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Spero M. Manson, PhD

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FOREWORD

I had the pleasure of serving on the external Scientific Advisory Committee of the National Institute on Minority Health and Health Disparities-sponsored Collaborative Research Center for American Indian Health, and of presenting twice at its annual conferences. In both capacities, I came away impressed by the work of the scholars, native and non-Native, whose research was featured in poster sessions and oral presentations. Their work is deeply rooted in the communities of which they are a part and showcase the promise for future efforts that chart new courses for such collaboration, informing the scientific agenda in terms of process as well as substance. I was also intrigued by the emerging metaphor of the River of Life that describes in colloquial, but compelling terms, the different perspectives, varying priorities, and complementary approaches of the partners—advocates, researchers, educators, providers, and tribal representatives—in addressing the challenges of this work.

Accordingly, I invited Drs. Elliott, Kenyon, and Heinzmann, the principal investigators, to consider a special issue of this journal as a vehicle for sharing the lessons learned. I could not be more pleased with the efforts of all who contributed to the ensuing conversation, which is as instructive as I had originally anticipated. Their articles reflect the possibility and power of embracing matters of tribal sovereignty, transdisciplinary collaboration, and sustainability through building local research capacity. This work further illustrates the advancements encouraged by a recently published issue of *Prevention Science* entitled *Promoting Health Equity through Rigorous, Culturally Informed Intervention Science: Innovations with Indigenous Populations in the United States*.[1] The growing body of literature, to which the present publication adds, attests to the ability of today's science, in the right hands, to respond to the needs, realities, and promise of indigenous communities. Thank you to the contributors for showing the path forward.

Spero M. Manson, PhD
Editor-in-Chief

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[1] Whitesell, N. R., Mousseau, A., Parker, M., Rasmus, & Allen, J. (2018). Promising practices for promoting health equity through rigorous intervention science with Indigenous communities. *Prevention Science,* Nov 16 [Epub ahead of print]. doi: 10.1007/s11121-018-0954-x

THE COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH'S PARTNERSHIP RIVER OF LIFE: SPECIAL ISSUE INTRODUCTION

DenYelle Baete Kenyon, PhD, Melissa Buffalo, MS, Jessica Heinzmann, BA, Michaela Seiber, MPH, Dorothy Castille, PhD, and Amy Elliott, PhD

Abstract: In 2012, the National Institutes of Health funded the Collaborative Research Center for American Indian Health (CRCAIH) to work toward two broad goals: 1) to build tribal research infrastructure, and 2) to increase research on social determinants of health in American Indian communities. As the introduction to this special issue of American Indian and Alaska Native Mental Health Research*, we highlight results from the Partnership River of Life evaluation tool in order to provide broader context for the other manuscripts presented here. Insights were gained during the Partnership River of Life group discussion and evaluation process of combining the groups' rivers to create one representation of the CRCAIH partnership. Detailed results underscore insights for similar transdisciplinary groups.*

CRCAIH OVERVIEW

In 2012, the Collaborative Research Center for American Indian Health (CRCAIH) was funded by the National Institutes of Health (NIH), National Institute on Minority Health and Health Disparities (NIMHD) to provide an infrastructure for building coalitions of stakeholders from multiple disciplines to interact in conducting cutting-edge transdisciplinary research. The coalition would include tribal communities, health and transdisciplinary researchers from academic institutions, community organizations, service providers and systems, government agencies, and others. The goal of this research was to eliminate health and other disparities experienced by American Indian (AI) communities in South Dakota (SD), North Dakota (ND), and Minnesota (MN). The goals of CRCAIH are two-fold: 1) build tribal infrastructure for research, and 2) increase research on social determinants of health in AI nations. CRCAIH encompasses an interdisciplinary team of diverse investigators whose research focus is on improving health and health outcomes in AI populations. CRCAIH embraces three values: tribal sovereignty,

transdisciplinary partnerships, and sustainability to address social determinants of health through strategic investment in building tribal research infrastructure. Community-based participatory principles guide the partnerships with tribal communities to advance regional and national capacity for research on social determinants of health specific to AI tribes.

Figure 1. Collaborative Research Center for American Indian Health Organizational Chart

Administrative

External Advisory Board

Executive Steering Committee

Pilot projects   Evaluation

Community Engagement & Innovation Division
- Community Advisory Groups
- Leading education and communication
- Dissemination of research results

Research

Projects

→ Pediatric Asthma
→ Kidney Donation Education
→ Emergency Room Utilization

Culture, Science & Bioethics Core
- Bridging aspects of traditional, western and academic, and policy sciences
- Develop trainings and reports

Regulatory Knowledge Core
- Regulatory support
- Develop tribal research review capabilities
- Develop reports & fact sheets

Methodology Core
- Data management services
- Study designs
- Report generation
- Statistical analysis

To accomplish these goals, CRCAIH assists tribes and researchers through three divisions (Administration, Community Engagement & Innovation, and Research) and three technical cores (Culture, Science, & Bioethics; Regulatory Knowledge; and Methodology; see Figure 1). CRCAIH currently works with five tribal partners: Oglala Sioux Tribe, Turtle Mountain Band of Chippewa Indians, Fond du Lac Band of Lake Superior Chippewa, Sisseton-Wahpeton Oyate, and

Rosebud Sioux Tribe, and previously also worked with Cheyenne River Sioux Tribe and Spirit Lake Nation (see Figure 2). This regional center started with strong researcher-tribal health partnerships in SD, and extended to ND and MN to address AI health disparity rates to become truly regional. This three state region also mirrors the main footprint of the lead health care organization (hospitals and clinics), which helped facilitate partnerships. For more details on the tribal nations' context, such as size of tribal lands, population, and economy, see "Not a One-Size Fits All Approach: Building Tribal Infrastructure for Research through CRCAIH" (Buffalo et al., 2019) in this special issue. All CRCAIH partners approved of being named in this article and special issue.

To invest in social determinants of health research, CRCAIH supported three large-scale research projects and fifteen pilot grants (for more details, see Elliott et al., 2016). Much care was taken to establish CRCAIH as a regional center and give it a separate identity from the institutional lead site (Sanford Research).

Figure 2. Map of Collaborative Research Center for American Indian Health Tribal Partners
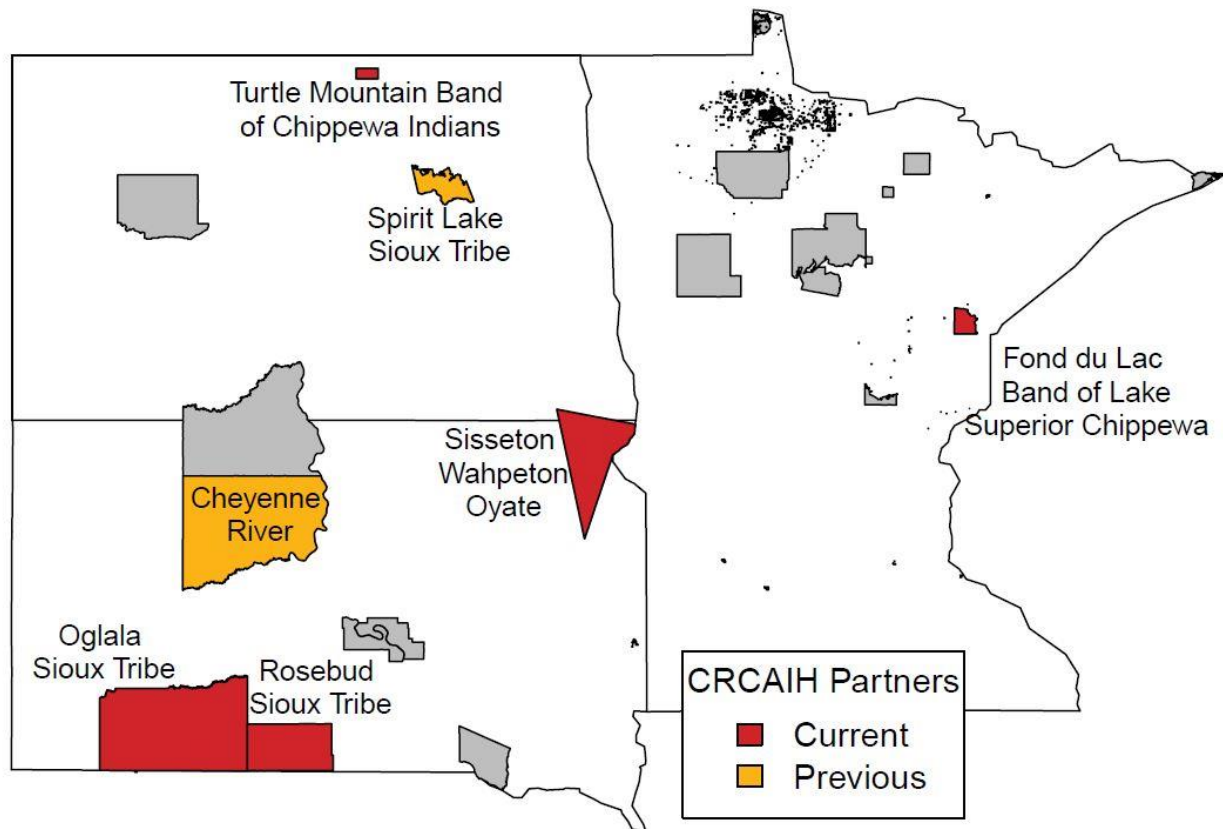
NIMHD Goals

CRCAIH has been funded by an NIMHD initiative to support transdisciplinary targeted research, implementation, and dissemination activities that transcend customary approaches and "silo" organizational structures and to address critical questions at multiple levels in innovative ways. This was accomplished through the support of Transdisciplinary Collaborative Centers (TCC) focused on health policy research and social determinants of health research (U.S. Department of Health and Human Services [DHHS], 2012). The initiative sought to ensure that culturally appropriate and relevant research would be conducted at the regional level and that findings could translate into sustainable individual-, community-, and system-level changes that improve population health.

Regional collaborative centers provide opportunities for institutions to achieve a broader reach than is otherwise possible while combining expertise and resources. At the same time, they foster applied research that is uniquely responsive to specific population-based, environmental, sociocultural, and political factors that influence health within a particular region. The concept of regional collaborative centers is structured around an overarching goal delineated in the NIH Health Disparities Strategic Research Plan (DHHS, n.d.), integrating research, capacity building, and outreach/dissemination to 1) develop a coordinated interdisciplinary approach to reduce and ultimately eliminate health disparities; and 2) develop opportunities to leverage resources and enhance collaboration.

Original CRCAIH Vision

The original vision for CRCAIH emerged over 10 years of collaborative work on various research projects with tribes (e.g., Angal, Petersen, Tobacco, & Elliott, 2016; Dukes et al., 2014; Hanson, Miller, Winberg, & Elliott, 2013; Kenyon & Carter, 2011; McMahon, Hanson, Griese, & Kenyon, 2015) and was at the forefront of the application to NIMHD. These early collaborations led to identification of the three primary values that became the overarching considerations for every component of CRCAIH. First, community engagement and establishing true partnerships based on mutual understanding and respect is essential. Second, sound research design, implementation, and analysis of research studies is necessary to answer important questions to improve AI health, with an emphasis on bringing results to the intervention stage. Third, the

researcher-community relationships need to result in equitable fiscal relationships and sound administrative management.

Once these foundational values were identified, the core service areas of regulatory, culture, and methodology services were developed by asking, "What do we wish had been in place 10 years ago?" These conversations between researchers and tribal collaborators led to identification of gaps in tribal research infrastructures and struggles with collaborating with investigators. These gaps included funding concerns, cultural knowledge deficits, and a strong desire from tribes to have a higher level of regulatory control over research happening on their lands and with their people. An example of a common funding gap is that unless a subcontract is issued, tribes do not get indirect costs for grants awarded to academic institutions. Given institutional review boards (IRB) are often supported, at least in part, through indirect funds obtained from external funding, this lack of funding makes the establishment and maintenance of a tribal regulatory infrastructure quite difficult. As detailed throughout this special issue, CRCAIH was designed with researchers and tribal partners specifically to fill these gaps and create a foundation for healthy and productive partnerships.

PARTNERSHIP RIVER OF LIFE EVALUATION

Through yearly work plans and strategic planning with the Executive Steering Committee, CRCAIH has continuously incorporated self-reflection and evaluation into the administration of the center. In addition to internal evaluation activities, CRCAIH twice worked with external evaluators to refine metrics of impact and assistance in articulating goals. In fall 2017, two CRCAIH staff (one representing the community engagement and innovation division and one tribal partner) attended an Engage for Equity (E2) workshop led by Dr. Nina Wallerstein and colleagues. One activity they participated in was the Partnership River of Life, a visual, narrative evaluation tool that helps partnerships tell the story of their journey through a river metaphor (Partnership River of Life Activity, n.d.). These CRCAIH representatives later facilitated this activity with the broader CRCAIH team at the summer 2018 tribal partner retreat. There were 12 total participants, 6 of those were researchers, 4 tribal partners, and 2 undergraduate summer interns. Conducting this activity when most partners were in person helped achieve an excellent dialogue that is paramount to in-depth topics such as this. The goals of utilizing this evaluation tool at the retreat was to review the six-year history of CRCAIH, facilitate the CRCAIH team

members' reflections on previous accomplishments, and help plan for the future. Attendees were split into three groups, mixing more seasoned members with newer members, and were given 45 minutes to create a river that visualized, from their perspective, the CRCAIH partnership over the years. While creating these visualizations, groups were told to reflect on the goals, processes, barriers, important or influential stages, factors that facilitated the work, obstacles that were challenging, and the future direction of the partnership. Upon groups' completion of the activity, the facilitators first shared their Partnership River of Life from the E2 workshop and guided conversation as the other three groups presented their rivers.

There were four very different rivers and approaches to the visualization, which was incredibly informative to see the groups' different perspectives reflected and which key aspects they chose to represent. To further utilize the tool for planning and reflection, the cores and divisions created a combined CRCAIH Partnership River of Life (see Figure 3) after the tribal partner retreat. For brevity and clarity, Figure 3 encapsulates the major events and reoccurring themes, but does not include all of the aspects in the four groups' various rivers.

Figure 3. Collaborative Research Center for American Indian Health Partnership River of Life – Summer 2018
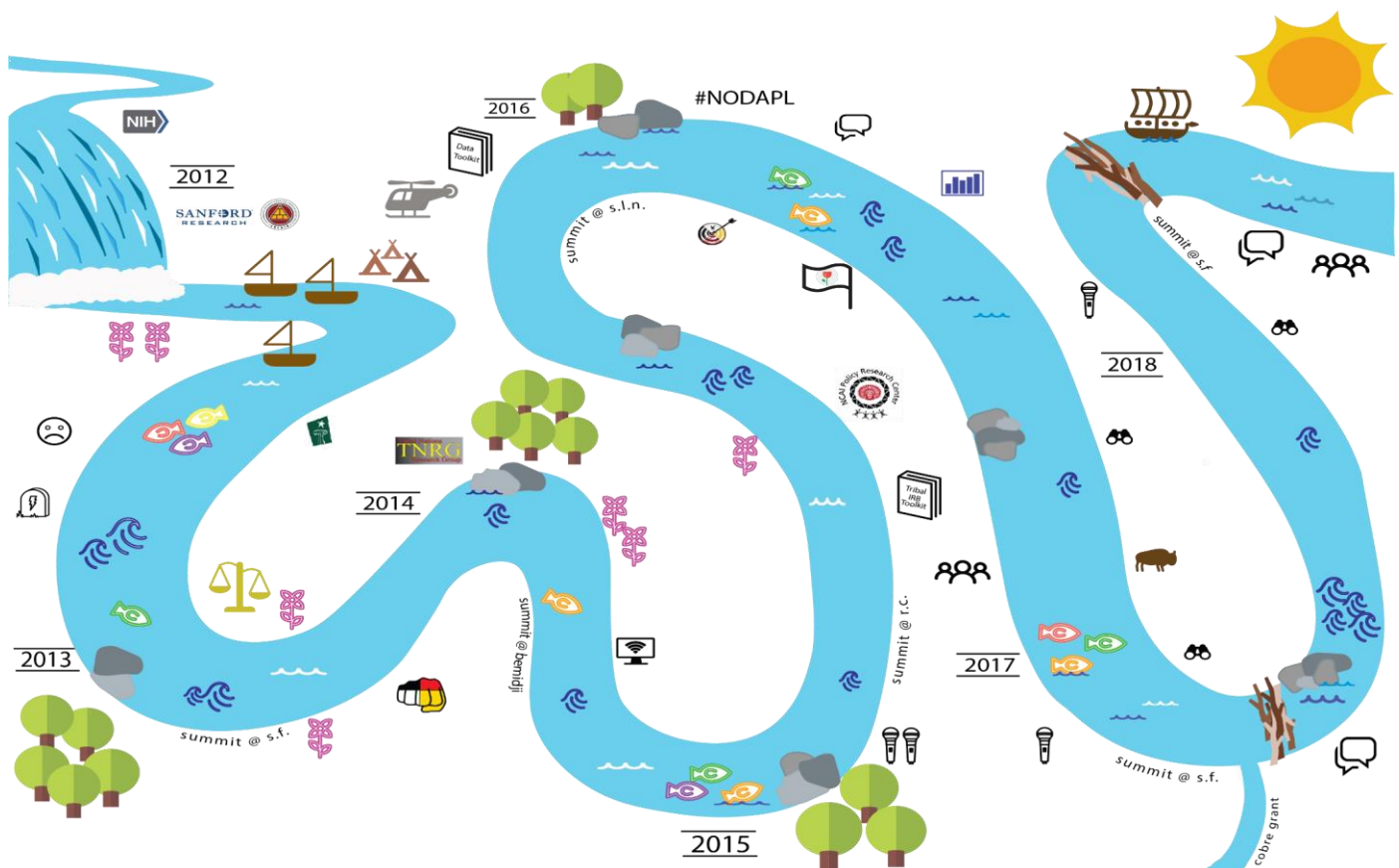
Key Constructs

Beginning

Most of the groups started their river in 2012 when the grant began, but the group that had the member with the longest tenure with CRCAIH included a small stream leading up to the waterfall representing the years of partnerships, discussions, and collaboration building that led to the establishment of CRCAIH. Examples of these early important factors included the Principal Investigator's and large project leaders' research (represented as three boats) and partnerships with the original tribal partners (symbolized by flowers), CRCAIH members' experience with previous employers (e.g., tribal colleges), and previous funding relationships with NIH and the National Science Foundation. The CRCAIH team readily acknowledged how the TCC grant from NIH was clearly instrumental in establishing CRCAIH.

CRCAIH experienced both positive and negative aspects after the funding commenced. The pervasive feeling was one of excitement about the NIH funding and momentum and promise that comes with growing partnerships. However, the new center also came with challenges of immediate need for hiring new staff to fill key organizational and support roles, such as the tribal research liaisons and project manager. At times, some aspects of building the center, such as the logo design discussion, seemed to take longer than planned. The largest setback early on was not solidifying the partnership with a tribe due to leadership turnover after the grant was submitted. Fortunately, this tribe later became a CRCAIH partner after further discussions.

Important Achievements

The groups' rivers had several instances of peaceful times where there were smooth waters, pooled water, fish, and thriving ponds, which represented bringing on new partners and solidifying partnerships. Important successes represented during these times included the Annual Summit, which was a time for everyone to come together to connect and network with others outside CRCAIH staff and disseminate successes. The tribal partners were highlighted as large flowers, to emphasize their integral role in the success of CRCAIH. Other important successes mentioned were the tribal selection process (including interest from many other regional tribes); building research review boards, tribal codes/ordinances (represented by scales of justice); review board processes becoming electronic (represented by computer with Wi-Fi symbol); Tribal Nations Research Group becoming a 501(c)3 non-profit (represented by logo); tribal community conferences (represented by microphones); research publications, presentations, pilot grant projects (represented by trees); tribal partner retreats (represented as discussion bubbles);

regulatory and data management toolkits (represented by books); NIH supplement grant (represented as a flag); new partnerships (e.g., National Congress of American Indians); external evaluations (represented by logos); and coordinated response to the proposed common rule changes. The regulatory toolkit was noted as an incredibly useful resource, not just for CRCAIH partners, but for tribes across the United States. The value of the toolkit helped provide CRCAIH a national presence with organizations, such as Public Responsibility in Medicine and Research (PRiM&R). A buffalo was included in one group's river to represent the tribes working for the protection and benefit of their tribes, and there was a movement toward data governance (represented by bar chart) near the end of the river. One group had represented a disagreement between the tribe and researchers early on and showed their positive partnership further down the river (represented by a sad emoji and groups of three people, respectively).

Influential Context

Particularly for the group who developed their river at the E2 workshop, there was much emphasis on the context of the importance of why CRCAIH was developed. They included aspects such as the negative perspective of research that tribes can have, due to cookie cutter approaches, helicopter research (represented by helicopter and teepees), researchers highly benefitting from research, and tribes being over researched (symbolized by the headstone—being researched to death). Other important contextual factors included historical trauma and the impacts of current events of the Dakota Access Pipeline movement (symbolized by #NODAPL). Another influencing factor included tribal sovereignty, which is integral to the rationale of why tribes wanted to be involved with CRCAIH and initiating laws and codes to regulate research (represented by a medicine wheel fist). A key event that emerged was the award of a large NIH Centers for Biomedical Research Excellence (CoBRE) grant to Sanford Research that created some confusion surrounding its relationship to CRCAIH, especially with the overlap of some staff and core services between the two Centers. This CoBRE grant was awarded around the same time the original PI (senior author - Elliott) moved to a different institution, creating difficult transitions, but also the opportunity for new voices and vision.

Challenges/Obstacles

Challenges were represented as boulders, pollution, rough waters, and river currents. In one, splashes and a swamp represented missed opportunities (not formalizing a tribal partnership in year 1, discontinuing partnerships). Notable challenges frequently mentioned were turnover in

staff (e.g., core directors), lack of funding opportunities (e.g., discontinuation of TCC mechanism), and unfunded continuation grants. Other challenges less frequently mentioned by groups were partnership disagreements, building trust, and tense debates over vision during partnership-building. Notably, one group highlighted how CRCAIH overcame a challenge by drawing two dams with the river flowing over it to represent the carryover funding and no cost extension that allowed CRCAIH to continue two additional years.

Future

In representing the end of the river, some groups focused on the need for grant funding, with one group symbolizing the importance of grant writing by a person fishing (represented in Figure 3 as binoculars). Additional themes that arose were a new energy, focus for shared vision, represented by staff on boats with the new PI (first author – Kenyon) leading. Unlike the earlier representations of the calm water after the earlier challenges, this later time was represented as a sense of stronger bonds, tighter collaboration, and focus on the work of obtaining more funding to continue the partnerships. A couple groups used the sun to represent nourishment and brighter days in the future. One group integrated question marks and depicted several smaller flowing streams to show it likely will not be another large grant to fund CRCAIH, but other smaller revenue streams.

Reflections

The evaluation tool was not only an opportunity to reflect and share memorable moments, but also as a time to discuss beginnings, influences, obstacles, and successful moments CRCAIH has had over the last 6 years. Unexpectedly, it also provided opportunity for renewed investment. Many of these aspects will be highlighted throughout this special issue. Completing the Partnership River of Life evaluation was particularly helpful to those staff newer to the CRCAIH partnership. Much of the debrief discussion focused on the large successes of CRCAIH, such as the Annual Summit. A sense of resilience and purpose was felt at the conclusion of the conversation. Despite key staff turnover, the group realized that the partnership is stronger than any one person due to the mission and overall purpose of CRCAIH. Another important recognition of a major successful outcome of the center was that the five tribal partner relationships were stronger than ever. Although CRCAIH's mission was to fund both research projects and tribal infrastructure building, the group felt the lasting effects on the tribe's infrastructure (e.g., research review board processes) would be CRCAIH's unique legacy.

Weeks later, important insights on the CRCAIH partnership continued during additional evaluation reflections on the Partnership River of Life outcomes with the core and division staff. As the main NIH funding stream to this partnership comes to an end, the two years of extension dollars have helped the transition, where members feel fortunate to have additional time to accomplish goals and process that the partnership will be irrevocably changing. An additional reflection was that members might feel a more urgent need or motivation to accomplish tasks in this final no cost extension period. It was not an initial goal for the tribal partners to work together in their efforts; however, the peer-to-peer assistance has been an unexpected and welcome outcome the past couple of years of the CRCAIH partnership. The cores' and divisions' work is now much more integrated (e.g., joint tribal partner calls are held bi-weekly), compared to earlier in the partnership where the cores and divisions worked more separately with each tribe, and quarterly tribal partner calls were held. Calls are more focused on joint product development (e.g., presentations, toolkit revisions), rather than building individual tribal research review board infrastructure. Having a smaller group of staff makes communication across the group easier. For example, projects are a more frequently combined effort due to the smaller core and division staff. As work is more integrated across core, division, and tribal partners, there is less of a distinction between CRCAIH administration and tribal partners. Tribal partners are more directly involved with the process of developing products and disseminating lessons learned, and with the opportunity to be co-authors, they have greater buy-in and satisfaction with products.

SUMMARY

In large, complex partnerships, it is very important to undergo regular self-reflection and dedicate time and attention to the operation of these partnerships. The Partnership River of Life is a helpful tool for strategic planning, which is particularly important in times of shifts in partnerships. For all the CRCAIH members, this exercise provided new vision and energy. Therefore, the Partnership River of Life evaluation tool proved useful for reflection on partnership building and continued work toward shared goals and vision. Utilization of this as a historical documentation and reflection tool is highly recommended to guide group conversation and strategic planning.

Goal of Special Issue/Structure

The main goal of this special issue of the *American Indian and Alaska Native Mental*

Health Research journal is to convey the immense impact of the creation of CRCAIH and resulting long-lasting impact. For example, CRCAIH's original funding through NIMHD of $13.5 million yielded a return on investment of over $26 million through partners' subsequent grant awards. CRCAIH became a hub of information, disseminating research on resources, trainings, grants, and research findings through the website (www.crcaih.org), twice-monthly listserv, social media (Facebook, twitter, LinkedIn), and Annual Summits.

This special issue aims to showcase the areas of impact and applicability to other partnerships, synthesize lessons learned, create a vision for future partnerships, and provide directions for future investment in tribal infrastructure and research in AI health. The issue continues with a manuscript extoling CRCAIH's fundamental values and detailing how AI community-based research is uniquely transdisciplinary (Heinzmann, Simonson, & Kenyon, 2019). The next manuscript discusses aspects of tribal partner research infrastructure building (Buffalo et al., 2019). The following manuscript represents the cores' work in building capacity in tribal research regulation and oversight (Around Him et al., 2019). The final section of the issue holds contributions from several CRCAIH pilot grant program (Becker, Heinzmann, & Kenyon, 2018) awardees. These papers detail important findings exploring concepts of Wicozani (overall health and well-being; Peters, Peterson, & the Dakota Wicohan Community, 2019), Wac'inyeya (hope for the future; Gray, Schrader, Isaacs, Smith, & Bender, 2019), and describes two parts of the intervention project, We RISE: indicators of health behavior change (McCormack, O'Leary, Moran, & Hockett, 2019) and development of a resource guide and training (O'Leary et al., 2019).

We hope the readers find the information detailed here helpful for their own social determinants of health work. There is much work to be done to continue to make progress in AI health equity, and an important factor is for tribes to continue building tribal research capacity.

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A TRANSDISCIPLINARY APPROACH IS ESSENTIAL TO COMMUNITY-BASED RESEARCH WITH AMERICAN INDIAN POPULATIONS

Jessica Heinzmann, BA, Anna Simonson, PhD, and DenYelle Baete Kenyon, PhD

Abstract: Social determinants of health and their effects on health outcomes create a complex system, with interaction between social, economic, physical, and biological factors necessitating research take a holistic approach. Transdisciplinary research, one of the three core values of the Collaborative Research Center for American Indian Health, seeks to go beyond methods of knowledge production occurring solely within disciplinary boundaries, because real-world societal problems do not adhere to such restrictions. Community involvement is an essential component for successful research partnerships with American Indian and Alaska Native (AI/AN) communities. We posit that transdisciplinary approaches, which considers community-level expertise as an equitable component on the research team, show great potential for advancing research in AI/AN communities.

Roughly 5.2 million people in the United States identify as American Indian and Alaska Native (AI/AN) alone or in combination with another race, making up 1.7% of the total population (U.S. Census Bureau, 2010). It is well documented that AI/AN populations experience significant health disparities (Indian Health Service, 2015; 2018), and the importance of recognizing social determinants of health and their effects on health outcomes are receiving increased attention in medical and health professional circles (Dankwa-Mullan et al., 2010; Secretary's Advisory Committee, 2010). This complex system, with its interaction between social, economic, physical, and biological factors, makes a multi-pronged approach to addressing certain health disparities more likely to be successful (Emmons, Viswanath, & Colditz, 2008; Ruffin, 2010). Research is needed to identify and understand how best to address the complex issues caused by social determinants of health.

A prior history of "bad research" has rightly led to suspicion and negative perceptions of researchers in many AI/AN communities (Davis & Reid, 1999; Hodge, Weinmann, &

Roubideaux, 2000). Research conducted without relevance to local concerns provides no new, useable information or tangible benefits to the tribe and only manages to further the researcher's career (Deloria, 1991; Wax, 1991). Furthermore, non-Native researchers often lack sufficient understanding of the historical context of AI/AN communities, and they frequently do not fully recognize the cultural uniqueness of each tribe (Davis & Reid, 1999). Outside researchers' lack of interaction with the communities they study gave rise to the term "helicopter researchers," which describes investigators who "fly in" to gather data and then "fly out" to write up their findings, with no attempt to connect with the community or provide them with relevant results (Hodge et al., 2000). To help improve research practices and relationships, scholars have heralded the benefits of community-based participatory research (CBPR), which ideally prioritizes community perspectives and knowledge and, therefore, promotes greater impact, relevance, and sustainability (Burhansstipanov, Christopher, & Schumacher, 2005; Caldwell et al., 2005). For researchers who work with AI/AN populations, including community perspectives and knowledge in research projects in all phases of the research process supports tribal sovereignty and allows for the inclusion of certain contextual factors that might affect the project but are not necessarily or readily apparent to an outsider (Burhansstipanov et al., 2005).

However, in order to conduct research that truly benefits AI/AN communities, we posit that an even more equitable research partnership is necessary. This requires a shift in our understanding of CBPR, which has a variety of interpretations that leave room for researchers to include community members in varying degrees, depending upon individual research agendas. Like many proponents of CBPR, we argue that community members should be involved in *all* stages of the research process, from conceptualization to publication, a notion that is not without its critics. This approach has been called "fanciful if not naïve" by some (Weiner & McDonald, 2013, p. 5), and perhaps this has its place. But as researchers who work with AI/AN communities, we have found that CBPR that adopts an inclusive, transdisciplinary framework is the best way to conduct research with Native populations. When addressing a truly complex problem, such as health disparities in AI/AN communities, moving to a transdisciplinary approach and employing a team from a variety of disciplinary backgrounds is necessary. In fact, a transdisciplinary approach that recognizes the interconnectedness of many of these determinants aligns well with AI/AN holistic worldviews, and the inclusion of community experts within the team is crucial to successful projects. Going a step further, we posit that transdisciplinary research with AI/AN communities dissolves the boundaries that separate

investigators from community members by re-conceptualizing what we mean by "expertise." In other words, transdisciplinary research should, according to its traditional definition, draw upon several academic disciplines, but it should also incorporate on equal footing the community "discipline" of tribal knowledge. Maintaining that community expertise is comparable to the knowledge acquired through advanced training in an academic discipline is an important step forward in the field and truly upholds tribal sovereignty, something that the Collaborative Research Center for American Indian Health (CRCAIH) aims to do.

COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH

Creation and Aims

CRCAIH was established in 2012 with a $13.5 million dollar grant from the National Institute for Minority Health and Health Disparities (NIMHD) as one of the Transdisciplinary Collaborative Centers (TCCs) for health disparities research. In describing the initial funding opportunity, NIMHD emphasized that improving minority health would require transdisciplinary frameworks that cut across organizational silos, fostering strong collaborations and integrative approaches with many disciplines (U.S. Department of Health and Human Services, 2012; see Kenyon et al., 2019, in this special issue). As such, CRCAIH—a multi-faceted endeavor comprised of three divisions (Administration, Community Engagement & Innovation, and Research) and three technical cores (Culture, Science, & Bioethics; Regulatory Knowledge; and Methodology)—was built on the core values of tribal sovereignty, sustainability, and transdisciplinary research and strives to bring together tribal communities and researchers from multiple disciplines in South Dakota, North Dakota, and Minnesota. Since 2012, CRCAIH has supported three large research projects and 15 pilot grants in AI social determinants of health. In addition to supporting these transdisciplinary research projects, the other primary aim of CRCAIH was to engage in formal partnerships with seven tribes in the region in order to assist them in building their own research infrastructures (Elliott et al., 2016; see Buffalo et al., 2019, in this special issue).

Key to implementing a transdisciplinary approach, CRCAIH staff come from a variety of disciplinary backgrounds. Experts in clinical psychology, epidemiology, family studies and human development, sociology, law, nutrition, public health, nursing, medicine, and maternal child health have served as directors of the cores and divisions and as the principal investigators

(PIs). Other staff come from a range of educational backgrounds, including economics, data science, biostatistics, early childhood development, human resources, business administration, nursing, health sciences, and psychology. Having staff from a wide skill set has allowed CRCAIH to offer capacity-building assistance to tribal partners in multiple areas.

Additionally, each research project and pilot grant employed team members with backgrounds relevant to their particular areas of focus, including tribal community partners, although not all research sites were located within reservation boundaries. The type and number of tribal community partners involved depended upon the study. For example, some pilot grants worked directly with tribal organizations' existing staff, while others hired local tribal community members to assist with recruitment and intervention delivery. AI/AN staff from various tribal affiliations were represented in all components of CRCAIH as evaluators, core directors, research specialists, community liaisons, and pilot grant investigators. Notably, half of CRCAIH pilot grant awardee PIs and Co-PIs were AI/AN. Invaluable expertise was brought to the project by staff who possessed knowledge of AI/AN history, values, and culture and utilized that lens when working in areas such as research ethics. One example of this was the development of a Cultural Narrative to accompany the lengthy final report of data collected during a tribal partner's Comprehensive Community Assessment (see Buffalo et al., 2019, in this special issue). The entire process was rooted in Dakota cultural values, and the resulting Cultural Narrative was key to disseminating findings in a useful and culturally sensitive way to the community (Around Him & Pickner, 2016).

In funding CRCAIH, the National Institutes of Health (NIH) understood that for tribal communities to be truly equal research partners and fully engage in research projects, there needs to be a substantial investment in tribal infrastructure. This investment is essential to upholding tribal sovereignty and thereby improving tribal-academic research partnerships. A number of power differentials stemming from the lingering effects of colonialism as well as absent (or inadequate) resources continue to impede tribes' ability to conduct and regulate research (Emmons et al., 2008; Manson, Garroutte, Goins, & Henderson, 2004). Tribal stewardship and regulation of research leads to meaningful and useful research results and ensures that the research conducted will benefit the tribe and proceed in a positive way (Oetzel et al., 2015). By electing to limit the number of fully partnering tribes, CRCAIH made funding available for each tribal partner to support one full-time equivalent employee. This strategic allocation meant tribal

partners would have staff dedicated wholly to research infrastructure building and could capitalize on the dedicated CRCAIH core/division support over the grant period.

Honoring Tribal Sovereignty

The uniqueness of each community meant a "one-size-fits-all" approach to research capacity building would neither honor tribal sovereignty nor meet the communities' needs effectively. The tribal partners were at various stages of developing their own research infrastructure when their CRCAIH partnerships began, with each having different needs and priorities they wished to address. The purpose of CRCAIH in providing capacity-building assistance was not to dictate what the tribal partners should do, but to provide tools, technical assistance, and financial support to help them enact their own vision for research and research regulation in their community. This aspect of CRCAIH has been particularly beneficial in working with AI/AN populations. As one pilot grant awardee expressed,

> I see data sovereignty as a part of public health, which is one of the inherent authorities of a sovereign government. We do not have that yet. We do not have public health infrastructure or the ability to analyze our own data. In order to exert our sovereignty in public health, we need our own capacity. … CRCAIH has fostered a climate for tribes doing their own investigation … [and] has done a lot to promote the different core capacities for actively participating in data and translating what is done to how it can benefit the tribe itself (A. Simonson, personal communication, March 26, 2019).

