll in these programs. There is also misunderstanding about the financial aspects of these programs and some people are deterred from enrollment because they believe that there will be costs (premiums and cost-sharing) required. Since IHS provides services at no cost, eligible people who believe that enrolling in public programs will impose costs on them choose not to enroll.

- Language/literacy barriers. Interviewees in 9 of the 10 States mentioned language/literacy issues as barriers to AI/AN enrollment. AI/ANs who do not speak English as their primary language and those who have limited literacy face barriers in learning about Medicaid, SCHIP, and Medicare and in completing applications. The fact that there are a large number of AI/AN languages compounds this problem as it would be difficult to translate outreach and education materials into all AI/AN languages.

- *Federal Trust Responsibility*. In 8 of the 10 States, interviewees stated that some AI/ANs believe that the Federal government has a trust responsibility to provide health care to AI/AN people and that, therefore, there is no need for them to apply for and enroll in other public programs.

- *Mistrust of Government*. In 7 of the 10 States, mistrust of the Federal or State government by AI/ANs was identified as a barrier to enrollment. The difficult historical relationship between AI/AN people and the Federal government was cited as the basis for mistrust. In addition, the complex relationships among the Tribes and State and Federal governments were also identified as an issue.

[18] Although services that are provided directly in IHS facilities are available and provided to anyone who is a member of a Federally Recognized Tribe, Contract Health Services (those that require referral to outside providers) may not necessarily be available to members of Federally Recognized Tribes outside of their home Reservation. (Personal communication with Balerma Burgess, IHS, December 3, 2003.)

- *Cultural barriers*. Interviewees in 7 of the 10 States mentioned cultural issues as barriers to enrollment. These issues include, for example, a greater reluctance of AI/ANs to pursue enrollment if they are turned down initially (regardless of the reason). In addition, some interviewees said that AI/AN cultures make people averse to revealing personal information, such as income information required by Medicaid and SCHIP and Medicare Savings Programs application forms. Cultural misunderstanding by non-AI/AN eligibility workers for State and Federal programs was also cited as a barrier to enrollment by some interviewees.

- *Welfare stig*ma. In 7 of the 10 States, interviewees mentioned welfare stigma as a barrier to enrollment in Medicaid, the Medicare Savings Programs, and sometimes SCHIP.

- *Lack of access to regular mail, telephone, fax, television, radio, and Internet service*. In 7 of the 10 States, interviewees said that lack of reliable access to usual forms of communication (e.g. mail, telephone) made it difficult for some people to apply for enrollment and also made outreach and education efforts more difficult.

Transportation barriers, financial barriers, lack of program awareness and knowledge, and language/literacy barriers were identified in most States as barriers to enrollment facing eligible AI/ANs. There are some unique complications and issues, however, for the AI/AN population. Financial barriers are likely to be a greater deterrent to enrollment for AI/AN eligibles who have direct IHS or Tribally managed health services available at no cost, even though access to Contract Health Services may be limited. In addition, the belief that the Federal government has a trust responsibility to provide health care to AI/ANs and that they should, therefore, not be required to enroll in Federal or State health insurance programs, is a barrier to enrollment that is unique to the AI/AN population.

Barriers Related to Tribal Leadership

In some States, interviewees stated that Tribal leaders fail to encourage Tribal members to enroll in public health programs and that this was a barrier to enrollment. The barriers to a Tribal leadership role in encouraging enrollment that were cited include:

- *Lack of knowledge/awareness of the benefits of Tribal member enrollment*. In 5 of the 10 States, interviewees said that some Tribal leaders might not understand Medicaid, SCHIP, and Medicare and so do not understand the benefits to Tribal members individually and to the community of enrollment. It was suggested that Tribal leadership might not understand that Tribal members who enroll in these programs and use IHS services are adding revenues that IHS can use to provide more services to all Tribal members.

- *Inadequate Tribal infrastructure and resources*. In 5 of the 10 States, interviewees noted that many Tribes do not have the infrastructure and resources that are necessary to conduct outreach and education and to provide application assistance to eligible Tribal members. They stated that Tribal leadership usually does not assign a priority to these activities, even if resources might be available.

- *Federal Trust Responsibility*. In 4 of the 10 States, interviewees cited Tribal leadership's views on the Federal Trust Responsibility to provide health care as a barrier to enrollment. Interviewees said that some Tribal leaders believe their promotion of Tribal member

enrollment in Medicaid, SCHIP, or Medicare may be lessen the Federal government's perception of their responsibility and others believe that encouraging the use of alternative resources to fund IHS, Tribal, or Urban Indian Health Clinics will cause IHS funding to decline proportionately.

Community leaders have a role in encouraging eligible people to enroll in Medicaid, SCHIP, and Medicare in any population group. This is even more the case for AI/AN communities, where Tribal leaders may have great influence and may set priorities for resources.

Barriers Related to IHS Programs

In all 10 of the case study States, interviewees stated that IHS and Tribal facilities on Reservations and Urban Indian Health Clinics do not have adequate resources to provide the outreach, education, and enrollment application and redetermination assistance that many AI/ANs need.

This lack of resources for effective IHS outreach activities is compounded by the fact that IHS has, for the most part, been unable to have its patient benefit staff trained alongside County and State workers on filling out application forms appropriately in order to assist its patient community in completing forms. If resources and training were available, IHS has the capability to conduct focused outreach because of its structured business offices at each IHS hospital and clinic and access to the patient community. Focused outreach through an IHS facility can be illustrated by the success at the W.W. Hastings Hospital in Tahlequah, Oklahoma, which was able to demonstrate a 45 percent increase in enrollment into entitlement programs over a one year effort.[19]

There also was frequent mention (eight of 10 States) of a lack of coordination and sharing of data between the IHS and State Medicaid and SCHIP agencies. Interviewees stated that these State agencies do not work with IHS to provide data on applicants who need assistance to complete the process, nor do they provide information on enrollees who are going through redetermination.

Inadequate training of IHS, Tribal health, and Urban Indian Health Clinic staff about eligibility rules and application requirements was also cited as a barrier in 7 of the 10 States. Of particular concern is the reported lack of training for patient benefit advocates physically located at IHS, Tribal, or Urban (I/T/U) facilities, as well as a lack of resources to hire and train these facilities. Nearly every type of interviewee identified non-I/T/U patients as those most likely to be under-enrolled in Medicaid and SCHIP. A common observation was that many individuals do not become enrolled in these programs until they face a medical crisis that causes them to seek medical attention. At that time, they may have already incurred substantial costs that will not be

[19] Personal communication with Balerma Burgess, IHS, November 28, 2003. Ms. Burgess also noted that, for the past five years, the IHS has been proactive at inviting Tribal programs to participate in its annual Partnership training/conference which is the Business Office, Medical Records and Contract Health Services programs, the functions that are the basis of third party revenues from Medicare, Medicaid, and private insurance. The number of Tribes attending has increased over this period. At the training/conference, all staff are trained on the third-party revenue cycle and its integrated health system, beginning with patient registration, patient benefits coordination, medical records management, coding, billing and accounts receivable.

paid for by IHS or Medicaid and SCHIP. Moreover, they have not received preventive services that may have eliminated or mitigated the medical crisis in the first place.

Barriers Related to Medicaid and SCHIP Programs

Across all 10 States, interviewees said that outreach and education focused on informing and assisting AI/AN people to enroll in Medicaid, SCHIP, and the Medicare Savings Programs was inadequate. Other barriers identified in a majority of States included:

- *Complexity of the application and redetermination process*. This was particularly cited as a problem for Medicaid enrollment, as SCHIP application processes were cited as simpler than those for Medicaid in most States. One of most frequently reported application and redetermination process barriers concerned many AI/ANs' inability to obtain supporting documentation. It was not uncommon for Tribal/IHS interviewees to report Tribal members' difficulties in obtaining official birth and marriage certificates either because they may not exist or there may be an associated cost.

