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

FINAL REPORT

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ACKNOWLEDGMENTS

DISCLAIMER

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EXECUTIVE SUMMARY

BACKGROUND

Health disparities between American Indians and Alaska Natives (AI/ANs) and the majority population in the United States are substantial and persistent. The Federal government provides health services to AI/ANs through the Indian Health Service (IHS), tribally managed health facilities, and Urban Indian health clinics (the "I/T/U" system). However, funding for these services has been limited and insufficient to meet all health care needs. Medicaid, State Children's Health Insurance Program (SCHIP), and Medicare revenues for services provided to AI/ANs who are enrolled in these programs may make it possible to augment services and expand access to health care for all AI/ANs who receive care through I/T/U facilities. However, there is little information available on the extent to which eligible AI/ANs are enrolled in Medicaid, SCHIP, and Medicare. Information on unique barriers to enrollment that may exist and on effective strategies that might be implemented to facilitate enrollment of AI/ANs into these programs is also limited.

OVERVIEW OF STUDY

In September 2001, the Centers for Medicare & Medicaid Services (CMS) funded a two-year study to examine barriers to enrollment of AI/ANs in Medicaid, SCHIP, and Medicare (including the Medicare Savings Programs)[2] and to identify strategies that may be effective for increasing AI/AN enrollment into 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.

This Final Report on AI/AN Eligibility and Enrollment in Medicaid, SCHIP, and Medicare presents the findings of the study.

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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

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

ELIGIBILITY AND ENROLLMENT ESTIMATIONS

The original objective of the quantitative component of this project was to develop estimates of AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare and to estimate the ratio of enrollment to eligibility by State and sub-State areas. However, significant data limitations were identified during the project and, as a result, the analysis conducted was primarily methodological to illustrate the effects of data and other issues that affect the feasibility of estimating AI/AN eligibility and enrollment in these programs.

The assessment of the feasibility of producing reliable estimates of AI/AN eligibility and enrollment focused on 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. Data availability and methods for developing AI/AN eligibility and enrollment estimates at the State level were examined for each of these 15 States, and analyses were conducted to produce best estimates of AI/AN eligibility and enrollment in the programs of interest and to assess the feasibility and limitations of these estimates. This report presents the results of the examination of data availability, methodological issues, and exploration of the feasibility of developing reliable estimates of the number of AI/ANs eligible for and enrolled in Medicaid, SCHIP, and Medicare.

Limitations of the Data

There are significant issues that affect the reliability and usefulness of the estimates of AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare. These include:

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

- The available data sources for these estimates are for different periods. This required that some data sources be projected or interpolated to a standard year. Again, the reliance on projections and interpolations introduces some degree of uncertainty as to the reliability of the estimates.

- The administrative data used to estimate AI/AN enrollment in Medicaid required a number of assumptions to be made in order to generate estimates. Estimates vary depending on the specific assumptions made and, therefore, have some inherent uncertainty that may affect the stability and reliability of the estimates.

- In addition, during the project, it was determined that the timeframe of the available data for SCHIP programs for most States was concurrent with start-up marketing and enrollment into the SCHIP program. Because of the data limitations and the timeframe problems, CMS decided not to present results of the SCHIP eligibility and enrollment analyses. Similarly, based on our analysis, CMS determined that it was not feasible to conduct sub-State analyses of AI/AN eligibility and enrollment into these programs. Reasons for this decision included the data issues described above, combined with the fact that Census data are not available for areas with small populations due to privacy requirements and inability to link Census ZIPCODE and County level data precisely to Reservation areas. Other program issues that arose included a lack of data to estimate eligibility for Medicaid medically needy programs, and limited and inadequate data to develop reliable estimates of AI/AN eligibility for disabled persons enrolled in the Medicare program.

Results of the estimations of eligibility and enrollment, and of the ratio of estimated AI/AN enrollment to estimated AI/AN eligibility, illustrate the substantial data problems discussed above. Although estimates can be made of the number of AI/ANs who are eligible for Medicaid, SCHIP, and Medicare, and estimates can be made of the number of AI/ANs who are enrolled in these programs, the ratio of enrollment to eligibility varies widely across definitions of AI/AN population. This is primarily a result of using self-reported Census data for the estimation of eligibility and the issue of definition of the AI/AN population as AI/AN only or as AI/AN only or in combination with other race(s), while estimates of enrollment in these programs are based on data that reports only primary race of enrollees. All of the data issues together resulted in a high degree of uncertainty and a low level of confidence in the separate estimates of AI/AN eligibility and AI/AN enrollment in Medicaid, SCHIP, and Medicare. Combining the eligibility and enrollment estimates in order to examine the extent of under-enrollment in each program by State (i.e., the "take-up rate") was even more problematic, given the low level of confidence in the individual eligibility and enrollment estimates. Examination of the take-up rates in the illustrative analyses indicates wide variation in results, depending on definitions of the AI/AN population used to generate eligibility estimates and other varying assumptions.

Alternative Approaches to Developing Estimates of AI/AN Eligibility and Enrollment

Problems with existing data sets that could be used to estimate AI/AN eligibility for Medicaid, SCHIP, and Medicare include a lack of precise data to identify respondents as members of Federally Recognized Tribes, members of non-Federally Recognized Tribes, and those who have some AI/AN heritage and maintain cultural and social ties to AI/AN communities. It might be possible to develop standard survey questions that could be used in all Federally funded surveys that would permit more precise identification of AI/AN race and group identification. If so, then future estimations of AI/AN eligibility could be improved. The second significant problem with existing data sets, with the exception of Census data, is that sample sizes are generally not large enough to produce sufficient numbers of AI/AN respondents to

permit analyses that focus on subgroups of the AI/AN population and urban, rural, and Reservation level analyses to be conducted. Substantial expansion of survey sample sizes would be necessary to obtain the larger AI/AN samples that would permit the estimation of AI/AN eligibility for Medicaid, SCHIP, and Medicare for alternative AI/AN subgroups and for State and sub-State geographic units.

Given these limitations and the small likelihood that existing surveys could easily be modified to permit the desired analyses to be conducted, we identified two alternative approaches that were discussed with CMS that could provide more reliable information as to whether there is AI/AN program under-enrollment: 1) new data collection, or 2) meta-analysis of existing survey data sources.

New Data Collection

First, if the definition of the AI/AN population were narrowed to include only members of Federally Recognized Tribes, it might be feasible to undertake new data collection based on Tribal enrollment lists obtained from either individual Tribes or from the Bureau of Indian Affairs. This survey could be limited to a sample of those who live on or near Reservations, using methods similar to those employed to conduct the 1989 National Medical Expenditure Survey (NMES) Survey of American Indians and Alaska Natives (SAIAN). If Tribes were willing to provide the survey sample frame from Tribal enrollment lists, which include addresses of all enrolled members, it might be feasible to survey members of Federally Recognized Tribes living both on or near and off-Reservations in urban or non-urban areas. A similar approach could be used to survey members of Tribes who are not Federally Recognized, to the extent that these Tribes maintain Tribal enrollment lists with names and addresses. However, any approach that relies on Tribal agreement to provide sample frames from Tribal enrollment lists would likely require extensive negotiation to obtain approval of the survey participation with each Tribe – a potentially lengthy and resource-intensive process. Other approaches to a survey of members of Federally Recognized or non-Federally Recognized Tribes that included non-Reservation areas would be substantially more expensive because of the small size of the target population, although there might be some approaches that would be less resource intensive that would build on on-going data collection efforts.

Meta-Analysis of Existing Survey Data

A more feasible and less costly approach would be a meta-analysis of existing survey data. Such an analysis could provide aggregate estimates for the 15 study states of the enrollment/eligibility ratio (or take-up rate). There are at least three national survey databases that would be useful in such an endeavor – the Current Population Survey (CPS), the Survey of Income and Program Participation (SIPP), and the National Health Interview Survey (NHIS). [5] One of the advantages of using these survey data over Census or administrative program data is that the race coding relies on self-reports in the context of an in-person interview so that it is less likely to be "missing" or coded as "other." In addition, most of the national health surveys obtain

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[5] One could also consider use of the National Survey of America's Families (NSAF), the Medical Expenditure Panel Survey (MEPS), the Survey of Program Dynamics (SPD), and the Health and Retirement Survey.

data on program enrollment, as well as a wide array of data on income and assets, family structure, and work history that is needed to estimate eligibility for the three programs in which CMS is interested.

The most obvious limitation of these survey data sets is their sample sizes for AI/ANs. Preliminary tabulations of the March 2001 CPS indicate there are 462 sample AI/AN children aged 17 and under in the 15 study States and 93 sample AI/ANs age 65 and over in these States. (This is without the expanded sample that has been fielded specifically to enable studies of SCHIP enrollment.) NHIS has the same approximate total sample sizes and the yield of AI/ANs should be roughly comparable, although it is difficult to predict this precisely given the different sample design used for the two surveys. SIPP sample sizes would be somewhat lower, but – given the availability of certain data items (e.g., assets) – it would be worth exploring. These numbers are sufficient for estimating the percentage of persons eligible for each of the three programs for the 15 study States as a group. While the numbers are not large, using three different data sets to conduct the analysis would allow increased confidence in the findings. Depending on sample sizes, some States might have to be combined for purposes of estimation.

Discussion of the Feasibility of Estimating AI/AN Eligibility and Enrollment

The objectives, methodologies, and results reported in this study illustrate the complexity and difficulties associated with estimating AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare. Lack of data sources that are comparable and consistent for estimating eligibility and enrollment are a major deterrent to producing reliable and valid estimates. In addition, the issue of alternative definitions of the AI/AN population in available data sources compounds the difficulties of estimation. The alternative strategies that might be considered for future research efforts include new data collection or attempts to use meta-analysis of existing survey data that potentially provide more consistent and comparable measures of program eligibility measures and program enrollment. However, designing and conducting a new survey would be a lengthy and costly process. Alternatively, conducting meta-analyses of data available from existing surveys might improve estimates, but would likely only be able to produce estimates for multi-State areas or at a national level, due to the small AI/AN population. This aggregation would limit the usefulness of the results and would not permit identification of States or sub-State areas where under-enrollment may be a substantial issue.

However, the analysis could provide more reliable estimates of AI/AN eligibility, enrollment, and the ratio of enrollment to eligibility at the national level that could be useful in assessing the extent to which under-enrollment exists, by program, and the characteristics of AI/ANs who are eligible but not enrolled. This information could provide a better foundation for designing programs that target specific segments of the AI/AN population for outreach and assistance.

CASE STUDIES

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. 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 and access issues. Individual case study reports were prepared for each State following the site visits and follow-up telephone interviews. The information in those reports has been analyzed and is summarized in a separate Summary Case Study Report.

Case Study 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 identify potential strategies that might be effective in 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 Medicaid, SCHIP, and Medicare?

- 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/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). [6]

- An Urban Indian Health Clinic. [7]

- State Medicaid, SCHIP, and other State agency staff 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.

Case Study 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 depleted well before the end of the fiscal year and, as a result, AI/AN people may not receive

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[6] 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 Technical Expert Panel members who felt that the study would benefit from extending the site visit to include several Tribes/Reservations in specific States
[7] North Dakota does not have an Urban Indian Health Clinic.

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 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 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. [8] Several interviewees from Tribal, State, and Urban

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[8] A logical extension of this suggestion would be to extend the 100 percent Federal medical 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).

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 Federal government 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 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 Case Study Approach 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. [9] 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.

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[9] 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 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.

These considerations and others would need to be assessed in order to determine whether the strategies identified by interviewees might be developed and implemented to reduce barriers and increase AI/AN enrollment in Medicaid, SCHIP, and Medicare.

SUMMARY AND DISCUSSION

The objectives of this study were to: 1) to estimate the number of AI/ANs who are eligible for and enrolled in Medicaid, SCHIP, and Medicare and to determine whether, and to what extent, under-enrollment is observed for this population, and 2) obtain information on unique and general barriers that affect AI/AN enrollment in these programs and on strategies that could be effective to facilitate and increase AI/AN program enrollment.

Due to significant limitations of currently available data, the study's findings suggest that it is not possible to reliably estimate AI/AN eligibility, enrollment, and take-up rates for the

Medicaid, SCHIP, and Medicare programs. Census 2000 provides the only complete and consistent data source for estimating eligibility for these programs for people who identify their race as AI/AN. However, the 2000 Census – for the first time – added questions that permit people to identify themselves with multiple races. The 1990 Census, which did not permit multiple race identification, indicated that there were less than 2 million AI/ANs. The 2000 Census reports over 4 million AI/ANs, either identifying as AI/AN race only (2.5 million) or in combination with other races (over 1.5 million). [10] Thus, between 1990 and 2000, the Census finds a 110 percent increase in the number of AI/ANs counted, compared with a 13 percent increase in the total United States (U.S.) population. This dramatic increase suggests that a substantial number of people may be reporting AI/AN race in 2000 that did not identify AI/AN as their primary race in 1990.

The data available to estimate AI/AN enrollment in Medicaid, SCHIP, and Medicare, by contrast, include only primary racial identifications. This difference in data sources results in inconsistent and unreliable estimates of the take-up rate (calculated as the estimated number of AI/ANs enrolled in specific programs divided by the estimated number of AI/ANs eligible for enrollment). These problems are exacerbated when estimates of eligibility and enrollment are made at the State and sub-State levels, due to small population numbers in most rural areas.

More reliable estimates of eligibility and enrollment at the national or State level would require additional targeted data collection, possibly focused on specific AI/AN population definitions (e.g., only enrolled members of Federally Recognized Tribes). The costs of such a data collection effort would likely be quite high. An alternative would be to conduct meta-analysis of existing survey data to produce estimates of eligibility and enrollment of AI/ANs. Sample sizes of various potential data sources would limit these estimates to national levels, however.

