TIPS FOR RESEARCHERS:
Strengthening Research that Benefits Native Youth
Acknowledgements

We offer our gratitude and acknowledgment for the thoughtful contributions of several distinguished scholars and Native youth advocates in developing this report and hope that this document will serve to spark additional discussion and reflection on the topic of Native youth research among researchers, tribal leaders, and other interested stakeholders.

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Intended Audience & Additional Resources

This document may prove useful to those involved in conducting research with AI/AN communities, including researchers, program managers, system leaders, and community-based investigators. Tribal leaders, government workers, and agencies may also find the content helpful as they determine data needs and oversee research efforts.

This document is not intended to be a comprehensive survey of best and promising practices but rather an introduction to some of the considerations researchers and stakeholders should keep in mind as they conduct research tasks, from identifying research needs, to designing research, to closing out research projects and disseminating data to communities. A resource guide is included at the end this document for further study and exploration of the topics.

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About the NCAI Policy Research Center

NCAI leadership launched the Policy Research Center in 2003 to pioneer a national tribal research center that would serve as a think tank focused on issues facing tribal communities. Guided by a diverse and distinguished advisory council, the NCAI Policy Research Center (PRC) works with our partners to provide the tools necessary to inform public policy debates with meaningful information. Our work is focused on shifting the discourse in Native policy from a problem-focused approach to truly proactive, future-thinking strategy development. The mission of the PRC is to provide tribal leaders with the best available knowledge to make strategically proactive policy decisions in a framework of Native wisdom that positively impact the future of Native peoples.

NCAI’s PRC also invites readers to join the PRC Quarterly Tribal Data teleconferences and PRC Quarterly Tribal Research teleconferences, as well as our annual, in-person Tribal Leader/ Scholar Forum, held in conjunction with NCAI’s Mid Year Conference. For more information on these and other NCAI PRC events, please visit http://www.ncai.org/prc
Introduction

American Indian and Alaska Native (AI/AN) youth deserve our very best. Although the phrase Native youth may hold different meanings for different audiences, use of the phrase here is meant to indicate AI/AN children and youth from the prenatal period to the age of twenty-four. Youth are a large and growing sector of AI/AN communities, making up 42 percent of the AI/AN population nationally and over 50 percent of the AI/AN population in some states like South Dakota. They are also growing up in contexts that are culturally, economically, environmentally, and technologically different from that of their parents and grandparents. Their notions of health, success, and identity are often distinct from those of other generations.

We need research with AI/AN youth in order to develop more meaningful understandings of their realities, create appropriate interventions, craft more effective systems, and support them in achieving their goals. Yet, there may be hesitation on the part of researchers as to the “burden” of designing research with AI/AN people first, as well as additional “burdens” of enlisting youth in the research enterprise. Researchers have a responsibility to secure tribal approval and engagement if they seek to collect and report research data at a tribal level; this process can take more time, however, it can also generate more meaningful research outcomes. Further, youth are considered “vulnerable populations” within research ethics, meaning that they need special and additional protections to ensure they are not harmed intentionally or inadvertently as a result of their participation in research. As a result, researchers may view research with AI/AN youth as “too hard”, leaving the potential benefits lost for lack of guidance and support to conduct research with these young people.

It is essential that research with and by AI/AN communities include youth to inform effective community and policy planning. Researchers must be made aware that the meaningful inclusion of youth in research often requires particular protocols and methodologies given the unique status of youth as “vulnerable populations” and unique characteristics, such as oftentimes being a more mobile group than adults. In this way, guidance to improve AI/AN youth research must serve dual goals of seeking to protect and benefit Native youth.

In the following report, the National Congress of American Indians (NCAI) Policy Research Center has invited several distinguished scholars to share their best practices to identify key aspects of ethics and process in research developed with and for Native youth. This report is designed to guide efforts to include AI/AN youth in research, so that the research generates the maximum benefit for AI/AN youth and their communities, and importantly, does no harm. It is titled, “Tips for Researchers” as we acknowledge that no one guide could be comprehensive enough to include all of the important aspects and nuances of the diverse contexts within which research with AI/AN youth is needed. Instead, we offer some broad insights in five key areas, or “Tips”, in the hopes that this can be tool for communities of researchers, youth, and youth advocates to come together around and use to develop context-specific discussions and partnered research goals. The five key areas with lead author annotations include the following:

1) Centering Youth Voices (Greg Tafoya)
2) Engaging Tribal Communities (Catherine Burnette)
3) The Power of Place-Based, Small-Scale Inquiry (Tarajean Yazzie-Mintz)
4) Expanding Tribal Youth Research in Urban and National Settings (Michelle Sarche)
5) Ethical Considerations (Deana Around Him)
Section 1: Centering Youth Voices

When youth are first, decisions are easy. AI/AN youth are a treasured group. They link the knowledge of the past with a new vision for the future, while living in the present. Working with AI/AN youth will never be straightforward – a researcher aiming to meaningfully engage youth in research must make an intentional effort to consider many dynamic contextual factors, which may include:

1) Values that AI/AN youth bring both as members of cultural and age-specific groups;
2) Place or status of youth in their community(ies);
3) Definition of AI/AN that has relevance to youth, tribe, and/or community;
4) Role of tribal governance, sovereignty, and politics in research;
5) Variability in community research capacities and resource availability;
6) Investments in youth by local, state, and national organizations; and
7) Researcher knowledge and relationships with AI/AN youth in a particular place.

Coming to understand these elements is important in developing a “systems view” of the realities facing Native youth. In light of the ways that AI/AN youth are often developing their identities across a range of roles and contexts, researchers may find that a systems view may be helpful in fostering research that benefits AI/AN youth. A systems view acknowledges the relationships and interconnected networks across all parts of Native communities, which have bearing and direct influence on the health and well-being of all people in the system. A systems view gives researchers permission to say “I don’t know” and encourages them to shift from the role of “expert” to “learner” as they attempt to orient themselves to a new and linked context. When researchers project that they are the expert, youth might be put off, may develop a sense that the researcher is more invested in his or her own agenda than in the best interests of the youth, and may hesitate to develop a more meaningful relationship with that researcher. As a result, AI/AN youth may develop a mistrust of research and researchers over time.

