

# **CULTURALLY SENSITIVE ASSESSMENTS AS A STRENGTH-BASED APPROACH TO WELLNESS IN NATIVE COMMUNITIES: A COMMUNITY-BASED PARTICIPATORY RESEARCH PROJECT**

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*Abstract: American Indians and Alaska Natives (AI/ANs) have a unique, traumatic, and alienating history of education in the U.S., which may be directly related to overall health and well-being. Community engagement is critical in well-being research with Native communities, especially when investigating culturally sensitive topics, such as early education experiences. This study investigates the value of a community-based participatory research approach in gaining valuable culturally sensitive information from Native people in a respectful manner. Assessment participation and feedback are analyzed and presented as indicators of Native participant engagement success in a potentially sensitive research project exploring early education experiences.*

## **INTRODUCTION**

American Indians and Alaska Natives (AI/ANs) experience a disproportionately high incidence of many serious diseases and of mortality and morbidity from disease and injury (Centers for Disease Control and Prevention, 2014; U.S. Department of Health and Human Services, 2015). Specific AI/AN health disparities include tuberculosis, chronic liver disease and cirrhosis, cancers, stroke, hypertension, diabetes mellitus, hypercholesteremia, unintentional injuries, pneumonia and influenza, and obesity. Furthermore, compared to the national average, AI/ANs experience elevated rates of mental health disorders, with a lifetime prevalence rate of 36% to 50%, and high comorbidity rates, including alcohol dependence and post-traumatic stress disorder (Bassett, Buchwald, & Manson, 2014; Beals et al., 2005). A critical first step in combating racial/ethnic health disparities is to understand the social context impacting the lived experiences of individuals of a disadvantaged group (Lillie-Blanton & LaViest, 2013).

Community-based participatory research (CBPR) has been touted as an effective approach in working with Native communities to reduce health disparities, because researchers and community partners work together in all stages of the research process (Duran et al., 2010; Walters et al., 2009). In this paper, the benefits of using a CBPR approach for a project on early education experiences, health literacy, and health status later in life was investigated as a necessary step to supporting wellness in older AIs.

Native communities have endured a long history of difficult and often damaging and unethical research (Hodge, 2012). Native communities and individuals, including the elderly, often are wary of engaging in any type of research, especially when initiated from academic institutions, which results in extremely low participation in studies, including clinical trials (Alvarez, Vasquez, Mayorga, Feaster, & Mitrani, 2006; Beech & Goodman, 2004; Moreno-John et al., 2004). Yet, comprehensive knowledge and understanding is needed if culturally sensitive and appropriate diagnostic procedures and interventions are to be developed. To increase AI/AN participation in research, it is essential to design and develop culturally sensitive assessments and data collection instruments that are more transparent, and to use culturally appropriate forms of engagement.

### **Community-based Participatory Research**

CBPR has emerged in the past decades as an alternative research paradigm that focuses on relationships between academic and community partners with principles of co-learning and mutual benefit, and incorporates community theories, participation, and practices into collaborative research efforts (Wallerstein & Duran, 2006). CBPR acknowledges and sets at the forefront the voice of communities as the primary source of expertise, and integrates education and social action to improve health and reduce health disparities. CBPR is being used by many Native researchers in their work with tribal and Indigenous populations. It is guided by a set of principles: 1) genuine partnership means co-learning (academic and community partners learning from each other), 2) research efforts include capacity building (in addition to conducting the research, there is a commitment to training community members in research), 3) findings and knowledge should benefit all partners, and 4) long-term commitments must be made to reduce disparities effectively (Israel et al., 2003).

With its intrinsic focus on a close community partnership, CBPR requires that researchers engage with the community early in the process. Community engagement empowers, seeks to create sustainability and healing, and is an essential element of initiatives and research to improve the health of Native communities. It has been identified as an indicator of well-being in past and emerging health research studies using CBPR (Hurst & Nader, 2006; Olshansky, 2012; Woods et al., 2013), and also is an important indicator of the impact and success of community-based programs (Aspin, Penehira, Green, & Smith, 2014; Hurst & Nader, 2006). Community engagement in CBPR includes the creation of a community advisory board to guide the design, development, and implementation of the research from the start.