Indeed, this quote highlights the importance of the capacity-building work CRCAIH has performed using a transdisciplinary approach.

Uniqueness of the Transdisciplinary Collaborative Center (TCC)

Like CRCAIH researchers, the other seasoned TCC investigators were already entrenched in research with their community-based partners (most often African American communities in the southern United States). They employed unique ways of investing in community members, including community-member research training and crowd-sourcing of pilot research projects. CRCAIH is different in that community partners are *tribal nations*, which

comes with a variety of complex factors that differ when compared to working with other minority and/or vulnerable populations. Federally recognized tribes are sovereign nations, and, as such, have the power to enact and enforce laws regulating research taking place on their lands (Harding et al., 2012). Exercising this authority becomes difficult without the appropriate financial resources and human capital. CRCAIH's support of regional tribes, particularly in helping to build and enhance their research infrastructure, supports tribal sovereignty and future tribal engagement in transdisciplinary research. As detailed above, the fact that CRCAIH was established as a capacity-building mechanism, with core and division support for tribal research infrastructure, was a drastically different use of resources.

Conceptualizing the Manuscript

As CRCAIH continued its work building tribal research infrastructure and supporting research projects, a theme that often arose was how the notion of transdisciplinary research was the next big step in advancing the field of AI/AN research. The way in which researchers view the connectedness of factors that impact social determinants of health is a product of their disciplinary perspective. In contrast, one of the core principles that CRCAIH was founded on, *transdisciplinary research*, goes beyond typical academic sector methods of knowledge production that occur within disciplinary restrictions, because real-world societal issues do not adhere to such rigid boundaries (Pohl, 2011). Transdisciplinary research in health disparities that extends beyond the traditional academic-scientific realm to involve a broader network of disciplines allows new perspectives to shine through, which in turn might reframe a project's focus (Abrams, 2006). It follows that having additional perspectives can provide a more nuanced and representative picture. This multifaceted lens has the ability to improve project design, community participation, as well as scientific rigor.

To be sure, the development of CRCAIH provided fertile ground for discussion. These ideas took shape in lively conversations between CRCAIH administration and NIH project officers and scientists about building transdisciplinary teams and the unique aspects of CRCAIH. These initial discussions were the seed for many of the ideas in the present manuscript.

Relationship of Transdisciplinary Research to Community-based Participatory Research

Depending upon the criteria used, the similarities between transdisciplinary research and CBPR tend to blur their boundaries. Pinning down concrete definitions that can be widely agreed upon is often difficult, if not impossible. We posit that ideally performed CBPR would meet the tenets of transdisciplinary research. In fact, some scholars have gone so far as to suggest that CBPR "requires a shift away from disciplinary to transdisciplinary research methods" (de la Torre, 2013, p. 4). As Leavy (2011) suggests, "In its best form CBR is necessarily a transdisciplinary modality of research" (p. 83). Yet most community-based research (CBR) does not reach the level of transdisciplinary for a variety of reasons. The level of synergies, collaboration, and integration that modalities reach in real world application tend to fall somewhere along a spectrum, with few achieving the highest levels. The difficulty of reaching this level, however, should not prevent the attempt. When working with AI/AN communities, transdisciplinary research is necessary, not just preferable.

Community-based Participatory Research

CBPR and related approaches (community-engaged research, action research, participatory action research, tribal participatory research) have grown in popularity in recent years, particularly in research that addresses health disparities in minority populations (Israel et al., 2010; Muhammad et al., 2015; Wallerstein & Duran, 2006). An oft-cited definition from the W. K. Kellogg Foundation Community Health Scholars Program (2001) describes CBPR as:

> a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities. (p. 2)

In her 1998 Review of Community-based Research, Israel and colleagues set forth eight key principles of CBPR, which was later expanded to nine (see Table 1; Israel et al., 2008). Numerous scholars have added to Israel's recommendations, especially when working with AI/AN communities, since there are other contextual factors to consider when working with tribes (e.g. Caldwell et al., 2005; Fisher & Ball, 2003; LaVeaux & Christopher, 2009; see Table 1).

Table 1
Principles of community-based participatory research, tribal participatory research, and transdisciplinary approaches

CBPR[a]	Tribal Participatory Research[b]	Transdisciplinary[c]
Community is unit of identity	Historical experience with research…work to overcome negative image of research	Focus on real-world problems
Builds on strengths and resources within the community	Recognize tribal sovereignty	Transcending and integrating disciplinary paradigms
Facilitates collaborative partnerships in all phases	Differential tribal & community membership	Participatory research
Integrates knowledge & action for mutual benefit of all partners	Understand tribal diversity and its implications	Search for unity of knowledge beyond disciplines
Promotes co-learning and empowers to address social inequities	Plan for extended timelines	
Involves cyclical and iterative process	Recognize key gatekeepers	
Addresses health from positive and ecological perspectives	Prepare for leadership turnover	
Disseminates findings and knowledge gained to all partners	Interpret data within the cultural context	
Long-term process & commitment to sustainability	Utilize Indigenous ways of knowing	

Note: [a] Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., III, & Guzman, J. R. (2008). Critical issues in developing and following CBPR principles.
[b] LaVeaux, D., & Christopher, S. (2009). Contextualizing CBPR: Key principles of CBPR meet the indigenous research context.
[c] Hadorn, G. H., Biber-Klemm, S., Grossenbacher-Mansuy, W., Hoffmann-Riem, H., Joye, D., Pohl, C., . . . Zemp, E. (2008). The emergence of transdisciplinarity as a form of research.

Transdisciplinary Research

Much like the plethora of terms somewhat analogous to the CBPR approach, transdisciplinary research has often been used interchangeably with interdisciplinary, cross-disciplinary, and multidisciplinary research (see Figure 1). Although the literature lacks a widely agreed upon definition of transdisciplinary research, attempts have been made to outline distinguishing features (Choi & Pak, 2006; Thompson, Owen, Lindsay, Leonard, & Cronin, 2017). Rosenfield (1992) described the nuanced differences of each type of research in an effort to provide distinction. Multidisciplinary is where researchers work in parallel or sequentially from their disciplinary-specific base to address a common problem. Interdisciplinary is defined as when

researchers work jointly but still from a disciplinary-specific basis to address a common problem. Finally, *transdisciplinary* differs in that researchers work jointly using shared conceptual framework that draws together disciplinary-specific theories, concepts, and approaches to address a common problem. Aboelela et al. (2007) concluded that there exists a "continuum of collaboration" along which research approaches fall, with transdisciplinary research requiring the highest degree of synthesis.

Figure 1. Conceptualizing differences among monodisciplinary, multidisciplinary, interdisciplinary, and trans-disciplinary research approaches
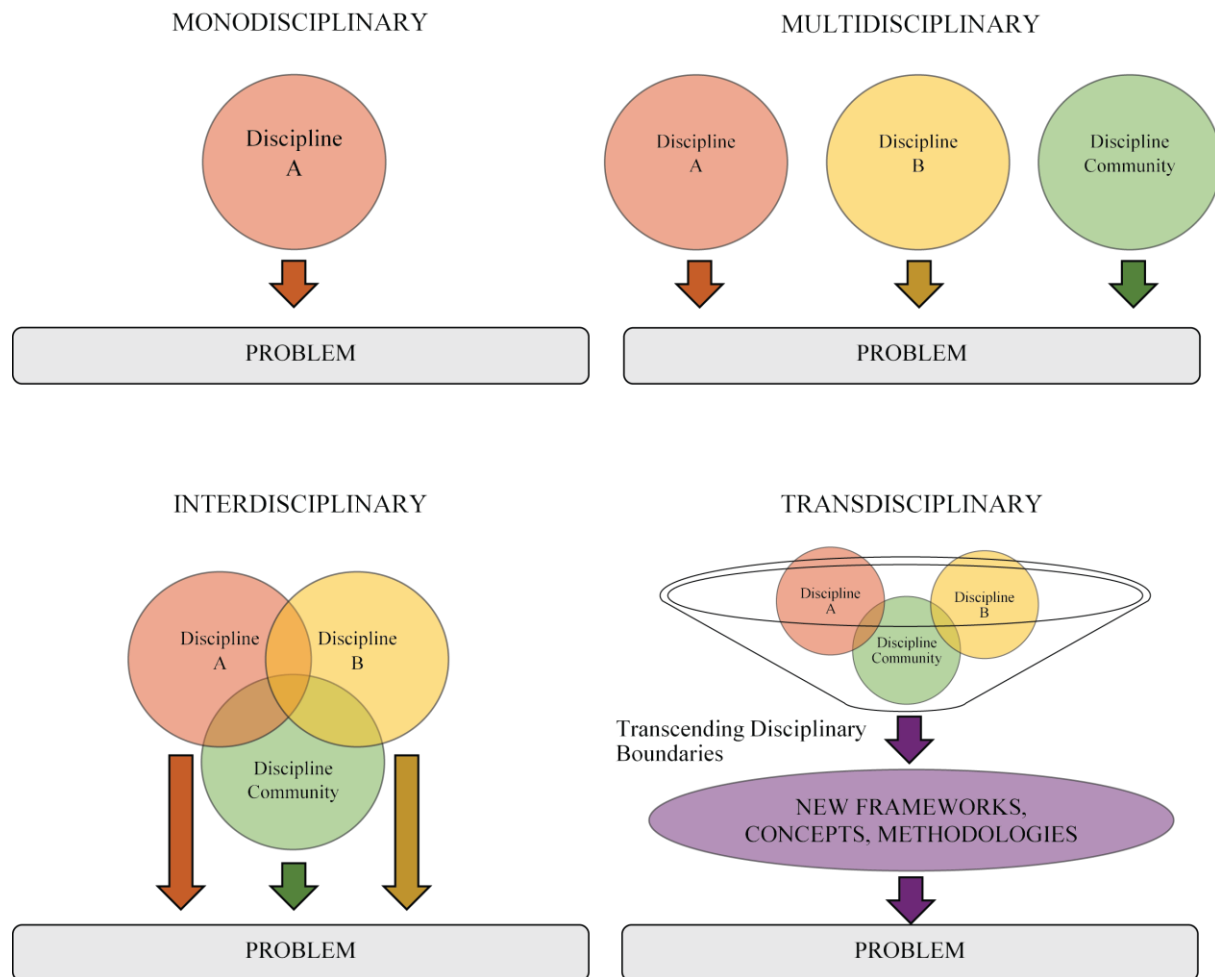
In seeking distinguishing characteristics of transdisciplinary research, Hadorn et al. (2008) laid out four criteria (see Table 1), two of which are distinct from CBPR: transcending and integrating of disciplinary paradigms, and the search for unity of knowledge beyond disciplines. Other researchers have identified three characteristics that differentiate transdisciplinary research from other similar modalities: problem focus, evolving methodology, and collaboration (Wickson,

Carew, & Russell, 2006). We feel the characterization of transdisciplinary research that includes three features—a) participatory research, b) focus on real-world, socially relevant issues, and c) transcending and integrating disciplinary paradigms (Hadorn et al., 2008; Wickson et al., 2006)—is a good fit for research with AI/AN communities and will be explored in subsequent sections.

Participatory Research

The disciplinary areas that come together to conduct research can be both within and outside of academia, encompassing researchers from various fields of study, practitioners, and other stakeholders (Leavy, 2011; Mobjörk, 2010). In this respect, transdisciplinary research has similarities to CBPR. In fact, some would contend that the success of transdisciplinary research in addressing health disparities is dependent on "the extent that TDR [transdisciplinary research] teams embrace a broad participatory community-based philosophy" (Abrams, 2006, p. 527). However, there is often an element of insider versus outsider status inherent to CBPR, which can make building trust in partnerships with outside organizations challenging. Having a local face of research in a community is a major step towards building trust in the research process. We suggest that for optimal research outcomes with AI/AN populations, the community must be included on the research team in a meaningful way.

Significantly, this is not only crucial to the autonomy of the tribe, but it can also make the research project more relevant and rigorous. Non-Native CRCAIH pilot grant awardees have reiterated how necessary tribal partnerships were for the work they did with tribal communities. For example, a non-Native pilot grant PI stated:

> Having that tribal expertise is critical. The project would not have been able to happen without the partnership … for a whole host of reasons. [We had tribal members] looking over the materials, the wording we used, the graphics we used, paying attention to those things I would not have paid attention to as closely. (A. Simonson, personal communication, March 26, 2019)

This transdisciplinary approach ultimately left the tribal community with a positive feeling about the project. "For so much of history it's been this top down approach, and we know that that's not an approach that works, especially with Native communities," noted the Native pilot grant co-PI. "To give them that autonomy, in a way that works for them, rather than saying, 'here's the

intervention,'" was critical to establishing and maintaining a good relationship between outside researchers and tribal community partners, she pointed out. In fact, even though the intervention was ultimately not statistically significant, the tribe remembers the project fondly:

> Every time I go back to council, they always say, 'that We Rise project was so cool!' They loved that we got into more of a soft social science, as opposed to the quantitative methods, [and] they really enjoyed seeing the effort that went into helping these young moms. That was something the tribal council was really appreciative of. (A. Simonson, personal communication, March 26, 2019; see McCormack, O'Leary, Moran, & Hockett, 2019 and O'Leary et al., 2019, in this special issue)

A principle of participatory research holds that not only should knowledge/findings be shared with all partners in an understandable manner, but that all partners also be involved in the dissemination process, including coauthoring publications and co-presenting at conferences (Israel et al., 2008). An example of this participatory process can be seen in transdisciplinary projects where community experts direct dissemination, such as a 2015 CRCAIH pilot grant project that involved a pregnancy health survey for new parents in a tribal community. The principal investigators were committed to sharing the results with the community in ways that were meaningful, culturally-responsive, and utilized a strengths-based approach. They enlisted the help of the Research Ethics And Dissemination (READ) core of Sanford Research to develop infographics that would facilitate dissemination of survey findings. READ staff worked collaboratively with the SWO First 1000 Days Initiative Interagency Forum, a community group comprised of representatives from a range of community programs, services, and businesses dedicated to creating collective impact to promote healthy families and children on the reservation (SWO First 1000 Day Initiative Interagency Forum, n.d.). Much care was taken to make these infographics reflective of and meaningful to the community, from photographs depicting AI/AN families to using words in the community's traditional language. Creation of each infographic was an iterative process, with multiple rounds of back and forth between READ and the Interagency Forum. The researchers and community wanted results presented in a strengths-based manner, highlighting positive survey results and acknowledging areas where there was room for

improvement. In the end, the CRCAIH stakeholders felt that CRCAIH's approach was less about publishing and more about serving the community. For example, one pilot grant PI stated:

> Sometimes it seems like the purpose of research is to write an article … so that other people that are studying in the field can stay current. But with the projects that I've been involved in with CRCAIH, [the question has] been: how can this apply to the programming that we are providing for the people we serve, … [and] how can we disseminate the results, not for the professionals, but for the people in the community? (A. Simonson, personal communication, March 26, 2019)

Research Topics Focus on Real-World, Socially Relevant Issues

The second aspect of transdisciplinary research is that it aims to address broad, complex societal problems (Hirsch Hadorn, Bradley, Pohl, Rist, & Wiesmann, 2006). It acknowledges that real world issues are often multi-dimensional and cannot be successfully or adequately addressed by a single discipline. This focus on real world problems lends itself to framing the issue as it is experienced by those impacted (Carew & Wickson, 2010). The results of this research are then practical outcomes that can be implemented to bring about change (Wickson et al., 2006). Transdisciplinary research differs from traditional positivist approaches to scientific knowledge in that "transdisciplinary contexts embrace a constructivist view of scientific knowledge, in which its value is tied to its societal relevance" (Thompson et al., 2017, p. 31). There is growing support for the idea that research must be socially relevant, issue-driven, and focused on contemporary problems, particularly for AI/AN populations (Deloria, 1991).

We argue that this focus on real-world problems is mandatory for research with tribes because of the aforementioned health disparities. Furthermore, research with AI/AN communities should focus on bringing about positive change. Tribes have long been the subjects of research where benefits to the tribes were not prioritized by the investigators (Deloria, 1991). Employing a modality of research that focuses on real-world problems serves the immediate needs of the community, which is paramount for research with tribal communities (Fisher & Ball, 2003). Herein lies another benefit of greater involvement of community members, not just in the data collection process, but also in the identification of what needs to be researched and how to go about that research. Involving community members who know specifically what issues a particular

tribe is facing certainly increases the relevance of the project and the likelihood that the outcomes will be of practical use.

CRCAIH's approach to building tribal research infrastructure supports the problem-focus aspect of transdisciplinary research in a variety of ways. Most tribal partners work to create and maintain a research inventory of projects conducted on their lands. Having access to a catalog detailing what types of research has been conducted allows for identification of research data that is available as well as potential research gaps. These gaps could assist tribes in developing a research agenda, another area of interest for CRCAIH tribal partners. A research agenda helps guide the direction of future research pursuits towards addressing issues most needed in the community.

Transcending and Integrating Disciplinary Paradigms

The third critical principle of transdisciplinary research is apparent in the term itself, transcending beyond disciplines, but is also more difficult to conceptualize. Ciesielski, Aldrich, Marsit, Hiatt, and Williams (2017) stated, "A key to getting better answers is asking better questions, and transdisciplinary perspectives can generate hypotheses that unidisciplinary perspectives might otherwise miss" (p. 125). Transcending disciplinary bounds is more than seeking feedback from collaborators outside one's home discipline. All collaborators are critical members of a team whose discipline-specific knowledge contributes to the development of innovative practices, approaches, and theories that go beyond each contributor's discipline. As one non-Native CRCAIH pilot grant awardee described working with tribal partners, "We all had different roles on the project, but none was more or less valued than the others. If I didn't have the tribal member's help, I wouldn't have had that expertise at the community level: communication, recruitment, nuances that non-Natives just miss" (A. Simonson, personal communication, March 25, 2019). Ultimately, the ability of researchers to respect and value the methods and knowledge systems of other groups, thus embracing a disciplinary humility, promotes this shift from cross/multi/inter-disciplinary to a transdisciplinary level. The difference reveals itself in the creation of something new versus incorporating one set of ideas into another discipline's framework.

This idea of researchers coming together to create new frameworks for addressing problems, in its exemplary version, is an ideal fit for AI/AN communities. This can present difficulty because Western academic disciplines are grounded in inherent cultural worldviews that idealize

methodologies, which preclude other knowledge systems (Smith, 1999). Many academics and community members have emphasized the need for moving beyond typical Western approaches. Indeed, scholars have stressed the importance of indigenous ways of knowing and traditional indigenous approaches in doing research with AI/AN populations (Caldwell et al., 2005).

Traditional Ecological Knowledge

One way in which scholars have utilized indigenous approaches is through traditional ecological knowledge (TEK). TEK has been described as a "cumulative body of knowledge, practice, and belief, evolving by adaptive processes and handed down through generations by cultural transmission, about the relationship of living beings (including humans) with one another and with their environment" (Berkes, Colding, & Folke, 2000, p. 1252). TEK has in recent years been used by academic and research communities as a way to incorporate the knowledge and voices of the populations they study into the research process itself. This practice has been both lauded and criticized. The message behind much of the literature on TEK is one of fair warning: uncritical applications of TEK by non-Native researchers harms Native populations and further alienates research communities from the populations they seek to study (Christie, 2006). This is not to say that it is impossible to include TEK in Western research methodologies, but the practice requires the space to be carefully and critically included. Scholars would caution against merely interpreting indigenous knowledge using Western research frameworks (Cochran et al., 2008). Successful applications of TEK and Western science take into consideration that TEK cannot be disconnected from its original context (Finn, Herne, & Castille, 2017).

The holistic approach of TEK continues to garner interest from federal and academic circles, particularly in complex issues relating to health and environment. Finn et al. explain, "Because TEK represents an understanding of the interconnectedness of environmental factors and human health, it has striking similarities to the concepts of the exposome and social determinants of health" (2017, p. 085006-3). However, there are some who suggest there are limitations on who can fully utilize TEK, which is one of the benefits of transdisciplinary approaches (Christie, 2006). Transdisciplinary research illustrates how a team comprised solely of non-Native researchers can pursue research with AI/AN communities in culturally relevant and effective ways. Frameworks and methodologies that are responsive and reflective of the community the researchers are working with will be more successful (Israel, Schulz, Parker, & Becker, 1998), and using methods inclusive of indigenous ways of knowing promote more appropriate and effective research (LaVeaux &

Christopher, 2009). In this way, transdisciplinary research with AI/AN populations can foster collaboration across academic fields and community knowledge without the misstep of attempting to graft TEK onto Western research methods.

The Community Discipline

We posit that when the *community itself* is viewed as analogous to an academic discipline, the experts in that discipline are the community members, thus creating an integral space for Native voices on the research team. Indeed, some scholars would agree that when engaging in transdisciplinary research in a community setting, the community is essentially one of the contributing disciplines (Emmons et al., 2008). Western science holds assumptions that can directly conflict with the notion that the community-level expertise should be seen as a discipline because it conceives of "researchers" as academics with advanced scientific degrees earned at traditional colleges. However, this convention leaves out a whole host of knowledge that is just as insightful, valuable, and vital to the success of a research project in a community. For transdisciplinary research, one must broaden the definition of disciplinary knowledge to *expertise in a specific area, whether by study, experience, or other, that can be used in addressing a problem*. A discipline provides a framework for learning and understanding. It provides the structure through which to view the workings of the world and ways to address problems. The problem-focus of transdisciplinary research calls for research team members who are qualified to tackle the issue by their proximity to the problem at hand (Carew & Wickson, 2010). Expertise in an academic discipline is acquired through years of study in formal education systems. Expertise in the "community" discipline also takes several years and cannot be taught or learned from books. That type of knowledge comes from personal and lifelong association, being a part of the community, interacting with its members, knowing the history of the people, their values, their culture; it is emic (or insider) knowledge. Expanding the limited definition of researcher opens up new modes of knowledge production capable of producing more relevant frameworks and solutions, a worthy goal for anyone who seeks to truly make a difference in the world by confronting disparities and exposing inequalities.

Elevating the community to the level of a discipline enables its contributions to do more than simply inform the research process and help non-Native investigators avoid cultural *faux pas*. Legitimizing community knowledge as an expertise at a disciplinary level goes further than assembling a community advisory board to check a box. Transdisciplinary approaches incorporate community expertise in ways that aren't simply paying lip service to community involvement.

Community members are key expert contributors, not merely an optional addendum to the research process. When the community is part of a team that develops new frameworks rather than a group charged with inserting cultural elements into Western science, there is greater potential for innovative and impactful results. Transdisciplinary research approaches with the community as a discipline compels research to keep focus on community benefit.

The critical role of the community-based research team member is exemplified in a research project focused on teen pregnancy prevention. Not only was it imperative to have a local champion, as is recommended by CBPR principles, the community-based team member's role and expertise transformed the project and changed the approach, which is arguably what raises the collaboration to the level of a transdisciplinary partnership. As an enrolled tribal member, life-long resident of the area, mother of four, high school coach, and with an outgoing personality, she was highly integrated into the community, and no one would question her Native identity as a tribal member. She brought a lifetime of wisdom, where her input and perspective as a member of this tribal community truly rose to the level of its own discipline. As a person who was not raised with many "traditional" Dakota cultural activities, her experience of being a Dakota woman was normative for the area. Her insight was invaluable to understanding the diversity of thoughts and readiness when developing content for youth to reflect on traditional AI values where there are families with a range of comfort levels with and knowledge of traditional teachings. For example, knowing the diversity of beliefs and knowledge within her tribe, she advocated the medicine wheel used in the curriculum to be framed as one example of how a medicine wheel could look and be utilized, and that the program's teachings do not intend to conflict with students' families' beliefs.

Her suggested approach highlighted the sensitivity that the recent reclamation of traditions needs to be respectful of the majority of AI families who are still dealing with the repercussions of forced assimilation policies. She advocated the team's main goal be that people with a variety of backgrounds of cultural knowledge could teach the curriculum and that the main mission was to teach the foundational cultural concepts and have the youth reflect on their beliefs and values and how it applied to their own behaviors. Therefore, the resulting curriculum included detailed background on the cultural concepts as well as suggested readings and videos for facilitators. Her perspective transformed the project for the better, as the team created a culturally-infused teen pregnancy prevention curriculum.

Flexibility of Approach

Although examples and approaches can be found in the literature, there is a lack of agreed-upon concrete framework and methodologies for implementing a transdisciplinary project and resulting outcomes (Mobjörk, 2010; Thompson et al., 2017). The positive aspect of this lack of structure according to Thompson et al. (2017) is that it "leaves space for transdisciplinary approaches to be shaped by the evolving network of participating scientists and stakeholders, according to their perspectives of the approach and what it embodies" (p. 31). For transdisciplinary research with AI/AN populations, this represents an opportunity for investigators to customize their approach to transdisciplinary research to grow and shape the methods that make sense for each community. It would be impossible to prescribe what transdisciplinary research would look like in all AI/AN communities because each unique community helps shape how the transdisciplinary approach takes form. The process can play out in a variety of ways, each organically manifesting during the course of the collaborative partnerships.

BARRIERS/CONSIDERATIONS

Achieving a level of integration for research to be considered transdisciplinary is difficult in any project, but conducting transdisciplinary research with AI/AN communities involves unique barriers and challenges that must be addressed. Building up tribal research infrastructure can help address some of those limitations.

Power Differentials

One caution for team formation is to be cognizant of power differentials and inequities due to structural/institutional resources, the impact of colonialism, and perceived levels of expertise (Muhammad et al., 2015; Wallerstein & Duran, 2006). For optimal results reflective of the true spirit of transdisciplinarity, care must be taken to prevent the dominant thought from superseding other perspectives. Successful transdisciplinary endeavors necessitate equity in the distribution of resources, which includes things like information, funding, and decision-making power (Emmons et al., 2008; Stokols, Misra, Moser, Hall, & Taylor, 2008), and thus reinforces the need for a robust tribal research infrastructure. Power differentials limit the success and sustainability of a project (Stokols et al., 2008), so taking steps to reduce those by enhancing/building community capacity for research is beneficial. One way in which CRCAIH addressed this potential barrier was through

annual Executive Steering Committee meetings where all members working on CRCAIH were brought together with an equal place at the table for sharing updates and strategic planning.

One thing that can negatively impact the success of the transdisciplinary project is the perception and/or creation of status differences in team formation (Stokols et al., 2008). Structures that consider academic researchers to be the experts and community stakeholders to be those who simply provide feedback privileges the voice of the researcher and does a disservice to the process. This is where recognizing community knowledge and tradition as expertise and the pursuit of thoughtful collaboration among all disciplines is truly beneficial to breaking down hierarchies and advancing research approaches toward true transdisciplinary work.

Differences in Organizational Cultures

Another barrier to transdisciplinary research involves differing organizational cultures, diverse worldviews, and educational backgrounds (Stokols et al., 2008). In the academic sector, the notion of "publish or perish" pressures researchers, often driving activities with a goal of generating publishable results that fit within the theoretical framework of their discipline as fast as possible (Stokols, 2006; Wax, 1991). In tribal communities dealing with health disparities, the more pressing needs of providing services and delivering interventions with immediate results take precedence. Communities desire research that will address concerns in a timely manner (Emmons et al., 2008), so with these urgent needs, waiting for the results of a 10-year longitudinal study is not practical. Another consideration for the academic sector is that research results need to be generalizable. Recent research directions with tribal communities stress the uniqueness of each tribe, the implication of which is research results may not be generalizable beyond that particular community.

With transdisciplinary team projects where all players are equal partners in the process, tension can arise around who drives the project and to what extent. Tribes are sovereign nations with the right to regulate research happening within their boundaries, which they are increasingly doing (Harding et al., 2012). Outside researchers need to ensure they are recognizing tribal sovereignty while collaborating on transdisciplinary projects. Additionally, researchers must also be aware of inherent power dynamics within each unique community. Communication becomes crucial as researchers navigate conflicts in respectful ways and make efforts to learn from alternative perspectives.

Even when team members are on the same page regarding project goals, differing organizational structure and cultures impact the execution of tasks designed to help achieve those

goals. One element of working with tribes is to be prepared for extended timelines (LaVeaux & Christopher, 2009). This can be due to things like changes in tribal council membership, office closures due to inclement weather or a death in the community, institutional processes that require multiple levels of approval, or lack of clarity on approval processes. In smaller offices, competing institutional demands means that staff might be pulled away from a larger goal to focus on addressing an urgent issue. When this happens frequently, the constant effort to "put out fires" can force other big picture projects to the back burner and impede progress towards long-term goals.

Institutional Resources and Technology

Some tribes are quite rural, spanning thousands of acres, and located far away from large urban centers, which is particularly true for the Northern Plains tribes. Limited ability to travel for face-to-face meetings with the rest of the transdisciplinary team necessitates dependence on other methods of communication. CRCAIH was able to utilize site visits, teleconferences, and online meetings (Skype, GoToMeeting) to maintain open and bidirectional communication with tribal partners while working to build research capacity. However, internet and phone service can be patchy in some areas of large reservations. CRCAIH has tried to overcome these barriers through flexibility and not being afraid to change directions and try new methods of connecting. For example, in-person tribal partner retreats became more common in the final years of the original grant.

Era of Budget Constraints

Tribes have faced various unmet infrastructure needs, from physical infrastructure for housing, health care, and education, to technology, employment, and workforce development (National Congress of American Indians, 2017). Tribal governments must prioritize where to invest their limited funds, and, unfortunately, research infrastructure is not always high on the list. Since the initial CRCAIH grant award in 2012, NIH has elected to discontinue the funding mechanism that supported building these Transdisciplinary Collaborative Centers. Subsequently, CRCAIH and partners continue to explore alternative funding options. Getting the tribal research office visibility in the community and with leadership will help to cement the value of continuing to invest in research infrastructure even without the support of federal grants. This infrastructure building is critical if community partners are able to come to the table as equals in research projects.

DISCUSSION

As previously stated, there has been a lack of agreement surrounding how one measures the success of a transdisciplinary project (Stokols, 2006). This isn't surprising considering the variety of unique factors that influence the trajectory of each collaborative partnership and the principle goals of sectors involved in the project. There is not a generalizable exemplar of what "good" transdisciplinary research with tribes looks like due to circumstances and contextual factors unique to each tribal community. One key component of good transdisciplinary research with tribes, however, is the *integral involvement* of the community. Because each community is distinctive in how the problem manifests and the strengths existing within the community, the approaches selected for addressing the issue cannot be summed up in a one-size-fits-all method. The community involvement for transdisciplinary research, as with CBPR approaches, is critical in determining the process and outcomes.

Having representation from various academic disciplines and community stakeholders as members of the research team does not necessarily imply the research conducted is transdisciplinary. Investigators must challenge themselves to critically analyze their approaches and whether community experts are being treated as equitable contributors and orchestrators of the research process throughout. As investigators reflect on current practices, they may discover that hosting a few focus groups and community advisory board meetings does not sufficiently bring in valuable community perspective to a level enabling research to go beyond their own disciplinary frameworks in doing problem-centered research. By involving community stakeholders as equals in all aspects of the research process – design, implementation, evaluation, and dissemination – with the goal to co-create new theoretical frameworks for addressing health disparities, we can move towards the transdisciplinary research ideal.

Researchers and funders should challenge themselves to broaden narrow Western-academic-centric definitions of what research is, what constitutes a discipline, and what credentials make for expertise. Doing so expands the knowledge base and tools for addressing issues in complex real-world scenarios. Some scholars have recommended that funders promote transdisciplinary research by financing only those projects that clearly engage community partners and prioritize the importance of culture when assessing needs and developing programs that mollify disparities (Finn et al., 2017, p. 085006-7). This makes for better research and gets closer to achieving the ultimate goal of improving health outcomes and reducing disparities. Couple CBPR with transdisciplinary research and you have a catalyst for real change. Imagine taking the

wisdom of the community itself, the traditional ecological knowledge, and promoting its integration with multiple other disciplines to develop new theoretical frameworks and concepts for addressing health disparities.

FUTURE DIRECTIONS

This manuscript posits that transdisciplinary approaches are necessary to working with AI/AN communities and has distinct benefits to utilize alongside CBPR approaches. The concept of a transdisciplinary approach is essential to attaining the ideal of a truly equal partnership in working in academic-community research. Even community-directed research may fall short if the community partner's knowledge is only applied or invited in certain aspects of a project. Implementing transdisciplinary principles provides a way to create these meaningful partnerships, which is particularly essential in conducting tribally-based research. This takes a considerable investment of time and resources to build the foundation of trust and understanding to move forward as an equitable, high-functioning team.

Since CRCAIH was funded, it can provide a model of how some transdisciplinary aspects were achieved. This transdisciplinary research lens and approach can help move the needle and drive the field of AI/AN health research forward through co-creation of new culturally-based approaches. Since transcending and integrating disciplinary paradigms is one of the major goals of transdisciplinary research, searching for a unity of knowledge and creating something bigger than simply mixing disciplines is a goal that necessitates a perspective that distinguishes community members' perspectives as a discipline.

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NOT A ONE-SIZE-FITS-ALL APPROACH: BUILDING TRIBAL INFRASTRUCTURE FOR RESEARCH THROUGH CRCAIH

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Abstract: The Collaborative Research Center for American Indian Health (CRCAIH) was created to foster tribal partnerships in the Minnesota, North Dakota, and South Dakota regions to increase capacity for tribal research. Since 2013, through community engagement and technical assistance from CRCAIH's cores and divisions, seven tribal partners have expanded research infrastructure and recognize the benefits of an established tribal research office. This manuscript showcases the unique approaches individual CRCAIH tribal partners have taken to build tribal research infrastructure. The unique experiences of the CRCAIH tribal partnership holds valuable lessons for other tribes interested in increasing research capacity through research review, regulation, and data management.

INTRODUCTION

As discussed in the introduction to this special issue, in September 2012, the Collaborative Research Center for American Indian Health (CRCAIH) was established through funding by the National Institute on Minority Health and Health Disparities (NIMHD). The two driving aims of CRCAIH has been to 1) build tribal research infrastructure and 2) increase the amount of transdisciplinary research in American Indian/Alaska Native (AI/AN) health. CRCAIH was designed to create a platform to connect tribal nations and health researchers from multiple disciplines to work in partnership to address significant health disparities.

Since 2013, the CRCAIH platform has fostered a tribal research partnership among seven tribes in the Minnesota, North Dakota, and South Dakota tristate region. The tribal partners include: Oglala Sioux Tribe, Cheyenne River Sioux Tribe, Turtle Mountain Band of Chippewa Indians/Tribal Nations Research Group (Turtle Mountain/Tribal Nations Research Group), Fond du Lac Band of Lake Superior Chippewa (Fond du Lac), Sisseton-Wahpeton Oyate of the Lake Traverse Reservation (Sisseton-Wahpeton Oyate), Spirit Lake Nation, and Rosebud Sioux Tribe.

Because an overview of the CRCAIH platform was previously detailed in Elliott et al. (2016), the emphasis and breadth of this manuscript focuses on how the CRCAIH tribal partners' capacity for research has increased and resulted in a lasting legacy of tribal research infrastructure. All CRCAIH partners approved of being named in this article and special issue.

The purpose of this manuscript is to: 1) detail the importance of building tribal infrastructure for research, 2) describe common/joint activities of the CRCAIH tribal partners, 3) showcase unique aspects of building tribal infrastructure, 4) highlight throughout how the CRCAIH cores and divisions helped tribal partners through capacity building technical assistance, and 5) feature unexpected outcomes and future directions for this work. Through sharing the common and unique activities of the CRCAIH tribal partners, this manuscript showcases how tailored approaches are optimal when developing and expanding tribal research infrastructure. Ultimately, by detailing these diverse processes, it demonstrates there is not a one-size-fits-all approach to building tribal research infrastructure. But the processes and lessons learned and described herein can serve as a guide to building or expanding tribal research infrastructure to fit the unique needs of other tribal nations.