- *Inadequate training of eligibility workers*. In 8 of the 10 States, interviewees mentioned barriers to enrollment related to training of eligibility workers. Several interviewees stated that some eligibility workers did not fully understand eligibility rules for different categories of Medicaid and sometimes denied enrollment to eligible AI/ANs. Other interviewees said that eligibility workers did not understand AI/AN asset issues and denied eligibility to AI/AN people who held Federal Trust Lands that should not have been included in asset determination.

- *Cultural competency.* Interviewees in 7 of the 10 States said that eligibility workers did not have adequate knowledge and understanding of AI/AN culture and communication styles to work effectively with AI/AN people. This lack of cultural awareness could be a barrier to AI/AN enrollment and may contribute to perceptions of some AI/ANs that eligibility workers discriminate against them.

- *State budget shortfalls*. Interviewees in 6 of the 10 States said that current State budget problems were a barrier to AI/AN enrollment in Medicaid, SCHIP, and the Medicare Savings Programs. The reasons cited included incentives for States to reduce the number of people enrolled in these programs (that is, deny eligibility) and a lack of funds for enrollment assistance.

Other issues mentioned in one-half or less of the case study States include: imposition of program fees/cost-sharing; Medicaid managed care that may limit access to IHS facilities; and State border issues (e.g., a Reservation may extend over State borders with an IHS facility located in one State but the Medicaid and SCHIP enrollee living in the other State).

Barriers Related to Federal Programs

Federal government issues that created barriers to enrollment that were mentioned in five or more of the case study States include:

- *Medicare premiums and cost-sharing*. Interviewees in all 10 States Stated that the Medicare premium was a deterrent to enrollment of AI/AN Medicare beneficiaries in Part B.

- *Complexity and processes for applying for SSDI*. In 6 of the 10 States, interviewees cited the difficulty of applying for SSDI as a major barrier to enrollment in Medicare. In particular, interviewees stated that most people are denied SSDI on their first application and that many AI/ANs do not pursue re-application either because they are reluctant to contest a government program denial or because they lack resources to appeal the initial decision.

- *Lack of outreach and education by the Federal government*. In 5 of the 10 States, interviewees stated that the Federal government should provide greater outreach and education on Medicaid, SCHIP, Medicare Savings Programs, Medicare, and SSDI. The general point made was that these are Federal programs and outreach and education should not be solely a State or local community responsibility.

- *Complexity of Federal-Tribal-State relationships*. Interviewees in 5 of the 10 States cited this issue, stating that it was very difficult to understand why the Federal government places responsibility on the States to enroll AI/ANs in Medicaid in order to have the State make payments to the IHS – a Federal agency – for services provided to AI/ANs, for which the Federal government then reimburses the State on a 100 percent basis. If the Federal government has a Trust responsibility to the AI/AN people to provide health care, interviewees Stated that it should do so directly rather than creating this complex process that is confusing and difficult for everyone to understand.

Other Federal issues cited in some States include: lack of coordination among Federal agencies, and inadequate cultural awareness and competency of Medicare and Social Security customer service staff.

DIFFERENCES IN PERCEPTIONS OF BARRIERS AMONG TRIBAL, STATE, AND URBAN INTERVIEWEES

The findings in this Case Study Report are based on the interviewees' perceptions and thus may only reflect the unique experiences or knowledge of those individuals. To further examine the barriers reported, and to explore the extent to which particular barriers are cited by different groups of respondents, the frequency with which a specific barrier was mentioned by Tribes, States, Urban Indian Health Clinic staff, and interviewees from other organizations was assessed. This comparative analysis was conducted separately for Medicaid and SCHIP barriers and for Medicare (and Medicare Savings Programs) barriers.

Results for Medicaid and SCHIP barriers are shown in Table 3. Key findings include:

- Tribal interviewees' most frequently cited barriers to Medicaid and SCHIP enrollment were: transportation (82 percent), lack of awareness/knowledge (82 percent), lack of outreach and enrollment assistance by IHS and States (82 percent each), complexity of the application/redetermination process (73 percent), and mistrust of government programs (50 percent).

- State interviewees' most frequently cited barriers to Medicaid and SCHIP enrollment were: lack of awareness/knowledge (80 percent), complexity of the application/redetermination process (70 percent), transportation (60 percent), financial issues (50 percent), and inadequate outreach and enrollment by IHS and States (50 percent each).

- Urban Indian Health Clinic interviewees' most frequently cited barriers to Medicaid and SCHIP enrollment were: complexity of the application/redetermination process (67 percent), inadequate training of IHS, Tribal, and Urban Clinic staff (56 percent), mistrust of government programs (44 percent), cultural barriers (44 percent), lack of outreach and enrollment assistance by IHS and States (44 percent), and inadequate training of State eligibility workers (44 percent).

State interviewees were more likely than Tribal interviewees to cite barriers related to Tribal leadership, and less likely to indicate there were barriers related to State Medicaid and SCHIP program operations. State interviewees were also more likely to say that State budget issues were barriers than were Tribal and Urban Indian Health Clinic interviewees. Fewer Urban Indian Health Clinic staff mentioned specific barriers related to individuals' circumstances compared with Tribal and State interviewees, but more frequently cited cultural barriers and inadequate training of staff and eligibility workers.

Table 3: Reported AI/AN Medicaid and SCHIP Barriers, by Respondent Type (for all 10 States)

Type of Interviewee	State		Tribal		Urban	
Total Interviewees	**10**	**Percent**	**22**	**Percent**	**9**	**Percent**
Barriers Related to Individual Tribal Members						
Transportation	6	60%	18	82%	1	11%
Financial	5	50%	6	27%	1	11%
Lack of awareness/knowledge	8	80%	18	82%	3	33%
Language/literacy	4	40%	10	45%	2	22%
Belief in Federal Trust Responsibility	2	20%	4	18%	2	22%
Mistrust of government	4	40%	11	50%	4	44%
Cultural issues	3	30%	5	23%	4	44%
Welfare stigma	2	20%	8	36%	1	11%
Limited access to communication devices	0	0%	4	18%	1	11%
Barriers Related to Tribal Leadership						
Lack of awareness/knowledge	2	20%	3	14%	0	0%
Inadequate Tribal infrastructure/resources	2	20%	4	18%	0	0%
Federal Trust Responsibility will be reduced	2	20%	3	14%	0	0%
Barriers Related to IHS Programs						
Inadequate outreach/enrollment assistance	5	50%	18	82%	4	44%
Lack of coordination/data sharing w/State	3	30%	9	41%	2	22%
Inadequate I/T/U staff training	2	20%	9	41%	5	56%
Barriers Related to State Medicaid and SCHIP Programs						
Lack of outreach/education activities	5	50%	18	82%	4	44%
Complex application/redetermination processes	7	70%	16	73%	6	67%
Inadequate training of eligibility workers	1	10%	7	32%	4	44%
Cultural competency issues	4	40%	9	41%	3	33%
State budget	5	50%	8	36%	3	33%
Imposition of program fees/cost-sharing	3	30%	3	14%	0	0%

Medicaid managed care	4	40%	5	23%	1	11%
State-to-State border issues	0	0%	5	23%	1	11%
Barriers Related to Federal Programs						
Complex application process (SSDI)	2	20%	2	9%	1	11%
Complex Federal-State-Tribal relations	1	10%	4	18%	0	0%
Lack of outreach/education activities	2	20%	1	5%	0	0%
Lack of coordination among Federal agencies	2	20%	1	5%	1	11%
Cultural competency issues	0	0%	2	9%	0	0%

Results for Medicare and the Medicare Savings Programs barriers are displayed in Table 4. Major findings include:

- Tribal interviewees most frequently mentioned financial barriers (82 percent), Medicare premiums/costs (82 percent), and lack of awareness/knowledge (68 percent) as barriers to AI/AN enrollment in Medicare and the Medicare Savings Programs.