Projects that utilize CBPR-related practices have been successful in engaging AI/AN communities to make meaningful changes related to environmental justice (Cummins et al., 2010) and substance use (Belone et al., 2012), to decrease barriers to healthy eating and exercising (Adams, Scott, Prince, & Williamson, 2014), and to culturally adapt interventions (Jumper-Reeves, Dustman, Harthun, Kulis, & Brown, 2014). Additionally, a recent systematic review revealed that 62% of studies implementing community engagement as a health promotion strategy used CBPR as their model (Cyril, Smith, Possamai-Inesedy & Renzaho, 2015). Such studies often include community advisory committees (CACs) in an effort to consult and engage the community, seek input regarding protocol development, and ensure cultural sensitivity. CACs, which in many tribal communities can serve as an alternative regulatory research body, such as an internal review board (IRB), are an established model for ensuring these objectives and give communities more control over the research process (Cummins et al., 2014; Quinn, 2004; National Congress of American Indians Policy Research Center and MSU Center for Native Health Partnerships, 2012; Strauss et al., 2001).

Studies such as this one represent an emerging cadre of research from different disciplines that draw on community engagement using CBPR and build on the innate strengths and resilience of Native people that have been passed down through many generations (Aspin et al., 2014). CBPR provides Native community members (in this study, elders) with the opportunities to tell their stories and influence the research process by providing a respectable and valuable place for engagement. That is, oral knowledge can significantly improve understanding of community needs and perspectives, and, via mutual learning and sharing, lead to healing. Being heard with genuine interest and attentiveness, and acknowledging and voicing past injustices without experiencing judgment, are empowering and healing. Such experiences allow individuals a sense of freedom from judgment and wholehearted engagement in the

research interview process, thus providing a sense of contribution (Polkinghorne, 1988; Pollock, 2005). This high level of trust from an individual or community that has directly or generationally incurred injustices is an indicator of wellness, showing that researchers have communicated proper respect and perspective in order for the trust to build, and in turn, the research process incorporates a health promotion strategy and builds on Native strengths and resilience (Aspin et al., 2014; Cyril et al., 2015).

The present study was part of a larger ongoing project investigating early education experiences, quality of education, and their association with health literacy and general health status in AI/ANs 55 to 80 years of age. The study utilized a CBPR approach and included a CAC consisting of 11 Native elders. Use of CBPR was strongly supported and encouraged by the CAC, which wanted to ensure a research approach that would promote resilience, healing, and well-being among this sector of the AI/AN population, which has long been overlooked and understudied in health research (Moss, 2016). CBPR was identified as the research orientation with the greatest potential to make this happen.

### **AI Education History**

Education is positively associated with greater health and well-being, including longer life expectancy, improved health and quality of life, and health-promoting behaviors (National Prevention Council, 2011). The traumatic and unique history of AI/AN education is tied closely to U.S. policies. In 1879, Captain Richard Henry Pratt in Carlisle, Pennsylvania, established the first government-run, off-reservation Indian boarding school, the Carlisle Indian Industrial School (Reyner & Eder, 2004). The establishment of this school, in accordance with the Mandatory Attendance Law of Native American children (Marr, 2002), marked the beginning of mass human rights violations that would continue for 100 years in over 460 different schools (Indian Country Diaries, 2006). These violations began with the forcible physical removal of children as young as 4 years old from their families. Defiant parents were faced with refusal of basic services and rations, imprisonment, and even death (Marr, 2002). A program of strict assimilation was embraced, prohibiting Indian language, clothing, religion, or personal expression not just in boarding schools, but also in other Indian day, mission, and parochial institutions (Adams, 1995). Captain Pratt's proposal to the U.S. Federal government was one that would "kill the Indian and save the man" (Pratt, 1973). Indian education through assimilation acted as both cultural genocide and a cost-efficient mechanism to deal with the "Indian problem" (Piccard, 2013). For example, many elders experienced ostracization not only from mainstream

society but also from their own tribal communities as a result of the boarding school experience. They often lost key elements of their heritage due to schools' drastic assimilation programs, and, thus, when they returned to their families and tribes, they could no longer practice their traditions and became outcasts among their own people.