The authors of this manuscript are the CRCAIH tribal partners and the CRCAIH staff from the Administration Division and the Community Engagement and Innovation Division. It is important to note and describe the authors because the focus of this paper is the partnerships and the tribes building their research infrastructure from their perspective. Each tribal partner utilized CRCAIH core and division support differently to best fit their infrastructure building needs at the time. As the tribal partners increasingly engaged with one another, the unique and broad support that was provided to them from each core and division became apparent, which heavily influenced this paper. Additionally, each core and division was accessed slightly different and some more than others. This paper would not be complete without the experiences from each tribal partner and sharing their processes and lessons learned.

Background

Past Tribal Research

Many tribal nations have faced a long history of unethical research occurring in their communities. High volumes of research conducted in tribal nations is due to many factors, such as the high prevalence of health disparities and the available funding from federal sources for research with diverse communities (Sahota, 2007). One often noted example of unethical research in a tribal

nation involves the Havasupai Tribe and researchers from Arizona State University. The Havasupai Tribe approved the collection of blood samples for a research project on diabetes. Researchers then used those blood samples for research in other areas counter to the tribes wishes and values, such as schizophrenia and population migration theory, and made the samples available to other researchers, all without obtaining tribal approval or consent of participants (Pacheco et al., 2013). These lines of research outside of the original diabetes project did not benefit the tribe, were stigmatizing, and did not include voluntary informed consent, resulting in highly unethical research and repercussions for years to come. Therefore, it is not surprising these types of ethical breaches, "have left AIAN communities wary of research practices based on exploitation, racism, and majority ethnocentrism" (Pearson, Parker, Zhou, Donald, & Fisher, 2018, pp. 28).

Historically, research done with tribal nations was almost entirely conducted by external researchers, who may have followed an external agenda and engaged in research that was not always in tribes' best interest (LaVeaux & Christopher, 2009). There was often little to no collaboration between the researcher and the tribe, and equal partnership was often not achieved. This type of exploitive, non-collaborative practice has been called "helicopter research," where a researcher comes in, conducts the research, gathers the data, and leaves (Oberly & Macedo, 2004). Helicopter research methods often do not report findings or provide valuable results back to the tribe, thus weakening trust (Lawrence, 2000). Research approaches like this err in not fully recognizing the strength of the tribe. Tribes and their respected members are essential to the research process. They are the experts and the storytellers of the people and the keepers of history and cultural knowledge.

Despite feelings of mistrust around research, tribes are tackling the challenge of building their research infrastructure in their respective communities because they feel research is an important and valuable tool. Tribal nations often face difficult challenges in conducting research or building research capacity, such as isolation due to their remote locations, having small populations, somewhat limited resources, protecting cultural knowledge, and facing frequent changes in tribal leadership, sometimes occurring every two years. Despite these challenges, tribes (such as the CRCAIH tribal partners) have begun to take more ownership of data and the research process. Increasing the capacity to build research is the result of tribes exercising their autonomy to make informed decisions that will benefit and protect their tribal nations.

Through this infrastructure building, tribes exercise their sovereign right to improve their quality of life, provide environmental protections, and work to address the ever-increasing health

disparities that affect their tribal members on a daily basis. Each CRCAIH tribal partner builds tribal infrastructure for research through community engagement, increased regulatory capacity, and data management to guide decision-making for tribal members. More importantly, as tribes build their infrastructure, they are taking ownership of the research data and establishing long-term relationships with researchers and institutions, so the benefit is mutual. From the researcher perspective, researchers can also benefit, as greater infrastructure for research results in higher quality research data. It also can result in stronger partnerships, where again, the quality of the data improves as it is more culturally appropriate (Oetzel et al., 2015). These long-term results can mean higher quality impacts on AI/AN community health outcomes.

Unique Tribal History

Across the United States, there are currently 573 federally recognized tribes, each having a special relationship with the government and their own traditions, histories, distinct languages, and ancestral lands. As a result of the General Allotment Act of 1887 (also known as The Dawes Act of 1887), tribes were forcibly displaced from 90 million acres of Indian land through the establishment of reservation lands and other various acts and treaties. The 24 tribal nations, spanning across Minnesota, North Dakota, and South Dakota, contain land with multiple types of ownership (i.e., trust, fee, restricted, tribal, individual Indian, and non-Indian), creating a checkerboard ownership pattern (Indian Land Tenure Foundation, n.d.). Seven of these tribal nations in the tristate region have been CRCAIH tribal partners. Each tribal nation is unique from one another, as is highlighted when examining the CRCAIH tribal partners' demographics (see Table 1). For example, the CRCAIH tribes differ greatly in tribal enrollment: the Spirit Lake Nation has an enrollment of 6,700, while the Oglala Sioux Tribe has almost 47,000 enrolled tribal members. This information is relevant to the research office as community engagement efforts will vary per community. Additionally, demographic location and number of tribal districts is information investigators may need to know. The CRCAIH tribes consist of Lakota, Dakota, and Anishinabe nations that share knowledge and lessons learned with one another while acknowledging each other's accomplishments in their respective tribal lands.

Tribal nations are tasked with making decisions that protect their citizens and benefit the whole community, ensuring their unique culture and traditions carry on and are taught to the younger generations, while simultaneously embracing technology and tools to better the overall health of the community. Tribal elders are often called upon to pass on traditional teachings to the next generation through providing knowledge and understanding of the past and emphasizing the

importance it has on today. Tribal leaders do their best to bring lasting positive impacts for the tribe using historical knowledge to guide and preserve balance in decision making to advance and improve the health of the whole nation. They are exercising their sovereignty, collaborating with external and internal organizations, preserving their culture, and working to address the various health disparities that often affect community members. As detailed in this paper, through a focus on policymaking, community engagement, and data management, each CRCAIH tribal partner works to balance the protection of their community with the potential benefits of research.

Table 1
Descriptive demographics for CRCAIH tribal partners

Name (Tribal Area)	State	Total area (sq mi)	Density (PPSM)	Total (% AI/AN only)	Enroll-ment	Unemploy-ment rate	Median household income	% of families below poverty level	% high school graduate or higher	% bachelor's degree or higher	# of graduate or professional degrees
Area											
				Population			**Economy**			**Education**	
Cankdeska Cikana Community College (Spirit Lake Reservation)	ND	399.63	10.9	4,399 (83.3%)	6,700[b]	9.0%	$31,447	39.7%	78.7%	12.5%	57
Cheyenne River Sioux Tribe (Cheyenne River Reservation[a])	SD	4,419.10	1.9	8,459 (75.9%)	15,993[b]	25.4%	$39,212	26.6%	85.1%	14.5%	171
Fond du Lac Band of Lake Superior Chippewa (Fond du Lac Reservation[a])	MN, WI	159.33	27.5	4,048 (39.1%)	4,146[c]	8.5%	$50,833	14.7%	87.7%	15.5%	126
Oglala Sioux Tribe (Pine Ridge Reservation)	SD	4,353.80	4.3	19,698 (83.8%)	46,855[b]	25.2%	$30,908	42.4%	78.7%	12.8%	243
Rosebud Sioux Tribe (Rosebud Indian Reservation[a])	SD	1,975.42	5.5	11,324 (78.7%)	35,062[d]	20.6%	$26,938	48.9%	77.9%	14.5%	199
Sisseton-Wahpeton Oyate (Lake Traverse Reservation[a])	SD, ND	1,508.73	7.5	11,269 (39.8%)	14,053[e]	7.5%	$48,236	14.3%	86.5%	17.0%	409
Turtle Mountain Band of Chippewa Indians / Tribal Nations Research Group (Turtle Mountain Reservation[a])	MT, ND, SD	237.43	38.1	9,303 (95.6%)	32,564[f]	5.7%	$32,665	33.2%	81.5%	21.6%	160

Note. Data for economy, education, and total population from U.S. Census Bureau 2012-2016 American Community Survey 5-Year Estimates accessed via My Tribal Area [web]. Data for total area and population density from U.S. Census 2010 Population and Housing Unit Counts. sq mi = square mile. PPSM = people per square mile. For population, percent AI/AN only does not include those indicating AI/AN in combination with some other race. Enrollment numbers include members living both on and off-reservation. Education level percent pertains to population age 25 years and over.

[a]Includes both on and off reservation trust land. [b]Bureau of Indian Affairs, Great Plains Region website (n.d.). [c]Fond du Lac Band of Lake Superior Chippewa BIA Enrollment Office (2018). [d]Rosebud Sioux Tribe BIA Enrollment Office (2018). [e]Sisseton-Wahpeton Oyate BIA Enrollment Office (2018). [f]Turtle Mountain Band of Chippewa Indians BIA Enrollment Office (2018).

Establishing CRCAIH Tribal Partnerships

CRCAIH invited applications from tribes in the three state region to join CRCAIH. Through the tribal selection process (Elliott et al., 2016), each tribe responded to questions on how this investment would leverage existing support and build on current capacity to foster research in the community. CRCAIH purposefully opted to limit the number of fully partnering tribes in order to maintain an appropriate level of the subcontract funding available to each partner. Although CRCAIH grant funding was limited to seven tribal nations out of the 24 total across the three states (see Table 1), those nations that were not selected or are no longer receiving funding are still supported with technical assistance for building tribal research infrastructure.

Each tribe's research infrastructure was at various stages when they partnered with CRCAIH and each differed in the vision for their research office. One commonality was that tribes first gained approval from tribal council through a tribal resolution, which is a standard practice when initiating partnerships and new plans. The tribal resolution was sought in order to assure broader support from tribal leadership to build research capacity and meet their research goals.

CRCAIH provided funding support for one full-time equivalent (FTE) employee per tribal partner as the Community Liaison. This critical position allowed the tribal partners to focus on working toward their goals of building infrastructure in research, rather than facing competing demands of other projects. Additionally, CRCAIH provided funding to each tribe for institutional review board (IRB) software, travel, and supplies (Elliott et al., 2016). Duties performed by the research office staff often began with developing or enhancing the tribal research review process, then moved into data management. Research office staff also conduct the day-to-day activities that keep their Research Review Boards functioning and monitoring current and past research.

TRIBAL INFRASTRUCTURE BUILDING

CRCAIH is comprised of three divisions (Administration, Community Engagement & Innovation, and Research) and three technical cores (Culture, Science, & Bioethics; Regulatory Knowledge; and Methodology). The primary aspects of tribal infrastructure building that the tribal partners dedicated their efforts to were research regulation and review, community engagement, and data management. Most tribes selected to focus primarily on research regulation and review at the beginning of their CRCAIH partnerships. In subsequent years, focus shifted to incorporate a greater focus on community engagement and data management. This is not to say that all tribal

research infrastructure building needs to follow this sequence, but for the CRCAIH tribal partners, addressing the elements in this approach at that time was the best fit for their communities in developing robust research infrastructure. The following sections will describe the tribal partners' commonalities as well as unique approaches used in the aforementioned three areas of infrastructure building (research regulation and review, community engagement, and data management).

Research Regulation & Review

A common theme among the CRCAIH tribal partners was that prior to the formation of the CRCAIH partnership, a mechanism for reviewing research was in place, in some capacity, within the tribe. For example, in October 2007, the Oglala Sioux Tribe created the Oglala Sioux Tribe Research Review Board (OSTRRB) to assist in controlling all research that was being conducted within the reservation boundaries. An important part of the purview of the OSTRRB was its responsibility for facilitating human subjects research and ensuring the rights and welfare of human subjects are protected during their participation. The OSTRRB was also created to secure the reservations' interests by making sure no false or misleading communication was being done in research.

Fond du Lac and Rosebud Sioux Tribe had a process in place (e.g., through tribal college) prior to the foundation of the CRCAIH partnership, but the boards had not been active for some time. Similarly, Cheyenne River Sioux Tribe, Spirit Lake Nation, and Sisseton-Wahpeton Oyate had informal processes in place (e.g., through the Cankdeska Cikana Community College and Sisseton-Wahpeton Oyate Human Services board), where final approval went before the tribal councils. Additionally, the Turtle Mountain research review process required tribal council approval.

Commonalities

This foundation of already established research regulation processes helped motivate the tribal partners to consider a range of options in research regulation approaches. Though the initial process may have been limited and informal, CRCAIH assisted the tribe in reviewing research processes, but tribes also understood the need and urgency to build upon their current processes. If tribal laws/codes, policies, and procedures for research were not already in place, creating them was significant and their first major task upon becoming CRCAIH tribal partners (see Table 2).

Table 2
CRCAIH tribal partner research review snapshot

	Fond du Lac Band of Lake Superior Chippewa	Oglala Sioux Tribe	Rosebud Sioux Tribe	Sisseton-Wahpeton Oyate	Turtle Mountain Band of Chippewa Indians
Research Review Body	FDL Human Services Division IRB	OST Research Review Board	RST Health Board	SWO Local Research Review Board	TMBCI Research Review Board (operated by Tribal Nations Research Group)
Approved Tribal Code	No	Yes	No	Yes	Yes
Registered FWA	No (in process)	Yes	No	No	Yes
Research Reviewed	Human Subjects	All	Human Subjects	Human Subjects	All
Number of Members	10	9 Current members with rotating Chair (could have 12 members so 3 vacancies)	11 (9 council reps, 2 at-large members)	5 minimum 8 maximum Chairperson serves six month term	10 members (7 members with 3 alternates) plus IRB Chair and IRB administrator
Frequency of Meetings	Monthly (every third Thursday of the month)	Monthly (every third Saturday of the month except in July) deadline for submissions on last Friday of previous month	Bi-Weekly (1st and 3rd Thursday of every month)	Monthly (4th Tuesday in 2019); Researcher's Submission Deadlines - Friday that occurs 3 weeks before the scheduled meeting	Monthly, (second Wednesday of each month) protocols due on the 28th of previous month
IRB Management	Axiom Mentor Software (not functioning; set up in process)	Axiom Mentor Software	Axiom Mentor Software (not functioning)	Axiom Mentor Software (not functioning; set up in process)	Axiom Mentor Software
Fee Structure	None	Sliding Scale 3% of total budget plus application fee (currently capped at $3,000)	Planned	In process of approval	Planned
Stipend for Board Members	No	Yes	No	Yes	No
Estimated Number of Protocols Reviewed per Year (last 3 years)	10-15	18	5-10	10-20	25

Note. Information provided by CRCAIH Tribal Partners as of May 2019.

Each tribe implemented their research codes slightly different. For the purposes of this paper, a research code is used generally and may refer to a tribal law, ordinance, protection act, or policies and procedures. A tribal research code protects the interest of researchers and the tribe by specifying all the responsibilities during the research project (Fisher & Ball, 2003). This code not only protects individual tribal members, but also plays a unique role compared to academic IRBs by taking into consideration the tribe as a community and protecting the knowledge and culture that each community holds. In general, the IRBs main goal is to protect the individual human subject's rights in research; however, many tribes have made the decision to take the additional step to review all research or data collection within their tribal nations. Whereas a tribal research code aims to guide research practice, a tribal research review board exists to review research protocols with an ethical and cultural lens. Tribal research review boards are often charged with protecting not only the individual research participant, but tribal communities as a whole, including the land, knowledge, and culture. This community level review provides additional protections and is the distinction that makes local, tribal research review so important. As the tribal partners became more established and passed their tribal research code, their finalized codes also provided the groundwork for other tribal partners. Research codes were shared among one another and were revised to fit the needs of each individual tribe.

Upon passing a research code and continuing to build their regulatory process, tribes wanted to create policies and procedures to guide and support a fully functioning research review board (RRB) to review, archive, monitor, and manage all research conducted within the reservation boundaries and on behalf of each respective tribe. Each RRB would recruit a diverse group of members, mostly tribal members, who represent a wide array of interests/expertise and who are highly qualified to serve on the board (OSTRRB, n.d.). In addition, the purpose of a qualified RRB was that every research proposal would receive a comprehensive, balanced, and thoughtful review (Sisseton-Wahpeton Oyate Research office, n.d.).

The role of the research office and RRB varies across the individual tribal partners. The tribal research office was often placed in a more administrative role as the RRB grew/adapted and RRB members became more knowledgeable of their role and duties to review new and ongoing protocols. The support the RRB gives to the research office is vital as the community members share their expertise and knowledge in order to make decisions that benefit the community at large.

Another major task in building research regulation for all tribal partners is creating a system to support the submission, review, and housing of research protocols. In the last few years, two tribal partners have been able to access and fully implement an online protocol submission software that has been key to streamlining some of the duties for staff (see Case Study 1 in the Appendix). The ability for external researchers to use an online submission process, complete with forms and guidance from afar, has been helpful for staff and RRB members. Initially, the transition to using an online submission software was very time consuming to implement; however, the tribal partners who utilize this system agree it reduces the burden of some tedious operations within the research office.

Core and Division Support

During this entire process, the Regulatory Knowledge Core (RKC) provided guidance and training in regard to ethics and regulatory support for both the tribal partners and their research review board members. The tribal partner RRB members would receive various ethical research trainings from CRCAIH cores and division staff and other external entities, such as Engage for Equity and the Indigenous Wellness Research Institute National Center of Excellence. Over the years of the CRCAIH partnership, RKC was instrumental in guiding tribal partners in regulatory processes through teleconferences, webinars, and in-person trainings to provide feedback and valuable resources.

Unique Aspects

One unique aspect specific to Oglala Sioux Tribe in supporting and sustaining the research office is the implementation of a fee structure for research reviews. This means Oglala Sioux Tribe charges a fee, assessed according to the current fee scale, to all approved research projects that occur within the exterior boundaries of the Pine Ridge Indian Reservation. This topic is often discussed during joint tribal partner meetings, and all tribal partners see the potential to benefit by planning to implement a fee structure in their community. Oglala Sioux Tribe has been the leader thus far in the conversation and providing guidance on the benefits of implementing a fee scale. Tribal partners need to determine whether the volume of research proposals exist in each tribe to implement a fee structure that would make RRB activities self-sustaining. In some tribal communities, utilizing this type of software may require tribal council approval in order to implement such a process.

Community Engagement

The tribal partners' community engagement efforts have been significant to building their tribal infrastructure for research. Tribal partners recognized the importance of educating and informing tribal members and stakeholders of the importance of promoting ethical research oversight throughout the years, but with a greater focus in the last few years. Helping tribal members of all ages understand the importance and benefits research can offer has taken time, and recognizing and understanding historical past harms is fundamental (Sapienza, Corbie-Smith, Keim, & Fleischman, 2007). In addition, these community engagement activities needed to occur as a continual process with each community, regardless of the longevity of the tribal research office.

Commonalities

Support from the community was crucial and involved more than just securing buy-in for CRCAIH activities. Engagement efforts also focused on including community members and informing them of the research processes, why research infrastructure was needed, and how beneficial it would be at present and in the future for considering participation in research projects. Additionally, gaining an understanding of the current knowledge and readiness for research from stakeholders was helpful and provided an understanding of the current processes. Outreach and engagement with tribal members is vital, not only from the start of establishing a research office, but throughout the process to increase the knowledge, understanding, and importance of research.

Relationship-building is complex, multi-faceted, and often time challenging. For tribes, relationships are historical, political, formal and informal, and personal (English et al., 2004). There are many various ways to engage and educate the community to build strong relationships, which often take time. Each tribal partner works with the community at large through various mediums such as attendance at local and district meetings, newsletters, maintenance of a current website, being inclusive with partners, and transparency with tribal members.

Some of the specific community engagement activities from the tribal partners included having a presence on social media (Tribal Nations Research Group has a website and a Facebook page), as well more traditional methods such as print (Sisseton-Wahpeton Oyate has a monthly newsletter shared with all the department administrators and is available on the research office website), and in-person methods (tabling at tribal health fairs). Tribal Nations Research Group utilized several community engagement methods in the process of gaining support for their Turtle

Mountain Band of Chippewa Indian Research Protection Act (see Case Study 2 in the Appendix). Other tribal partners, such as Sisseton-Wahpeton Oyate, used in-person, community engagement efforts to gather support for their research code. This required repeated visits to each of Sisseton-Wahpeton Oyate's seven districts to meet with the tribal membership and provide education on the importance of research projects, research oversight, and data sovereignty. In addition to this, the tribal membership was asked to carefully review the proposed Sisseton-Wahpeton Oyate Research Code and provide feedback and ultimately their approval.

Core and Division Support

The CRCAIH Community Engagement and Innovation Division (CEID) assists the tribal partners in coordinating community engagement activities, such as on-going dissemination efforts. The tribal partners' community engagement activities were not always the highest priority as other tasks became more urgent, such as establishing a research code and a RRB, which had impending timelines and concrete outcomes. Community engagement approaches vary at different stages in the journey of building research, and initially, the community engagement aims were to identify health priorities, establish community advisory boards, and assist community liaisons in developing strategies to address each tribe's health disparities, demonstrating flexibility and responsiveness. These initial plans were modified to meet tribes' differing needs and timelines. Regardless, community engagement has always been present, as CEID was tasked with the significant role of building relationships and trust with tribal partners, that is often relegated to multiple dialogues, which takes time (Wallerstein & Duran, 2006). Trust was key and needed in order to garner support from the broader community, which included not only tribal leadership, but elders, youth, department heads, and others who may not be directly tied to the research office, but who are members of each tribal nation.

Unique Aspects

Recently, the community liaison from Rosebud Sioux Tribe worked with staff from community engagement and the regulatory knowledge core to host a lunch and learn with the Rosebud Sioux Tribe Health Administration to discuss the proposed Rosebud Sioux Tribe Research Code and update the tribal Health Board on the work of the community liaison. The response and support from the board and their desire to push the code forward for approval was evident. The board understood the urgency for an approved code and brought leaders' attention back to the main reason for wanting to become a CRCAIH partner, which is to protect their tribal

nations from potentially harmful research and to increase the overall research capacity. Rosebud Sioux Tribe was the last tribe to partner with CRCAIH, and in 2016, they had the opportunity to conduct a comprehensive assessment of the tribe's readiness for research development and engagement and to develop a Tribal Research Infrastructure Snapshot through a supplement grant with support from CRCAIH cores and divisions (see Case Study 3 in the Appendix).

Three CRCAIH tribal partners hosted their own community research conferences, over the last five years, exemplifying their dedication to community engagement and the importance of bringing research results back to the community. CEID partnered with Oglala Sioux Tribe and Cheyenne River Sioux Tribe to hold community research conferences in the spring of 2015 through a NIH conference grant. The goal of these conferences was to bring together tribal leaders, community members, and research partners to report back to the communities what has been accomplished to address their health needs and future directions for continued health improvement. In subsequent years, Cheyenne River Sioux Tribe has continued to host an annual community research conference. In 2017, Tribal Nations Research Group coordinated and hosted their first annual Data Matters conference to showcase how data is used to address important health, environmental, cultural, educational, and economic development issues within the community. These conferences are exemplars of community engagement around research. They have featured presentations from nationally renowned researchers along with local programs and investigators showing the importance of research and how it can influence the community.

Data Management

In the last few years, a strong focus for CRCAIH tribal partners has been on addressing matters pertaining to data management, influenced by priorities of the tribe. The broad concept of data management encompasses a variety of tasks and holds different meanings for each partner, but is inspired by the underlying goal of exercising data sovereignty. Data sovereignty allows tribes to govern and oversee the collection, ownership, and application of their own data and research (USIDSN, 2018; NCAI/PRC, 2009). For one tribal partner, data management might mean how research results from a study will be given back to a tribe (timing, frequency, hard copy or digital, summarized or raw data). For others, data management priorities include deciding where the data will be stored, when the tribe does not allow a cloud-based server to be used, and who has access to that information.

Core and Division Support

At the outset, the Methodology Core (MC) was designed to employ statisticians to assist tribes in analyzing their data, which would fill a gap because not many tribes have access to epidemiologists. However, most tribal partners were not at that stage of data governance at the start of their partnerships with CRCAIH. Therefore, similar to the CEID, the MC adjusted their aims from study design, report generation, statistical analysis, and data collection form design, to meet the current needs of each tribal partner. Staff from the MC developed and delivered webinar trainings on topics related to research study design, literature searches, and computer software. At the request of tribal partners, in-person trainings were presented on other aspects of data management, such as use of office software programs (Microsoft Excel and Access) to store and manage information. Tribal partners know the value of the data they own and desire to find ways to use this data to drive decision-making, which begins with having a strong data management plan in place. One of the first steps for many was cataloging research conducted in their community, but there were still many other aspects of data management where infrastructure could be built.

In response to these needs, a data management toolkit was developed in 2016 that contains practical tools and guidance for tribal organizations in collection and sharing research data. During a careful review of the toolkit at a tribal partner retreat two years later, tribal partners and CRCAIH core and division staff discussed edits to improve its use and understanding so other tribal nations could build upon ongoing data efforts and work toward the goal to use research results to make informed decisions. These conversations between tribal partners after trying to utilize the toolkit shed light on what could be enhanced and improved as they began to focus more heavily on data management and data governance.

Commonalities

The policies and procedures around data use, return, and storage have a great impact on the usefulness of research data for the community. Recognizing the value of data in policy and decision-making, tribal partners are eager to find ways to store and utilize data collected during the course of research projects. Tribal communities oftentimes see a reoccurring theme, where inaccurate or an absence of data and/or reporting issues may exist (Espey et al., 2014). Lack of accurate data acutely impacts policy-making and program planning. It is critical for tribal nations to become drivers of data collection efforts that are not only accurate, but also meaningful in addressing pressing health needs.

The biggest outcome for the tribal partners in regards to data management has been working toward the results, through owning the rights to the data by established data sharing agreements, and the ability to work with researchers to return results that benefit the community and address solutions to addressing existing health disparities. This attention to increasing capacity will assist tribal leadership in understanding and addressing health issues in their communities through research results, while at the same time, assisting researchers who work with tribes to better understand the community and the resources available to them (English et al., 2004).

In an effort to get accurate data specific to their communities, tribes often will conduct a community needs assessment or community health assessment. This data is a valuable tool for tribal leadership and program directors to use in decision-making, gauging the progress towards community wellness goals over time, as well as being used in grant applications. The best way to accomplish this is to conduct a comprehensive culturally-appropriate needs assessment (see Case Study 4 in the Appendix). Often this research is redundant with previous research others have conducted; therefore, tribes cataloging past research and having a larger say in the direction of research for their tribe will only move science forward as well as push the timeline ahead to make a more immediate impact on their communities.

Unique Aspects

Tribal Nations Research Group has taken their focus on data a step further by applying for and receiving various foundation funding (e.g., the Bush Foundation) to support planning for a regional data hub. The implementation of a regional data hub would provide broader opportunities for building fruitful collaborations between partners and community empowerment. With the focus on data that is tribally-driven and controlled, members could have access to an online dashboard for timely data retrieval. In addition, using data to apply for service delivery grants, tribal leadership could use data to make evidence-based decisions about policies to positively impact their tribal members and address results from needs assessments.

KEY BARRIERS

Staffing

The process of building tribal research infrastructure requires a great deal of time and resources. In an environment that is short-staffed, community liaisons often have to take on a variety of roles. Prioritizing tasks and honing time management skills enable staff to meet the

needs of their growing offices. As each office grows in its capabilities, new responsibilities arise. This constant building and enhancing of regulatory systems benefits the tribe, but at the same time increases workloads and oftentimes puts pressure on the community liaisons charged with maintaining the office. Funding from CRCAIH supports one FTE employee, and some tribes have elected to utilize the FTE to partially support two staff with other funding picking up the balance. Being stretched too thin has led to requests for additional staffing by some partners.

Another staffing challenge relates to employee turnover. The specific set of knowledge and skills required to manage the operations of the research office takes time to acquire. Training on research ethics, computer software systems, and effective community engagement takes time, as does getting to know the general role and purpose the research office serves, as well as getting to know partners and core resources available for assistance. As many offices are housed under tribal government, the hiring process must follow certain guidelines for advertising open positions. The time needed to find someone with the qualifications to fill vacancies may not allow for an overlapped training period with departing staff, making transition memos and documentation of procedures essential for continued smooth operation of the office.

Tribal Leadership

Changes in tribal leadership also have the potential to impact the building of tribal research infrastructure. Having leadership support and buy-in legitimizes the office and highlights its value to the tribe. Changeover in elected leadership may lead to the need for liaisons to reorient the tribal council to the purpose and duties of the research office, as well as emphasize the importance of research in tribal communities (Burhansstipanov, Christopher, & Schumacher, 2005). For example, the Rosebud Sioux Tribe tribal council members are elected at-large by enrolled members, the President and Vice President are elected for a term of three years, and the Secretary and Treasurer are elected for two-year terms (Buffalo & Bordeaux, 2017). This underscores community liaisons' roles as advocates for research in addition to regulators of the research process. Additionally, tumultuousness in tribal leadership can push back action on certain items necessary to advance the progress of the research office, such as passing official laws/ordinances regulating research.

Sustainable Funding

As eluded to earlier, one key barrier to building tribal research infrastructure is the potential lack of adequate funding. In addition to the salaries of each community liaison, there is the cost for maintaining online IRB submission software, stipends/reimbursements for RRB members, office supplies, and facility operation costs, plus any costs associated with travel and professional development activities. If tribal resources are stretched thin, as they often are, it is challenging to make research infrastructure a funding priority. Some tribes are seeking to recoup operational costs in the form of fees assessed on research projects as they go through the IRB approval process. A challenge of using this funding stream lies in projecting operational costs and implementing a fee structure that brings in enough money to support the office while not being overly burdensome to investigators.

Institutional Infrastructure

Building optimal tribal research infrastructure requires institutional infrastructure already be in place, such as fiscal and technology infrastructure. Tribal offices comprised of staff with knowledge of grants contracting are needed if the tribe is partnering on grants or the many regulations surrounding management of Federal grant dollars. Hold-ups in processing and failure to be responsive can delay subcontract awards and funding allocation, putting the research office in jeopardy of temporarily closing. Also beneficial is having a mechanism in place that can relieve some of the expense burden incurred by staff in paying for travel and waiting for reimbursement.

Educating Researchers

Non-native researchers oftentimes have limited knowledge of the community they are interested in working with or preconceived notions of a community's problems, creating an instant barrier (Chadwick et al., 2014). This also applies to Native researchers from different tribes, who are less familiar with the tribal nation's culture or research processes they are interested in working with. Additionally, these researchers might have expectations that the community liaison will guide them to the correct people within the community, will answer every question they have, or sometimes have even assumed the liaison may assist in collecting data. The time needed to educate, guide, and direct interested researchers has become a need most community liaisons recognize, but in reality do not have dedicated time for, and in doing so, lose valuable time for other activities

within the research office. RRBs ask researchers how both the tribe and the researcher will benefit from the proposed project, and what is their current or prior knowledge they have about the tribal nation. Many times, the community liaison takes on a role that is not expected of other IRBs to guide and educate the researcher.

Without a doubt, tribal nations want support and solutions to the numerous health disparities that can exist, and oftentimes leadership, health boards, or the local research review boards encourage mindful researchers to build connections and lasting relationships. Researchers can make the most of their time in tribal communities if they take the necessary steps to educate themselves about the tribe prior to conducting research. There is understanding that some researchers face pressures to advance their knowledge and careers; however, this education is a key component of their professional and personal development (Bruggs & Missaghian, 2006). Learning about the community or tribal nations that the researchers are interested in will not only help them to be more knowledgeable, but their awareness of the tribe's history, past research wrongs and community strengths will show they have taken the time to understand the people and the tribe. Tribes will continue to expand and build research infrastructure, and as researchers continue to conduct research that benefits the tribe, they will together conduct better quality research.

RELATIONSHIPS

Tribal Partners' Relationships

Perhaps one of the greatest outcomes of the CRCAIH partnerships has been the relationships formed between tribal partners that not only flourished over time, but also created an invaluable network. The peer-to-peer guidance and support the community liaisons are able to provide to one another is unmatched. Initially, tribal partners participated in one-on-one calls with CRCAIH cores and divisions at frequencies each determined would be most beneficial to them. Quarterly teleconferences with all partners and cores and divisions were held as well as one large group meeting at the CRCAIH Summit. These infrequent large group calls and separate teleconference meetings served to build individual infrastructure, but weren't very conducive for tribal partners to get to know one another. In Fall 2016, the first of three tribal partner retreats was held. The retreat provided time for partners to gather face-to-face to share expertise, provide feedback on challenges, identify ways to serve as resources for each other, and ultimately foster

connections for future collaborations.

The following year, the tribal partners collaborated intensely on their group panel presentation, each completing a research poster and facilitating a workshop at the CRCAIH Summit. The engagement from audience members was greatly welcomed and brought many questions during the Q&A portion of the tribal partner panel presentation on sustainability, infrastructure, and the benefits of implementing a fee structure. This huge undertaking led to the establishment of a regular biweekly group teleconference with all tribal partners and some members of CRCAIH cores and divisions. These more frequent meetings helped foster tribal partners' motivation to find ways to be a support to other local tribes building their infrastructure for research. At the third tribal partner retreat, the idea arose for the development of a tribal partner toolkit, revising the current data management toolkit with all partners contributing and evaluating their partnership with CRCAIH and next steps as the original NIH funding comes to a close. Although support from CRCAIH cores and divisions is still relevant and maintained, having support from one another has proved invaluable and has created a stronger unified voice in becoming a part of the national movement in tribal research infrastructure.

CRCAIH Network Relationships

Much effort has been taken by CRCAIH over the last seven years to establish and foster relationships on the local level, not only with each tribal partner community liaison, but with the larger community, department heads, tribal colleges, and surrounding universities, to name a few. On a national level, CRCAIH works to build relationships with larger entities in support of tribal research infrastructure who see the need to support this work by attending and presenting at various conferences and sharing the unique work that each tribal partner is doing in their tribal nations. One example of this has been with the IRB toolkit, which has found an interested national audience.

It must be noted that the CRCAIH tribal partners also assisted CRCAIH cores and divisions in building and improving its own infrastructure and practices. As the tribal partners built their research infrastructure, CRCAIH core and division staff, the majority of whom were also conducting research with tribes on other projects, became more responsive to tribes and their needs in regards to research, data, dissemination, and assisting researchers and institutions in navigating and building relationships with tribes. Through working more closely on CRCAIH goals of building tribal research infrastructure, the CRCAIH core and division staff's research projects

likely became more responsive on issues of tribal data sovereignty and culturally respectful research protocols. Research liaisons from each tribe provided guidance and feedback so researchers approach tribes in a respectful and cultural manner. Tribes want research that benefits their tribes just as much as it will benefit researchers and institutions.

CRCAIH was built with the intention that it was to go beyond the life of the grant, and currently in place is a website that houses a number of research tools and resources for tribal leaders, interested researchers, and others interested in collaborating or connecting with a tribe or other researchers. Relationships take time, and that is something CRCAIH core and division staff have definitely learned as they worked with each tribal partner. Over the last two years, as previously mentioned, CRCAIH has held biweekly tribal partners conference calls to allow the partners to talk more often with one another and for CRCAIH core and division staff to take the time needed to hear from tribal partners as a group. This was a change in infrastructure building as limited time between partners was provided and has definitely made for a greater and deeper impact on relationships and research infrastructure building for everyone. However, trust needed to occur at a culturally appropriate pace, in order for the tribal partners to be comfortable in sharing and asking for assistance as best fit for each tribe.

Research Office Visibility

As tribes continually work to engage their peers, communities, and stakeholders on the importance of research infrastructure and sustainability, there are still instances where knowledge of infrastructure existence in their community goes unnoticed. At the end of the day, the research office must be readily identifiable in order to truly protect and benefit the entire community. There have been a few instances where proposals went before the tribal council or the tribal college, and the RRB coordinator or the community liaison hears about it after the research project has been approved and started. Securing their presence and the work of the office within the tribe is a constant job that they must balance with the rest of the necessary work in establishing and sustaining capacity of the RRB. CRCAIH continues to look for innovative and practical ways for each community liaison to network and reach as many tribal members, tribal departments, leaders, and potential investigators as possible. Developing relationships on a continual basis assists in the ultimate purpose of creating and expanding upon the need to build and sustain research infrastructure.

CONCLUSIONS & FUTURE DIRECTIONS

In conclusion, the lessons learned from the CRCAIH tribal partners' experience on research infrastructure building can be widely applied to Indigenous communities throughout the world. Control of research review and data governance is essential to the full realization of tribal sovereignty in the research context. Although all the tribal partners joined CRCAIH with different needs and strengths, they used the resources of CRCAIH initially to focus on research protections and then moved into development of data management policies and collection of data. The CRCAIH tribal partners have demonstrated it is possible to navigate the journey from passive recipients of research, to a fully engaged partnership on research projects. Steps that facilitated this process was the establishment of running a high-quality local research review process, organization of data clearinghouses, and leadership of independent research projects. For example, CRCAIH tribal partners focus on the positive outcomes from data, examine what currently works within their tribe, and reinforce the strength and resiliency that exists in tribal nations through cultural and historical knowledge, which helps increase the overall equity for tribal communities. Through tightened, more efficient, and well-informed research review processes, tribes have and will continue to approve research that truly benefits the community.

