

## Volume 23, Issue 3, 2016

# Centers for American Indian & Alaska Native Health

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## American Indian and Alaska Native Mental Health Research

### Volume 23, Number 3, 2016

Editor-in-Chief Spero M. Manson, PhD

#### Journal Manager Natasha Floersch

Introduction Jami Bartgis, PhD	i
Indigenous youth-developed self-assessment: The Personal Balance Tool Rachelle Barraza, Jami Bartgis, PhD, and Fresno Youth Council	1
Women finding the way: American Indian women leading intervention research in Native communitie Maria Yellow Horse Brave Heart, PhD, Josephine Chase, MSW, PhD, Jennifer Elkins, PhD, MSSW, Jennifer Martin, BSW, Jennifer Nanez, MSW, LMSW, and Jennifer Mootz, PhD	ies 24
The intersection of software and strengths: Using internet technology and case management softwa to assist Strength-Based Practice <i>Michael D. Clark, MSW and Dale W. Brien</i>	are 48
In their own words: Success stories from The Great Lakes Native American Research Center for Health Matthew Dellinger, PhD, Brian Jackson, MEd, and Amy Poupart	h 68
Ego strengths, racial/ethnic identity, and well-being among North American Indian/First Nation adolescents Barbara Gfellner, PhD	87
American Indian Elders' resilience: Sources of strength for building a healthy future for youth Carmella B. Kahn, MPH, Kerstin Reinschmidt, PhD, Nicolette I. Teufel-Shone, PhD, Christina E. Oré, MPH, Michele Henson, MPH, and Agnes Attakai, MPA	117
American Indian and Alaska Native resilience along the life course and across generations: A literatur review	re
	134
Continued on next page	

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Native Transformations in the Pacific Northwest: A strength-based model of protection against substance use disorder	
Stacy Rasmus, PhD, James Allen, PhD, William Connor, PhD, William Freeman, PhD, Native Transformations Community Action Board, and Monica Skewes, PhD	158
Partnering with American Indian communities in strength-based collaborative health research: Guid principles from the Fort Peck Ceremony of Research Project	ing
Elizabeth Rink, PhD, MSW, Elizabeth Ann R. Bird, PhD, Kris Fourstar, BS, Adriann Ricker, MPH, Winona Runs-Above/Meyers, AA, and Rachel Hallum-Montes, PhD	187
Strength-based well-being indicators for Indigenous children and families: A literature review of indigenous communities' identified well-being indicators Jennifer Rountree, PhD and Addie Smith, MSW, JD	206
Perceptions and use of community- and school-based behavioral health services among urban American Indian/Alaska Native youth and families Julie Salvador, PhD, Jessica Goodkind, PhD, and Sarah Feldstein Ewing, PhD	221
Entrepreneurship education: A strength-based approach to substance use and suicide prevention for American Indian adolescents Lauren Tingey, PhD, Francene Larzelere-Hinton, BA, Novalene Goklish, BS, Allison Ingalls, MPH, Todd Craft, Feather Sprengeler, Courtney McGuire, MPH, and Allison Barlow, PhD, MPH	or 248
Culturally sensitive assessments as a strength-based approach to wellness in Native communities: A community-based participatory research project Steven P. Verney, PhD, Magdalena Avila, PhD, Patricia Rodríguez Espinosa, MS, Cecilia Brooke Cholka, MS, Jennifer G. Benson, MS, Aisha Baloo, BS, and Caitlin Devin Pozernick, BS	271

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#### INTRODUCTION

#### Jami Bartgis, PhD

It is with great pleasure that we release the first special issue on *Strength-based Approaches to Wellness in Indian Country* in the journal *American Indian and Alaska Native Mental Health Research*. This issue includes a wide range of articles that address how strength-and resilience-based approaches can support public health policy, research, and practice improvements broadly to better serve Indigenous peoples. It is my hope that this special issue inspires public health policy makers, researchers, and health care professionals to challenge the current paradigm for working with Indigenous populations and to support more strength-based and culturally congruent models. To do this, we must think outside the box and build on the inherent strengths that lie within Indigenous communities in a number of ways.

First, strength-based approaches to health and wellness in tribal communities are not new, but are embedded in diverse tribal best practices, established by systematic observation over centuries, that have been passed down orally from generation to generation. The oral transmission of tribal best practices results in increased supervision and fidelity through a one-on-one mentorship model in which training typically occurs over decades. Two articles published in this special issue identify tribal science as "Indigenous ways of knowing." Unlike randomized clinical trials used Western science, tribal science has collected knowledge of long-term effects of practices that are in tune to the role of the environment. For example, Brave Heart and colleagues address tribal best practices for healing from historical and intergenerational trauma, and Tingey and colleagues address the potential of entrepreneurship education to improve environmental conditions for the promotion of sobriety and life (i.e., prevention of substance abuse and suicide). I acknowledge these diverse tribal best practices and worldviews are an important foundation of *Strength-based Approaches to Wellness in Indian Country*.

Second, unlike Western health beliefs, tribal worldviews recognize the "whole" person within the context of the environment and implement tribal best practices that are holistic in approach, including the entire family and spirituality. In effect, health and spirituality are not separated, but integrated. You will learn more about the holistic model in the article by Rountree

and Smith that examines the literature from a relational worldview, identifying key resilience factors for Indigenous peoples. I acknowledge the importance of holistic medicine and healing practices as a strength-based approach passed down using Indigenous methods for serving tribal and urban Indian communities.

Third, inherent in many tribal worldviews is the concept that "energy follows thought." While the exact expressions, applications, and practices of this concept vary significantly from tribe to tribe, it has important implications for our collective work in public health. In many tribal cultures, the concept that energy follows thought is applied to day-to-day living in diverse ways. As examples, one should not cook food for the family when experiencing a negative mood or the food will taste bad; one should not speak ill of others, as doing so might make them sick; one should not predict a negative event happening in the future or one could make it happen; and one should not participate in dancing during a time of mourning, as doing so may pass that grief on to others. While outsiders may consider this concept and the various applications to be superstitions, tall tales, or myths, they actually have a basis in Western science, and the Indigenous ways of knowing may be much more advanced than current Western science.

The first Western scientific advancement in the field of behavioral health to support this *thought energy* concept is Cognitive Behavioral Therapy (CBT). CBT is the most commonly accepted intervention for a wide range of mental and behavioral health issues; it is based on the general idea that what a person thinks or says through self-talk will impact how that person feels, and how the person feels will then impact how that person interacts with the world. Hence, CBT teaches people to restructure thinking (i.e., thought) to be more positive and realistic so that it may impact their feelings and behaviors (i.e., energy). CBT also has important implications for family and other interpersonal relationships: if a person changes his/her behavior toward others, then they may change their response to the person.

The second Western scientific advancement to support the concept that energy follows thought is the self-fulfilling prophecy. In a hallmark study by Robert Rosenthal and Lenore Jacobson, teachers actually influenced the achievements of randomly selected students just by being led to believe that these students were "late bloomers" and were going to excel in the classroom. Hence, teacher expectations (i.e., thought) of students actually impacted the student performance (i.e., energy).

I propose that the energy we create in public health matters for addressing the health disparities of tribal peoples—both for those trying to recover from mental illness or behavioral conditions, and for the lives of all people through the expectations we set for them. You will see

this highlighted in this special issue. For example, Clark identifies how "out of balance" current clinical assessments are because they only assess deficits, and further hypothesizes that such assessments may pathologize individuals. This idea is backed up by Barraza and youth colleagues, who are publishing a youth-developed self-assessment tool; they identify that deficit-based assessments may decrease youth motivation to get help and could negatively impact their outlook on life. While I believe Western scientific advances have hardly begun to explore how our *thought energy* can impact us and the world around us, they do provide important ideas for us to consider about the energy we are creating in our professional lives and what impact that might have on Indigenous peoples.

At the policy level, federally funded grant programs typically create silos by requiring an often exclusive focus on an illness, disease, or problem. Clark refers to this as the "stranglehold that silos and categorical financing have wrought on [Indigenous] communities." Grants often require the measurement of a disease or illness and, more often, require the use of evidence-based practices that have not been created or tested for diverse tribal peoples. As policy makers we must ask ourselves: What energy are we creating when we silo a person's health by requiring exclusive focus on substance abuse within federal grant programs for Indian Country, without attending to the underlying current and historical trauma driving many addictions? What energy are we creating when we require measurement of negative experiences exclusively? How did we get to the place where we would impose practices on a community for whom the evidence base does not exist?

At the research level, we develop standardized screenings, assessment tools, and research methods that tend to be similar. While there are many measures of depression and hopelessness, it is much more difficult to find measures of happiness and hopefulness. How did it happen that, in our expert research opinions, we thought it was more valid and meaningful to measure the worst side of life than the best? What energy might that create for a behavioral health patient on a first visit filling out the assessment packet, in a profession where a significant number of patients drop out after the first session?

At the practice level, we implement evidence-based interventions that are normed on a few populations. We make a diagnosis and develop a treatment plan that is focused on addressing the problem/illness/condition. Unless a system of care is being implemented, the treatment and interventions are distinctly separate and there is generally a failure to include spirituality as a part of holistic health. Rarely do practitioners attend to the whole person within

their environment through the coordination of comprehensive services. What kind of energy do our intake processes and treatment interventions bring to patients? Does this energy impact people's willingness to seek care? Does this energy impact the outcomes patients achieve?

While the U.S. public health model has given some attention to the importance of strength-based approaches like those inherent within Indigenous worldviews, the current initiatives being rolled out to Indian Country continue to be focused primarily on problems, illness, and disease and to emphasize these as "real outcomes" over health promotion and wellbeing. Because the current federal initiatives separate physical health, mental health, and substance abuse, and create other silos based on a linear worldview, they are often in opposition to the worldviews of local tribal communities and may be contributing to ongoing health disparities. As an example, tribal communities have been experiencing youth suicide disparities for over 40 years and have continually struggled to be allowed to use tribal best practices as an intervention for a number of reasons (e.g., historical prohibition of tribal religious health practices, requirements to use evidence-based practices, lack of acceptance of Indigenous ways of knowing in Western science).

As we work to implement culturally appropriate models of care, it is critical that policy, practice, and research consistently support tribes and urban Indian organizations to implement strength-based strategies that are grounded in local community beliefs about health and wellbeing if we are ever to improve health disparities. Brave Heart and colleagues call on us to stop "pathologizing explanations for disparities." We believe that this special issue will allow us to raise the visibility of strength-based wellness approaches in Indian Country and highlight the great work that is already being done in policy, research, and practice. We also believe that this special issue will begin to raise challenges of the current public health approach toward Indigenous communities and to generate solutions that will better fit diverse tribal worldviews while improving the health and well-being of tribal populations.

I am very thankful for the dedication and commitment of the Journal Manager at *American Indian and Alaska Native Mental Health Research* who worked tirelessly to publish this special issue. Without her this special issue would not have been possible. I am also thankful to Dr. Spero M. Manson, Editor in Chief, for the commitment to publishing an online peer-reviewed journal to support access and learning for Indigenous communities. Most importantly, I am thankful for all of the incredible scholars who submitted and are publishing articles in this issue as they are leading the way in improving the conditions of tribal populations.

I hope that you enjoy this special issue on strength-based approaches and that it advances your thinking about the energy you create in the role you serve to address health disparities for Indigenous peoples.

Wado (Thank you), Jami Bartgis, PhD

#### REFERENCE

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## INDIGENOUS YOUTH-DEVELOPED SELF-ASSESSMENT: THE PERSONAL BALANCE TOOL

Rachelle Barraza, Jami Bartgis, PhD, and Fresno Native Youth Council

Abstract: The Fresno American Indian Health Project (FAIHP) Youth Council developed and pilot tested a strength-based, holistic, and youthfriendly self-assessment tool grounded in the Medicine Wheel, a framework and theoretical orientation for teaching wellness in many tribal communities. This paper summarizes the development of the Youth Personal Balance Tool and the methods used for tool revisions through two separate pilot studies and ongoing process evaluations across 3 years. Using a community-based participatory evaluation model, FAIHP leveraged community resources to implement an annual youth Gathering of Native Americans to support youth in healing from historical and intergenerational trauma and restoring communities to balance by making them a part of the solution. This tool is one of many outcomes of their work. The Youth Council is offering the tool as a gift (in line with the cultural value of generosity) to other Indigenous communities that are searching for culturally competent self-assessment tools for youth. The authors believe this tool has the potential to progress the field in strengthbased, holistic, youth-friendly assessment as a culturally competent method for Indigenous evaluation and research.

#### INTRODUCTION

In 2011, the Fresno American Indian Health Project (FAIHP) was awarded a 3-year planning grant from the Substance Abuse and Mental Health Services Administration (SAMHSA), entitled Circles of Care, to support the Fresno Native community in developing a comprehensive plan for implementing a system of care that would meet the needs of local Native youth and families in Fresno, California. To support these efforts, FAIHP used a community-based participatory research (CBPR) model. CBPR is a model for research and evaluation that engages the community as an active and equal partner, builds upon local strengths and resources, integrates community knowledge and wisdom, values the voice of consumer experts, and returns

data to the community where the results can have the greatest effects for improving the health and well-being of local families (LaVeaux & Christopher, 2009; Minkler & Wallerstein, 2008). Through this process, FAIHP mobilized a Youth Council to provide youth a voice and involvement in the project. The Youth Council was an integral part of, and made a number of contributions to, the Circles of Care project, including the development and interpretation of a youth survey; the development and implementation of a youth Photovoice project; strategic planning to support the development of a system of care model through an annual community event, Gathering of Native Americans (GONA); and the development of the self-assessment tool that will be presented in this article.

#### **Purpose of Paper**

The primary purpose of this paper is to describe the process used by the Youth Council to adapt and develop a self-assessment tool, Personal Balance, and to provide the tool as a gift to other communities from the Fresno youth. However, this paper also serves two additional purposes: 1) to highlight the community-driven evidence base of GONA that has been the guiding framework and change agent for the project, and 2) to act as a forum to begin raising awareness of the importance of strength-based, holistic, and youth-friendly self-assessment as a culturally competent method for Native communities implementing a system of care to address youth with mental health needs or for prevention.

