



Federal Data Collection in American Indian/Alaska Native Communities

This paper presents recommendations to federal agencies for data collection in American Indian/Alaska Native (AI/AN) communities. The National Congress of American Indians Policy Research Center (NCAI PRC) has developed this paper in response to numerous requests from federal agencies soliciting advice about how to improve data collection processes in AI/AN communities. Overall, we recommend that federal agencies openly consult with tribal governmental officials, and seek their insights and support.

This paper is meant to serve as a guide for federal agencies engaged in data collection, as well as the analysis, interpretation, and implementation of data in the development of policies and programs. The intention of this paper is to provide practical advice about data collection in AI/AN communities and to begin a related dialogue with federal agencies. The NCAI PRC would welcome feedback and questions about this paper.¹

There is a critical need for accurate, meaningful, and timely data collection in American Indian/Alaska Native (AI/AN) communities. Accurate data collection and community-based planning captures true needs, and thus can drive larger programmatic funding resulting in a cost-effective use of federal resources. Federal agencies are charged with collecting data in AI/AN communities, as well as from the general U.S. population, in order to determine budget requests; support and strengthen budget justifications; allocate resources; provide services; conduct strategic planning; and comply with statutory and regulatory reporting processes. Tribes also collect their own data for local program management, comprehensive and strategic planning, and as part of broader efforts towards self-governance and self-determination. A wide variety of data are collected in AI/AN communities, including information related to demographics, health, education, culture, economics, taxation, crime, natural resources, and land.

AI/AN tribes are sovereign governments with a Nation-to-Nation relationship with the U.S. Tribes are increasingly exercising their sovereignty over data collection efforts and research more broadly, such as by enacting research regulation codes which apply to any studies conducted on tribal lands.² Tribal government consultation and approval of data collection efforts is vital. The federal government has a trust responsibility for AI/AN communities rooted in federal policies, derived in part from historical treaties signed between the U.S. and tribes. The trust responsibility includes the protection of Indian trust lands, tribal sovereignty and self-governance, and provision of social, medical, and educational services for tribal members.³ To fulfill the federal trust responsibility, it is vital for federal agencies to collect adequate data in AI/AN communities. Without accurate information on the current needs in Indian Country, it is not possible for federal agencies to appropriately address those needs. Federal agency data

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²Sahota, P. Research Regulation in American Indian/Alaska Native Communities: Policy and Practice Considerations, NCAI PRC, 2007. <http://www.ncaiprc.org/research-regulation>

³Friends Committee of National Legislation. The Origins of our Trust Responsibility Towards the Tribes. April 8, 2008. http://www.fcnl.org/issues/item.php?item_id=1300&issue_id=95

collection is important for tribes' local allocations of resources and service provision, as well as for federal-level decision making.

The sections below discuss the following:

- (1) Reasons federal data collection is needed in AI/AN communities;
- (2) Challenges in past data collection efforts; and
- (3) Practical recommendations for future data collection by federal agencies in AI/AN communities.

Reasons Data Collection is Needed

There are a number of reasons that data collection is needed in AI/AN communities:

Federal budget planning, resource allocation, and service provision. Having accurate data on the needs in AI/AN communities is vital for federal agencies to plan and justify their budgets, allocate resources, and provide services. In the past, some federal agencies have simply increased their budget requests for AI/AN communities from previous years by a certain percentage without collecting current, up-to-date data on the actual need for their services in Indian Country. Adequately fulfilling the federal trust responsibility to AI/AN communities requires having accurate data on the real needs of these communities. Critical needs in AI/AN communities often go unmet, and accurate data can help federal agencies to more effectively allocate existing resources. Collection of certain kinds of data by federal agencies is also mandated by law. Although AI/AN peoples comprise a small percentage of the overall U.S. population, the federal government has a special obligation to provide adequate services to these communities because of the federal trust responsibility.

Tribal budget planning, resource allocation, and service provision. As sovereign governments, tribes manage their own programs and provide local services to their citizens. Having accurate data on local needs is critical for tribes to: plan their own budgets, including requests for federal funds; apply for grants; allocate local resources; and provide services. For example, data on crime patterns on a reservation could help the tribal government to make decisions about how many police officers to assign to particular areas.