A shift away from assimilation policies for AI/AN education did not occur until the passing of the 1972 Indian Education Act (U.S. Senate, 1972). This act recognized that AI/ANs have unique languages and cultural needs that impact academic performance, and established a comprehensive plan to meet these unique AI/AN student needs.

Thus, in the 1930s, 40s, and 50s, the time when older AI/ANs attended primary and secondary school, there was marked variability in education quality and experiences. In many cases, education was rarely a quality experience, but instead was part of individual and tribal historical trauma (Evans-Campbell, 2008; Walters et al., 2011). Negative school experiences have a lifelong impact on the health of AI/AN elders via the embodiment of early social contexts and environments (Krieger, 2011); that is, such experiences are translated into poorer physical health in later life via the internalization of oppression and marginalization, as well as by stress processes, leading to wear and tear on the body and mental well-being.

For these reasons, AI/AN elders bring rare experiences and perspectives in studying the impact of education on health and well-being. Despite the importance of education as a determinant of health and well-being, and the unique education history of AI/ANs, the impact of education on health in older AI/ANs is not well understood and warrants greater research exploration.

This project sought to: 1) engage Native elders to participate in the CAC and form a research partnership grounded in CBPR, 2) design and develop culturally sensitive assessment instruments, and 3) conduct culturally sensitive assessments in a way that engages Native elders and honors their stories. We hypothesized that qualitative analyses would reveal positive experiences and statements of appreciation by participants during the potentially sensitive portions of the assessments (described below) in this CBPR project.

## METHODS

### The Role of the CAC

The CAC was instrumental in providing critical cultural insight, feedback, and guidance at all levels of the study. Local AI/AN researchers and educators recommended key individuals as potential CAC members. The research team then used a snowball or chain referral strategy to connect with the potential members, and the principal investigator reached out with an explanation of the goals of the CAC and an invitation to participate. The CAC consisted of 11 elders who were professionals, caregivers, or stakeholders from many different disciplines (e.g., health care, veterans associations, Native health, Native government and other community agencies, academia, and Native education). Our research team held four formal key meetings with the CAC at convenient times for participants over the course of 6 months. Each meeting covered various components of the project, including variables of interest, questionnaire content and questions, a review of the history of research abuse with Native communities, respect and appropriate conduct of the researchers, the collective research experience, and co-developing and piloting the study's instruments. These meetings were critical in anchoring the study in ways that were aligned culturally with Native elders, and ensuring a process that was embedded in participatory engagement at all levels. The CAC also offered feedback regarding the length of the sessions, demonstrating respect for participants, cultural humility, and compensation (both monetary and handmade culturally related gifts). The CAC identified this project as a wellness-promoting research approach to working with older AI/ANs. Having the CAC's approval of a study that benefits the individual participants as well as the broader AI/AN elder community was critical, as studies without tangible benefits may be met with resistance, or may not be approved by the community or various human subject review organizations.

Moreover, the CAC provided invaluable feedback on the assessment sessions. The CAC stressed that AI participants may perceive the assessment sessions as intimidating due to past negative education and research experiences, and provided suggestions to increase trust and rapport. Suggestions included interviewer personal and cultural self-disclosure, a script that explained the assessment and its purpose in user-friendly, non-technical language, continued and genuine expressions of appreciation for stories told and information shared, attention to emotions displayed, ample opportunities for emotional sharing free of bias and judgment, and awareness of nonverbal behavior. Additionally, the CAC suggested revisions to questions that were potentially difficult and complicated. For example, a question assessing participants' perceptions

of their school quality in comparison to regional and national schools was originally developed using the ladder style typically employed to assess perceived social class or hierarchy. The CAC felt that this approach was too complicated, and recommended that the ladders be replaced by a single line in which participants could make marks representing school quality. The CAC also made suggestions related to emotions that might be elicited by the questions (e.g., structuring the assessments so that all of the negative questions were not grouped together, and ending the session on a positive question).