While facing challenges, including discouragement and skepticism from some professionals within national and academic settings regarding the use of strength-based measurement approaches, FAIHP is committed to implementing such approaches in service and assessment to be congruent with the cultural beliefs and worldview of the community served. It is our hope that the work of the Youth Council will highlight the importance of strength-based interventions and assessments, as well as the ability of youth to make substantial contributions to the implementation of a system of care. It is also our hope that this tool will be useful to other communities wanting to support these approaches for youth self-assessment. It is important to note that this article is based on the local knowledge and experience of the Fresno Native community, and the work was driven by local youth.

#### GONA

GONA is a community intervention model that is tied to a major annual event; it is used by FAIHP to support Fresno urban Native and area Rancherias/tribal youth and their families to begin healing from historical and intergenerational trauma, and for strategic planning and sustainability for a system of care. GONA is a 20-year-old manualized curriculum developed by intertribal mental health providers, leaders, and community healers with funds from the Center on Substance Abuse Prevention at SAMHSA. Few published studies have examined process or outcomes of GONA (Aguilera & Plasencia, 2005; Chino & DeBruyn, 2006; Nelson & Tom, 2011).

While the intervention was developed for substance abuse prevention, at its core, GONA addresses historical and intergenerational trauma to bring youth and families back to balance using local tribal teachings. In this respect, GONA is a strength-based prevention program. It is implemented through a 4-day event that teaches youth ages 12-18 years four basic themes of living that have a strong basis in Indigenous worldview: Belonging, Mastery, Interdependence, and Generosity. GONA works to reduce risks, such as substance abuse and suicide, and increase protective factors by building assets based on these four themes. At the event, youth learn about how they belong within their history and cultures (Belonging); the gifts they have been given upon birth to learn to use for community service, and the importance of healing from historical and intergenerational trauma to effectively master those gifts (Mastery); the roles all community members have to support and contribute to one another (Interdependence); and the importance of giving back by sharing individual gifts and talents within the community to help maintain positive health and well-being (Generosity).

Further, the curriculum addresses real-world issues that youth are facing as a result of historical and intergenerational trauma, including substance abuse, depression, suicide, gang violence, abuse, and other issues that youth identify as concerns in the local community. The program focuses on building up cultural knowledge, identity, and connection to family and community with a focus on healing to move forward as a healthy community together. GONA allows a community to define the four themes and discuss healing and prevention for future generations in the form of community-based strategic planning for youth and family services.

While all communities utilizing the GONA curriculum follow the same four themes and process, the content and discussion around the themes change based on the local culture and context. For example, one community may be struggling with prescription drug abuse while another is dealing with youth gangs. Communities also have unique cultural teachings, protocols

and ceremonies that would be utilized at the event. Each of these communities would go through the same process for determining how to address their local concerns, but the "problems," "solutions," and culture to address them will differ. Each year, the words of the youth that are expressed through GONA activities are presented to the FAIHP Board of Directors to guide policy and planning for the system of care.

#### Youth Council Involvement in Evaluation Activities and Program Planning

As the Circles of Care project began, FAIHP staff members mobilized quickly to develop a community advisory group, made up of adult community members. However, the Youth Council took over a year to formalize. At the beginning of the project, staff members worked with youth who attended the Youth Clubhouse at FAIHP and with an evaluator to support the Circles of Care evaluation activities. The Youth Clubhouse is a FAIHP-sponsored, communitybased youth prevention/health promotion center that supports school-age youth after school and for special events on weekends and during summers. Youth attendees provided early assistance in the development of a number of evaluation activities, including a youth survey to support a community needs assessment. While these youth were extremely helpful, there was still no coordinated effort to formalize a Youth Council reflecting a consistent youth voice on the project.

In 2012, FAIHP supported an 18-year-old high school senior (first author on this paper), a naturally emerging youth leader, to organize and formalize the Youth Council. To begin this process, she worked with FAIHP staff members to recruit Native youth ages 12-18 years to participate in a range of evaluation activities, including a Photovoice project and key informant interviews with elders. Involving youth in these evaluation activities increased their ability to identify community needs and strengths and to consider how they could be a part of community change and growth for the future. These activities also built the capacity of the Youth Council for its future work in adapting and pilot testing the Youth Personal Balance Tool.

#### METHODOLOGY

The development, pilot testing, and adaptations of the tool took the Youth Council 2 years to complete (see Table 1 for chronological timeline of events). The methods, described in detail below, included an interactive process for adapting the Adult Personal Balance Tool into a

form that would be applicable to youth, a pilot of the tool at the 2013 GONA, revisions to the tool based on youth feedback, a pilot of the tool at the 2014 GONA, and a final revision presented in this publication.

Chronological Timeline of Events: Youth Personal Balance Tool		
2013		
January	Youth Leader began recruitment to increase participants on the Youth Council	
February	Family-driven youth-guided training with Alan Rabideau and Shannon CrossBear	
March	Youth leader supported Youth Council in adaptation of Adult Personal Balance Tool to Youth Personal Balance Tool	
July	Planned and implemented first youth-driven pilot of the tool at GONA	
August	Revisions were made from the tool based on youth feedback from pilot	
September	Began disseminating the tool for consideration and use by other Native communities	
2014		
June	Tool approved by County of San Diego Behavioral Health Services for use by the San Diego American Indian Health Center as a youth-driven self-assessment tool as part of their Mental Health Services Act-funded PEI program	
July	Planned and implemented second youth-driven pilot of the tool at GONA	
August- October	Revised the tool to address measurement issues and to provide improvements based on youth feedback from the pilot	
October	Finalized Personal Balance Tool and began writing manuscript.	

Table 1

#### **Assent Process**

It is important to note that parental consent was not obtained for the development and pilot testing of the Youth Personal Balance Tool for a number of reasons. First, the process was a youth-developed initiative, inspired by their desire to have a better way of assessing their own health. Second, Personal Balance was as a teaching tool within GONA curriculum. During both pilots, youth completed and kept Personal Balance self-assessments, as the tool was a teaching activity and was not being used for evaluation purposes. Therefore, no personal data were collected from youth. Third, the questions asked during the pilots were related to development of the tool; again, no personal data were collected beyond basic demographics. Finally, this manuscript underwent formal review and approval by both the Youth Council and the adult community advisory group, which included parents and extended family of many of the participating youth.

While parental consent was not obtained, youth did support an assent process with one another. All youth who participated in pilot activities were adequately informed about the study and the voluntary nature of their participation, and were given the opportunity to ask questions at any time. This information included an overview of the purpose of the pilot; the types of questions that would be asked about how to improve the tool; the importance of keeping their completed tools confidential, as the tool represented their private information; the expected outcome of the pilot (i.e., to publish the tool as a gift for other communities); the fact that information provided to the youth facilitator about the revisions would remain confidential; and a reminder that participation was completely voluntary and there would be no negative consequences for anyone who chose not to participate.

Youth who assented were asked to provide oral confirmation that they understood the pilot study and were volunteering to participate. All youth recruited for the pilots chose to participate; none dissented. Incentives were privileges, like going to lunch first at the event, or gaining GONA tokens incorporated into the event to exchange for t-shirts and other small prizes.

#### **Adult Personal Balance Tool**

The Youth Personal Balance Tool was substantially adapted from a similar tool for adults. In the summer of 2013, FAIHP hosted a training with Alan Rabideau and Shannon CrossBear focused on youth and family engagement in developing a system of care. Mr. Rabideau and Ms. CrossBear provide important support to tribes and urban Indian organizations nationally in developing systems of care that are driven by youth and family voices. During this training, the presenters used an unpublished Personal Balance Tool they had developed for adults as a self-assessment of mental, physical, emotional, and spiritual health (A. Rabideau & S. CrossBear, personal communication, May 27, 2015). Respondents complete 20 items regarding their health by rating each on a 5-point scale. Each of the four health elements (mental, physical, emotional, and spiritual) constitutes 5 items. Then they must chart their responses on an actual Medicine Wheel so they can visualize the elements of health in which they are excelling and those that need improvement. The tool is also linked to traditional teachings about the Medicine Wheel so that participants can consider these elements in a cultural framework.

The participating youth identified with the self-assessment tool as strength based and holistic, but had concerns that it was not applicable to youth experiences. With encouragement from the presenters, the youth leader took the tool to a Youth Council meeting for review, and

the Council agreed to adapt it to be more relevant and friendly for Native youth. The youth believed that the revised tool would help them to assess their own holistic health (mind, heart, body, relational, and spirit) using a cultural framework for thinking about growth and change over the lifespan.

#### **Process for Adapting the Tool**

The adaptation of the Tool took place over a series of Youth Council meetings. To facilitate the adaptation, the youth leader read each question aloud to the other youth, and the entire Council had open discussion about how each item could be applied to youth. On some items, youth used visual aids to support the adaptation. For example, when revising the item about "responsibility," youth listed all the types of responsibilities they had. Once youth began making language suggestions, the youth leader would type them out and return them to the Council for additional discussion at subsequent meetings. Youth contemplated each item to ensure that 1) they all understood each item in the same way, 2) the item had relevance and meaning for youth, and 3) the adaptation still fit within the relevant quadrant of health (i.e., mental, physical, emotional, and spiritual). To ensure relevance, youth referred to the health quadrant definitions in the adult tool before and after item content revision. On one occasion, youth moved a content item into a different quadrant because they believed, through consensus, that the item was a better fit based on the GONA themes (Belonging, Mastery, Interdependence, Generosity). The FAIHP social marketing coordinator worked with the youth to make these changes in electronic form.

The Council kept much of the original design of the adult tool. The revised youth tool also contains 20 self-assessment items, 5 for each element of health. However, the youth made other significant adaptations, including completely changing much of the items' content, changing the colors and instruction layout, and changing the traditional teachings description so that it better matched the GONA curriculum that was being implemented in the local Fresno Native community. Nineteen of the 20 items on the tool underwent some change from the adult version focused on making them more relevant and understandable for youth. As noted earlier, when youth made substantial changes, they paid special attention to ensure that the adapted item still matched the health element that it was intended to measure.

#### Learning Example for Youth Readers:

Adult Tool Item: There is something in my life right now that is strictly about providing "service" to others.

Youth Tool Item Revision: I do things in my life just to help others (such as being there for someone in a tough time, volunteering, or helping elders; North, Mental, Elder, Generosity)

#### Medicine Wheel as the Personal Balance Tool Framework

As with the original tool developed for adults, the Youth Personal Balance Tool is based on the Medicine Wheel. The youth had numerous discussions about the tribal diversity and beliefs related to the Medicine Wheel. For example, some tribes use different colors to represent each of the four directions, many tribes believe there are seven directions, and still others do not use the Medicine Wheel at all. The youth identified the need to humbly apologize if the tool offends anyone, as this was not their intent. The Medicine Wheel represents a more Indigenous worldview for considering their own health and well-being, as compared to a linear, deficitbased approach (Cross, 2003).

In the tool, the four directions-east, south, west, north-represent the lifespan (i.e., infancy, childhood, adulthood, elderhood); the area of health (i.e., mental, physical, emotional, spiritual); and the GONA themes (i.e., belonging, mastery, interdependence, generosity). See Table 2. The colors were retained from the adult version, except that youth changed the color white to blue so they could "see it" with a crayon when they colored in their Medicine Wheels.

Description of the Four Directions		
EAST	Sense of Belonging: Personal pride, respect,	
Spiritual	connectedness, faith, prayer, purpose, vision, love	
Yellow	(INFANCY)	
SOUTH	Mastery of Skills/Gifts: self-esteem, accomplishments,	
Emotional	happiness and enjoyment, impulse/emotional control,	
Red	sensitivity, forgiveness, attitude (CHILDHOOD)	
WEST	Interdependence: Humility and accepting responsibility,	
Physical	practice and reaching your potential, power/control,	
Black	physical health, having vision/reaching goals (ADULTHOOD)	
NORTH	Generosity: Problem solving; wisdom; freedom from fear,	
Mental	hate, jealousy, etc.; commitment to lifelong learning and	
Blue	service; doing things in moderation; truth (ELDER)	

Table 2

While tribal stories related to the concept of a Medicine Wheel vary greatly, the four directions support individuals, families, and the broader community to maintain health and balance. An individual is born to the east and is closely connected to the spiritual while learning how he/she belongs in the world. The south represents the child that is closely connected to the emotional where he/she learns how to master the environment. The west represents adulthood and the increased responsibilities of supporting both youth and elder parents. This is the time when an individual is closely connected to the physical and is learning how to live in interdependence with others. Finally, to the north is elderhood, closely connected to the mental and a time when the individual is very generous, giving back wisdom to the community.

#### **Original Adaptation**

The development of the Youth Personal Balance Tool took several months during the first (original) adaptation process. The tool was also modified following the 2013 and 2014 pilot testing sessions to incorporate ideas for improvement from youth who participated in the focus groups. These modifications were minimal when compared to the original adaptation (see Appendix A for item-by-item comparison of the adaptations).

#### 2013 Pilot

Once the tool had been adapted from the adult version, the youth worked with the project evaluator to pilot test it at the 2013 GONA. The youth leader, who previously had attended GONA facilitator training, first facilitated the GONA mini-teaching on wellness using the Medicine Wheel as a part of the Day 3 GONA curriculum (for a copy of the curriculum, contact the SAMHSA Tribal Training and Technical Assistance Center at www.samhsa.gov/tribal-ttac) and then facilitated administration of the tool to a group of approximately 50 Native youth ages 12-18 years.

As part of the GONA curriculum, youth are divided into "Clans" (families) to mirror the structure of many tribal communities. Through these Clans, youth work together to develop a sense of belonging, mastery, interdependence, and generosity to contribute to the whole. At this GONA, youth were organized into seven Clans, each with seven youth members and a Clan Elder, who was a selected local adult. The project evaluator supported the pilot test by passing out copies of the tool, making sure youth had supplies, and answering questions from the youth leader about data collection activities. The youth leader reviewed instructions for completing the tool with all youth, and the Clan Elders provided support in a small-group setting. The youth

leader and the project evaluator circulated to provide one-on-one support (e.g., reading items aloud for youth who needed literacy support, answering questions). Youth then participated in a discussion of the tool questions related to strengths, areas needed for growth, and setting personal goals for improving one's balance. At the close of the session, a number of youth raised their hands and asked if they could "bring back [our] Medicine Wheel tool" next year so they could see what progress they had made.