Tribal eligibility for federal grants. Data collection from AI/AN communities and federal agency coordination of these data is important for AI/AN communities to be eligible for certain federal grants. For example, the Edward Byrne Memorial Justice Assistance Grant Program is administered by the Department of Justice.⁴ This grant provides funding to improve the functioning of local criminal justice systems, including efforts aimed at addressing violent crime, serious offenders, and federal controlled substances. It is a critical source of basic funding to local criminal justice systems. The estimated total FY 2009 appropriation for these grants is \$546 million.⁵ Applicants to this large grant program are required to provide data from their jurisdictions to the Federal Bureau of Investigation's (FBI) National Crime Information Center

⁴<http://www.ojp.usdoj.gov/BJA>

⁵<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=3b84473b0f52f42561216fcbfe9fb7e9&cck=1&au=&ck=>

(NCIC), which is a computerized index of criminal justice information available to federal, state, and local law enforcement criminal justice agencies.⁶

Historically, AI/AN communities submitted their police report data to the Bureau of Indian Affairs (BIA) as part of the requirements of tribal police departments with self-determination contracts (P.L. 93-638). The FBI did not input this data into the NCIC because the BIA's crime categories were different from the FBI's. Because tribal data were not entered into the NCIC, tribes were not eligible to apply for Byrne Formula Grant funds. The Bureau of Justice Statistics was recently able to work with the FBI to have AI/AN community data entered into the NCIC so that, tribes are eligible to apply for Byrne Grant funds. However, there may still be problems with data compatibility, because the BIA crime codes may not match those used by the FBI. A related problem is that tribal and BIA police departments do not always have access to the NCIC, which they could use to look up background information on suspicious individuals.

Regarding health data, anecdotal evidence suggests that several AI/AN communities were not able to apply for Indian Health Service (IHS) Health Promotion and Disease Prevention grants because they did not have access to local data.⁷ Health Promotion and Disease Prevention is one IHS program aiming to improve access to local health data. The goal of this effort is to provide tribes with a source of information for program evaluation, community mobilization, and securing needed resources (e.g., grants). Collection and effective coordination of AI/AN data by federal agencies is thus critical for ensuring AI/AN communities have equitable access to federal grant funds.

Disparities in health, economic, and social issues. AI/AN communities face significant disparities compared to the general U.S. population in health, economic, and social issues, and quantifying these disparities through data is vital. For example, AI/AN communities experience a lower life expectancy than the general U.S. population (72.3 years vs. 76.9 years), and have higher mortality rates from tuberculosis (750 percent higher), alcoholism (550 percent higher), diabetes (190 percent higher), homicide (100 percent higher), and suicide (70 percent higher).⁸ AI/AN communities also experience higher unemployment rates (22 percent for non-gaming tribes and 15 percent for gaming tribes)⁹ and a higher poverty rate (26 percent, which is 2.5 times the national average).¹⁰ The Native American home ownership rate is estimated to be as low as 33 percent, which is less than half the rate for the general U.S. population.^{10, 11} The statistics quoted here are approximations, as completely accurate data for these issues has not always been collected in the past (as is discussed further below, under *Challenges in Past Data Collection by Federal Agencies*). Accurate data on health, economic, and social disparities is vital for quantifying the gap between Indian Country and the rest of the U.S. population. Having accurate

⁶<http://www.fas.org/irp/agency/doj/fbi/is/ncic.htm>

⁷Personal communication with Dwayne Jarman, DVM, MPH, LCDR USPS, Prevention Specialist, IHS Health Promotion Disease Prevention Program. Sept. 23, 2009.

⁸Indian Health Service Fact Sheets: Indian Health Disparities. <http://info.ihs.gov/Disparities.asp>

⁹Harvard Project on American Indian Economic Development: A Databook of Socioeconomic Change Between the 1990 and 2000 Censuses.

¹⁰National American Indian Housing Council. Indian Housing Fact Sheet.

<http://www.naihc.net/news/index.asp?bid=6316>

¹¹"Homeownership in Indian Country," The Enterprise Institute, 2004.

data will help federal policy makers, tribal governments, and private institutions to begin addressing these disparities.