The reality of working with AI/AN youth is that they have diverse identities that encompass values from traditional to western worlds; they may reside on or off tribal lands – or balance living in multiple places; they are digitally linked through private (and less public) social media, despite geographically remote locations; they are often very conscious about privacy and issues they find personal to their own experience; and they are very perceptive about adults approaching them, especially researchers and other professionals. Yet, with these and many other complexities at play, AI/AN youth come from such a diversity of cultures that there is no one way of understanding the characteristics they may embody. In my time working with AI/AN youth, I have found that many may often have strong community connections grounded in historical legacies of resilience and resistance, as well as core values based in collective pride and honor; they may be very competitive; they are often rich in humorous spirit; and they often see the world from individual, peer/group, and community levels simultaneously.

Importantly, all adult stakeholders are key parts of the system, but will always have a knowledge gap by virtue of not being youth in the system. It is important to acknowledge that the lives of today’s youth are complicated by a range of dynamics that were not a part of the experience of earlier generations. Adults may not know what is going on in the lives of AI/AN youth, rather they can only try to come to an informed understanding from the youth themselves. This requires that researchers invest in learning about the youth’s local context and by developing appropriate relationships with the youth as the experts in their own lives. In other words, researchers committed to generating meaningful and measurable outcomes in their work with AI/AN youth must employ coordinated, systems approaches that are driven by youth, so that the research can have the most positive benefit.
In sum, a systems view:

- Allows a researcher to gain insight on the realities facing Native youth from the contexts within which Native youth live and from the youth themselves.

- Requires researchers to embrace their role as guests in a system where other relationships are already in place; this is true even in the case where a researcher is working in a community that is their own as they are operating in a distinct role and must develop relationships from this new orientation. Researchers operating under federal, state, or external policies are part of an outside

Case Example: Honoring Cultural Strengths as Prevention

Consider the case of a researcher who learns about high substance abuse rates of Native youth in her community. National, state, and county data suggest that this is a priority health concern for the local leadership. The researcher has a relationship with a tribal member, and wants to engage tribal leaders by proposing a research idea focused on exploring the early use of drugs by Native youth. Moreover, the researcher has been building relationships with the local tribal epidemiology center and a network of others in the local region with experience leading tribally-partnered research. The National Institutes for Health (NIH) has also just released a request for proposals emphasizing investigations into youth substance abuse in Indian Country.

The researcher learns through initial engagement with local program staff that the tribal community has little formal data specific to the issue. Community partners indicate a need for a youth leadership program that fosters community responsibility, language, and cultural strengthening activities, as well as a program that explores depression and social disconnect for older youth as priority health issues of concern. There are potential partners that include service providers, educators, and program representatives who work directly with Native youth; these partners have expertise from what they have observed in serving youth, hearing directly from youth about their views, and other youth-centered insights about dynamics that the researcher would never know without partnership. Meanwhile, these partners indicate a need for assistance in completing a Centers for Disease Control and Prevention (CDC) funded community health assessment project that is data heavy and presents challenges given a lack of local technical capacity and infrastructure, such as a lack of specific computer software, outdated computers, and limited internet access and speed. This is an example of how a researcher can be challenged with an initial scientific inquiry idea that may not align with tribal community and youth priorities.

By volunteering to assist the tribe in completing the health assessment, the researcher learns about indicators of health and health status outcomes that connect local concerns around depression and substance abuse, as well as increased risks for suicide. Further, the researcher learns how all of these risk factors and outcomes can be addressed through leadership development and cultural strengthening approaches that build upon existing protective factors, such as a history resilience and cultural pride. A revised research proposal receives positive feedback and is supported with approvals to construct a project for funding with enthusiastic tribal government support. Native youth who learn of the proposal are excited and eager to participate in a research project that honors their strengths. While there are a lot of partnership goals to negotiate over time, it is clear that the researcher is willing to invest in the systems of relationships that inform youth health.
force and influence, which necessitates guest status. Guests who listen carefully to community wisdom can generate research that is actionable and beneficial to AI/AN youth.

• Encourages a researcher to look beyond analyses that describe Native youth as “high risk”, “at risk”, and “vulnerable”. Instead, by exploring the systems Native youth navigate through and experience, researchers may come to see the value of employing a strengths-based perspective. Youth are the only insiders to their lives, with knowledge of the solutions and actions required for supporting them to achieve wellness.

• Centers local and Indigenous knowledges. Academic culture tends to place value on institutional credentials over other expertise, which can create uneven power dynamics and tension in research partnerships. Recognizing local capacities and knowledge honors existing relationships and networks and can also prevent duplication of ineffective or existing initiatives. By centering local perspectives, research will be more likely to develop efforts that are priorities of youth and their communities. A researcher may find that research activities that resonate with a tribe or AI/AN community can lead to increased community engagement and support.

Section 2: Engaging Tribal Communities

Tribally-driven research can lead to more meaningful outcomes and benefit to tribal communities. In order to develop effective research partnerships, researchers must be aware of the importance of developing a community-based orientation in the work, including appropriate roles and knowledge of local genealogy of research. There may be various degrees of social distance between researchers and tribal partners (varying by tribal affiliation, education, income, age, gender etc.) that can affect the dynamics of conducting research in partnership. Researchers wanting to work with tribal communities to conduct research that benefits Native youth may come from a variety of backgrounds, both tribal members and non-tribal members. If researchers are tribal members, they may not come from the community(ies) in which they work. If they are from the community in which they work, researchers may have left their home for a period of time to attain higher education or pursue work elsewhere and may need to rebuild relationships and trust with community members. Moreover, a context of historical oppression and trauma imposed upon Native communities has affected the baseline trust of research itself, making relationship-building and power-balancing all the more important in the research context (Burnette & Sanders, 2014). Detailed discussion of the complexities about conducting this work are beyond the scope of this report, however researchers have noted that it is highly important to prepare to work in an ethical and culturally sensitive way with tribal communities (Burnette, Sanders, Butcher, & Rand, 2014).