Demographic data were collected on Day 1 as a part of a separate and ongoing cross-site evaluation of GONA, which is being conducted in partnership with the San Francisco Bay Area GONA and is evaluating youth outcomes at pre-, post-, and 6-month follow-up assessment points. While not all participating youth provided their demographic information, 38 of the participants in the cross-site evaluation pre-assessment group administration did report it, as shown in Table 3. In 2013, all youth identified as being AI, and some also identified an additional ethnic background, as they could select all ethnic groups that applied.

Table 2

Fresno GONA Demographics: 2013			
Age (years)	Range Mean Median Mode	12-18 13.9 14 12	
Gender	Female Male Transgender/Other Missing	18 (47.4%) 20 (52.6%) 0 0	
Sexual Orientation	Heterosexual Homosexual Bisexual I don't know Would rather not say Other Missing	32 (84.2%) 1 (2.6%) 1 (2.6%) 0 4 (10.5%) 0 0	
Ethnicity	American Indian Other Missing	38 (100%) <sup>a</sup> 0 0	

<sup>a</sup> Some youth identified an additional ethnic background: Hispanic (10), Caucasian (3), African American (2), Pacific Islander (1) Youth participating in the pilot were diverse in a number of ways. While the vast majority were members of a wide range of California tribes, there were several out-of-state tribes represented. The youth were also at varying levels on the continuum of care for behavioral health-related service (i.e., prevention, treatment, recovery support), and some were involved with child welfare and justice systems.

Immediately following the group administration of the tool, the youth leader asked for eight volunteers to provide input on how the tool could be improved. She selected diverse youth from those who raised their hands to participate. Four males and four females from various tribal and geographical backgrounds, both urban and rural, provided feedback in a targeted focus group. The youth leader led this focus group in a separate and private space with support from the project evaluator, who took notes on necessary changes and the impact of the tool for the participating youth. The questions asked during the focus group included: 1) What did you like most about the Youth Personal Balance Tool?; 2) In what ways could the tool be improved?; and 3) What did you learn from the tool, if anything?

Based on feedback from the 2013 pilot test, the Youth Council made a second adaptation and then disseminated it to national sources so that other communities could benefit immediately from its use. This process of dissemination resulted in increased interest among both tribal and urban Indian communities, and led to a second pilot and revision in 2014.

#### 2014 Pilot

By early summer 2014, the tool had reached the San Diego American Indian Health Center (SDAIHC), a neighboring urban Indian health organization that was searching for strength-based and youth-friendly assessment tools to measure the impact of their Youth Center, which is contracted with the County of San Diego, Behavioral Health Services Division, to provide prevention and early intervention programming for local Native youth in San Diego, funded by the California Mental Health Services Act (MHSA). SDAIHC presented the Youth Personal Balance Tool to their MHSA partners at the San Diego County Department of Mental Health, who approved the tool for youth self-assessment, as required by the MHSA-funded project.

However, after the youth conducted the second revision following the 2013 pilot, the San Diego County partners identified a few items that still needed improvement. Specifically, three items lists of options separated by "and," impacting the validity of the questions, as some youth may not experience all the options listed in the item.

#### Learning Example for Youth Readers:

"I do things in my life just to help others (such as being there for someone in a tough time, volunteering, and helping elders)." In this example, a young person might do one or two of these things, but not all three. How would the youth answer this question and still be accurate or valid?

Once the Youth Council received the news that the tool had been approved for use by Native youth in San Diego County, they became excited about working out these measurement challenges and re-piloting the tool. The Youth Council once again made changes (third adaptation) during a Council meeting a month later to improve the targeted items. The Council then began planning a second pilot test at the 2014 GONA that was scheduled for late summer.

In preparation for the 2014 pilot, the Youth Council met onsite at the GONA event with the youth leader and project evaluator to develop the methods and recruiting process for the pilot study. The Council determined they would replicate what they did in the 2013 pilot, with two improvements that would build more knowledge and skills for members. First, in the 2013 pilot, the youth leader recruited youth for the focus group by asking for volunteers, as she knew enough details about the youth to select a diverse sample from the volunteer pool. However, in 2014, the Youth Council members chose to recruit the focus group participants so they could learn and apply new evaluation skills.

The Youth Council members received training and consultation from the project evaluator on the history and purpose of an Institutional Review Board for the protection of the community, and on how to recruit in a way that honored youths' voices and choices. The training included a history of research with American Indian/Alaska Native (AI/AN) people and the importance of protecting and respecting the community. Youth learned about privacy and confidentiality and about the importance of voluntary and informed consent. The project evaluator provided practice scenarios, allowing the youth to problem solve collectively and ensuring they understood how to recruit youth as fully informed volunteers without coercion. The Youth Council members all made verbal agreements to one another that they would uphold the standards of voluntary and informed consent to protect themselves and other youth and to promote self-determination for young people.

On Day 3 of GONA, the youth leader implemented the wellness mini-teaching and facilitated a group administration of the tool with approximately 70 youth. Given the larger number of youth, there were 10 Clans with 10 Clan Elders. The methods were consistent with the

2013 pilot. Again, while not all youth present provided demographic information, data were available for 65. Many of these youth had attended the first GONA, and demographics were similar to those in 2013 (see Table 4).

Table 4Fresno GONA Demographics: 2014		
Age (years)	Range Mean Median Mode	12-17 13.8 13 13
Gender	Female Male Transgender/Other Missing	30 (46.2%) 26 (40.0%) 0 9 (13.8%)
Sexual Orientation	Heterosexual Homosexual Bisexual I don't know Would rather not say Other Missing	47 (72.3%) 2 (3.1%) 2 (3.1%) 2 (3.1%) 2 (3.1%) 2 (3.1%) 1 (1.5%) 9 (13.8%)
Ethnicity	American Indian Other Missing	52 (80.0%) <sup>a</sup> 4 (6.2%) 9 (13.8%)

<sup>a</sup> Some youth identified an additional ethnic background: Hispanic (16), Pacific Islander (3), Caucasian (2), African American (2), Asian (2)

Immediately following the group administration of the tool, six new youth were recruited by the Council members present to participate in the focus group for product improvement. The youth included three males and three females; five were from local California tribes that lived in the Fresno urban area and the surrounding tribal Rancherias, and one was from an out-of-state tribe. For the 2014 pilot, the Youth Council members chose to stay during the focus group to support the youth they recruited and to learn about the focus group process. This procedure differed from the 2013 pilot, when only the youth leader and project evaluator were present. It is possible that the presence of the Youth Council members impacted the feedback provided, but it is unknown if it increased or decreased feedback. On one hand, having known "peers" present could make the youth feel more comfortable to express their thoughts and ideas. On the other hand, it could have limited feedback from youth who may not have wanted to disagree with or risk disappointing others.

Before beginning the focus group, the youth leader reiterated that participation was completely voluntary and youth could leave at any time if they chose not to continue, without any penalty or negative impact. They were also informed that they were being asked to provide some input and feedback on what they thought about the Youth Personal Balance Tool they had just completed, and that the Youth Council hoped to publish the tool as a gift to other Native youth programs that want to support strength-based, holistic, youth-friendly self-assessment. This new information was provided only to the youth in 2014, as the decision to publish only came after San Diego County approved the tool. Youth were also informed that the publication format would be an online paper, so everyone could access the tool once it was accepted for publication. One youth asked how long it would take to be published, and the project evaluator advised that it would be at least a year. Youth were informed that they would not be asked to talk about how they answered items on the tool, as it was their own private tool for setting personal goals. They were also informed that their names would not be associated with the information they provided, but that some factors, including gender, their locations of residence (urban/rural), and a general description of the tribes they represented (California, non-California), would be identified. Each participant then was asked to give some verbal response if they agreed or disagreed. All youth confirmed their voluntary participation, and some expressed their excitement about a youth-developed and published tool.

#### **Final Tool Revision**

Following the 2014 pilot, the Youth Council made a final (fourth) adaptation based on the feedback provided. As with previous adaptations, the FAIHP social marketing coordinator replicated changes in electronic form. The final version is presented in Appendix A of this paper.

#### RESULTS

The results section highlights findings from the pilot focus groups and the lessons learned by FAIHP in engaging youth in evaluation activities. Each of these findings will be discussed.

#### 2013 Pilot

The youth participating in the focus group commented that the tool was easy to understand. They also noted the relevance of the items to young people, the positivity of the items, and the fact that the tool included all elements of their being (i.e., mental, physical, emotional, spiritual). The youth requested a number of specific changes to improve the tool's usefulness and clarity. For example, they wanted to use crayons instead of pencils so they could better see where they needed to improve. They also wanted to see the tool in color. Youth also indicated that the tool "really helped me learn areas in my life that I need to improve," that "it helped me set my own goals for all parts of me," and that, before using the tool, "I only ever thought about health in the physical." The initial reception of the tool by the youth participating at the 2013 Fresno GONA was encouraging.

#### 2014 Pilot

As in the first pilot study, youth made tangible suggestions, such as reorganizing the page order so instructions come sooner and changing the color white in the Medicine Wheel tool to turquoise, as some tribes use this color in their Medicine Wheel. This change was suggested to support usability and improve visual impact of areas of strength and needs for growth ("we can't see the color white"). Youth also struggled with three of the items and suggested changes to improve language clarity.

Youth from the focus group reported that the tool helped them learn more about their "inner-self" and "learn how to balance," that it gave them a better idea about health in all areas (i.e., mental, physical, emotional, spiritual), and that it supported them in considering where they wanted to grow and improve their own "whole" balance. One youth simply stated, "It helped me see that I need to work on [issue] and [issue]." Another youth reported, "I know what color [health area] I need to work on." Youth also discussed how different this tool was from what they normally experienced in health and prevention programs. They liked the tool much more than typical assessment instruments and noted that it was positive and more fun to complete. Observations made by the youth facilitator and the project evaluator during the facilitation indicated that some youth struggled to find the scale to reference because it was located after the items. Further, the smaller group instruction by Clan was critical to support the large number of youth in the pilot.

#### Lessons Learned for Engaging Youth in Evaluation and Planning

The youth leader who successfully supported the coordination of the Council reflected on a number of lessons she learned in engaging other youth and supporting partnership with staff members. First, engaging youth is often more challenging than engaging adults for developmental and historical reasons. Developmentally, adults and youth have different levels of language skill, and adults may use words or jargon that are unknown to youth, resulting in ongoing communication challenges and frustration. Historically, youth services and programs are built by adults with little input from or value placed on youth voice, leading youth to believe that their voice will not really matter. Due to such issues, a substantial amount of time and trust building is required to develop a common language and collective vision in youth-adult partnerships.

Second, FAIHP staff members recognized that having too many adults in the room limited youth responses at council meetings, so the staff-to-youth ratio during meetings has been decreased to 1-2 supporting adults for every 10 youth.

Third, youth wanted to have more informal meetings (i.e., oral discussions in a comfortable setting as opposed to paper-driven meetings in a board- or schoolroom setting), as they reported receiving enough structured activities at school. While a staff member documents the meeting minutes and youth feedback, the meetings are focused on topical discussions and/or project planning in a comfortable setting. As of the writing of this manuscript, the Youth Council continues to meet and provide direction and support to the local project.

To further support trust building, belonging, and bonding, the team integrated 'relational' reinforcements into the informal meetings. For example, the Council might go bowling and then have a discussion about agenda topics while eating a meal together. Fun, youth-developed activities directly linked to monthly Council meeting have led to increased participation.

The youth leader also reflected on the importance of having "patience" and being "persistent." She made phone calls to youth every week (sometimes multiple times a week) and worked with FAIHP to ensure youth had transportation to all events. These activities were necessary to support youth participation.

Finally, the youth reflected on the importance of staff members *doing what they say they will do*, and of learning to trust adults to follow through with their commitments. This finding also links to historical experiences of youth feeling they are being used as "tokens" in community grant programs (e.g., when they provide input but nothing observable changes within the system). FAIHP has learned the importance of informing youth about how the organization is using their input to take action for them, which has resulted in increased youth commitment to the evaluation and willingness to share their time and insight with adults.

Creating ongoing feedback loops to the Youth Council and Youth Clubhouse has been another effective strategy for increasing youth involvement with the evaluation and youth knowledge about how their voice is resulting in local changes. For example, at the annual GONA, the FAIHP Executive Director provides the attending youth with information about changes that were made to GONA because of youth input into the previous year's evaluation. Since 2012, the cross-site evaluation project being conducted in partnership with the San Francisco Bay Area GONA has collected longitudinal data for youth participating in the annual GONA. Each year youth are provided information about the study so they can give voluntary informed consent, and the vast majority of youth participate. In the 2015 Fresno GONA, 93% of the attending GONA youth participated in evaluation activities.

Today, the Youth Council continues to support FAIHP in the system of care implementation through a formal System of Care initiative funded by SAMHSA; this support includes ongoing review and assistance in the development of this article.

#### DISCUSSION

This youth-developed project provides a number of contributions to the literature for exploring strength-based models for assessment that are culturally competent. Over a 4-year process evaluation of the Circles of Care, and now through the System of Care initiative, the community has experienced a significant impact and positive outcomes using the GONA model, including the development of the Youth Personal Balance Tool that the youth modeled after the GONA themes. Although the lessons learned and best practices cannot be fully described in this manuscript, the impact has been documented through rigorous program evaluation on multiple levels. On the community level, GONA is supporting youth and families in building a stronger sense of identity, confidence, hope, and vision for the future, and in the belief that they are a part of the solution, as documented by mixed methods data (Bartgis, 2013, 2014, 2015). Over the course of the project, more than 20 youth and other community members have either entered academic institutions/continuing education programs or have gained employment in social or human services with county agencies, tribes, schools, and area AI/AN-serving organizations.

The program has also led to stronger connections with the community, as well as access to spiritual and cultural activities. For example, local elders have made personal commitments to supporting GONA, bringing in more cultural teachings and ceremonies each year, as requested by the youth. Volunteers are contributing on a daily basis to the local services at FAIHP, and volunteerism for GONA is substantial, exceeding over \$50,000 of in-kind support just over the 4-day event. Many families take a week of vacation, and some even take time off without pay, to attend. Others take time off to be trained as GONA facilitators. GONA has also supported an entire network of community partners, with multiple agencies sending some of their most vulnerable youth to participate and staff members of those agencies contributing in-kind service.