Two measures relevant to this study were developed in partnership with the CAC: the Quality of Education Questionnaire (QEQ), and the end-of-session questionnaire. The QEQ was initially developed partially by the researchers and then completed and refined based on feedback from the CAC. The CAC suggested the end-of-session questionnaire to better allow participants to provide feedback during the assessment and ideas for improving the assessment experience to better serve AI-specific needs in future studies.

### **Sample and Settings**

Participants were recruited from a large urban area in the Southwest. Potential participants were first screened for age (55 to 80 years) and self-reported AI identification. No participants identified as AN in this sample; therefore, the sample is referred to as “AI” henceforth. Each participant completed a written consent form and assessment sessions as part of the larger study on education experiences and health literacy in older AIs. These sessions were held in offices or small conference rooms at community clinics and health care centers. For the present paper, we analyzed the number of participants to date ( $n = 24$ ) regarding participant engagement and feedback during the assessment process. Specifically, we analyzed a questionnaire administered at the end of each session that invited participants to report their perceptions and session feedback. Participants were compensated via a \$20 department store gift card per hour or part thereof. The University of New Mexico Institutional Review Board (IRB) and the Southwest Tribal Native American Research Center for Health IRB in New Mexico approved this project.

### **Research Assistant Training**

All study team members, including the principal investigator, co-investigator, and research assistants at the graduate ( $n = 4$ ) and undergraduate ( $n = 7$ ) levels, come from diverse racial/ethnic minority backgrounds; the principal investigator (the first author) is AN and three research assistants are of AI heritage. The multicultural team had a deep commitment to social justice and dedication to the study's aims and goal. Research assistant training included regular meetings with a clinical psychology doctoral student to learn about assessment and interviewing, with particular sensitivity to issues of potential emotional salience to the study population. Cultural training consisted of key readings on multicultural counseling and reflective listening techniques, one-on-one meetings, role playing, shadowing experienced interviewers, and regular meetings with researchers to reinforce good practices. The training experience was tailored to each research assistant, with the trainer and the research assistant coming to a consensus that they were ready to begin working with participants. Research assistants expressed appreciation for the opportunity to learn more about multicultural techniques and to continue learning as participant sessions were discussed, or during session transcription.

All team members conducting interviews ( $n = 5$ ) were trained in basic interviewing skills (Sommers-Flanagan & Sommers-Flanagan, 2013), affirmation and positive regard, and specific interviewing techniques, such as open-ended questions and reflections (Miller & Rollnick, 2012). Research assistants also were provided with CBPR education using discussion, presentations, articles, and application. The research team met with the principal investigator and co-investigator to better understand what it means to apply CBPR principles within the context of psychology and research partnering with a Native Elder CAC and AI elders.

### **Measures**

Participants completed a series of questionnaires and structured interviews over two assessment sessions, with the second session being optional. The first session included the measures of demographics, education experiences, and health literacy, and a health status questionnaire. The second, optional session included cognitive assessments and other health literacy and mental health questionnaires. Both sessions ended with an end-of-session questionnaire assessing participants' experiences during the interview and assessment process. In the present paper, we will discuss findings related to these end-of-session questionnaires.

### **End-of-Session Questionnaire**

This questionnaire was developed with the CAC to ask about general impressions of participants' experiences during the session. It was intended to collect information on satisfaction with the sessions, as well as for potential improvements by the team, depending on feedback. Questions asked participants to share their experiences completing the questionnaires and assessments, their thoughts on what we were measuring, whether they experienced anxiety and which sections were more anxiety provoking, and general feedback and suggestions for future improvement.