Assessing strengths of AI/AN communities. Data collection is necessary for assessing the strengths and potential resources in AI/AN communities as well. For example, an often quoted statistic is that Indian Country collectively has 10 percent of the energy resources in the U.S. However, the accuracy of this statistic or its source is not well established. Furthermore, an assessment of the specific types of energy resources available in Indian Country (i.e., minerals, oil, natural gas, renewable energy resources, etc.) has not been conducted. AI/AN communities' resources could be broadly defined to include elements such as potential economic development opportunities, energy resources, cultural strengths, educational institutions, and the potential inherent in AI/AN people. Assessments of AI/AN community strengths and potential resources may help federal and tribal policymakers to shape future programs and grant opportunities for further developing these resources. For example, an assessment of energy resources could be used to design federal grants for development of these resources by AI/AN communities as part of economic development efforts.

Advocacy for AI/AN communities. Accurate data have become important for advocacy efforts by organizations and communities seeking to influence policy. For AI/AN communities to advocate strongly for their needs, they require complete and accurate data about the scope and magnitude of issues facing them, particularly in today's data-driven policy environment.

Challenges in Past Data Collection by Federal Agencies

There have been a number of problems with past data collection efforts by federal agencies in AI/AN communities:

Lack of data or inaccurate data. In the past, some data collection efforts by federal government agencies have not produced accurate or comprehensive data regarding AI/AN communities. For example, there are not adequate data on the energy resources in Indian Country, as noted above. Similarly, in the past, there were not accurate data on the number of farms in AI/AN communities, as each reservation with farms would be counted as a single farm.¹² However, the 2007 Census of Agriculture, administered by the U.S. Department of Agriculture (USDA) National Agricultural Statistics Service, counted the number of actual farms in AI/AN communities for the first time. Statistics on unemployment and poverty are also difficult to pinpoint for AI/AN communities. The Bureau of Labor Statistics (BLS) does not collect data on reservation unemployment rates, and so the unemployment rates for states with large reservations are likely to be understated.¹³ These data are important because they impact federal appropriations, allocation of resources, and service provision. For example, three states with significant AI/AN populations—Alaska, Minnesota, and North Dakota—were all excluded from recent legislation passed by the House of Representatives (H.R. 3548) which extended unemployment benefits for states with unemployment rates of at least 8.5 percent. All three

¹²U.S. Department of Agriculture. Agriculture Census Data Now Available for American Indian Reservations. 2009. http://www.agcensus.usda.gov/Newsroom/2009/06_19_2009.asp

¹³More information on the BLS' methodology for collecting unemployment data is available at http://www.bls.gov/cps/eetech_methods.pdf

states had unemployment rates just below 8.5 percent in the second quarter of 2009, and if AI/AN unemployment data for these states were accurate, it is likely that the total rate for these states would have met the threshold for the benefits extension. Finally, AI/AN individuals have been undercounted in past iterations of the Census. The 1990 Census undercounted them by an estimated 12.2 percent on reservations and 4.5 percent in all geographies.¹⁴ Undercounts were likely less in the 2000 Census, but were still a problem. NCAI and other partner organizations are working to increase awareness of the Census' importance in Indian Country and to improve response rates from AI/AN communities.¹⁵

Lack of adequate centralized processes and systems to collect and analyze data. Tribes often receive multiple requests for data from federal agencies that are inconsistent, repetitive, time consuming and lack a method or form of electronic collection. Frequently, the federal offices tasked with reporting have no formal process and/or centralized data collection system to organize data. Further, the tribes may lack systemic capability to complete accurate and timely requests for data or program performance.

Sample Size. AI/AN people comprise a relatively small segment of the overall U.S. population. As a result, it is difficult to collect data that are accurate and generalizable across Indian Country. In large-scale studies of the general U.S. population, the sample sizes taken from AI/AN communities are often too small to produce reliable data across diverse geographic regions. Oversampling may be important for collecting accurate data and resulting policymaking related to Indian Country.