While GONA has made a significant impact, it is also important to acknowledge the complimentary and contributing model of CBPR and the role of the Circles of Care and System of Care. The CBPR process supports youth and families as equal partners in evaluation, and empowers them to use the data the community collects to create solutions. The data also have been used for local quality improvement and documenting best practices. Second, the funding and technical support provided through the Circles of Care and System of Care were critical resources for this effort. These resources, GONA as an adaptable cultural framework to guide the process, and CBPR as an evaluation capacity-building model were identified as the key ingredients for the Fresno area community's success. Today, the community is on the road to implementing a culturally competent, holistic system of care model, with human resources and partnerships that have the potential to be sustainable for generations to come.

The authors believe that the Youth Personal Balance Tool developed through this initiative serves as a youth-friendly and culturally competent self-assessment. There are few, if any, self-assessment tools that have been adequately tested and normed on AI/AN populations, and standardized tools currently used in the field may not adequately capture AI/ANs' cultural experiences, making them less effective for Indigenous populations (Beals et al., 2005; Demarchi, Bohanna, Baune, & Clough, 2012; Jimenez, Garroutte, Kundu, Morales, & Buchwald, 2011). The authors believe this to be the first youth-developed self-assessment tool that has ever been published by Native youth in the U.S. academic literature. While our team recognizes that this tool may never be adequately standardized due to the small size of the AI/AN population, we do believe that the tool can be useful in youth self-assessment and in setting personal goals for holistic health.

The authors also propose that the tool has the potential to make important contributions to the field as a model that better matches the worldview of Native communities. We suggest that the strength-based items, youth-friendly terms, and cultural grounding of the tool actually increase youth motivation to use it. One of the biggest challenges in the field of youth assessment is increasing participants' interest and motivation to complete tools accurately. This challenge can be even more pronounced in Native communities because of tribal/cultural beliefs about the power of positive and negative words (Goodkind, Gorman, Hess, Parker & Hough, 2014), and the fact that many health care systems rely on disease- or deficit-based methods and tools for measuring outcomes (Benjamin, 2011). Many tribal cultures believe that energy that can come from one's words and thoughts. Assessment items or measures that use negative terms, such as illness, disease, or problems, may result in negative thinking and behaving. On the other hand, measures listed in positive terms could have a related positive effect.

While more research is needed on the Personal Balance Tool and other related approaches, we hypothesize that strength-based and holistic approaches are more culturally competent and could be as reliable for tracking health status than are the current disease- and deficit-based tools most commonly used. Further, we would hypothesize that deficit-based assessment actually may decrease motivation for youth to change/grow and could negatively impact their outlook on life and willingness to participate in services.

Finally, we propose that the process of adapting and developing this tool demonstrates that youth can make important contributions to evaluation and highlights the usefulness of the CBPR process for engaging Indigenous youth. This tool is one of many products that the Youth Council supported through FAIHP Circles of Care initiative. We know it will not be the last.

#### Suggested Uses of the Youth Personal Balance Tool and Future Research

We suggest use of the Youth Personal Balance Tool as a process for supporting youth in self-assessment and setting personal holistic goals. This study did not use the tool to measure changes in holistic health for young people; rather, it allowed youth to keep their own tool as a resource for themselves.

When administering the tool it is important to have all of the right supplies ready, especially during group administration. It is important that the tool be printed in color with four colored crayons, corresponding to the colors on the Medicine Wheel, available to each participant.

For group administration during prevention programming, is it also very important to ensure there is plenty of space for youth to spread out. Given the tool uses color, it is easy see and some youth feel embarrassment if their tool does not have much color and others nearby can see it. Creating private space is very important so the youth can be open and honest with themselves without fear of others seeing. The authors believe that this tool also could be very useful in one-on-one settings to support youth in setting goals for a holistic health treatment plan. Future research should consider calculating a composite score for the 4 quadrants and a total score to examine the potential of the tool to capture health outcomes and to evaluate the influence of youth intervention programs. Future research also should examine the relationship between the tool and other measures used for assessing health outcomes for Native youth receiving services.

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#### ACKNOWLEDGEMENTS AND DISCLAIMERS

Tribal, Native, American Indian/Alaska Native, and Indigenous may be used interchangeably in this article, but the authors want to honor the incredible diversity of the youth who participated in this project and the diversity of tribal people around the world with similar historical experiences and overarching worldviews. Given this diversity, the Youth Personal Balance Tool may not be consistent with the beliefs of all Indigenous communities.

The Youth Council would like to acknowledge Shannon CrossBear and Alan Rabideau for their work in developing the Adult Personal Balance Tool and Mike Colvard for supporting the tool's graphics and multiple electronic revisions. The authors would like to acknowledge the larger team conducting a longitudinal evaluation of GONA outcomes for tribal youth since 2012. The team is a current partnership among the Fresno American Indian Health Project, Native American Health Center, Inc., California Consortium of Urban Indian Health, the National Council of Urban Indian Health, and the University of Oklahoma Health Sciences Center.

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	Adult Tool	Adapted Youth Tool
1.	I am the first to admit my mistakes and I take constructive criticism well.	I take responsibility for my mistakes and actions.
2.	I consider my options before making a decision and I ask for help when I need it.	I talk with elders about my options before making a decision.
3.	In addition to my family, I belong to at least two other groups, organizations, or clubs that I take an active role in.	I belong and actively participate in clubs and afterschool activities (church, sports, Native gatherings/ceremonies, etc.).
4.	I recognize when my children/others do well and I make an effort to tell them.	When my family and friends do well I try to tell them.
5.	I believe that "Practice makes perfect" and I recognize and I make strides towards improving the areas I need to.	I try to practice things I need to or can improve on, to reach my goals.
6.	I am "pro-active" rather than reactive and I try to consider what abilities and knowledge I must have prior to pursuing something.	I feel connected to my family.
7.	Each day I do something fun that I enjoy and I am usually more happy than sad.	Each day I do something positive that I enjoy. I'm usually happy.
8.	I complete all projects that I start and I try to find solutions or help before I give up on anything.	I do things in my life just to help others (such as being there for someone in a tough time, volunteering, or helping elders).
9.	People do things that I ask because they respect me and not by threat and I can accept things I cannot change.	Most people like me but if they don't I'm okay with it.
10.	In my life right now, I believe that I am free of fear, hate, jealousy, and selfishness.	I'm not afraid to step up to be a leader, role model, or mentor in my community.
11.	I can identify something in my life that I have a noble passion for. This passion is part of what I strive for everyday.	There is something that I have in my life right now that I have a passion for and am excited to do it everyday.
12.	I can control my impulses and emotions so that I do not do or say something that I will later regret.	I can usually control my reactions and emotions so that I don't do anything I will later regret.
13.	There is something in my life right now that is strictly about providing "services to others."	I feel safe (such as in the community, in my family or at school).
14.	I am committed to a goal of life-long learning such that I attend trainings, classes and other educational activities and I make a daily effort to learn something new.	I make an effort to learn something new everyday.
15.	I take care of my physical body by exercising, watching my diet and being careful as to what I take into my body.	I take care of my body (such as exercising, watching my diet, and/or choosing to be drug free)

Appendix A Adult Personal Balance Tool and Adapted Youth Personal Balance Tool Items

continued on next page

	Adult Tool	Adapted Youth Tool
16.	I have opportunities in my life to be a leader, role model or mentor and I earned this responsibility.	I have dreams or visions that help guide me.
17.	I am quick to forgive others that have hurt me and I try to place myself "in other's shoes" before making a judgment of them.	I am quick to forgive others that have hurt me and I try to place myself "in other's shoes" before making a judgment of them.
18.	When I find something that I really enjoy, I try to do it or experience it in moderation so that I do not become satiated by it.	When I find something I really enjoy, I do it in moderation. I try to balance it in my life so it doesn't take over everything I do.
19.	When I go to sleep my dreams help guide me and I have at least one "vision" for myself or another person close to me.	I am aware that my actions affect not only me but those around me.
20.	I believe that not everything has to be explained or have a rational reason. I can believe in things that are "unseen."	I believe that even though we can't see Creator or spiritual world, we know it exists.

Appendix A, continued Adult Personal Balance Tool and Adapted Youth Personal Balance Tool Items

## WOMEN FINDING THE WAY: AMERICAN INDIAN WOMEN LEADING INTERVENTION RESEARCH IN NATIVE COMMUNITIES

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Abstract: Although there is literature concentrating on cross-cultural approaches to academic and community partnerships with Native communities, few address the process and experiences of American Indian women leading federally funded and culturally grounded behavioral health intervention research in Native communities. This paper summarizes relevant literature on community-engaged research with Native communities, examines traditional roles and modern challenges for American Indian women, describes the culturally grounded collaborative process for the authors' behavioral health intervention development with Native communities, and considers emergent themes from our own research experiences navigating competing demands from mainstream and Native communities. It concludes with recommendations for supporting and enhancing resilience.

Despite the need for effective behavioral health interventions within American Indian and Alaska Native (AI/AN) treatment settings, few empirically supported or evidence-based treatments (EBTs) exist for AI/ANs (Gone & Alcantara, 2007; Gone & Trimble, 2012; Indian Health Services [IHS] National Tribal Advisory Committee on Behavioral Health & Behavioral Health Work Group, 2011). The high level of need among AI/ANs is reflected in the lifetime prevalence of any mental health disorder, ranging from 35% to 54% (Beals, Manson, et al., 2005; Beals, Novins, et al., 2005; Oetzel, Duran, Jiang, & Lucero, 2007). Mental health disorders rank in the top 10 leading causes of hospitalization and outpatient treatment within IHS (IHS, 2015). Disparities between AI/ANs and the general U.S. population across the lifespan in behavioral health persist, though much variability exists based on geographic region, cultural group, and gender (Allen, Levintova, & Mohatt, 2011; Denny, Holtzman, & Cobb, 2003; Espey et al., 2014; Gone & Trimble, 2012; Wexler, Silveira, & Bertone-Johnson, 2012).

Al/ANs also experience significant levels of historical trauma. Historical trauma is understood as the collective trauma exposure within and across generations, including interpersonal losses and unresolved grief (Brave Heart, 2003; Brave Heart, Chase, Elkins, & Altschul, 2011; Whitbeck, Adams, Hoyt, & Chen, 2004; Whitbeck, Chen, Hoyt, & Adams, 2004); as well, Al/ANs are at high risk for post-traumatic stress disorder (PTSD; Beals et al., 2013; Manson, Beals, Klein, Croy, & the AI-SUPERPFP Team, 2005; Tsosie et al., 2011). Many have emphasized that AI/AN mental health must be understood within the context of Al/AN histories of collective traumas and the damages those and subsequent traumas have caused in terms of culture, identity, and spirituality (Brave Heart, 1998, 1999a, 1999b; Gone & Alcantara, 2007; Walls & Whitbeck, 2012). Increasing consensus exists that historical trauma is an important part of AI/AN emotional, mental, and psychological experience (Brave Heart, Elkins, Tafoya, Bird, & Salvador, 2012; Evans-Campbell, 2008; Gone & Trimble, 2012; Mohatt, Thompson, Thai, & Tebes, 2014; Walters & Simoni, 2002; Whitbeck, Adams et al., 2004). While AI/ANs think often about such historically traumatic events and losses (Whitbeck, Adams et al., 2004; Whitbeck, Chen et al., 2004), current EBTs do not specifically target this reality.

Although there is literature addressing cross-cultural approaches to academic and community partnerships in research with Native communities (Dickerson & Johnson, 2011; Hartmann & Gone, 2012; Holkup et al., 2009; Katz, Martinez, & Paul, 2011; Thomas, Rosa, Forcehimes, & Donovan, 2011; Wallerstein & Duran, 2010), few articles address the experiences of AI/AN women leading behavioral health intervention research as Principal Investigators (PIs). This paper describes our process and experiences as AI/AN women and non-AI/AN women allies engaging Native communities in developing culturally grounded intervention research to address depression, PTSD, and the impact of collective generational traumatic events. The remaining sections of this article 1) summarize relevant literature on community-engaged approaches for participatory research with Native communities; 2) examine traditional roles and modern challenges for AI/AN women; 3) describe the collaborative process for the authors' behavioral health intervention development with Native communities; and 4) consider emergent themes from our research experiences. Themes include our individual responses to AI/AN multigenerational trauma; navigating multiple identities as AI/AN women (or allies), clinicians, and researchers; traditional Native cultures as protective factors in prevention of and early intervention with behavioral health challenges; and the role of AI/AN women and non-AI/AN women as allies in this process. It concludes with recommendations for other AI/AN intervention research projects and for supporting and enhancing resilience in Native communities to address behavioral health issues.

### **COMMUNITY-ENGAGED APPROACHES WITH AI/ANS**

There is limited empirical information regarding EBTs for AI/ANs. AI/ANs are absent or underrepresented in behavioral health outcome studies and clinical trials. Moreover, the necessary translational research where common EBTs are culturally adapted for AI/AN settings, is rare (Gone & Alcantara, 2007; Miranda, 2011; Miranda et al., 2005). Engagement and retention of AI/ANs in treatment is complicated by underutilization, mistrust, barriers in establishing a therapeutic alliance, suspicion of government-sponsored treatment, concerns about the lack of cultural sensitivity of providers, and limited IHS funding for mental health services (Gone, 2004, 2008, 2010; Novins et al., 2004). The unique relationship of AI/AN communities with the federal government as sovereign nations facing a history of colonization also may impact the view AI/ANs have of EBTs as based in Western medical practices that are foreign to the traditional practices and Indigenous interventions they view as appropriate and helpful (Gone, 2009). AI/ANs may regard standard mental health treatment, even in IHS facilities, as an arm of colonization and, as a result, often are reluctant to seek care (Gone, 2008).

Numerous researchers have recommended developing community-based and culturally informed interventions to treat AI/AN behavioral health problems (Croff, Rieckmann, & Spence, 2014; Dickerson & Johnson, 2011; Gone & Trimble, 2012; Yuan, Bartgis, & Demers, 2014). Community-engaged approaches, often beneficial in intervention development, vary in design and by name. Some examples include community-based participatory research (CBPR), involved research, collaborative research, community-based research, action research, participatory action research (PAR), participatory research, mutual inquiry, action/science inquiry, cooperative inquiry, critical action research, empowerment evaluation, feminist participatory research, and community-partnered participatory research (Israel et al., 2005; Minkler & Wallerstein, 2008). However all of these methods share the following common principles: they are cooperative, involve co-learning and local community capacity building, are empowering, and balance research and action (Israel et al., 2005; Minkler & Wallerstein, 2008; Montoya & Kent, 2011; Wallerstein & Duran, 2010). Ideally, these participatory approaches share power and benefit the communities involved through action and information dissemination (Israel et al., 2005).