- State interviewees most frequently mentioned lack of awareness/knowledge (40 percent) as a barrier to AI/AN enrollment in Medicare and the Medicare Savings Programs.

- Urban Indian Health Clinic interviewees most frequently mentioned lack of awareness/knowledge (56 percent), complexity of the application/redetermination process (56 percent), financial barriers (44 percent), Medicare premiums/costs (44 percent), and inadequate IHS outreach and education (44 percent) as barriers to AI/AN enrollment in Medicare and the Medicare Savings Programs.

Urban Indian Health Clinic staff were more likely than either Tribal or State interviewees to cite mistrust of government, language/literacy, and cultural barriers. Tribal interviewees were more likely to mention financial barriers and Medicare costs than were State interviewees. State respondents, however, were more likely to cite language/literacy barriers and lack of coordination and data sharing between the State and IHS as barriers.

Table 4: Reported AI/AN Medicare and Medicare Savings Programs Barriers, by Respondent Type (for all 10 States)

Type of Interviewee	State		Tribal		Urban	
Total Interviewees	**10**	**Percent**	**22**	**Percent**	**9**	**Percent**
Barriers Related to Individual Tribal Members						
Transportation	2	20%	5	23%	0	0%
Financial	3	30%	18	82%	4	44%
Lack of awareness/knowledge	4	40%	15	68%	5	56%
Language/literacy	3	30%	4	18%	3	33%
Belief in Federal Trust Responsibility	3	30%	9	41%	1	11%
Mistrust of government	0	0%	3	14%	3	33%
Cultural issues	0	0%	1	5%	3	33%
Welfare stigma	2	20%	4	18%	1	11%
Limited access to communication devices	1	10%	3	14%	0	0%
Barriers Related to Tribal Leadership						
Lack of awareness/knowledge	1	10%	1	5%	0	0%
Inadequate Tribal infrastructure/resources	0	0%	0	0%	0	0%
Federal Trust Responsibility will be reduced	0	0%	1	5%	0	0%

Barriers Related to IHS Programs						
Inadequate outreach/enrollment assistance	3	30%	8	36%	4	44%
Inadequate I/T/U staff training	0	0%	5	23%	1	11%
Lack of coordination/data-sharing w/State	2	20%	1	5%	1	11%
Barriers Related to State Medicaid and SCHIP Programs						
Lack of outreach/education activities	3	30%	7	32%	3	33%
Complex application/redetermination processes	2	20%	5	23%	5	56%
Inadequate training of eligibility workers	1	10%	2	9%	0	0%
Cultural competency issues	1	10%	3	14%	2	22%
State budget	0	0%	0	0%	0	0%
Imposition of program fees/cost-sharing	1	10%	2	9%	0	0%
Medicaid managed care	0	0%	0	0%	0	0%
State-to-State border issues	0	0%	0	0%	0	0%
Barriers Related to Federal Programs						
Imposition of Medicare premiums/cost-sharing	3	30%	18	82%	4	44%
Complex application process (SSDI)	0	0%	2	9%	1	11%
Complex Federal-State-Tribal relations	0	0%	3	14%	0	0%
Lack of outreach/education activities	1	10%	4	18%	1	11%
Lack of coordination among Federal agencies	1	10%	3	14%	1	11%
Cultural competency issues	0	0%	1	5%	1	11%

DISCUSSION

Unique barriers to enrollment for the AI/AN population raised in the interviews conducted for this study are primarily the result of the relationship between the Federal government and AI/AN Tribes, and the complex Federal-Tribal-State government-to-government relationships.

FINDINGS: STRATEGIES TO FACILITATE AI/AN ENROLLMENT IN MEDICAID, SCHIP, AND MEDICARE

INTRODUCTION

During each set of interviews conducted for this study, interviewees were asked to suggest strategies that, in their view, would be effective in reducing barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare. They were also asked to comment on the entities that they believed should have the responsibility for implementing and financially supporting each identified strategy. The strategies suggested were then categorized by the entities that interviewees suggested should be responsible for implementing and paying for the activity or program proposed by the strategy. These entities include:

- *All Involved Entities: Tribes, IHS, States, and Federal Government*. There were a number of strategies that interviewees said should be carried out, either independently or jointly, by all of the entities that are involved in AI/AN health care and program enrollment.

- *States*. Some strategies were indicated as a specific responsibility of State governments.

- *Federal*. Some strategies were indicated as a specific responsibility of the Federal government.

This information was organized in the same manner as in the preceding section on barriers to enrollment. First, the information collected was organized by State in order to examine the extent to which individual strategies were suggested across States. Table 5 presents information on whether a specific strategy was suggested by any respondent group in the State. The information in Table 5 does not reflect the frequency with which a specific strategy was suggested, but rather shows that the strategy was mentioned by at least one individual in the interviews conducted in the State. Next, the frequency with which specific strategies were suggested by Tribal, State, Urban Indian Health Clinic, and other organizations' respondents is presented and compared across types of interviewees in Table 6. Because the strategies mentioned are for the most part common to Medicaid, SCHIP, Medicare, and the Medicare Savings Programs, they are not separated in the tables presented below.

Again, as is the case with the discussion of barriers to enrollment, it is important to bear in mind that the suggested strategies are based on interviewees' perceptions of the problem and possible solutions. There is little or no information available to determine whether specific strategies would be effective or whether they would be feasible based on costs or political considerations. However, the strategies listed in this section should be viewed as those that knowledgeable people who are involved in AI/AN health care and public program enrollment issues believe would be effective.

SUGGESTED STRATEGIES FOR REDUCING BARRIERS AND FACILITATING ENROLLMENT BY STATE

States in which interviewees mentioned a specific strategy to reduce barriers and facilitate AI/AN enrollment are presented in Table 5.

Table 5: Suggested Strategies to Increase AI/AN Enrollment in Medicaid, SCHIP, Medicare, and Medicare Savings Programs, by State

Suggested Strategies (Percent of States Reporting Strategy)	AK	AZ	MI	MN	MT	ND	OK	SD	UT	WA
Strategies Related to Tribes/IHS/State Governments/Federal Government										
Funding for AI/AN-specific outreach/ enrollment assistance (100%)	●	●	●	●	●	●	●	●	●	●
Targeted outreach/enrollment assistance funding directed to Tribes/Urban Indian Health Clinics (100%)	●	●	●	●	●	●	●	●	●	●
Educational/marketing activities on program benefits to individuals and Tribes (100%)	●	●	●	●	●	●	●	●	●	●
Develop Tribal-specific outreach and enrollment materials (90%)	●	●		●	●	●	●	●	●	●
Strengthen Tribal/IHS incentives for enrollment (70%)	●	●	●	●		●			●	●
Focused outreach and education to elders for Medicare Savings Programs (60%)	●					●	●	●	●	●
Strategies Related to State Governments										
Develop collaborative working relationships among State-Tribes-IHS (100%)	●	●	●	●	●	●	●	●	●	●
Simplify application/redetermination processes (80%)		●	●	●	●	●	●	●		●
Improve Medicaid and SCHIP training for Tribal/IHS/Urban staff (80%)	●	●	●	●	●		●	●		●
Improve eligibility worker program knowledge, focused on AI/AN issues (70%)	●	●			●	●	●	●	●	
Limit redetermination to annual or less frequent (70%)	●	●	●		●	●	●	●		
Out-station eligibility workers on Reservations (70%)		●		●	●		●	●	●	●
Develop AI/AN cultural competency programs for State staff (50%)		●			●		●	●	●	
Educate eligibility workers on AI/AN history, Federal Trust Responsibility, and legal issues (40%)		●		●	●	●				
Exempt AI/AN enrollees from managed care enrollment/program fees/cost-sharing (40%)	●		●			●			●	
Recruit and hire AI/AN eligibility workers (30%)				●	●				●	

