

EXECUTIVE SUMMARY

Background and Methods

This report is based on the findings from a study funded in 2005 by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), U. S. Department of Health and Human Services (DHHS), entitled *Data on Health and Well-being of American Indians, Alaska Natives, and other Native Americans (AI/AN/NA)*. The objectives of this study were to:

- Systematically review federal and other data sets to assess the extent to which data on health and well-being of the American Indian/Alaska Native (AI/AN) and Native Hawaiian/Pacific Islander (NH/PI) populations are available and adequate for identifying and monitoring measures of health and well-being for these groups;
- Prepare a data catalog with information on available data sets with adequate samples of the AI/AN and NH/PI populations for identifying and monitoring health and well-being and for supporting research that could provide useful insights into factors that contribute to disparities; and
- Identify gaps in the available data, current initiatives underway within DHHS and other federal agencies that may reduce these gaps, and strategies that, if implemented, could improve the availability and quality of data on AI/AN/NA health and well-being.

To address the third objective, this report identifies gaps in AI/AN/NA data on health and well-being, strategies for improving AI/AN/NA data availability and quality, and some current initiatives underway within DHHS and other federal agencies that are intended to improve these data.

The findings in this report are drawn from a review of the literature and available reports on AI/AN/NA data, analysis of detailed profiles of 67 data sources that were included in the *Data Catalog on AI/AN/NA Health and Well-being*, an earlier product of this study, and interviews with 13 knowledgeable individuals who provided information on current initiatives underway and additional strategies that could improve the availability and quality of data on AI/AN/NA health and well-being. In developing the data catalog, we identified a set of policy areas relevant to AI/AN/NA health¹ and well-being, including child well-being, economic well-being, educational achievement and opportunities, elder well-being, family well-being, housing indicators, justice system indicators, military/veterans' issues, and transportation quality and availability. The data catalog analysis focuses on the availability of data sets to address each of the identified policy areas.

¹ Health policy topics considered in the catalog include such areas as health status (e.g., self-reported health status, disability rates, mortality/morbidity rates, trends over time); disease-specific prevalence and incidence (e.g., prevalence of diabetes, tuberculosis, sexually transmitted diseases); health disparities of priority interest (e.g., prenatal care/birth outcomes, cancer mortality, substance abuse, alcohol use, mental health, suicide); factors contributing to measured health disparities (e.g., access to health care, utilization rates, health insurance coverage, health care financing, socioeconomic factors, preventative measures); evidence-based practices and programs that address causes of health disparities, result in positive health outcomes, and are generalizable/replicable; and the role of traditional medicine in AI/AN/NA communities.

The methodology used for this study has some limitations, most notably, only 67 data sets were thoroughly reviewed; it was not possible to fully examine the quality of the data sets; and only a limited number of knowledgeable individuals were interviewed to obtain information on current and planned initiatives to improve AI/AN/NA data. Although only 67 data sets comprise the foundation for this report, it is unlikely that there are many other federal or other publicly available databases that have sufficient sample sizes of AI/AN/NA and include measures of health and well-being that would substantially affect the findings of this analysis. (There are of course still yet fewer data sets containing information on individual tribes or other subgroups.) Because it was not possible for us to fully examine the quality of individual databases, it is possible that analysts and researchers who use these data sets may identify quality issues that will result in additional gaps pertaining to the health and well-being policy areas. Finally, it is very likely that the limited number of knowledgeable people who were interviewed were not aware of all of the current and planned initiatives within DHHS and other organizations. Thus, there likely are more activities underway and planned than are presented in this report that could contribute to improved data on AI/AN/NA health and well-being. Given these caveats, this report provides the reader an overview of gaps in AI/AN/NA data, strategies to improve data, and some information on current initiatives that may be valuable in leading to improved data in the future.

Findings: Data Availability and Gaps, By Policy Area and Population Groups

Our analysis of the 67 data catalog profiles indicates that there are more than two data sets available for each of the major policy areas listed earlier, both for the combined AI/AN and combined NH/PI population groups. There are fewer data sets available that permit examination separately of the AI, AN, NH, and PI population groups. When the available data sets are limited to those with sample sizes of 200 or greater, the number of data sets available to examine primary policy issues is reduced (Table ES-1). For most policy issues and population groups, however, there are data sets that can be used to produce information without requiring aggregation of data or special statistical techniques.