Community-engaged approaches that are common in research focusing on AI/AN populations include CBPR (Katz, Martinez, & Paul, 2011; Wallerstein & Duran, 2010), PAR (Mohatt et al. 2004; Wexler, 2006), and other AI/AN-specific community engagement strategies (Fisher & Ball, 2003; Hartmann & Gone, 2012; Holkup et al., 2008; Salois, Holkup, Tripp-Reimer, & Weinert, 2006; Thurman, Allen, & Deters, 2004). Wallerstein and Duran (2010) asserted that CBPR can be utilized for translational implementation research. While participatory strategies are preferential to research that does not involve community input, academic researchers are frequently the ones to initiate projects with Native communities (Chino & DeBruyn, 2006). Here, we focus on research strategies that transcend the approaches used to date and assert that AI/ANs have our own models of intervention and implementation that canand should-play a primary role in the development and testing of EBTs for behavioral health treatment in AI/AN settings. Rather than simply seeking to translate the Western research strategies, we actively incorporate traditional AI/AN knowledge and practice (Chino & DeBruyn, 2006; Gone, 2012). Collaboration with traditional healers and use of sanctioned traditional cultural approaches is common among AI/ANs (Beals, Manson, et al., 2005; Beals, Novins, et al., 2005; Novins et al., 2004) and likely plays a critical role in ensuring appropriate engagement and retention in clinical care.

# AI/AN WOMEN: TRADITIONAL ROLES AND MODERN CHALLENGES

In a number of Native communities, women have been the culture carriers and political advisors, either informally through consultation with male relatives (Brave Heart, 1999a) or more formally, as in the selection and advising of AI/AN leaders. For some tribes where multiple wives traditionally were permitted, these were non-sexual unions, typically with the wife's widowed or single sisters needing a home until they were married to other men. Federal government policies limited the power of AI/AN women, as treaties were only negotiated with AI/AN men and imposed the use of a family surname, with implicit male ownership of women and children. Moreover, the predominant European influence included the legacy of legalized domestic abuse such as the "rule of thumb," referring to English law permitting a man to beat his wife with a board no thicker than the width of his thumb (U.S. Commission on Civil Rights, 1982). Over time, with the introduction of alcohol, changing cultural influences, and the impact of warfare on the frontier, these relationships with multiple wives became sexual unions, but still, for the most part, had the agreement of the first wife. Reservations were established,

confiscating AI/AN land, with the emphasis on individual land ownership rather than collective land caretaking. Beginning in 1879, the Carlisle Indian School became the standard for enacting the policy of "the removal of children from all tribal influence...and the employment of officers of the army as teachers" (U.S. House of Representatives, Committee on Indian Affairs, 1879) and the early location of the boarding schools far away from traditional homelands. With the inception of the boarding schools, the European American culture prevailed, including the legacy of oppressing women and children. Testimonies of boarding school trauma abound in many Native communities through the 1970s, including physical and sexual abuse, as well as prohibitions against speaking AI/AN languages and practicing AI/AN spirituality (Chase, 2011). The trauma experienced in the boarding school system undermined the traditional roles and power of AI/AN women and contributed to the learned behavior of physical and sexual abuse of AI/AN women and children in many Native communities. Boarding school trauma also has undermined the status of AI/AN men as the warriors and protectors of the tribe. Traditionally, in many AI/AN cultures, women and children were sacred and were never considered the property of men, and domestic violence was not tolerated (Brave Heart, 1999a, Brave Heart et al., 2012). Although AI/AN women have made significant contributions to AI/AN leadership in modern times as elected officials and have asserted traditional strengths in many ways across generations, currently AI/AN women also have the highest rates of violent and interpersonal trauma risk of any racial or ethnic group. AI/AN women experience higher prevalence of interpersonal violence (Bachman, Zaykowski, Lanier, Poteyeva, & Kallmyer, 2010; Beals et al., 2013; Oetzel & Duran, 2004; Yuan, Belcourt-Dittloff, Schultz, Packard, & Duran, 2015) and are at least twice as likely to be a victim of rape, sexual assault, or other violent crime (Evans-Campbell, Lindhorst, Huang, & Walters, 2006; Oetzel & Duran, 2004).

AI/AN women have obligations to their respective Native communities while simultaneously navigating often competing and culturally antithetical expectations from the academic research environment and funders. This conflict leads to unique challenges in developing, designing, and executing research projects in Native communities. As a group of AI/AN women and non-AI/AN women allies, our team's journey on the path to leading the development of behavioral health intervention research is consonant with a modern fulfillment of our traditional roles as women: nurturers, caretakers, and culture carriers, with the capacity to be *winyan was'aka* ("strong women" in Lakota) for the survival of our nations in the face of overwhelming odds.

#### THE CONTEXT: THE IWANKAPIYA (HEALING) STUDY

The Iwankapiya study seeks to address a gap in the availability of culturally grounded EBTs for AI/ANs; further, it includes AI/ANs in development, design, and delivery of treatments. Evaluation is done in a manner consonant with traditional AI/AN cultural values. In this National Institute of Mental Health-funded pilot study, eligible AI/ANs in two different communities, one rural reservation and one urban, are randomly assigned to two distinct and promising evidence-based interventions targeting depression, grief, and PTSD symptoms: 1) group Interpersonal Psychotherapy (IPT) only; and 2) group IPT combined with the Historical Trauma and Unresolved Grief intervention (HTUG). The following sections briefly describe these two interventions.

IPT, which focuses on the interpersonal context for depression and the relationship of current life events to mood, has demonstrated clinical efficacy (Weissman, Markowitz, & Klerman, 2000) among various groups, including Latino and African American adults (Miranda et al., 2005), low-income women with PTSD (Krupnick et al., 2008), and tribal villagers in Uganda (Bolton et al., 2007; Verdeli, 2008; Verdeli et al., 2003). Although the etiology of depression is complex, psychosocial contexts contribute to triggers for depressive episodes. Those triggers typically fall into one of four categories: grief, social role transition (e.g., marriage), role dispute (e.g., marital conflict), or interpersonal deficits. IPT connects mood and life events, "diagnosing" the primary focal interpersonal problem area related to the depression (Markowitz et al., 2009). There also is increasing evidence that IPT is an effective treatment for PTSD (Bleiberg & Markowitz, 2005; Krupnick et al., 2008; Markowitz et al., 2015).

Selected as a Tribal Best Practice (Echo Hawk et al., 2011), HTUG is based upon the historical trauma paradigm, which includes the historical trauma response. The historical trauma response refers to a constellation of features that have been observed among massively traumatized populations, including depressive symptoms, psychic numbing, self-destructive behavior, and identification with the dead (Brave Heart, 1998; Brave Heart et al., 2012). Historical trauma has been operationalized in measures of historical loss (i.e., thoughts about historical losses in AI/AN history) and historical loss-associated symptoms (i.e., anxiety, PTSD, depression, anger, and other symptoms prompted by those thoughts; Whitbeck, Adams, et al., 2004; Whitbeck, Chen, et al., 2004). Historical trauma provides a context for current trauma, grief, and loss across the lifespan by rooting them in the collective psychosocial suffering across generations. Ideally, this collective suffering is addressed in a group milieu. In an AI/AN

traditional cultural worldview, time is fluid and the past is present. Contemporary individual suffering is rooted in the ancestral legacy and continues into the present. Traditionally, one cannot separate oneself from the influences of the ancestral suffering. There is an interrelationship with all of creation. Time is non-linear, circular, and simultaneous. If one heals in the present, one can go back in time and heal the suffering of the ancestors (Brave Heart, 2001a, 2001b; Brave Heart, 2003).

The initial version of HTUG was delivered to a small group of primarily Lakota adults (Brave Heart, 1998). It incorporated traditional culture, language, and ceremonies as well as clinical trauma and grief intervention strategies in a 4-day psychoeducational group experience in the Black Hills of South Dakota. It included four major components: 1) didactic and videotape stimulus material on Lakota trauma (*confronting the history*), 2) a review of the dynamics of unresolved grief and trauma (*education about trauma and grief*), 3) small-group exercises and sharing (*cathartic release of emotional pain*), and 4) the *oinikage/inipi* (Lakota purification) ceremony and a traditional grief resolution Wiping of the Tears ceremony (*transcending the trauma*). HTUG has the advantage of being adaptable to specific AI/AN history and culture. For the current Iwankapiya study, HTUG has been adapted to address the histories and healing traditions of multiple AI/AN groups.

# THEMES EMERGING FROM OUR PROCESS

Similar to the process of acculturation, AI/AN women researchers often navigate competing demands and priorities from AI/AN communities and from mainstream academic environments. Themes emerging from our research experience that will be discussed in this section center around the emotional responses of the research team to their own multigenerational and lifespan trauma; multiple identities as AI/AN women, clinicians, and researchers; the impact of historical trauma in Native communities; the importance of traditional AI/AN culture as a protective factor for prevention and early intervention with behavioral health challenges; and the role of non-AI/AN women as allies.

#### Voices of AI/AN Women Leading the Research

Congruent with Salois et al. (2006), our research is a "sacred covenant" as it arose from our own grounding and immersion in our traditional AI/AN cultures and ceremonies. This traditional foundation to our approach, including clinical practice in AIAN communities, culminated in the development of HTUG and a Native collective to advance healing for AI/ANs —the Takini Network. *Takini* is a Lakota word meaning "to come back to life or be reborn." In 1992, we formed the Takini Network and also delivered the first HTUG as a 4-day intensive immersion intervention (Brave Heart, 1998). Our HTUG model and research are grounded in the Lakota *Woope Sakowin*—Seven Laws—which are guiding principles for how we are to live our lives. These laws include generosity; compassion; humility; respect; courage; development of a great mind, including the capacity for patience, silence, and tolerance; and wisdom. We began as AI/AN women first, grounded in our own AI/AN cultures, becoming clinicians. Our work evolved into conducting clinical intervention research that sought to maximize its helpfulness to our communities. We began collaborating with compassionate non-AI/AN women allies who were committed to advancing our work, which they believe will help Native communities as well as other oppressed populations.

Some of us began providing direct clinical behavioral health services to our Native communities over 35 years ago. We have sought to enact traditional values such as generosity. We have further incorporated reciprocity in research, with a cornerstone being the provision of some benefit to community members who would participate in the process. The Iwankapiya study includes the same principles by providing treatment at no cost to participants, providing opportunity for healing, and training community providers to help sustain the work. An integral part of conducting research in AI/AN communities is relationship building and collaboration with other service providers in the community (i.e., tribal school parent advisory committees and school staff; tribal, federal, and state behavioral health programs; elders; local culture informants and traditional healers; tribal colleges; and urban health providers). Networking with local providers and community members has been a key factor in implementing successful interventions and supports sustainability post-intervention. Ongoing presence and involvement fosters receptivity and supports relationships in Native communities, enhancing sustainability. For example, the initial development of HTUG included ceremonies to guide us in the process and to ensure, on a traditional cultural level, the sacredness of our work. Our initial HTUG interventions were held in sacred places in the Black Hills, and one of our traditional healers gave us a closing piece of the intervention based upon a Lakota grief resolution ceremony. Participants formed a kinship network, building upon the importance of relationship and connection in Native communities. As AI/AN women, we have found that nurturing professional as well as personal relationships is essential for creating authentic services and interventions.

As AI/AN women we bring to our research our experiences of being culturally and spiritually immersed in our own Native communities. Researching and writing about AI/AN historical legacy can be overwhelmingly painful, as well as cathartic and healing. Commitment to this work can keep us immersed in the pain and traumatic past, but for a greater good—to help the *Oyate* (the People) to heal. Writing and developing manuscripts and research proposals often means revisiting a history that is simultaneously collective, generational, familial, and idiosyncratic, and that spans the past as well as the present. In our loyalty to our ancestors, we unconsciously remain loyal to their suffering through internalization of generational trauma, enacted as the need to suffer as a memorial; vitality is a betrayal to ancestors who suffered so much (Brave Heart, 1998). However, part of the healing process is to let go of this guilt for being joyful. We recognize as Takini that we are *wakiksuyapi* (memorial people; Brave Heart, 2000), and still healing as we are helping others to heal.

As AI/AN women and AI/AN researchers, our work is both a professional and a spiritual commitment. We are not immune to trauma in our own families and communities, to experiencing and witnessing the suffering, and to carrying the trauma of our ancestors. We bring this to our clinical work and to our research. Being AI/AN women, we experience racial and gender discrimination, ongoing oppression and exclusion; in academic and professional settings, we are underrepresented, particularly at higher academic ranks. It is common for AI/ANs to be challenged to adhere to academic expectations while encountering marginalization and a glass ceiling in work settings (Walters & Simoni, 2009). We struggle with allowing for personal care and personal time; we often experience guilt at taking time away for enjoyment, given the degree of suffering in AI/AN communities. Additionally, our process of writing may be different from that of mainstream colleagues due to cultural differences in thinking and organizing; AI/ANs typically exhibit more circular thought processes and communicate using traditional AI/AN storytelling and metaphor. Questions frequently are answered by sharing a story. Clarification or interpretation of that sharing then is often met with another story, particularly with older AI/AN adults (Brave Heart, 2001a, 2001b; Chase, 2011). Our processing style often follows a cultural norm of deliberation, looking at everything that could be even remotely related to the topic at hand, writing in a narrative, storytelling format first; and then, once we feel that no stone is left unturned, we begin to narrow and edit. This process results in a very rich, thoughtful, and comprehensive product, often with the eloquence of our ancestors, who carefully deliberated before making decisions so that all decisions would be wise ones. However, in the climate of academia with its demand for rapid production of manuscripts, the traditional AI/AN process

may run counter to expectations for advancement. Further, because we are writing about collective AI/AN traumatic experiences to which we have a personal relationship, manuscript development requires time for our own emotional processing, empathic attunement to our AI/AN relatives with whom we work, and working through our own personal pain in order to be of the highest service to our communities as well as our commitment to excellence in all aspects of our work.