The second component of this study was designed to obtain insights and information from a wide variety of people through case studies of 10 States to understand barriers to AI/AN enrollment in Medicaid, SCHIP, and Medicare and effective strategies to reduce such barriers. The individuals interviewed included representatives from Tribes, Indian Health Service Areas and Service Units, Urban Indian Health Clinics, and State Medicaid and SCHIP offices. Results of these interviews provided useful information on perceived barriers to enrollment in each program and identified strategies that could facilitate AI/AN enrollment in Medicaid, SCHIP, and Medicare. The most often identified strategies emphasized increased outreach, education, and one-to-one assistance with enrollment, as well as greater involvement and direct funding for Tribes, Tribal organizations, and Urban Indian Health Clinics to undertake these activities.

AI/ANs face many challenges that contribute to their documented poor health status. Although financial barriers to accessing health care are only one of these challenges, enrollment in Medicaid, SCHIP, and Medicare for those who are eligible offers the potential to increase access to health services by expanding revenues available to the IHS and Tribally managed health facilities, as well as increasing financial access to health services for AI/ANs who do not

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[10] See: Ogunwole, Stella, The American Indian and Alaska Native Population: 2000, Census 2000 Brief. U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau Washington, DC: Issued February 2002.

use IHS or Tribally managed health facilities. Results of this study provide information and strategies that, if implemented, may increase AI/AN enrollment in these programs.

BACKGROUND AND PURPOSE OF STUDY

BACKGROUND

Health disparities between AI/ANs and the majority U.S. population are substantial and have been particularly resistant to improvement. A recent Centers for Disease Control and Prevention (CDC) report on trends in racial and ethnic rates for Healthy People 2000 health status indicators (HSIs) between 1990 and 1998 concluded:

> "The findings concerning American Indian and Alaska Natives stood out for six of the HSIs. Between 1990 and 1998, the lung cancer death rate for American Indian or Alaska Natives increased by 28 percent, the percent of low birth weight infants increased by 11 percent, the suicide death rate increased by 8 percent, the total death rate and the breast cancer death rate each increased by 4 percent, and the stroke death rate increased by 3 percent. While the changes in the suicide, breast cancer, and stroke death rates were not statistically significant, American Indians or Alaska Natives do not appear to have experienced the same improvements in these indicators as the other racial/ethnic groups experienced. While there may be alternative explanations for these findings, such as improvement in the identification of native peoples during this period, further investigation is needed." [11]

The poor health status of the AI/AN population relative to the U.S. population overall has been well documented. [12] The AI/AN population has lower life expectancy, higher age-adjusted mortality rates, and specific health indicators that are in some cases dramatically higher than for the overall U.S. population (e.g., 180 percent higher rate of Sudden Infant Death Syndrome).

The causes of poorer health status, high morbidity, and premature death among and within AI/AN populations are diverse. Poverty, poor living conditions and sanitation, and residence in rural and frontier areas with scarce health providers and facilities disproportionately affect AI/ANs. [13] In addition, the AI/AN population faces a number of unique financial and non-financial barriers to access to health services. A brief overview of the history and structure of

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[11] Keppel KG, Pearcy JN, Wagener DK. Trends in Racial and Ethnic-Specific Rates for the Health Status Indicators: United States, 1990-1998. Healthy People Statistical Notes, No. 23. Hyattsville, MD: National Center for Health Statistics, January 2002, page 9

[12] T. Young, "Recent Health Trends in the Native American Population," in Changing Numbers, Changing Needs: American Indian Demography and Public Health, National Research Council, pp 53-75; U.S. Department of Health and Human Services, Trends in Indian Health, 1997, Indian Health Service

[13] Promises to Keep: Public Health Policy for American Indians & Alaska Natives in the 21st Century, M. Dixon and Y. Roubideaux (eds.). The American Public Health Association, 2002; T. Kue Young, The Health of Native Americans: Towards a Biocultural Epidemiology. Oxford University Press, 1994; American Indian Health: Innovations in Health Care, Promotion, and Policy, E. Rhoades, M.D. (ed.). The Johns Hopkins University Press, 2000.

AI/AN health care is provided below, followed by discussion of some of the factors that affect AI/AN access to and use of health services.

History and Background of AI/AN Health Care [14]

Federally Recognized American Indian Tribes and Alaska Native corporations have a unique government-to-government relationship with the United States, based on Supreme Court decisions, treaties, legislation, and Executive Orders. Health services have been provided to AI/ANs since the early 19th century as a part of the Federal government's trust responsibility. As early as 1832, provision for physician services were included in treaties between the Federal government and AI/AN Tribes. Dr. Emery Johnson and Dr. Everett Rhoades, former Directors of the Indian Health Service, have stated "Tribal leaders…paid in advance for health services for their people, the premium being paid in the form of the land." [15]

The Department of Interior was given responsibility for management of AI/AN programs beginning in 1849. By 1880, the Federal government managed four hospitals employing 77 physicians to provide health services to AI/AN people. In 1921, Congress passed the Snyder Act, 25 USC § 13, that authorized the appropriation of funds for AI/AN health care. Since that time, Congress has annually appropriated monies for this purpose.

In 1954, under P.L. 83-568, AI/AN health programs were transferred from the Bureau of Indian Affairs, U.S. Department of the Interior, to the Public Health Service, U.S. Department of Health, Education, and Welfare (now the Department of Health and Human Services). The Division of Indian Health was renamed the Indian Health Service in 1968. Although the IHS functions within the Department of Health and Human Services, funds for IHS are provided through the Department of the Interior appropriations.

The IHS provides services directly and through Tribally contracted and operated health programs to approximately 1.6 million of the approximately 2.5 million AI/ANs who are members of Federally Recognized Tribes. The Federal AI/AN health system includes 36 hospitals, 63 health centers, 44 health stations, and 5 residential treatment centers. In addition, 34 Urban Indian Health Centers receive some funding through IHS to provide a range of health and referral services. Under P.L. 93-638 self-determination contracts, Tribes and Alaska Native corporations manage 13 hospitals, 158 health centers, 28 residential treatment centers, 76 health stations, and 170 Alaska village clinics.

The IHS is not an entitlement program or an insurance program and the services that it provides to eligible AI/ANs are limited by the amount of funding appropriated by Congress. IHS provides two types of services: 1) direct health care services provided by IHS or Tribally managed facilities; and 2) Contract Health Services that cannot be provided directly by IHS or Tribally managed facilities and must be referred out to private health care providers and facilities. Contract Health Services funds are limited and are available to eligible AI/ANs only to

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[14] Much of the information in this section is drawn from the Indian Health Service website (www.ihs.gov).
[15] E. A. Johnson and E.R. Rhoades, "The History and Organization of Indian Health Services and Systems," in American Indian Health: Innovations in Health Care, Promotion, and Policy. The Johns Hopkins Press (Baltimore): 2000, p. 75.

the extent that funds are available. Life-threatening illnesses or injuries are given the highest priority and other services may not be authorized when funds are not available.

Generally, any member of a Federally Recognized Tribe may obtain care at any IHS hospital or clinic if the facility has the staff and capability to provide the medical care. However, there are additional requirements for eligibility to receive approval for Contract Health Services, including the requirement that the patient reside on a Reservation of any Federally Recognized Tribe or reside within the specific Contract Health Service Delivery Area for the patient's Tribe. An AI/AN who lives away from his or her home Reservation may be able to obtain health services that are available through any IHS facility, but it is less likely that Contract Health Services will be available. In addition, some Tribally operated hospitals and health clinics restrict services to members of their own Tribe.

Financial Barriers to Access to and Use of Health Services

Health care for AI/ANs may be provided through the IHS, tribally managed health facilities, and Urban Indian Health Clinics (sometimes called the "I/T/U system"). Tribally managed health facilities and Urban Indian Health Clinics receive some or a majority of their funding from the IHS. Medicaid, SCHIP, and Medicare revenues provide supplemental funds for services provided to the AI/AN population through the I/T/U system. Financial barriers to care, however, are a significant problem for those who rely on the I/T/U system for health services because they are not funded at a level that is sufficient to meet the needs of the AI/AN population. In addition, supplemental revenues from Medicaid, SCHIP, and Medicare are dependent on enrollment of eligible AI/AN people into these programs and there is some evidence that under-enrollment is a significant issue for this population.

The IHS has estimated that funds appropriated by Congress cover approximately 60 percent of health care needs of eligible AI/AN people. [16] On a per capita basis, IHS funding declined by nearly 20 percent between 1987 and 1998. [17] Total U.S. per capita spending for health care was $3,619 in 1998, compared to IHS funding of $1,186 per capita for AI/ANs who live on or near Reservations and use IHS facilities. [18] Total estimated per capita expenditures paid through all sources of financing, including out-of-pocket costs, for the AI/AN population were about 58 percent of average U.S. per capita expenditures in 1998. For those who reside on or near Reservations, IHS-funded health services often constitute the primary or only source of health care available. Estimates of insurance coverage indicated that, in 1998, 37 percent of AI/ANs relied exclusively on the IHS (or tribally-operated facilities funded by IHS) for health care and/or were otherwise uninsured. [19] While the IHS budget has increased since 1998, it remains significantly under-funded at a level that is estimated to be only 50 percent to 60 percent of the average per capita health expenditure in this country.

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[16] Information obtained from http://www.ihs.gov/General Web/HelpCenter'Customer Services'approp.asp, accessed November 28, 2003.
[17] D. Cox and K. Langwell, Sources of Financing and the Level of Health Spending for Native Americans, The Henry J. Kaiser Foundation, Washington, D.C., October 1999.
[18] If IHS funding were extended to provide health care to AI/ANs, regardless of residence, the per capita amount available to provide these services would be $736.
[19] Op cit., Cox and Langwell, 1999

IHS and tribally managed health facilities were authorized to bill Medicaid and Medicare programs for services provided to those who are enrolled in these programs, and augment their funding through these additional revenues, under the provisions of the Indian Health Care Improvement Act of 1976. In fact, Congress has assumed that these third-party revenues will be obtained for AI/AN health in budgeting for the IHS since that time. [20] However, many IHS and tribally-operated facilities do not have the data systems or experience with billing to permit them to fully recover these additional revenues, particularly given the unique complexities of Medicaid and Medicare payment rules for this population. [21] A recent Agency for Health Care Research and Quality conference on "Addressing Critical Needs of Healthcare Systems Serving American Indians and Alaska Natives" (June 12-14, 2000) emphasized the importance and difficulties of billing for third-party reimbursement. [22]

Barriers to Enrollment in Medicaid, SCHIP, and Medicare

The extent to which IHS and tribally operated health facilities may be able to increase revenues through billing of public programs is also dependent on enrollment of eligible AI/ANs in these programs. There is considerable evidence that many AI/ANs eligible for Medicaid, SCHIP, and Medicare are not enrolled. One recent study estimated, for example, that up to 78 percent of AI/AN elders were eligible for, but not enrolled in, one or more public programs. [23]

Past research on barriers to public insurance program enrollment for the AI/AN population [24] found that the major barriers were lack of information on how to enroll and the need, in some cases, for one-to-one assistance to help eligible individuals through the enrollment process. In addition, AI/ANs have unique health communication needs because of their Tribal service structures and Indian Country's historical tension with the U.S. government. Many of this population remain separated from the mainstream by an array of linguistic, educational, and cultural barriers. Identified obstacles that must be taken into account in designing programs to increase AI/AN enrollment in Medicare, Medicaid, and SCHIP include language and literacy, a strong oral tradition rather than reliance on print materials, rural isolation and lack of telephones and transportation, cultural traditions that emphasize privacy and reserve in talking with others about health and income, and the need to develop a relationship of trust and confidence with individuals.

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[20] Testimony of Myra M. Munson, J.D., M.S.W. before the Senate Committee on Indian Affairs regarding the Reauthorization of the Indian Health Care Improvement Act, H.R. 2440 and S. 556, Title IV and Amendments to the Social Security Act, July 23, 2003.

[21] Ibid.

[22] www.ahcpr.gov/news/ulp/Tribal, accessed November 9, 2001.

[23] Elder Voices, Developing an Educational Outreach Strategy for Indian Communities: Final Report. Albuquerque Service Unit Area, Indian Health Service, January 2001.

[24] Examples include The Robert Wood Johnson Foundation, Covering Kids program; Barents Group of KPMG Consulting, Inc., Market Research for Beneficiaries/Social Marketing, for CMS; National Indian Council on Aging, Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations, for CMS; Elder Voices, Developing an Educational Outreach Strategy for Indian Communities, for the Indian Health Service; and National Indian Health Board, Strategies for Increasing Enrollment of American Indians and Alaska Natives in Medicaid, SCHIP, and Medicare, for the Indian Health Service.

Non-Financial Barriers to Access and Use of Services

A number of studies have found that, even when AI/ANs are insured, fewer services are used despite the greater prevalence of serious health problems and chronic conditions among this population. This is particularly the case for primary care physician visits and use of preventive and early detection services. [25] IHS data, for example, indicate that only 67 percent of AI/AN women receive prenatal care in the first trimester of pregnancy, compared with 81 percent of U.S. All Races women. [26] Infant mortality rates that are nearly 40 percent higher and a Sudden Infant Death Syndrome rate that is 180 percent higher than for the general U.S. population also suggests that the lack of primary and preventive care has disastrous consequences for this population. Similarly, AI/ANs are more likely to have diabetes than other racial/ethnic groups. The fact that diabetes is the fourth leading cause of death among elderly AI/ANs [27] suggests that inadequate access to and use of primary care and preventive services by those diagnosed with diabetes contributes to the high mortality rates and years of potential life lost rates for this population.

Reasons for lower use of services by AI/ANs may include financial barriers to access, scarcity of health professionals and health facilities, and transportation barriers in rural and frontier areas. In addition, cultural beliefs and lack of awareness of the importance of primary and preventive services also are factors that result in lower use of services. A number of pilot projects and programs targeted to health issues such as prenatal care, substance abuse, and diabetes management have been tested and implemented over the past decade to increase use of services. [28] Although these pilot projects have provided many useful lessons, rigorous evaluation of program effectiveness and dissemination of "best practices" findings from the pilots for broader application of successful programs have both been limited.