Table 5: Suggested Strategies to Increase AI/AN Enrollment in Medicaid, SCHIP and Medicare Programs, by State (continued)

Suggested Strategies (Percent of States Reporting Strategy)	AK	AZ	MI	MN	MT	ND	OK	SD	UT	WA
Strategies Related to Federal Government										
Improve Medicare program training for Tribal/IHS/Urban staff (80%)		●		●	●	●	●	●	●	●
Improve Federal-State-Tribal government-to-government relationships (80%)	●	●		●	●	●		●	●	●
Develop Tribal Medicaid option (70%)		●	●	●		●		●	●	●
Targeted outreach/enrollment assistance funding directed to Tribes/Urban Indian Health Clinics (70%)	●			●	●	●		●	●	●
Exempt AI/AN Medicaid and Medicare enrollees from premium/cost-sharing (30%)	●					●			●	
Require States to share administrative match funds with Tribes (20%)					●			●		
Develop strategy to assist people to apply to SSDI (20%)			●				●			
Improve AI/AN cultural competency awareness of Federal staff (20%)		●			●					
Make program application information inaccessible to other State agencies (10%)							●			

Suggested Strategies Directed to All Involved Entities

The first category of suggested strategies are those that interviewees believed should be the responsibility, individually and jointly, of all of the entities that have responsibilities for AI/AN health care and program enrollment. Key strategies suggested encompass the following:

- *Increase Funding for AI/AN-Specific Outreach and Enrollment Assistance*. In all of the 10 case study States, interviewees said that funding should be provided or increased for AI/AN-specific outreach and enrollment assistance. In nine of the 10 case study States, this strategy included the development of Tribal-specific outreach and enrollment materials that are culturally appropriate, with messages, language, and design (e.g., use of visuals and familiar faces) that resonate among the specific Tribal members, and that are perhaps translated into the appropriate AI/AN language(s).

- *Provide Increased Outreach and Enrollment Assistance Funds Directly to Tribes and to Urban Indian Health Clinics*. Furthermore, interviewees in all 10 States suggested that the majority of funding for outreach and enrollment assistance should be provided directly to Tribes and to Urban Indian Health Clinics. This would allow Tribes and clinics themselves to design and implement Tribal- or community-specific outreach and enrollment assistance activities with these funds.

- *Develop Educational/Marketing Program for Tribal Leaders and Tribal Members*. Interviewees in all 10 States said that an educational/marketing program should be developed and implemented to increase Tribal leaders' and Tribal members' awareness of the benefits of enrolling in Medicaid, SCHIP, and Medicare.

- *Develop Outreach and Enrollment Assistance Strategies Targeted to AI/AN Elders*. Interviewees in six of the 10 States Stated that focused outreach and enrollment assistance strategies would be important to assist AI/AN elders to understand and enroll in the Medicare Savings Programs.

- *Strengthen Tribal/IHS Incentives to Promote AI/AN Program Enrollment*. Interviewees in seven of the 10 States suggested strengthening Tribal/IHS facility incentives to promote AI/AN program enrollment. This included increasing the facility's ability to successfully bill third-party insurance through improved infrastructure for coding, billing, auditing, and follow-up billing and enrollment systems (e.g., improved computer billing systems and improved training for coding and billing clerks).

The major theme, clearly, of suggested strategies that encompass all of the involved entities is that more outreach, education, and enrollment assistance specifically directed to AI/AN people is needed, and that the majority of this outreach, education, and enrollment assistance should be developed either by individual Tribes or with extensive input from Tribes.

Suggested Strategies Directed to States

Suggested strategies that are directed to the States fall into five categories:

- *Improve Collaborative Working Relationships Among the States, Tribes, and IHS*. This suggestion was mentioned by interviewees in all 10 case study States and reflects the reported lack of coordination and cooperation among these entities on Medicaid and SCHIP enrollment issues. While the problem was noted in all States, interviewees were not specific about the best approach to achieve this goal, although some suggested that efforts should be made to bring together the State agency staff, Tribal leaders and staff, and IHS staff on a regular basis to discuss Medicaid and SCHIP issues. Others suggested that States should commit to a formal consultation process with the Tribes on Medicaid and SCHIP policy changes that affect Tribal members. Interviewees in several States noted the importance of a Medicaid and SCHIP liaison who is American Indian or Alaska Native in improving relationships in their State.

- *Increase Training for State/County Eligibility Workers and Others Who Assist AI/AN Enrollment Processes*. Interviewees in 8 of the 10 case study States suggested that the State should provide and improve Medicaid and SCHIP program training for Tribal, IHS, and Urban Indian Health Clinic staff. There was considerable concern that staff at these organizations have inadequate knowledge and understanding of program eligibility rules and application procedures and, as a result, are not able to effectively assist AI/AN people with enrollment. There was also considerable concern that gaining such knowledge is extremely time-consuming for staff, particularly for patient benefit advocates who are often responsible for enrollment assistance. In seven of the 10 States, interviewees also mentioned that eligibility workers should be provided training on programmatic issues specific to AI/AN eligibility. This suggestion particularly related to issues of asset determination and Trust lands, Medicaid estate recovery, cost-sharing exemptions, and ability of AI/AN enrollees to continue to use IHS providers after enrollment in Medicaid and SCHIP. In five States, interviewees also suggested that training of eligibility workers should include cultural issues

that are important to working effectively with AI/AN clients. In four States, interviewees suggested that training be provided to eligibility workers to increase their knowledge of AI/AN history, the Federal Trust Responsibility, and legal issues affecting AI/AN eligibility and enrollment in Medicaid and SCHIP.

- *Implement Additional Strategies for Eligibility Workers*. In addition to increased training for eligibility workers and others, interviewees in 7 of the 10 States said that it would be helpful if States would place eligibility workers on Reservations or in Urban Indian Health Clinics. This would address two major barriers: 1) transportation difficulties would be reduced; and 2) eligibility workers assigned to work on Reservations and in Urban Indian Health Clinics would have the opportunity to develop in-depth relationships and understanding of AI/AN culture, history, and eligibility issues that are unique to this population. Interviewees in three States put forth a related suggestion that States should make greater efforts to recruit and hire eligibility workers who are American Indians or Alaska Natives.

- *Simplify Application and Redetermination Processes*. In 8 of the 10 States, interviewees recommended that the application and redetermination processes for Medicaid, particularly, and SCHIP should be simplified and made less burdensome. In seven of the 10 States, interviewees suggested that redetermination should be required annually or even less frequently. These suggestions were consistent with the substantial majority of interviewees' perceptions that the complexity of the application/redetermination process, including attainment of supporting documentations, is a deterrent to enrollment in Medicaid and SCHIP.

- *Exempt AI/AN Enrollees from Managed Care Programs and from Program Fees/Cost-Sharing*. Interviewees in 4 of the 10 case study States suggested that special provisions to exempt all AI/AN enrollees from participation in managed care and waiving Medicaid program fees and cost-sharing requirements (as is the case for SCHIP) for AI/AN enrollees would encourage higher enrollment.