### **Analytic Strategy**

We employed an inductive or data-driven approach to qualitative data analysis (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). Within this framework, we used a thematic content analysis approach (Burnard et al., 2008). Four members of the research team analyzed transcripts of the end-of-session questionnaire independently using an open coding approach. During this process, we met several times as a group to discuss commonalities and differences in our codes, to refine our coding system, and to develop a codebook. After reaching saturation, coding categories were reduced to overarching themes. After four rounds of coding, we met again and reached consensus on themes and subcodes. A majority vote (3 out of 4) was employed when disagreements occurred. Thus, we employed an iterative and collaborative approach to coding and theme generation (Saldeña, 2009). After themes were generated, we presented to the larger team in another effort to validate findings and obtain feedback. Finally, we applied an enumeration process to our codes in order to quantify participants' experiences and offer a frequency count for different codes.

## **RESULTS**

### **Descriptive Analyses**

Table 1 presents participant demographics. Participants reported a variety of education attainment, school settings, and language abilities. Noteworthy for this study is that all participants who started Session 1, which included the potentially culturally sensitive structured interview related to education experiences, voluntarily completed the session. Most of the participants (71%) completed Session 2, which included cognitive assessments. Furthermore, all

participants agreed to return for Session 2, though some were not able to keep appointments because they moved outside the area, could not be contacted for scheduling and confirmation, or had unreliable transportation.

**Table 1  
Selected Participant Characteristics**

		<b>Men (n = 12)</b>	<b>Women (n = 12)</b>
Age, years	Mean (SD)	65 (10.2)	65 (8.1)
Study session completed	Session 1	12 (100.0%)	12 (100.0%)
	Session 2	7 (58.3%)	10 (83.3%)
Education (highest level achieved) <sup>a</sup>	Less than high school degree	1 (8.3%)	0 (0%)
	Graduated high school	0 (0.0%)	1 (8.3%)
	Some college	5(14.7%)	4 (33.3%)
	Associates/technical degree	2 (16.7%)	4 (33.3%)
	Bachelor’s degree	2 (16.7%)	0 (0.0%)
	Advanced degree	2 (16.7%)	3 (25.0%)
Speak more than one language	Yes	7 (58.3%)	11 (91.7%)
English language proficiency	Not at all / A little	0 (0.0%)	1 (8.3%)
	Somewhat well / Very well	12 (100.0%)	11 (91.7%)
Tribal language proficiency	Not at all / A little	8 (66.6%)	5 (41.7%)
	Somewhat well / Very well	4 (33.3%)	7 (58.3%)
School system attended at some point in education	Public school	8 (66.6%)	11 (91.7%)
	Mission school	1 (8.3%)	1 (8.3%)
	BIA <sup>b</sup> day school	4 (33.3%)	2 (16.7%)
	Religious or parochial school	2 (16.7%)	3 (25.0%)
	BIA <sup>b</sup> boarding school	3 (25.0%)	7 (58.3%)

<sup>a</sup> There was one value missing for women; <sup>b</sup> = Bureau of Indian Affairs;

**Qualitative Analyses**

**End-of-Session Questionnaire**

Responses to this questionnaire were classified into six overarching themes that encompassed different experiences during the sessions included: 1) Reminiscing or remembering, 2) Reflecting or self-insight, 3) Benefits related to participation in the study, 4) Experiences with team members, 5) Feedback for the study, and 6) Experiences directly related to the assessment or interview process.

**Theme 1: Reminiscing or Remembering**

Within the reminiscing theme, nine participants reported good experiences while remembering prior events. A male in his fifties expressed: “For a minute here, I was back in [hometown] with all my friends, it really made me feel good.” Neutral statements also were observed among three participants such as “It brought my memories back within me” (female in late fifties). Seven participants also remembered negative incidents. In response to a question about which components were more anxiety provoking, the same female participant stated: “The part where I was talking about my dad, who has passed. Talking about my family, mom, grandpa and how I grew up as a low income family.”