Purpose of Study

In September 2001, CMS funded a two-year study to examine barriers to enrollment of AI/ANs in Medicaid, SCHIP, and Medicare (including the Medicare Savings Programs), 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,

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[25] K. Langwell and J. Moser. Disparities in Health Status and Use of Services: American Indians Enrolled in Medicare Managed Care Plans. Centers for Medicare and Medicaid Services, Baltimore, MD: June 2001, found that American Indians enrolled in Medicare managed care plans were less likely to see a primary care physician or a specialist physician than were other enrollees, but were more likely to be hospitalized and to use ER services. Also, K. Beauregard, P. Cunningham, and L. Cornelius, Access to Health Care: Findings from the Survey of American Indians and Alaska Natives, AHCPR Pub. No. 91-0028, July, 1991; P. Gordon et al., "Mammography and Pap Smear Screening of Yaqui Indian Women", Public Health Reports 109 (1), January-February, 1994: 99-104.

[26] U.S. DHHS, Indian Health Service, Regional Differences in Indian Health, 1998-99, Rockville, MD, 2000.

[27] P. Eggers and L. Greenberg, "Racial and Ethnic Differences in Hospitalization Rates Among Aged Medicare Beneficiaries, 1998," Health Care Financing Review 21 (4), Summer 2000: 91-105.

[28] For example, the Health Resources and Services Administration's Healthy Start program; the University of Colorado's Healthy Nations project; Native American Research and Training Center, University of Arizona, Tucson; Native Elder Health Care Resource Center, University of Colorado Health Sciences Center; National Center for American Indian and Alaska Native Mental Health Research, University of Colorado Health Sciences Center; Center for American Indian and Alaska Native Health, The Johns Hopkins University, Native American Prevention Research Center, University of Oklahoma Health Sciences Center, and numerous diabetes management initiatives funded by Federal, State, and private organizations.

Project HOPE's Center for Health Affairs, 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 based on AI/AN population, geographic diversity, diversity of State Medicaid and SCHIP programs and eligibility criteria, and presence of significant urban Indian populations. [29] Eligibility and enrollment estimates were developed for each of the 15 States using a variety of data sources obtained from the 2000 U.S. Census, IHS, and CMS.

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.

This Final Report presents background, methods, and results of the analysis of the feasibility of developing quantitative estimates of AI/AN eligibility for and enrollment in Medicaid, SCHIP, and Medicare. In addition, a summary of the case study methods and findings is provided, including the most frequently cited barriers to AI/AN enrollment in these programs and the most frequently mentioned strategies for addressing those barriers to facilitate increased AI/AN program enrollment. The final section of the report discusses the findings, limitations of the study, and suggestions for future research that could improve understanding of AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare.

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[29] 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.

DATA AND METHODOLOGICAL ISSUES FOR ESTIMATING ELIGIBILITY AND ENROLLMENT OF AI/ANS IN MEDICAID, SCHIP, AND MEDICARE

OVERVIEW

In this section, we describe study design issues that were identified early in the project and the approach that was developed to estimate AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare. Then, we discuss data limitations and methodological issues that were encountered and implications for the feasibility of developing reliable estimates of eligibility, enrollment, and differences between these estimates.

STUDY DESIGN ISSUES

Three major issues were identified during the study design phase of the project that affected the analysis conducted, which are discussed below:

- The definition of AI/AN that would be used in the study.

- The time period that would be the basis for the analysis.

- The definition of sub-State areas for which estimates would be made.

Definition of the AI/AN Population to be Studied

Several alternative definitions of the AI/AN population could be used for this study and each alternative has implications for selection of databases that would be used and the methodological approach that would be selected for estimating eligibility and enrollment. These alternatives include:

- AI/ANs who are identified on IHS Patient User files (i.e., those who live on or near Reservations and/or who travel to IHS facilities to receive health services).

- AI/ANs who are members of Federally Recognized Tribes (reported on Bureau of Indian Affairs (BIA) data files), regardless of residence.

- AI/ANs who are members of Federally Recognized Tribes and who reside on or near Reservations (also reported on BIA data files).

- AI/ANs who self-identify race on Census 2000 files as American Indian or Alaska Native. This definition includes members of Federally Recognized Tribes, members of non-Federally Recognized Tribes, and others who report AI/AN race but are not affiliated with a Tribe.

Census 2000 also introduces an additional definitional complication. In previous Censuses, respondents were asked to self-identify as one primary race. Census 2000 offered respondents the option of indicating multiple racial backgrounds, if appropriate, and did not request that the respondent indicate primary racial identification. Thus, a decision to define AI/AN as only those who indicated AI/AN only would result in under-counting the AI/AN

population by limiting the population only to those who are single-race. Alternatively, a decision to define the AI/AN population as all who indicated their race as either AI/AN only or AI/AN in combination with another race would likely over-count the population by including a number of people who may have had a distant ancestor who was AI/AN but who have little or no current identification with AI/AN culture or traditions. This issue was a substantial one since less than 2 million people reported AI/AN race on the 1990 Census, 2.5 million reported AI/AN race only on the 2000 Census, and over 4 million reported AI/AN race only or in combination with another race.

CMS indicated that it would prefer that the study offer the opportunity to examine, to the extent possible, each of these alternative (overlapping) AI/AN populations, without limiting the choice to one of these definitions. Consequently, a decision was made to develop eligibility estimates separately for those who reported AI/AN race only and for those who reported AI/AN race, either only or in combination with another race.

The definitional issue also affects the estimates of enrollment in Medicaid, SCHIP, and Medicare since the racial identifiers available on the source databases may be self-reported, or State or County eligibility workers may record their own assessment of an individual's race. While self-reported data may generally be assumed as accurate, racial data reported by an observer may have limitations. An IHS study regarding the accuracy of AI/AN race coding on death certificates found that, on average, about 11 percent of AI/AN deaths were miscoded as other races. Further, in some States, the miscode rate was as high as 47 percent. [30] However, the Medicaid, SCHIP, and Medicare data sources indicate only one race and do not include multiple racial identifications. As a result, it is more likely that the enrollment data sources represent primary AI/AN racial identification.

Timeframe

A central element of this project was amassing and analyzing multiple data sources for developing estimates of eligible and enrolled AI/ANs in Medicaid, SCHIP, and Medicare. A major issue for the design was identifying time periods for which all data sources were available and/or developing methodologies for controlling for variations in the time periods covered by different analytic files.

Ideally, all data sources for the estimates of AI/AN eligibility and enrollment would be available for the same time period. However, review of the many different sources of data found that this was not the case. For example, the key file for estimating the number of AI/ANs enrolled in Medicare is the linked 1999 IHS/Medicare enrollment database. In contrast, key data for estimating the Medicare-eligible AI/AN population come from both the 1990 and 2000 Census.

In order to develop the best possible estimates from this array of data, it was necessary to select a study year once the data sources had been finalized and initial estimates had been

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[30] See: Support Services International, Inc., Methodology for Adjusting IHS Mortality Data for Inconsistent Classification of Race-Ethnicity of American Indians and Alaska Natives Between State Death Certificates and IHS Patient Registration Records. Report prepared for the Indian Health Service: Rockville, MD: November 1996.

developed, and adjust all estimates to correspond to the study year. This decision was made in conjunction with the CMS Project Officer.

An additional issue related to the timeframe of available data affected the estimates of AI/AN eligibility and enrollment in SCHIP programs. The most current data sources available for SCHIP estimates were for 1999 and 2000. This period coincided with start-up of the SCHIP program in many States. As a result, these States reported very low overall enrollment in SCHIP and significant enrollment growth was observed over the 1999-2000 period, reflecting the impacts of small numerical increases in enrollment as the programs were introduced. This timing issue made it problematic to estimate reliable AI/AN enrollment numbers that would reflect the potential "steady State" enrollment of AI/AN children into SCHIP. With CMS agreement, a decision was made to forego estimates of SCHIP enrollment in any of the 15 study States.

Sub-State Areas

The original scope of work for this project included estimation of AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare for each of the study States and for sub-State regions within these States. Discussions with CMS about the sub-State estimates resulted in a decision to explore the feasibility of making estimates at the County level and at the Reservation level. However, as the estimation process went forward, it became apparent that credible County-level and Reservation-level estimates could not be produced. Most study States are predominately rural, with low population density. Individual County populations were very low in many cases and the number of AI/AN people who would be eligible and enrolled in the programs of interest was very small – sometimes in single digits. These very small numbers were problematic because of the necessity of ensuring individual privacy and the inherent instability of estimates based on small numbers.

Efforts to develop Reservation-level estimates were also unsuccessful. In part, this was because there is no unique mapping available from the U.S. Census between counties and Reservations. The Census Geography shows American Indian areas mapping only to blocks and to the Nation, but not to other geographic units. [31] Reservations may cross County and State borders and many Tribes have Trust Lands that are not on or adjacent to Reservations. Using the Census Bureau "Reservation" designation, many Reservations also have substantial non-AI/AN populations. For example, the Agua Caliente Reservation in California has 172 people who self-identify as AI/AN out of a total population of over 20,000. Other States do not have Reservations, even though they may have Trust Lands. For example, Oklahoma is a Tribal Designated Statistical Area with only one Reservation but with a substantial AI/AN population living throughout the State. Alaska also has only one designated Reservation but has 14 Alaska Native Regional Corporations and Alaska Natives reside in a large number of traditional villages throughout the State. These issues were discussed with CMS and a decision was made to limit the estimates of AI/AN eligibility and enrollment to the State-level.

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[31] U.S. Census Geography, accessed at http://factfinder.census.gov/home/ep/epss/census.geography.html.

STUDY METHODOLOGIES AND DATA SOURCES

The estimates of AI/AN eligibility and enrollment in Medicaid, SCHIP, and Medicare that were to be developed, under the contract, included: (1) estimation of the number of AI/AN people eligible for each program, in each of the 15 States; (2) estimation of the number of AI/AN people enrolled in each of the programs, for each of the 15 States; and (3) comparison of the eligibility and enrollment estimates to assess whether under-enrollment was observed in each State. The methodology and data sources used for each of these analyses are described below.

Eligibility Estimates: Methods and Data Sources

The purpose of this analysis was to estimate eligibility of the AI/AN population for Medicaid, SCHIP, and Medicare at the State level for the 15 study States. In order to do this, data and methods were required to:

- Define the population of AI/ANs.

- Determine program eligibility.

- Make estimates for each State.

Each of these issues is described briefly here, with a more detailed discussion of data sources and technical approach to estimation following and provided in Appendix B.

Defining American Indians and Alaska Natives. As discussed above, the study population could be defined based on AI/AN self-identification or according to membership in a Federally Recognized Tribe. In addition, the 2000 Census data permit identification of those who indicated AI/AN as their only race and of those who indicated AI/AN race alone or in combination with another race. Our approach for the eligibility estimates was to use the number of people reporting AI/AN race only, who were estimated to be eligible for a program, as a lower bound estimate. The upper bound estimate was defined as the number of people reporting AI/AN race only or in combination with another race who were estimated to be eligible for a program.

Determining Program Eligibility. Each of the four programs [32] required a different set of data elements to model program eligibility criteria. To estimate eligibility for Medicaid and SCHIP, we gathered background information on program eligibility criteria and determination in each of the 15 States. This required collecting information on the income standards applied, methods used for measuring assets, rules concerning family composition and age, and any other pertinent program regulations. We also reviewed the substantial literature on estimating Medicaid and SCHIP eligibility using person-level survey data to gain insights on the general process of applying program eligibility criteria to large databases. [33] Because of the variability

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[32] For purposes of estimating program eligibility, we consider the Medicare aged and Medicare disabled as separate programs since the requirements are entirely distinct.

[33] See, for example, Davidoff AJ, Garrett AB, Makuc DM, Schirmer M. "Medicaid-eligible children who don't enroll: health status, access to care, and implications for Medicaid enrollment," Inquiry 2000 Summer; 37(2):203-18; Irvin C and Czajka J. Simulation of Medicaid and SCHIP Eligibility: Implications of Findings From 10 States. Final Report submitted to the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, August 16, 2000; Selden TM, Banthin JS, Cohen JW. "Medicaid's Problem Children:

across States and between the two programs even within a given State, each State-program pair's eligibility rules were applied to the data in a separately constructed algorithm. Given data limitations, however, it was difficult to accurately reflect all eligibility requirements in these algorithms. As discussed below, we estimated upper and lower bounds where appropriate.

Data Sources

Because no single data source includes all of the required information, four different primary sources of data were used. Complete data from the 2000 U.S. Census were not available during the database development phase of this project. Aggregate population counts, however, from the 2000 Census were used as control totals. Each of the data sources used for the eligibility estimates is described in detail below.

Census 2000 Summary Data—100% File. Certain types of population counts were available on the Census website. Specifically, we obtained population counts for the AI/AN population by sex and age (available in 1 to 5 year age increments) and poverty level for each County in the United States. Counties were aggregated to conform to the 1990 data (described below). Estimates were made separately based on "AI/AN only" responses and based on "AI/AN only or in combination with other races."

1990 Public Use Microdata Samples (PUMS)—5%. File. Person-level (micro-) data from the 1990 U.S. Census were purchased from the U.S. Census Bureau. The largest available data set is the 5 percent sample; the smallest geographic unit for which these data are available is the PUMA (public use microdata area – a County or groups of contiguous counties with a population of at least 100,000 persons). The data set includes a wide variety of data items, including the following variables of interest:

- Age

- Family relationship variables

- Race

- Tribe

- Poverty status

- Disability indicator

- Employment status

- Social security income receipt

Eligible but Not Enrolled," Health Affairs 1998, 17(3):192-200; and Selden TM, Banthin JS, Cohen JW. "Waiting in the Wings: Eligibility and Enrollment in the State Children's Health Insurance Program," Health Affairs, 1999, 18(2):126-133.