Suggested Strategies Directed to the Federal Government

Suggested strategies that would be the responsibility of the Federal government and its agencies include:

- *Improve Federal-Tribal-State Relationships*. Interviewees in 8 of the 10 case study States said that improving the Federal-Tribal-State government-to-government relationships would reduce barriers and facilitate enrollment of AI/AN people in public programs. This issue was related to interviewees' perceptions that Medicaid and SCHIP, particularly, place States in the middle of the Federal-Tribal relationship with respect to the Federal Trust Responsibility to provide health care to members of Federally Recognized Tribes. In seven of the 10 States, interviewees suggested that one way to address this problem was for the Federal government to make a Tribal Medicaid program option available. Since the Federal government pays 100 percent of the cost of Medicaid services provided within IHS/Tribal facilities, a Tribal Medicaid program would permit Tribes to have responsibility for program management, eligibility determination, and the provision of outreach and enrollment assistance to Tribal members. Interviewees in two States suggested that the Federal government should require

States to share administrative match funds with Tribes, which would then assume responsibility for outreach and enrollment assistance to Tribal members.

- *Fund Tribal and Urban Indian Health Clinic Outreach and Enrollment Assistance Programs*. In 7 of the 10 States, interviewees suggested that the Federal government should provide funds to Tribes and Urban Indian Health Clinics to conduct Tribal- or community-specific outreach and enrollment assistance activities for Medicaid, SCHIP, Medicare, and the Medicare Savings Programs. If such funding were available, Tribes and clinics could design and carry out culturally-effective outreach and would be able to hire Tribal or local community members with knowledge of cultural and other issues that are important to developing trusting and effective one-to-one relationships with AI/ANs eligible for public program enrollment.

- *Develop and Provide Medicare and SSDI Program Training to Tribal, IHS, and Urban Indian Health Clinic Staff*. Interviewees in 8 of the 10 case study States suggested that the Federal government should design and conduct training programs on the Medicare program and its benefits. In two of the 10 States, it was recommended that the Federal government develop programs to assist AI/AN people to understand and apply for SSDI as a means of obtaining Medicare enrollment. Interviewees generally stated that most Tribes, IHS, and Urban Indian Health Clinic staff lack sufficient knowledge of Medicare and SSDI to be able to provide useful assistance to AI/AN clients eligible for these programs.

- *Exempt AI/AN Enrollees from Premiums and Cost-Sharing Requirements*. Interviewees in 3 of the 10 States suggested that the Federal government exempt all members of Federally Recognized Tribes from paying premiums and cost-sharing when they are enrolled in Medicaid or Medicare. This exemption would be consistent with the Federal rule that exempts AI/AN SCHIP enrollees from cost-sharing, and would address the concerns that many AI/AN eligibles have about additional costs that may be associated with enrolling in Medicaid or Part B of Medicare.

- *Provide Cultural Competency Training to Federal Program Customer Service Staff*. In 2 of the 10 States, interviewees suggested that Federal customer service staff be provided cultural training so as to provide more effective service to AI/AN people who contact them for assistance.

- *Prohibit States from Internal Sharing of Medicaid and SCHIP Program Application Information.* In one State, interviewees specifically requested that Federal policy be changed to prohibit State Medicaid and SCHIP agencies from sharing Medicaid and SCHIP program application information with other State agency staff (e.g., child support enforcement, child welfare, foster care).

DIFFERENCES IN SUGGESTED STRATEGIES AMONG TRIBAL, STATE, AND URBAN INTERVIEWEES

Tribal, State, and Urban Indian Health Clinic interviewees differed in the frequency with which they made specific suggestions of strategies to reduce barriers to AI/AN enrollment in

Medicaid, SCHIP, Medicare, and the Medicare Savings Programs. Table 6 provides information on the proportion of interviewees who suggested individual strategies, by type of respondent.

Table 6: Suggested Medicaid, SCHIP, Medicare, and Medicare Savings Programs Strategies, by Respondent Type (for all 10 States)

Type of Interviewee	State		Tribal		Urban	
Total Interviewees	**10**	**Percent**	**22**	**Percent**	**9**	**Percent**
Strategies Related to Tribes/IHS/State Governments/Federal Government						
Funding for AI/AN-specific outreach/ enrollment assistance	6	60%	16	73%	6	67%
Targeted outreach/enrollment assistance funding directed to Tribes/Urban Indian Health Clinics	5	50%	13	59%	4	44%
Educational/marketing activities on program benefits to individuals and Tribes	6	60%	18	82%	4	44%
Develop Tribal-specific outreach and enrollment materials	3	30%	11	50%	4	44%
Strengthen Tribal/IHS incentives for enrollment	2	20%	7	32%	1	11%
Focused outreach and education to elders for Medicare Savings Programs	2	20%	8	36%	2	22%
Strategies Related to State Governments						
Develop collaborative working relationships among State-Tribes-IHS	5	50%	16	73%	4	44%
Simplify application/redetermination processes	1	10%	8	36%	3	33%
Improve Medicaid and SCHIP training for Tribal/IHS/Urban staff	2	20%	13	59%	4	44%
Improve eligibility worker program knowledge, focused on AI/AN issues	2	20%	7	32%	3	33%
Limit redetermination to annual or less frequent	3	30%	8	36%	2	22%
Out-station eligibility workers on Reservations	3	30%	9	41%	6	67%
Develop AI/AN cultural competency programs for State staff	0	0%	5	23%	1	11%
Educate eligibility workers on AI/AN history, Federal Trust Responsibility, and legal issues	1	10%	4	18%	0	0%
Exempt AI/AN enrollees from managed care enrollment/program fees/cost-sharing	3	30%	2	9%	1	11%
Recruit and hire AI/AN eligibility workers	1	10%	1	5%	2	22%

Table 6: Suggested Medicaid, SCHIP, Medicare, and Medicare Savings Programs Strategies, by Respondent Type (for all 10 States) (continued)

Type of Interviewee	State		Tribal		Urban	
Total Interviewees	**10**	**Percent**	**22**	**Percent**	**9**	**Percent**
Strategies Related to Federal Government						
Improve Medicare program training for Tribal/IHS/Urban staff	2	20%	9	41%	4	44%
Improve Federal-State-Tribal government-to-government relationships	2	20%	9	41%	2	22%
Develop Tribal Medicaid option	1	10%	5	23%	2	22%
Targeted outreach/enrollment assistance funding directed to Tribes/Urban Indian Health Clinics	4	40%	11	50%	4	44%
Exempt AI/AN Medicaid and Medicare enrollees from premium/cost-sharing	1	10%	3	14%	0	0%
Require States to share administrative match funds with Tribes	0	0%	2	9%	2	22%
Develop strategy to assist people to apply to SSDI	0	0%	1	5%	1	11%
Improve AI/AN cultural competency awareness of Federal staff	0	0%	2	9%	0	0%
Make program application information inaccessible to other State agencies	0	0%	2	9%	0	0%

Strategies Directed to All Involved Entities

The strategies directed to all involved entities – Tribes, IHS, State Governments, and the Federal government – focused on increasing funding for outreach and enrollment assistance, developing culturally-appropriate and Tribal-specific educational materials, and designing informational/ marketing programs to educate Tribal leaders and members on the benefits to individuals and to all Tribal members of increasing the number of AI/AN people enrolled in Medicaid, SCHIP, and Medicare.