Some of the research considerations that are important to examine before entering into this work include:

• Acknowledging the context of historical oppression;
• Working to offset power imbalances between research and tribal entities;
• Upholding reciprocity and offering true benefit to tribal communities;
• Creating mutual respect and trust;
• Finding harmony among multiple worldviews;
• Fostering deep commitment and responsibility; and
• Honoring the sacred aspects of research (Burnette & Sanders, 2014; Burnette, Sanders, Butcher, & Salois, 2011).
Tribal partners in two Southeastern tribes identified a community challenge: violence against Native women and girls. Research has evolved to focus on developing a framework of historical oppression and resilience/resistance to understand and address health disparities experienced by Native youth and their families (Burnette & Figley, in press). As a researcher wanting to build upon strengths, the first years of my work were invested in understanding whether and how I could contribute as a non-tribal researcher. As a White woman working with tribal communities to reduce health disparities and promote strengths and resilience, I worked hard to prepare myself both ethically and pragmatically. The overarching goal of my research has been to contribute to the enhancement of wellness of tribal communities, so that they might sustain this tribally-driven work. To do so, I reached out to both tribal and non-tribal experienced researchers and community members for constant feedback. In addition, I worked with these partners to ensure power dynamics were balanced or diminished over time. Without this preparation, the subsequent research would not have been appropriate or effective. I have made a long-term commitment to working with these two tribes, which has led to increased research on risk and protective factors related to mental health and substance use outcomes designed to benefit youth and their families.

For example, our work together has expanded to include the development of a critical ethnography, which includes exploring power dynamics that create inequality and health disparities. In particular, we discuss the context of historical oppression and resilience/resistance demonstrated by both tribal groups (Burnette & Figley, in press). To gain the perspectives of all community members about culturally specific risk and protective factors, this research included approximately 30 individual interviews each with youth, elders, adults, and professionals (approximately 120 from each tribe), 3-4 focus groups with each constituent (approximately 12 focus groups from each tribe), and approximately 30 whole-family interviews from each tribe, speaking with a total of approximately 250 people from each tribe. Research participants note that this work has enabled tribal members to tell their stories in ways that made sense to them, and this process of story-telling has been affirming and positive. Likewise, attaining grants to provide compensation for participants’ time and contributions was essential.

In working with youth, it was important to follow the tribal protocols that were learned from gaining familiarity and trust with each tribe. Initially, I tended to speak first with the most accessible participants, (e.g., professionals and adults). After conducting focus groups and interviews with professionals and adults and gaining trust, these partners were more willing to open the door for youth to participate. It was important to be flexible in this process, enabling tribal partners to guide the process rather than impose a restrictive data analysis plan. Particularly for tribal members who were unfamiliar with research, beginning with focus groups provided an opportunity for them to get comfortable with the process and researcher(s), and also to sign up for individual and family interviews if they wanted. This relationship-building process—from a more group-based context to more personal encounters—enabled the pace of research relationships to emerge gradually.

The recruitment process varied by context. In the tribe with more infrastructure and resources, the recruitment of youth and families primarily occurred through an afterschool program. I was introduced to a trusted partner at the afterschool program through a cultural insider, and this partner facilitated youth and parent recruitment in a seamless way. In the tribe with less infrastructure and resources, focus groups were arranged through trusted partners who worked in schools and community agencies. However, youth interviews were primarily gained informally after completing family interviews and through word of mouth. Because there was less infrastructure in this tribe, families were the primary way relationships were facilitated between youth and research partners.

My experience conducting research in these two contexts was strikingly different, yet equally successful. It was essential to be flexible and follow the lead of tribal partners and to conduct research within a relational framework. From this work, we have developed a follow-up survey to uncover whether the emergent risk and protective factors identified predict mental health and substance use and have found promising results. This research has also informed the development of a family strengthening program to prevent substance abuse and violence among tribal families. Youth will sit on the community advisory board in this CBPR study, which will be facilitated by tribal members. This long-term research has been a reciprocal, relational, and an affirming process of culturally-grounded work that ultimately aims to benefit tribal youth and their families.
Research partners should identify for themselves what each of these considerations looks like in their particular context and then discuss how they may impact the partnership together. Recommendations for conducting culturally sensitive and ethical research with tribal communities may include spending time in tribal communities, listening to community members, becoming educated about local history if one is not from the community, focusing on and reinforcing tribal strengths, building relationships with community and cultural insiders, practicing humility and transparency, supporting tribal self-determination and appropriate methodologies—such as community-based participatory research (CBPR)—facilitating the development of a research infrastructure, investing resources, allowing for flexibility, and advocating for tribal goals (Burnette, et al., 2014). Once trust is gained, these adults provide the opportunity to work with youth through mutually beneficial research.

In addition to preparing to engage with community members in an appropriate way, the voices and perspectives of youth are essential to include in research and are indispensable to research partnerships that benefit Native youth. Researchers must acknowledge that the contexts of AI/AN youth vary considerably. In addition, different tribes may have different protocols for working with youth that stem from cultural roles and responsibilities and past experiences with external partners. AI/AN youth may frequent programs and organizations that have a unique capacity for understanding youth, such as schools or after-school programs, and these entities might be important partners for research. Likewise, researchers working with tribes with less program infrastructure may partner with family or other community-based organizations. A recent systematic review of risk and protective factors for Native youth substance abuse and mental health outcomes found that the most robust factors that predict such outcomes were family and relational factors (Burnette & Figley, 2016). Thus, when preparing to work with youth, it is essential that researchers work to include peers, family, and others in key relationships with them.

The next section provides a case example of how to operationalize some of these insights by highlighting the experience of a non-tribal researcher who has been working on a long-term basis with two distinct Southeastern tribes (whose identities are kept private) in research aimed at benefitting tribal youth.

**Section 3: The Power of Place-Based, Small-Scale Inquiry**

While Native-focused research at the regional and national levels has value for certain questions, inquiry focused at the community level that emerges from within Native communities and institutions contributes in a very rich way. Everything I learned about relevant and purposeful research conducted from within Native communities has taught me that inquiry-driven, context-specific, and small-scale research is a powerful way to begin to lay the foundations, processes, and systems toward sustainable action and change. Questions generated from within youth groups, early childhood centers, elementary schools, and within informal spaces offer us all valuable opportunity to understand how research and action from within communities leads to significant empowerment and innovative possibilities.