2000-2002 Current Population Survey (CPS). CPS data were obtained and used for benchmarking of the Medicare eligibility estimates and for estimating the number of elderly eligible for Medicaid in each State.

General Methodology

The basic approach to estimating program eligibility relied on the 1990 5 percent micro-data (PUMS). Overall population counts were adjusted using published data available from the 2000 Census. For all data items, with the exception of income, the population and its characteristics were inflated to the 2000 population control totals. Thus, for example, we inflated the total number of elderly (65 years of age or older) AI/ANs according to 2000 counts assuming that the same proportion of elderly AI/ANs who reported receiving Social Security income in 1990 received such income in 2000. While this assumption may be somewhat crude, it was the only feasible approach without an undue use of resources. Estimates of the percent of persons at various poverty levels were updated using Census 2000 State and County estimates produced by the U.S. Census Bureau.

As discussed above, substantial differences in the count of AI/ANs occur depending on whether respondents were allowed to identify multiple races, as was done in the 2000 Census. Given these differences, we used the number of persons identifying as "AI/AN only" as a lower bound on all estimates of the size of the population and "any AI/AN" as an upper bound.

Basic Approach. The approach described here was used for most estimates described below. It involves no updating of the underlying parameter; rather, we applied 1990 parameter estimates to the 2000 population counts. The steps are as follows, using the percent of the elderly receiving Social Security income to illustrate:

1. Using 1990 data, create cells within each County or grouping of counties for AI/ANs defined by age*sex.

2. For age 65 or older cells, estimate percent receiving Social Security income for each cell (still using 1990 data).

3. Create identical age*sex cells for AI/ANs at the County level, using 2000 data.

4. Apply estimated percent to 2000 data cells – apply to each County within the 1990 groupings.

Updating Percent below Poverty Level. The method described here was used for updating the percent of persons living below the Federal Poverty Level. For each County or grouping of counties, the following was calculated by age group (<5 years; 5-17; 18+):

% in poverty (1998)

((% in poverty (1990)) X (% of AI/ANs in poverty (1990)) X (# AI/ANs (2000)))

An additional step was to derive estimates for the percent of persons living below different multiples of the Federal Poverty Level. Those used by States to determine Medicaid

eligibility range from below 100 percent (for certain categorical eligibility) to as high as 300 percent of poverty. [34] Data from the 2000 Census were used to estimate relationships at the State level between 100, 125, and 200 percent of poverty.

The detailed methodology developed for Medicare, Medicaid, and SCHIP eligibility estimates is presented in Appendix B to this Report.

Enrollment Estimates: Methods and Data Sources

Upper and lower bound enrollment estimates were calculated for each of the programs of interest. Lower bound estimates were based on the result of direct individual-level comparisons of race/ethnicity codes reported in various administrative data files. In contrast, upper bound estimates attempted to account for additional AI/ANs that would have been identified if it were possible to directly verify the race/ethnicity of all Medicare, Medicaid, and SCHIP beneficiaries.

Data

Multiple data sources were used to develop the enrollment estimates, described next.

Medicare Enrollment Data Base (EDB). The Medicare EDB contains individual-level information on individuals enrolled in the Medicare program, including unique identification information (e.g., Social Security Number (SSN), name, address), demographics (e.g., age, sex, race/ethnicity, date of death), and program administrative information (e.g., reason for program entitlement, Part A/Part B enrollment, Medicare+Choice plan enrollment). We used the latest monthly unloaded EDB as of November 1, 2002. This file contains information on anyone ever enrolled in Medicare and historical information since they enrolled. From this file we extracted information for persons enrolled in Medicare on December 31, 1999, and living in one of the 15 study States.

Medicaid Statistical Information System (MSIS). The MSIS enrollment files for 1999 were used for developing estimates for Medicare, Medicaid, and SCHIP. The MSIS data files consist of four quarterly data files for each State. For each quarter, Medicaid enrollment is recorded on a monthly basis. Further, race/ethnicity and address are reported.

IHS Patient Registry File. The IHS Patient Registry File was a primary source for directly identifying AI/ANs enrolled in the three programs. This data file contains the cumulative set of records for individuals receiving IHS services. Individuals can (and often do) have multiple records in this file. The initial file provided by the IHS contained 4,594,589 records. This initial file was reduced to 2,640,132 records by eliminating duplicate/dummy records and records without SSNs.

SCHIP. There are three types of SCHIP programs: (1) expansions of existing Medicaid programs (five of the study States), (2) new stand-alone State programs (five of the study States), or (3) combinations of Medicaid expansion and stand-alone programs (five of the study States). Administrative data on expansion program enrollments were contained in the MSIS data files.

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[34] For example, the higher Federal Poverty Level used by Alaska in determining Medicaid eligibility was accounted for in this approach.

However, data on stand-alone SCHIP program enrollments were not centrally available through CMS. Instead, we obtained the SCHIP data directly from the 10 study States that had either a new stand-alone State program or a stand-alone program in combination with a Medicaid expansion. As indicated by the summary information in Table 1 for these 10 States, the data varied considerably in terms of level of detail across the States. As discussed in the following sub-sections, estimates of lower and upper bound SCHIP program enrollments were driven in part by the level of detail contained in these data.

Table 1. Summary of SCHIP AI/AN Data Available for Analysis for Study States with Stand-Alone SCHIP Programs

State	SCHIP Program Type	Years	Unit of Analysis	All State or AI/AN Only	SSNs
Arizona	Separate	Enrolled as of 12/1/02	Person	State	No
California	Combination	1999 and 2000	County	AI/AN only	No
Michigan	Combination	1999 and 2000	Person	State	No
Montana	Separate	1999-2002	Person	State	No
New York	Combination	Enrolled as of 12/02 and 04/03	Person	AI/AN only	Yes
North Dakota	Combination	1999 and 2000	Person	State	Yes
Oregon	Separate	1999 and 2000	Person	State	Yes
South Dakota	Combination	1999 and 2000	Person	State	Yes-2000, No-1999
Utah	Separate	1999 and 2000	Person	State	Yes
Washington	Separate	2000	Person	State	Yes

Notes: Arizona data include children enrolled in the SCHIP program as of 12/01/99; enrollment dates range from 1998 to 2002. New York data include children enrolled in the SCHIP program as of 12/2002 and as of 04/2003.

Lower Bound Estimates

Medicare. For Medicare, lower bound estimates were obtained based on the results of direct matches between the Medicare EDB, the IHS Patient Registry File, and Medicaid MSIS files. The EDB and IHS data were merged as part of an effort that was separate from this project. Beneficiaries in this file were coded as AI/AN if they were either coded as such in the original EDB or were recoded as AI/AN as a result of a match to the IHS data. Unfortunately, the race code from the IHS data was not added to the EDB, but instead the existing race code on the EDB was overwritten. Therefore, it is not possible to determine the prevalence of race code discrepancies between the EDB and IHS data files. [35]

The second stage in creating these lower bound estimates consisted of matching Medicaid MSIS data to the merged EDB/IHS file by SSN. This was done to validate the race/ethnicity

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[35] A binary variable indicating whether a beneficiary was found in the IHS data this file was added to the EDB file. This field allowed us to calculate an EDB/IHS match rate, which was important for making upper bound estimates.

codes of dual eligible Medicare beneficiaries.[36] This match increased the number of Medicare beneficiaries identified as AI/ANs in the EDB by about 4 percent for the 15 study States.

Medicaid. In order to develop geographic-specific estimates of AI/ANs in Medicaid, it was necessary to make several decisions on place of residency, MSIS race/ethnicity coding, and definition of Medicaid enrollment, as follows:

- Place of Residence. We decided to use individuals' fourth quarter addresses from the MSIS files as their full year addresses. As noted above, up to four different possible residences could be reported in the MSIS for a given year. Therefore, in order to avoid counting individuals multiple times during a calendar year, it was necessary to uniquely fix the person to one place of residence.

- MSIS Race/Ethnicity Coding. We decided to use information from the MSIS fourth quarter (i.e., Q4) to set the baseline race/ethnicity of Medicaid enrollees. Race/ethnicity coding varied by about one to two percent across the quarterly MSIS files. Further, this variation did not appear to be systematic (e.g., going from unknown race in Q1 to Black in Q2). The selection of Q4 was consistent with our decision on place of residence information.

- Medicaid Enrollment. We defined Medicaid enrollees to include all individuals enrolled during December 1999. Medicaid enrollment status is reported on a monthly basis within the MSIS data. Because individuals changed status (in some instances multiple times) during a calendar year, it was necessary to determine a decision rule for what constitutes a 1999 Medicaid enrollment.

The lower bound Medicaid enrollment estimates were calculated using the same basic approach as was used for generating the Medicare lower bound estimates, except that the base file was comprised of the MSIS quarterly files instead of the EDB. The MSIS was supplemented with race codes from the IHS patient registry file and the EDB. Both the MSIS-to-IHS and the MSIS-to-EDB match were conducted in this study. All Medicaid beneficiaries (enrolled in December 1999 and not enrolled in Medicaid-SCHIP expansion programs) that were identified as AI/AN in either the MSIS, IHS, or EDB data files were considered to be AI/AN for the lower bound estimates.

SCHIP. For SCHIP, the lower bound estimates were calculated based on SCHIP program type. For States with only Medicaid expansion programs, the same process as Medicaid was used for beneficiaries on the MSIS enrolled in the expansion program as of December 1999. For States with separate programs, the lower bound estimate calculation varied by State. For States not providing SSNs, the lower bound estimates were a direct count from the State-provided data. For States providing SSN, the lower bound estimate includes any person on the State file identified as AI/AN on the State file, the IHS patient registry, or the MSIS files. For States with combined programs (Medicaid expansion and separate State programs), two separate lower bound estimates were calculated – one for the Medicaid expansion using the same methods as States with only Medicaid expansion programs and one for the separate State program using the same method as States with only separate programs.

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[36] An enrollee was considered an AI/AN if coded as such on either the Medicare EDB or Medicaid MSIS data files.

<u>Upper Bound Estimates</u>

Upper bound estimates were created by estimating the additional number of AI/AN beneficiaries that would have been identified if all AI/ANs within the study States had been confirmed by direct matching with other data files. For example, because only a portion of Medicare-enrolled AI/ANs use IHS services and are in the IHS files, the lower bound estimates were based on a partial validation of race/ethnicity coding contained in the EDB. As such, several approaches were explored for obtaining estimates of the number of additional beneficiaries that would have been identified as AI/AN.

Medicare. The upper bound Medicare estimates consist of three components: (1) the number of beneficiaries coded as AI/AN on the EDB (after the IHS Match), (2) the number of beneficiaries coded as non-AI/AN on the EDB, but matched to the MSIS with a race code of AI/AN (miscodes), and (3) estimates of the number of additional miscodes that would have been detected if all of the beneficiaries on the EDB were matched to an external data source. Or:

1. AI/AN$_{Lower Bound}$ = AI/AN$_{EDB/IHS}$ + AI/AN$_{MSIS miscodes}$

2. AI/AN$_{Upper Bound}$ = AI/AN$_{Lower Bound}$ + (est)AI/AN$_{Add miscodes}$.

The first two components are identical to those in the lower bound estimates. The third component was calculated by using the results of the EDB-to-MSIS match to identify (a) the number of beneficiaries coded as AI/AN on the EDB that matched the MSIS (confirmed), (b) the number of beneficiaries coded as non-AI/AN on the EDB that matched an MSIS record coded as AI/AN (miscodes), and (c) the number of beneficiaries coded as AI/AN on the EDB that did not match the IHS and MSIS files (unconfirmed).

This information was used to calculate a Confirmed to Miscode Rate (CMR), which consisted of data element (a) divided by data element (b). For example, if the CMR was equal to 5, then that implies that five beneficiaries would be confirmed as being AI/AN for every one record that was found to be miscoded as non-AI/AN. The CMR was divided into the number of unconfirmed records to estimate the number of additional AI/ANs that would have been found if these records were confirmed by direct matching to either the IHS or MSIS data files. More rigorously stated, estimates of additional AI/AN miscodes were calculated as:

1. (est)AI/AN$_{Add miscodes}$ = (number of unconfirmed AI/AN)/CMR,

where

2. 4. CMR = (AI/AN$_{MSIS confirmed}$)/(AI/AN$_{MSIS miscodes}$).

As an illustration of this approach, consider Aged Medicare AI/ANs for Alaska. [37] As presented in the next section, the number of beneficiaries coded as AI/AN on the EDB (after the IHS match) for Alaska is 5,746 and the number of additional AI/ANs identified after the MSIS match (miscodes) is 68, which gives the lower bound estimate of 5,814. Of these reported AI/ANs, (a) 2,355 were successfully matched to the MSIS (confirmed), (b) 68 additional

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[37] These data are reported in Table 2 below.

beneficiaries were identified as AI/AN by the MSIS match (miscodes), and (c) 53 were unconfirmed by the initial IHS-to-EDB match. The CMR is 34.63 (=2,355/68), and the estimated number of additional miscodes that would have been detected if all AI/ANs were confirmed is 2 (=53/34.63). [38] The upper bound estimate for Alaska, therefore, is equal to 5,816 (=5,814+2).

Medicaid. For Medicaid, a similar approach is used. Confirmed AI/ANs included those in the MSIS that matched IHS or EDB records as AI/ANs, miscodes included MSIS non-AI/ANs that were coded as AI/ANs in either the IHS or EDB data, and unconfirmed AI/ANs in the MSIS included those that did not match either the IHS or EDB data. Estimates of the number of additional miscodes were obtained through the same CMR calculation.

SCHIP. For SCHIP Medicaid expansion programs, the same method as for Medicaid was used. For separate State programs not providing SSNs, the upper bound estimate is the same as the lower bound estimate as the data did not support an estimate of additional AI/ANs. For separate State programs, a similar approach to Medicaid and Medicare was used. The number of confirmed cases (AI/AN on State and AI/AN on IHS or MSIS), the number of unconfirmed cases (AI/AN on State and not on IHS or MSIS), and the number of additional AI/ANs (non-AI/AN on State and AI/AN on either IHS or MSIS) were estimated. A CMR was calculated and applied to the unconfirmed cases count. For States with combined programs, an upper bound was calculated for each part of the combined program and added together.