While Tribal interviewees were more likely to mention each of these strategies than were State interviewees, a majority of State interviewees also suggested three of the five strategies and a smaller proportion suggested the remaining two strategies. Urban Indian Health Clinic interviewees were generally less likely than Tribal interviewees, but somewhat more likely than State interviewees, to suggest each strategy. The exceptions were that Urban interviewees were less likely than Tribes or the State interviewees to indicate it would be useful to fund Tribes to conduct Tribal-specific programs and less likely to suggest an educational/marketing program to increase awareness of the benefits to all Tribal members of increased enrollment in public programs. Urban Indian Health Clinics generally serve all AI/ANs in their area, without regard for Tribal affiliation and, as a result, may perceive the idea of providing funding to specific Tribes for outreach and educational programs as less beneficial to them.

Strategies Directed to States

With respect to specific strategies directed to States, Tribal interviewees were generally more likely to make these suggestions and State interviewees were less likely to make these

suggestions. Fifty percent of State interviewees, 73 percent of Tribal interviewees, and 44 percent of Urban Indian Health Clinic interviewees suggested that developing collaborative working relationships between States, Tribes, and the IHS would be helpful.

State interviewees were least likely to suggest that simplifying the application process would be useful, but were more likely to suggest that simplifying and limiting the redetermination process would be helpful than were Urban Clinic interviewees.

State interviewees were also least likely to suggest that increased training for State/County eligibility workers would be a useful strategy, while both Tribes and Urban interviewees were more likely to suggest these strategies.

Strategies Directed to the Federal Government

Forty percent of States, 50 percent of Tribes, and 44 percent of Urban Indian Health Clinic interviewees suggested that the Federal government provide funds directly to Tribes and Urban Indian Health Clinics to conduct outreach and provide enrollment assistance. Twenty percent of States and more than 40 percent of Tribes and Urban Indian Health Clinic interviewees also suggested that the Federal government develop and provide training on Medicare for Tribal, IHS, and Urban Indian Health Clinic staff. Twenty percent of States, 41 percent of Tribal, and 22 percent of Urban Indian Health Clinic interviewees additionally suggested improving Federal-Tribal-State relationships.

At least one interviewee in 7 of the 10 States suggested that a Tribal Medicaid Program strategy be developed (Table 5). However, it was more likely to be mentioned as a useful strategy by Tribal and Urban Indian Health Clinic interviewees (about 23 percent) and less likely by State interviewees (10 percent).

No State interviewees suggested that States should be required to share administrative matching funds with the Tribes, that the Federal government implement a program to assist with applications for SSDI, or that training in cultural issues should be provided to Federal employees who work with AI/AN people.

DISCUSSION

The greatest agreement among Tribal, State, and Urban Indian Health Clinic interviewees was that more outreach and application assistance tailored to the AI/AN population would be a useful strategy to reduce barriers and facilitate enrollment in Medicaid, SCHIP, and Medicare. There was considerably less agreement among Tribes, State agencies, and Urban Indian Health Clinic interviewees about the need for more training for State/County eligibility workers and for the simplification of Medicaid and SCHIP application processes, with most Tribes and Urban Clinic interviewees stating that these strategies were needed and few State agencies' interviewees suggesting these strategies. State Medicaid and SCHIP interviewees were also less likely than Tribal and Urban interviewees to make suggestions about strategies that the Federal government might undertake to increase enrollment in these programs.

DISCUSSION

The information and findings presented in this report provide interesting and useful insights into the perceptions of Tribal, State, IHS, Urban Indian Health Clinic, and other organizational interviewees in the 10 States that received site visits. More than 300 people participated in the group and individual interviews conducted with staff from Medicaid, SCHIP, and Tribal liaison agencies, 22 Federally Recognized AI/AN Tribes or Tribal organizations, 9 Urban Indian Health Clinics, and 10 other organizations involved in AI/AN health and public program enrollment.

AI/ANs have a unique relationship with the Federal government through treaties, statutes, executive orders, and case law that designate Tribes as quasi-sovereign (or sovereign dependent) nations within the U.S. These treaties, statues, orders, and law also establish a Federal Trust Responsibility that includes provisions that the Federal government will provide health care and other support and assistance to members of Federally Recognized Tribes. The Federal responsibility for AI/AN health care is addressed through funding of the Indian Health Service, which provides direct services to AI/ANs through funding of Tribal- or IHS-operated health facilities. In addition, a limited amount of funding is provided to support Urban Indian Health Clinics. Enrollment of eligible AI/ANs into Medicaid, SCHIP, and Medicare supplements the IHS funds and permits more services to be provided to a larger number of AI/ANs.

Interviewees identified a number of issues unique to AI/ANs that serve as barriers to enrollment in Medicaid, SCHIP, and Medicare. These include the relationship between the Federal government and Federally Recognized Tribes that may include Federal provision of health care and other services to members of these Tribes, and Tribal sovereignty issues that affects Federal-Tribal-State government-to-government relationships. The historical experiences of Tribes with Federal and State governments appear to have resulted in a degree of mistrust that affects the willingness of some AI/ANs to apply for enrollment in Federal- and State-sponsored health programs. Additionally, in many cases Tribal leaders and Tribal members perceive that the Federal Trust Responsibility to provide health care to the Tribes means that Tribal members should not need to apply for assistance through Medicaid, SCHIP, or Medicare. Many interviewees also Stated that the fact that IHS services are available for routine primary and preventive care and some referral services for serious illnesses causes some AI/ANs to question the need to enroll in these programs. However, the IHS operates on an annual budget that has been set at levels that are insufficient to provide adequate services to meet the needs of the AI/AN population. Contract Health Services – services that cannot be provided and must be referred out to private providers – are particularly a problem for IHS- and Tribally managed health facilities to provide. The available funds for Contract Health Services is often depleted well before the end of the fiscal year and, as a result, AI/AN people may not receive these services at all or may face long delays in obtaining care unless their condition is immediately life-threatening. A number of interviewees suggested that Tribal leaders and Tribal members frequently are not aware of how increased public program enrollment might benefit the entire Tribe by providing additional third-party Medicare, Medicaid, and SCHIP revenues to IHS- and Tribally managed health facilities, thus making more services available to all Tribal members.

In addition to these barriers that are unique to AI/AN populations, interviewees identified other barriers that included: lack of awareness about the existence of the programs (particularly

SCHIP and the Medicare Savings Programs); limited knowledge of benefits and eligibility criteria for all of the programs; transportation barriers; language and literacy barriers; complexity of application and redetermination processes; and cultural barriers. Because a high proportion of AI/ANs resides in rural areas on Reservations with high poverty rates and low educational levels, these barriers may be substantial deterrents to enrollment.

This study was not able to quantify the magnitude of the impact of specific barriers on enrollment rates. As a result, it is only possible to speculate which barriers are likely to have a significant impact on enrollment. The concentration of the AI/AN population in rural areas does suggest that transportation barriers may be substantial given long travel distances, lack of reliable personal transportation, limited access to public transportation to reach County or State eligibility offices, and the poor conditions of Reservation roads. In addition, outreach, education, and enrollment assistance has been found to be a much greater challenge in remote areas that require outreach/enrollment workers to travel long distances to reach clients and where televisions, radio stations, and newspapers are less available than in urban areas. The large number of different languages spoken by AI/ANs may also be a greater barrier to providing appropriate outreach and education. Many AI/AN languages are spoken languages only, requiring the use of non-written communication modes such as television, radio, and videotapes to effectively reach some people.