Geographic and language barriers. Collecting data in AI/AN communities can be difficult because many AI/AN communities are located in rural areas with poor roads. Within reservations, a significant number of households may not receive mail, and so must be visited in person, which can make data collection difficult. In addition, many homes have unmarked addresses. Boundaries of tribal lands are also not always clearly aligned with state or country lines. Finally, in some AI/AN communities, language poses a challenge to data collection, particularly in communities with significant numbers of native language speakers who may need data collection instruments translated from English. Partnering with tribal governments can help federal agencies to navigate local barriers to data collection.

Mistrust of data collection and federal government agencies. There has been a mixed history of data collection by researchers and federal government agencies in AI/AN communities, with past data having been misused or used in ways that are not shared with communities. A recent, prominent case of data misuse involved genetic specimens collected from the Havasupai Tribe, which were used without tribal members' consent for unauthorized studies.¹⁶ Although this case did not involve the federal government, such instances of data misuse by researchers affect how tribal citizens perceive all data collection efforts. Regarding federal agencies more specifically, community members have expressed concerns that the data collected about them in the Census

¹⁴Lujan, C. As Simple as One, Two, Three: Census Underenumeration Among the American Indians and Alaska Natives, 1990.

¹⁵www.indiancountrycounts.org

¹⁶Couzin-Frankel, J. DNA Returned to Tribe, Raising Questions About Consent. *Science*. 2010. 328(5978):558.

might be misused or shared with other government agencies.¹⁷ Past governmental efforts at “registering” tribal citizens are remembered as harmful to AI/AN communities because data were used to take land, relocate communities, or forcefully remove children to boarding schools. As a result, AI/AN community members sometimes still resist “registering” for government IDs, voting, or any other purpose with governmental entities. This type of mistrust is particularly challenging for intensive data collection efforts such as the Census. Furthermore, tribes often question who will “own” data once it is collected and how it will be used. Concerns about data ownership may prevent some AI/AN communities from sharing data with the federal government. However, partnering with tribal governments may help federal agencies to overcome historical mistrust in their data collection efforts.

Recommendations for Data Collection in AI/AN Communities

Based on the importance of meaningful, accurate, and timely data for AI/AN communities as well as past challenges in data collection, we suggest that federal agencies consider the following recommendations:

Inclusion of AI/AN communities in national data sets. We recommend that AI/AN communities be included in data collection by federal agencies whenever possible, particularly for large national data sets. For example, as noted above, AI/AN communities are not always included in the calculation of state unemployment rates, but they should be because of the importance of these data for policymaking and resource allocation.

Oversampling of AI/AN populations in national data sets. Some national data sets include sample sizes of AI/AN communities that are too small for generalization across Indian Country. For example, the American Community Survey of the U.S. Census only publishes annual data estimates for geographic areas with a total population of all races of 65,000 or more. The only American Indian reservation in this category is the Navajo Nation. Data for areas with populations of less than 20,000, which includes most Indian reservations, are estimated based on data collected over the past five years.¹⁸ To facilitate more detailed data collection and analysis, federal agencies could consider oversampling from AI/AN communities as part of national data sets. For the American Community Survey program, the Obama Administration proposed increased appropriations of \$44 million in FY 2011 to: increase sample sizes in AI/AN communities to improve tract-level data accuracy; enhance field and telephone center data collection; conduct a 100 percent non-response follow up operation in remote Alaska and small AI/AN and Native Hawaiian homeland areas, and for additional review of three-year and five-year data. We strongly support this proposed appropriations increase to the American Community Survey program and more broadly, we recommend continued efforts to oversample AI/AN communities in national data collection.¹⁸ Geographic diversity is important in any oversampling efforts across Indian Country, as AI/AN communities are extremely diverse across as well as within geographic regions.

¹⁷Puente, M. Census 2000 Ethnographic Studies, Final Report, 2004.

¹⁸National Congress of American Indians. April 14, 2010. Testimony Before the House and Senate Commerce, Justice, Science, and Related Agencies Appropriations Subcommittee.