FINDINGS

Results of the estimations of eligibility and enrollment, and of the ratio of estimated AI/AN enrollment to estimated AI/AN eligibility, illustrate the substantial data problems discussed above. Although estimates can be made of the number of AI/ANs who are eligible for Medicaid, SCHIP, and Medicare, and estimates can be made of the number of AI/ANs who are enrolled in these programs, the ratio of enrollment to eligibility varies widely across definitions of AI/AN population. This is primarily a result of using self-reported Census data for the estimation of eligibility and the issue of definition of the AI/AN population as AI/AN only or as AI/AN only or in combination with other race(s). Table 2 on the following page illustrates the issues raised by the different Census data definitions of AI/AN race. (Additional tables presenting the findings of the analysis of AI/AN eligibility, enrollment, and take up rates for Medicare are presented in Appendix C.)

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[38] Estimates are rounded to the nearest whole number.

Table 2. AI/AN Aged Medicare Eligibility and Enrollment: Illustrative Estimates

State	AI/AN Aged Population		Enrollment		Take Up Rates			
	AI/AN Only	AI/AN (Multiple Race)	Lower Bound: EDB with IHS/MSIS	Upper Bound: Indirect Estimate	Direct Estimate (Multiple Race)	Indirect Estimate (Multiple Race)	Direct Estimate (AI/AN Only)	Indirect Estimate (AI/AN Only)
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)
Alaska	5,728	6,361	5,814	5,816	0.91	0.91	1.02	1.02
Arizona	14,199	16,348	11,809	11,816	0.72	0.72	0.83	0.83
California	20,238	38,449	8,516	12,095	0.22	0.31	0.42	0.60
Michigan	3,158	7,136	2,044	2,274	0.29	0.32	0.65	0.72
Minnesota	2,276	3,312	2,331	2,373	0.70	0.72	1.02	1.04
Montana	2,711	3,257	2,810	2,823	0.86	0.87	1.04	1.04
New Mexico	10,413	11,401	8,993	9,009	0.79	0.79	0.86	0.87
New York	5,895	11,655	2,567	7,959	0.22	0.68	0.44	1.35
North Dakota	1,339	1,497	1,375	1,377	0.92	0.92	1.03	1.03
Oklahoma	18,845	29,001	21,565	21,640	0.74	0.75	1.14	1.15
Oregon	2,302	4,853	1,943	2,073	0.40	0.43	0.84	0.90
South Dakota	2,775	3,057	2,754	2,760	0.90	0.90	0.99	0.99
Utah	1,098	1,432	816	824	0.57	0.58	0.74	0.75
Washington	4,637	8,057	3,919	4,059	0.49	0.50	0.85	0.88
Wisconsin	2,320	3,394	2,117	2,173	0.62	0.64	0.91	0.94
Total	97,934	149,210	79,373	89,071	0.53	0.60	0.81	0.91

Notes: Col a. Number of 65+ individuals reported as AI/AN only on 2000 Census.
Col b. Number of 65+ individuals reported as AI/AN in addition to another race/ethnicity on the 2000 Census.
Col c. From Table 2, Col (d).
Col d. From Table 3, Col (g).
Col e. Equals Col (c)/Col (b).
Col f. Equals Col (e)/Col (b).
Col g. Equals Col (c)/Col (a).
Col h. Equals Col (e)/Col (a).

There is substantial variation across States in the number of people who report AI/AN as their only race relative to the number who report AI/AN race in combination with another race. For example, the number of aged AI/ANs estimated to be eligible for Medicare (the denominator of the take-up rate) varies substantially in some States, depending on whether those who report AI/AN race only or those who report AI/AN alone or in combination with other race(s) are counted. In California, an estimated 14,199 aged AI/ANs are eligible for Medicare if those who report AI/AN race only are counted. If the definition used is AI/AN only or in combination with another race, then an estimated 38,449 AI/ANs are eligible for Medicare – a difference of 190 percent. This difference averages 152 percent across the 15 States, from a low of 111 percent in Alaska to a high of 226 percent in Michigan. Since the number estimated to be eligible for Medicare is the denominator of the take-up rate, the take-up rate will vary substantially in States where there is a large difference in the number of people reporting AI/AN race only and the number reporting AI/AN race only or in combination with other races.

The enrollment estimates are based on primary race identification, usually self-reported, of AI/ANs who may be AI/AN only or in combination with other races. While the Census multiple race indicator includes anyone who believes they have some AI/AN heritage, the enrollment data generally is likely to count those who have a close identification with AI/AN race and culture – a number that is probably lower than the Census estimates of AI/AN only or in combination with other races. To further complicate the calculations of take-up rates, estimates of the number of AI/ANs enrolled in Medicare (the numerator of the take-up rates) also vary. The lower bound aged AI/AN Medicare enrollment estimate is the number of identified AI/ANs on the Medicare EDB and the upper bound enrollment estimate is based on the adjustment made to account for misidentification of race (described above).

The impact of these definitional issues is observed by examining the take-up rates in Table 2 above. The Medicare aged enrollment-eligibility ratio in North Dakota is 0.92 (column (e)) for AI/ANs who report AI/AN race only or in combination with other races. The ratio is 1.03 (column (g)) if those who report AI/AN race only are used for the eligibility estimates in the denominator. These ratios are not changed when the enrollment adjustment for misidentification is made (columns (f) and (h)). For California, on the other hand, which has a much higher proportion of people reporting AI/AN race in combination with one or more other races, the ratio ranges from 0.22 (column (e)) to 0.42 (column (f)). The enrollment adjustment has a substantial effect in the California estimates, increasing the take-up rate for AI/ANs only or in combination with other races from 0.22 to 0.31 (column (f)) and from 0.42 to 0.60 (column (h)).

Similar results are observed for the Medicaid program, due to the same data limitations. (Tables presenting the results of the Medicaid eligibility, enrollment, and take up rate analysis are presented in Appendix C.) The complexities of modeling Medicaid eligibility rules add further uncertainties to the Medicaid estimates. As a result, across all of the 15 States, the average take-up rates range from 0.64 - 0.74 for AI/ANs only or in combination with other races and from 0.93 - 1.06 for those who report AI/AN race only.

SUMMARY

The objective of this component of the study was to estimate the extent to which AI/ANs may be under-enrolled in Medicaid, SCHIP, and Medicare, by using available data to estimate

the number of AI/ANs that are eligible for and enrolled in each of these programs in 15 States. During the study, a number of issues were identified that significantly affect the degree of confidence that should be placed in these estimates.

The primary issues raised by this exploration were associated with substantial data limitations and with difficulties in defining consistently the population of interest. The available data sources – particularly for estimating eligibility – do not offer all the data that are required to determine whether individuals are eligible for enrollment in each program. As a result, estimation of the number of AI/ANs who are eligible is subject to some degree of uncertainty.

The definition of who is an American Indian or Alaska Native varies and results in considerable uncertainty in the estimates. First, because the 2000 Census allowed respondents to identify multiple races, there are substantial differences in the count of AI/ANs depending on whether one includes persons who reported being "only AI/AN" or persons who reported being AI/AN as one of multiple race designations.

An additional complication arises due to the different determinations of AI/AN race in the data used to estimate AI/AN eligibility and AI/AN enrollment in these programs. Using two different sources of data for the numerator and denominator of the take-up rate is problematic. The numerator data – used to calculate enrollment – is largely based on self-reported or observational reports of race. Validation of these data by comparing IHS patient user data files to program enrollment data on race is useful, but has some limitations. IHS data include primarily persons living on or near Reservation areas. While this is a substantial proportion of the AI/AN population, it does not include all of the population of interest. In addition, the definition of who is an American Indian or Alaska Native using IHS data is determined by rules related to IHS eligibility and relies primarily on membership in a Federally Recognized Tribe. In contrast, the denominator data by definition employ a much broader definition of who is AI/AN. Using these two different sources together results in take-up rates that are unreliable.

One additional issue is that the time periods for the data sources differ. Population counts from the Census data used for the eligibility estimates are for April 1, 2000, while the administrative databases used for the enrollment estimates cover a number of different time periods, including the end of 1999 for Medicare, last quarter 1999 for Medicaid, and 1999 to 2000 for SCHIP. [39]

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[39] We considered using data from the BIA for this study, but rejected this source as it was deemed incompatible. The BIA annually produces a report providing estimates of Tribal service populations and labor market information for the nation's Federally Recognized Tribes. This information is collected from the individual tribes via a survey form and pertains to the population eligible for services from the BIA – enrolled members and members from other Tribes who were eligible to use the Tribe's BIA-funded services. There are three particular data items that could be of interest: (1) BIA Tribal Enrollment; (2) BIA Total Indian Reservation Service Population; and (3) BIA percent of the AI/AN population that is unemployed and/or employed but with incomes below the Federal Poverty Level. Data from BIA are not comparable to other sources for several reasons. In terms of defining the AI/AN population, BIA data use Tribal enrollment data that are generally based on blood quantum. Total Indian Reservation Service Population includes those enrolled in Federally Recognized Tribes living on or near the Reservation as well as children of enrolled members who may not themselves be eligible and members of a Federally Recognized Tribe living on a different Reservation than the one through which they are eligible. Thus, at a local level, the BIA data are not likely to correspond to other sources based on use of services (IHS) or residence (Census). BIA data on poverty

County-level estimates introduce another source of error particularly in using the 1990 Census micro-data (a 5 percent sample). Because not all data elements and required cross-tabulations were available from the 2000 Census, we relied on the 1990 public use micro-data for some estimates (e.g., the proportion of persons receiving Social Security income). In many counties, the number of elderly AI/ANs and non-elderly disabled AI/ANs was quite small, leading to unstable estimates. In addition, cross-County movements – either in terms of changes in residence or obtaining health care in a different County than the County of residence – contribute to the instability of estimates.

Finally, Census data may undercount the AI/AN population. There was a severe undercount of American Indians in the 1990 Census; while a great deal of effort was made in the 2000 Census to improve methods and it is generally felt that the count was more accurate, there remains some uncertainty about the completeness of the count of the number of AI/ANs in the 2000 Census.

All of these issues contribute to the inability to generate reliable and valid estimates of the number of AI/ANs who are eligible for and enrolled in Medicaid, SCHIP, and Medicare. The results of the analyses that were conducted, presented through illustrative estimates, indicate the significant limitations of current data sources and the lack of confidence that should be placed in the estimates that were generated.

Alternative Approaches

Problems with existing data sets that could be used to estimate AI/AN eligibility for Medicaid, SCHIP, and Medicare include a lack of precise data to identify respondents as members of Federally Recognized Tribes, members of non-Federally Recognized Tribes, and those who have some AI/AN heritage and maintain cultural and social ties to AI/AN communities. It might be possible to develop standard survey questions that could be used in all Federally funded surveys that would permit more precise identification of AI/AN race and group identification. If so, then future estimations of AI/AN eligibility could be improved. The second significant problem with existing data sets, with the exception of Census data, is that sample sizes are generally not large enough to produce sufficient numbers of AI/AN respondents to permit analyses that focus on subgroups of the AI/AN population and urban, rural, and Reservation level analyses to be conducted. Substantial expansion of survey sample sizes would be necessary to obtain the larger AI/AN samples that would permit the estimation of AI/AN eligibility for Medicaid, SCHIP, and Medicare for alternative AI/AN subgroups and for State and sub-State geographic units.

Given these limitations and the small likelihood that existing surveys could easily be modified to permit the desired analyses to be conducted, we identified two alternative approaches that were discussed with CMS that could provide more reliable information as to whether there is AI/AN program under-enrollment: 1) new data collection, or 2) meta-analysis of existing survey data sources.

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tend to fluctuate seasonally and are subject to change when AI/ANs working off-Reservation lose their jobs and return home. Thus, it is not likely to be comparable to Census figures

New Data Collection

If the definition of the AI/AN population were narrowed to include only members of Federally Recognized Tribes, it would be feasible to undertake new data collection based on Tribal enrollment lists obtained from either individual Tribes or from the Bureau of Indian Affairs. This survey could be limited to a sample of those who live on or near Reservations, using methods similar to those employed to conduct the 1989 NMES of American Indians and Alaska Natives. If Tribes were willing to provide the survey sample frame from Tribal enrollment lists, which include addresses of all enrolled members, then it might be feasible to survey members of Federally Recognized Tribes who live both on/near and off-Reservations in urban or non-urban areas. A similar approach could be used to survey members of Tribes that are not Federally Recognized, to the extent that these Tribes maintain Tribal enrollment lists with names and addresses. However, any approach that relies on Tribal agreement to provide sample frames from Tribal enrollment lists would likely require extensive negotiation to obtain approval of the survey participation with each Tribe – a potentially lengthy and resource-intensive process. Other approaches to a survey of members of Federally Recognized or non-Federally Recognized Tribes that included non-Reservation areas would be substantially more expensive because of the small size of the target population, although there might be some approaches that would be less resource intensive that would build on on-going data collection efforts.

Meta-Analysis of Existing Survey Data

A more feasible and less costly approach would be a meta-analysis of existing survey data. Such an analysis could provide aggregate estimates for the 15 study states of the enrollment/eligibility ratio (or take-up rate). There are at least three national survey databases that would be useful in such an endeavor – the CPS, the SIPP, and the NHIS. [40] One of the advantages of using these survey data over Census or administrative program data is that the race coding relies on self-report in the context of an in-person interview so it is less likely to be "missing" or coded as "other." In addition, most of the national health surveys obtain data on program enrollment, as well as a wide array of data on income and assets, family structure, and work history needed to estimate eligibility for the three programs in which CMS is interested.