**Theme 2: Reflecting or Self-insight**

Participants also shared subjective experiences that went further than simply remembering. We classified these as reflection or self-insight. Seven participants included statements that can be conceptualized as positive reflections, such as “Made me think of how much I have done. People I forgot. Places I’ve been. Things that I have done and experienced that made me what I am today” (female in mid-fifties) and “Education is greatly needed for oneself. Just looking back at where I was and how I came forward and still would like to learn more” (female in late sixties). Eight participants reported insights that were conceptualized as negative due to their emotions. They were not necessarily related to the session, but to reflecting on cultural values and practices overall: “The last questions, because they made me cry and I felt guilty about how I don’t practice my culture more when I know I can” (female in her sixties responding to the question about which study portions were more anxiety inducing). It is worth noting that the last questions on the second session are related to historical losses experiences by AI/ANs, such as loss of land and languages. (Whitbeck, Adams, Hoyt, & Chen, 2004). Other reflections ( $n = 9$ ) were neutral, including statements such as “It gave me back my reality about life as a young person. Also understood how everything has changed over all as I grow up from a young lady to an elderly person to this present,” made by a female in her fifties. Finally, five participants made statements indicating some intention for future action: “Depressed. Especially the last ones. But I am going home and will try harder to help my children understand why our culture and traditions are so important” (female participant in her sixties, referring to historical Native losses).

### **Theme 3: Benefits Related to Participation in the Study**

Participants also spoke about personal benefits as a result of participating in the study. Twenty-nine separate statements referred to having fun or being excited. A male in his late fifties stated: “It really made me feel good. This was really exciting for me and I really enjoyed it” and “It felt good. I love doing and taking these questionnaires. Bring them on.” Two participants reported feeling understood: “It made me feel I am not alone” (female in her late fifties), while six others reported that they enjoyed telling their story: “It felt good to share my past journey because they were my milestones. And someone was actually open to listen and take the time to do so” (female in her mid fifties). Moreover, 10 participants reported feeling as if they were making a difference and wanting to help: “I am glad to see a study come about education. I’m glad to help, it may answer some questions and be some help to the next generation. I was impressed very much” (female in early sixties) and “I just hope my answers help in some ways” (female in her late sixties). Three participants indicated wanting to share more: “I wanted to say more...to tell you all I feel” (female, late sixties) and “Wish we had more talks and time” (female, early sixties).

### **Theme 4: Experiences with Team Members**

In many cases ( $n = 12$ ), participants made comments related to team members, their race/ethnicity, and their kindness and willingness to listen and make them feel comfortable. A female in her late sixties stated “You, [team member’s name], really helped me out and helped me understand. I could ask you. That’s really good and you were really kind.” Another female in her early sixties wrote “I was very comfortable speaking to a Native American woman. I felt they understood me and I didn’t have to explain very much because they know where I was coming from.”

### **Theme 5: Feedback for the Study**

Furthermore, several quotations related to feedback for the study. First, some included statements related to being happy for the study ( $n = 5$ ): “I think it’s good that something like this is been done to help our Natives in ways that they need help” (female in late sixties). Second, 35 quotations related to general feedback for the study, including wanting coffee, liking our colored paper, thanking us for the water and the snacks, wanting to watch some culturally related videos, and so on. Eighteen of these 35 quotations did not include any feedback or suggestions for improvement.

**Theme 6: Experiences Directly Related to the Assessment or Interview Process**

Finally, the last theme was related to experiences directly pertaining to the interview or assessment process. Many participants reported positive experiences. Thirty-three quotations reflected general positive experiences such as “Very interesting. I enjoy it. Felt no anxiety. Pleasant experience” made by a male in his late sixties, while 4 other quotations showed that participants enjoyed exercising their brains and being challenged by the assessments: “I enjoyed working my brain, besides just reading” (female in early sixties) and “First, using my brains, i.e., getting it off the shelf for usage. A good exercise makes you think to the max until your brain trips out—refuses to think” (male in early seventies). Twenty-six other quotations were classified as neutral in terms of assessment related experience, for instance: “OK. Not too complicated or feel in any way uncomfortable with it” (female in late fifties).