In the research endeavor, I believe strongly that knowledge from specific communities can become universal knowledge. But first, we must acknowledge that rooted in the particular – values, beliefs, practices, circumstances – tribal communities can re-prioritize their needs above all others and can intentionally seek to address their central concerns today – not tomorrow, or in 5-10 years. The critical point is to begin the research from the needs of the community and individual community members. Then we can develop methods and questions that will drive that inquiry. And perhaps, as a result, we may uncover findings that impact a broader set of people or communities.
**Case Example: Starting Place Questions & Shared Place Questions**

At four tribal colleges, teams of early childhood educators, parents, and children are engaged in context specific inquiries. They each ask questions about how to ensure that Native language and culture have a foundational space within the learning environment. They seek local knowledge and resources to support their inquiry and as a result desire to see immediate results – tangible results, such as children speaking and singing in Native languages. They also hope to see that language and singing are connected to developmentally appropriate knowledge, such as mathematical thinking, and seeing and reading the world around them. Most importantly, they seek to ensure they are connected to tribal members and family through strong, caring relationships built upon tribally-informed health and wellness.

A parent says, “I want to know how to strap my child into the car seat properly. That’s my research inquiry.” This is a question of interest to an individual parent. Though this may not be the research inquiry the researcher expected to pursue, this is a Starting Place Question, a research inquiry driven by the interests and needs of a community member, and relevant to the needs of that parent. Starting with the community member’s question, pursuing the individual inquiry of this parent, and working with the parent on ways to investigate that question follows an inquiry path from Starting Place Questions to Shared Place Questions. Shared Place Questions are questions that may be of interest to a larger group of parents and community members, may dig into the broader issues raised by the parent’s initial question, and may connect with the researcher’s questions of interest. Therefore, the process of investigating a parent’s Starting Place Questions – in this example, the proper way to strap a child into a car seat – can lead to the generation of Shared Place Questions, more general or universal questions of interest, such as:

- What makes my baby comfortable?
- How do I keep my baby safe?
- How do we know when a baby is properly strapped in?
- What kinds of car seats work for different babies?
- Why does one car seat work better than others?
- How do I interact with my baby during transitions from one setting to another?
- How does my baby react to transitions from one setting to another?
- What is the quality of connection between my baby and me at different times of the day?
- What factors impact the quality of that connection?

As the questions evolve, elements of the initial research inquiry emerge at two levels: 1) by building the foundation for a trusting relationship between the individual parent and research team, and 2) by linking a parent’s need for car seat safety information with the desire to foster culturally grounded notions of health and wellness.

To develop inquiries that matter, researchers have to focus on the questions that are in front of them, within the community. If the focus is on generalizable results, or methodologies developed from outside the community, then researchers will miss the primary work that is needed in communities. Researchers must first legitimize the questions that emerge from the community, and investigate these questions. These may be linked to larger questions, and perhaps innovative methodologies may be utilized to pursue these questions, but community-based research must originate in the questions and methodologies of the community.
Many methodologies have become accepted as legitimate for implementation with Native communities, and a shorthand has developed to refer to these methodologies. However, the development of a shorthand often washes out the depth and complexity of the methodology. For example, community-based research has been shortened to “CBR,” and participatory action research has been shortened to “PAR.” When a researcher uses these names or acronyms, there is often a belief that researchers are speaking a common language. However, each of these methods require researchers to be in deep and relevant dialogue with community members prior to and during the inquiry process, a dialogue that will make the methodology look different and unique in each setting – based on the community’s questions and needs, and the way in which the methodology can be implemented to best serve the community’s inquiry needs.

In fact, these methodologies are best conceptualized as philosophies and approaches, not steps to be taken. The approach requires the researcher to think of the community’s needs (not their own) as driving the research. The specific ways in which the methodology is implemented will vary from community to community, from individual inquiry to individual inquiry.

One way to think about this concept of inquiry is to think of frybread, a food that is common across Indian Country. There are many different recipes for frybread. Across different communities, frybread may look and taste different – different flavors come to the forefront, and there are differences in size, puffiness, taste, and texture. These differences may be based on different traditions, available ingredients, climate and location, how and in what the bread is fried, and philosophies about food. Yet there are commonalities: water, salt, flour, etc. So, when we talk about frybread, we are talking generally about a familiar food and cultural connection, but each of us may be thinking about a different taste, texture, or experience. There is not one way to make frybread, and not one taste for frybread. Similarly, there is not one way to implement community-based research inquiry or participatory action research.

The evidence for successful community research is in relationships researchers develop with communities. These relationships develop into questions that can be investigated systematically and that will help immediately to address issues important to the community. This can also give individuals and the community a process for investigating, in a small-scale way, their own questions as they develop into researchers within their own communities. These are the essential ingredients of purposeful and important research with Native communities. Ultimately, as with frybread, if a community does not see itself in the ingredients, they are not going to want to partake of it.

What needs to happen in order for researchers from within and outside of tribal communities to support and engage in this type of inquiry stance and approach?

- Be prepared to suspend methodology discussions until you understand the goals of inquiry from the perspective of those the research will inform.
- Be prepared to suspend the idea that the research knowledge you are uncovering and revealing must be generalizable. See the varied processes and the approaches as a generative process that may include protocols that are not talked about outside of the community.
- Avoid dropping a research package of results and findings into communities – help communities unwrap and discover what research is.
- Researchers bring with them passionate areas of inquiry; however, tribal communities have their own passionate areas of inquiry that may then become buried in the process.
• Have the intention to **take the inquiry from collective visioning through implementation, through full reflection, and then plan to disseminate information together.**

• **Consider with the community the policy implications**, particularly on the local level, of the inquiry work you have done together.

**Section 4: Expanding Tribal Youth Research in Urban and National Settings**

Tribal communities, tribal leaders, tribal youth-serving organizations and programs, and federal agencies charged with supporting the health and wellbeing of tribal youth all require data to inform their advocacy efforts, program decisions, and policy priorities. Much of the current research data on tribal youth development come from studies that have been carried out in one or a few specific tribally-defined communities. These data are critical for informing our understanding of youth development within those specific tribal communities, and, as highlighted in Section 3, contribute to our understanding of AI/AN youth beyond those communities and spark further inquiry. Two important areas for expanding our understanding of and inquiry into tribal youth development are within urban tribal communities and within tribal communities that are national or regional in scope.