The most obvious limitation of these survey data sets is their sample sizes for AI/ANs. Preliminary tabulations of the March 2001 CPS indicate that there are 462 AI/AN children aged 17 and younger in the 15 study states and 93 AI/ANs aged 65 and older in these states. (This is without the expanded sample that has been fielded specifically to enable studies of SCHIP enrollment.) NHIS has the same approximate total sample size and the yield of AI/ANs should be roughly comparable, although it is difficult to predict precisely given the different sample design used for the two surveys. SIPP sample sizes will be somewhat lower, but – given the availability of certain data items (e.g., assets) – it would likely be worth exploring. These numbers are sufficient for estimating the percentage of persons eligible for each of the three programs for the 15 study States as a group. While the numbers are not large, using three different data sets to conduct the analysis would allow increased confidence in the findings. Depending on sample sizes, some States might have to be combined for purposes of estimation.

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[40] One could also consider use of the National Survey of America's Families (NSAF), the Medical Expenditure Panel Survey (MEPS), the Survey of Program Dynamics (SPD), and the Health and Retirement Survey.

Medicaid/SCHIP

The basic approach that would draw on analysis of existing survey data has been used previously for overall estimates of Medicaid and SCHIP eligibility. [41] In order to simulate eligibility for each of the two programs, one of the first steps is to gather background information on program eligibility determination in each of the 15 States. This requires collecting information on the income standards applied, methods used for measuring assets, rules concerning family composition, and any other pertinent regulations, as was done for this study. Because of the variability across States and between the two programs within a given State, each State-program pair's eligibility rules must be simulated in a separately constructed computer algorithm. Each survey varies in the types of information collected, but all can be used to approximate eligibility. [42] The level of intricacy in modeling of eligibility could vary according to time, resource, and sample size constraints.

The results from this process would provide an estimate of the number of AI/AN persons eligible for each Medicaid and SCHIP program across the 15 States. Calculation of the number of AI/ANs enrolled in the programs is more straightforward. For the CPS, data about program enrollment is obtained once during administration of the March supplement. For the NHIS, program enrollment is also asked only once during the interview. SIPP, in contrast, collects data on a monthly basis during interviews that take place every four months; because Medicaid and SCHIP status may change over time, rules would be required to define the relevant time period for being enrolled.

Medicare

Estimating eligibility for Medicare, at least with respect to the elderly population, is more straightforward. For persons 65 years old or older, eligibility for Part A of Medicare (health insurance or HI) is primarily based on having paid in to Social Security for 40 quarters. Using survey data, it would be possible to define the eligible population as those persons who are 65 or older and who receive Social Security benefits (or Railroad Retirement benefits). As described above for Medicaid/SCHIP, program enrollment is reported on each of the surveys.

Discussion of the Feasibility of Estimating AI/AN Eligibility and Enrollment

The objectives, methodologies, and results reported in this study illustrate the complexity and difficulties associated with estimating AI/AN eligibility and enrollment in Medicaid, SCHIP,

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[41] See, for example, Davidoff AJ, Garrett AB, Makuc DM, Schirmer M. "Medicaid-eligible children who don't enroll: health status, access to care, and implications for Medicaid enrollment," Inquiry 2000 Summer; 37(2):203-18; Irvin C and Czajka J. Simulation of Medicaid and SCHIP Eligibility: Implications of Findings From 10 States. Final Report submitted to the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, August 16, 2000; Selden TM, Banthin JS, Cohen JW. "Medicaid's Problem Children: Eligible but Not Enrolled," Health Affairs 1998, 17(3):192-200; and Selden TM, Banthin JS, Cohen JW. "Waiting in the Wings: Eligibility and Enrollment in the State Children's Health Insurance Program," Health Affairs, 1999, 18(2):126-133

[42] Neither CPS nor NHIS have data on assets; due to confidentiality issues, NHIS must be used in the NCHS Research Data Center, presenting some logistical problems; NSAF may have less reliable data for Native Americans because it is a telephone survey and this population (at least those living on or near Reservations) have extremely high rates of noncoverage by telephones.

and Medicare. Lack of data sources that are comparable and consistent for estimating eligibility and enrollment are a major deterrent to producing reliable and valid estimates. In addition, the issue of alternative definitions of the AI/AN population in available data sources compounds the difficulties of estimation. The alternative strategies that might be considered for future research efforts include new data collection or attempts to use meta-analysis of existing survey data that potentially provide more consistent and comparable measures of program eligibility measures and program enrollment. However, designing and conducting a new survey would be a lengthy and costly process. Alternatively, conducting meta-analyses of data available from existing surveys could improve estimates but would likely only be able to produce estimates for multi-State areas or at a national level, due to the small AI/AN population. This aggregation would limit the usefulness of the results and would not permit identification of States or sub-State areas where under-enrollment may be a substantial issue. However, the analysis could provide more reliable estimates of AI/AN eligibility, enrollment, and the ratio of enrollment to eligibility at the national level that could be useful in assessing the extent to which under-enrollment exists, by program, and the characteristics of AI/ANs who are eligible but not enrolled. This information could provide a better foundation for designing programs that target specific segments of the AI/AN population for outreach and assistance.

CASE STUDIES: IDENTIFIED BARRIERS TO ENROLLMENT AND SUGGESTED STRATEGIES

OVERVIEW

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 the case study objectives, 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 the persons other than AI/ANs only 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 United States. 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.

Other Barriers to Enrollment in Medicaid, SCHIP, and Medicare [43]

Other 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;

- Communication barriers, including limited access to television, radio, the Internet, and telephone, as well as lack of a permanent mailing address, [44] 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;

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[43] 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.

[44] 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. Source: Personal communication from Balerma Burgess, IHS, November 28, 2003.

- 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-certification 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.

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?

For the comparative case study, information from key informants was gathered through in-person and follow-up telephone interviews, individual case studies of each State were prepared, and comparisons were developed across the 10 States to identify unique and common themes that emerged from the interviews. A detailed description of the site visit methodology and analytic methods is provided in Appendix C to this report, a list of organizations interviewed is provided in Appendix D, and the interview guide is included in Appendix E.

LIMITATIONS OF CASE STUDY

The case study component of this study was developed to obtain information on AI/AN barriers to program enrollment and suggestions for strategies to facilitate enrollment from Tribal representatives, State officials, health providers that serve AI/AN populations, and other knowledgeable people. In the 10 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 reliability and validity of the findings. These limitations include:

- Individual interviewees expressed their views and perceptions, based on their own experiences and situations. No independent validation of these views and perceptions was conducted by the project team 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 Tribes/Reservations. [45] 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

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[45] 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.

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: IDENTIFIED 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.

Most identified 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 Member Circumstances and to State Medicaid/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 State to identify differences across States in issues raised by any respondents. Table 3 presents this information, with a circle indicating that one or more interviewees in a specific State identified the indicated barrier as an issue. Table 4 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, and are reported and summarized in the separate Summary Case Study Report submitted to CMS.

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 4 presents information on whether a specific barrier was reported as an issue by any interviewee in the State. The information in Table 4 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 3. 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 Member Circumstances										
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 Organization and 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/SCHIP Organization and 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 Organization and 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 Member

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. [46] 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.

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[46] 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.)

- 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.

- 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 stigma. 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 facilities on Reservations and Urban Indian Health Clinics do not have adequate resources to provide the outreach, education, and enrollment application/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. [47]

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

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[47] 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

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 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 Social Security Disability Income (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.

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: SUGGESTED STRATEGIES TO INCREASE 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 4 presents information on whether a specific strategy was suggested by any respondent group in the State. The information in Table 4 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. We also compared the frequencies with which specific strategies were suggested by Tribal, State, Urban Indian Clinic, and other organizations' respondents, and are reported and summarized in the separate Cross-Cutting Case Study Report submitted to CMS.

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.

States in which interviewees mentioned a specific strategy to reduce barriers and facilitate AI/AN enrollment are presented in Table 4.

Table 4: 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/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%)				●	●				●	

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.

- <u>Develop Outreach and Enrollment Assistance Strategies Targeted to AI/AN Elders</u>. 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.

- <u>Strengthen Tribal/IHS Incentives to Promote AI/AN Program Enrollment</u>. 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).

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.

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, 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 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 employees who work with Medicare and Social Security Retirement and Survivor's Benefits, Social Security Disability Income (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.

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.

SUMMARY AND DISCUSSION

The objectives of this study were to: 1) estimate the number of AI/ANs who are eligible for and enrolled in Medicaid, SCHIP, and Medicare and to determine whether, and to what extent, under-enrollment is observed for this population, and 2) obtain information on barriers that affect AI/AN enrollment in these programs and on strategies that could be effective to facilitate and increase AI/AN program enrollment.

Due to significant limitations of currently available data, the study's findings suggest that it is not possible to reliably estimate AI/AN eligibility, enrollment, and take-up rates for the Medicaid, SCHIP, and Medicare programs. Census 2000 provides the only complete and consistent data source for estimating eligibility for these programs for people who identify their race as AI/AN. However, the 2000 Census – for the first time – added questions that permit people to identify themselves with multiple races. The 1990 Census, which did not permit multiple race identification, indicated that there were less than 2 million AI/ANs. The 2000 Census reports over 4 million AI/ANs, either identifying as AI/AN race only or in combination with other races. Thus, between 1990 and 2000, the Census finds a 110 percent increase in the number of AI/ANs counted, compared with a 13 percent increase in the total U.S. population.

This dramatic increase suggests that a substantial number of people may be reporting AI/AN race who would not identify AI/AN as their primary race.

The data available to estimate AI/AN enrollment in Medicaid, SCHIP, and Medicare, by contrast, include only primary racial identifications. This difference in data sources results in inconsistent and unreliable estimates of the take-up rate (calculated as the estimated number of AI/ANs enrolled in specific programs divided by the estimated number of AI/ANs eligible for enrollment). These problems are exacerbated when estimates of eligibility and enrollment are made at the State and sub-State levels, due to small population numbers in most rural areas.

More reliable estimates of eligibility and enrollment at the national or State level would require additional targeted data collection, possibly focused on specific AI/AN population definitions (e.g., only enrolled members of Federally Recognized Tribes). The costs of such a data collection effort would likely be quite high. An alternative would be conducting meta-analysis of existing survey data to produce estimates of eligibility and enrollment of AI/ANs. Sample sizes of various potential data sources would limit these estimates to national levels, however.

The second component of this study was case studies of 10 States to obtain insights and information from a wide variety of people, including representatives from Tribes, Indian Health Service Areas and Service Units, Urban Indian Health Clinics, and State Medicaid and SCHIP offices. Results of these interviews provided useful information on perceived barriers to enrollment in each program and also identified strategies to increase AI/AN enrollment in Medicaid, SCHIP, and Medicare. The most frequently identified strategies emphasized increased outreach, education, and one-to-one assistance with enrollment, as well as greater involvement and direct funding for Tribes, Tribal organizations, and Urban Indian Health Clinics to undertake these activities.

Given these findings, if is of interest that the current Senate version of the reauthorization of the Indian Health Care Improvement Act includes provisions that would authorize "funding for tribes for outreach services, including education regarding eligibility and benefits, translation services, and transportation to eligibility offices (section 404 of S. 556 and section 402 of H.R. 2440)." [48] In addition, the bill includes provisions that would eliminate premiums, deductibles, and copayments for AI/ANs enrolled in Medicaid and Medicare and, if passed into law, would reduce financial barriers to enrollment in the programs. [49]

American Indians and Alaska Natives face many challenges that contribute to their documented poor health status. Although financial barriers to accessing health care are only one of these challenges, enrollment in Medicaid, SCHIP, and Medicare for those who are eligible offers the potential to increase access to health services by expanding revenues available to the Indian Health Service and Tribally managed health facilities, as well as increasing financial access to health services for AI/ANs who do not use IHS or Tribally managed health facilities. Results of this study provide information and strategies that, if implemented, may increase AI/AN enrollment in these programs.

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[48] Statement by Mim Dixon to Senate Committee on Indian Affairs Hearing on Reauthorization of the Indian Health Care Improvement Act, July 23,2003.
[49] Ibid.

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APPENDIX A: TECHNICAL EXPERT PANEL MEMBERS AND PROJECT CONSULTANTS

Technical Expert Panel (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
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: DETAILED METHODOLOGY FOR ESTIMATION OF NUMBER OF PEOPLE ELIGIBLE FOR MEDICARE, MEDICAID, AND SCHIP

Methodology for Estimating Medicare Eligibility

<u>Aged</u>

Upper and lower bound estimates were developed for the number of elderly AI/ANs that were eligible to enroll in Medicare. The lower bound estimate uses 1990 Census micro-data to estimate the proportion of persons 65 and over receiving Social Security income and applies that proportion to the 2000 counts of persons 65 and over. The 1990 micro-data were used to estimate the proportion of persons receiving Social Security income because the 2000 micro-data were not yet available. We produced these estimates at the area (areas are aggregations of counties and are the smallest geographic unit provided on the micro-data), as well as for each of the 15 states. We then tested the estimated percentages of the proportion of persons receiving Social Security income for each area (using a chi-square) to see if variation across areas within a State was significantly different. If there was statistically significant variation, we used the area-level estimates where sample sizes allowed (defined as the number of observations being greater than 20). If sample sizes were too small to be reliable or there was no statistically significant variation across counties, the State-level proportion was used. Four of the 15 states had significant variation across areas in the estimated proportions (Montana, New Mexico, Oklahoma, and South Dakota). The upper bound estimate simply counts all persons 65 and over using the 2000 Census data. Upper and lower bounds were estimated using, first, single and, then, multiple race reporting.

<u>Non-Aged Disabled</u>

We used the 1990 Census data to estimate the proportion of persons less than 65 years of age who were likely to be not working due to disability. This estimated proportion was applied to the 2000 population estimate for AI/ANs from 21 to 64 years of age. As with the Medicare elderly, we used an area proportion where possible. We tested across areas within each State to see if the variation was statistically significant (using chi-squares). For the four states with no variation, we used the State average. For the other states, we used the area proportion unless there were fewer than 50 cases or the proportion was zero, in which cases we used the State proportion. Estimates were produced for persons reporting race as AI/AN only or as AI/AN as one of multiple races.