The last category within this assessment or interview-related theme pertained to different types of negative experiences. Of these, 10 were coded as general negative experiences: “It was challenging for me when timing was part of the assessment” (female in mid fifties). Six quotations were classified as negative, but due to participants’ desire to perform well: “It made me feel bad that I could not do a lot of the stuff. I want an A” (male in late sixties). Nine quotations related to negative experiences, particularly regarding math assessment in the education achievement component. For instance, in response to which questions were more anxiety provoking, a male participant in his late fifties wrote: “The math, I do not like math. Never did.” Finally, five quotations were related to the historical Native losses questionnaire and realizations of losing values and cultural practices. A female in her sixties wrote in response to the question about which components were more anxiety provoking: “The last questions because they made me cry and felt guilty about how I don’t practice my culture more when I know I can. Thank you for helping me realize this,” and, in response to a question about what she thought the study was trying to assess, “To see if American Indians really care about our culture and traditions. Or to see how much we have assimilated. I feel like crying and tears are welling up in my eyes.”

**DISCUSSION**

Conducting research with members of tribal communities requires sensitivity to the justifiable mistrust of researchers by many tribal communities (Norton & Manson, 1996), with particular attention to issues of relationship and reciprocity (Holkup et al., 2009). The qualitative results emphasize the power of CBPR and of conducting assessments in a culturally appropriate

manner. A large portion of participants reported that they enjoyed remembering stories of their childhood and education experiences. In addition to simply remembering past events, participants reported having insights into their life stories, and some reported a commitment to changing their behavior going forward as a result of these insights (e.g., teaching their children more about their culture). Many participants reported some personal benefit as a result of their participation in the study. These included having fun, feeling understood, having an opportunity to tell their story, and feeling like they were making a difference; some even expressed a desire to spend more time with their interviewers to share more. We also found some evidence in the participants' feedback that having a diverse team of researchers made a significant difference during the assessments. This finding further exemplifies the need for racially/ethnically diverse researchers and professionals who may be able to work more effectively with, and gain the trust of, AI/AN communities. We also were encouraged by the number of participants who reported being glad that we were doing the study, and who reported not having any suggestions for improvement. Our team also paid close attention to the presence of anxiety during the interview and assessment portions, and to any potential signs of distress among participants. While some participants reported anxiety, particularly around academic achievement measures (i.e., math-related assessments), most reported good or neutral experiences. Some negative experiences also can be attributed to participants wanting to excel during the assessments, or, as stated by a participant, to "get an A."

It is worth noting that many negative experiences reported by participants were not necessarily due to the study, but were a reflection of their often-traumatic history and harsh lives—stories that often are silenced or ignored in the larger U.S. society. While not the topic of the present paper, descriptions of abuse and neglect in school settings, of extreme poverty and of loss (both personal and cultural) were substantial among participants. Some of these were reported on the end-of-session questionnaire as being somewhat difficult or sad for participants to talk about. In particular, several of the quotations captured by our themes were reflections made after questions about historical Native loss during the optional Session 2. The participants' willingness to share deeply private and traumatic stories with us reflects positively on the research team's ability to establish rapport and trust with them, and demonstrates the team's commitment to providing benefits to them and the overall AI/AN community. In addition, a majority of the participants returned for the optional Session 2. These results appear to indicate positive experiences for participants overall, likely due to the study team's CBPR approach, and success in establishing collaborative relationships with the CAC and the participants both before

and during the data collection process. Also significant to the success of this study was the research team's ability to understand and respond to cultural nuances, both in observed behavior and oral expressions. Our team was able to place interactions and comments within the larger context of marginalization and trauma often experienced by participants and to validate them while participants shared their stories, thus building trust and rapport.

Our findings contrast greatly with past research in Native communities, which often has been unhelpful and unethical (Hodge, 2012), or has had iatrogenic effects (e.g., exploitation; Walters et al., 2009). Thus, the project and methods reflect a potentially useful approach for conducting qualitative wellness research with Native elders and other AI/AN subpopulations.