In addition to our own personal and family trauma, we are frequently exposed to secondary trauma through stories shared by individuals in workshops and interventions of their past and ongoing abuse, grief, loss, and tragedy. Also, due to our knowledge of historical trauma, we may be hypervigilant to historical trauma responses and carry extra concern for participants, so that it is sometimes difficult to maintain objectivity. We carry the People in our hearts and make decisions with the People in mind, including the future seven generations. Such commitments derive from the traditional teachings and values that we embrace and that guide us in our lives and in our work. We are educating our non-AI/AN colleagues in academia about these concerns, which our non-AI/AN allies understand. Being an AI/AN PI on a study is uncommon. In the past, some of us have been discouraged and told we could never fulfill the role of PI as AI/AN women. However, our traditional healers have continued to encourage and motivate us, and our traditional ceremonies sustain us. In more recent years, we have developed non-AI/AN allies—both women and men—who are interested in mentoring and facilitating the development of female researchers, including AI/ANs.

#### Navigating the Landscape

Carrying out the study is akin to whitewater rafting, given the multiple challenges. We have to negotiate multiple Institutional and Research Review Boards (IRBs/RRBs), including university and AI/AN sites as well as IHS. Despite enthusiastic and supportive IRB/RRBs, navigating multiple deadlines can be challenging, as every change requires approval from each entity. Limited resources in Native communities also can be a challenge. Capacity for carrying out research in terms of infrastructure and financial resources is limited. Despite research incentives, people still have transportation barriers (i.e., bad roads, long travel distances, old vehicles that break down), and communication challenges due to unreliable and intermittent cell phone coverage. Because of the poverty on many reservations, cell phones are sometimes cut off due to lack of payment, or people run out of gas money. Often people are in crisis and must focus on basic survival needs. These realities, combined with the lack of community services (e.g., child care), complicate participation in interventions or consistency in attendance. Transportation, poverty, and child care issues are still prevalent for urban AI/ANs as well. Many have personal and family health challenges and familial deaths, which may impact participation and attendance. We have witnessed the determination and resilience of AI/ANs who have persevered and maintained their commitment to participate in healing interventions despite overwhelming challenges such as personal loss, trauma, homelessness, and extreme poverty.

### Voices of Non-AI/AN Women Allies Supporting the Research

For those of us who are non-AI/AN women, our pathways to this work are inextricably linked to a lifelong commitment to social justice and sociopolitical advocacy rooted in our own personal and professional experiences. For some of us, this commitment stems from our Jewish heritage; a religion with a longstanding emphasis on social justice and social action through the values of *tzedakah* (righteousness), *gemilut chasidim* (acts of loving kindness), and *tikkun olam* (repairing the world; Accomazzo, Moore, & Sirojudin, 2014). For others, this commitment stems from growing up in states such as South Dakota and bearing witness to the discrimination, inequalities, and trauma AI/ANs experience both on and off reservations. We recognize the disjuncture between AI/AN culture and the predominant present-based, individualistic, and meritocratic (i.e., "pulling yourself up by your bootstraps") models and explanations for the behavioral health disparities among AI/ANs and the general U.S. population. Supporting research that advances treatment approaches that are Indigenous, contextual, and systemically informed may help shift discourse away from individualistic and pathologizing explanations for disparities.

Non-AI/AN collaborators can enrich AI/AN-led intervention research projects by contributing diverse perspectives and interpretations regarding methodological design, clinical processes, and study outcomes. Being outside of the culture allows distance and provides multiple perspectives, which, in turn, balances any blind spots AI/AN women may carry, especially given the toll that immersion in the trauma can take on inside researchers. The more objective, removed, and fresh outsider perspectives that allies bring also offer empathy and validation of AI/AN experiences. In addition to providing background, instrumental, and logistical support, this kind of emotional support from allies can be motivating and empowering for AI/AN researchers navigating the challenges of upholding scientific rigor and cultural responsiveness in settings with limited resources.

#### WOMEN FINDING THE WAY: RECOMMENDATIONS AND FUTURE DIRECTIONS

This paper describes the process and experiences of AI/AN researchers and non-AI/AN women allies engaging AI/AN communities in developing culturally grounded clinical intervention research to address depression, PTSD, and the impact of collective generational traumatic as well as ongoing events. Below are recommended strategies for successful engagement with AI/AN communities to support healing and enhance resilience:

- Start with the theoretical and practice wisdom, your own cultural experience and grounding. Traditional AI/AN cultural factors can be sources for renewal and healing (Walters & Simoni, 2002); for example, recognizing the value of ceremonies and culture to guide the healing work, connecting with AI/AN elders and traditional leaders to ask for help and blessings. Developing relationships with other AI/AN women researchers and non-AI/AN allies as mentors and collaborators can be invaluable for guidance in balancing multiple roles.
- *Practice cultural humility.* Cultural humility, recommended for education and training of medical practitioners and researchers, incorporates ongoing self-evaluation of knowledge, skills, and interactions with diverse cultures, cognizance of power imbalances, and a commitment to respectful collaborations with communities (Tervalon & Murray-Garcia, 1998). It is critical for outside researchers to be conscious of biases and privilege and be willing to take a "not-knowing" stance, which may include becoming more familiarized with community-engaged, critical, and decolonizing research strategies. It also may include being a non-participant observer ahead of time as part of project planning and preparation. Trust can be developed by being consistent, humble, and sincere-including honesty about our limitations and strengths as well as a willingness to admit when we do not have an answer. For example, while non-AI/AN allies were culturally competent and aware of differences in communication style prior to the beginning of this project, they developed a greater understanding by observing early planning phase meetings and trainings. It is through these experiences that they learned to become more comfortable with listening and taking a step back from the agenda to allow the time and space for the telling of stories and talking in metaphors. Cultural humility also includes recognition of our privilege as heterosexual AI/AN and non-AI/AN women writing this paper.

- Recognize and respect AI/AN wisdom, knowledge, and intelligence. Facilitate healing from within the community by using culturally based community engagement that gives equal weight to local knowledge and Western scientific rigor. In this approach, cultural wisdom informs and leads research design and community engagement. One way to achieve this balance is by seeking collaboration with local AI/AN experts who may not be formally identified as such by academic researchers, but may be regarded as wisdom-keepers in terms of AI/AN knowledge (i.e., AI/AN history, language, and culture). Also, someone may hold Western credentials, but still defer to cultural experts for guidance. The ideal approach is to have access to both Western-trained and culturally oriented expertise, along with reading and studying AI/AN history from the perspective of AI/ANs, and valuing oral tribal historical accounts.
- Be prepared to have contingency plans. A project may not unfold according to one's original plan, requiring perseverance and ingenuity. In resource-poor settings, researchers must be able to leverage available resources in creative ways to adapt when problems or disruptions occur. In these cases, knowledge of local programs and resources is important. Collaborators, particularly a study monitoring team, can be instrumental in implementing alternate plans that also maintain fidelity to the original proposed model. Research costs (i.e., transportation, outreach, refreshments—which often are culturally expected) likely will be higher in rural reservation settings. Due to poverty and limited phone access, outreach home visits may be necessary, requiring extra time, fuel, and expense. In addition to the cultural significance of sharing food, participants traveling long distances to get to the study site in rural reservation settings may need to be fed upon arrival, particularly given conditions like diabetes and malnourishment. In urban settings, participants who lack a permanent address due to homelessness and housing instability may be difficult to locate, may lack transportation, and also may be malnourished.
- Be prepared to play multiple roles. On any given day, a research team member's role may
  include conducting outreach, providing supplies, setting up equipment, interviewing research
  candidates or participants, co-facilitating interventions, making copies of data collection
  forms, and so on. Researchers also may need to be creative in finding suitable space.
  Typically there are no facilities set up for research on the reservation. In urban settings,
  meeting outside of academic institutions is often preferable for AI/AN participants. Research
  team members need to find locations to conduct interviews that ensure confidentiality.

Research at crowded IHS facilities is challenging, and use of confidential space has to be negotiated clearly. An alternative may be identifying use of other tribal program space where confidentiality can be maintained. However, this approach also can be challenging due to limited availability of such locations.

- Be patient and flexible. Inclement weather, community crises, and illness are all challenges, particularly for remote rural reservation sites with high rates of trauma exposure related to the prevalence of life-threatening health conditions, elevated accident rates, and consequent frequent deaths. Creative adaptation to these conditions may require rescheduling, outreach, crisis intervention skills, compassion, and sensitivity. At times, these crises may impact the researchers' own families directly. Having research teams where coverage and support is available is important and can enhance flexibility. Being prepared to contribute long hours devoted to engaging community members and providers as well as establishing trust and reliability will facilitate increased resources. Having credibility can save a project that might otherwise be vulnerable to noncompletion. If people in the community recognize researchers' sincerity and dedication they will be willing to go the extra mile to assist and support a project, and possibly advocate on your behalf with others to see it succeed.
- *Recognize that ongoing community trauma and loss will impact your research.* Incorporate a trauma-informed care framework into the planning, programming, and implementation of research projects.

[A] program...that is trauma informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff and others involved in the system; and responds by fully integrating knowledge about trauma into policies, procedures and practices, and seeks to actively resist re-traumatization (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014, p. 9).

Trauma-informed principles include safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment; and cultural, historical, and gender issues (for more details see SAMSHA, 2014). For example, knowing that crises and/or losses frequently occur for participants requires research team members to be consistent and reliable. We avoid changing meeting dates, times or locations. We maintain communication with participants, especially those who seem more vulnerable. When possible, plan for backup support in terms of consultants who are considered experts in trauma and loss in AI/AN communities.

• Make the best effort to implement some form of sustainability. Although continuation of a service or project at full capacity may prove infeasible, it is crucial to ensure some sense of continuity and hope. In communities with such limited services, it can be devastating if participants are left without any supportive base after the program. Fostering peer support as part of behavioral interventions is one strategy to increase a supportive environment. For example, some sites start peer support groups so that participants will be able to continue meeting periodically once a study ends, in addition to being linked to existing professional services. Traditional cultural resources in the community, or church groups for those who practice other faiths, are important resources to facilitate sustainability of gains made in behavioral health interventions. Booster sessions or reunions after the study can be incorporated into the design as funding permits; also, volunteers and supervised behavioral health student interns may be available to assist. A number of colleges and universities increasingly have students interested in working with tribal communities.

Traditionally, AI/ANs have Indigenous practices to address behavioral health, including primary preventive measures. For example, culturally congruent mourning processes first permitted emotional cathartic release, followed by a limited period of mourning and cognitive reframing to enhance acceptance of deaths, and utilized coping strategies such as self-soothing and calming through prayer, song, and smudging, which served to facilitate mourning resolution. Conditions that are now viewed as behavioral health disorders were addressed through ceremonies to restore balance and interpret symptoms within a culturally congruent context, typically resulting in their resolution. People with unusual behaviors often were seen as special individuals with gifts, rather than being stigmatized and isolated. Through HTUG, we emphasize this traditional and strength-based approach to healing, normalizing, and destignatizing trauma responses and unresolved grief, and focus on restoring traditional strengths and culturally congruent practices for enhancing coping strategies. In our experience, framing modern behavioral health symptoms within the historical collective context gives participants an empowering foundation for addressing both collective and individual manifestations of behavioral health issues such as depression, trauma response features, and interpersonal conflicts. As women leading the way in this healing behavioral health intervention research, we are restoring the role of AI/AN women as the culture carriers and caretakers for our families and extended kinship networks. We carry the People in our hearts; contribute to healing

the current, past, and future seven generations; restore joy and hope to our communities; and facilitate resilience and transcendence of the trauma. We are contributing to the mending of the Sacred Hoop in fulfillment of the prophecy (Black Elk & Neihardt, 1972) and return to the sacred path of healing—*Iwankapiya*.

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# THE INTERSECTION OF SOFTWARE AND STRENGTHS: USING INTERNET TECHNOLOGY AND CASE MANAGEMENT SOFTWARE TO ASSIST STRENGTH-BASED PRACTICE

Michael D. Clark, MSW and Dale W. Brien

Abstract: The focus of this investigation is the helping professionals working within American Indian and Alaska Native (AI/AN) communities. This article looks at how innovative technology—in the form of automated case management software and Internet connectivity—can assist effective implementation of Strength-based Practice and agency services within tribal courts and the many other helping agencies that serve AI/AN populations. We seek to expand practice knowledge by reviewing the benefits that this software and Internet connectivity can offer to agency operations and exploring how they can assist case management services.

### INTRODUCTION

This article will first review Strength-based Practice (SBP) as it applies to courts and helping agencies on American Indian and Alaska Native (AI/AN) lands. The second task is to outline SBP before we turn to an examination of case management, a dominant casework practice across many AI/AN agencies. Finally, we investigate how new technology, in the form of automated case management software and the digital interconnectivity of agencies (via cloud-based or common data platforms), can assist and improve the application of SBP. As this software and Information Technology (IT)<sup>1</sup> are relatively new and constantly improving, there is not a sizeable body of work to build upon. Therefore, we offer a descriptive report from years of direct observation—with the hope of further contributing to a topic that has not experienced robust investigation.

<sup>&</sup>lt;sup>1</sup> Information Technology (IT) is defined as the study, design, development, implementation, and support or management of computer-based information systems. IT deals with the use of electronic computers and computer software to convert, store, protect, process, transmit, and securely retrieve information (Kajan, 2002).

Improving the application of SBP calls for a beginning definition for this type of collaborative practice. Saleebey (2002) notes that SBP is a focus on the possibility and potential of clients, rather than an exclusive view of their failures and flaws. It is the effort to assess and mobilize clients' strengths (e.g., talents, knowledge, capacities, resources) in the service of achieving their goals and visions to create a better quality of life.

To frame this introduction, we turn to the six terms used in journalism—who, what, where, when, how and why. The focus of this investigation is the management and staff members working within Native communities (who). This article looks at case management within these agencies, with a specific examination of the functions and benefits of SBP (what). The setting encompasses tribal courts and the many helping agencies that serve AI/AN populations (where). (We specifically mention tribal courts as we find courts frequently lead the way for budget expenditures and early adoption of new technology, yet we are interested in all helping agencies across an AI/AN community.)

This review also examines innovative technology available to AI/AN agencies at the writing of this review (when). The critical juncture of this investigation is how the use of technology—in the form of automated case management software and Internet connectivity (how)—can assist in the effective agency practice of SBP (why).