Longitudinal collection of data in AI/AN communities. Data should be collected from AI/AN communities regularly over long periods of time. Longitudinal data collection facilitates assessments of program effectiveness over time, as well as traces trends in various issues facing Indian Country. Longitudinal data collection may also help to overcome problems of small sample size in some cases. Even if there are not enough data in a particular year to make generalizations across Indian Country, analysis of data accumulated over several years may allow for drawing more robust conclusions. For data collection efforts that are based on small samples taken often over time, such as the new Census data collection methodology, longitudinal data collection is even more important. Consistent data collection over time in AI/AN communities also helps to build trust and stronger long-term relationships between federal agencies and Indian Country. Finally, longitudinal data collection can help to justify federal agency budget requests. Data demonstrating improvement in outcomes for AI/AN communities based on past program efforts can help to make the case for increased resources allocated for Indian Country.

Comprehensive data collection in AI/AN communities. Data that are collected in AI/AN communities will be most useful if they are in-depth and comprehensive. For example, the NASS' current practice of counting all farms on reservations is a significant improvement over the previous method of simply noting the presence or absence of farming in a community (i.e., counting a reservation as a single farm if it contained any farms). AI/AN communities would benefit from comprehensive assessments of their resources and needs. As noted above, there are few data on specific types of energy resources in Indian Country. A comprehensive assessment of these (e.g., solar, wind, water, oil, natural gas, coal, minerals, biofuels, etc.) would be much more beneficial for future planning in AI/AN communities than the currently available general statistic that 10 percent of energy resources in the U.S. are on Indian lands. There is also a lack of comprehensive data on housing needs in Indian Country, including types of housing, home ownership rates, number of residents per home, etc. Collecting such specific data for individual AI/AN communities and geographic regions is important for federal agencies such as the Department of Housing and Urban Development to be able to justify their federal budget requests, allocate resources within Indian Country, and in general, fulfill the federal government's trust responsibility to provide services to AI/AN communities.

Consistency of data collected from AI/AN communities with other national data sets. Data collected in AI/AN communities should be formatted consistently with data collected in other parts of the U.S. Achieving this objective may require staff from federal agencies to coordinate with one another on data collection efforts to ensure consistency of formatting. Such consistency is important so that AI/AN data can be included in national data sets, such as the FBI's NCIC, as noted above. Inclusion in national data sets will help to ensure that overall data for geographic areas including AI/AN communities are accurate, as in the case of BLS employment data. Inclusion of AI/AN community data in national data sets is also important for ensuring AI/AN communities are eligible for federal grants, as noted above.

Coordination between federal agencies on collection of similar kinds of data. Some federal agencies collect similar kinds of data, and coordination between these agencies for data collection and seeking of AI/AN community input would be useful. For example, unemployment data are collected by the BLS and the BIA, but these statistics are not consistent for AI/AN

communities. The U.S. Geological Survey monitors the quality of water in AI/AN communities, and such data collection would ideally be coordinated with other similar efforts by the Environmental Protection Agency (EPA). A central committee that coordinates data collection between agencies might be one way of streamlining those efforts.

The Office of Management and Budget (OMB), which oversees federal data collection efforts generally, potentially could convene a committee specific to Indian Country. Such a committee could coordinate efforts to gather input from and communicate with AI/AN communities about data collection. Coordination between agencies that collect related data, even if those data are not exactly the same, would also be useful.

Within the Department of Health and Human Services, for example, agencies collect multiple kinds of data that when viewed together, can provide a more comprehensive view of a community's health. Health indicators, such as disease rates, could be compiled along with socioeconomic indicators for a single community or region in order to provide a more detailed portrait of the links between health and socioeconomic disparities. Linking these types of data is part of the ongoing collaborative effort between the Tribal Epidemiology Center of the United South and Eastern Tribes, Inc. (USET), the IHS Health Promotion and Disease Prevention, and the IHS Division of Epidemiology and Disease Prevention (discussed in greater detail below under *Collaborations for data collection and analysis with AI/AN communities and affiliated researchers*).

Finally, coordination between agencies on the definition of “American Indian/Alaska Native” or “Native American” would also be useful. Different agencies have inconsistent definitions of these variables, and so comparison of data collected across agencies is difficult. These variables are complex and politically sensitive, but dialogue among different agencies and AI/AN communities about defining terms such as “American Indian,” “Alaska Native,” and “Native American” would help to improve coordination of data collection in Indian Country.