<u>Modifications to Initial Approach to Estimating Medicare Eligibility</u>

We conducted a number of tests to benchmark our estimates. With regard to the proportion of AI/ANs reporting receipt of Social Security income, we calculated, for the 15 study states, the percentage of the non-Hispanic white population reporting receipt of such income for purposes of comparison. These proportions were uniformly higher for the White population: the State averages among elderly AI/ANs were between 54 and 87 percent, compared to 85 to 92 percent among non-Hispanic Whites. It is not clear how much of these differences are due to

actual differences versus differences in accuracy of reporting. In addition, during this phase of the analysis and, in particular, when examining initial program take-up rates, it became clear that estimates of the Medicare eligible population (especially for the aged population) appeared to underestimate the true number of Medicare eligible AI/ANs. Analysis of 2000-2002 Current Population Survey (CPS) data for the 15 study states found that 91.9 percent of elderly AI/ANs were enrolled in Medicare, while only 82.7 percent were receiving Social Security, indicating that a proportion of AI/ANs were gaining Medicare eligibility by other means than Social Security entitlement. In addition, preliminary calculations yielded take-up rate estimates of in some instances several hundred percent, which also suggested that the Medicare eligibility estimates may be somewhat low. (Given the particularly low take-up rates we obtained for California, we analyzed the California Health Interview Survey data and estimated that 92.8 percent of elderly AI/ANs report being covered by Medicare.) In response to these findings, a decision was made to use Census population totals – rather than the estimates based on receipt of Social Security income – for calculating the take-up rate estimates.

Methodology for Estimating Medicaid and SCHIP Eligibility

Although the Federal government establishes general guidelines for the Medicaid program and for SCHIP, eligibility requirements are actually established by each State. Thus, eligibility information was gathered on a State-by-State basis and for a number of different eligibility groups. Within each State, the Medicaid estimates were calculated separately for each of the following eligibility groups while SCHIP estimates apply only to children:

- Children

- Pregnant women

- Parents.

- Adults, not parents

- Aged (SSI)

We were unable to calculate estimates for medically needy individuals (individuals who have spent over a given percentage of their income on medical expenses) because there are no available data on medical expenditures for AI/ANs at the County level (or even the State level). SCHIP eligibility estimates were calculated separately in states that had a separate program, and are included in Medicaid estimates where there is a Medicaid expansion. For combined programs (CA, MI, NY ND, and SD), individuals are allocated to Medicaid or SCHIP depending on their specific eligibility.

<u>Children</u>

We obtained information on State eligibility criteria for children for both Medicaid and SCHIP.[50] While there are relatively limited data available to make eligibility estimates, we based our calculations on population counts by age and relative to the Federal Poverty Level.

We used State and County level data from the 2000 Census to count the number of AI/AN children below the poverty level. [51] Separate estimates were made for the following age categories: 0-5, 6-16, and 16-17.

Two issues arose with respect to the poverty status data. First, since income (poverty status) data is only available from the Census long form, this information is based on a sample of persons rather then the universe. The result is that there were many counties in which we had to work with small sample sizes. Depending on the sample size in a given County, we calculated weighted State/County poverty proportions for each of the age categories. If the population was small, the State portion of the proportion was weighted more heavily and if the population was large the County portion of the proportion was weighted more heavily.

The second issue with respect to the poverty status data is that, as of the time of our analysis, the Census Bureau had only released poverty status by race for below 100 percent of the poverty line and greater than 100 percent of the poverty line (rather than, for example, the number of persons between 100 and 125% of the poverty level). Thus, we had to interpolate estimates of the number of children below other specific poverty levels (e.g., 200 percent of the poverty line). We developed an interpolation chart that allowed us to estimate the proportion of children in a given age for each of the specific Medicaid thresholds for each of the 15 states.

The interpolation chart was based on our estimation of the continuous income or poverty status distribution for three groups – children less than 18 years of age; parents; and the 65 and over population. We used the 2000 Census Supplementary Survey; the public use file contains approximately 300,000 observations, with the ratio of total family income to the Federal Poverty Level as a continuous variable. Because the number of observations for AI/ANs was limited, we pooled states into two groups – predominantly Reservation states (AZ, MT, NM, ND, SD, and UT) and all others. Based on the estimated continuous distribution, we could estimate the proportion of the particular group falling between any two poverty status levels.

As an example of how the interpolation was used, we can look at Santa Cruz County, Arizona, where information from the Census Bureau tells us that 45 percent of children 0 to 5 are estimated to be under 100 percent of the poverty line. However, in Arizona children 0 to 5 are

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[50] Medicaid figures were from Table 1: State Income Eligibility Guidelines from a study entitled "Making It Simple: Medicaid for Children and CHIP Income Eligibility Guidelines and Enrollment Procedures; Findings for a 50-State Survey." Center on Budget and Policy Priorities, The Kaiser Commission on Medicaid and the Uninsured, October 2000: http://www.kff.org/content/2000/2166/hjksmall.pdf. The SCHIP eligibility guidelines come from the Centers for Medicare and Medicaid website detailing the different states' children health insurance updated program information in their SCHIP Annual Reports: http://cms.hhs.gov/schip/charST99.pdf (ST: AK, AZ, CA, MI, WA, MT, SD, MN, ND, NM, NY, OK, WI, OR, and UT).

[51] Counts by sex, age, and poverty status were obtained from http://factfinder.census.gov at the County level. The downloaded table's name is listed as PCT75C. Poverty Status in 1999 by Sex and Age (AI/AN Alone) on the website.

eligible for Medicaid if they are under 140 percent of the poverty guideline. Based on our interpolation chart, the proportion of eligible children in the 0-5 age category is 54.9 percent. The proportions of children in each age category eligible for Medicaid are calculated using this methodology for each County. This same approach was also used to estimate the SCHIP proportions for the 0-17 age category.

We applied these new proportions to the Census 2000 population counts for the 0 to 18 population data. [52] This results in the estimated number of AI/AN children in each specific age category eligible for Medicaid for each County in the 15 states. For the number of SCHIP eligible children we applied the proportion calculated in step 6 to the total population of children 0-18 and then subtracted the total number of children eligible for Medicaid. If the State did not have a separate SCHIP program then the number of children eligible for SCHIP was left as 0 for counties in these states (i.e., the number was included with the Medicaid estimates).

Pregnant Women

Because there are no available data on the number of pregnant women, we used the 0-5-age category proportion to approximate the birth rate among AI/ANs. Instead of simply using 1/5 of children 0-5 under 100% FPL to estimate the proportion of pregnant women under 100% FPL, we used a slightly higher proportion (0.3) to account for miscarriages and abortions. After interpolating the proportion of pregnant women eligible for Medicaid in each State (based on the eligibility rules for each State) we applied the new proportion to the population of 0-5 year-olds.

Parents

We obtained information on State eligibility criteria for parents. [53] We used State and County level poverty estimates from the Census 2000 data [54] to calculate separate poverty estimates for married and single parents. The same methodology described above was used to overcome small sample sizes for certain counties. Depending on the size of the County population from this sample data we calculated weighted State/County poverty proportions for single and married parents. If the population was small, the State portion of the proportion was weighted more heavily and if the population was large, the County portion of the proportion was weighted more heavily.

Since the proportions calculated in are based on 100 percent of poverty we used the interpolation chart described above to estimate the proportions based on the specific Medicaid thresholds for each of the 15 states. For instance, in Minnesota married parents under 275 percent of the poverty guideline are eligible for Medicaid. Thus, using Wilkin County, Minnesota as an example – 11 percent of married parents are estimated to be under 100 percent of the poverty line. According to our interpolation method, 42.3 percent of married parents are

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[52] We used Summary File 1, PCT12C. Sex by Age for the AI/AN Alone population.
[53] Table 3: Countable Income-eligibility Thresholds and Earnings Disregards Policies, All Applicable Eligibility Categories from a study "Expanding Family Coverage: States' Medicaid Eligibility Policies for Working Families in the Year 2000." Center on Budget and Policy Priorities, February 2002: http://www.cbpp.org/1-2-02health.pdf.
[54] Summary File 3, PCT160C. Poverty Status in 1999 of Families by Family Type by Presence of Related Children under 18 Years by Age of Related Children for the AI/AN Alone Householder.

under 275 percent of poverty and thus eligible for Medicaid. The proportions of single and married parents eligible for Medicaid are calculated using this methodology for each County.

We applied these new proportions to the Census 2000 counts of married and single parents.[55] This derives the estimated number of AI/AN Alone married and single parents for each County in the 15 states. Married parents in North Dakota, Utah, and Wisconsin were not covered in 2000 so the number of married parents eligible was left at 0 for counties in these states.

Adults, Not Parents

In 2000, Oregon was the only study State in which adults who are not parents were eligible for Medicaid. We used Oregon State and County level poverty estimates for the 18 to 64-age category from the long form (sample) Census 2000 data.[56] The same approach as described above was used to deal with small sample sizes in some counties. We based our estimates on the number of adults eligible, subtracting out the estimated number of pregnant women and parents eligible in each Oregon County.

Aged

There are several ways in which the aged population can be eligible for Medicaid. Institutionalized elderly are eligible based on income and some community-based elderly are eligible through State home and community-based waivers. For community-based elderly, other routes to eligibility are based on State-specific income standards and/or eligibility for SSI. Because of limited availability of the specific data items needed and small aged sample sizes, we used as a proxy for eligibility the proportion of AI/AN elderly receiving SSI. Estimates were based on the March 2000 Supplement to the Current Population Survey and the estimated proportion was then applied to the Census 2000 65 and over population data to derive the estimated number of AI/AN Alone elderly eligible for Medicaid for each County in the 15 states.

As with the Medicare estimates, two sets of Medicaid estimates were prepared: one for single AI/AN race identification and one for multiple race identification.

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[55] Summary File 1, P35C. Family Type by Presence and Age of Related Children for the AI/AN Alone Householder.
[56] Summary File 3, PCT75C. Poverty Status in 1999 by Sex by Age for the AI/AN Alone.

APPENDIX C: TABLES SHOWING RESULTS OF ESTIMATES OF AI/AN ELIGIBILITY, ENROLLMENT, AND TAKE UP RATES: MEDICARE AND MEDICAID PROGRAMS

Table C.1. Direct Lower Bound Estimates of AI/AN Aged Population Estimated in Medicare

State	AI/AN Population (CENSUS) (AI/AN Only)	AI/AN Population (CENSUS)(AI/AN Multiple Race)	Count of AI/ANs from Matched EDB/IHS Data	Lower Bound Estimate of Enrollment(including IHS/MSIS Matches)	AI/AN Multiple Race Take up Rate	AI/AN Only Take up Rate
	(a)	(b)	(c)	(d)	(e)	(f)
Alaska	5,728	6,361	5,746	5,814	0.91	1.02
Arizona	14,199	16,348	11,706	11,809	0.72	0.83
California	20,238	38,449	8,058	8,516	0.22	0.42
Michigan	3,158	7,136	1,957	2,044	0.29	0.65
Minnesota	2,276	3,312	2,156	2,331	0.70	1.02
Montana	2,711	3,257	2,723	2,810	0.86	1.04
New Mexico	10,413	11,401	8,830	8,993	0.79	0.86
New York	5,895	11,655	2,064	2,567	0.22	0.44
North Dakota	1,339	1,497	1,345	1,375	0.92	1.03
Oklahoma	18,845	29,001	21,114	21,565	0.74	1.14
Oregon	2,302	4,853	1,836	1,943	0.40	0.84
South Dakota	2,775	3,057	2,669	2,754	0.90	0.99
Utah	1,098	1,432	767	816	0.57	0.74
Washington	4,637	8,057	3,719	3,919	0.49	0.85
Wisconsin	2,320	3,394	2,085	2,117	0.62	0.91
Total	**97,934**	**149,210**	**76,775**	**79,373**	**0.53**	**0.81**

Notes: Col a.   Number of 65+ individuals reported as AI/AN only on 2000 Census.
Col b.   Number of 65+ individuals reported as AI/AN in addition to another race/ethnicity on the 2000 Census.
Col c.   Number of Aged Medicare beneficiaries coded as AI/AN after EDB/IHS match.
Col d.   Number of Aged Medicare beneficiaries coded as AI/AN after EDB/IHS/MSIS match.
Col e.   Equals Col (d)/Col (b).
Col f.   Equals Col (d)/Col (a).