**Table ES-1. Data Gaps, by Policy Area and Population Group—
Data Sets With 200 or More Sample Size for Each Population Group**

Policy Area	AI/AN	AI	AN	NH/PI	NH	PI
Child Well-being	>2	Gap	Gap	>2	Gap	Gap
Economic Well-being	>2	Limited	Limited	>2	Limited	Limited
Education	>2	Limited	Limited	Limited	Limited	Limited
Elder Well-being	>2	Gap	Gap	Limited	Gap	Gap
Family Well-being	>2	Limited	Limited	>2	Limited	Limited
Health	>2	>2	>2	>2	>2	Limited
Housing	>2	Limited	Limited	>2	Limited	Limited
Justice System	>2	Gap	Gap	Limited	Limited	Gap
Military/Veterans	Limited	Gap	Gap	Gap	Gap	Gap
Transportation	>2	Limited	Limited	Limited	Limited	Limited

Note: “>2” indicates that there are more than two data sets that permit analysis of the policy area for the specific population group. “Gap” indicates that no data set was identified for that policy area for the specific population group. “Limited” indicates that only one or two data sets were identified for the policy area for the specific population group.

Major findings of this analysis of data sets with at least 200 sample size include:

- For the combined AI/AN population, there are more than two data sets for each policy area, with the exception of military/veterans issues.
- For the combined NH/PI population, five of the 10 policy areas are covered by data sets; there are limited data (i.e., two or fewer data sets) for education, elder well-being, justice system issues, and transportation issues; and no data sets are available for examination of military/veterans issues.
- For the AI and AN populations separately, there are more than two data sets available to examine health issues, no data sets available to examine child well-being, elder well-being, justice system issues, and military/veterans issues and limited data available for each of the other policy areas.
- For the NH group separately, there are more than two data sets available to examine health issues, limited data available to examine economic well-being, education, family well-being, housing, justice system issues, and transportation issues. No data sets are available to examine child-well-being, elder well-being, or military/veterans issues.
- For the PI group separately, there are gaps in data availability for child-well-being, elder well-being, justice system issues, and military/veterans issues and limited data available for examination of each of the six other policy areas.

While we found no gaps in the available data for the combined AI/AN group and only one gap for the combined NH/PI data, there are a substantial number of policy areas for which data are not available to examine health and well-being for the separate AI, AN, NH, and PI groups. It is important, also, to remember that the data sets examined may vary in the indicators available to examine specific issues within a policy area. For some policy areas and issues, there may be inadequate data for analysis of disparities in health and well-being for these population groups, by demographic, geographic, or economic characteristics, even though some data on the issue/policy area may be collected and usable for aggregate analysis.

Findings: Strategies and Current/Planned Initiatives for Improving AI/AN/NA Data Availability

Information on issues that affect AI/AN/NA data availability and quality and strategies to address these issues has been drawn from the literature reviewed, from the discussions held with DHHS staff and other knowledgeable individuals, and from our own assessment of the information obtained and reviewed for this study. We also obtained information from the discussions on current and planned initiatives within DHHS and other federal agencies that may, over the next few years, result in improved data and greater data availability to address a range of health and well-being issues for the AI/AN/NA population groups. Below, the issues that affect data availability and quality and the strategies for improving data that were identified are

summarized. Following that we briefly describe current and planned initiatives within DHHS and other federal agencies related to these strategies.

Issue 1: Small Population Size: AI/AN constitute 1.5 percent² of the U.S. population and NH/PI constitute about 0.3 percent of the U.S. population. Because of their small numbers, many federal and other surveys do not have sufficient sample sizes to obtain representative data for these groups. Several strategies were identified that would address the small population issue, including: 1.a) increase sample sizes of federal surveys to ensure that sufficient samples are obtained to permit analysis of AI/AN and NH/PI health and well-being issues; 1.b) over-sample the AI/AN and NH/PI population in federal surveys in order to obtain sufficient sample sizes for these groups; 1.c) aggregate multiple years of data from surveys that are conducted annually to obtain sufficient AI/AN and NH/PI sample sizes; 1.d) fund and conduct additional methodological studies to develop new approaches to using small samples for estimating AI/AN and NH/PI health and well-being; and 1.e) explore the potential for developing partnerships with AI/AN and NH/PI communities to conduct local area versions of major federal surveys that could supplement national survey data.