The NIH investment in CRCAIH resulted in a beautiful and dynamic partnership between an academic research entity, tribal nations, and a national-level AI policy research center. The administering of one-on-one, tailored technical assistance, in addition to the training opportunities, is one critical mechanism of investment for change that bears fruit. It is only through this crucial investment in community building that the needle will be moved on AI health disparities. Throughout CRCAIH's existence, 68-72% of the grant budget went outside of the CRCAIH core and division services to support tribal partners and research projects in building research capacity and infrastructure. These early investments in infrastructure and human capital helped position tribes to be more competitive for future funding opportunities and to engage in more equitable research partnerships. Having solid research infrastructure and positions dedicated to research oversight empowers tribes to advance research stewardship and to have a front seat in the decision-making process.

The CRCAIH tribal partners continue to demonstrate the benefit of investing in tribal research infrastructure through directing capacity-building efforts among their own nations, researchers, and other tribal nations. As recent recipients of the National Indian Health Board Area/Regional Impact award, the CRCAIH tribal partners are leaders who serve as mentors to

other tribes in the region who do not yet have the capacity or tools, but have the desire to take control of research on their lands, as well as mentors to researchers to improve the science of AI health research. At CRCAIH's annual research summits, the tribal partners have emerged as compelling storytellers, spreading their successes and lessons learned, which is a wonderful way to educate both audiences of other tribal nations interested in growing their research infrastructure and academic researchers.

As the tribal partners move forward and continue to support research projects for their tribe that may help reduce existing health disparities, continuing to increase the inclusion of tribal leaders and researchers in the design of projects and the contribution of multi-discipline research to develop methodology that speaks to the community as a whole and its citizens is necessary. This effort goes beyond the purpose of community-based participatory research and recognizes Tribal Nations' sovereignty, including the preservation of the cultural and traditional knowledge of tribes in the development of research projects.

Much of these tribal research infrastructure building processes can be replicated in other tribal nations. Like the CRCAIH tribal partners, many groups, such as the U.S. Indigenous Data Sovereignty Network through the University of Arizona, provide valuable resources, such as papers, articles, Indigenous Data Initiatives, and the opportunity to be part of their growing network through their website (USIDSN, 2018). The Saginaw Chippewa Indian Tribe of Michigan are dedicated to increasing tribal data governance, through efforts such as tribal data repositories and protecting their community, tribal sovereignty, and information (Henry, 2018).

Moving forward, CRCAIH will continue to engage not only tribal partner research coordinators in the mission of building tribal research infrastructure, but also through innovative community engagement methods to bring diverse groups of stakeholders together to discuss research to continue to build on this momentum on a national level. As this work continues, the tribal partners will continue to engage and support other tribal nations in this important and necessary work to increase tribal sovereignty, as some tribes are not yet at a place to begin building their tribal infrastructure for research or have access to the tools and resources (https://www.crcaih. org/training-and-resources.html), which we hope is one of CRCAIH's lasting legacies.

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APPENDIX

Case Study 1: Oglala Sioux Tribe Implementing Axiom Mentor IRB

The transition from a paper-based system to an IRB tracking software has been invaluable to the Oglala Sioux Tribe Research Office and the Research Review Board (RRB). The Oglala Sioux Tribe (OST) was the first tribe in the Northern Plains region to utilize this electronic research management system for submissions, review, and tracking of all research that would be conducted within their reservation boundaries (Elliott et al., 2016). Upon implementing Mentor IRB, the process has been streamlined, and having a central system that is available online and fully supports building a tribe's research capacity is ideal and saves time for the OST RRB Coordinator. The software not only assists the community liaison in their day-to-day functions, but also allows potential and current investigators to submit and update their protocol with use of the online system, as well as allows IRB members to log in and review all protocols prior to a board meeting. Axiom Mentor IRB and its many features, such as reminders for invoicing and upcoming deadlines, auto-populating of information, and customizable notifications and tabs, assists the coordinator immensely.

Furthermore, the community liaison serves as support to the other CRCAIH tribal partners implementing the software. Not only has OST provided their knowledge and experience with Axiom Mentor, they have led key discussions on the importance this tool has in building capacity, emphasizing the efficiently and flexibility in the software. An instruction manual is currently in the works for new Principal Investigators working with OST as well as an orientation packet for new RRB members. Therefore, through capacity building with one tribe, the knowledge is spread and assists many others. Axiom Mentor IRB is the primary IRB software that assists CRCAIH tribal partners in managing and monitoring current and past research within their tribe. Additional CRCAIH tribal partners have implemented Mentor IRB software to different extents and have found it increases efficiency exponentially.

Case Study 2: Turtle Mountain Band of Chippewa Indians/Tribal Nations Research Group: Community Engagement to Approve and Pass the TMBCI Research Protection Act

The partnership between Turtle Mountain Band of Chippewa Indians (TMBCI) and CRCAIH began in August 2013, and within one year, TMBCI's Research Protection Act was approved and enacted. The tribe wanted to regulate all research within the reservation boundaries,

not just human subjects' research, and started first with an established code to guide research. From the start of the partnership, staff began drafting a research code modeled from the Indigenous Research Protection Act (Indigenous Peoples Council on Biocolonialism, n.d.) and made the necessary adjustments to reflect and protect the members of the TMBCI. Upon a rough draft being approved by the legal department, the code went into the local tribal newspaper for comment for 90 days. Additionally, copies were mailed to all tribal departments, current researchers engaging in research with the TMBCI nation, IRBs within the state, and academic institutions, such as University of North Dakota and North Dakota State University, for feedback and review. A public meeting was held in February 2014 to highlight and discuss the code and the importance of the regulated research and to respond to any feedback or comments from community members and leadership. Across the next five months, an additional three open public meetings were held, a 30-day comment went out to the Tribal Council, and on July 31, 2014, the Research Protection Act was approved and put into place. The community involvement was key in how quickly the code was passed and how supportive the tribe overall was in seeing the need to build research capacity for the members of the TMBCI.

Case Study 3: Rosebud Sioux Tribe Supplement Grant

In 2015, as the most recent tribe to partner with CRCAIH, Rosebud Sioux Tribe (RST) was best situated to conduct a comprehensive review of tribal readiness for research development, which was the second aim of the NIH CRCAIH supplement grant. Tribal community data was collated and nine stakeholders were interviewed regarding the community's perspective and knowledge of research and their readiness for research using the Community Readiness Model (Tri-Ethnic Center, 2014).

The RST Community Profile resulted in a 23-page document that included a tribal overview, demographics, health status, customs and traditions, current programming, and current research review process. This profile serves as a helpful tool for the researchers, stakeholders, and others new to the community. Additionally, results from the interviews revealed that although research is a low priority compared to other ongoing tribal health care crises, there is an understanding as to why it could be low and the immediate health needs of the community that take precedence. This profile is used both by community members and those new to working with RST and is particularly useful for potential researchers and staff working in such departments as the Indian Health Service, who currently uses the profile for staff orientation. The profile has been

referenced by a few reports and has also been used in conversations regarding the need to build research infrastructure with RST stakeholders and leadership, proving just how valuable this document is for the community. CRCAIH partners feel strongly that it is the responsibility of potential researchers to learn the tribal culture and context they want to work with, and resources such as this profile are essential to accomplish that goal.

Case Study 4: Cultural Narrative of the Spirit Lake Nation 2015 Comprehensive Community Assessment

In the summer of 2015, 285 tribal members completed the Comprehensive Community Assessment (CCA), a 111-question survey that asked about individual health status, factors that influence health, and opinions on critical needs for the Spirit Lake Nation (SLN) under the guidance of the Cankdeska Cikana Community College (CCCC). The resulting data was analyzed, interpreted, and compiled in to a lengthy final report. The CCCC went beyond simply reporting by also creating a "cultural narrative" to complement the report.

The Dakota cultural values provided a foundation for the CCA process and informed their approach to understanding the health and well-being of the community. The four directions (west, east, north, and south) and the four primary colors (black, yellow, red, and white) were represented as the individual, family, community level, and society. Findings were placed within a specific section to guide and support healthy change in the community, based on the results. Through Dakota teachings, health is defined as including spiritual, physical, emotional, and mental well-being, and applying these teachings, as did their ancestors, who were scientists, exhibits the resiliency and ingenuity that is still strong for the SLN people (Around Him & Pickner, 2016). This document was key in disseminating local findings that were culturally-tailored for their tribal members and guides the future work of tribal programs.

TRIBAL IRBS: A FRAMEWORK FOR UNDERSTANDING RESEARCH OVERSIGHT IN AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES

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Abstract: Tribal Institutional Review Boards (IRBs) and other entities that oversee research for American Indians and Alaska Natives are important and unique. They reflect and respond to community needs, changes in research, and revisions to research policy. We provide a framework to capture this dynamism by building on existing work and offering a way to describe the scope of entities that oversee tribal research. As federal research regulations are revised, and policies are developed in response to a rapidly advancing research landscape, it is critical that policy makers, IRB professionals, researchers, and tribal communities have clarity regarding the Tribal IRB.

BACKGROUND

Scholars and leaders in American Indian and Alaska Native (AI/AN) communities have noted that the work of mainstream university and medical center Institutional Review Boards (IRBs) alone is inadequate for ensuring research protections for AI/AN peoples (Champagne & Goldberg, 2005; Deloria, 2003; Freeman, n.d.; Harding et al., 2012; LaFrance & Crazy Bull, 2009; National Congress of American Indians [NCAI] Policy Research Center, 2017; n.d.). As a result, several tribes have established their own processes for oversight of research activities on their lands and with their citizens. In addition, other entities that serve AI/AN individuals and communities, on and off tribal lands, have also established processes for research oversight. The goal shared by many of these entities is often two-fold: to ensure protection within and benefit from research participation for both AI/AN individuals and communities (Fort Peck Institutional Review Board, n.d.; Navajo Nation Department of Health, n.d.; Oglala Lakota College, n.d.; Salish Kootenai College, n.d.; Sisseton-Wahpeton Oyate Research Office, n.d.-a; Southwest Tribal

Native American Research Center for Health [NARCH], n.d.; Tribal Nations Research Group [TNRG], n.d.).

Population and Historical Context

The AI/AN population in the United States is in truth a collective of several populations represented by 573 federally recognized tribes (Bureau of Indian Affairs, 2019) and several tribal nations not officially recognized by the federal government (i.e., state-recognized tribes). These populations are spread across 326 federally recognized reservations, off-reservation trust land areas (U.S. Census Bureau, 2018), and urban and rural communities throughout the United States. Federally recognized tribes are sovereign; therefore, each has a government-to-government relationship with the United States, creating a unique context for research oversight and policy (U.S. Department of the Interior Indian Affairs, 2019). This manuscript summarizes primary mechanisms for research oversight in AI/AN communities and the related considerations for upholding ethical research for these populations. Throughout the manuscript the terms *tribe* and *tribal community* are used in addition to *American Indian and Alaska Native (AI/AN)* to refer to communities and groupings of AI/AN peoples in the United States. The term *tribally based research* refers to research involving individuals residing on tribal land, or research utilizing a tribe's natural, historical, or cultural resources.

It has been a little over 50 years since the establishment of U.S. laws to protect human participants in research. These national laws were established in response to national and international recognition of research abuses and in response to the development of global research ethics standards and review processes (Maloney, 1984; Rice, 2008). U.S. IRBs were established to protect the rights and welfare of people participating in research studies, and the requirement for IRBs and IRB review evolved from a policy directive in 1966 issued by U.S. Surgeon General William Stewart (Breault, 2006; Office of the Surgeon General, U.S. Public Health Service, 1967). A little more than a decade later in 1979, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research drafted the Belmont Report, which outlines ethical guidelines for research involving human participants (U.S. Department of Health and Human Services [USDHHS], n.d.). Subsequently, through efforts in 1981 and 1991, the Belmont Report was incorporated into the U.S. federal research policy known as the "Common Rule," or 45 CFR Part 46.

Present Day Relevance and Intended Audience

Even after the establishment of federal research policies and the IRBs tasked with implementing them, AI/AN peoples have continued to experience research abuses—indicating that mainstream ethical standards, policies, and IRBs have not been successful in preventing research-related harms to tribes (Fixico, 1980; Garrison & Cho, 2013; Hodge, 2012; LaFrance & Crazy Bull, 2009; Manson, Garroutte, Goins, & Henderson, 2004). Research violations involving AI/AN populations have only recently been publicly recognized and contribute to a long history of oppression experienced by these populations (Brave Heart & DeBruyn, 1998; Office of the Surgeon General, 2001; Whitebeck, Adams, Hoyt, & Chen, 2004). The history of research ethics violations includes multiple accounts of research conducted without permission and research conducted without participation of the relevant AI/AN communities in the research process (Morton et al., 2013; Norton & Manson, 1996; Solomon & Randall, 2014). Significant harms have resulted from these research violations, and they have occurred at both the individual and community levels (Morton et al., 2013; Norton & Manson, 1996; Solomon & Randall, 2014).

The purpose of this manuscript is to acknowledge the diversity of mechanisms for research oversight that presently exist in AI/AN communities and present a framework to help clarify the role and scope of the various entities involved in such activities. The recent growth and dynamism of tribal research oversight warrants acknowledgement and deeper understanding. This manuscript is intended to serve as a tool for many, including those engaged in tribal research or research oversight with tribal communities, tribal policy makers, federal policy makers, and research funding agencies. To ensure that AI/AN peoples are both adequately protected within and benefit from research, it is important that all existing tribal research oversight processes are recognized and more clearly understood. While we acknowledge that it is likely we are not aware of all tribal IRBs or research oversight processes serving AI/AN peoples, this manuscript documents those known to the authors and for which there is publicly available information. We provide the most comprehensive published listing to date (Table A1 in Appendix), and we anticipate that our proposed framework will be amenable to the continued growth of tribal research oversight processes in the future.

Author Perspectives and Experience

The authors represent, or were previously affiliated with, the Collaborative Research Center for American Indian Health (CRCAIH), Tribal Nations Research Group (TNRG), and Sisseton-Wahpeton Oyate Local Research Review Board (SWO LRRB). The primary content of the manuscript is based on insights derived from our individual and collaborative experiences with Tribal IRBs and other AI/AN research oversight entities. CRCAIH has provided education, tools, and technical support for the establishment of new Tribal IRBs and the growth of existing Tribal IRBs (Angal & Andalcio, 2015; Elliott et al., 2015). These services are part of the larger aim of the center to facilitate and support the building of tribal research infrastructure, with the goal of addressing health inequities experienced by American Indian communities in South Dakota, North Dakota, and Minnesota (Collaborative Research Center for American Indian Health, 2013; Elliott et al., 2015). TNRG is an organization created to promote high quality research relevant to the Turtle Mountain Band of Chippewa Indians, to "improve the quality of life for all Tribal Members, through culturally competent, custom-fit research," and for the promotion of public and private economic development and opportunity (TNRG, n.d.). TNRG provides a variety of research and data collection services. TNRG also founded and manages the system of tribal research oversight for their Tribal Nation, the Turtle Mountain Band of Chippewa Indians Research Review Board (TNRG, n.d.). The SWO LRRB is a part of the Tribal Research Office established by the Sisseton-Wahpeton Oyate Tribal Council. This board provides research oversight for the Sisseton-Wahpeton Oyate Tribal Nation by reviewing research proposals and granting permission to researchers to conduct research on the Lake Traverse Reservation (Sisseton-Wahpeton Oyate Research Office n.d.-a).

Current Mechanisms for Understanding Research Oversight in AI/AN Communities

Tribal Nations are currently using research to address the health of their communities (Crazy Bull, 1997; Fisher & Ball, 2003; Mariella, Brown, Carter, & Verri, 2009; National Institutes of Health [NIH] Center for Research Capacity Building, 2015; Swisher, 1992) and lead initiatives to ensure that tribally based research is beneficial to both the individuals who participate and their communities (Crazy Bull, 1997; Harding et al., 2012; Manson et al., 2004; Solomon & Randall, 2014; Swisher, 1992). However, the mechanisms of research oversight in AI/AN communities are wide-ranging. A comprehensive review of the literature (Angal, Petersen, Tobacco, & Elliott,

2016; Brugge & Missaghian, 2006; Gribble & Around Him, 2014; Harding et al., 2012; Henderson, 2018; Kelley, Belcourt-Dittloff, Belcourt, & Belcourt, 2013; LaFrance & Crazy Bull, 2009; Manson et al., 2004; Morton et al., 2013; NCAI Policy Research Center, 2017; Saxton et al., 2015; Yuan, Bartgis, & Demers, 2014) and engagement with several entities involved in tribal research oversight has revealed a clear gap in characterizing these diverse and evolving mechanisms.

A decade ago, LaFrance and Crazy Bull (2009) identified three distinct entities engaged in research oversight in AI/AN communities: 1) Indian Health Service (IHS) IRB, 2) Tribal College IRB, and 3) Tribal IRB. Since LaFrance and Crazy Bull's characterization, there has been tremendous growth in the number of entities involved in providing research oversight for AI/AN peoples. Use of the term *Tribal IRB* has become widespread, and it is commonly used to describe many entities that provide oversight of research involving AI/AN peoples. In addition, use of *IRB* in the name of a research oversight entity is sometimes thought to signify a federally registered review body and other times is not formally linked to a federal designation. This array of interpretations poses challenges for many, including tribal and non-tribal entities that provide research oversight, those involved in tribal research more broadly, and those involved in policy development. It leads to cross communication and general confusion around research oversight in AI/AN communities, and it could potentially contribute to inadequate oversight of research involving AI/AN peoples.

AN UPDATED FRAMEWORK

We propose an updated framework (Table 1) that expands the structure provided by LaFrance and Crazy Bull (2009) to account for the current landscape of research oversight in AI/AN communities and to improve understanding for those engaged in research oversight, the conduct and funding of research, and related research policy development. As noted above, these revisions are necessary for several reasons. The updated framework offers greater clarity and recognizes the growing variety of entities engaged in the important work of research oversight for AI/AN peoples. Our hope is that it will further ensure adequate and appropriate research oversight is provided in a streamlined process—a benefit to AI/AN peoples and the research community at-large.

The updated framework includes two of the three distinct types of AI/AN research oversight denoted by LaFrance and Crazy Bull (2009) and, in addition to renaming the third type, adds a fourth. We narrowed the "Tribal IRB" designation provided by LaFrance and Crazy Bull (2009) to specify recognition of research oversight authorized by a "Tribal Nation." We also introduced the designation of "Tribally Based or Focused Organization/Department." Entities within this type were not distinct in the LaFrance and Crazy Bull (2009) framework; they may not have been in existence or well-known at the time. Furthermore, we have provided a conscious re-ordering of the categories placing entities that provide research oversight for Tribal Nations first: 1) Tribal Nation, 2) Tribal College, 3) Tribally Based or Focused Organization/Department, and 4) IHS. For each mechanism in the framework, there are special cases where an entity may engage in more than one type of research oversight, and these are described in detail below.

Table 1
Framework for understanding oversight in AI/AN communities

Tribal Nation	Tribal College	Tribally Based or Focused Organization/ Department	Indian Health Service (IHS)
Entity authorized to provide the ethical review and monitoring of research for one Tribal Nation or for a single reservation home to more than one Tribal Nation	Entity that provides the ethical review and monitoring of research for a Tribal College or University (TCU)*	Entity in an existing organization or department that provides the ethical review and monitoring of research for that organization or department and is within a Tribal Nation, and/or serving a Tribal Nation or Nations, and/or serving AI/AN peoples	An entity designated by IHS to provide the ethical review and monitoring of research conducted in IHS facilities within IHS regional or national designations

*Includes tribally and federally chartered colleges and universities. See the "Tribal College Research Oversight" section for further information.

Several factors were taken into consideration in determining how to organize this updated framework. For example, components of jurisdiction, including geography, content, and authorizing entity, each factored into our conceptual thinking. Ultimately, we decided the most collaborative, respectful, and effective approach was to acknowledge and build on what exists and may be easily recognized among those engaged in AI/AN research and research oversight. In this spirit, we have retained the names proposed by LaFrance and Crazy Bull (2009), as well as the names that existing tribal research oversight entities have given themselves. Thus, the primary

characteristics highlighted by the nomenclature in this framework are a combination of geographic and structural jurisdiction. This concept is explained in more depth below under the heading "Jurisdiction, Authority, and Other Considerations." Furthermore, it is important to note that this framework introduces terminology that is recommended for use *in addition to* the existing names of entities providing tribal research oversight. See "Applying the Framework" below for more detail. A table listing AI/AN research oversight entities known to the authors at the time of publication, and according to this framework, is provided in the Appendix.

Tribal Nation Research Oversight

Tribal Nation research oversight may be used to describe research oversight by a board or committee authorized by a tribal government to provide the ethical review and monitoring of research on behalf of a tribal nation or for a single reservation home to more than one tribal nation. It is the only mechanism in this framework that denotes the explicit legal authority of a tribal government to provide research review and monitoring on behalf of an entire Tribal Nation or reservation. This research oversight entity may be the tribal governing body applying its own research code, such as the Tribal Council of the Confederated Tribes of the Coos, Lower Umpqua, and Siuslaw Indians (The Confederated Tribes of the Coos, 2002), or a Business Council, such as that of the Confederated Tribes of the Colville Reservation (The Confederated Tribes of the Colville Reservation, n.d.). It may also be a separate board with primary responsibility for the ethical review of tribally based research for the Tribal Nation, such as existing boards that carry the name "Tribal IRB" or "Tribal Research Review Board (RRB)." Examples of these types of boards serving a single Tribal Nation are the Tribal Nations Research Group (TNRG, n.d.), the Sisseton-Wahpeton Oyate Local RRB (Sisseton-Wahpeton Oyate Research Office, n.d.-b), and the Choctaw Nation of Oklahoma IRB (Clark, 2016). The Fort Peck IRB, like the Tribal Council of the Confederated Tribes of the Coos, Lower Umpqua, and Siuslaw Indians (mentioned earlier; The Confederated Tribes of the Coos, n.d.), serves a single reservation home to more than one tribal nation (i.e., the Assiniboine and Sioux Tribes; Fort Peck Institutional Review Board, n.d.). It is important to note that this description and the additional examples in the Appendix refer to entities authorized by tribal governments (e.g., in a research code or law); however, as sovereign nations, all tribal governments have the power and authority to provide research oversight in the absence of having authorized another entity to do so (Deloria, 2003).

Tribal College Research Oversight

The *Tribal College* mechanism refers to entities that are commonly referred to as "Tribal College IRBs." These entities typically review research based at their tribal college and/or college facilities, and/or research in which the college students, staff, or faculty are engaged. Note that this designation primarily refers to tribally controlled colleges; however, it also includes colleges that operate under the authority of the federal government, such as Haskell Indian Nations University. Examples of *Tribal College* IRBs are the Oglala Lakota College IRB and Institutional Animal Care and Use Committee (Oglala Lakota College, n.d.), the United Tribes Technical College IRB (United Tribes Technical College, n.d.), and the Salish Kootenai College IRB (Salish Kootenai College, n.d.). See Appendix for additional examples.

Tribally Based or Focused Organization/Department Research Oversight

Tribally Based or Focused Organization/Department research oversight is proposed to describe the type of research oversight offered by an existing organization or department within a Tribal Nation, serving a Tribal Nation or Nations, or serving AI/AN individuals, which provides the ethical review of research for that particular organization or department. This includes both reservation-based organizations and organizations based in other settings off reservations or tribal lands, including urban settings. Entities responsible for this type of research oversight are distinct from those responsible for *Tribal Nation* research oversight in that they have a more limited scope of work and usually are not responsible for the oversight of *all* tribally based research for a particular Tribal Nation, reservation, or community. For example, in some communities, a Tribal Historic Preservation Office (THPO) reviews and provides oversight for certain types of research on behalf of a tribe. An example of this is the Sisseton-Wahpeton Oyate THPO (Sisseton-Wahpeton Oyate Tribal Historic Preservation Office, n.d.). It is important to note that this designation is distinct from *Tribal College* research oversight, as tribal colleges and universities have been granted their own designation consistent with LaFrance and Crazy Bull's (2009) original framework.

IHS Research Oversight

IHS research oversight encompasses entities commonly referred to as "IHS Area IRBs," which provide research oversight that corresponds to the twelve geographical areas defined by

IHS: Alaska, Albuquerque, Bemidji, Billings, California, Great Plains, Nashville, Navajo, Oklahoma, Phoenix, Portland, and Tucson (IHS, n.d.-b). Typically, these entities are responsible for the oversight of research conducted in IHS facilities in tribal communities within the geographical areas defined by IHS. However, historically, IHS Area IRBs have offered to provide oversight for research in tribal communities more broadly, for example when tribal communities do not have an IRB. IHS IRBs may also be of service in situations when research requires review by a federally registered IRB, and a tribal community does not have such a designation (IHS, n.d.-b). When serving as the IRB, or "IRB of record," for a tribal community, IHS IRBs typically require documentation of approval from the Tribal Council, or an entity designated by the Tribal Council, prior to approving any research activities (IHS, n.d.-b).

Special Cases within the Proposed Framework

There are some special cases in this proposed framework. For example, boards or committees providing research oversight for a community may provide more than one type of research oversight. The Navajo Nation Human RRB (NNHRRB) is a good example, as it provides both *Tribal Nation* and *IHS* research oversight. The NNHRRB is also referred to as the Navajo Area IHS IRB (Navajo Nation Department of Health, n.d.). Other exceptions are research oversight entities that serve a consortium of Tribal Nations. Using our framework, we will refer to these types of entities as a *Tribally Based or Focused Organization/Department.* One example of this type of Tribal IRB is the Southwest Tribal IRB, which provides supplemental review of research to tribes located in New Mexico, Colorado, and Texas (Southwest Tribal NARCH, n.d.).

Other examples of special cases are the Indian Health Council IRB and the California Rural Indian Health Board IRB. Both are IRBs that serve multiple tribal communities and according to our framework provide *Tribally Based or Focused Organization/Department* research oversight. The Indian Health Council Tribal IRB in California is part of a health care center that provides health care and social services (Indian Health Council Inc, n.d.; Morton et al., 2013). The health care center was founded by a consortium of nine tribes, and it has two clinics and several outreach programs serving the North San Diego County reservations of the Inaja-Cosmit, La Jolla, Los Coyotes, Mesa Grande, Pala, Rincon, San Pasqual, and Santa Ysabel (Indian Health Council Inc, n.d.). Similarly, affiliated with a health care consortium, the California Rural Indian Health Board IRB serves the California Rural Indian Health Board, a network of tribal health programs with

membership including Feather River Tribal Health, Inc.; Warner Mountain Indian Health Program; United Indian Health Services; Tule River Indian Health Center; Redding Rancheria Tribal Health Center; Toiyabe Indian Health Project; Karuk Tribal Health Program; and the Chapa-De Indian Health Program (California Rural Indian Health Board, n.d.-a).

APPLYING THE FRAMEWORK

It is important to note that research involving AI/AN communities may fall under the purview of more than one research oversight entity. For example, one research study may need review by more than one, and even potentially all four, types of research oversight entities in this framework – *Tribal Nation*, *Tribal College, Tribally Based or Focused Organization/Department,* and *IHS*. Use of this framework will support awareness of the research oversight entities that may exist for tribal communities, thus adding clarity to communications about the review of research protocols for those both within and external to such communities.

Within a specific tribal community, applying this framework could help ensure that one entity providing research oversight, such as a tribal college, is aware of the existence and scope of another entity (e.g., a Tribal Historic Preservation Office). Therefore, when a research project requires oversight from both entities, the need for collaboration will be clear. The framework could also help prevent misunderstandings when applied by external partners who are less familiar with the landscape of tribal research oversight. For example, it could deter instances of a Principal Investigator erroneously believing, and perhaps reporting in publications, that a project has been approved by a Tribe or Tribal Nation, when in fact the research was approved by a *Tribally Based or Focused Organization/Department* research oversight entity. The framework may also avert researcher requests to a Tribal Council when a separate body has been designated as the *Tribal Nation* research oversight entity within the community.

Research oversight entities within tribal communities may choose to apply the framework in practical ways, to position their work within a broader range of responsibilities or delineate a specific scope of oversight. For example, tribal entities whose primary responsibility is not research regulation or oversight, such as a Tribal Council, Tribal Historic Preservation Office, or Health Board, could insert research oversight language into their list of services provided. For instance, a Health Board that performs ethical review of research for their Tribal Nation can include "Tribal Nation research oversight" in their list of responsibilities or, if they choose,

establish a public presence as the "_____ Nation Health Board and the _____ Nation IRB." Likewise, in cases where an entity's scope of research oversight is limited, such limitations could be clearly specified within the entity's name or mission. For instance, a Tribal Historic Preservation Office, which may review historical and cultural research, could reference the scope of research that it reviews using language such as, "The _____Tribal Historic Preservation Office, which serves as the Tribal IRB for historical and cultural research," or "The _____ Tribal Historic Preservation Office, which provides oversight for historical and cultural research."

Use of the framework in conjunction with the existing names for tribal research oversight entities is encouraged. Thus, an entity that identifies itself as a Tribal IRB can simply clarify their scope of review or oversight by referring to themselves as a Tribal IRB that provides, for example, *Tribally Based or Focused Organization/Department* research oversight or *Tribal College* research oversight. Awareness of how the U.S. Office for Human Research Protections (OHRP) uses the term "IRB" is also important for understanding this recommendation. The OHRP is part of the U.S. Department of Health and Human Services (USDHHS), and it maintains regulatory oversight over biomedical and behavioral research involving human participants that is conducted or supported by USDHHS (USDHHS, n.d.).

Entities that review and regulate research can become federally registered through the OHRP's established registration process. Within the OHRP's database of registered entities, each entity is referred to as an "IRB" and assigned a number. According to a personal communication with staff from the OHRP, an OHRP registered entity responsible for the ethical review and regulation of research can have any name, and there is no requirement that the name contain the words "review" or "board" (H. Blatt, personal communication, 2014). The OHRP also lists registered entities in their database using "IRB" in the name irrespective of the entity's actual name (H. Blatt, personal communication, 2014). Therefore, for ease of reference, we use the term "IRB" throughout the remainder of this manuscript, like the OHRP uses it, to refer to any entity reviewing research or providing research oversight.

JURISDICTION, AUTHORITY, AND OTHER CONSIDERATIONS

With growing attention to tribal sovereignty in research, issues surrounding tribal jurisdiction and enforcement of research laws have emerged as important topics of discussion at local and national levels. These concepts factored into the development of the framework proposed in this

manuscript and deserve further elaboration as part of our effort to clarify the role and scope of the diverse entities that oversee tribally based research. Insights gleaned through the work of CRCAIH, TNRG, and SWO LRRB relate to three primary types of jurisdiction used by Tribal IRBs and other entities responsible for AI/AN research oversight—*geographic, structural,* and *content-specific* jurisdiction—which are presented in the following sections. The importance of the authority of research oversight entities is also discussed, as well as differences in sources of authorization.

Geographic and Structural Jurisdiction

For the purposes of this framework, we define *geographic* and *structural jurisdiction* in terms of physical boundaries. Using the example of a school, jurisdiction that is *structural* in nature would be jurisdiction over research that involves the school, the school property, and/or that engages students and faculty. Another example of *structural jurisdiction* is jurisdiction over research that involves an organization (other than a school), which means that oversight is provided for research that occurs in that organization's facilities or with that organization's staff and other patrons. An example mentioned earlier in the paper is that of a health clinic. *IHS* jurisdiction of research oversight can also be thought of as both structural and geographic.

To understand how we define *geographic jurisdiction* for this framework, it is helpful to consider those IRBs that provide *Tribal Nation* research oversight. Some limit their jurisdiction to research activities conducted within the tribe's reservation boundaries or tribal lands. Language like "within the reservation" or "reservation boundaries" might be used in policy, with the right to such jurisdiction based on federal law and tribal government jurisdiction over a tribe's land. In some instances, *Tribal Nation* IRBs have considered providing research oversight for research projects that aim to recruit tribal members who reside near, but outside of, the tribe's reservation boundaries or tribal lands. An example is research proposed in a school that exists outside a reservation's borders but serves many tribal children who reside both within and near the reservation's borders. The difficulty of establishing jurisdiction outside of tribal lands has been acknowledged, and one suggestion is that *Tribal Nation* IRBs and administrators of such schools establish a collaborative relationship that allows for appropriate oversight of research projects involving tribal children attending the school.

The challenge of overseeing all research involving tribal members anywhere in the United States, or in the world, has also arisen in discussions with Tribal Partners at CRCAIH, including TNRG and SWO LRRB. Among the tribes partnering with CRCAIH, the belief in such an

approach has been met with a reality of the practical challenges related to its implementation and enforcement, as it would entail trying to provide oversight of research for an enormous geographic area and on lands that may not be tribal or reservation-based. It would also entail trying to enforce tribal policy on lands and in communities outside of a tribe's legal jurisdiction. The intersection of the legal and ethical implications of this topic warrants further deliberation, especially given that tribal perspectives on and capacities to address this topic may be diverse.

Content-Specific Jurisdiction

In addition to making determinations regarding *geographic* or *structural jurisdiction*, it is important to consider that there is also *content-specific jurisdiction* for many Tribal IRBs and other entities responsible for AI/AN research oversight. Some Tribal Nations and/or Tribal IRBs have developed policies around the content of their research review and oversight. In our experience, it is helpful to do so. A challenge shared by new or developing *Tribal Nation* IRBs is determining the scope of their research oversight activities, or the content that they will review and monitor on behalf of the tribe. Several *Tribal Nation* IRBs have developed policies stating that they will review *all* research, not only research involving human participants. This means for example, basic science, conservation, environmental, animal, housing, education, historical, and cultural research.

Some *Tribal Nation* IRBs also consider all data collection activities occurring on their reservation or tribal lands to be under their jurisdiction. The Turtle Mountain Band of Chippewa Indians RRB is one example (TNRG, 2014). Furthermore, many Tribal IRBs review and provide approval for presentations and publications related to both tribally based research and non-research projects. These efforts to provide oversight beyond the mainstream understanding of human subjects' research, and beyond research in general, are to protect tribal citizens and communities from harm or stigmatization. They also are designed to ensure that both the outcome and process of the projects under review are beneficial to the community and, at minimum, do not put the community at risk.

Authority

An important distinguishing characteristic of existing Tribal IRBs is their source of authorization, or rather the entity that provides an IRB with authority to operate and have jurisdiction for research oversight. This characteristic is also a factor in the diversity of existing

tribal research oversight entities. In our framework the source of authority for *Tribal Nation* research oversight is the tribal government. The source of authority for *Tribal College* research oversight is usually the college itself, although in some cases it can be the respective tribal government. It is important to note that tribally controlled colleges are enabled by charters issued from their respective tribal governments. An exception is the case in which a tribal government has authorized its *Tribal College* IRB to provide research oversight for the entire Tribal Nation. Examples of this are the Sitting Bull College IRB, which provides research oversight for its college and for the Standing Rock Sioux Tribe (M. Mongoh, personal communication, 2016), or the Fort Peck IRB*,* which provides research oversight for Fort Peck Community College and the Fort Peck Assiniboine & Sioux Tribes of the Fort Peck Reservation (Fort Peck IRB, n.d.). See Appendix for more detail.

The source of authority for *Tribally Based or Focused Organization/Department* entities is usually the organization or department itself. However, it can be the tribal government, particularly if the organization or department is located on tribal land. An example of this is the Fond du Lac Band of Lake Superior Chippewa Human Services Division IRB, which received authorization from the tribal governing body, the Reservation Business Committee. Moreover, jurisdiction for this IRB is structural in nature, as it pertains exclusively to research that engages the Human Services Division (C. Bassett, personal communication, 2016).

The source of authority for *IHS* research oversight IRBs is the Indian Health Service (IHS) and, therefore, the federal government (IHS, n.d.-a). The exception to this is when authority is shared by the federal government and a tribal government, for example when a Tribal IRB is both authorized by IHS and the government of a Tribal Nation. As described earlier, the Navajo Nation Human Research Review Board (NNHRRB) aligns with this scenario (Navajo Nation Department of Health, n.d.).