Competent delivery of the SBP approach requires both a mindset of how helpers seek to understand clients (the viewing) and a skill set of how we practice (the doing), which combine to empower practice (Clark, 2010). We believe technology can enhance this process, with an added third dimension—a tool set—of implements or devices that can expand and improve the delivery of SBP. For example, a strength-based assessment instrument, when used correctly, provides balanced information from clients regarding both resources and deficits. In similar fashion, case management software and linking of helping agencies via a common data platform can enhance SBP in a variety of ways:

- Allowing staff members to gather and collate information with other helping agencies to better understand clients
- · Improving continuity of care that fits clients' needs and schedules
- Creating pathways to increase clients' involvement in services
- Improving communication among all parties by sharing information that is more current, applicable, and accurate
- Increasing the efficiency of SB assessments

• Offering guides (e.g., text boxes and pop-up windows) within the program to channel staff members to more client-centered case planning and service monitoring.

It is also important to note the assistance this technology provides is not Native-specific but would apply equally to Western and AI/AN helping agencies. We seek to expand practice knowledge by reviewing these benefits and call for more research with AI/AN communities that are starting these technology initiatives.

### SBP

SBP (Clark, 1998, 2009), as practiced in tribal courts and AI/AN helping agencies, is drawn from numerous positive models of potential, optimism, and possibility, including the Strengths Perspective (Saleebey, 1992, 2013), Resilience (Wolin & Wolin, 1993), Optimism (Seligman, 1991), Hardiness (Kobasa, 1979; Pearsall, 2003), Empowerment (Duran & Duran, 1995; Leigh, 1998), Motivational Interviewing (Miller & Rollnick, 1991; Stinson & Clark, in press), and solution-focused approaches (Berg, 1994; DeJong & Berg, 1998; Miller, Hubble, & Duncan, 1996). SBP is not a collection of techniques to apply "on" someone; it is the efforts or goals one would strive for "with" another. It has more to do with what clients have than with what they lack. It considers how people have been successful rather than how they have failed. This approach works to resolve presenting problems, but does so through a focus on potential rather than pathology.

Pertinent to this article, the application of the SBP to Native cultures presented by Waller and Yellow Bird (2002) has merit, particularly because some of the strengths and virtues of Native cultures have long been used against them and reframed as deficits.<sup>2</sup> For example, Native people have been stereotyped as suspicious and mistrusting by Western business leaders who seek to start commercial ventures with tribes (Keown, 2010). Yet the genocide, ethonocide, and broken agreements AI/ANs have suffered from colonialization lead Waller and Yellow Bird (2002) to classify so-called "suspicion and mistrust" as a strength—a healthy response that enabled Native people to survive the relentless onslaught of the dominant culture (p. 53).

<sup>&</sup>lt;sup>2</sup> In their 2002 book chapter, Waller and Yellow Bird describe 12 Native strengths: resistance, sovereignty, separation, positive cultural identity, tribal colleges, suspicion and mistrust, intertribal celebrations, kinship-mutual assistance-distributive justice, traditional healing and spirituality, storytelling and legends, humor, and political activism.

### **SBP** Principles

Six essential principles guide and drive SBP (Clark, 2013):

1. Expect that clients have the strengths and resources for positive change. Problems are generally why clients find their way to helpers, but fixating on problems will not solve them. We must focus on strengths, competencies, and beliefs because it is these assets that will finish the job.

2. All views matter but clients' worldviews matter more. Pay attention to clients' worldviews and cultural contexts. There are many ways to look at a situation, but utilizing clients' views improves outcomes. Over 40 years of motivational research (Clark, 2015) suggest positive outcomes are improved when we include clients' views and allow for more of their participation in designing their case plans. We would do well to stay mindful of a statement made by one of the developers of the solution-focused treatment model, Berg (1994): "Stay close to the client's view of the problem and possible routes to solution, since it is he or she who will be asked to do the necessary changing" (p. 36).

**3.** Engagement and establishing the client/staff alliance are critical. Even the best approaches will fail if clients do not want to participate. One should start with client engagement, or forget starting at all. SBP places a great emphasis on establishing such a relationship. Why? Treatment research is voluminous and resolute on this subject: good relationships lead to good outcomes. Of the many factors that contribute to treatment outcomes, one of the most important is the therapeutic alliance (Duncan, Miller, Wampold, & Hubble, 2010). Spanning multiple helping disciplines, over 1,000 empirical studies have found evidence that the therapeutic alliance facilitates positive change outcomes (Orlinsky, Grawe, & Parks, 1994).

4. Assessments must be balanced. Hodge, Limb, and Cross (2009) note that, while AI/AN cultures exhibit rich tribal diversity, one theme woven throughout AI/AN traditions and beliefs is harmony and balance. This theme parallels the call from SBP to ensure that a balanced view of clients (strengths and successes as well as problems and failures) is assessed. It is critical to understand that any staff member can be completely accurate about clients, yet be completely unbalanced. One can assess all of the flaws and past failures and wind up with an accurate assessment of only half of the person under review if his/her strengths, skills, and past successes are not been assessed or reported. According to many traditional cultures, an individual who is out of internal harmony and balance can experience sickness (Duran & Duran, 1995). It would seem that when assessments are out of balance and incorporate only deficits, failures, and flaws, the resulting services might induce a form of illness as well.

**5. Transition problems to "wants."** If we want to improve motivation, then we need to turn presenting problems into clients' "wants" rather than considering only clients' needs. Assessing and setting case goals based on hopes and wants will induce clients' intrinsic motivation. This approach calls us to focus on possibility, keeping an eye on a better future, and the creation of justifiable optimism, which all promote movement toward clients' aspirations. A diagnosis or an assessment should not become a verdict or a sentence. We do not know the upper limits of any client's abilities to grow and change. Clients would be better served if we kept a focus on their promise and possibility.

6. Every environment is full of resources. AI/AN communities can be viewed as having multiple problems, or as Truer (2012) reports, they can be viewed more accurately as storehouses and reservoirs of energy, ideas, talents, and tools. For every young mother who wants to finish a GED or start a class at a community college, there is an older woman close by who could watch her children. Waller and Yellow Bird (2002) note that professional helpers are not always the first line of defense in many communities where informal helping systems are accessed. A focus on collaborating with informal helpers can be time well spent for staff members working in AI/AN agencies.

## CASE MANAGEMENT SOFTWARE

Working with clients has become increasingly complicated as helping staff often are called on to manage social, medical, behavioral, and financial issues. Case management software is a computer program that seeks to simplify and improve case management tasks and duties, especially related to record keeping. Case management is a collaborative process in which a staff member assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet clients' health and human service needs. It is characterized by advocacy, communication, and resource management and promotes quality and cost-effective interventions and outcomes (Commission for Case Manager Certification, n.d.). Case management software has been available for over 15 years and usually contains electronic abilities for data entry, client tracking, data analysis by electronic review of records, collection and collation of evidence and outcome data, and communication and collaboration with others.

Case management software can be expensive, and technology often advances dramatically every few years. Finding efficient and effective software that ends up as a right fit for AI/AN agencies can prove elusive. It's important for agency staff to come prepared and know what is available to find the best options and features for their specific needs. There are great differences in software costs, coupled with a variety of hardware options. Space constraints do not allow an adequate review of hardware and software types and prices; however, we list some new features in case management software from the IT field to review. This list—efficiency, simplicity, security, connectivity, collaboration, and effectiveness—is not meant to be exhaustive, but rather to build a knowledge base of options.

# Efficiency

Staff members are happy to tell anyone that software has automated repetitive and routine tasks—freeing up time for more important and complex tasks. For example, case management software can enable one-time data entry rather than having to repeatedly enter the same data. Case information entries (e.g., name, birthdate, address, phone number) populate and fill in every field wherever needed. If data fields require changing (i.e., new address, additional case information), then the staff member merely enters the revised information once and the software updates that information wherever it is listed elsewhere. Staff members and agency administrators can be assured that case files are current and accurate across all forms and fields, which would be hard to guarantee with paper files.

#### Simplicity

Information can be accessed with ease, even with cases that have a long agency history and are extremely large. The newest technology boasts the ability to move to any point, section, or page within a large case file through four clicks or less of a desktop mouse. Additionally, with cloud-based technology, there are no tools to load locally. The IT server (where the software is housed) may be 100% web based, requiring only Internet access and a common browser. Some AI/AN communities do not want any community data stored beyond their borders. In that case, an IT server can also be housed locally to keep all data on site. The simplicity with which a staff member can send or receive information—as compared to a traditional paper/manila file folder system—defies comparison.

### Security

Speak about tribal records being stored "off-reservation" in cloud-based servers and many administrators get nervous. Yet a full understanding of digital files finds they are *more secure than paper files*. Digital files are electronic files that appear on a computer screen, as opposed to hard-copy paper files. Digital files can be printed to become paper files and paper files can be electronically scanned and stored on a computer to become digital files.

Digital files are fully HIPPA compliant and offer greater protection of client confidentiality than paper files. Data are encrypted and password protected. Who can access data, and at what level, are determined by agency administrators. For example, some staff members can only enter data but never withdraw data. Case management files operate with the same security as financial records used by the banking industry. It is also critical to consider that most unauthorized viewing of files, or outright theft of files, is done by agency staff members inside the building. With case management software, a digital file that is opened is forever stamped with the time/day/name of the person who opened it. Anyone who opens a file is identified, even after business hours. With digital files, there is never a time that "no one is around" to illegally view or copy materials. Paper files stored in filing cabinets or records rooms do not enjoy this level of security.

### Connectivity

Case management software, placed on computers at different agencies and connected by a common data platform (see Figure 1), finally represent the ability to knock down professional "silos." Client information can be shared easily within an agency or across community agencies, allowing for "open-but-safe" exchange of information that breaks through the frustration and inefficiency of proprietary turf wars. This ability to connect helpers and agencies reminds us that resources are only valuable if people can access them. Access is agreed upon with signed "release of information" forms and memorandums of understanding between departments or community agencies. This software can socialize silos for more effective sharing of information. Many agencies start with just what they currently share with neighboring agencies via paper (e.g., reports, releases of information, forms). Being able to share by the push of a button what in the past had to be mailed or hand delivered is a great improvement.

### Collaboration

New technology can link agencies together to share information, replacing a hit-or-miss "grapevine society" with a more complete "digital society." Protocols are put into place—with proper authorization—to share data by organized methods. Critical information about clients, as well as information about community services and resources, can be pooled. Gaps in services can be detected and duplication of services can be corrected, with quicker response time and less wasted effort.

#### Effectiveness

Agencies seek more uniformity in their services. Agency directors hope that evidencebased practices, risk assessments, and other approaches will be applied consistently from office to office. The odds of uniform delivery are increased with the use of software. Text boxes and pop-up windows can be designed to appear on computer screens, reminding staff members to include necessary information or ask critical questions. Software can help guide these efforts without surrendering human decision making. This software also can harness the power of feedback to allow needed corrections in a case plan, which can be made available through in-themoment feedback (Miller & Tilsen, 2011), instead of requiring departments to wait to gain feedback about service outcomes until the services have ended.

### Customization

Customization means modifying software to tailor forms, tribal logos, and procedures to suit the agency that purchases the software. For example, the look and format of a child protective services report form might differ dramatically from one AI/AN community to the next. Agencies do not have to leave behind important and well-used tools and methods, but must ensure that vendors can move forms, charts, and databases into their software systems. Forcing staff members to learn to use a new form, simply because the vendor could not customize the existing one, is both poor service and culturally dismissive.

Finding customizable case management software (i.e., telling computers what to do, rather than using out-of-the-box software that was developed away from AI/AN communities and that leaves the computer telling staff members what to do) is key to efficiency and ease. Is the software built by Native developers who have worked in AI/AN agencies ("process first") rather than by technicians from Silicon Valley ("product first")? Grandbois (2005) notes that

many Western-trained practitioners and advocates often are not prepared to provide culturally competent services for AI/AN people that respect their belief systems and history. We find this problem can occur with the products and services of Western software companies as well. More Native software companies, staffed by AI/AN personnel, recently have emerged and are working to fit their products to agency processes—so critical for customization and buy-in. The Spirit Lake Nation (Fort Totten, ND) and the Turtle Mountain Band of Chippewa Indians (Belcourt, ND) are two examples of tribes that have researched and secured software companies staffed with Native developers and IT technicians. It is suggested that AI/AN communities that are interviewing software vendors consider screening providers about staff composition and assess the company's values.

### How Case Management Software Can Assist SBP

The first author has provided training in SBP for over 18 years, delivering programs to agencies located both off and on Native lands. Staff members often left these training sessions feeling energized and eager to implement SBP upon their return to work. Yet tracking research in post-training follow up (Clark, 2008) found that changes were not always achieved. Out of several considerations that blocked implementation, one obstacle seemed consistent—the policies and procedures of the agencies did not support SBP. The individual had changed but the environment had not.

To review how technology might help the integration of SBP into agency services, we need to examine the common day-to-day efforts of agency personnel. There are six standard case management functions that are common to all casework efforts: engagement, linking, assessment, case planning/implementation, advocacy, and monitoring. If case management software and Internet connectivity can increase staff efficiency and effectiveness, it would be evident within these case management duties.

### **Six Case Management Functions**

# 1. Engagement

To what extent can software "engage" a staff member? A first benefit involves software's ability to help with the mountains of paperwork—an oft-cited contributor to job dissatisfaction and staff burnout (Miller, Hubble, & Mathieu, 2015). Buy-in is quick when staff members realize how software can reduce workloads. High-volume, routine, repetitive tasks that require extensive paperwork are the very tasks with which software helps. Paperwork time is reduced, thereby

increasing face-to-face time with clients. For support staff who work in records management, feelings of effectiveness and job satisfaction are substantially increased (M. Dennis, personal communication, November 24, 2014).

Training to use the new software is another important feature for engagement. After purchasing expensive software, many agency directors have been frustrated to find staff members reluctant to use it. Onsite training that uses simple, easy-to-understand terms and is based on incremental steps can help those who are anxious about a computer's complexity.

When onsite trainers leave, are "job aids" left behind? These aids are often paper copies that offer step-by-step instructions for a multitude of tasks, coupled with audiovisual libraries full of short how-to videos that offer round-the-clock reference help for problem solving and skill building—and encouraging engagement and confidence.

### 2. Linking

If the system is housed on a network, then accessibility can extend to others, beyond the person to whom the case was assigned. A network means all computers within an agency communicate with one another and become an agency filing cabinet. Digital files placed on this shared system can be edited, as long as the person has the authorization and clearance to access them.