**Opportunities for Tribal Youth Research in Urban Settings**

According to the last Census, 71 percent of the AI/AN population resides off tribal lands across the United States (Urban Indian Health Institute, 2013). Cities with the largest populations of AI/ANs include: New York City, New York (111,749); Los Angeles, California (54,236); and, Phoenix, Arizona (43,724). Cities with the largest percentage of AI/ANs include: Anchorage, Alaska (12.4%); Tulsa, Oklahoma (9.2%); and, Norman, Oklahoma (8.1%) (US Census Bureau, 2012). Although many AI/ANs live in urban areas, there is relatively little research on the health and well-being of urban AI/AN populations in general, and even less research on urban AI/AN youth development (Rutman, Park, Castor, Taualii, & Forquera, 2008; Yuan, Bartgis, & Demers, 2014). The limited data that do exist suggest that urban AI/AN youth may experience even greater health disparities relative to their reservation-based peers and non-AI/AN urban youth (Freedenthal & Stiffman, 2004; Rutman et al., 2008). Reasons for these disparities reflect the unique challenges faced by AI/ANs living in urban areas including a history of forced relocation, limited access to healthcare services, discrimination, and other challenges of urban life (National Urban Indian Family Coalition, 2008). Researchers have the opportunity to support advocacy efforts on behalf of urban AI/AN youth by partnering with urban AI/AN communities to conduct studies that document the strengths and needs of urban AI/AN youth, deepen our understanding of risk and protective factors unique to AI/AN youth development within urban contexts, and explore interventions that are relevant in diverse urban AI/AN cultural contexts.

Urban AI/AN communities are tribally-diverse and not represented by the same kinds of governing bodies as federally-recognized tribal communities. Researchers are nonetheless charged with the same kinds of community-engaged and -driven approaches as researchers working with federally- or state-recognized tribal communities (National Urban Indian Family Coalition, 2008; Yuan et al., 2014). This includes working with urban Indian organizations, health boards, centers, and other entities representing the needs and interests of the tribally diverse populations residing in urban communities. This may also include working with the tribal nations of which urban AI/AN individuals are citizens. It also includes working with urban tribal community members and youth as research advisory board members, research project staff, study participants, and, most importantly, the beneficiaries of research. Resources referenced in this document can be accessed to learn more about research priorities for urban AI/AN youth, as well as best
practices for community-engaged research with urban AI/AN communities (National Urban Indian Family Coalition, 2008; Roberts & Jette, 2015; Yuan et al., 2014).

Opportunities for Tribal Youth Research that is National or Regional in Scope

National and regional level data are important for understanding strengths and needs common among AI/AN youth across the country, or within a particular region of the country, regardless of their individual or cultural differences as members of specific tribes or tribal communities. These data support national and regional dialogues on critical issues of youth well-being including health, education, and justice that transcend geographic or tribal boundaries. These data can serve as a powerful collective voice in advocating for resources to support strengths and address needs that are national or regional in scope. They also offer a point of comparison for individual tribal communities to determine the relative standing of their youth to national or regional averages. National or regional level data are complementary to, and not a replacement for, locally-driven and contextualized data.

Unfortunately, regional or national level data for AI/ANs of any age can be difficult to find or may be limited in their utility (Faircloth, Alcantar, & Stage, 2015; Malone, Knas, Cavanaugh, & West, 2016; Watanabe-Galloway, Duran, Stimpson, & Smith, 2013). In the report, “The Asterisk Nation,” NCAI describes the asterisk that too often appears in place of a data point for AI/ANs whose numbers in large national or regional studies are too small to support reliable estimates or acceptable margins of error. Researchers, therefore, have an important role to play in addressing the data gap for understanding the strengths and needs of Native youth on a national or regional scale. With their knowledge of the kinds of community-based and tribal participatory research approaches that are considered best practice for research at the local tribal community level (e.g. (Fisher & Ball, 2003)), they can help drive studies that address Native youth development priorities by serving as principal investigators of those studies or consultants to organizations that conduct those studies. Alternatively, funding agencies must prioritize national or regional Native youth research and provide the appropriate level of resources to support this work in ways that align with tribal best practices and protocols for research, including those related to ownership of data. Greater representation of AI/AN youth in national or regional studies also likely depends on tribal research review entities’ willingness to adapt research review policies and procedures to fit this national or regional context in ways that may be different than their application to research focused on the local context. As the case example below highlights, a model for implementing tribal best practices for research on a national or regional scale can center on the formation of a community that itself transcends geographic or tribal boundaries – one that is national and inter-tribal in scope, united around a common Native youth cause.
Case Example: AI/AN Family and Child Experiences Survey

In 2013, a community of tribal Head Start directors and researchers, from tribal communities and universities across the country, and federal partners from the Administration for Children and Families (ACF) came together to form the American Indian and Alaska Native Family and Child Experiences Survey (AI/AN FACES) Workgroup. With support from ACF, the Workgroup convened to address the fact that to that point, AI/AN Head Start programs had not been included in any of the national studies of Head Start. The Head Start Family and Child Experiences Survey (FACES) is the flagship study of Head Start programs nationally. It provides a wealth of descriptive information on the needs of children and families served by Head Start, as well as the characteristics and quality of the Head Start programs that serve those children and families. FACES data inform Head Start practice and policy to best meet the needs of Head Start children and families over time. Since 1997, FACES has been conducted every three years with Head Start programs nationally, except those operating in Region XI, which includes the 146 Head Start programs operated by federally-recognized tribes or tribal consortia. Region XI programs serve nearly half of the AI/AN children in Head Start nationwide.

The critical need for nationally-representative data for Region XI has long been known to tribal Head Start programs, researchers, and federal partners alike (US Department of Health & Human Services, 2004). However, owing to tribal concerns about research, the unique protocols for research involving sovereign tribal nations, and the paucity of measures and methods needed for the kinds of culturally- and scientifically-grounded research that tribal nations rightfully demand, the gap remained. After its formation in 2013, AI/AN FACES workgroup members met regularly (occasionally in person, and extensively by phone) to plan for a study of tribal Head Start children and families that was both scientifically- and culturally-grounded. The Workgroup advised on priority measurement domains of early cognitive and social-emotional development, family functioning, and Head Start program characteristics and quality; appropriate measurement tools and their administration within tribal contexts; research review protocols and procedures involving sovereign tribal nations; and, the analysis, interpretation, and dissemination of findings.