Consistency of data collected from AI/AN communities within Indian Country. Federal agencies that collect data from AI/AN communities should ensure that the data are consistently aggregated and formatted across communities. Such consistency is needed for building larger data sets with results that can be generalized across geographic regions and Indian Country as a whole. The way in which data variables are defined can also have significant impacts on grant funding available to AI/AN communities. For example, the Indian Reservation Roads (IRR) Program provides funding to reservation or tribal communities for transportation assistance.¹⁹ This program is jointly administered by the BIA and Federal Highway Administration (FHWA) Federal Lands Highway Office. The Tribal Transportation Allocation Methodology (TTAM) is a formula for distribution of funds to AI/AN communities and includes vehicle miles traveled, which is derived from an inventory of Indian reservation roads. In order to conduct this inventory, the BIA asked for data from AI/AN communities on roads running through their lands, but did not specifically define exactly which roads to include. As a result, different communities included various roads in their individual inventories, with some accounting for only internal roads and others including interstate highways and county roads. Inconsistencies between different communities' inventory methodologies have caused disparities in the

¹⁹25 CFR Part 170. Indian Reservation Roads Program; Final Rule. Federal Register 69(137):43090-43141.

proportion of funding allocated relative to the sizes of communities' land base and road networks. In this case, consistent criteria for which roads should be included in the inventory and the related measure "vehicle miles traveled" are critical for ensuring equity in the proportional funding received by AI/AN communities for their transportation infrastructure needs. Thus, it would be helpful for AI/AN communities if they received specific, consistent guidance on how data variables are defined when they are asked to provide data to federal agencies.

Education, outreach, and technical assistance for AI/AN communities prior to data collection. AI/AN communities often receive requests for data to be submitted to the BIA and other federal agencies. Education and outreach to communities before data are collected is important. Communities are more likely to be responsive to federal data collection efforts if they have received clear information about why such data are needed and how those data will help Indian Country. Furthermore, technical assistance and clear instructions should be provided to communities about the process of data collection. Data forms and requested variables should be clearly defined and when necessary, training should be provided to communities regarding data collection. In the past, there have been many examples of federal government agency requests for data, such as the number of teachers, crime statistics, or unemployment data from communities, but these requests have not been well-defined. As a result, AI/AN communities have not seen merit in such poorly explained requests for data and have responded by submitting data in inconsistent formats that cannot be combined across Indian Country, ignoring requests for data altogether, or submitting inaccurate estimates rather than precise data.

Federal agencies can help to improve the quality and quantity of data collected in AI/AN communities by providing clear instructions and definitions of data variables to communities, and by offering organized training sessions or other forms of technical assistance regarding data collection. Additionally, federal agencies should establish clear policy and guidance regarding data collection, security and use of data. For example, it may be helpful to include contact information on data forms for a specific agency staff member who is available to guide AI/AN communities through data collection. Providing sample calculations or completed forms might also be useful for communities. Finally, providing funding and opportunities for AI/AN community staff to receive training in data collection would also be useful so that communities can build capacity to collect their own data.

Minimize redundancy and administrative burdens in data collection. Before asking AI/AN communities to collect new data, federal agencies might assess what data have already been or are being collected. Existing data sets may be good sources of information, and using such data is easier for both federal agencies and AI/AN communities than collecting new data. When new data are needed, federal agencies can help communities by reducing the administrative burdens of data collection. For example, agencies could attempt to minimize the number of data sources and variables required and thus, the work necessary for AI/AN communities to collect data.

Consultation with AI/AN communities on data collection. Federal agencies requesting data from AI/AN communities should consult with communities about data collection whenever possible. Communities can help to define the data variables that should be collected, the format of data collection templates, and methods for data collection that will be most meaningful and convenient for them. Assessing which kinds of data are most meaningful and helpful for AI/AN

communities should be a key part of consultation with them. Broad consultation throughout Indian Country will also enable federal agencies to benefit from the expertise of AI/AN communities. As sovereign governments, most tribes have their own data collection procedures related to their jurisdictions and program management, and they know what methods work best for them. They may also already have data collection models or specific data they have collected that could be shared with federal agencies. Similarly, communities may be able to help define data that are too sensitive to collect and should not be sought by federal agencies. AI/AN communities have much to offer federal agencies seeking to improve data collection in Indian Country. Some federal agencies have already begun taking steps towards detailed consultation regarding data collection. For example, the Centers for Disease Control and Prevention (CDC) has established tribal workgroups as part of defining the objectives and data collection methods for Indian Country in Healthy People 2020.