Issue 2: Geographic Dispersion and Rural Concentration of the AI/AN and NH/PI Populations: The AI/AN and NH/PI populations are geographically concentrated in rural areas and are geographically dispersed among the general population when they are not residing on reservations or in Native Hawaiian homelands. Rural concentration increases the barriers to inclusion in nationally representative survey samples, and geographic dispersion makes it more difficult to develop sampling strategies that would increase AI/AN/NA representation in national surveys. Strategies that were identified to address these issues include: 2.a) develop and implement new methods for cost-effective identification of AI/AN and NH/PI who reside outside reservations/homelands to permit cost-effective sampling; 2.b) increase rural sample sizes or over-sample AI/AN/NA in these areas to ensure that data on AI/AN residing on reservations and NH residing on homelands are available; and 2.c) fund and conduct research to develop new methodological approaches that would make maximum use of existing data from rural areas, while protecting privacy and confidentiality of respondents.

Issue 3: Misclassification of Race: Race may be reported by officials other than the individual or family members, particularly in vital statistics and administrative databases.³ Studies have shown that misreporting of race may occur often and that the magnitude of misreporting varies geographically. One strategy was identified that would address this issue: 3.a) develop new requirements and guidelines for accurate reporting of race/ethnicity on vital statistics records and administrative databases and provide training for those who are responsible for reporting.

Issue 4: Lack of/Inconsistent Collection of Race Identifiers in Some Data Sources: Race may not be identified or reported on some state and local databases and different states may report race using different racial identifiers. One strategy was identified to address this issue: 4.a) develop guidelines and encourage or require state agencies to collect uniform race/ethnicity data for all federally funded and federal-state jointly funded programs.

² The 2000 Census reports that 0.9 percent of the population lists American Indian/Alaska Native as their only race, while 1.5 percent indicate AI/AN race either alone or in combination with one or more other races.

³ Here, administrative databases include program-specific databases, disease registries, and disease surveillance systems.

Issue 5: Inadequate Racial Representation, Limited Response Rates, and Question Interpretation:

The sampling strategies used for some surveys (e.g., emphasis on urban samples rather than rural) may reduce the likelihood that AI/AN and NH/PI will be representatively included in the survey sample frame. In addition, the use of certain survey methods (e.g., by telephone) may reduce the number of AI/AN and NH/PI due to an inappropriate fit of the method with the circumstances of the target population. Finally, there is also some evidence that cultural and language differences of these populations may result in interpretation and response to survey questions that differ from those of the general population. Strategies that have been identified to address these issues include: 5.a) review sample designs for existing surveys to identify their potential to include AI/AN and NH/PI representatively in surveys and develop approaches that could increase representation; 5.b) fund and conduct additional research on approaches that could increase AI/AN and NH/PI response rates and test/implement these approaches; and 5.c) conduct ongoing cognitive testing of current and new survey instruments and questions to assess the influence of cultural differences in question interpretation and develop alternative wording, if necessary.

Issue 6: Exclusion of Pacific Insular Areas from Some Surveys: The Pacific Insular Areas include dependent territories of the U.S. (Guam, American Samoa, and the Northern Mariana Islands) and the Freely Associated States for which the U.S. provides defense, funding grants, and social services to its citizens (Micronesia, Palau, and the Marshall Islands). Because these areas are very distant from the U.S. mainland and are scattered across a very large geographic area in the Pacific Ocean, most national surveys do not include these territories and Freely Associated States. One strategy was identified to remedy this issue: 6.a) include Pacific Insular Areas in most relevant surveys and other data collection, either routinely or periodically.

Issue 7: Inadequate Collection of Data on AI/AN/NA Subgroups: There are few data sets available to provide information on AI, AN, NH, and PI as separate groups, although there is evidence that there may be substantial differences in health and well-being among these groups. Similarly, there is little data available on members of federally recognized tribes, despite the unique government-to-government relationship and federal obligations established by treaties with these tribes. One strategy was identified to address this issue: 7.a) refine racial identifiers to better focus on subgroups of AI/AN and NH/PI populations and design and implement data collections to obtain sample sizes sufficient for analysis of health and well-being for specific subgroups.