Data collection was completed during the 2015-2016 Head Start year with 21 randomly selected Head Start programs operating in federally-recognized tribal communities. Approval was obtained from each of the participating programs’ tribal research review entity. Over 900 3- and 4-year old children and their families served by these programs completed surveys and assessments of children’s development; 81 percent of children were AI/AN, 19 percent were non-AI/AN children who were also served by the tribal Head Start programs. A sample of this size of young AI/AN children nationally is unprecedented. Findings from the study are beginning to be shared and will be available on the AI/AN FACES page of the ACF website. Importantly, these data will be archived and available as a restricted use dataset with Research Connections at the Interuniversity Consortium for Political and Social Research at the University of Michigan. The hope of the AI/AN FACES Workgroup – especially the tribal Head Start directors who have advocated strongly for these data for many years – is that the findings of the study will be shared broadly and be used to inform Head Start policy and practice to best serve the needs of all children served by AI/AN Head Start.
Section 5: Ethical Considerations

For decades, research has been framed as a taboo subject in tribal communities, in large part due to prominent cases of research ethics violations and a general lack of knowledge related to tribal sovereignty and cultures. In reality, however, tribal peoples are often keenly aware of the promise that research can hold; they simply want it to be conducted in a way that is respectful of and beneficial for their individual citizens and communities. To ensure that research with AI/AN youth, specifically, both embodies basic principles of ethical research – respect for persons, beneficence, and justice – and accommodates desires for broader community benefit, it is important to consider the following topic areas within the research process: confidentiality, consent, referral context, law and jurisdiction, study design, and sustainability. In the paragraphs that follow, possible challenges and solutions relative to each of these areas are presented. It should be noted, though, that this is by no means a comprehensive “ethics checklist”, and weighing these aspects of research with AI/AN youth is not something that only occurs at the beginning of a study; reflection on them throughout the research process is ideal.

First, the ability to maintain participant confidentiality within a study is important for research occurring at any level – community, regional, or national. For community-based research in small populations in particular, youth may be reluctant to participate in a study focused on a stigmatizing topic area that is carried out in a physical space that will easily link them to the study content. Certain methodologies may also need careful consideration. Focus groups, for example, are often utilized in tribal research based on recognition of valued traditional forms of communication. However, youth may hesitate to fully participate in discussions if there is a risk of disclosing personal behavior or beliefs that could be stigmatized by others. Community-involved approaches, such as CBPR and PAR, can help to protect participant confidentiality. AI/AN youth know their contexts and preferences best; involving them in all phases of research, from development to design and dissemination, is a good practice.

Researches must also carefully consider the role that community confidentiality has in their work. For valid reasons, communities may request that tribal identifiers be removed from all publications and presentations. Stakeholders, including the researchers and community members engaged in the research activities, should discuss possible unintended consequences of community confidentiality, including limits on the ability to: advocate for resources, contribute to understanding of intertribal differences, acknowledge tribal partners, and include local co-authors on publications. Preference for community confidentiality must be upheld; though, it should also be acknowledged that as research relationships evolve and benefits are actualized, it is possible that the community’s preference could change over time.

Research involving AI/AN youth may require additional consideration related to consent. In some tribal communities, kinship and extended family care are quite common. Oftentimes in these situations, legal guardianship may not be established. And, in some cases, youth may not know that a family figure is not related to them in the biological sense of the indicated relationship (e.g., a child may be raised with a father figure that is biologically unrelated, or a maternal figure may biologically be an aunt). Researchers need to make decisions about how the consent process will take place in these contexts, specifically, whether children without established legal guardianship can participate. Studies involving genetic components in particular, need protocols that account for these circumstances and guide interactions should the need to disclose results to biological family members arise at some point in the research process. Clearly, the focus of the intended research will determine to what degree family structure will influence study consent processes.

Decisions related to age of consent and assent for participation in a study may also require discussion with community experts. Tribal communities may have specific beliefs about the developmental age at
which youth are able to provide individual consent. There may even be instances when, given the burden of an issue or need for research on a particular topic, communities will request that the age of consent be lowered to adequately account for the local context and provide valid data. For example, a community may request that age of consent for a maternal and child health study aiming to enroll pregnant women be lowered from 18- to 16-years-old to accommodate high rates of early childbearing. In any case, consent-related decisions in research involving AI/AN youth should be guided by an authorized tribal research oversight body, and if possible a Community or Youth Advisory Board or similar entity.

The referral context for research with AI/AN youth is critically important and equally challenging. Oftentimes, the very outcome of focus in a study has resulted, in part, due to the limited resource setting. Not all tribal communities and contexts are the same; however, it is true that some of our youth face quite difficult circumstances. In one recent survey of approximately 288 AI/AN youth living on a Northern Plains reservation, researchers found that a large percentage of 15-24 year olds reported lifetime experience of abuse (physical 30%, emotional 48%, and sexual 20%), neglect (emotional 42%, physical 42%), witness of mother’s abuse (40%), and suicide attempt (30%) (Brockie et al., 2015). In such a setting, a research team focused on a particular clinical topic, such as asthma, could have thorough plans in place for referral to clinical services and encounter other service needs related to mental health, substance use/abuse, or child abuse/neglect, that fall completely outside of the researchers’ expertise.

Community partners are the best resource for developing a referral plan for research involving tribal youth. Furthermore, while local experts can easily direct researchers to existing referral resources, researchers who can tap into their own networks to link communities and youth with new services provide an added benefit. Giving feedback and documentation of referral issues back to the tribe or community partner can also be a valuable process where local data and tracking capacity is limited. And yet, even with the best intentions and referral plans in place, referrals may not actually lead to receipt of follow-up services. Thus, culturally appropriate debriefing for study participants and staff is essential for research on sensitive topics. For example, offering an opportunity to smudge at the close of a study visit or at regular study staff meetings can facilitate processing of difficult-to-disclose, or -receive, information no matter what the referral context may be.