This study aligns well with the key principles of CBPR presented in the Introduction. In using co-learning as the first key principle (Wallerstein & Duran, 2006), CBPR acknowledges the expertise of tribal and non-tribal communities and the fact that learning is a bi-directional and reciprocal process, rather than a hierarchical one. In this project, approaching urban AIs early on contributed to a research process that was participatory and collaborative and focused on engaging and sustaining co-learning from the partnership. CBPR focuses on the experience and expertise of the very community with which it seeks to partner and from which it seeks to co-learn. The second CBPR principle seeks to build capacity, and this project focused on engaging AIs in the feedback and design of culturally sensitive assessments used to learn about older AIs' early childhood experiences and health. The CAC provided training to the research assistants regarding culturally designed instrumentation questions, and the project provided insight and training on how this type of research usually was conducted with non-tribal populations. As part of the third CBPR principle, the findings benefit tribal communities by furthering the knowledge base for improving the health of Native elders. Also critical to the findings was the research team's sensitivity to, and ability to address, many of the cultural nuances that were embedded in the way participants communicated information, and the team's ability to respond to questions from a culturally experienced context. The fourth principle of CBPR involves long-term commitments to reduce disparities. There are few studies that focus on Native elder health from which more culturally appropriate policy-based interventions can be designed. Taken together, the CBPR approach used in this project indicates critical steps toward promoting wellness in Native communities.

Spontaneous responses provided by some participants also indicated a sense of wellness developing within the sessions. These statements referred to progress over one's lifetime, importance of education and continuing education, recognition of historical Native loss, and

educating children and future generations about the importance of AI culture. Some participants expressed appreciation for the opportunity to share their stories and felt understood by the team members. Furthermore, some participants reported that research is important for the health and welfare of AI communities. Such statements are consistent with theories and reports that qualitative interviewing speaks to the importance, healing capacity, and the human necessity of telling one's story (Madison, 2012; Polkinghorne, 1988; Pollock, 2005).

### **Study Limitations**

This study has several limitations. First, the sample was from a Southwest urban Indian population and likely does not represent the vast diversity of the 567 federally recognized tribes (U.S. Department of the Interior, Indian Affairs, 2016) distributed throughout the U.S. Much cultural and education diversity exists among tribal groups and individuals within a tribe. Furthermore, much variation exists along the acculturation/assimilation continuum among AI/ANs; this variation may not have been represented in this sample. Assessment sessions were conducted in English, and likely would not represent experiences of individuals who speak their tribal language predominantly. Also, we present a qualitative analysis of the engagement of the AI participants, by prompting for perceptions and feedback with open-ended questions at the end of the session; that is, we did not directly ask specific questions to test specific hypothesis about their responses. However, this qualitative interviewing technique likely allowed for more spontaneous and genuine responses than specific questions would have. Finally, we did not test the CBPR approach directly versus other research approaches. However, previous approaches have been less effective and sometimes harmful, and simply using a CBPR approach may have been the only ethical choice to avoid causing harm or distress.

## **CONCLUSIONS AND FUTURE DIRECTIONS**

This study presents preliminary evidence that culturally sensitive and designed assessments successfully engage older AIs, and likely obtain more valid information from AIs than many traditional research approaches. The findings suggest that AI participants, who historically have been mistreated through research endeavors and often are still wary of research sessions, actively engaged in answering interview questions regarding early education experiences that have traumatized Native communities and individuals. Furthermore, successful engagement of the CAC and AI participants in this project provides support for CBPR and

qualitative interviewing as a strength-based approach to wellness in Indian Country. The CBPR approach and the CAC were critical and invaluable in the success of this project. Based on the findings, we recommend identifying diverse community members who can serve as members of a Native CAC and incorporating key CBPR principles when conducting research with Native communities in both rural and urban settings. This participatory approach is especially critical when the research project encroaches upon culturally sensitive information that may yield valuable insights into reducing health disparities in the longer term.

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### ACKNOWLEDGEMENTS

This work was funded by the Robert Wood Johnson Foundation Center for Health Policy at UNM, and the Grice Foundation through the Department of Psychology, University of New Mexico. We are grateful for the Community Advisory Committee's wisdom and dedication that make this project possible. We offer special thanks to our research assistants, Justina Avila, Celina Herrera, Ivette Miramontes, Latisha Beth Rico, Andreina "Suzie" Sainvilmar and Estrella Villicana, for their help in recruitment and data entry. We are also very grateful to the American Indian participants who volunteered and genuinely engaged in the study.

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