Clear and frequent communication with AI/AN communities on uses of data. In addition to consulting with communities on the process of data collection, federal agencies could help ensure accurate and comprehensive data collection through frequent outreach and transparent communication with communities about how data will be used. If AI/AN communities understand the uses of data, they will be more likely to submit their own accurate data. Once data have been collected, analyzed, and used to inform federal budgets and other policymaking, federal agencies should share these results with AI/AN communities whenever possible. Knowing that the data they submitted made a difference in resource allocation and service provision will make it more likely that AI/AN communities will continue to share their data with federal agencies in the future. Communication with communities about uses of data should also include ways in which data will not be used and confidentiality procedures in place to protect sensitive data and the identity of individual AI/AN communities. For example, individuals' health information should be protected as required by the Health Insurance Portability and Accountability Act of 1996.²⁰ Past problems with data collection have resulted in mistrust by some communities of federal government agencies, as noted above. Clear communication about ways data will be secured/protected and how they will be used is important for overcoming this historical challenge.

Collaborations for data collection and analysis with AI/AN communities and affiliated researchers. Closer collaboration between federal agencies and AI/AN communities in both data collection and analysis would enhance the quality and quantity of data that are collected. Partnering with tribal governments may help federal agencies to address challenges in data collection, such as the historical mistrust and geographic barriers (e.g., remote locations, poor roads) of some AI/AN communities. AI/AN individuals may be more likely to trust their fellow community members when asked for personal data, and so federal agencies should consider hiring individuals from within AI/AN communities as data collectors.

Regarding data analysis, transparency of federal agency activities would be enhanced if AI/AN communities were provided with access to databases that include them. Communities should be able to analyze data themselves when possible, and to have a means of communicating with federal agencies about any discrepancies they find in data sets. Access to compiled Indian Country data sets is also important for AI/AN communities to better understand how data are

²⁰U.S. Department of Health and Human Services, Health Information Privacy. <http://www.hhs.gov/ocr/privacy>

being used. For example, the Internal Revenue Service (IRS) has recently been collecting information in Indian Country as part of tax audits, but has not shared its methodology with all AI/AN communities. It has been difficult for tribes to determine how the IRS' treatment of one AI/AN community compares with its auditing procedures for other communities. AI/AN communities have therefore been unable to understand exactly how the IRS makes certain determinations from the information being collected.²¹

Providing access to databases for researchers outside of federal agencies can also be useful for those agencies and AI/AN communities. Most federal agencies do not have adequate staff time to conduct all the data analyses that would be useful. Collaboration with outside researchers at universities or other institutions may be one way for federal agencies to obtain more comprehensive analyses of data collected from AI/AN communities. Any sharing of data should be done carefully and with adequate protections for sensitive data and confidentiality/anonymity of individual AI/AN communities. Finally, AI/AN communities should be consulted about the ways data are analyzed and how results are interpreted. Federal agencies may sometimes draw conclusions about the meaning of data that differ from community members' lived experiences. AI/AN communities' input should be sought on data analysis results and conclusions before related decisions are made about policies and programs.

One example of an ongoing collaboration for data analysis is that between the Tribal Epidemiology Center of the United South and Eastern Tribes, Inc. (USET), IHS Health Promotion/Disease Prevention, and the IHS Division of Epidemiology and Disease Prevention. They are working together to build a community health profile methodology and data portal as a model for a unified public health infrastructure in Indian Country. A community health profile is a compilation of measures in multiple categories that help to describe a community's health status and the resources available to address those health needs. AI/AN communities have a wide range of capacities to develop such community health profiles, as well as diverse levels of available health data and infrastructure to collect and analyze such data. Tribal Epidemiology Centers are charged with collecting and analyzing data related to community health profiles as part of their public health mission, but do not yet have a convenient and standardized method for doing so. The USET Tribal Epidemiology Center, in collaboration with its partners at IHS, is attempting to build a data portal which would serve as a unified source of data from which to build community health profiles. The data portal would be an internet-based way for secure and easy sharing of data with AI/AN communities, and would include diverse data sources, from health indicators to socioeconomic data. The data included in the portal would be compiled from diverse sources, including primary health data from IHS' Resource Patient Management System (RPMS) and Clinical Reporting System (CRS), as well as secondary data derived from the Census, the National Death Index, Birth Records, the Behavioral Risk Factor Surveillance System, etc. These data would be consolidated into one place, the data portal, which AI/AN communities can use to efficiently generate community health profiles for themselves. A sample community health profile generated from these data sources is available on the USET Tribal Epidemiology Center website.²²