CONCLUSION

Research oversight in AI/AN communities is complex. However, this complexity exists for important reasons, including the sovereign right of tribes to govern activities occurring on their lands and with their peoples and genuine interests in ensuring protection and benefits for AI/AN individuals and communities engaged in research activities. We hope this framework helps bring recognition to the variety of entities engaged in this important work. A positive outcome would be

the identification of additional Tribal IRBs, beyond those shown in our Appendix. For instance, entities not identified through our efforts due to lack of a public presence may be inspired to declare their existence and role. This could be facilitated either through the encouragement of tribal community members or others they engage within the research process, such as the research community and funders.

We also hope that by offering a framework to navigate the landscape of Tribal IRBs, we have identified opportunities to improve collaboration and efficiency both in the conduct of research and its oversight within AI/AN communities. For example, our goal is that by applying this framework diverse audiences will begin to put in place the policies and supports needed to strengthen relationships both among Tribal IRBs and between Tribal IRBs and research oversight bodies external to tribal communities, such as non-tribal academic and federal IRBs. With tribal authority over research explicitly acknowledged in the revised Common Rule (USDHHS, 2017b), clarity around Tribal IRBs will be invaluable. We anticipate that more people will become aware of the need to engage and respect Tribal IRBs in their work, and this framework can serve as a resource for orienting to the complex but necessary environment of Tribal IRBs.

Tribal IRBs and other entities that provide research oversight for AI/AN communities are essential, not only because of the negative history of research with tribes, but also because research is being used more and more by tribal communities as a tool for building capacity and improving the well-being of AI/AN peoples. Entities that fall within the framework proposed in this manuscript will continue to evolve in response to community needs, changes in the types and focus of tribally based research, and academic and federal policy revisions. The framework offered in this manuscript provides shared language and structure to account for this dynamism. It provides a simple way to describe the scope of a Tribal IRB or other research oversight entity by building on work that precedes it and using familiar terminology. The updated framework is also flexible enough to grow with the inevitable progression and change that will continue with the *Tribal IRB*, particularly in the areas of tribal jurisdiction and enforcement. In this time of rapidly developing research technology, revisions to federal research regulations such as the Common Rule (USDHHS, 2017b), and development of new research policies at places like NIH (USDHHS, 2017a, 2017b), it is more important than ever that policy makers, IRB professionals, researchers, and tribal communities have a mutual understanding and shared terminology regarding research oversight in AI/AN communities.

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APPENDIX

Table A1
Fifty known entities providing research oversight for AI/AN communities as of April 2019

Tribal Nation	Tribal College	Tribally Based or Focused Organization/ Department	Indian Health Service
1. Blackfeet Nation IRB Browning, MT	**1. Aaniiih Nakoda College IRB** (formerly Fort Belknap College) Harlem, MT www.ancollege.edu/online_resources/pdfs/IRB.pdf	**1. California Rural Indian Health Board** Sacramento, CA https://crihb.org/institutional-review-board/	**1. Alaska Area IHS IRB** Anchorage, AK http://anthctoday.org/aairb
2. Cherokee Nation IRB Tahlequah, OK http://www.cherokee.org/Our-Government/Boards-Commissions/Institutional-Review-Board	**2. Bay Mills Community College IRB (BMCC IRB)** Brimley, MI https://www.bmcc.edu/about-bmcc/governance-administration/research-and-special-projects	**2. Chickasaw Nation Department of Health IRB*** (also known as Chickasaw Nation Research Review Board) Ada, OK	**2. Bemidji Area IHS IRB** (Publication Review Committee) Bemidji, MN
3. Chickasaw Nation Research Review Board* (also known as Chickasaw Nation Department of Health IRB) Ada, OK	**3. Chief Dull Knife Community College Institutional Review Board** Lame Deer, MT http://www.cdkc.edu/CDKC_IRB.pdf	**3. Eastern Band of Cherokee Indians Cultural Institutional Review Board (CIRB)*** Cherokee, NC	**3. Billings Area IHS IRB*** (also known as Rocky Mountain Tribal IRB) Billings, MT https://www.rmtlc.org/rocky-mountain-tribal-institutional-review-board/
4. Choctaw Nation of Oklahoma IRB Idabel, OK	**4. College of Menominee Nation IRB** Keshena, WI	**4. Eastern Band of Cherokee Indians Medical Institutional Review Board (MIRB)*** Cherokee, NC http://www.cherokee-hmd.com/MIRB/index.html	**4. Great Plains Area IHS IRB** (formerly Aberdeen Area IHS IRB) Aberdeen, SD
5. Colorado River Indian Reservation (CRIT) Ethics Review Board Morgantown, AZ http://www.crit-nsn.gov/crit_contents/ordinances/Human-and-Cultural-Research-Code.pdf	**5. Dine College Institutional Review Board** Tsaile, AZ https://warriorweb.dinecollege.edu/ICS/Faculty__Staff/Committees__Taskforces/Institutional_Review_Board	**5. Fond du Lac Band of Lake Superior Chippewa Human Services Division IRB** Cloquet, MN	**5. IHS National IRB** Rockville, MD https://www.ihs.gov/dper/research/hsrp/
6. Eastern Band of Cherokee Indians Cultural Institutional Review Board (CIRB)* Cherokee, NC	**6. Haskell Indian Nations University IRB** Lawrence, KS http://www.haskell.edu/IRB	**6. Gila River Research Review Committee** Sacaton, AZ	**6. Nashville Area IHS IRB** Nashville, TN

Table A1 Continued
Fifty known entities providing research oversight for AI/AN communities as of April 2019

Tribal Nation	Tribal College	Tribally Based or Focused Organization/ Department	Indian Health Service
7. Eastern Band of Cherokee Indians Medical Institutional Review Board (MIRB)* Cherokee, NC http://www.cherokee-hmd.com/MIRB/index.html	**7. Little Big Horn College** Crow Agency, MT	**7. Hopi Cultural Preservation Office*** Kykotsmovi Village, AZ http://www8.nau.edu/hcpo-p/research.html	**7. Navajo Area IHS IRB*** (also known as the Navajo Nation Human Research Review Board) Window Rock, AZ http://www.nnhrrb.navajo-nsn.gov/
8. Fort Peck IRB (formerly Fort Peck Community College IRB) Poplar, MT http://www.fortpeckirb.org	**8. Navajo Technical University Committee on Institution Research (IRB)** Crownpointe, NM http://www.navajotech.edu/academics/committee-on-institution-research	**8. Indian Health Council Inc. IRB** Valley Center, CA	**8. Oklahoma City Area IHS IRB** Oklahoma City, OK
9. Ho-Chunk Nation IRB Black River Falls, WI http://www.ho-chunk nation.com/Laws/Title3-HealthAndSafety/3HCC3%20Tribal%20Research%20Code%2005.05.05.pdf	**9. Northwest Indian College IRB** Bellingham, WA http://www.nwic.edu/wp-content/uploads/2017/03/IRB-Manual-2013-12-02.pdf	**9. Rocky Mountain Tribal IRB*** (also known as Billings Area IHS IRB) Billings, MT https://www.rmtlc.org/rocky-mountain-tribal-institutional-review-board/	**9. Phoenix Area IHS IRB** Phoenix, AZ
10. Hopi Cultural Preservation Office* Kykotsmovi Village, AZ http://www8.nau.edu/hcpo-p/research.html	**10. Oglala Lakota College IRB and Institutional Animal Care and Use Committee** Kyle, SD http://www.olc.edu/administration/committees/irb.htm	**10. Southwest Tribal IRB** Albuquerque, NM http://www.mynarch.net/SW_Tribal_IRB.aspx	**10. Portland Area IHS IRB** Portland, OR http://www.npaihb.org/health-research/
11. Muscogee (Creek) Nation McAlester, OK http://www.creeksupremecourt.com/wp-content/uploads/T22-NCA10-124.pdf	**11. Salish Kootenai College** Pablo, MT http://irb.skc.edu/		**11. Tucson Area IHS IRB** Tucson, AZ
12. Navajo Nation Human Research Review Board* (also known as Navajo Area IHS IRB) Window Rock, AZ http://www.nnhrrb.navajo-nsn.gov/	**12. Sitting Bull College IRB*** (also known as Standing Rock Sioux Tribe IRB) Fort Yates, ND https://sittingbull.edu/sitting-bull-college/community/institutional-review-board/		

continued on next page

Table A1 Continued
Fifty known entities providing research oversight for AI/AN communities as of April 2019

Tribal Nation	Tribal College	Tribally Based or Focused Organization/ Department	Indian Health Service
13. Oglala Sioux Tribe Research Review Board Pine Ridge, SD	**13. Southwestern Indian Polytechnic Institute Institutional Review Board (SIPI IRB**) Albuquerque, NM https://www.sipi.edu/apps/ pages/index.jsp?uREC_ID=8 29035&type=d&pREC_ID= 1308738		
14. Pascua Yaqui Tribe Research Review Committee Tucson, AZ http://www.pascuayaqui-nsn.gov/_static_pages/tribal codes/	**14. Stone Child College IRB** Box Elder, MT http://www.stonechild.edu/i mages/PDFs/Stone_Child_C ollege_IRB.pdf		
15. Sisseton-Wahpeton Oyate Local Research Review Board Sisseton, SD http://www.swo-nsn.gov/ departments/department-of-education/research-office/	**15. United Tribes Technical College IRB** Bismarck, ND https://uttc.edu/institutiona l-review-board/		
16. Standing Rock Sioux Tribe IRB* (also known as Sitting Bull College IRB) Fort Yates, ND https://sittingbull.edu/sittin g-bull-college/community /institutional-review-board/			
17. The Confederated Tribes of the Colville Reservation Business Council Nespelem, WA https://www.colvilletribes.c om/archives-records			

Table A1 Continued
Fifty known entities providing research oversight for AI/AN communities as of April 2019

Tribal Nation	Tribal College	Tribally Based or Focused Organization/ Department	Indian Health Service
18. The Confederated Tribes of the Coos, Lower Umpqua, and Siuslaw Indians Tribal Council Coos Bay, OR https://ctclusi.org/assets/57 f698b2c9e22cf96e000003.p df			
19. Tohono O'odham Nation Institutional Review Board Sells, AZ http://tolc-nsn.org/docs/ Title17Ch8.pdf			
20. Turtle Mountain Band of Chippewa Indians Research Review Board Belcourt, ND http://www.tnrg.org/researc h-protection.html			
21. White Earth Nation Research Review Committee White Earth, MN http://www.whiteearth.com /data/upfiles/files/Judicial% 20Services/ILB%20code.pdf			

^Information in this table was compiled from several sources (Indian Health Service, n.d.-b; United States Office for Human Research Protections (OHRP), n.d.; Arizona Biomedical Research Commission, 2016; California Rural Indian Health Board, n.d.-b; Montana State University, n.d.), but primarily the IHS IRBs website, the OHRP database of Registered IRBs, and the Montana State University website listing of Tribal College IRBs. There are likely additional entities responsible for AI/AN research oversight not shown in this table, and it should not be interpreted as an exhaustive list. Additionally, hyperlinks were only included for entities that have a public web presence via their own webpage or direct links to their policies, codes, or procedures.

*Designates an entity that falls under two categories, and therefore is listed twice, but is counted only once. For example, the Navajo Nation Human Research Review Board/Navajo Area IHS IRB falls within the *Tribal Nation* and *Indian Health Service* categories; however, it is a single entity only counted once for the count shown in the table's title.

DEVELOPING AN INDIGENOUS MEASURE OF OVERALL HEALTH AND WELL-BEING: THE WICOZANI INSTRUMENT

Heather J. Peters, PhD, Teresa R. Peterson, EdD, and the Dakota Wicohan Community

Abstract: A Native community developed the Wicozani Instrument, a 9-item self-report measure, to assess overall health and well-being from an Indigenous epistemology. The Wicozani Instrument measures mental, physical, and spiritual health and their importance to an individual's quality of life. The instrument's validity and reliability was examined through two studies. Study 1 utilized standardized measures from Native (i.e., Awareness of Connectedness Scale) and Western (i.e., Psychological Sense of School Membership and Suicide Ideation Questionnaire) epistemologies with Native and non-Native youth. Study 2 utilized a community created measure (i.e., Indigenous Healing Strategies Scale) with Dakota women. Results suggest the Wicozani Instrument is valid and reliable. The development of an Indigenous measure of overall health and well-being addresses Western atomistic frameworks, which often perpetuate the perception of Native identity as a risk factor for poor health, and works to disrupt the Cycle of Native Health Disparities.

INTRODUCTION

Wicozani (i.e., overall health and well-being) has long been a central factor in Dakota life ways. Despite the long standing importance of health and well-being, the decimation of Native culture and life ways, through colonization and assimilation policies, and subsequent historical trauma (Mohatt, Thompson, Thai, & Tebes, 2014) have been linked to health disparities[1] between Natives and the broader United States population (e.g., Espey et al., 2014; Minnesota Department of Health, 2014). These health disparities persist despite mental and physical health professionals' efforts and funding from government agencies, foundations, and universities dedicated to addressing these health disparities, in part because of the use of measurement tools and interventions created from Western paradigms. Persistent health disparities have created a state in

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[1] According to the U.S. Department of Health and Human Services (USDHHS, n.d.) disparity refers to the "differences in health outcomes that are closely linked with social, economic, and environmental disadvantage - are often driven by the social conditions in which individuals live, learn, work, and play" (p. 4).

which Native identity is perceived as a risk factor for poor health, in turn, leading to prescriptive stereotypes, an external locus of control, learned helplessness, and a self-fulfilling prophecy, which perpetuates these health disparities. To address these problems, and disrupt the Cycle of Native Health Disparities (see Figure 1), a Dakota community created the Wicozani Instrument to assess overall health and well-being from an Indigenous paradigm.

Figure 1. The Cycle of Native Health Disparities
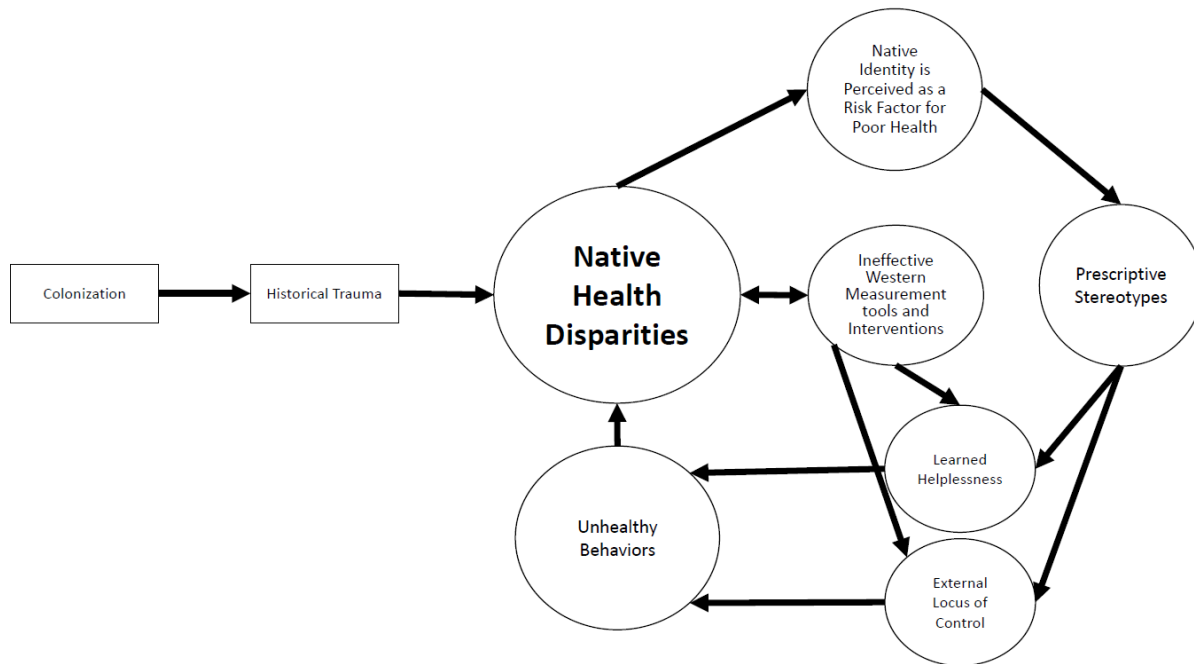
Colonization led to historical trauma and subsequent health disparities between Native communities and the broader U.S. population. Health professionals and researchers have primarily used Western-based measurement tools and interventions to address the health disparities. These ineffective strategies have led to the persistence of health disparities in Native communities. The persistence of these health disparities has created a state in which Native identity is perceived as a risk factor for poor health, which, in turn, leads to prescriptive stereotypes and subsequent external locus of control and learned helplessness. The Western-based measurement tools and interventions also directly contribute to a Native person's learned helplessness and external locus of control. Individuals with learned helplessness and external locus of control engage in unhealthy behaviors that perpetuate the health disparities between Native communities and the broader U.S. population.

One of the reasons health disparities between Natives and the broader U.S. population persist today is that most government, foundation, and university researchers and health providers approach their work from a Western, rather than the Native communities', paradigm. Paradigms are the beliefs (i.e., ontology, epistemology, axiology, and methodology) that guide the actions of researchers when developing and testing measurement tools and interventions. For example, most researchers and health professionals attempt to address a health disparity in a Native community

by using culturally adapted interventions, designed for and normed from non-Native populations, or culturally based interventions, designed for specific Native cultural groups (Allen et al., 2011). Although both of these approaches include cultural content and activities, the measurement tools, intervention, and content of the intervention are all grounded in a Western theoretical system (Allen et al., 2011). Approaching health disparities in Native communities from a Western paradigm is problematic.

The Western ideology used to create most measurement tools and interventions can never be truly removed, even when measurement tools and interventions are culturally adapted or culturally based. Complete removal of Western ideology is challenging because Western beliefs (e.g., individualism, rationalism, dualism, objectivity, universal truths) are often incompatible with Indigenous beliefs (e.g., collectivism, relationality, subjective knowledge, multiple truths or realities; Bear, 2000; Burnette & Billiot, 2015). For example, Western ideology indicates that objective experts can use the scientific method to uncover universal truths, whereas Native ideology indicates that all people have valuable subjective knowledge and multiple realities and truths co-exist. These paradigms are fundamentally incompatible and produce drastically different interventions. For example, an intervention from Western ideology would likely focus on treating the individual who has the health problem, whereas an intervention from Native ideology would likely work with the individual along with their family, community, and environment. Case in point, Barker, Goodman, and DeBeck (2017) recently wrote that suicide interventions that stem from Western approaches, which often focus on individual frameworks, are ineffective, and a growing body of research indicates they are culturally discordant. Incompatibilities such as these leads to distrust of measurement tools, interventions, and people associated with these efforts. Further, use of Western-based measurements and interventions intentionally or unintentionally impose Western values, beliefs, and systems of care upon Native individuals, families, and communities (Goodkind et al., 2011) and serve as a further means of colonization (Lucero, 2011). The use of mainstream measurement tools and interventions can also be seen as an infringement on Native sovereignty and a violation of Native self-determination (Nebelkopf & Wright, 2011). Further, creating measurement tools and interventions without Native involvement privileges the dominant mainstream researchers' perspectives and relegates Native practice professionals and participants to the receiving end of the research dissemination process. These factors help explain why health disparities in Native communities still exist.

The persistence of health disparities in many Native communities has created a state in which simply being Native is considered a risk factor for poor health (e.g., diabetes, suicidality, obesity, substance abuse, coronary heart disease). Perceiving a person's Native identity as a risk factor attacks the person's culture and is in direct opposition to how many Native people view their culture as a source of strength. Further, most health professionals and researchers perceive health and culture as unrelated concepts even though Indigenous researchers have called for the use of cultural revitalization to create health equity for Indigenous populations (e.g., Blaisdell, Denniston, & Miller, 1998; Eggington, 2012). Unfortunately, rather than viewing Native culture as integral to health and part of the solution, most health professionals and researchers perceive Native identity and culture as a risk factor for poor health. These messages, when seen and heard often enough, actually begin to prescribe future unhealthy behaviors. Prescriptive stereotypes falsely inform individuals how a specific group should think, feel, and behave (Terborg, 1977), thus leading to a self-fulfilling prophecy (Madon, Jussim, & Eccles, 1997; Merton, 1948). For example, when a Native youth consistently hears "Native people are overweight and have diabetes," they may begin to believe that their Native identity has sentenced them to a life of obesity and diabetes. This belief leads to an external locus of control (Rotter, 1966), the belief that their behavior has no impact on their health, as well as learned helplessness (Seligman, 1975), learning that they are helpless and unable to affect their health. Thus, Native youth may see no reason to engage in healthy behaviors and may more easily fall prey to the appeal of unhealthy behaviors, thereby increasing the likelihood of poor health. We contend the ineffective use and over reliance on Western-based measurement tools and interventions have contributed to the consistent health disparities between Natives and the broader U.S. population and created a state in which Native identity is perceived as a risk factor for poor health, which in turn, leads to prescriptive stereotypes, external locus of control, learned helplessness, and a self-fulfilling prophecy which further perpetuates these health disparities (see the Cycle of Native Health Disparities, Figure 1).

Research and theories support connections between the variables found in the Cycle of Native Health Disparities. For example, higher levels of external locus of control predict higher levels of stress, depression, intake of junk food, substance abuse, and physical illness symptoms (Gore, Griffin, & McNierney, 2016). This research clearly links external locus of control to poor health outcomes. Other researchers have demonstrated the influence of health professionals' stereotypes on individual patient's learned helplessness. For example, elderly persons accepted nurses' negative stereotypes (i.e., elderly patients are dependent, psychopathological, and sick)

and, as a result, became more passive and developed learned helplessness (Solomon, 1982). The Theory of Reasoned Action (Fishbein & Ajzen, 1975) and its successor, the Theory of Planned Behavior (Ajzen 1991), provide theoretical support for the Cycle of Native Health Disparities. Health professionals and researchers should understand that colonization, historical trauma, and social determinants of health, and not Native identity, contribute to health disparities found in Native communities.

Western approaches, which perceive Native identity as a risk factor for poor health, work from a deficit-based model by focusing on the negative (e.g., diabetes, suicide), thus perpetuating the prescriptive stereotypes and the very health disparities they are trying to address. Further, Western approaches typically place power in the hands of the perceived experts (e.g., doctor, researcher, nurse, or psychologist), which further contributes to an external locus of control and learned helplessness. Additionally, Western approaches tend to address one health disparity at a time and predominantly use "objective" measures (e.g., weight, blood pressure, suicidal ideation) to evaluate a Native person's health. The Western approach often disempowers Native people, both individually and collectively, and devalues their strengths and ways of knowing.

To address the above mentioned problems, and to disrupt the Cycle of Native Health Disparities, a Dakota community used an Indigenous paradigm to create the Wicozani Instrument, a 9-item self-report measure. To support this work funding was secured from the Collaborative Research Center for American Indian Health (CRCAIH). This project aligned with CRCAIH's vision to "promote collaborative research partnerships with tribal communities, research institutions, and health care entities through capacity building to conduct innovative research that improves American Indian health" and core values (i.e., transdisciplinary, sustainability, and tribal sovereignty). For example, this project supported tribal sovereignty by utilizing CRCAIH's Tribal IRB Toolkit, located at https://crcaih.org/irb-toolkit.html, to create an IRB process that Dakota Wicohan now uses when new research is being proposed or previous research is being disseminated.

In Dakota language, *wicozani* means overall health and well-being. From a strength-based approach, the Dakota co-researchers focused on overall health and well-being, rather than on measuring a specific health disparity. By focusing on overall health and well-being, rather than on ailments and sickness, individuals have space to consider what health looks and feels like. While there is diversity among Native communities, the Wicozani Instrument may appeal to many Native communities because health is defined from an Indigenous perspective, in that it is viewed through a holistic lens and relies upon the understanding of relationality and interdependence between

physical, mental, and spiritual health. Dakota people have always understood the interconnectedness of health. Further, Indigenous ways of knowing indicate that the power belongs in the hands of the individual because everyone has the capability of knowing (e.g., gauging their own level of health), and their perspective is valid. The Wicozani Instrument gives agency to the individual because they, rather than experts, describe how they know if someone's mind, body, and spirit are healthy, and asks the individual to assess their own mental, physical, and spiritual health and to indicate how important these aspects are to their quality of life.

Members from the Dakota Wicohan community expressed being tired of health practitioners defining, measuring, and viewing their health solely through a deficit-based lens and wanted the opportunity to define health for themselves, assess their own health, and determine its importance to their quality of life. This paper describes the development and preliminary validation of the Wicozani Instrument. The validity and reliability of the Wicozani Instrument was assessed in two studies. Study 1 utilized standardized Native and Western measures with Native and non-Native youth whereas Study 2 utilized a community created measure with Dakota women.

GENERAL METHOD

Overview

In both studies, we assessed the validity and reliability of the Wicozani Instrument. We will provide an overview of our research team and the Wicozani instrument followed by descriptions of each of the studies' methods, materials, and results.

Research Team

Dakota Wicohan research partners and a research team used Indigenous epistemologies and Community Based Participatory Action Research to inform their work. Dakota Wicohan research partners included several staff, elder advisors, and board members, all from the Dakota community. The research team, consisted of the two primary investigators (i.e., one Dakota, one European American) and six research assistants (i.e., two Dakota, one biracial Dakota and European American, three European American). The Dakota research partners shaped all phases of the research projects (e.g., conceptualization, design, data collection, data analysis, and writing).

Materials

The Wicozani Instrument

The Wicozani Instrument was created in order to measure the impact Dakota Wicohan programming (e.g., Wikoska & Wiciyena, girl leadership programs; Koska, boy leadership program; Sunktanka Wicayuhapi, they care for horses program; Tiwahe, family gatherings) had on community members' *wicozani*. Dakota Wicohan research partners wanted to create a simple measure that was easily accessible to both youth and elders. After numerous discussions with Dakota research partners and Dakota Wicohan community members, the two primary investigators proposed an instrument and sought feedback from the Dakota Wicohan research partners. This collaborative process resulted in the Wicozani Instrument, a 9-item measure (see Appendix A) that is grounded in Indigenous paradigms such as focusing on *wowasake*, an individual's strengths, valuing the individual's self-knowledge, and the Dakota concept of *wicozani*, overall health and well-being. Overall health and well-being from a Dakota perspective emphasizes the relationality and interconnectedness of mental, physical, and spiritual health. Interconnectedness between mental, physical, and spiritual health acknowledges that when one aspect of health is affected, all aspects of health are affected. Thus, the concept of *wicozani* recognizes interdependency as a crucial relational aspect of health.

Individuals were asked to answer, in writing, the question, "How does someone know if their "Mind" is healthy (your thoughts and emotions)?" Then they were asked, "How do you rate your mental health" on a 5-point scale ranging from *extremely poor* (1) to *excellent* (5). Individuals were asked to answer the same questions for their body and physical health and for their spirit (your religious or spiritual beliefs) and spiritual health. Lastly, individuals were asked to indicate "How important is your mental health to your quality of life?" on a 5-point scale ranging from *very unimportant* (1) to *very important* (5). Individuals were asked to answer the same question for their physical health and spiritual health. The Wicozani Instrument has two subscales. The first, the Wicozani Self-Knowledge subscale, consists of three items (questions two, four, and six) and assesses an individual's perception of their *wicozani*, their current overall health and well-being. The second, the Importance of Wicozani to Quality of Life subscale, consists of three items (questions seven, eight, and nine), is the antecedent subscale, and assesses how important an individual's *wicozani* is to their quality of life. The antecedent subscale was designed to capture an individual's desire for overall health and well-being.

DATA ANALYSIS

One research assistant entered data directly into a statistical software program called, Statistical Package for the Social Sciences (SPSS). A second research assistant cleaned the data. The validity and reliability of the Wicozani Instrument was examined through the use of Pearson correlations, coefficient alphas, and paired-samples *t*-tests.

Study 1

Overview

Study 1 examined the relationship between the Wicozani Instrument and the Awareness of Connectedness Scale (ACS; Mohatt, Fok, Burket, Henry, & Allen, 2011), the Psychological Sense of School Membership Scale (PSMM; Goodenow, 1993), and the Suicidal Ideation Scale (SIQ; Reynolds, 1988). The ACS was chosen because it incorporates the Lakota concept of *mitakuye oyas'in*, the awareness of connectedness to family, community, and environment. This concept mirrors the Dakota philosophy of *mitakuye owas'in*, which loosely translates as 'all my relatives' and conveys the interconnectedness between all things. The PSMM was chosen because sense of belonging is a central feature of Indigenous worldview (Wilson, 2008), and the very fabric of Dakota culture is based on relationality (Deloria, 1998; Friesen et al., 2015). Further, researchers contend that sense of belonging is important to everyone because it is a basic human function and a component of well-being that leads to positive emotions, behaviors, and outcomes (Hagerty, Lunch-Bauer, Patusky, Bouwsema, & Collier, 1992; Strayhorn, 2012). The SIQ was chosen because American Indian youth have the highest rate of suicide-related fatalities in Minnesota and in the nation (Centers for Disease Control & Prevention, 2010; Minnesota Department of Health, 2014). Thus, suicide in Native communities is the type of health disparity that health professionals have been trying to address primarily from a Western perspective. Further, we wanted to explore if using an Indigenous measure of overall health could be used in place of a Western measure, which puts the power in the hands of perceived experts rather than Indigenous people, takes a deficit rather than a strengths-based approach, focuses on one health disparity (i.e., suicidal ideation) instead of the interconnectedness of health, and uses an "objective" measure rather than a measure that taps into Indigenous peoples' self-knowledge. Lastly, from a Dakota epistemology, strong *wicozani* and suicidal ideation cannot co-exist.

Method

Participants

Dakota Wicohan's Board of Directors, the partnering school, and the university's institutional review board approved Study 1. Participants included sixth and tenth grade social studies students. The school partner was located within a rural/tribal community area in Minnesota and at the time of the study had a 25.7% Native and 65.6% White student population (Minnesota Department of Education, 2014). A total of 147 students, 93 sixth-grade students (age $M = 11.17$, $SD = .423$; 47 females, 44 males, 2 missing data) and 54 tenth-grade students (age $M = 15.21$, $SD = .412$; 28 females, 26 males), completed the in-class questionnaire (i.e., the Wicozani Instrument, ACS, PSMM, and demographic information). The sixth-grade students identified their racial and ethnic backgrounds as Native ($n = 23$), Native and European American ($n = 1$), Native and another cultural background ($n = 5$), European American ($n = 57$), Latino American ($n = 1$), African American ($n = 1$), or other ($n = 1$). Four sixth-grade students had missing racial and ethnic background data. The tenth-grade students identified their racial and ethnic backgrounds as Native ($n = 10$), Native and European American ($n = 9$), Native and another cultural background ($n = 2$), European American ($n = 31$), or Latino ($n = 2$). Students who indicated that they had either full Native cultural background or biracial Native cultural background were combined into one Native American group for data analysis. Students who had missing cultural background data ($n = 4$) or whose cultural background was something other than Native or European American ($n = 10$) were excluded from analyses. All students in the sixth and tenth grade social studies classes were invited to complete the SIQ either before or after school. Twenty-five of the 147 students (17.0%) completed the SIQ (20 sixth-grade students; 12 Native, 8 European American, and 5 tenth-grade students; 5 Native, 0 European American).

Materials

Awareness of Connectedness Scale. The Awareness of Connectedness Scale (ACS) (Mohatt et al., 2011) is a 12-item scale which is grounded in Indigenous philosophies such as the Yup'ik concept of *ellanaq*, the Lakota concept of *mitakuye oyas'in*, and general knowledge of pan-Indian concepts such as the medicine wheel. The scale uses a Likert-style scoring system with five options ranging from *not at all* (1) to *a lot* (5). The ACS assesses awareness of self as a member of a broader human and natural community, including an awareness of connections between one's own well-being and the well-being of other entities in the various ecological spheres that one occupies. The ACS assesses the degree to which a person endorses the concept of interrelatedness between

self, family, community, and natural environment. The scale includes two-item Awareness-Individual and Awareness-Family subscales, and four-item Awareness-Community and Awareness-Natural Environment subscales. Cronbach's alpha for the final 12-item ACS was an acceptable .85. Alpha coefficients for the 4-item subscales were in the conventionally acceptable range (Nunnally & Bernstein, 1994), but alphas for the 2-item subscales were lower (.54 and .61).

Psychological Sense of School Membership. The PSSM was developed by Goodenow (1993) to measure belongingness within schools. All 18 items of the PSSM were written in a 5-point Likert format, with choices ranging from *not at all true* (1) to *completely true* (5). The PSSM total scale was initially tested through three separate studies with internal reliability Cronbach alpha coefficients of .88, .88, and .82 (Goodenow, 1993). The PSSM subscales were tested through exploratory and confirmatory factor analyses. The Cronbach's alpha scoring provided the following results: perceptions of caring adult relationships .73, acceptance or belongingness at school .72, and rejection or disrespect .70, indicating internal reliability (You, Ritchey, Furlong, Shochet, & Boman, 2011). These studies also found good predictive and construct validity.

Suicide Ideation Questionnaire. The Suicidal Ideation Questionnaire (SIQ) screens people for severity or seriousness of suicidal ideation (Reynolds, 1988). There are two self-report forms: a 30-item version designed for 10th- to 12th–grade students, named SIQ, and a 15-item version originally designed for seventh- to ninth-grade students, named the SIQ-JR. Although the SIQ-JR was originally designed for youth between the ages of 12-14 years, it has been used with other adolescents as well (Hovey & King, 1996; Sieman, Warrington, & Magano, 1994). The questionnaire utilizes a Likert-style scoring system with seven options ranging from *I never had this thought* (0) to *almost every day* (6). The SIQ-JR has been utilized with American Indian adolescents (e.g., Keane, Dick, Bechtold, & Manson, 1996; LaFromboise, Medoff, Lee, & Harris, 2007; Novins, Beals, Roberts, & Manson, 1999). The SIQ-JR had a test retest reliability of .89 over approximately three weeks (Reynolds & Mazza, 1999). The SIQ-JR was found internally consistent (α = .96) in a sample of Native American boarding school high school students (Dick et al., 1994).

Procedure

The superintendent of the school partner sent letters and e-mails to all parents/guardians describing the purpose of the study, information regarding what and when data would be collected, and the voluntary nature of participation. Students completed the Wicozani Instrument, ACS, PSSM, and demographic information during class. Research assistants provided directions for filling out the questionnaire, answered any student questions, and explained that participation was

voluntary. Survey completion times ranged from ten to twenty minutes. Students needing assistance with reading or writing completed the questionnaire with the help of a paraprofessional. After students completed the questionnaire, the research assistant invited them to complete the SIQ/SIQ-JR outside of class. Parents/guardians completed and returned a consent form prior to their student(s) completion of the SIQ/SIQ-JR. Students had four opportunities, either before or after school, to complete the SIQ/SIQ-JR. The following protocol was initiated once a student completed the SIQ/SIQ-JR. Dakota researchers scored the SIQ/SIQ-JR. If an adolescent scored at or above the cut off scores for the SIQ/SIQ-JR, or endorsed a specific number of critical items, Dr. Peters, a licensed psychologist and one of the primary investigators, was notified and performed an immediate assessment utilizing the Teen Suicide Risk Assessment Worksheet and the Risk Factor Checklist for Teen Suicidal Behavior and Suicide (King, Foster, & Rogalski, 2013). When imminent risk was identified a parent/caregiver, along with an appropriate local authority (i.e., school counselors and or tribal social services department), were informed of the student's suicidal ideation, and a referral was made to a mental health professional for a more comprehensive suicide risk assessment. Additionally, Dr. Peters, mailed a follow-up letter to the parent/caregiver that included local mental health resources along with additional information (e.g., local resources; Questions to Ask about Suicidal thoughts; Suicide Prevention Resources for schools; Suicide Warning Signs for Parents; Tips for Communicating with Teens; King et al., 2013). If no imminent risk was present, Dr. Peters provided the individual with referral information and encouraged them to talk to their parent/caregiver and a school counselor.