Strategies suggested by interviewees to reduce barriers and to facilitate AI/AN enrollment in Medicaid, SCHIP, and Medicare were strongly focused on increased culturally-appropriate outreach and education materials and activities, and providing one-to-one assistance with application and redetermination processes. Many interviewees recommended that State governments and/or Federal government provide training to Tribal, IHS, and Urban Indian Health Clinic staff on Medicaid, SCHIP, and Medicare benefits, eligibility requirements, and application processes so they can better provide the one-to-one assistance needed. In addition, many interviewees suggested that simplifying the application process and making redetermination less frequent would be useful strategies. A number of interviewees also suggested that State/County eligibility workers – and Social Security Administration (SSA) employees who work with Medicare and Social Security Retirement and Survivor's Benefits, SSDI, and, Supplemental Security Income (SSI) application processes – be given more training on program and eligibility determination issues and on AI/AN history and legal issues that affect eligibility determination. Cross-training of these eligibility workers is also important because most AI/ANs do not consider CMS programs separately from SSA programs; eligibility workers need to be knowledgeable about both agencies' programs. In addition, some interviewees also suggested training for eligibility workers to increase cultural awareness.

Several interviewees proposed additional strategies that address unique issues for the AI/AN population. A number of interviewees suggested that the Federal government provide funding to Tribes and Urban Indian Health Clinics to develop and implement locally-directed and AI/AN-specific outreach and enrollment assistance programs, either directly or through requiring that States provide a share of Medicaid and SCHIP administrative match funds to Tribes for this purpose. Some interviewees suggested that the Federal government establish a Tribal Medicaid option that would permit Tribes to manage their own Medicaid programs and determine eligibility for Tribal members. Several interviewees from Tribal, State, and Urban Indian Health Clinics also suggested that developing processes to improve Federal-Tribal-State

government-to-government relationships would be useful for reducing barriers and facilitating enrollment in these programs.

- Limitations of this study may affect the validity of the findings and the extent to which they can be generalized to all AI/AN populations in the same or different States (described above). These include:

- Individual interviewees expressed their views and perceptions, based on their own experiences and situations. The project team did not conduct an independent validation of these views and perceptions and, therefore, the interview findings may be based on inaccurate information and/or limited experiences that may not be generalizable.

- Information was obtained in only 10 States and, while these States have large AI/AN populations, the findings may not be generalizable to other States that may have different characteristics and AI/AN populations.

- Detailed information was obtained from only 22 Federally Recognized AI/AN entities or organizations across the 10 States, which does not encompass all Tribes in these States.20 Thus, although the findings may reflect the characteristics and experiences of the Tribes/Reservations interviewed, they may not necessarily extend to other Tribes with different cultures, histories, and experiences that were not interviewed.

- At the time the site visits for this project were conducted, many States were experiencing budget shortfalls that were causing State governments to consider or institute cutbacks in Medicaid and SCHIP program benefits and/or outreach funds. The changes that were being contemplated may have affected the perceptions of Tribal and State interviewees about barriers to enrollment in these programs and strategies to increase AI/AN enrollment. The study findings might well be different if the site visits had been conducted during a period of economic expansion and State budget surpluses.

However, the extensive number of individuals who participated in the interviews conducted in the 10 States (more than 300 individuals), and the comprehensive review process for the individual State case study reports undertaken for this project, suggest that this study can provide a basis for developing and testing strategies that may be successful in reducing barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare.

The specific strategies that have been suggested by participants in this study are wide-ranging, from relatively narrow, targeted strategies (e.g., provide more training on program eligibility criteria to State/County eligibility workers) to strategies that would require substantial changes in Federal and State policy (e.g., develop a Tribal Medicaid option). The feasibility of specific strategies has not been assessed in this study. However, it would be necessary to consider feasibility in considering and choosing specific strategies that might be implemented. The most important feasibility considerations are: 1) the cost of the strategy, if extended to all

[20] Additional information was obtained from a larger number of Tribes through meetings with Indian Health Boards and input from TEP members and project consultants. This information, however, was more general and less detailed in nature than that obtained through visits or follow-up telephone interviews with individual Tribes.

AI/AN populations; and 2) the political issues that would need to be addressed to implement the strategy.

With current Federal, State, and Tribal budget constraints, some strategies might require more resources relative to the benefits obtained than are considered reasonable. Similarly, strategies that would require Congress to act before they could be implemented and/or that would require negotiations between the Federal government, States, and Tribes (such as a Tribal Medicaid option) could take many years to develop and implement. These considerations should be assessed in order to determine whether the strategies identified in this study might be developed and implemented to reduce barriers and increase AI/AN enrollment in the Medicaid, SCHIP, and Medicare programs. Additionally, alternative ways to fund these strategies could be pursued. For example, CMS might consider using Department of Health and Human Services' education and outreach-targeted funds for reducing health care disparities among racial and ethnic minority populations to fund oral translation of educational materials into Native American languages, which are primarily spoken rather than written. Furthermore, ways to reduce strategy development and implementation costs could also be pursued. For example, CMS might consider using existing initiatives involving Tribal colleges and universities to help develop culturally-appropriate educational materials, at lower cost than might be obtainable through marketing firms.

REFERENCES

Baca, R. "A Voice for Indian Elders." *The IHS Provider*, May 1998, pp 62-66.

Bird, M., Bowekaty, M., Burhansstipanov, L., Cochran, P.L., Everingham, P.J., and Suina, M. *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives*, 2002.

Cox, D., Langwell, K., Topoleski, C., and Green, J.H. *Sources of Financing and the Level of Health Spending for Native Americans*. Prepared by Barents Group LLC for The Henry J. Kaiser Family Foundation, October1999.

Elder Voices. *Developing an Educational Outreach Strategy For Indian Communities*. Prepared by Elder Voices, January 2001.

Forquera, R. *Urban Indian Health*. Prepared by The Seattle Indian Health Board for The Henry J. Kaiser Family Foundation, November 2001.

Indian Health Service, Office of Public Health, Department of Health and Human Services. *Trends in Indian Health*, 1989-1999. Obtained from the Indian Health Service Internet website, http://www.ihs.gov/PublicInfo/Publications/trends98/.

Kauffman, J.A. *Reauthorization of the Indian Health Care Improvement Act: Background and Issues*. Prepared by Kauffman and Associates, Inc. for The Henry J. Kaiser Family Foundation, October 1999.

Kauffman, J.A., Hansen, P., and Paternoster, V. *Into the Future: Indian Health, Medicaid, Managed Care & SCHIP*. Prepared by the National Indian Health Board for the Indian Health Service and the Centers for Medicaid and Medicare Services, December 2001.

Klerman, L. "Nonfinancial Barriers to the Receipt of Medical Care". *The Future of Children*, Winter 1992, pp.171-183.

Lado, M.E., Reyes, L., and Casini, S. *New York Lawyers for the Public Interest's Ombuds Project Medicare Savings Program*. Prepared by the New York Lawyers for the Public Interest, Inc., November 2000.

National Indian Council on Aging. *PRO-West Vulnerable Populations Project: Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations; American Indian and Eskimo Populations in the States of Washington, Idaho, and Alaska Study*, 1999.

National Indian Health Board. *Tribal Perspectives on Indian Self-Determination and Self-Governance in Health Care Management (Executive Summary)*, 1998.

Native American Indian: Art, Culture, Education, History, and Science. *Maps: GIS Windows on Native Lands, Current Places, and History*, Undated. Obtained from Internet website, http://www.kstrom.net/isk/maps/Tribesnonrec.html.

Schneider, A. and Martinez, J. *Native Americans and Medicaid: Coverage and Financing Issues.* Prepared by The Center on Budget and Policy Priorities for The Kaiser Commission on the Future of Medicaid, December 1997.

State of Washington Medical Assistance Administration (with the Washington Dual Outreach Coalition). *Building Partnerships for Innovative Outreach and Enrollment of Dual Eligibles: A Statewide Outreach Coalition's Use of an Enhanced Community Identification (CID) Strategy to Increase Dual Eligible Enrollment*, July 2000.

The Robert Wood Johnson Foundation. *Covering Kids Communications Kit: Reaching American Indian and Alaska Native Families*, August 2001.