Related to referral, law and jurisdiction issues must also be examined in research with AI/AN youth. In some areas, tribal and state laws for mandatory reporting of issues, such as child abuse or neglect, threat of harm to self or others, alcohol/substance use in pregnancy, domestic violence, and minor alcohol or substance use, may differ. Researchers must be fully informed about the legal standards they are expected to uphold and have a plan in place. They must also clearly communicate their duty to report to participants. The legal and jurisdictional components of research in tribal communities may be new territory for many researchers, but it is important to not shy away from these aspects of research with AI/AN youth. Local partners can assist with navigating unfamiliar issues, and having a Memorandum of Understanding, Tribal Resolution, or Tribal Law in place to support the research is recommended.

Jurisdiction over research processes in general can also be complex. It can take time to understand whom to approach for approval of research activities in rural, reservation, and urban settings. In some cases, a tribe may have their own research oversight body (e.g., Research Review Board (RRB), Institutional Review Board (IRB), or cultural preservation office) responsible for review and approval of research on their tribal lands and/or with their tribal citizens. In other cases, they may rely on regional or national research oversight processes at institutions such as the Indian Health Service or a university. It may also be the case that several research oversight bodies are required to review protocols prior to implementation. No matter the process in place for a specific project, it is advisable to begin learning about and engaging with the process as early as possible to ensure timely review.
From a researcher’s perspective, ethics may not play a primary role in selection of a study design, but from a tribal perspective, and especially in resource limited contexts, it can be very important. Some tribal communities may express reluctance to engage in research with designs that solely utilize observation, or employ a standard of care or placebo control group. Often, this reluctance grows from a belief that participation in research activities should provide some benefit to all participants. In settings where resources are extremely limited, a researcher posing an observational or placebo-controlled study design should ask whether the design is defensible given the level of need. Both researchers and communities must also understand that more complex study designs (e.g., delivering a secondary curriculum to a control group) have real implications for overall study costs and staff demands.

This challenge-area, however, also provides a window of opportunity for study design innovation and education. Working closely with tribal youth and partners to develop study designs that meet local needs and uphold rigor within and across tribal communities can offer important lessons to academia and other populations. Also, in some instances, education on existing study designs and their rationale can help community oversight bodies, researchers, and tribal leaders weigh various options and come to an informed decision that benefits all stakeholders engaged in the research project.

Finally, both communities and funders of research often desire assurance of sustainability. Yet, when resources and human capital are limited, sustainability can seem out of reach. Some within the research enterprise may question whether long-term sustainability is even an obligation that researchers should be expected to meet. Nevertheless, for researchers committed to addressing this challenge, it’s important to take steps to acknowledge sustainability limitations up front. Researchers can also make efforts to step outside of their academic/researcher box and connect with advocates to leverage additional resources and capacity. Clearly communicating these efforts, and their value, to community partners can help to provide transparency and demonstrate commitment to seeing the research reach beyond the study period.

It is also critical that researchers present on their work to various audiences (e.g., tribal leaders throughout the U.S., program audiences, funders) and segments of the community or communities involved in the research (e.g., local leaders, the general public, and youth). Doing so in a timely manner is also vital for maintaining trust and momentum for the work. Most importantly, researchers should build meaningful training opportunities for youth, and others within tribal communities, into their studies. Across the U.S., tribal communities are eager to have more AI/AN scholars lead the research that occurs with their citizens. Sustainability becomes a more realistic and attainable goal when it is conducted in a way that fosters confidence and skill-building in AI/AN youth and helps them begin to shift the narrative of research with tribal communities from one of ethics violations and harm, to one of benefit and value.
To illustrate how the various considerations for ethical research with AI/AN youth described above come together in a research study, consider a situation where a university research team partners with two reservation-based tribal populations to investigate a recently documented increase in incidence of low birth weight (LBW) deliveries. Tribe 1 has had numerous research studies take place on their reservation and in recent years formed their own Research Review Board, while Tribe 2 is fairly new to engagement with research and often calls on the neighboring Tribe 1’s RRB to review research protocols they receive.

Without clear evidence to indicate cause for the increase in LBW deliveries, members of the university research team rely on partners from a prior research study with Tribe 1 to form a Community Advisory Board (CAB). They also contact the Health Administrator and Tribal College President at Tribe 2 to help identify individuals from their reservation that could serve on the CAB. The university research team proposes a multi-site prospective cohort study that would enroll women prenatally in clinics on both reservations, and then follow them through delivery and up to one-month after the birth of their child. Both tribes have concerns that this study design does nothing to address the immediate health and development needs of the LBW infants. Additionally, based on data from other on-going studies, Tribe 1 is aware that opioid and prescription drug abuse has recently increased within their community, particularly among young people ages 15-24.

Tribe 1 notes that approximately 40 percent of firstborn infants are delivered to women age 18 and under, and requests that research on their reservation allow for consent at age 16. They also share their concern about a possible link between increased opioid/prescription drug abuse and LBW deliveries with Tribe 2 and the university researchers. Tribe 2 suspects that similar issues are present in their community, but with limited local data they cannot be certain that the same trends exist for their population. Tribe 2 also expresses great concern that finding a link between opioid/prescription drug abuse in pregnancy and LBW deliveries could stigmatize their young women and children.

To better meet the needs of both tribal communities, the tribes suggest that youth from each community also serve on the CAB. The university team engages in multiple phone and face-to-face CAB meetings and even requests pre-review meetings with Tribe 1’s RRB, which is familiar with legal and jurisdictional requirements for both reservations. Together, with insights from the CAB and other partners on both reservations, the research team demonstrates their commitment to addressing the increased incidence of LBW deliveries and improving health on the reservations with a multi-pronged approach. They agree to begin with a prospective cohort study and secure tribal MOUs that protect substance using pregnant women from prosecution. They also draw on local expertise to develop a referral plan and secure supplemental treatment and detox services through their networks at the university. Prior to beginning the study, the researchers agree that publications will maintain community confidentiality, and the tribes agree that as results from the study emerge they will revisit their position and consider mechanisms that allow for tribal disclosure. The CAB also requests that a cultural participation measure be added to the list of assessments. Last, the researchers commit to identifying and working with the community on grants to provide intervention services in the areas identified for target within the cohort study. They also link the communities to research and program officials within their university who work in the area of child development in order to strengthen local services for newborns with special needs.