Discussions with a limited number of knowledgeable individuals within DHHS, Census, and other organizations identified a number of current or planned initiatives that would improve AI/AN/NA data availability and quality. All but three of the strategies identified above had current or planned initiatives underway that would, at least partially, address the associated issue. The three strategies for which there were no current or planned initiatives underway are: 1) increasing sample sizes of relevant federal surveys; 2) over-sampling of AI/AN/NA within existing relevant federal surveys; and 3) increasing sample sizes for AI/AN/NA residing on reservations, AN villages, and NH homelands. Each of these strategies would potentially require substantial additional costs to implement. In addition, the strategy to improve PI data by including the Pacific Insular Areas in relevant federal surveys is under study, but is not actually being implemented as a strategy. Again, the cost of implementation of this strategy is likely to be high, depending on whether these areas were included periodically or routinely in federal

surveys. Current or planned initiatives are underway for all of the other strategies, either within federal agencies, states, or through academic-native community partnerships. None of these strategies would likely involve high additional costs, and most could be implemented for relatively modest costs.

Summary and Conclusions

The review of the availability of data on AI/AN/NA health and well-being identified a number of findings, including:

- There are some data available on health and well-being of the combined AI/AN and NH/PI populations for all of the health and well-being policy areas that were the focus of this study.
- There are fewer data available, however, when the data sets examined were restricted to those that had sample sizes for each combined group of at least 200—a number that would permit analysis of the health and well-being issue for some characteristics (e.g., age, gender). Specifically, for the AI/AN combined group, there are limited data (i.e., only one or two data sets) to examine military/veterans issues. For the NH/PI combined group there are limited data to examine education, elder well-being, justice systems issues, and transportation issues, and there are no available data sets to examine military/veterans issues.
- Data to examine measures of health and well-being for the separate AI, AN, NH, and PI groups are much less available than for the AI/AN combined and NH/PI combined groups. Given the evidence that there may be substantial differences in health and well-being among these subgroups, the lack of available data to measure these differences is an important issue.

The study identified a number of issues that contribute to the availability of data on health and well-being of the AI/AN/NA population and strategies for addressing these issues to improve data availability and quality. Interviews with a small number of knowledgeable individuals were conducted to identify current initiatives underway within DHHS and other federal agencies that would potentially result in improvements in availability and quality of AI/AN/NA data. A substantial number of initiatives are underway or planned in the future, and these current initiatives address all but three of the strategies that were identified in this report. The three strategies that have not been addressed within DHHS are those that would likely involve the highest costs to implement (e.g., increasing sample sizes of federal surveys to obtain larger numbers of AI/AN/NA respondents).

It is important to recognize that these current initiatives would advance the objective of improving data availability and quality, but individually would not fully address this problem. For instance, strategies that focus on research to identify new statistical approaches for small area/population estimation may produce a set of methodologies that could improve the usefulness of the available data, but implementation of those methodologies might involve complex and potentially costly software development that might be prohibitive. Similarly, research and cognitive testing to identify differences among populations in understanding and

interpretation of survey questions is a relatively low-cost strategy; however, implementation of strategies to address these differences and improve data quality may involve high additional costs.

A comprehensive approach to addressing the data gaps identified could involve the following steps:

- A DHHS-wide coordinated approach to implement many of the identified strategies across DHHS agencies that both use and collect data on health and well-being issues. Such a coordinated approach would involve soliciting information from these agencies on the key issues for measuring, monitoring, and conducting research on health and well-being disparities, sharing of information gained from current and planned initiatives across DHHS agencies, and identifying a process for determining specific approaches that would be adopted and used consistently in DHHS surveys and administrative databases. This could be accomplished through an incremental approach that begins with coordination among several key DHHS agencies, with the DHHS Data Council perhaps taking a lead role in the process. This effort could then be expanded over time to involve additional DHHS agencies in the process.
- Coordination and sharing of results of current initiatives among all federal agencies that use and collect data on AI/AN/NA health and well-being. This coordination and sharing of findings could lead to development of a process for adopting and implementing consistent data collection strategies to improve these data.
- Working with states to improve the completeness, accuracy, and consistency of collection of race identifiers to ensure that vital statistics and administrative databases contain accurate identification of AI/AN/NA people.
- Consultation and involvement of AI/AN/NA tribes and communities as partners in the process of improving these data, to ensure that strategies that are identified and implemented have the support of these populations and that the approaches that will be implemented also reflect the priorities of the population that will benefit from improved data.

If the coordination strategies outlined above are implemented, it is likely that the availability and quality of data on AI/AN/NA health and well-being will substantially improve. This outcome will require that a long-run focus be maintained on the need for and importance of data to measure, monitor, and analyze disparities in health and well-being of this population. In addition, consideration of the potential benefits relative to costs of alternative strategies may be useful for guiding the decisions that will support these important data improvements.