Table C.2. Indirect Upper Bound Estimates of AI/AN Aged Population Estimated in Medicare

State	Count of AI/ANs from Matched EDB/IHS Data	Confirmed AI/AN by MSIS Match	Confirmed AI/AN by MSIS or IHS Match	Miscoded Identified by MSIS Match	Confirmed Miscode Ratio by MSIS Match	Estimate of Additional Miscodes	Upper Bound Estimate of Enrollment 1999	AI/AN Multiple Race Take up Rate	AI/AN Only Take up Rate
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(I)
Alaska	5,746	2,355	5,693	68	34.63	2	5,816	0.91	1.02
Arizona	11,706	4,753	11,365	103	46.15	7	11,816	0.72	0.83
California	8,058	307	5,659	458	0.67	3,579	12,095	0.31	0.60
Michigan	1,957	165	1,521	87	1.90	230	2,274	0.32	0.72
Minnesota	2,156	692	1,990	175	3.95	42	2,373	0.72	1.04
Montana	2,723	685	2,621	87	7.87	13	2,823	0.87	1.04
New Mexico	8,830	2,114	8,624	163	12.97	16	9,009	0.79	0.87
New York	2,064	128	692	503	0.25	5,392	7,959	0.68	1.35
North Dakota	1,345	468	1,319	30	15.60	2	1,377	0.92	1.03
Oklahoma	21,114	3,486	20,538	451	7.73	75	21,640	0.75	1.15
Oregon	1,836	196	1,597	107	1.83	130	2,073	0.43	0.90
South Dakota	2,669	1,001	2,595	85	11.78	6	2,760	0.90	0.99
Utah	767	394	700	49	8.04	8	824	0.58	0.75
Washington	3,719	614	3,289	200	3.07	140	4,059	0.50	0.88
Wisconsin	2,085	121	1,874	32	3.78	56	2,173	0.64	0.94
Total	76,775	17,479	70,077	2,598	6.73	9,698	89,071	0.60	0.91

Notes: Col a. Number of Aged Medicare beneficiaries coded as AI/AN after EDB/IHS match.
Col b. Number of Aged Medicare beneficiaries confirmed as AI/AN by matching with MSIS data.
Col c. Number of Aged Medicare beneficiaries confirmed as AI/AN by matching with either the MSIS or IHS data.
Col d. Number of Aged AI/AN Medicare beneficiaries identified as being miscoded in the EDB by matching with the MSIS data.
Col e. Calculated as Col (b)/Col (d).
Col f. Calculated as (number of unconfirmed AI/ANs) x Col (e), where unconfirmed AI/ANs equals Col (a) – Col (c).
Col g. Equals lower bound estimate (Table 2, Col (d)) + Col (f).
Col h. Equals Col (g)/(Table 2, Col (b)).
Col i. Equals Col (g)/(Table 2, Col (a)).

Table C.3. Summary of Direct and Indirect Eligibility and Enrollment Estimates of the AI/AN Aged Population in Medicare

State	AI/AN Aged Population		Enrollment		Take Up Rates			
	AI/AN Only	AI/AN (Multiple Race)	Lower Bound: EDB with IHS/MSIS	Upper Bound: Indirect Estimate	Direct Estimate (Multiple Race)	Indirect Estimate (Multiple Race)	Direct Estimate (AI/AN Only)	Indirect Estimate (AI/AN Only)
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)
Alaska	5,728	6,361	5,814	5,816	0.91	0.91	1.02	1.02
Arizona	14,199	16,348	11,809	11,816	0.72	0.72	0.83	0.83
California	20,238	38,449	8,516	12,095	0.22	0.31	0.42	0.60
Michigan	3,158	7,136	2,044	2,274	0.29	0.32	0.65	0.72
Minnesota	2,276	3,312	2,331	2,373	0.70	0.72	1.02	1.04
Montana	2,711	3,257	2,810	2,823	0.86	0.87	1.04	1.04
New Mexico	10,413	11,401	8,993	9,009	0.79	0.79	0.86	0.87
New York	5,895	11,655	2,567	7,959	0.22	0.68	0.44	1.35
North Dakota	1,339	1,497	1,375	1,377	0.92	0.92	1.03	1.03
Oklahoma	18,845	29,001	21,565	21,640	0.74	0.75	1.14	1.15
Oregon	2,302	4,853	1,943	2,073	0.40	0.43	0.84	0.90
South Dakota	2,775	3,057	2,754	2,760	0.90	0.90	0.99	0.99
Utah	1,098	1,432	816	824	0.57	0.58	0.74	0.75
Washington	4,637	8,057	3,919	4,059	0.49	0.50	0.85	0.88
Wisconsin	2,320	3,394	2,117	2,173	0.62	0.64	0.91	0.94
Total	**97,934**	**149,210**	**79,373**	**89,071**	**0.53**	**0.60**	**0.81**	**0.91**

Notes: Col a.   Number of 65+ individuals reported as AI/AN only on 2000 Census.
Col b.   Number of 65+ individuals reported as AI/AN in addition to anther race/ethnicity on the 2000 Census.
Col c.   From Table 2, Col (d).
Col d.   From Table 3, Col (g).
Col e.   Equals Col (c)/Col (b).
Col f.   Equals Col (e)/Col (b).
Col g.   Equals Col (c)/Col (a).
Col h.   Equals Col (e)/Col (a).

Table C.4. Direct Lower Bound Estimates of AI/AN Population in Medicaid

State	AI/AN Eligibility Estimate (AI/AN Only)	AI/AN Eligibility Estimate (Multiple Race)	AI/ANs in Medicaid (MSIS Only)	AI/ANs in Medicaid (MSIS with IHS/EDB Match)	Multiple Race Take up Rate	AI/AN Only Take up Rate
	(a)	(b)	(c)	(d)	(e)	(f)
Alaska	22,493	27,313	23,643	24,320	0.89	1.08
Arizona	63,121	71,365	68,309	72,083	1.01	1.14
California	62,305	117,404	17,246	33,330	0.28	0.53
Michigan	8,080	18,230	4,647	4,716	0.26	0.58
Minnesota	18,119	26,818	21,618	23,768	0.89	1.31
Montana	14,634	17,359	15,948	16,698	0.96	1.14
New Mexico	54,769	60,569	48,034	52,879	0.87	0.97
New York	17,772	35,350	6,579	7,779	0.22	0.43
North Dakota	8,399	9,608	9,745	9,814	1.02	1.17
Oklahoma	n/a	n/a	44,718	59,646	n/a	n/a
Oregon	10,811	20,147	7,486	10,507	0.52	0.97
South Dakota	25,347	27,791	25,532	26,637	0.96	1.05
Utah	6,215	8,580	6,933	7,321	0.85	1.18
Washington	28,312	48,642	19,355	26,206	0.54	0.93
Wisconsin	9,688	14,438	4,540	8,115	0.56	0.84
Total*	**350,065**	**503,614**	**279,615**	**324,073**	**0.64**	**0.93**

Notes: * Totals exclude Oklahoma.
Col a.   Estimated number of non-medically needy Medicaid eligible individuals reported as AI/AN only on 2000 Census.
Col b.   Estimated number of non-medically needy Medicaid eligible individuals reported as AI/AN in addition to another race/ethnicity on the 2000 Census.
Col c.   Number of non-medically needy AI/ANs enrolled in Medicaid as of December 1999.
Col d.   Number of non-medically needy AI/ANs enrolled in Medicaid as of December 1999 after match to IHS and EDB data files.
Col e.   Equals Col (d)/Col (b).
Col f.   Equals Col (d)/Col (a).

Table C.5. Indirect Upper Bound Estimates of AI/AN Population in Medicaid

State	AI/ANs in Medicaid (MSIS Only)	Confirmed AI/ANs by IHS/EDB Match	Miscodes Identified by IHS/EDB Match	Confirmed to Miscode Ratio by IHS/EDB Match	Estimate of Additional Miscodes	Estimate of Enrollment 1999	Multiple Race Take up Rate	AI/AN Only Take up Rate
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)
Alaska	23,643	22,313	677	32.96	38	24,358	0.89	1.08
Arizona	68,309	60,314	3,774	15.98	414	72,497	1.02	1.15
California	17,246	8,148	16,084	0.51	17,775	51,105	0.44	0.82
Michigan	4,647	2,212	69	32.06	2,421	7,137	0.39	0.88
Minnesota	21,618	13,749	2,150	6.39	1,254	25,022	0.93	1.38
Montana	15,948	9,120	750	12.16	573	17,271	0.99	1.18
New Mexico	48,034	40,871	4,845	8.44	733	53,612	0.89	0.98
New York	6,579	409	1,100	0.37	16,594	24,273	0.69	1.37
North Dakota	9,745	8,675	69	125.72	59	9,873	1.03	1.18
Oklahoma	44,718	35,385	14,928	2.37	3,934	63,580	n/a	n/a
Oregon	7,486	4,952	3,021	1.64	1,546	12,053	0.60	1.11
South Dakota	25,532	21,719	1,105	19.66	182	26,819	0.97	1.06
Utah	6,933	5,206	388	13.42	126	7,447	0.87	1.20
Washington	19,355	12,948	6,851	1.89	3,459	29,665	0.61	1.05
Wisconsin	4,540	3,172	3,575	0.89	1,397	9,512	0.66	0.98
Total*	**279,615**	**213,808**	**44,458**	**4.81**	**46,571**	**370,644**	**0.74**	**1.06**

Notes: * Totals exclude Oklahoma.
Col a. Number of non-medically needy AI/ANs enrolled in Medicaid as of December 1999.
Col b. Number of non-medically needy Medicaid enrollees confirmed as AI/AN by matching with IHS and EDB data.
Col c. Number of non-medically needy AI/AN Medicaid enrollees identified as being miscoded in the MSIS by matching with IHS and EDB data.
Col d. Calculated as col (b)/col (c).
Col e. Calculated as (number of unconfirmed AI/ANs) x col (d), where unconfirmed AI/ANs equals col (a) - col (b).
Col f. Equals lower bound estimate (Table 5, col (d)) + col (e).
Col g. Equals col (f)/(Table 5, col (b)).
Col h. Equals col (f)/(Table 5, col (a)).

Table C.6. Summary of Direct and Indirect Eligibility and Enrollment Estimates of the AI/AN Population in Medicaid

State	AI/AN Medicaid Eligible Population		Enrollment		Take Up Rates			
	AI/AN Only	Multiple Races	Lower Bound: MSIS IHS/EDB	Upper Bound: Indirect Estimate	Direct Estimate (Multiple Race)	Indirect Estimate (Multiple Race)	Direct Estimate (AI/AN Only)	Indirect Estimate (AI/AN Only)
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)
Alaska	22,493	27,313	24,320	24,358	0.89	0.89	1.08	1.08
Arizona	63,121	71,365	72,083	72,497	1.01	1.02	1.14	1.15
California	62,305	117,404	33,330	51,105	0.28	0.44	0.54	0.82
Michigan	8,080	18,230	4,716	7,137	0.26	0.39	0.58	0.88
Minnesota	18,119	26,818	23,768	25,022	0.89	0.93	1.31	1.38
Montana	14,634	17,359	16,698	17,271	0.96	1.00	1.14	1.18
New Mexico	54,769	60,569	52,879	53,612	0.87	0.89	0.97	0.98
New York	17,772	35,350	7,679	24,273	0.22	0.69	0.43	1.37
North Dakota	8,399	9,608	9,814	9,873	1.02	1.03	1.17	1.18
Oklahoma	n/a	n/a	59,646	63,580	n/a	n/a	n/a	n/a
Oregon	10,811	20,147	10,507	12,053	0.52	0.60	0.97	1.12
South Dakota	25,347	27,791	26,637	26,819	0.96	0.97	1.05	1.06
Utah	6,215	8,580	7,321	7,447	0.85	0.87	1.18	1.20
Washington	28,312	48,642	26,206	29,665	0.54	0.61	0.93	1.05
Wisconsin	9,688	14,438	8,115	9,512	0.56	0.66	0.84	0.98
Total*	**350,065**	**503,614**	**324,073**	**370,644**	**0.64**	**0.74**	**0.93**	**1.06**

Notes: * Totals exclude Oklahoma.
Col a.   Estimated number of non-medically needy Medicaid eligible individuals reported as AI/AN only on 2000 Census.
Col b.   Estimated number of non-medically needy Medicaid eligible individuals reported as AI/AN in addition to another race/ethnicity on the 2000 Census.
Col c.   From Table 5, col (d).
Col d.   From Table 6, col (f).
Col e.   Equals col (c)/col (b).
Col f.   Equals col (e)/col (b).
Col g.   Equals col (c)/col (a).
Col h.   Equals col (d)/col (a).

APPENDIX D: SITE VISIT METHODOLOGY AND ANALYTIC APPROACH FOR CASE STUDIES

Site Visit Methods

For each of the 10 States selected for the case study component of the project, site visits were conducted to:[57]

- Two Tribes/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 Center directors).[58]

- An Urban Indian Health Clinic.[59]

- State Medicaid, SCHIP, and other State Offices with knowledge of AI/AN issues relevant to enrollment.

In addition, other 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 all Tribes in a State, AI/AN referral hospitals, AI/AN epidemiological centers, and AI/AN elder housing facilities). In several site visits, County or State Medicaid/SCHIP eligibility workers were also included in group interviews.

The specific Tribes/Reservations that participated in the site visits were selected with input from the project's TEP, project consultants, and CMS and IHS staff. Obtaining agreement from Tribal leaders to participate in the site visits was a lengthy process that required extensive discussion and explanation of the project. Ultimately, all but two Tribes/Reservations that were initially contacted agreed to participate in the site visits. Once agreement was obtained, each Tribe/Reservation 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.

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[57] The 10 States selected for site visits were those with the largest AI/AN population, based on Bureau of Indian Affairs and IHS data.

[58] 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 Technical Expert Panel members who felt that the study would benefit from extending the site visit to include several Tribes/Reservations in specific States.

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

- 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

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 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 Clinics, and other organizations visited or interviewed through follow-up telephone contacts. These individual summaries were reviewed by the site visit team and finalized. A Case Study Report was then prepared for each State that included background information and individual summaries for each Tribe, Urban Indian Clinic, State offices, and other organizations interviewed. A common format was developed for the State Case Study Reports to facilitate cross-site comparisons and analysis.

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

For the comparative case study, information from key informants was gathered in a highly structured method across multiple sites through in-person and follow-up telephone interviews. The project team used a single interview discussion guide in each State to ensure that each 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 the case study, then by classifying identified program barriers and suggested strategies into project team-standardized categories, by constructing matrices by category and type of interviewee, for each State, and finally, by creating matrices that summarized and tabulated frequencies of barriers and strategies by type of interviewee. Cross-case comparisons were 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.

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.

APPENDIX E: 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/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 State Health Insurance Assistance Program
Phoenix Indian Medical Center
State of Arizona, Arizona Health Care Cost Containment System (AHCCCS)/KidsCare (Medicaid/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/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/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/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/SCHIP)
State of South Dakota, Eligibility Office

Utah

Fort Duchesne IHS Service Unit
State of Utah, Department of Health (Medicaid/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/SCHIP)
Yakama Nation
Yakama PHS Indian Health Center

APPENDIX F: 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?