²¹As of 2007, the IRS had conducted audits of 139 tribes, according to a June 28, 2007 letter from the Acting IRS Commissioner, Kevin Brown, to Sen. Charles Grassley. NCAI staff estimate that the IRS has conducted audits of 40 new tribes per year, bringing the total number of AI/AN communities audited to over 200.

²²<http://www.usetinc.org/Programs/USET-THPS/TribalEpiCenter/Reports.aspx>

Consider cultural factors in data collection efforts. Since time immemorial, AI/AN communities have collected and shared their own data as part of Indigenous ways of knowing and relating to the world. These cultural perspectives continue to inform how AI/AN communities define data collection needs today. Cultural factors are important in many aspects of data collection. The way that questions are phrased, for example, may need to be different in AI/AN communities than for other groups in the U.S. Consultation with AI/AN communities about data collection can help to ensure that questions are phrased appropriately. It may also be useful for federal agencies to train their staff in cultural competency for working with AI/AN communities. Many staff of federal agencies do not have extensive experience working in Indian Country. Inviting AI/AN community members to provide cultural competency training is one possible strategy federal agencies could consider, in addition to organized consultations across Indian Country. When possible, federal agencies should respect the cultural perspectives of AI/AN communities in development of data collection instruments rather than applying one set of criteria to all groups in the U.S.

Respect for AI/AN community perspectives not only involves how questions are asked but also which data are collected. For example, the Tribal Governance Group of the Exchange Network, which includes a number of AI/AN communities, has been working with the EPA to develop a survey on AI/AN communities' capacity to respond to emergencies. This survey was submitted to OMB for review, and after several months the OMB recommended the survey be shortened, citing the Paperwork Reduction Act. The Tribal Governance Group shortened the survey, but that version was also not approved by OMB. AI/AN community members involved in these discussions were concerned that the OMB did not view a detailed survey on emergency preparedness as an urgent need in Indian Country. However, members of the Tribal Governance Group, who have direct experience working with AI/AN communities, feel that this survey is very much needed because of the lack of related data in Indian Country. Thus, cultural factors and the unique expertise of AI/AN communities are important to consider in defining how data are collected and which data elements are included.

Include AI/AN communities in research grants. Many federal agencies administer competitive research grant programs, and research outside the federal government can be an important source of data for AI/AN communities. These research grants are often geared towards academic researchers and do not always include AI/AN communities in the grant criteria. For example, the EPA's Office of Research and Development provides large multi-year grants to research institutions for adaptation research, but the grant criteria preclude AI/AN communities from applying. One potential strategy federal agencies might consider is to create smaller-scale grants that specifically are targeted towards individual AI/AN communities so that they can conduct research relevant to their specific community needs. For larger federal grants awarded to research institutions, such as universities, one requirement of the award could be the inclusion of AI/AN communities in research projects which directly deal with issues facing these communities or in areas where traditional tribal knowledge has been proven to be valuable (e.g., the knowledge of Alaska Native villagers in Arctic climate assessments). For grants that are available to AI/AN communities, federal agencies could include AI/AN individuals on grant review panels. Making the grant review process more equitable for AI/AN communities may enhance their success rates in obtaining competitive funds.

Conclusion

Effective data collection in Indian Country is critically needed, and is an important mandate for federal agencies. Although there have been historical challenges in data collection, there are a number of practical steps federal agencies can take to improve current and future data collection efforts in Indian Country. In order to fulfill the federal government's trust responsibility to AI/AN communities, federal agencies require accurate data on the needs and assets of AI/AN communities. Close consultation and collaboration with AI/AN communities will also help to facilitate effective data collection.