The UCLA Center for Health Policy Research and The Henry J. Kaiser Family Foundation. *Racial and Ethnic Disparities in Access to Health Insurance and Health Care*, April 2000.

Wellever, A., Hill, G., and Casey, M. "Commentary: Medicaid Reform Issues Affecting the Indian Health Care System". *American Journal of Public Health*, February 1998, pp.193-195.

Wolff, E.G.C. and Marx, K.E. "The Indian Health Service and Medicaid Reform: The Issues Surrounding 1115 Waivers and the Reauthorization of the Indian Health Care Improvement Act". *The IHS Primary Care Provider*, March 1999, pp.33-38.

APPENDIX A: TEP MEMBERS AND PROJECT CONSULTANTS

TEP Members		
Name	**Organization**	**State**
Jim Crouch	California Rural Indian Health Board	California
Mim Dixon	Mim Dixon & Associates	Colorado
Pamela Iron	National Indian Women's Health Resource Center	Oklahoma
Spero Manson	Division of American Indian and Alaska Native Programs, University of Colorado Health Sciences Center	Colorado
Beverly Russell	National Council of Urban Indian Health	Washington, DC
Nancy Weller	National Association of State Medicaid Directors Tribal Work Group; Alaska Dept. of Health and Social Services	Alaska
Laura Williams	Association of American Indian Physicians	California
Jonathan Windy Boy	Montana/Wyoming Tribal Leaders Council	Montana
Julia Ysaguirre	Native American Program Coordinator, Arizona Health Care Cost Containment System/KidsCare	Arizona

Project Consultants		
Name	**Organization**	**State**
Rebecca Baca	Elder Voices	New Mexico
David Baldridge	National Indian Project Center (formerly with the National Indian Council on Aging)	New Mexico
Ralph Forquera	Seattle Indian Health Board	Washington
Carole Anne Heart	Aberdeen Area Tribal Chairmen's Health Board	South Dakota
Jo Ann Kauffman	Kauffman & Associates	Washington
Frank Ryan	I&M Technologies	Maryland

APPENDIX B: TRIBES, URBAN INDIAN HEALTH CLINICS, AND OTHER ORGANIZATIONS INTERVIEWED

Alaska

Alaska Native Health Board
Alaska Native Medical Center
Alaska Native Tribal Health Consortium
Alaska Native Tribal Health Directors
Denali Kid Care
Kasigluk Health Clinic
Southcentral Foundation
State of Alaska, Department of Administration, Division of Senior Services
State of Alaska, Division of Medical Assistance (Medicaid and SCHIP), State Federal and Tribal Relations
Yukon Delta Regional Hospital
Yukon-Kuskokwim Health Corporation

Arizona

Inter Tribal Council of Arizona
Navajo Area IHS (Area Office and Chinle, Fort Defiance, Kayenta, Tuba City, and Winslow Service Units)
Navajo Nation Division of Health
Navajo SHIP
Phoenix Indian Medical Center
State of Arizona, Arizona Health Care Cost Containment System (AHCCCS)/KidsCare (Medicaid and SCHIP)
Tucson IHS Area (Area Office and San Xavier Health Center, Sells Hospital, and Pascua Yaqui Health Program)
Tucson Indian Center

Michigan

American Indian Health & Family Services of South East Michigan
Covering Michigan's Kids (Robert Wood Johnson Pilot Program)
Grand Traverse Band of Ottawa/Chippewa
Inter-Tribal Council of Michigan
Sault Ste. Marie Health & Human Services
State of Michigan, Department of Community Health (Medicaid and SCHIP)

Minnesota

Bemidji IHS Area Office
Elder's Advocate, Leech Lake Elders Division
Elders Lodge, St. Paul
Fond du Lac Band of Ojibwe
Great Lakes Inter-Tribal Epidemiological Center
Hennepin County Medical Center
Mille Lacs Band of Ojibwe
Minneapolis Indian Health Board
Senior Linkage Line and Health Insurance Counseling, Metropolitan Area Agency on Aging
State of Minnesota, Board on Aging Indian Elder Desk; Wisdom Steps Coordinator
State of Minnesota, Department of Human Services (Medicaid and SCHIP)

Montana

Billings IHS Area Office
Chippewa-Cree Tribe of the Rocky Boy's Reservation
Crow Reservation
Fort Belknap Reservation
Great Falls Indian Family Health Clinic
Indian Health Board of Billings
Montana/Wyoming Tribal Leaders Council
State of Montana, CHIP Office (SCHIP)
State of Montana, Human and County Services Division (Medicaid)

North Dakota

Family Health Care Center
North Dakota Indian Affairs Commission
Northland Health Care Alliance
State of North Dakota, Department of Human Services (Medicaid)
State of North Dakota, Healthy Steps (SCHIP)
State of North Dakota, several County Social Services Directors
Trenton Indian Service Area
Turtle Mountain Reservation

Oklahoma

Cherokee Nation
Chickasaw Nation Carl Albert Indian Hospital
Choctaw Nation Health Service Authority
Citizen Potawatomi Nation Health Center
Covering Kids, Oklahoma (Robert Wood Johnson Pilot Program)
Indian Health Care Resource Center of Tulsa
Lawton Area Health Board
Lawton IHS Service Unit
Oklahoma Health Care Authority (Medicaid and SCHIP)
Tahlequah IHS Service Unit

South Dakota

Crow Creek Reservation
Native Women's Health Center
Rosebud Sioux Reservation
Sioux San Indian Health Service Hospital
South Dakota Urban Indian Health, Inc.
State of South Dakota, Department of Social Services (Medicaid and SCHIP)
State of South Dakota, Eligibility Office

Utah

Fort Duchesne IHS Service Unit
State of Utah, Department of Health (Medicaid and SCHIP)
Utah Indian Health Board
Utah Indian Walk-In Center
Uintah-Ouray Reservation

Washington

CMS Regional Office X
Covering Washington's Kids (Robert Wood Johnson Pilot Program)
Lummi Nation
Seattle Indian Health Board
State of Washington, Department of Social and Health Services (Medicaid and SCHIP)
Yakama Nation
Yakama PHS Indian Health Center

APPENDIX C: INTERVIEW GUIDE

Issues for Site Visit Interviews

1. Are there AI/AN people here who are eligible for enrollment in Medicare, Medicaid, or SCHIP who are not enrolled?
   a. Is under-enrollment in Medicare a serious problem?
   b. Is under-enrollment in Medicaid a serious problem?
   c. Is under-enrollment in SCHIP a serious problem?
   d. Is under-enrollment of people who are QMBY/SLMBY-eligible a serious problem?
2. Do you think that most people who are eligible know about the programs?
3. What are reasons that people might not want to enroll in Medicare, Medicaid, or SCHIP?
4. Are there ways that information about the programs could be provided that would be more helpful to people who may be eligible?
5. Do you know people who have tried to enroll in Medicare, Medicaid, or SCHIP who have had problems? What types of problems do most people have?
6. Are there people who have difficulties with re-enrollment/verification processes? What types of problems do people have?
7. Are there any special programs or assistance here to help people enroll in Medicare, Medicaid, and SCHIP?
   a. Outreach/education about the programs?
   b. Help with paperwork for enrollment?
   c. Legal assistance?
   d. Transportation/child care assistance?
   e. Benefits counselors or CHRs who help people enroll?
   f. Other programs?
   g. Who runs these programs?
8. How long have these programs or special assistance been operating? Do you think they've been effective in increasing enrollment?
9. Does your State help people to enroll in Medicaid or SCHIP?
10. What do you think should be done to help more people who are eligible to enroll in these programs?