Results

The means, standard deviations, and intercorrelations for questions two (i.e., mental health), four (i.e., physical health), six (i.e., spiritual health), seven (i.e., importance of mental health to quality of life), eight (i.e., importance of physical health to quality of life), and nine (i.e., importance of spiritual health to quality of life) on the Wicozani Instrument are presented in Table 1 for Native ($n = 50$) and European American ($n = 88$) students. Internal consistency reliability was examined for the Wicozani Self-Knowledge subscale (i.e., questions two, four, and six) with a coefficient alpha of .79 for Native students, which is acceptable, and .80 for European American students, which is good. Internal consistency reliability was examined for the Importance of Wicozani to Quality of Life subscale (i.e., questions seven, eight, and nine) with a coefficient alpha of .74 for Native students, which is acceptable and .66 for European American students, which is

questionable. A paired-samples *t*-test was conducted to compare Native students' scores on the Wicozani Self-Knowledge subscale (*M* = 2.88, *SD* = .78) and the Importance of Wicozani to Quality of Life subscale (*M* = 3.39, *SD* = .59), *t*(49) = -6.95, *p* = .00. A paired-samples *t*-test was conducted to compare European American students' scores on the Wicozani Self-Knowledge subscale (*M* = 2.85, *SD* = .84) and the Importance of Wicozani to Quality of Life subscale (*M* = 3.34, *SD* = .63), *t*(85) = -5.62, *p* = .00. For both groups, participant scores were significantly higher on the Importance of Wicozani to Quality of Life subscale than the Wicozani Self-Knowledge subscale.

Table 1
Means, standard deviations, and intercorrelations of the Wicozani Instrument's questions

Question	*M*	*SD*	1	2	3	4	5	6
Native Students (*N* = 50)								
1. Mental health	2.84	.89	-	.55***	.66***	.51***	.48***	.52***
2. Physical health	2.92	.85		-	.47**	.58***	.54***	.27
3. Spiritual health	2.88	1.04			-	.49***	.47**	.72***
4. Imp. of mental	3.40	.73				-	.49***	.57***
5. Imp. of physical	3.46	.61					-	.43**
6. Imp. of spiritual	3.32	.82						-
European American Students (*N* = 88)								
1. Mental health	2.81	.99	-	.55***	.58***	.34**	.13	.15
2. Physical health	2.99	.94		-	.57**	.03	.29**	.22*
3. Spiritual health	2.76	1.04			-	.34**	.23*	.53***
4. Imp. of mental	3.43	.68				-	.31**	.47***
5. Imp. of physical	3.48	.69					-	.45***
6. Imp. of spiritual	3.08	1.05						-

Note. Higher scores for items one through three indicates a higher self-rating of that aspect of health. Higher scores for items four through six indicates a higher perceived importance of that aspect of health to their quality of life.
* *p* < .05. ** *p* < .01. *** *p* < .001.

The Wicozani Self-Knowledge subscale score had a significant positive correlation with the ACS total scale and all ACS subscales for both Native (*r*'s ≥ .32, *p*'s ≤ .02) and European American students (*r*'s ≥ .23, *p*'s ≤ .04; see Table 2). The Importance of Wicozani to Quality of Life subscale score had a significant positive correlation with the ACS total scale and all ACS subscales for both Native (*r*'s ≥ .35, *p*'s ≤ .01) and European American students (*r*'s ≥ .36, *p*'s ≤ .001; see Table 2).

Table 2
Intercorrelations between the Wicozani Instrument's subscales and the ACS

Question	1	2	3	4	5	6	7
Native Students (*N* = 50)							
1. Wicozani Self-Knowledge	-	.74***	.59***	.32*	.41**	.59***	.61***
2. Imp. of Wicozani		-	.58***	.35*	.53***	.55***	.57***
3. ACS Total			-	.83***	.75***	.95***	.90***
4. ACS Family				-	.50***	.77***	.59***
5. ACS Individual					-	.65***	.64***
6. ACS Community						-	.76***
7. ACS Natural Environment							-
European American Students (*N* = 88)							
1. Wicozani Self-Knowledge	-	.41***	.56***	.23*	.40***	.56***	.53***
2. Imp. of Wicozani		-	.54***	.44***	.36**	.47***	.43***
3. ACS Total			-	.74***	.77***	.95***	.89***
4. ACS Family				-	.43***	.69***	.50***
5. ACS Individual					-	.72***	.59***
6. ACS Community						-	.78***
7. ACS Natural Environment							-

Note. Wicozani Self-Knowledge = Wicozani Self-Knowledge subscale; Imp. of Wicozani = Importance of Wicozani to Quality of Life subscale; ACS = Awareness of Connectedness Scale.
* *p* < .05. ** *p* < .01. *** *p* < .001.

For Native students the Wicozani Self-Knowledge subscale score and the Importance of Wicozani to Quality of Life subscale score had a significant positive correlation with the PSSM total scale and two PSSM subscales (*r*'s ≥ .29, *p*'s ≤ .05). For European American students the Wicozani Self-Knowledge subscale score and the Importance of Wicozani to Quality of Life subscale score had a significant positive correlation with the PSSM total scale and all three PSSM subscales (*r*'s ≥ .23, *p*'s ≤ .05; see Table 3).

For Native students, the Wicozani Self-Knowledge subscale score had a significant negative correlation with the SIQJR (*n* = 12, *r* = -.58, *p* = .05) and a negative correlation that approached significance with the SIQ (*n* = 5, *r* = -.87, *p* = .06). For Native students the Importance of Wicozani to Quality of Life subscale had a significant negative correlation with the SIQ (*n* = 5, *r* = -.93, *p* = .02) and a non-significant correlation with the SIQJR (*n* = 12, *r* = -.45, *p* = .12). For European American students, the SIQJR had a negative non-significant correlation with the Wicozani Self-Knowledge subscale (*n* = 7, *r* = -.44, *p* = .32) and a negative correlation that approached significance with the Importance of Wicozani to Quality of Life subscale (*n* = 8, *r* = -.69, *p* = .06).

Table 3
Intercorrelations between the Wicozani Instrument's subscales and the PSSM

Question	1	2	3	4	5	6
Native Students (*N* = 50)						
1. Wicozani Self-Knowledge	-	.74***	.52***	.35*	.53***	.24
2. Imp. of Wicozani		-	.45**	.29*	.47**	.16
3. PSSM Total			-	.78***	.85***	.74***
4. PSSM Caring Relationship				-	.59***	.50***
5. PSSM Acceptance					-	.36**
6. PSSM Rejection						-
European American Students (*N* = 88)						
1. Wicozani Self-Knowledge	-	.41***	.58***	.44***	.61***	.25*
2. Imp. of Wicozani		-	.42***	.48***	.23*	.23*
3. PSSM Total			-	.78***	.86***	.77***
4. PSSM Caring Relationship				-	.54***	.47***
5. PSSM Acceptance					-	.45***
6. PSSM Rejection						-

Note. Wicozani Self-Knowledge = Wicozani Self-Knowledge subscale; Imp. of Wicozani = Importance of Wicozani to Quality of Life subscale; PSSM = Psychological Sense of School Membership.
* *p* < .05. ** *p* < .01. *** *p* < .001.

Study 2

Overview

Study 2 examined the relationship between the Wicozani Instrument and the Indigenous Healing Strategies Scale (Peterson, Peters, & the Dakota Wicohan Community, 2013). The Dakota Wicohan research partners decided to create their own scale to measure the influence of their programing on concepts important to the Dakota Community. This approach is similar to other successful social movements led by local and grassroots Indigenous peoples who have accessed their own ideas and cultural practices (Smith, 1999) rather than utilizing colonial methods and strategies. Dakota Wicohan's program strategies are rooted in decolonizing and revitalizing approaches that aim to restore cultural traditions and language use among individuals, families, and community. Dakota Wicohan's program strategies are designed to facilitate *kiksuya* (remembering), *kiyuwaste* (reclaiming), and *kiciyuwaste* (reconnecting) to Dakota history,

language, relatives, and relationship to *Mni Sota Makoce*[2]. It was important to Dakota Wicohan leadership to gauge both participant's desire to engage in a behavior and their actual engagement in a behavior, in these three areas (i.e., *kiksuya*-remembering, *kiyuwaste*- reclaiming, and *kiciyuwaste*- reconnecting) in order to evaluate programming effectiveness. Further, the Dakota Wicohan community believes that the actual behavior of reclamation (i.e., returning value to something that has been devalued) of cultural lifeways and values positively contributes to *wicozani*. Thus, we expected correlations between the Wicozani Self-Knowledge subscale and the Indigenous Healing Strategies subscales, that measure actual engagement in a behavior, and no correlations with the Indigenous Healing Strategies subscales, that measure participant's desire to engage in a behavior. Considering many believe the stripping away of cultural lifeways have contributed to historical trauma and health disparities, there is reason to believe the reintroduction of cultural lifeways will bring about healing and address health disparities.

Method

Participants

Dakota Wicohan's Board of Directors and the university's institutional review board approved Study 2. Participants included 35 women, who were members of the Dakota Wicohan community, (age $M = 40.7$, $SD = 14.8$) and ranged in age from 18 to 73 years of age.

Materials

The Indigenous Healing Strategies Scale. The Indigenous Healing Strategies Scale has three sections, *kiksuya* (remember), *kiyuwaste* (reclaim), and *kiciyuwaste* (reconnect). Each section is comprised of two parts: desire to engage in a behavior (i.e., do you want to) and actual engagement in a behavior (i.e., do you actually). Section 1 asks participants, "In your day to day life to what degree do you want to (or actually) *kiksuya* (remember): Remember our Dakota history; Remember our Dakota language; Remember our Dakota relatives; and Remember our relationships to Mnisota makoce (our land)?" Section 2 asks participants, "In your day to day life what degree do you want to (or actually) *kiyuwaste* (reclaim; i.e., recover, redeem, restore): Reclaim our Dakota language; Reclaim our Dakota life ways; Reclaim our relationship with land; and Reclaim our relationship with people?" Section 3 asks participants, "In your day to day life to what degree do you want to (or actually) *kiciyuwaste* (reconnect; i.e., reconcile, heal, made whole

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[2] *Mni Sota Makoce* translates to the land that reflects the skies or land of cloudy waters and is used to refer to the land in Minnesota.

again) with: Reconnect with myself as a Dakota person; Reconnect with our *tiwahe* (family); Reconnect with our *tiospaye* (extended family); Reconnect with our *oyate* (Dakota community); and Reconnect with our Global Indigenous community?" Participants answered each question on a 6-point scale ranging from *never* (1) to *very frequently* (6). The questions related to desire to engage in a behavior (i.e., do you want to) were combined within each of the three sections resulting in three Indigenous Healing Strategies Desire (IHSD) subscales: IHSD Kiksuya ($n = 4$, remember); IHSD Kiyuwaste ($n = 4$, reclaim); and IHSD Kiciyuwaste ($n = 5$, reconnect). The questions related to actual engagement in a behavior (i.e., do you actually) were combined within each of the three sections resulting in three Indigenous Healing Strategies Actual Engagement (IHSAE) subscales: IHSAE Kiksuya ($n = 4$, remember); IHSAE Kiyuwaste ($n = 4$, reclaim); and IHSAE Kiciyuwaste ($n = 5$, reconnect).

Procedure

At a Tiwahe[3] gathering, women from the Daktoa Wicohan community were invited to fill out a questionnaire that included demographic information, the Wicozani Instrument, and the Indigenous Healing Strategies Scale. Research assistants provided directions for filling out the questionnaire, answered any questions, and explained that participation was voluntary. Participants were not requested to sign a consent form given the history of broken treaties between Indigenous communities and government agencies. The women took the questionnaires home and returned them within a two-week period.

Results

The means, standard deviations, and intercorrelations for questions two (i.e., mental health), four (i.e., physical health), six (i.e., spiritual health), seven (i.e., importance of mental health to quality of life), eight (i.e., importance of physical health to quality of life), and nine (i.e., importance of spiritual health to quality of life) on the Wicozani Instrument are presented in Table 4 ($N = 35$). Internal consistency reliability was examined for the Wicozani Self-Knowledge subscale (i.e., questions two, four, and six) with a coefficient alpha of .72, which is acceptable, and the Importance of Wicozani to Quality of Life subscale (i.e., questions seven, eight, and nine) with a coefficient alpha of .98, which is excellent. A paired-samples *t*-test was conducted to compare participants' scores on the Wicozani Self-Knowledge subscale ($M = 2.90$, $SD = .61$) and

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[3] Tiwahe (family) gatherings are one of Dakota Wicohan's programs, rooted in the strategy of reclaiming and reconnecting family through social gatherings (e.g., meals, fun, and social events rooted in language).

the Importance of Wicozani to Quality of Life subscale ($M = 4.30$, $SD = 1.29$), $t(33) = -6.09$, $p = .00$. Participant scores were significantly higher on the Importance of Wicozani to Quality of Life subscale than the Wicozani Self-Knowledge subscale.

Table 4
Means, standard deviations, and intercorrelations of the Wicozani Instrument's questions

Question	M	SD	1	2	3	4	5	6
1. Mental health	3.18	.63	-	.44**	.71***	-.12	-.12	-.14
2. Physical health	2.44	.93		-	.35*	-.17	-.06	-.19
3. Spiritual health	3.09	.70			-	.04	-.06	.07
4. Imp. of mental	4.34	1.14				-	.94***	.98***
5. Imp. of physical	4.23	1.14					-	.92***
6. Imp. of spiritual	4.40	1.14						-

Note. Higher scores for items one through three indicates a higher self-rating of that aspect of health. Higher scores for items four through six indicates a higher perceived importance of that aspect of health to their quality of life.
* $p < .05$. ** $p < .01$. *** $p < .001$.

The Wicozani Self-Knowledge subscale score had significant positive correlations with all three IHSAE subscales (r's $\geq .37$, p's $\leq .03$) and non-significant correlations with all three IHSD subscales (r's $\leq -.34$, p's $\geq .053$; see Table 5). The Importance of Wicozani to Quality of Life subscale had non-significant correlations with all IHSAE and IHSD subscales (r's $\leq -.06$, p's $\geq .75$; see Table 5).

Table 5
Intercorrelations between the Wicozani Instrument's Subscales and the Indigenous Healing Strategies Scale

Question	1	2	3	4	5	6	7	8
1. Wicozani Self-Knowledge	-	-.11	.02	.37*	.25	.53**	.34	.53**
2. Imp. of Wicozani		-	.03	-.06	-.00	-.05	-.05	-.13
3. IHSD *Kiksuya*			-	.49**	.62***	.21	.69***	.44**
4. IHSAE *Kiksuya*				-	.56**	.69***	.39*	.55**
5. IHSD *Kiyuwaste*					-	.42*	.56**	.50**
6. IHSAE *Kiyuwaste*						-	.27	.51**
7. IHSD *Kiciyuwaste*							-	.82***
8. IHSAE *Kiciyuwaste*								-

Note. Wicozani Self-Knowledge = Wicozani Self-Knowledge subscale; Imp. of Wicozani = Importance of Wicozani to Quality of Life subscale; IHSD = Indigenous Healing Strategies Desire subscale; IHSAE = Indigenous Healing Strategies Actual Engagement subscale; *Kiksuya* = remember; *Kiyuwaste* = reclaim; *Kiciyuwaste* = reconnect.
* p < .05. ** p < .01. *** p < .001.

DISCUSSION

The results from Study 1 and Study 2 provide evidence of the reliability and validity of the Wicozani Instrument and the usefulness of assessing *wicozani*, overall health and well-being, from an Indigenous epistemology. Results indicate that Native and European American youth and Dakota Women perceive a strong inter-relationality between mental, physical, and spiritual health, providing empirical evidence for the Dakota concept of *wicozani* (overall health and well-being). The idea that overall health or well-being is reflective of physical, spiritual, and mental health is in line with other definitions of holistic health (Matthews, Kilgour, De Rossi, & Crone, 2011). Regarding reliability, the coefficient alpha scores for Native and European American youth and Dakota women suggest adequate to good internal consistency for the Wicozani Self-Knowledge subscale and adequate to excellent internal consistency for the Importance of Wicozani to Quality of Life subscale. The consistent results, between the Wicozani Instrument and the ACS and PSSM, across Native and European American youth, except for one PSSM subscale, provides evidence that the Wicozani Instrument possesses external validity. The measure possesses strong face validity because on the surface it appears to measure (i.e., *wicozani*, overall health and well-being) what it does measure (i.e., mental, physical, and spiritual health). The Wicozani Instrument demonstrates strong convergent validity in that its subscales correlated with measures (i.e., ACS, PSSM, SIQ, IHSAE subscales) that it should theoretically correlate with. Further, as expected, the Wicozani Instrument demonstrates discriminant validity because both subscales did not significantly correlate with the IHSD subscales. This finding is in line with Dakota worldview because desire to engage in a behavior, in and of itself, will not improve health. Together, these findings provide evidence of the reliability and validity of the Wicozani Instrument.

Although only a few Native ($n = 17$) and European American ($n = 8$) youth completed the SIQ, three out of the six possible correlations were significant. Further, the non-significant correlations ranged from moderate (e.g., - .44) to quite strong (e.g., -.87; Evans, 1996). These results demonstrate, in line with Dakota worldview, a strong inverse relationship between suicidality and *wicozani*. Thus, preliminary evidence suggests, youth at risk for suicidal ideation may be identified from a strengths-based approach by focusing on *wicozani* and using the Wicozani Instrument. However, given the small sample size further research is warranted before health professionals begin using the Wicozani Instrument in place of currently used measures of suicidal ideation.

The fact that only 17% of youth who completed the Wicozani Instrument completed the

SIQ highlights some advantages of taking a strengths- versus deficit-based approach. Specifically, our school partner allowed the administration of the Wicozani Instrument during class but required that the SIQ be administered outside regular school hours. Further, IRB protocols required parental consent and student assent before completion of the SIQ but not the Wicozani Instrument. Further, stigma regarding suicidal ideation still exists (e.g., Scocco, Castriotta, Toffol, & Preti, 2012) and may have prevented youth participation. Thus, our results suggest that taking a strengths-based approach (e.g., overall health and well-being; the Wicozani Instrument) is more appealing to community partners, provides more data, and is less stigmatizing than taking a deficit-based approach (e.g., health disparity; SIQ).

The significant differences found between participants' scores on the Wicozani Self-Knowledge subscale and the Importance of Wicozani to Quality of Life subscale can be used to facilitate healthy behaviors and address health disparities from an Indigenous perspective. For example, health professionals often work from a Western approach (i.e., value expert opinion and objective data) when they provide empirical evidence as to why Native people or communities should eat healthy foods, exercise, or monitor their glucose levels. Alternatively, from an Indigenous perspective, health professionals could incorporate the Native person's self-knowledge and subjective truth. By completing the Wicozani Instrument participants demonstrate to themselves that they believe their *wicozani* is important to their quality of life, yet they rate their *wicozani* lower than its importance. Thus, health professionals can illicit from the client information about why and how their *wicozani* is important to their quality of life and strategies they would like to engage in to increase their *wicozani*. This approach is in line with some of the central tenants of motivational interviewing, such as raising awareness of the discrepancy between the goal and actual behavior, an emphasis on personal choice, and facilitating change. Motivational interviewing is an effective strategy for increasing healthy behaviors (Miller & Rollnick, 1991) and suggests the usefulness of the Wicozani Instrument and its potential positive impact on Native people and their communities.

The Wicozani Instrument begins to disrupt the Cycle of Native Health Disparities. Specifically, the Indigenous view of multiple realities is at the center of the Wicozani Instrument in that each person has the opportunity, and ability, to define what a healthy mind, body, and spirit mean to them. Giving Native people the opportunity to create their own definitions and factors of health, and valuing their perspective and knowledge, gives the individual power to create their own narrative, identify where they are at on their continuum of health, and take ownership over

their health. This strengths-based approach, which focuses on overall health and well-being, facilitates Native people seeing themselves as healthy and as having the ability to build on existing areas of healthy behavior. Further, this approach assumes that Native people innately possess strength and "a natural capacity for behaving, thinking, or feeling in a way that allows optimal functioning and performance in the pursuit of valued outcomes" (Linley & Harrington, 2006, p. 88). This agency begins to disrupt the external locus of control and learned helplessness that has emerged from decades of health professionals perceiving Native identity as a risk factor for poor health. After witnessing the negative impact health care workers' prescriptive stereotypes had on elderly residents, Solomon (1982) recommended that health care workers be educated in order to destroy the myths and work in a growth-oriented context. These recommendations are similar to our calls for health professionals to stop perceiving Native identity as a risk factor for poor health and to begin viewing culture as integral to Native health and part of the solution to health disparities.

Limitations and Future Research

One limitation of the two studies is that the populations included participants from two Native communities from a limited geographical area. Further, the composition of our non-Native youth were all European American. This over- and under-representation of identities within society is problematic. Thus, future researchers should replicate this work with different Native and non-Native communities. Although the findings between the Wicozani Instrument and the SIQ were strong, only 17% of youth completed the SIQ. Thus, further research is warranted before health professionals begin using the Wicozani Instrument in place of currently used measures of suicidal ideation. Additionally, future researchers should examine the relationship between the Wicozani Instrument and other measures of health disparities, which are less stigmatizing than suicidal ideation, in an attempt to gather more participation. Also, future researchers could utilize qualitative approaches to work with community and health professionals to gather feedback regarding their perspectives of the Wicozani Instrument. A next step for our research team entails examining the qualitative data provided on the Wicozani Instrument, specifically, participants' definitions of a healthy mind, body, and spirit (i.e., "How does someone know if their Mind (body or spirit) is healthy"). Lastly, although, we focused on an Indigenous-based measurement tool, there is great need for cultural interventions (Allen et al., 2011) that disrupt the Cycle of Native Health Disparities and focus on the actual causes of health disparities (e.g., colonization, historical

trauma, social determinants of health) rather than the symptoms.

CONCLUSION

The results demonstrate the Wicozani Instrument is a valid and reliable measure of overall health and well-being, is in line with Native epistemology, and disrupts the Cycle of Native Health Disparities. Taking an Indigenous, rather than Western approach, to address health disparities can begin changing the current perception that Native identity is a risk factor for poor health and disrupt the ensuing cycle of prescriptive stereotypes, external locus of control, learned helplessness, and the self-fulfilling prophecy which perpetuates health disparities between Natives and the broader U.S. population. Further, the Wicozani Instrument begins to address the frustration of those who feel like they are overly-measured solely by narrowly-defined and compartmentalized instruments (e.g., weight, blood pressure). The Wicozani Instrument focuses on overall health and well-being through a holistic lens and relies upon the understanding of relationality and the interdependence between physical, mental, and spiritual health. This instrument gives health professionals an additional measurement tool that places the power in the hands of the individual, values their ways of knowing, and views their perspective as valid. Further, health professionals can use the discrepancy between a participant's Wicozani Self-Knowledge subscale score and their Importance of Wicozani to Quality of Life subscale score, to increase an individual's internal motivation for healthy behavior change. Additionally, the Wicozani Instrument, because of its strengths-based approach and focus on overall health and well-being, was more appealing to our community partners, provided more data, and was less stigmatizing than the deficit-based approach which focused on suicidal ideation. Approaches which place Native people and their ideologies at the center of the solution, rather than on the receiving end of Western ideology and health care, support a movement of decolonization and reclamation of Native identity and epistemologies as strengths and facilitate effective approaches that align with community-defined health and well-being.

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Appendix A

The Wicozani Instrument

Please complete each question to the best of your ability.

1) How does someone know if their *"Mind"* is healthy? (your thoughts and emotions)

_____

_____

2) How do you rate your "*mental health*" (please circle)? (your thoughts and emotions)

Extremely Poor	Below Average	Average	Above Average	Excellent
1	2	3	4	5

3) How does someone know if their *"body"* is healthy?

_____

_____

4) How do you rate your "*physical health*" (please circle)? (your body)

Extremely Poor	Below Average	Average	Above Average	Excellent
1	2	3	4	5

5) How does someone know if their *"spirit"* is healthy? (your religious or spiritual beliefs)

_____

_____

6) How do you rate your *"spiritual health"* (please circle)? (your religious or spiritual beliefs)

Extremely Poor	Below Average	Average	Above Average	Excellent
1	2	3	4	5

7) How important is your "*mental health*" to your quality of life (please circle)?

Very Unimportant	Unimportant	Neither Important or Unimportant	Important	Very Important
1	2	3	4	5

8) How important is your *"physical health"* to your quality of life (please circle)?

Very Unimportant	Unimportant	Neither Important or Unimportant	Important	Very Important
1	2	3	4	5

9) How important is your *"spiritual health"* to your quality of life (please circle)?

Very Unimportant	Unimportant	Neither Important or Unimportant	Important	Very Important
1	2	3	4	5

USING GOAL SETTING AND ATTAINMENT TO IMPACT INDICATORS OF HEALTH BEHAVIOR CHANGE AMONG YOUNG AMERICAN INDIAN WOMEN: THE WE RISE (RAISING INCOME, SUPPORTING EDUCATION) STUDY

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Abstract: The purpose of the present study was to assess the association between setting and attaining goals and indicators of health behavior change (psychological general well-being index, self-efficacy, and health locus of control) among young American Indian mothers. A total of 60 women were randomized to either intervention or control. At the end of the 6-month intervention, goal attainment was not significantly associated with the three outcomes of interest. However, resource program contacts and goal track were associated with confidence in completing goals and health locus of control internality, respectively. Lessons learned and future research needs are discussed.

INTRODUCTION

Among both male and female American Indians and Alaska Natives (AI/ANs) across the United States, death rates are approximately 46% higher than Whites (Espey et al., 2014). This is strikingly higher in the Northern Plains, where all-cause mortality is 89% higher among AI/AN males than White males, and 92% higher among AI/AN females than White females (Espey et al., 2014). While decreases in all-cause mortality have been seen among Whites over the past two decades, these decreases have not been seen in the AI/AN population (Espey et al., 2014). The top five leading causes of death among males include heart disease, cancer, accidents, diabetes mellitus, and chronic liver disease, and among females include cancer, heart disease, accidents, diabetes mellitus, and stroke (Espey et al., 2014). Tobacco use, alcohol use, obesity, inactivity, metabolic syndrome, and access to care all contribute to mortality and disparities in mortality between AI/ANs and Whites (Espey et al., 2014).

In addition to individual health behaviors, it is well-documented that socioeconomic status, specifically income and education, is associated with health disparities, especially in minority

populations such as AI/ANs (Robert Wood Johnson Foundation, 2009). These social determinants of health, including income, education, and occupation, are not directly affecting health, per se, but are serving as proxies for other determinants of health (Angell, 1993). Previous research supports that changes in these three factors can lead to positive health behaviors for individuals and potentially their young children (Hanson & Pourier, 2015; Pampel, Krueger, & Denney, 2010). Interventions with potential for the greatest impact are those that address social determinants of health (Galea, Tracy, Hoggatt, Dimaggio, & Karpati, 2011). It is important to give priority to interventions focusing on the health of women of child-bearing age and children to minimize the impact of inequality early on in life (Adler & Newman, 2002). Effective interventions are needed to improve socioeconomic status and reduce the burden of health disparities in Indian Country and should build upon existing frameworks of support.

The goal of the Collaborative Research Center for American Indian Research (CRCAIH) is to "improve AI health through examination of social and environmental influences on health" (CRCAIH, n.d.). More specifically, CRCAIH aims to facilitate and support the development of relationships between tribes and researchers in this space, and to fund pilot work addressing regional AI health issues (CRCAIH, n.d.). Through these efforts, local research professionals from a tribal community and faculty from an 1862 land-grant university were able to build upon existing work and leverage strengths and knowledge to develop and test an innovative intervention intended to tackle underlying factors contributing to health disparities among AIs, while promoting existing community resources and programs.

The We RISE (Raising Income, Supporting Education) Study aimed to improve socioeconomic factors in young AI mothers with an intervention that encouraged setting and attaining goals related to income, occupation, or education, as well as utilization of community resources. The goal of We RISE was to impact beliefs and, ultimately, behaviors related to health, such as locus of control, general well-being, and self-efficacy. Therefore, the purpose of the present study was to assess the association between setting and attaining income-, occupation-, and education-related goals and indicators of health behavior change among young AI women.

METHODS

This randomized controlled trial consisted of an intervention where participants worked with a trained mentor (research staff) to set and attain a goal related to either income (i.e., personal

finance), occupation (i.e., job skills), or education (i.e., advancing education). Additionally, participants utilized a community program from a study-developed resource guide, which contained a brief description of resources available locally, plus contact information. This resource guide was developed in consultation with program representatives from within the community, some of which participated in a study-sponsored poverty and culture training (see O'Leary et al., 2019, in this special issue). Outcomes of interest in the present study included psychological general well-being, self-efficacy, and health locus of control. Study participants provided written consent, and all protocols and procedures were approved by the South Dakota State University Institutional Review Board. Local and regional tribal approval was also obtained.

Participants

To estimate a correlation coefficient of $r = 0.265$ between the intervention groups and the primary and secondary outcome measures with 80% power and a significance level of $\alpha = 0.05$, 60 individuals needed to be recruited ($n = 30$ in each group). Women were eligible for the study if they met the following inclusion criteria: 1) aged 18-30 years, 2) enrolled tribal members, 3) high school graduates, 4) have custody of and living with a child aged 0-12 years, and 5) interested in setting a goal related to job skills, education advancement, or personal finance. Women were not eligible for the study if they had a cognitive disorder impairing them from completing the intervention, if they planned to move out of the area during the study, or if a member from their household was already participating in the study. Participants were recruited through public advertising (including social media), Women Infant and Children (WIC) offices, social service offices, and health care providers in local communities. Participants that met the inclusion criteria and signed the informed consent were randomized to either the intervention or control group using a random number generator that linked participant ID with study group assignment.

Study Design

All participants completed data collection at baseline and six-months post-baseline. At these two study visits, data collection included a questionnaire and brief physical assessment. The questionnaire captured demographics and medical history (Centers for Disease Control and Prevention, 2016) and information related to outcomes of interest. Outcomes of interest included the psychological general well-being index (PGWBI), which was used to determine perceived

general well-being (Chassany, Dimenäs, Dubois, Wu, & Dupuy, 2004) and has been deemed valid and reliable among Northern Plains AIs (Leonardson, 2003). The PGWBI provides a global score (0 to 110) in addition to several sub-scales, including anxiety, depressed mood, positive well-being, self-control, general health, and vitality (Chassany et al., 2004). Self-efficacy encompassed both importance of setting goals and confidence in goal attainment and was assessed using a modified version of a readiness ruler, originally used to determine importance of and confidence in change behavior (Center for Evidence-Based Practices, 2010). Health locus of control was assessed using the Multidimensional Health Locus of Control Scale (Wallston, 2005), which has been used in AI populations previously (Egan et al., 2009) to capture scales for internal, chance, and powerful others. Additionally, height (to the nearest 0.5 cm), weight (to the nearest 0.1 kg), and blood pressure were measured and recorded by trained study personnel.

At the baseline visit, intervention participants also completed a session with a study mentor that included goal setting and developing an action plan. The mentor used motivational interviewing techniques (Miller & Rollnick, 1991) to facilitate an exploration of goals related to education advancement, finances, and job skills and guided participants in choosing a goal that was of interest to them and that would provide the most personal benefit. Education advancement goals included things such as completing college admission paperwork or attaining perfect attendance and a specific grade point average in college courses. Financial goals included reducing debt or starting a savings plan. Examples of occupation-related goals included creating a resume or attaining a certification, such as Certified Nursing Assistant. Intervention participants evaluated attainment of their goal during their final visit.

Two additional study visits occurred at 2- and 4-months post-baseline for intervention participants. At these visits, participants met with a mentor to monitor and document progress toward their goal and make necessary revisions to their action plan. If barriers were encountered, the mentor would use motivational interviewing techniques to help the participant make a plan to overcome barriers. No physical assessments were completed during these visits. Data on goal progress, frequency of resource program contacts, and frequency of support person contacts were collected.

Monetary incentives were provided for completion of study visits. Study participants received $25 per visit for completion of the baseline and final visit. Individuals in the intervention also received $25 per visit for the completion of study visits at 2- and 4-months post-baseline.

RESULTS

All analyses were conducted using Stata version 14.2 for Windows. Differences in demographics between intervention and control groups were examined using independent *t*-tests (continuous variables) and chi-squared tests of independence (categorical variables). Regression analyses were used to examine associations between independent variables and the outcomes of interest. Linear regression was used to determine the association between intervention status and indicators of health behavior change outcomes of interest (perceived general well-being, self-efficacy, and health locus of control), while controlling for baseline value of the outcome. Similarly, linear regression was used to determine the association between indicator of health behavior change outcome of interest and aspects of the intervention (including goal attainment, contacts, and goal track).

Table 1
Study participant demographics at baseline (mean ± SE)

	Control *n* = 30	Intervention *n* = 30	*p*-value
Age (y)	25.7 ± .49	25.9 ± .57	.75
Married (no/yes)	21/9	18/11	.52
Education (HS/HS+)	11/18	15/15	.35
Taking Classes (no/yes)	23/7	23/7	1.0
Employed Full-time (no/yes)	14/16	19/11	.19
Annual Household Income (<6k, 6k+)	12/18	8/22	.27
Social Readjustment Rating Scale	441 ± 151	503 ± 134	.76
Hierarchy of Needs Assessment			
Deficiency Motivators (0-4)	2.5 ± .27	3.0 ± .22	.11
Growth Motivators (0-4)	2.4 ± .24	2.9 ± .23	.17
Total score (0-8)	4.9 ± .44	5.9 ± .40	.09
Global Well-Being (0-110)	73.5 ± 4.1	76.7 ± 3.5	.56
Self-Efficacy			
Important to complete goals	8.6 ± .34	8.8 ± .36	.72
Confident in completing goals	7.6 ± .38	7.5 ± .41	.97
Health Locus of Control			
Internal	28.7 ± 1.1	30.6 ± .76	.17
Chance	19.6 ± .70	18.7 ± 1.1	.47
Powerful Others	21.3 ± .75	22.6 ± 1.1	.37

Continuous variables compared using independent t-test
Categorical variables compared using chi-squared test

Randomization was successful and baseline demographic characteristics did not differ between groups (Table 1). Overall, 52 women completed follow-up data collection ($n = 26$ intervention). At the end of the study, psychological general well-being index, self-efficacy (importance of and confidence in goal setting and attainment), and health locus of control scores and sub-scores did not vary by intervention status (Table 2). Among those in the intervention group, 6-month goal attainment (yes/no) was not significantly associated with the three indicators of health behavior change outcomes of interest.

When examining the association between aspects of the intervention itself and indicators of health behavior change at the end of the study, resource program contacts and goal track emerged as significant for confidence in completing goals and health locus of control internality, respectively (Table 3). As number of resource program contacts increased, so did confidence in goal attainment. And compared to women who set a job skills goal, women who set an education advancement goal had lower internal locus of control scores at the end of the study (32.3 vs. 28.9, $p = .02$). Several other factors approached statistical significance (Table 3).