As the study is implemented, youth serving on the CAB express interest in learning more about health research careers, so the university researchers agree to build extra days into their upcoming trips to the reservations in order to visit the local high schools and present on their career paths. Inspired by the interest displayed on their visits, the researchers work with their university colleagues to secure two dedicated slots within the high school summer internship program for youth from the reservations. As the study progresses, Tribe 2 has difficulty fully engaging with the study protocol due to limited local research infrastructure and relies heavily on Tribe 1 and the university researchers for guidance.

At the close of the study, results indicate a clear link between increased opioid/substance abuse in pregnancy and LBW deliveries for both tribes, and the research team makes good on their initial plan to develop a culturally appropriate intervention study. Moreover, results from an analysis of the cultural participation measure, completed by an undergraduate student from Tribe 1, show a significant association between young mothers’ participation in cultural activities and healthy birth outcomes. These analyses lead to a new line of tribally-driven research activities focused on youth resilience and culture in both communities. Finally, Tribe 2 acknowledges their need for stronger local research capacity and uses lessons from their experience to begin forming their own RRB.
Conclusion

There is no one way to cultivate Native youth research. However, without centering Native youth voices, fostering relationships with youth families and communities, celebrating the rich diversity of each context, trying to use data to develop better understandings of the realities facing Native youth, or committing to an ethical approach to the work, research with Native youth will not lead to meaningful outcomes. These cases provide several snapshots into how to build meaningful research on a foundation of youth voice and reciprocal community-based relationships. When tribes and communities drive the research, that research can have real benefit for Native youth and their families.

References


Selected Resources

The following selected resources may be useful in advancing the research goals of a variety of stakeholders. They were selected with a range of audiences in mind, including: researchers new to tribal and AI/AN contexts, researchers aiming to deepen their relationships in AI/AN communities, students, tribal partners in research, and tribal leaders driving their community’s research.


This book discusses the impact on Indigenous peoples by colonizing powers, including the assault of modern society on Indigenous society, the commercialization of Indigenous language, culture, art, knowledge, and the lack of consent, acknowledgment or benefit of knowledge and enterprises taken. This book illustrates why current legal protections are inadequate to protect Indigenous knowledge and puts forward ideas for reform.


This article discusses the dilemma that emerges when protocols taken from Western research paradigms are applied to research in Indigenous communities. The authors raise a number of ethical issues related to voice and privilege that should be resolved in order to be inclusive of multiple perspectives.


This article discusses ethical codes of conduct in research with Aboriginal peoples or with external partners. It speaks to the rights of Aboriginal peoples to participate as principals and partners in research that affects their identity and culture.


This article examines how Indigenous knowledge can be used to understand student behavior and school climate in Indigenous school settings, particularly within the Canadian Indigenous context.

This article describes a unique research approach that places American Indian and Alaska Native communities at the center of every phase of the research process; from the research design to collecting, analyzing, and interpreting the data and reporting findings. It asserts that in order to produce lasting change, researchers must work within a historical framework that considers the impact of oppression, discrimination, and disempowerment on American Indian and Alaska Native communities. It also addresses the need for tribal oversight, building community research capability, and utilizing culturally specific methods. The Tribal Participatory Research approach advocates a strong, collaborative relationship between tribes and researchers and offers mechanisms for building these types of partnerships.


This book illustrates how historically Western researchers have failed to consult properly with or include Indigenous populations in research studies, but that this trend is slowly changing. Through a comprehensive review of examples, the book highlights how Indigenous knowledge can contribute to improved research design and delivery and has tremendous impact on Indigenous peoples as well as the researcher.


This article discusses how only tribal nations themselves can identify potential adverse outcomes to proposed research projects in their communities and how it is the responsibility of researchers to ensure all parties understand the assumptions and methods of the research. The authors assert that sovereignty, ethics and data sharing are critical areas for investigators to address when conducting Community-Based Participatory Research, particularly in a health or natural resource related field. Further, the article presents a model material and data-sharing agreement for use.

Manson, S. M., Garrouette, E., Goins, R. T., & Henderson, P. N. (2004). Access, relevance, and control in the research process: Lessons from Indian country. *Journal of Aging and Health, 16,* 58S–77S. This article aims to illustrate successful strategies in working with American Indian and Alaska Native communities in aging and health research by emphasizing access, local relevance, and decision-making processes. Findings indicate that local review and decision making reflect the unique legal and historical factors underpinning tribal sovereignty. Although specific approval procedures vary, there are common expectations across these communities that can be anticipated in conceptualizing, designing, and implementing health research among Native elders.

is meaningful and appropriate. Through this tool, NCAI encourages investigators to use these resources to identify aspects of the research process that may be unique to Native communities; concepts of power, knowledge, and culture that may be important for research inquiry in these contexts; and elements of research objectives, methodology, analysis, outcome, and data ownership that may differ in Native communities. Resources for Indigenous researchers working with their own Native communities are limited, reflecting a critical gap in the literature; however, NCAI has included some sources throughout that explore this perspective.


This document was developed collaboratively by the National Congress of American Indians Policy Research Center and Montana State University’s Center for Native Health Partnerships to share insights that emerged out of tribal research regulation and research partnership work to foster responsible research with AI/AN communities. It is a collective attempt to provide a set of resources for researchers with a commitment to developing research that benefits Native peoples. While it draws on perspectives from those in Montana, it offers broad insights for researchers working with Native communities in many places.


Research has historically been utilized as a tool of Indigenous colonization and it remains a powerful reminder of the continued marginalization of Indigenous peoples. This book looks at the historical and philosophical history of Western research and the different ways colonialism and imperialism are imbedded in research methodology and knowledge seeking. It also examines how Indigenous researchers are starting to reclaim control of Indigenous ways of knowing; yet, many still grapple with frustrations with Western research paradigms and the persistent “othering” of Indigenous populations.


This book describes how Indigenous researchers in Canada and Australia work within a research context of Indigenous ways of being and knowing. Through their partnerships, these researchers seek to make careful choices in the selection of topics, methods of data collection, analysis, and presentation of information in order to be accountable to Indigenous communities.