Table 2
Post-intervention scores (mean ± SE) for indicators of health behavior change outcomes of interest (and their reference values)

	Control $n = 26$	Intervention $n = 26$	*p*-value
Psychological General Well-Being Index			
Anxiety (0-25)	18.3 ± .79	18.4 ± .79	.945
Depressed Mood (0-15)	12.6 ± .47	13.1 ± .47	.492
Positive Well-Being (0-20)	14.5 ± .65	14.4 ± .65	.929
Self-Control (0-15)	11.9 ± .49	12.1 ± .49	.855
General Health (0-15)	12.4 ± .36	12.1 ± .36	.630
Vitality (0-20)	13.5 ± .65	13.6 ± .65	.870
Global Score (0-110)	83.4 ± 2.7	83.5 ± 2.7	.963
Self-Efficacy			
Important to Complete Goals (0-10)	8.6 ± .26	9.0 ± .25	.300
Confident in Completing Goals (0-10)	8.0 ± .29	7.9 ± .28	.738
Health Locus of Control			
Internality (6-36)	30.3 ± .69	29.9 ± .68	.669
External Chance (3-36)	19.4 ± .86	19.6 ± .84	.876
External Powerful Others (6-36)	20.9 ± .83	19.3 ± .83	.193

Linear regression examining significance of intervention status while controlling for baseline value of outcome

Table 3
Coefficients and confidence intervals for intervention aspects and association with indicators of health behavior change outcomes while controlling for baseline value of health behavior change outcome

	4m Goal Attainment	2m Goal Attainment	Support Person Contacts	Resource Program Contacts	Goal Track 1 vs 2	Goal Track 1 vs 3
Perceived General Well-Being Index						
Anxiety	3.1 [-0.22, 6.40]*	1.7 [-1.6, 4.9]	.67 [-1.6, 2.9]	-.97 [-3.4, 1.5]	2.5 [-3.7, 8.6]	2.1 [-1.1, 5.4]
Depressed Mood	0.82 [-1.01, 2.65]	.83 [-.84, 2.5]	.68 [-.46, 1.8]	-.72 [-2.0, .56]	1.6 [-1.8, 5.0]	.87 [-.95, 2.7]
Positive Well-Being	0.59 [-2.08, 3.26]	.77 [-1.6, 3.1]	.09 [-1.6, 1.7]	1.1 [-2.7, .54]	.98 [-3.5, 5.5]	.42 [-3.0, 2.2]
Self-Control	0.94 [-0.77, 2.64]	.58 [-1.0, 2.2]	.05 [-1.1, 1.2]	.88 [-.21, 2.0]	.69 [-2.4, 3.8]	.54 [-2.2, 1.1]
General Health	0.12 [-1.3, 1.5]	.18 [-1.4, 1.1]	.18 [-.72, 1.1]	.07 [-.83, .97]	.09 [-2.3, 2.5]	-.44 [-1.7, .83]
Vitality	0.62 [-1.8, 3.0]	1.4 [-.75, 3.5]	-.70 [-2.2, .82]	-.21 [-1.8, 1.3]	-1.5 [-5.6, 2.6]	-1.5 [-3.7, .66]
Global Score	5.5 [-3.1, 14.1]	4.9 [-2.9, 12.6]	1.3 [-4.3, 6.8]	-1.5 [-7.3, 4.4]	2.7 [-12.8, 18.2]	-.77 [-9.1, 7.6]
Self-Efficacy						
Important to Complete Goals	.42 [-.57, 1.4]	-.31 [-1.3, .63]	.24 [-.41, .89]	.11 [-.55, .77]	.78 [-1.1, 2.7]	.16 [-.79, 1.1]
Confident in Completing Goals	-.13 [-1.3, 1.1]	.79 [-.30, 1.9]	-.03 [-.81, .76]	.82 [.10, 1.5]**	-.67 [-2.8, 1.5]	-.48 [-1.6, .67]
Health Locus of Control						
Internality	-1.5 [-4.4, 1.4]	.76 [-2.1, 3.6]	-.07 [-2.4, 2.3]	1.1 [-.74, 3.0]	-4.1 [-8.6, .40]*	-3.3 [-6.0, -.71]**
External Chance	-.88 [-5.1, 3.3]	.42 [-2.9, 3.8]	-.27 [-2.7, 2.2]	-1.0 [-3.6, 1.5]	-2.7 [-9.6, 4.3]	.16 [-3.9, 4.2]
External Powerful Others	-1.8 [-6.9, 3.2]	-1.5 [-5.8, 2.7]	-2.2 [-4.9, .45]*	2.4 [-.33, 5.2]*	-.37 [-9.1, 8.3]	.09 [-4.8, 5.0]

Goal track 1 = job skills
Goal track 2 = personal finance
Goal track 3 = educational advancement

* *P*-value > .05 & < .10
** *P*-value ≤ .05

DISCUSSION

Interventions that address the root causes of health disparities among AIs are needed. As such, the present study aimed to improve socioeconomic factors in young AI mothers by using motivational interviewing to encourage the setting and attainment of goals related to income, occupation, or education, as well as utilization of community resources. Although participation in

the intervention did not lead to differences in indicators of health behavior change at the end of the study, results do provide useful insight into individual elements of the intervention that should be examined further. Furthermore, suggestions for future research in this area are provided.

Socioeconomic factors, particularly income, occupation, and education, are associated with health disparities experienced by AI/ANs (Robert Wood Johnson Foundation, 2009). Improving socioeconomic status by improving these factors can lead to improved health behaviors (Hanson & Pourier, 2015; Pampel et al., 2010). Because this was a pilot study and only 6-months in duration, indicators of health behavior change that could serve as proxies for longer-term changes in health behavior were assessed. Indicators of health behavior change included an assessment of psychological general well-being index, health locus of control, and self-efficacy related to goal-setting and attainment. These factors were chosen because of their relationship with long-term health behaviors and outcomes (Pampel et al., 2010).

At the end of the study, intervention status was not associated with any of the measured indicators of health behavior change. However, this lack of change may be due to baseline scores being more favorable than anticipated. At the beginning of the study, mean global PGWBI scores were 76.7 in the intervention group (max score being 109 for control group and 108 for intervention group), leaving little room for improvement. Likewise, importance of goal setting was high, as was confidence in completing goals (mean scores were 8.8 and 7.5, respectively). Internal health locus of control was also high (mean of 30.6), while chance was low (mean of 18.7). Together, these assessments speak to the resilience of the study participants – despite disadvantaged situations (as evidenced by social readjustment and rating scale) and low socioeconomic status (as evidenced by income and education), perceived general well-being and internal locus of control can be seen. This should be considered when developing interventions focused on changing socioeconomic factors in this population.

Because the intervention itself was not significantly associated with the chosen indicators of health behavior change, elements of the intervention were explored individually to determine if certain pieces were significant on their own. While 6-month goal attainment itself was not associated with any of the indicators of health behavior change, attainment was relatively low among the 26 intervention completers ($n = 15$). As part of the intervention, goals that were specific, measurable, and achievable with a defined timeline were encouraged. However, the use of motivational interviewing as part of the goal-setting process meant ultimate control of the goal

was up to the participant. As such, not all goals were necessarily achievable for one reason or another. Further development of supports for goal achievement is warranted.

Resource program contact was associated with confidence in goal attainment, such that increased confidence at the end of the study was associated with an increased number of contacts. Perhaps participants who had more contacts with resource programs were better able to utilize their services and supports, thus enhancing confidence. Future work should explore the importance of community-connectedness and social support in interventions aiming to improve social determinants of health among AIs. Goal topic also appears to be important, with higher health locus of control internality seen among women who set a job skills goal compared to those who set an education advancement goal. Job skills goals may have been more attainable in general, and education advancement goals may have had more potential barriers and thus be more difficult to attain. For example, someone may have set an educational advancement goal related to perfect attendance in a college course; however, a seemingly uncontrollable barrier related to childcare or transportation prevented this, thus leaving the individual feeling like they lacked internal control of the situation.

There are limitations to this pilot study. Although a sample size calculation was performed, it assumed that participants would meet the goal that they set; however, only 58% did. Additionally, attrition in the intervention group ($n = 4$) was greater than anticipated, but due to circumstances outside of the control of the study team. These issues likely impacted the ability to determine a significant effect of the intervention on the indicators of health behavior change that were examined. Despite these limitations, this pilot study has strengths, including the uniqueness of its approach in addressing health disparities. This study can provide lessons learned for future research aiming to improve socioeconomic status among disadvantaged populations, including connecting individuals with community resources and focusing on occupation-related achievements. Further data analysis is warranted on variables related to percent of goal attainment to understand factors that promoted or hindered goal attainment.

CONCLUSION

Innovative interventions are needed to address socioeconomic status and, ultimately, health disparities, particularly among young AI mothers. Setting and achieving goals related to advancing income, education, or job skills may be one way to improve socioeconomic status. In a longer or more intensive goal-setting and attainment intervention, with a larger sample size, changes in

indicators of health behavior change may be seen, particularly if goals are focused around job skills. The long-term benefits of changes in internal locus of control as a result of goal attainment need further exploration.

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DEVELOPING THE TRIBAL RESOURCE GUIDE AND THE POVERTY AND CULTURE TRAINING: THE WE RISE (RAISING INCOME, SUPPORTING EDUCATION) STUDY

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Abstract: The We RISE Study aimed to support young American Indian mothers on a tribal reservation by addressing social determinants of health at an individual and community-wide level. To address community-based barriers, the study developed the Tribal Resource Guide, a comprehensive list of available resources that was created through partnerships with community programs and staff. In addition to the guide, the study also developed the Poverty and Culture Training in order to train program staff at numerous community programs to better understand and serve lower socioeconomic and/or Native clients. The two projects facilitated collaboration between community programs and provided tools for programs to address barriers and ultimately better serve their target audience. Despite challenges, the transdisciplinary approach used with the local community maximized potential for success. This process and model could be duplicated in communities with similar demographics, resources, and barriers.

INTRODUCTION

Throughout the United States, there is a great need to address the social, economic, and health disparities and gaps in care that exist among minority populations (Advocates for Human Potential, Inc, 2015; Moghani Lankarani & Assari, 2017). The Collaborate Research Center for American Indian Health (CRCAIH) aims to use a transdisciplinary approach to address these social determinants of health among American Indians (AIs) in the Northern Plains by supporting researchers across disciplines and community members in pilot projects like We RISE (Raising Income Supporting Education).

Poverty poses numerous supply and demand barriers to health service access, which contributes to poor health outcomes (Ensor & Cooper, 2004). Individuals on the lower end of the socioeconomic status (SES) scale are frequently segregated into communities with poorer

resources, fewer opportunities for preventative health care, less general and health education, and worse environmental conditions (Cooper & Mulvey, 2015; Ensor & Cooper, 2004). Resource deficits can be financial, emotional, psychological, spiritual, and physical, including health, mobility, and transportation. These social, health, and resource deficits common on AI reservations are a prime example of how a zip code can be a better predictor of health than genetic code (Seavey, 2008).

American Indian Disparities

These disparities also exist in many tribal communities. Nationally, AIs die at higher rates than other Americans in many categories. For example, AIs die at rates 4.7 times higher from chronic liver disease and cirrhosis, 2.8 times higher from diabetes mellitus, and 1.6 times higher from suicide (Indian Health Service, 2015). In addition to these health disparities, AIs also have a high rate of trauma, violence, unintentional injuries, and substance abuse, which negatively impact health (Companion, 2008). There is a large body of evidence that suggests that racial health disparities and long-term outcomes are associated with socioeconomic conditions over time (Assari, 2018; Companion, 2008; Farmer & Ferraro, 2005; Moghani, Lankarani, & Assari, 2017). An editorial by 14 Native researchers affiliated with the National Institutes of Health calls for "a new approach to health disparities intervention research…that addresses the root causes of health disparities, the disparities in money, power and resources that have existed since colonization in order to improve the health of the AI/AN population" (Blue Bird Jernigan et al., 2015, pp. S376), which is exactly what the innovative We RISE study aimed to do.

Study Background and Significance

Young AI mothers with poor access to resources and, many times, a lack of adequate support systems struggle to promote healthy lifestyles for themselves and their children. However, perhaps it is not only access to resources, but rather lack of understanding of the resources that are available and how to utilize them that hinders the improvement of health disparities (Ensor & Cooper, 2004). Additionally, to compound difficulties in connecting young AI mothers to the resources available to them, community programs unknowingly have common barriers that reduce the utilization of their resources, which often stems from a lack of understanding of poverty and culture.

Because these poverty and health issues are widespread among communities of color, in particular tribal nations, we developed the We RISE study, tailored for AI populations with low SES and poor health outcomes that are underutilizing community programs and resources. The study consisted of three components, each with a unique target audience: 1) the Tribal Resource Guide, targeted for individuals from the community; 2) the Poverty and Culture Training, targeted for the community workforce; and 3) the We RISE intervention, targeted for young AI mothers in the community. The We RISE study used community-based participatory research methods to develop the Tribal Resource Guide, Poverty and Culture Training, and the We RISE intervention, which aimed to impact social factors influencing health behavior through motivational interviewing techniques, goal setting with attainment, and improved utilization of community resources.

Each component of the study had a unique purpose, with an underlying theme of impacting social determinants of health by improving access and utilization of community resources. The Tribal Resource Guide, which included local program contact information and a description of resources, was developed to improve knowledge and utilization of available resources. The Poverty and Culture Training aimed to improve knowledge of poverty and Lakota culture, encourage programmatic changes to increase access and reduce individuals' barriers to resources, and strengthen existing relationships between community programs. The We RISE intervention component is discussed in more detail in a previous article in this special issue (see McCormack et al., 2019). The Tribal Resource Guide was used with the young AI mothers who participated in the We RISE intervention, but because the resources young AI mothers need is essentially the same as the resources needed by the community-at-large, the Tribal Resource Guide was intended to benefit the entire community. Likewise, the Poverty and Culture Training was geared directly to the community program workforce, but the impact of the training is presumed to benefit young AI women in the community. This paper will explain the process and results from both the development and dissemination of the Tribal Resource Guide and the Poverty and Culture Training. An editorial by 14 Native researchers affiliated with the National Institutes of Health calls for "a new approach to health disparities intervention research…that addresses the root causes of health disparities, the disparities in money, power and resources that have existed since colonization in order to improve the health of the AI/AN population" (Blue Bird Jernigan et al., 2015, pp. S376), which is exactly what the innovative We RISE study aimed to do.

METHODS

The concept and design for the We RISE CRCAIH pilot project began with a transdisciplinary partnership between tribal community professionals and researchers at the State's 1862 land-grant university. However, uniquely, this project was driven by local professionals from the tribal community, as opposed to a university or researcher approaching a tribal community with a preconceived intervention that may not meet the community's needs, or lacks cultural relevance. The We RISE team came from diverse disciplines including public health, epidemiology, sociology, American Indian studies, nutrition, and community development. This approach and partnership between the tribal community professionals and the university researchers across disciplines exemplifies the transdisciplinary methods used from concept to dissemination and promotes mutual beneficence for the tribal community, participants, and research team. All protocols and procedures were originally approved by the South Dakota State University Institutional Review Board (IRB) and the Great Plains IRB. Local tribal approval was also obtained.

Target Population

This study was conducted with a Lakota tribal nation, which is languished by extreme poverty (> 25% of families below the federal poverty level) and numerous health disparities, despite a variety of social and health programs available to community members. Located in rural north-central South Dakota, the reservation is roughly the size of Connecticut, with a population density of one to two people per square mile (U.S. Census Bureau, 2017a; U.S. Census Bureau, 2017b). Table 1 identifies demographic and general health data for the two counties that make up the reservation and the state of South Dakota for comparison. Overall, when compared to South Dakota, the population is more rural and has a higher proportion of AIs, unemployment, children in poverty, young people who are not working or in school, and poor housing conditions. The reservation also has a lower proportion of people age 65 years and older, adults with college experience, and lower median household income. Additionally, there are nearly twice as many adults reporting poor or fair health and deaths under age 75 in the study population.

Table 1
Population demographic and general health data

	County A	County B	South Dakota
% Rural	64.1%	73.5%	43.3%
% below 18 years of age	36.6%	32.7%	24.6%
% 65 and older	9.6%	7.5%	16.0%
% American Indian and Alaskan Native	73.2%	71.4%	9.0%
% of adults (age 25-44) with some college	45%	44%	68%
% of population (age ≥16) unemployed but seeking work	8.5%	4.2%	2.8%
% of children in poverty	33%	47%	17%
Median household income	$38,500	$30,800	$54,900
% of population (age 16-24) who are not working or in school	38%	35%	10%
% of households with overcrowding, high housing costs, lack of kitchen or lack of plumbing	19%	24%	12%
% of adults reporting poor or fair health	23%	28%	12%
Number of deaths under age 75 per 100,000	930	510	330

(County Health Rankings & Roadmaps, 2018a; County Health Rankings & Roadmaps, 2018b)

Tribal Resource Guide

Development

The team began by first developing a list of known community programs that offer a variety of resources (i.e., housing, wellness, childcare, and cultural). The team had informal interviews with resource experts in the community to identify programs missing from the list. The final list included 138 programs. Questions were developed by the WeRISE team, local elders, and community stakeholders, to interview representatives from the list of identified community programs. Utilizing community advisors from a variety of disciplines was another form of community-based participatory research. Attempts were made to contact program representatives in administrative positions to obtain the most accurate information, but if this was not possible, other professionals, such as administrative assistants or receptionists, were interviewed. The survey collected contact information, including official program name, person completing survey, phone and fax number, physical address, and webpage or social media pages. Resource questions included, "What resources does your program offer and how can they be accessed?", "Can non-tribal members use your resources?", and "Is there anything else you want us to know about tribal programs or resources?" This final question often resulted in recommendations for other programs to contact that offer resources to the Tribal community. Each representative was also asked to

categorize their program into one of the following: 1) Education & Childcare; 2) Financial; 3) Food & Nutrition; 4) Health & Wellness; 5) Housing, Home Improvements, & Utilities; 6) Leisure & Recreation; 7) Religious; and 8) Legal & Cultural.

A total of 132 interviews from the list of 138 were completed over the course of three months. Six programs on the list were unreachable, and 15 programs interviewed indicated that they do not currently offer a resource; after removing these 117 programs remained. Upon completion of surveys from all local programs willing to participate, data were organized into a guide. Total estimated time to gather and enter surveys was 350 hours. The first version of the Tribal Resource Guide listed programs alphabetically and identified the category(s) to which it was classified with a symbol. Because this tribal nation is home to both tribal members and non-tribal members, resources that were only available to enrolled tribal members were indicated with an asterisk (*).

To further the transdisciplinary approach, the guide was updated at the end of the study based on feedback from intervention participants and key stakeholders from the local community. Changes included the addition of 35 programs that were not originally identified, program descriptions were made more concise, and the guide was reorganized by category then alphabetically to improve usability. This resulted in some programs being listed in more than one category when appropriate. The final 32-page version of the Tribal Resource Guide featured 152 programs, a section for national emergency phone numbers, a section for local emergency phone numbers, and a variety of local photos.

Dissemination

All We RISE intervention participants (McCormack et al., 2019) were provided the Tribal Resource Guide during the study. Six hundred copies of the final Tribal Resource Guide were distributed to the general public and to all the programs featured in the guide. The Tribal Resource Guide was also disseminated online. Project staff contacted local community programs who have a webpage to facilitate sharing of the guide. Partner institutions, including CRCAIH and the subawardee, Missouri Breaks Industries Research, Inc., also shared the guide on their webpage (CRCAIH, n.d.; Missouri Breaks, n.d.). Missouri Breaks Industries Research, Inc. also highlights programs from the guide periodically on social media, with a link to the full Tribal Resource Guide. The online presence allows individuals to download and save or print a copy of the guide. For sustainability of the Tribal Resource Guide, a partner specializing in economic opportunity plans to maintain the document and provide updates as businesses change and evolve. Following local

dissemination, there were requests for additional print copies, so local programs are opting to print additional guides at their own expense, which demonstrates the need for and value of the Tribal Resource Guide.

Poverty and Culture Training

Structure and Content

Another initiative of We RISE was to improve knowledge of Lakota culture and the culture of poverty, encourage programmatic changes to increase access by reducing individuals' barriers to resources, and strengthen existing relationships between community programs by facilitating the Poverty and Culture Training for the local community workforce. A majority of the community members are Lakota and/or facing poverty, so knowledge about the community can translate to improved services. Community programs often struggle to reach their target population because of circumstances that come with poverty and lack of collaboration between programs. For example, some programs opt to discontinue services to individuals who miss three appointments, regardless of the reason for missing the appointment (i.e., no transportation or childcare).

The agenda for the training is provided in the Appendix. The three-and-a-half-hour training was led by local professionals knowledgeable on the subject matter, such as people trained in community leadership and development, trauma-informed care, and Lakota culture. Local professionals were used to maximize community buy-in for the training. The objectives of this training were to 1) educate community program staff on poverty and culture; 2) bring community stakeholders together to network, share resources, and ideas; and 3) discuss effective recruitment and retention strategies that reduce barriers to resources.

The training included concepts tailored to the local community from "A Framework for Understanding Poverty: A Cognitive Approach" by Ruby Payne because the local professional had experience with Ruby Payne's work (Payne, 2005). Case examples focused on reducing the social costs of poverty, strengthening the workforce, and building a more prosperous and sustainable community. A copy of Ruby Payne's framework was provided to each program that attended the training, and participants were encouraged to share the book and concepts from the training with other staff in their program to reach more professionals.

Trauma-informed care, stories of resilience, and the seven Lakota values were also incorporated into the training. Because of the stress and trauma often associated with low income and minority status, discussion on historical trauma of the Lakota, toxic stress, Adverse Childhood

Experiences, and symptoms of trauma was led by project staff to provoke empathy for community members who have experienced trauma. Stories of resilience were then shared to demonstrate the profound ability of the Lakota people to bounce back and break the cycle of trauma. Fostering resilience through relationships and community collaborations was shared as a method for program staff to be part of the solution to enhance community services and empowerment. The Lakota values of courage (*wóohitike*), compassion (*wówauŋšila*), generosity (*wówačhaŋtognake*), wisdom (*wóksape*), patience (*wówačhiŋthaŋka*), respect (*wóyuonihaŋ*), and humility (*wóuŋšiič'iye*) were embedded in the training to demonstrate the application of Lakota culture to better serve our community. Incorporation of Lakota values and acknowledgment of community strengths ensured cultural and community relevance. Symptoms of trauma, resilience, and practicing the Lakota values are essential understandings to a resilient and united community.

Administrators, owners, and leaders of all 138 community resource programs identified on the list developed for the Tribal Resource Guide were invited to the Poverty and Culture Training via postcards and email. After rescheduling twice for inclement weather, the Poverty and Culture Training was held in December 2016. Twelve individuals representing nine different community programs attended the training.

Evaluation

To evaluate short-term outcomes of the training, two surveys were conducted: 1) a pre- and post-evaluation to assess the knowledge of poverty and Lakota culture, and 2) a survey to assess program procedures and policies regarding recruitment and retention which was collected before the training and three months later.

The pre- and post-evaluations were collected before and after the training and included five questions. Two true/false questions were asked: 1) "Poverty is more about a lack of resources than it is about money," and 2) "Relationships and education are key ingredients to help individuals and families living in poverty." Three multiple-choice questions were asked relating to the Lakota values important for community programs to practice, symptoms of trauma, and ways community programs can help individuals build resilience. All 12 participants completed pre- and post-evaluation materials. Percent of correct responses for each question and the mean percent correct from all participants combined was analyzed from the pre- and post-evaluations to assess a change in knowledge (see Table 2).

Table 2
Pre- and post-training evaluation and results

Questions	Responses	Pre-Training Results	Post-Training Results
1. Poverty is more about a lack of resources than it is about money.	a. **True** b. False	a. 12/12 (100%)	a. 12/12 (100%)
2. Relationships and education are key ingredients to help individuals and families living in poverty.	a. **True** b. False	a. 12/12 (100%)	a. 12/12 (100%)
3. Which Lakota values are important for community programs to practice? Select all that apply.	a. **Humility & Patience** b. **Respect & Compassion** c. Prayer & Wisdom d. Fairness & Responsibility	a. & b. 6/12 (50%)	a. & b. 10/12 (83%)
4. Drugs, alcohol, risky sexual behavior, violence and incarceration are...	a. Lifestyle choices b. Examples of moral character c. **Symptoms of trauma** d. None of the above	c. 6/12 (50%)	c. 10/12 (83%)
5. Which component in this list does NOT build resilience?	a. Individual factors, like personality b. **Experiences a person has throughout life** c. Community, such as local resources working together d. Relationships that are stable and supportive	b. 5/12 (42%)	c. 6/12 (50%)
		Mean score: 68%	Mean score: 84%

Bold = correct response

The recruitment/retention survey was collected before the training and three months following the training, with one survey for each program represented. Of the nine programs that completed the initial recruitment/retention survey, eight completed the 3-month follow-up survey online. The survey collected before the training asked six multiple-choice questions and one qualitative open-ended question (question 6). Questions 1-4 each had one response that was coded as favorable and two responses that were coded as non-favorable. Participants were asked to select all that apply for questions 5 and 7; each response selected was coded as favorable. The total favorable responses possible was 13; mean total favorable responses for all programs were reported. A comparison of baseline data and the 3-month recruitment/retention survey data on program policies was analyzed to measure intermediate impact. Three additional multiple-choice questions (questions 8-10) were asked at only 3-month follow-up survey; responses were purely informational and not coded as favorable or non-favorable (see Table 3). Because funding and time constraints did not allow for community input during the design of the training, the participants were allowed to write-in feedback on the training structure and content.

Table 3
Recruitment/retention evaluation and results

Questions	Responses	Training Day Results	3-Month Follow-Up Results
1. Does your program currently have a written process or policy for recruiting or reaching out to community members?	a. **Yes** b. No c. Don't Know	**Yes 5/9 (55%)** No 4/9 (45%)	**Yes 5/8 (63%)** No 3/8 (38%)
2. Does your program currently have a written process or policy for retaining clients to ensure they keep coming back?	a. **Yes** b. No c. Don't Know	**Yes 3/9 (33%)** No 6/9 (67%)	**Yes 5/8 (63%)** No 3/8 (38%)
3. Does your program have a no-show policy? If yes, please explain.	a. Yes b. **No** c. Don't Know	Yes 3/9 (33%) **No 6/9 (67%)**	Yes 2/8 (25%) **No 6/8 (75%)**
4. Does your program currently advertise its services or resources to the general public?	a. **Yes** b. No c. Don't Know	**Yes 6/9 (67%)** No 3/9 (33%)	**Yes 7/8 (88%)** No 1/8 (13%)
5. If yes to previous question, what methods do you currently use to advertise? Select all that apply.	**a. Paid newspaper ad** **b. Free newspaper articles** **c. Radio** **d. Printed materials** (flyers, banners brochures, etc.) **e. Social media** (Facebook, Twitter, etc.)	Mean total advertising methods = 1.89 out of 5 possible	Mean total advertising methods = 4 out of 5 possible
6. What changes, if any, do you plan to make at your place of work to assist customers as a result of the training?	Open response	Highlights in text	
7. Does your program currently offer any of the following services for clients? Select all that apply.	**a. Childcare assistance** **b. Transportation assistance** **c. Snacks or beverages** **d. Scheduling flexibility**	Mean total services = 2 out of 4 possible	Mean total services = 2.63 out of 4 possible
		Mean total favorable responses = 6.11 out of 13 possible	Mean total favorable responses = 9.5 out of 13 possible
Additional 3-Month Follow Up Questions			
What changes, if any, did you make at your place of work to assist customers as a result of the training?	Open response		Highlights in text
What have you done with the Ruby Payne Poverty book since the training? Select all that apply.	a. Read it or parts of it b. Looked through book, but did not read it c. Nothing d. Shared it with others		a. 6/8 (75%) b. 1/8 (13%) c. 1/8 (13%) d. 4/8 (50%)
How much do you feel the training has impacted your work with those in poverty?	a. A lot b. Somewhat c. Not at all d. Not sure		a. 4/8 (50%) b. 3/8 (38%) c. 0 d. 1/8 (13%)
Would you recommend a poverty and culture training like you attended to others?	a. Yes b. No c. Not sure		a. 7/8 (88%) b. 0 c. 1/8 (13%)

Bold = favorable response

RESULTS

Tribal Resource Guide

At the time of publication, a total of 600 printed Tribal Resource Guides have been distributed, reaching all 20 communities on the reservation. Three programs have shared the Tribal Resource Guide on their webpages. Before the We RISE study began, the tribe's webpage identified 29 tribal programs with limited descriptions and contact information. As a result of the resource guide being posted on the tribe's webpage, all 50 tribal programs that offer a resource and 102 other non-tribal programs are now identified with accurate and up-to-date information and descriptions of resources. As a result of online dissemination, one other Tribe in the region recognized the need for and value of a Tribal Resource Guide and sought advice and assistance to replicate the We RISE process to create a guide specific to their reservation.

Poverty and Culture Training

According to the pre- and post-evaluations, knowledge of poverty and Lakota culture, determined by the percent of correct responses, went from 68% before the training to 84% after the training (Table 2). Each participating program was assigned a total number of favorable responses before the training and three months after the training for comparison. One program did not complete the 3-month follow-up survey, two programs showed no change in favorable responses, and six programs showed an increase in favorable responses. Of the 13 possible favorable responses on the recruitment/retention survey, the mean favorable responses for all participating programs went from 6.11 before the training to 9.5 at the 3-month follow-up (Table 3).

Program representatives who participated in the Poverty and Culture Training were asked what policy or protocol changes they made as a result of the training. Two programs established a new written process or policy for retaining clients to ensure they keep coming back, which was encouraged during the training. One program reported initiation of advertising services or resources to the general public, and several others reported expanding advertising services, which was also encouraged at the training. Additionally, 75% of respondents reported reading the Ruby Payne book or parts of it, and 50% shared it with a colleague. When asked if the training had impacted their work with those in poverty, 88% said "a lot" or "somewhat," and 88% indicated they would recommend the training to others.

DISCUSSION

Together, the Tribal Resource Guide and Poverty and Culture Training facilitated connecting individuals to resources, and it supported community programs to collaborate and interact with individuals more effectively. The process of disseminating details on resources in a user-friendly guide and training the community workforce on poverty and culture were relatively simple and low-cost approaches to addressing a community need. These approaches were not without barriers, but the overall impact exceeded the difficulties faced.

Tribal Resource Guide

Barriers

Barriers experienced in development of the Tribal Resource Guide include inconsistencies and changes in reported services, miscategorized programs, and dissemination challenges. Identifying all the community programs that offer a resource and staying informed about the continuous changes in resource availability was a challenge. This is why it was important to keep a list of changes needed and additions to the first version of the guide. The continuous changes are often due to variable funding from short-term grants or donations, as well as changes in administration and program goals. The initial plan for dissemination included an area on the local Chamber of Commerce webpage that would allow searching for resources by keyword, eligibility, or category. Due to staff turnover, this was not able to be accomplished. However, We RISE project staff are committed to working with future Chamber of Commerce personnel to make this plan a reality as soon as possible.

Successes

A great strength to the We RISE project is that it was conducted on a reservation that has many existing resources that were simply underutilized. Compiling, organizing, and disseminating the Tribal Resource Guide generated the opportunity for the entire community to learn about available resources and access them more easily. We RISE intervention participants, Poverty and Culture Training participants, and community program staff interviewed for the development of the Tribal Resource Guide consistently reported enthusiasm that the guide was developed because of the great need for community members to know what resources are available to them to increase utilization of community programs. Of the program staff who were interviewed, many expressed feelings that "no one knows what we do here." For many of the community programs, getting a

new client in the door created opportunities for expansion and reach on both an individual and community level. Community members also benefit through improved accessibility to resources.

Poverty and Culture Training

Barriers

Winter weather negatively impacted the number of programs that were able to participate in the Poverty and Culture Training, as many that were pre-registered were unable to attend, which is an unfortunate, but common, barrier in rural communities. Additionally, we were unable to get all of the programs who participated in the training to complete the online 3-month follow-up recruitment/retention evaluation.

Successes

The programs that were represented at the Poverty and Culture Training had the opportunity to learn from each other and discuss possibilities for collaboration. Fostering discussion on poverty and culture enables partners to work together in addressing mutual barriers. The Poverty and Culture Training facilitated collaboration and a better understanding among the various community programs, which provided them with tools to ultimately better serve their target population. The bottom line is that without open conversations, nothing changes. One participant commented, "I believe all tribal officials, department heads, and state programs working within the reservation should attend a poverty training."

When asked about program changes made as a result of the training (Table 3, question 6), one program stated, "[Staff are] more understanding of barriers people face due to poverty. [Staff] work harder to reduce barriers within the organization so interested persons can participate in meetings and events." Another program stated, "Being understanding and flexible with scheduling is much more effective for retention. Also, staff have a better appreciation for the circumstances that come with poverty."

CONCLUSION

Collaborating with community program staff and key stakeholders to develop and disseminate the Tribal Resource Guide and providing a culturally appropriate training on poverty were effective methods of using CRCAIH's transdisciplinary approach to community-based participatory research in this Lakota community. As a result of this partnership between the local

tribal community and the university, transdisciplinary research capacity was enhanced for the tribal community and the university-based research professionals. It is plausible that this process and model could be duplicated in communities with similar demographics, resources, challenges, values, and needs.

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APPENDIX

Poverty and Culture Training Agenda

12:45 PM   Pre-Surveys

1:00 PM   Welcome, Prayer, Introductions, & Ice Breaker

1:15 PM   Understanding who we are and where we come from: Poverty and barriers to relationships

- Poverty defined
- Resource continuum
- Hidden rules of poverty
- Emotional deposits and withdrawals

2:15 PM   Trauma, resilience & Lakota culture

- Trauma – Historical trauma of the Lakota, toxic stress and Adverse Childhood Experiences (ACE's)
- Symptoms of trauma
- Resilience – what it is, how it's built, why it's important to the community
- Lakota values – what they are, how programs can use them, why they are important to the community

3:00 PM   Break

3:15 PM   Breaking down silos discussion

- What Lakota values can we use as professionals to break down silos in our community?
- What changes can be made to meet the needs of community members living in poverty?

3:45 PM   Where we go from here

4:15 PM   Post-Surveys

4:30 PM   Closing

WAC'INYEYA: HOPE AMONG AMERICAN INDIAN YOUTH

Jacqueline S. Gray, PhD, Lisa Schrader, Devon S. Isaacs, BA, Megan K. Smith, MA, and Naomi M. Bender, PhD

Abstract: This article examines what gives American Indian youth hope. The project included 56 rural tribal youth in focus groups across a Northern Plains reservation. The participants completed a Youth Personal Balance Tool to provide perspective on the balance according to a medicine wheel model of their lives. The focus groups asked questions from a strengths-based perspective about what gives them hope and how they could show others they were hopeful. The project culminated with the youth developing creative representations of hope and presenting these projects to family and community.

INTRODUCTION

Wac'inyeya means "strong youth" in Lakota. Taking the perspective of what makes the youth strong, this study focused on "hope" and what gives Native youth hope. Many times research projects focus on the problems that impact people and society; however, in indigenous communities we, as researchers, hear from community members the need to focus on the resiliency of the people and what helps them be strong during adversity. With this perspective in mind, we gathered information on the factors that promote well-being and hope for indigenous youth.

Suicide Among American Indian Youth

Suicide disproportionately affects the American Indian (AI) population in the United States. Among AI communities, suicide is the second leading cause of death (Gray & McCullagh, 2014). Among the 18 states in the National Violent Death Reporting System (NVDRS), the American Indian/Alaska Native (AI/AN) rate was 350% higher than other racial/ethnic groups (Leavitt et al., 2018), and AIs aged 15-34 years of age complete suicides at a rate that is 150% higher than the general population (Centers for Disease Control and Prevention [CDC], 2013). Further, when compared with youth across all races in the United States, the suicide completion rates among AI youth aged 15-24 years old is two times more for AI males and three times more

for AI females (CDC, 2013). In particular, one Northern Plains tribe had a suicide rate of 60 per 100,000, which is 465% the national rate of 12.9 per 100,000 (CDC, 2015; Oglala Sioux Tribe Suicide Task Force, 2016). Suicide rates for other groups typically increase with age, whereas suicide rates are the highest among AI youth and actually decrease with age (Gray & Mason, 2014).

These daunting statistics highlight the importance of research that addresses the epidemic of suicide among AI youth. However, research that investigates the positive aspects of AI communities is severely lacking. O'Keefe, Tucker, Wingate, and Rasmussen (2011) expressed the need for research that focuses on factors that decrease suicide rather than examining the factors that increase suicide risk. Therefore, this study sought to explore positive characteristics of hope that serve as protective factors in AI communities.

Construct of Hope

To address the paucity of positive research, the current study sought to investigate hope among AI youth that could be protective factors against suicidality. Several protective factors have been identified for AI youth. Chandler and Proulx (2006) found that higher cultural continuity resulted in lower suicide rates among AI youth. Cultural continuity was defined as a tribal community having the ability to maintain cultural ties to the history of their tribe and the amount of tribal self-government they possessed. This suggests that AI youth who perceived a connection with their tribal ancestry and sovereignty of their tribe had lower rates of suicide. Similarly, Borowsky et al. (1999) found that connectedness with family and discussing problems with their family and friends were protective factors for AI youth against suicide attempts. Most notably, however, this study found that increased protective factors were more effective in reducing the probability of suicide attempts than were decreasing risk factors. This points to the need for research that focuses on positive attributes that can be used as protective factors for AI youth. O'Keefe and Wingate (2013) suggested using positive psychology as a tentative theoretical framework to investigate possible protective factors for AI youth. Specifically, it was suggested that the relationships among hope, optimism, and suicidal behavior should be examined (Wingate et al., 2006).

Snyder and Lopez (2002) define hope as a person's belief that they can find pathways to their goals, and this results in motivation for using these pathways. Further, they posit that these hopeful thoughts motivate the emotions and well-being of a person. Studies that have examined

this relationship have found that higher levels of hope were associated with lower levels of suicidal ideation in AI youth (O'Keefe et al., 2011; O'Keefe & Wingate, 2013). This suggests hope as a potential protective factor. Previous research has found that hope moderates the relationship between rumination and suicidal ideation (Tucker et al., 2013), and hope negatively predicts burdensomeness and belongingness, which is connected to suicidal ideation (Davidson Wingate, Rasmussen, & Slish, 2009). Conversely, previous research has found that hopelessness about thwarted belongingness, perceived burdensomeness, and hopelessness about these constructs predicted variance in suicide risk and suicidal ideation (Tucker et al., 2013. This research further highlights the relationship of hope to suicidality. Hope has been researched in AI communities, and researchers have found similar results. O'Keefe and Wingate (2013) found that higher hope ratings were correlated with lower thwarted belongingness, perceived burdensomeness, and suicidal ideation. Further, higher levels of hope were correlated with higher levels of acquired capability.

This research suggests that hope is a potential factor related to preventing suicidality and promoting well-being for AI communities. Many AI communities, however, follow a well-being model that is holistic in nature and is grounded in the balance of interpersonal relationships and in the natural and spiritual world (Rountree & Smith, 2016). Since the medicine wheel is important in the beliefs and understanding of the tribe collaborating with the research, we sought to view the assessments and outcomes around the cultural tenants of this tribe. In following the holistic worldview of AI communities in the Northern Plains, the current study used the conceptualization of the medicine wheel employed by Barraza, Bartgis, and the Fresno Native Youth Council (2016) as part of the Fresno American Indian Health Project (2014). The medicine wheel is comprised of the four directions representing lifespan (i.e., infancy, childhood, adulthood, elderhood) and areas of wellbeing (i.e., mental, physical, emotional, spiritual; See Figure 1.). Further, the techniques of community-based participatory research (CBPR) were used in order to maintain a collaborative process with harmony and balance between the AI community and the researchers.

Culturally Responsive Methodology in AI Suicide Research

Joseph Trimble, arguably one of the foremost advocates of ethical cross-cultural research in AI communities, wrote extensively about critical methodology issues in Indian Country (Trimble, 1977). In his work, the researcher is described as a "sojourner," or person who resides temporarily within AI communities. The researcher is, in the majority of cases, an outsider who

must build relationships and earn trust throughout the research process. As such, certain "guiding assumptions" must be understood by the researcher (Whitbeck, 2006). These include resisting the urge to Pan-Indianize cultures that are quite heterogeneous; understanding that Indigenous-specific knowledge is a valuable ally in prevention work and is not inferior to Euro-centric epistemologies; that population-specific risk and protective factors must be considered in the context in which they both exist and interact; that ownership is key to successful prevention work; and that many AI youth desire to understand their identity and experiences within the context of cultural knowledge (Whitbeck, 2006).

Figure 1. The Medicine Wheel as viewed among the plains tribes is fluid with the sectors blending into one another. The figure below illustrates this concept.
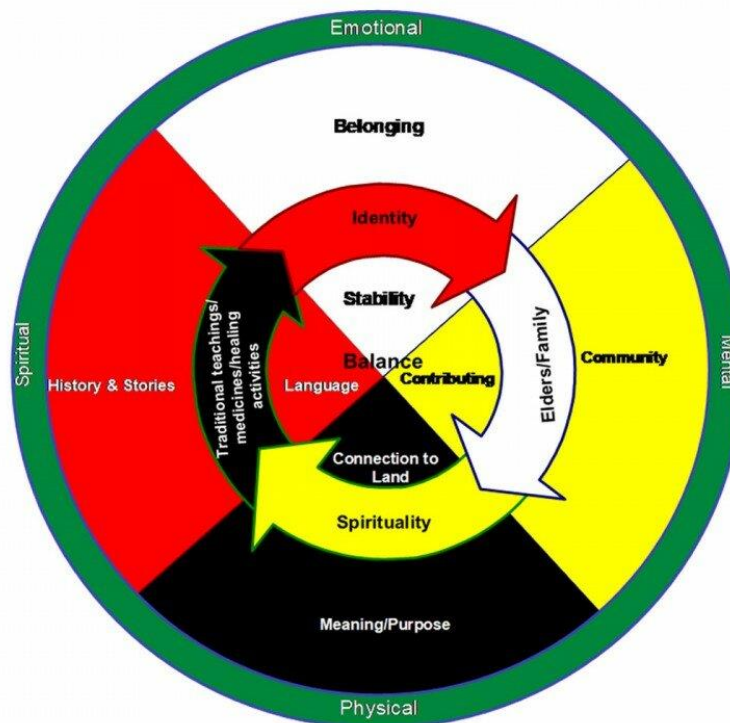
Community-based participatory research (CBPR) is a collaborative research process with the researcher and community members being partners in the process and decision making of the research with equity between partners (Israel et al., 2008, p.48). CBPR is an approach for working with the community (or tribe) and sharing ideas, concepts, and applications from the beginning of the project through the dissemination of the results is critical to establishing the equity in the partnership and developing the sustainability beyond the research project.

Historically, suicide prevention and intervention programs in AI communities have relied heavily on evidence-based practice but have rarely sought information or feedback directly from community members prior to or after implementation (Walker, Whitener, Trupin, & Migliarini, 2015). This CBPR project resulted in the collaboration of an AI university researcher and an AI community leader working with youth to address the question, "What gives AI youth hope?" The progressive nature of this research opportunity allowed investigators to address two key issues in research methodology currently utilized in AI communities. First, how do researchers address suicide prevention/intervention using a strengths-based and culturally salient approach? Second, how might CBPR be utilized to conceptualize the construct of hope in the participating communities? Therefore, two key pieces of information were necessary for this study: 1) how might we use our research questions to elicit strengths from community members who have primarily been viewed in terms of weaknesses, and 2) how might we gain investment and engagement during an exploration of the construct of hope while retaining the rich and remarkable voices of AI youth.

METHODS

Strength-based approaches "empower" and "mobilize" communities in addressing difficult problems such as suicide (McMahon, Kenyon, & Carter, 2013). In addition, CBPR has been described as both a collaborative and systematic approach for creating social change (Jernigan, 2010). In CBPR, researchers work in relationship with participants, and participants act as key stakeholders in the research process. In addition, the research questions must be relevant to the needs of the community and dissemination of findings intended to directly benefit community members. Furthermore, CBPR builds capacity for AI community members to actively use their unique worldviews and ways of knowing as integral tools for problem solving. CBPR methodologies have been used in AI communities with success across multiple domains including substance abuse prevention, diabetes and obesity prevention, and suicide prevention (Ellis, 2004; Mohatt et al., 2004; Santiago-Rivera, Skawen:nio Morse, Hunt, & Lickers, 1998; Satterfield et al., 2003; Thurman, Plested, Edwards, Foley, & Burnside, 2003). This study allowed the researchers to integrate both strengths-based and CBPR approaches in the Hope Study.

Furthermore, in order to be culturally responsive and flexible with the needs of the community, the researchers implemented a creative photo-voice style project in two phases of the

study (Jennings & Lowe, 2013; Minthorn & Marsh, 2016). This was intended to capture the "voice" of the participants about what gives them hope in their own words and images. Capturing the voice of the Native youth acting as co-researchers within this CBPR framework was crucial to building relationships and promoting self-efficacy (Catalani & Minkler, 2010). The researchers also note that topics such as hope, while promoting hope, might also elicit memories of times of hopelessness in the face of difficulties. Further, participants might lack the ability to verbalize the construct of hope under the influence of difficult emotions. The creative aspect of the Hope Study allowed for multiple means of communication of hope (both verbal and visual). Maintaining flexibility (holding the photo-voice method loosely) also allowed for multiple avenues of expression from traditional arts and crafts, dance, photography, two-dimensional art forms, poetry, and song.

Goal of the Study

The primary goal of the Hope Study was to explore what gives hope to AI youth living in communities that experience high rates of suicide and to do so using a strengths-based, culturally appropriate approach based on input from AI community members.

Approval

Research approvals were received from both the university institutional review board and the partnering tribal research review board prior to proceeding with the study. In addition, a letter of support was received from the tribal president and tribal housing department in response to the immediate need for suicide research supporting culturally based programs in the community.

Participants

Participants were recruited via convenience sampling through tribal members (which we identify as "group leaders") and in collaboration with the tribal housing department and other tribal youth programs. Recruitment fliers were distributed through all tribal districts by group leaders and partnering tribal members. The flier announced a "confidential research opportunity for American Indian (AI) youth ages 14-24." The request for participation announced the opportunity as a study in which participants would talk in groups about the construct of hope with an end result of creating and presenting a project on hope for dissemination to tribal members. Interested

participants were asked to sign up at the tribal housing department. As a result, 56 AI youth (male = 55%, female = 45%) were enrolled to take part in the study. Participating youth were self-identified members of one of the nine tribal districts constituting the partnering tribal community. Participants were 13-24 years of age ($M = 16.30$, $SD = 2.70$), and 73% reported themselves as full-time students.

Informed Consent

Both consent and assent were sought prior to participation in the study. As part of a concerted effort to conduct respectful and beneficial research with tribal youth, the consent/assent forms carefully explicated the details of the study, the voluntary nature of participation, the duration of the study, and potential risks and benefits. The purpose of the study was defined as an invitation to be part of a focus group in which the participant "will be asked to fill out a brief demographic form" as well as "questions about you and what gives you hope and your ideas about hope among other youth." The duration of the study was listed as "about one month" in which the participant would attend three groups lasting about 1½ to 2 hours each. Participants were informed that the focus groups would be recorded and that they could choose to skip any questions that made them uncomfortable or for which they declined to answer.

Informing participants as to risks and benefits of the study was a crucial component of the informed consent/assent process due to the historically negative implications of early research in Indian Country. Risks were listed as discomfort with answering questions or talking in front of a group. Instructions were included for whom to contact in the event of distress. These contacts were defined as group leaders who were instructed in how to conduct a referral for resources at an accessible Indian Health Service (IHS) clinic within the community. Group leaders were invested and respected adult members of the tribal community with experience in working within the culture and with AI tribal youth. Group leaders were asked to keep a confidential contact list of participants so that well-being checks could be conducted if needed. In addition, the investigators for the study are an experienced psychologist and social worker with the social worker being well-versed in the needs and available resources of the participating community. As incentive for participating in the study, AI youth received a $50 gift card for each meeting they attended. An additional, and important, benefit of participation in the research was noted as contributing to education about hope for the given community as a means of better-informing suicide prevention programs. In the community presentation of the creative projects participants were acknowledged

for their ability and autonomy in "giving back to the community" by providing ways that they gained hope and developed resiliency to crisis.

Procedures

The Hope Study consisted of a training phase and three distinct research phases (data collection, creative project, dissemination). The training phase was intended to familiarize the adult group leaders with the study procedures as well as discuss the logistics of data collection. Materials such as audio-recording devices, flip-charts, paper materials, and art supplies for creative projects were also distributed during this phase. The first research phase, or data phase, was primarily for building rapport, quantitative (demographics and YPBT) and qualitative (focus group) data collection, and for transitioning into subsequent phases. In the second phase, or creative phase, participants worked in conjunction with adult group leaders to create a personal project centered on developing a visual representation of hope. In the third phase, or dissemination phase, participants were asked to present their creative projects (contingent on comfort level) back to their respective communities. In this third phase, feedback would also be sought from participating community members as to reactions to creative projects and suggestions for interpreting reactions.

Training Phase

This initial phase was conducted with tribal group leaders and the co-investigator on tribal lands. Group leaders were invested and respected adult members of the tribal community with experience in working within the culture and with AI tribal youth and an IHS facility was reasonably accessible within the community for any youth determined to be at risk of suicide. Group leaders were asked to keep a confidential contact list of participants so that well-being checks could be conducted if needed. These group leaders work in the communities with at-risk youth and already have a relationship with them. During this phase, materials were distributed to representative group leaders from each of the nine districts. This consisted of packets with all necessary printed materials and surveys as well as art supplies, flip-charts, and audio-recording devices. In addition to holding a training session covering the proposed outline of the data phase, time was spent with group leaders generating discussion. This discussion portion proved incredibly valuable in understanding the concerns of the community. Additionally, the researchers were

greatly impressed by the dedication shown by community members who wished to give back to the community and help support the youth.

The use of a CBPR approach with the research assistants from the community being trained to conduct the focus groups helped the participants to trust the facilitators and sincerely work on the projects. The enthusiasm of the research assistants for the project helped the participants to be more honest and forthcoming with their responses as they knew their ideas were being valued and could be a way they could give back to the community.

Phase One

During the first phase of the Hope Study, group leaders were asked to gather demographic and consent/assent forms from participants prior to beginning the focus groups. Each group leader also collected confidential contact information should a well-being check be needed. Group leaders opened with the ice breaker exercise (which was not recorded). Upon completion of this rapport-building exercise, group leaders distributed the Youth Personal Balance Tool (YPBT) and delivered instructions. Group leaders were on hand to answer questions or assist as needed. After a brief break, audio recording equipment was turned on and the focus group began. Group leaders delivered focus group questions verbally and instructed participants to use pre-determined pseudonyms during discussion to protect privacy. Group leaders provided adequate time for answering questions as ideas were shared across the group. Responses were also recorded on the provided flip-charts. Responses were then ranked according to order of importance as a group. The session ended with a brief discussion of the second (creative) phase, and participants were encouraged to meet individually with group leaders as needed to discuss ideas for their creative project.

Phase Two

Phase two consisted of participants meeting as a group with group leaders to work on their creative projects using the provided art materials. Participants were instructed that they could use any creative method necessary for representing their ideas about hope (e.g., visual art, poetry, traditional crafts, etc.). Group leaders were on hand throughout the entirety of this phase to monitor for any signs of distress. The creative projects will be discussed in another article later.

Phase Three

This phase was included for dissemination of research back to tribal leaders and invested community members. This will be discussed in a later article. As an added function of the CBPR

framework, feedback will also be sought regarding the resulting creative projects and emerging themes regarding hope among tribal youth.

Ice Breaker Exercise

The ice breaker exercise was included as a way for group members to gain initial ease with the process of talking about themselves. This portion of the study was led by adult group leaders who asked for the participant to give their name and some background information on why they chose to participate in the focus groups. Example questions for the ice breaker exercise include, "What made you want to be a part of this focus group" and "Share with us something (an interesting fact) that most people would not know about you." This was also the portion of the focus group where participants could indicate a pseudonym which they would use for paper and pencil surveys and audio recorded portions of the group meetings to aid in maintaining confidentiality.

Demographics

Demographic forms were administered via paper and pencil and requested information on sex, age, grade in school, employment (if applicable), and education (highest level completed). An option was available for indicating that a participant was not currently in school or identified as a homemaker or volunteer. Information was also sought on which tribal group the participant was affiliated with.

Youth Personal Balance Tool

The Youth Personal Balance Tool (YPBT; Barraza et al., 2016; Youth Council of The Fresno American Indian Health Project, 2014) was chosen based on its use of a culturally relevant medicine wheel framework consistent with many AI worldviews and use of a CBPR model. The youth version of this scale was developed and piloted through The Fresno American Indian Health Project (FAIHP) Youth Council and adapted from a previous unpublished version developed for adults (A. Rabideau & S. CrossBear, personal communication, May 27, 2015 as cited in Barazza et al., 2016). The YPBT is based on a Likert scale format ranging from "0" (very untrue) to "4" (very true) and consists of 20 total questions drawn from one of four domains. These four domains are situated within a visual representation of a medicine wheel (Cross, 2003). These domains consist of: "spiritual" (corresponding with the direction of east and color yellow); "emotional (south, red); "physical" (west, black); and "mental" (north, blue; see Figure 2 for a visual representation of the medicine wheel).

Figure 2: Youth Personal Balance Tool medicine wheel created by FAIHP
(Barraza et al., 2016; Youth Council of The Fresno American Indian Health Project, 2014)
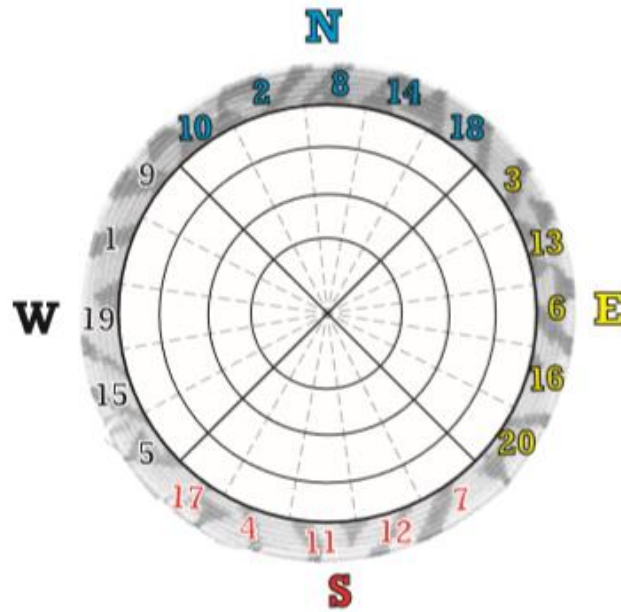
Participants are asked to answer all 20 statements first and to pick only one score (0 to 4) for each statement (see Table 1 for examples of statements). Participants are then instructed to "chart" their numeric responses in the circular medicine wheel model. The model is arranged by domain with each question corresponding to a quadrant (domain) and color. Colored pencil or pens (yellow, red, black, and blue) are used to "shade in" each "slice" of the circular model as it corresponds with the question. Any remaining slices of the circular model are shaded in with gray. Shading in respective portions constitutes an active and engaged portion of the focus group. Participants were then asked to consider which quadrants had the most shading and which were the grayest. Shaded portions constituted areas of strength, whereas gray portions were areas that could benefit from additional attention to increase balance across domains.

Further YPBT instructions state, "A possible goal may involve increasing the color in one quadrant so that all four quadrants are as close to equal as possible and striving towards fulfillment" (Barraza et al., 2016; Youth Council of The FAIHP, 2014). For example, if the physical domain was primarily shaded gray but the mental domain was primarily shaded blue (an area of strength) then a participant may reflect on problem solving and other mental skills to increase physical well-being. A major goal of completing the YPBT was to increase awareness of areas of strength and promote introspection on ways in which the participant might create balance and harmony within their lives in an autonomous manner.

Table 1
Sample questions and domains from the Youth Personal Balance Tool*

Domain	Statement
Spiritual	• I have dreams or visions that help guide me. • I believe that even though we can't see the Creator or spiritual world, we know it exists.
Emotional	• There is something that I have in my life right now that I have a passion for and am excited to do it every day. • When my family and friends do well I try to tell them.
Physical	• I take care of my body (such as exercising, watching my diet, and/or choosing to be drug free). • I take responsibility for my mistakes and actions.
Mental	• I make an effort to learn something new every day. • I talk with elders about my options before making a decision.

*Barraza et al., 2016; Youth Council of The Fresno American Indian Health Project, 2014

Focus Group Questions

Focus group questions were developed by Hope Study researchers based on input and feedback from the culturally embedded co-investigator. The focus group questions consisted of six open-ended questions delivered during a group discussion led by adult group leaders. For example, questions asked were: "When you get discouraged, what gives you hope?" and "How would someone else know you were hopeful?". Questions were intended to be brief but thought provoking to generate room for discussion among participants. Adult group leaders were helpful in creating a safe space for communicating ideas and instructed to monitor for signs of distress if they emerged.

Table 2
Focus group questions on hope

1. Would you introduce yourself and tell us a little about if you are in school and what you like to do?

2. What are your favorite things to do?

3. What are your dreams for the future?

4. When you get discouraged, what gives you hope?

5. If you were to tell someone about being hopeful for the future, how would you describe or show them you were hopeful?

6. How would someone else know you were hopeful?

Data Analysis

Analysis of pilot data collected during the Hope Study were analyzed using both quantitative and qualitative methods. Descriptive statistics were calculated for both demographics and the YPBT using SPSS 23.

Theme analysis was used to code the focus group portion by coding initially, identifying related themes, and then recoding into that paradigm of themes. The emergent themes naturally mapped onto the YPBT medicine wheel framework (i.e., focus group responses generally coded into one of the four domains: spiritual, emotional, physical, or mental). Team members were responsible for the coding.

RESULTS

Quantitative

The 20 items of the YPBT produced a Cronbach's alpha of 0.79. Data from the YPBT indicated that there were no significant differences between males and females across all domains (See Table 3). The physical domain indicated more activity for males ($M = 3.44$, $SD = 0.37$) than females ($M = 3.43$, $SD = 0.35$). The mental domain was lowest for males ($M = 3.10$, $SD = 0.43$), and the spiritual domain was lowest for females ($M = 2.98$, $SD = 0.66$). Although there were no great differences in responses on the YPBT, it did indicate a good degree of balance over the four domains for our participants.

Table 3
Male and female participant mean scores and standard deviation for the domains of the Youth Personal Balance Tool*

Domain	Male M (SD)	Female M (SD)
Spiritual	3.12 (0.57)	2.98 (0.66)
Physical	3.44 (0.37)	3.43 (0.35)
Mental	3.10 (0.43)	3.12 (0.38)
Emotional	3.23 (0.58)	3.24 (0.58)

* Barraza et al., 2016; Youth Council of The Fresno American Indian Health Project, 2014

Qualitative

The themes from the focus groups also fit the four domains of the medicine wheel: physical, mental, emotional, and spiritual. Each group, as defined by the YPBT, were east (spiritual, yellow), south (emotional, red), west (physical, black), and north (mental, white; Barraza et al., 2016).

The east and spiritual domain represented the sense of belonging, personal pride, respect, connectedness, faith, prayer, purpose, vision, and love, or the infancy of development. This included things the participants liked to do such as riding horses, being in nature, and being by him/herself. Favorite things that were reported under this domain included "looking at the stars," "spending time in nature," and "playing with animals," highlighting their identity and connectedness. When asked what gave them hope, the focus was on a sense of accomplishment and purpose in life including "my culture," "achievement," "being myself," and "looking forward to the future." Participants indicated that someone else would know they were hopeful spiritually by how inspiring they were to others by motivating them, inspiring them, letting them know that "life is about possibilities," and "telling them it's all worth it." The youth believed others would know they were hopeful by their resiliency and capability for growth that would be demonstrated by "bouncing back" and "showing them you can change for the better."

The south and emotional domain represented mastery of skills and gifts, self-esteem, accomplishments, happiness and enjoyment, impulse and emotional control, sensitivity, forgiveness, and attitude, or the childhood of development. The things they liked to do that fit with the emotional were helping family or spending time with family and friends. Favorite things in the emotional domain included "cruising," "hanging out with friends," and "being around people that make me happy," with an emphasis on family and friends. What gave the participants hope in the emotional domain included developing self-esteem and happiness through relationships including family, friends, and children. Others would know our participants were hopeful through the emotional domain by being "there for them" and telling "them everything will be okay" and "look how far you've come." Emotionally the youth felt that others would know they were hopeful by their attitudes and achievements and by their "laughter," "smiling," "positive attitude," "reactions," and "accomplishing my goals."

To the west is the physical, representing interdependence, humility and accepting responsibility, practice and reaching your potential, power and control, physical health, vision, and reaching goals, or the adulthood of development. The physical interests that were described included sports, being active, and building things. The favorite things identified in the physical

domain included "running," "playing basketball or football," and included things within sports and physical health areas. The things that gave the participants hope in the physical domain included that sense of physical wellness. In the physical domain, participants would use their actions to describe or show their hopefulness by talking "to them," "give them a call," and approaching "them with open arms," demonstrating the physical connection. Physically, others would know the youth were hopeful by their physical and verbal communication demonstrated by "my expressions, words, actions, and by asking me."

Finally, the north or mental domain represents generosity; problem solving; wisdom; freedom from fear, hate, jealousy, and other negative emotions and behaviors; commitment to lifelong learning and service; doing things in moderation; and truth, or the elder of development. Those activities within the spiritual domain included writing, poetry, music, art, reading, and fixing things. Favorite activities within the spiritual domain included "singing," "drawing," "painting," and "playing video games," which were areas of creativity and mental stimulation. The spiritual domain was represented as giving hope by creativity and self-expression through writing poetry, music, art, and fixing things. In the mental domain the participants would describe or show their hopefulness by modeling hope. This would be done by teaching "them about life," working "hard," "don't quit," and "show them they should finish school," demonstrating mental toughness, persistence, and productivity. The ways that participants believed others would know they were hopeful that were in the mental domain involved dedication, commitment, and perseverance. This would be demonstrated by "seeing me working hard," "staying focused," "getting good grades," and "finishing school."

DISCUSSION

It was important that the data be interpreted culturally to be more meaningful, useful, and appropriate for the community. Since the data fit into a medicine wheel set of domains it allowed for this cultural interpretation.

The participants in this project put a high emphasis on goal attainment as a measurement of hope. Most of them recognized the importance of education in achieving their goals. Because of the high numbers of youth dropping out of school, it is important to find ways for them to continue to achieve, get an education, and make progress toward their goals.

Close trusting and supportive relationships were also important. Sharing of hope was

largely focused on relationships and peer-mentoring in which hope was actively communicated and taught to others. Family and a sense of belonging emerged as a dominant factor for generating and reciprocating hope. This would indicate work in strengthening family and social relationships in healthy ways would be important to promote hope and resilience.

The participants in this study appeared to be well-supported in the physical domain; however, increased support for healthy self-expression, connectedness, positive self-identity, and emotional regulation may help create a balanced approach to hopeful living.

Limitations

Because this project was focused on a small group of youth in a single reservation the findings cannot be generalized to all youth or even AI youth, but must be looked at as an initial examination of hope among one small group. Further qualitative analysis is needed to strengthen the emerging themes and the association between the thematic elements. Recommendations from this project lay the groundwork for development of strengths-based approaches that address the high suicide rates based upon development of strong relationships, supporting activities that value the different abilities of youth, and giving back to the community and family in ways they feel are valuable.

Future Directions and Implications for Prevention/Intervention Work

Recommendations for practice and intervention development would include a family-oriented approach that would strengthen and build healthy relationships. Finding ways to explore the efficacy of peer-to-peer mentoring and support that provides a way to give back as well as a support network for times of stress. Also, the validation of individual personal growth through goal-setting and goal completion could be instrumental in promoting hope. Honoring those completing goals brings value and self-esteem to the individual that they are finding success in a way that is meaningful to the individual. Finding ways to recognize individual strengths, abilities, and talents demonstrates that all have a way to contribute to the community and be a part of it. Even the little toe serves a purpose. Utilize creative forms (art, writing, music, dance, building, etc.) to engage youth in positive self-expression that will develop a sense of value and accomplishment. Continuing to support physical activities such as sports, culture camps, horse camps to encourage healthy social interactions, and relationship building will provide those

networks for help when things do not go as well. Having opportunities for youth to address leadership in the communities where their ideas and suggestions are heard and considered demonstrate to the youth that they can be vehicles for positive change in their communities. Volunteering to help elders and being role models for those younger will help give them hope for the future while drawing upon the strength and resilience of their history. Identifying ways that helped the community survive and continue will reinforce the resilience that is a part of who they are. Use of the YPBT on a regular basis with youth can help them monitor their progress toward a balanced life. It can also be helpful in setting goals and making changes in their lives that lead to a stronger and healthier outcome.

CONCLUSION

The Wa'cinyeya (Hope) Project found that youth among this tribe found hope in feelings of connectedness, a connection with nature and spirituality, and education. Connectedness was found in positive family relationships, wanting to be a good example to their children, and in participating in team sports where they feel leadership, feel like a vital part of the team, and have hope of following a role model, such as Kyrie Irwin (an American Indian NBA player). The connection with nature and spirituality are indicated in cultural aspects of feeling connected to the whole when in nature and, even if not participating in cultural ceremonies of spirituality, feeling spiritual when observing and interacting in nature. In general, the youth reported feeling that education was an essential part of attaining their goals, and those goals also gave them hope. With respect to the medicine wheel, the physical, mental, spiritual, and emotional aspects were present in the responses from the youth. Community members are making plans to utilize the results of this study to integrate the results into suicide prevention planning and programming. By integrating the ideas of the youth into future planning, the information becomes sustainable and more effective in future work.

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We would like to dedicate this manuscript to the life of the participant who completed suicide during the course of the study and the many valuable contributions she made to the project. We wish you peace and happiness.

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COMMENTARY

A MOVEMENT TO RECLAIM AMERICAN INDIAN HEALTH THROUGH TRIBAL SOVEREIGNTY, COMMUNITY PARTNERSHIPS, AND GROWING TRIBALLY-DRIVEN HEALTH RESEARCH

Victoria M. O'Keefe, PhD

Indigenous peoples have been engaged in resistance against the destructive effects of colonialism on Indigenous land, lives, all living things, and its impacts on the health and well-being of Native peoples since the first arrival of settlers in the Americas. This resistance, at its core, has been a movement to preserve Indigenous peoples, lands, identity, and ways of knowing, learning, respecting, and living harmoniously with the world. In the past half century, the spirit of Indigenous resistance has found its way to the field of health research. Starting with thought-leaders like Vine Deloria Jr. in 1969, Indigenous scholars have pointed to problematic and harmful research practices that have taken place on tribal lands, and that have sought to expand the Western canon of scientific knowledge without providing solutions to, with, and for Indigenous communities. Since that time, a narrative around collective protection, collaborative research partnerships (i.e., community-based participatory research in all its forms), and tribal sovereignty over research is increasing rapidly.

This special issue of *American Indian and Alaska Native Mental Health Research* takes a giant step forward – beyond a collective resistance against harmful research practices – to a reclamation of collaboration, Indigenous knowledge, strengths, and tribal sovereignty within health research. This group of articles highlights a diverse coalition of tribal communities, transdisciplinary health researchers, academic institutions, community organizations, service providers, and federal agencies that comprise the Collaborative Research Center for American Indian Health (CRCAIH; Kenyon et al., this issue). CRCAIH goals include improving AI health through strategic development of tribal research infrastructure and sustainability of health research with a focus on social determinants (Kenyon et al., this issue). Supported by the National Institutes of Health, the CRCAIH provides a promising pathway to eliminate health disparities among AI communities—Oglala Sioux Tribe, Turtle Mountain Band of Chippewa Indians, Fond du Lac Band of Lake Superior Chippewa, Sisseton-Wahpeton Oyate, Rosebud Sioux Tribe, Cheyenne River Sioux Tribe, and Spirit Lake Nation—in the Northern Plains and Upper Midwest regions.

Guided by the collaborative leadership of the CRCAIH, a predominant theme articulated by many voices in this special issue is the critical role of tribal sovereignty to determine the bounds and the unique protocols and practices of research on tribal lands with AI peoples. More specifically, contributing authors impart how research with AI/AN tribal nations is distinct given their status as sovereign nations with the right to self-govern (National Congress of American Indians, 2015). By honoring sovereignty over tribal research infrastructure, the CRCAIH and participating communities are together exerting protection of tribal citizens (Around Him et al., this issue) and resisting a legacy of harmful research practices with AI communities. Protection through upholding sovereignty over research maintains the CRCAIH goal to enhance tribal research infrastructures and is underscored throughout this special issue. Two articles provide informative frameworks to better understand various ways tribes may engage in research oversight and review (e.g., establishing tribal research offices and IRBs) and data governance (Around Him et al.; Buffalo et al.; this issue). Of particular importance, these articles communicate the continual impact of CRCAIH through IRB and data management toolkits, as well as a comprehensive and current list of Tribal IRBs, publicly available to all AI/AN communities (Around Him et al.; Buffalo et al.; this issue). Though CRCAIH was established as a regional coalition, these examples highlight the tremendous outputs and benefits accessible to tribes across Indian Country seeking to increase tribal sovereignty over health research. Related subthemes within this special issue include: 1) the importance of transdisciplinary partnerships guided by tribal community collaborators; and 2) strengths-based approaches to research that promote Indigenous knowledge to address health and wellness issues and solutions.

Several articles featured in the issue exemplify the transdisciplinary and collaborative goals of the CRCAIH to eliminate AI health disparities and achieve wellness among tribal communities. A unique feature of the CRCAIH's collective work includes describing tribal communities' local knowledge with equivalence, and the same or more respect afforded to academic disciplines (Heinzmann, Simonson, & Kenyon, this issue). True and genuine collaborations with tribal communities is exemplified by honoring tribal partners' vital knowledge and observations as commensurate with the highest standard of scientific inquiry and exposition. In this vein, authentic tribal community partnerships must hold respect for the tradition of Indigenous knowledge, science, and research established thousands of years ago (Thomas, Donovan, Sigo, & Price, 2011). The tenets that define how sovereignty operates within transdisciplinary community-based research collaborations go further than epitomize resistance against norms of Western academic

disciplines as a sole source or standard of knowledge, but rather reclaim Indigenous knowledge and ways of living as being the highest standard of health science within Indigenous communities. Consider for example, how local tribal knowledge is incorporated into CRCAIH projects highlighted in this issue: knowledge of Lakota culture and social/cultural determinants of health were the focus of a training for a local community workforce (see O'Leary et al.); and one Dakota community developed the Wicozani measure derived from local understandings of holistic health and wellness (i.e., physical, mental, spiritual health, and quality of life; see Peterson, Peterson, & The Dakota Wicohan Community). Collaboration with AI communities in setting local goals regarding research infrastructure and projects upholds tribal sovereignty and can be seen as a form of hopeful resistance to encourage positive futures of health research with communities.

The aforementioned themes revolving around protection of Indigenous peoples through sovereignty over research and transdisciplinary and tribal community-based collaborations provide a necessary foundation for successful research collaborations resulting from the CRCAIH that are rooted in local strengths. There is a prominent movement to elevate the importance of strengths-based research with AI/AN communities that address local priorities around health and wellness (e.g., Morse, McIntyre, & King, 2016; Henson, Sabo, Trujillo, & Teufel-Shone, 2017; Thomas, Rosa, Forcehimes, & Donovan, 2011; Wexler et al., 2015). Important examples of strengths-based research projects featured in this special issue demonstrate how community collaborators are pivotal in defining health and wellness holistically through a tribally-specific lens. Through community-engaged research, these projects spotlight AI youth defining what gives them hope to inform future suicide prevention programming (Gray, Schrader, Isaacs, Smith, & Bender, this issue), development of the Wicozani (Dakota concept for overall health and wellness) measure (Peters, Peterson & the Dakota Wicohan Community, this issue), and an intervention study to address social determinants of health through improving goal setting and self-efficacy (McCormack, O'Leary, Moran, & Hockett, this issue). All of these studies incorporate local tribal cultural values and a strengths-based focus throughout research processes and outcomes with significant promise to create sustainable change with tribal community partners.

While the movement towards reclaiming Indigenous-led research, inquiry and exposition grows—with important documented advancement from this issue—we continue to find ourselves in a time in which resisting unjust research is necessary for the survival of Indigenous lands, communities, and cultural values to be carried forward to future generations. As of this writing, Native Hawaiians and other supporters are protecting Mauna Kea, a sacred mountain that holds

significant cultural values and spaces, from scientists and academic institutions attempting to disrupt this sacred place with the Thirty Mile Telescope (About Mauna Kea, 2019). When Indigenous peoples engage in resistance, these movements often center around themes that illustrate community and collective strength (e.g., "we exist, we resist, we rise") to protect Indigenous peoples and lands. Indigenous resistance is continuous and "defines freedom not as the absence of settler colonialism, but as the amplified presence of Indigenous life and just relations with human and nonhuman relatives, and with the earth" (Estes, 2019, p. 248). The CRCAIH aligns with these movements by bringing together diverse stakeholders to increase tribal sovereignty over research and promotes protection of tribal citizens, true collaborations, and research focused on strengths to elevate the health and well-being of AI communities. While the CRCAIH promotes tribal self-determination over research from one regional center, the impact, sustainable transdisciplinary partnerships, and tools developed by this coalition are models for Indian Country and all scientific communities striving to achieve Indigenous health equity.

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