Security is tight. Staff members' levels of access will depend on what actions they will perform in shared files. Making files publicly available to a shared system does not mean they are available to anyone at any time. Digital files still comply with HIPPA conditions, and all necessary release of information forms are still signed. Many can add data to a digital file, but only select individuals can view a file and far fewer, with the highest authorization, can take data from a file. Consider an agency that performs drug-screening urinalysis for referred clients. A staff member can be authorized to immediately enter the results of that morning's test into clients' files, but s/he would not be allowed to view the files. Sharing agreements, access trees, and authorizations for who can access which files are well planned, agreed upon, and very strict.

Considering the term *linking* ushers in the issue of Internet connectivity. The terms "digital exclusion" or "digital isolation" can be applied to many AI/AN agencies. There are two issues related to isolation. First, many areas across Indian Country lack Internet access (Sullivan & Louten, 2013). For AI/AN agencies that lack Internet connectivity, there are versions of case management software that can be loaded directly onto staff computers. The second issue speaks to agencies that are connected to the Internet, yet still remain isolated from each other. In these

instances, staff members may be connected to the larger world via the Internet within their homes, but at work, lack any connection to agencies that are located down the street or even with a co-worker in the office right next door.

This problem is further compounded by the fact that, once connected, agencies often lack the openness to share data with other organizations. Schoech (2010) reports, "In larger agencies, data often resides in outdated remnant systems that serve their intended purpose but hinder connectivity because data is isolated in unlinked information silos" (p. 10). Landsbergen & Wolken (2001) point out that, due to the lack of mutual trust among agencies, each agency often ends up collecting its own information about the same subject. It seems agencies are very eager to view information from their neighbors, but seldom want to share their own data with others.

Here is an important intersection of SBP and case management software. SBP calls on organizations to begin a culture of sharing by viewing knowledge as belonging to the collective good, rather than as proprietary pieces of data (Menon & Brown, 2001). Historically, the power of Native cultures was found in their ability to share information and link with each other. Waller and Yellow Bird (2002) cite "kinship, mutual assistance and distributive justice" as one of the 12 strengths of Native peoples while reminding us, "In many Indigenous societies, human beings are inextricably interconnected through a complex web of relationships, including relatives by blood, clan, tribe and adoption" (p. 55). It would seem that, to find our collective strength, we who work in AI/AN agencies are called to reclaim our culture, or—put another way—go "back to the future."

Aside from individual networks within any AI/AN agency, all helping agencies can be linked across an AI/AN community via a digital platform. Figure 1 represents a reservation linked via a digital platform.

The various issues and benefits related to sharing data are too broad for the scope of this article. For the purposes of this review, we note three important reasons to share information: 1) coordinating and integrating client services, 2) overcoming distance and rural isolation, and 3) gathering the most current and accurate information for client assessments and case planning, which comes from all who have knowledge of and contact with the case.



Figure 1 Example of a Reservation Linked by a Digital Platform

#### 3. Assessment

SBP reminds us that assessments are one snapshot of a person's life. They are never to be thought of as the total sum of a client. They remain important efforts that guide case plans and calculate services. Case management software and Internet connectivity offer two benefits—standardized assessment and more current and comprehensive case information to improve decision making.

Standardized assessment ensures that the same assessment instrument is used for all clients (standardized) and is accurate, measuring what it is supposed to measure (valid). Also, it should make no difference whether clients are assessed in the morning or afternoon, one day or the next, or by one worker or another (reliable).

Case management software helps the process because staff members avoid repetitive data entry and clients do not have to undergo similar assessments at multiple agencies. Repetitive entry of the same data has plagued staff members, but it can also lead to inaccurate reports from clients. Research shows that, the more clients have to fill out the same assessment form, the more inaccuracies result (M. Dennis, personal communication, November 24, 2014). With an agency using a common data platform, the client data could be readily available (with client permission) and automatically filled in to the new form, so staff members at the next agency only have to ask assessment questions that are specific to their field.

There is a second benefit to strength-based assessment assisted by case management software and Internet connectivity. Edwards et al. (2009) state, "There is a move away from opinion-based decision-making to decision-making that is grounded in evidence" (p. 554) When

agencies have the ability to collaborate in real time on clients they share, it can help overcome the two greatest obstacles to successful assessment, inaccurate and incomplete information. Simply put, more accurate and complete information that assesses both risk and protective factors (deficits and strengths) allows for more effective decision making for developing the case plan. In the absence of automation, we ask staff members to gather such data by "trying harder" in a manual fashion, or by going door-to-door between agencies and often across communities all considered weak responses to a large problem.

# 4. Case planning/Implementation

Phillips and Berman (1995) note that case management—assisted by software technology—increased staff members' ability to match clients' identified needs. It also improved service coordination while increasing the number of relevant referrals. Consider a staff member logged into a AI/AN community network where he or she can access local resources, by topic, in a format that is both community wide and up to date. If an agency changes its criteria for admission, has new hours, or has relocated, staff members know of these changes in real time. Phillips and Berman (1995) add, "A social service agency cannot effectively apply case management as a service delivery system without reviewing, evaluating and reprogramming its information processing capability" (p. 89).

A common data platform connecting agencies across a community can increase the amount of available client information to enable more accurate decisions and illuminate ways to proceed. Think of puzzle pieces dumped in disarray (manual information gathering by one individual), and then consider the completed puzzle picture gleaned from a shared file.

### 5. Advocacy

Advocacy is partnering with and working in support of clients and ensuring choice to find all the options available. Advocacy is realized when agencies make use of case management software and Internet connectivity, which can "advocate" for multiple parties—clients, staff members, agency supervisors, and agencies themselves (as seen from the perspective of agency administrators).

Advocacy-Client. Case management software using Internet connectivity can now allow a client information portal. There is much help to be realized by providing persons in treatment with access to information from sections of their files. Resources are only helpful if people can access them. A client information portal can allow clients to communicate with their providers and monitor their case plans. The portal can be constructed as a one-stop site for helping them stay on track. It changes the old system of "who you know" to a new system of "you <u>can</u> know" to increase clients' empowerment. With this portal, clients can:

- Check next appointment time, agency hours, location/address, and any particular building information to help increase the success of first visits;
- Check their treatment status (intake, evaluation, inpatient treatment);
- Monitor their own attendance record;
- Receive special notices from their case manager or enable other resource staff members to post messages to their account;
- Check on the due date of assignments and agency requirements;
- Check financial issues and balances due, with the ability to pay balances online;
- Print documents (e.g., 12-step attendance forms, schedules for recovery meetings and parenting classes, job openings);
- Schedule appointments online, and request services (e.g., a checklist with a send button for those who need a ride, child care, food, housing, employment).

As with all digital file procedures, the types of information that can be accessed (permissions, authorizations, open vs. controlled) are governed by the agency. We use what we can to leverage clients' connectivity and inclusion. Many clients own smart phones, or can borrow a phone or computer to check their file.

Advocacy-Staff. Staff members are supported by time-saving features that allow more efficiency. Paperwork duties are reduced considerably where descriptive data are entered only once and then auto-updated to other sections of a file. Software helps overburdened workers stay organized, with monthly, weekly, and daily calendars popping up to note pending assignments and deadlines. Most software programs have home screens that quickly display all pertinent data. Staff members also are able to look over their full caseloads with a summary screen, with reminders and cues for cases that are missing forms, notes, or other mandatory paperwork.

Case management software also can be utilized as a strength-based tutorial. As described earlier, cues and text boxes can pop up to help staff members stay focused on important efforts for SBP. For example, Saleebey (2002) notes that one such effort is assessing client needs—and doing so *from clients' own perspectives*—honoring their ideas and requests wherever possible. In this example, a pop-up window can remind a staff member that a client had requested an employment referral, acting as a prompt to ensure the staff member completes this task. There is versatility to this software feature, as pop-up windows can be programmed to help coach and

guide staff members to increase fidelity. When high caseloads and hectic schedules overload staff members, a pop-up window's ability to remind them of needed efforts or upcoming events can ease distractions and reduce mistakes. It is important to note that these prompts suggest directions, offer advice, and guide efforts—but they do not take discretion away from staff members or force decisions upon them.

Advocacy-Supervisors. These at-a-glance features also are available to line staff supervisors, who can instantly bring up any staff member's caseload to assess if casework is completed and files are up to date. Their drive to ensure staff accountability by keeping an eye on task completion is simplified. For their department needs, they can evoke automated assessments and generate weekly, monthly, quarterly, or annual statistics to substantiate objectives and goals.

Advocacy-Administrators/Agency. Software can generate reports with ease from all case data to assist awards, grant requirements, reporting requirements, and community needs. Such software also improves the ability to gain needed resources. Administrators can quantify change for any individual case, but also can monitor changes and track all cases within their agency. These tracking and reporting abilities also are available at the highest level to aggregate community data. When all agencies are connected via a community-wide common data platform, the work that grant administrators must accomplish is supported. They can simply set data parameters and choose the fields to gather both historical data and up-to-the-minute reports from all community groups.

# 6. Monitoring

The conventional notion of monitoring is to remind staff members that, once a plan is implemented, the case manager should remain open and flexible to changes that may be needed. No plan is static, as client lives and linked resources are dynamic and ever changing. Yet the important question for busy workers is, "Who is to monitor?"

There is merit to having many "eyes" on a case and gaining input from multiple agencies regarding a common client. Many staff members can recall a case that ended badly, as no one could see the case in its totality and intervene, due to insulated files. These cases did not fail because the information was not there, but because the information was not shared.

Monitoring is greatly enhanced by a common data platform that links agencies and allows collaboration among agencies who work with a common client. We do not believe monitoring via this technology has to be "Big Brother" or "Big Bully." Rather, this dual nature—technology coupled with SBP—ensures greater balance, client participation, and dignity.

#### WRAP UP

There are five issues we wish the reader to consider as we close:

- 1) The call for cost-saving measures seems constant. Some agency directors find that the time-saving features of automated case management software can help already too-busy staff members respond to rising workloads. These features allow them to keep their current staffing levels and help existing workers operate more efficiently. Can a tribe help to ward off the effects of shrinking budgets by linking all helping agencies via the Internet through the help of a common data platform? Shoemaker (2009) believes sharing knowledge is the key to managing shrinking budgets. We call for more investigation into this issue.
- 2) Research regarding Strength-Based Case Management (SBCM) supported by the National Institute on Drug Abuse, completed by Rapp and Lane (2013), found using SBCM increased client linkage to treatment and retention in care. Getting people into needed services and keeping them in services can be a motivator for using SBP in Native case management services.
- 3) The principles of SBP sync with core values for much of Indian Country. SBP provides a way to shift the professional discussion from a deficit focus to one of strengths and values of diverse peoples. The dominant Western society brought us the "science of falling down"; the SBP approach has the ability to bring AI/AN helping efforts to a "science of getting up."
- 4) We authors seem to have unbridled optimism about the benefits found within this software and Internet connectivity. While we are not fanatical enthusiasts, we remain unapologetic regarding the payoffs we believe lie in wait for communities that incorporate this technology. Phillips and Berman (1995) note, "Computers differ from other tools in that they are not passive, that computer technology participates actively in shaping its own environment" (p. 11). With the right software, community services can be shaped to empower strength-based, client-focused, and outcome-informed strategies that better connect helpers and clients.
- 5) We are not completely optimistic; there are many reasons for concern. Most funding comes by way of categorical grants—grants where money may be spent only for narrowly defined purposes. Categorical funding may not allow the expense of new software. There also is financial overhead and extra effort needed to join all helping agencies into a common data platform. Training must be completed, and a certain amount

of pushback from staff members would be expected. Agreements must be reached, security protocols fashioned, and memorandums of understanding negotiated for data to be shared. Effort is needed from within an agency, among tribal agencies, and from helping groups beyond community borders.

## CONCLUSION

Native helpers tend to value learning in a collective way. Yet Western culture has seemed to turn helping into isolated or individual efforts. Some AI/AN communities have made progressive efforts to connect multiple helping agencies and to provide strength-based services to clients in truly innovative ways. Can Native cultures break the stranglehold that silos and categorical financing have wrought on their communities? We call for more research and practice knowledge of this Internet connectivity and make a call to follow AN/AN communities that are starting these initiatives. Western communities, for all their technological rhetoric and bluster, have not yet been able to name one community that has brought all their helping agencies into shared connectivity. The White Bison prophecy (Native Heritage Project, 2012) has many variations; the essence of this prophecy predicts that the salvation of the world will begin with Native people. Might the White Bison prophecy begin on Native land, realized in part by the tribes that have implemented this new technology? Might the Native world bring about this harmony, to unify all nations by once again unifying, from within, each Native community.

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# IN THEIR OWN WORDS: SUCCESS STORIES FROM THE GREAT LAKES NATIVE AMERICAN RESEARCH CENTER FOR HEALTH

Matthew Dellinger, PhD, Brian Jackson, MEd, and Amy Poupart

Abstract: In 2009, the Great Lakes Native American Research Center for Health (GLNARCH) set out to generate a promotional video that highlights the successes of the program. Ten GLNARCH interns were interviewed and filmed for participation in the promotional video using a documentary production style. During the editing and transcription process, interviewer responses were noted for relevance to theoretical frameworks—specifically, tribal critical race theory, mentoring, and cultural compatibility—which guided GLNARCH program design. Quotations were transcribed to illustrate these themes. Though the interviews were not intended as a formal qualitative analysis, powerful narratives that are relevant to participatory research emerged. The emergence of narratives that align with relevant theoretical frameworks suggests a novel methodology for a culturally responsive, participatory reporting system.

# **INTRODUCTION**

The central goal of the National Institutes for Health (NIH)-funded Native American Research Centers for Health (NARCH) is to promote research by and for American Indian/Alaska Native (AI/AN) communities as well as to train AI/AN health professionals. There are 10 NARCH centers throughout the U.S., in Alaska, Arizona, Montana, North Dakota, Oklahoma, Oregon, Washington, and Wisconsin. It is generally understood that an effective way to reduce health disparities in Indigenous populations is to train health professionals from within these populations (Eschiti, 2004; Gracey & King, 2009; Thomas, Rosa, Forcehimes, & Donovan, 2011; Warne, 2006). Unfortunately, higher education often fails to resonate with Native students due to differences in Indigenous and Western perspectives on knowledge (Brayboy, Fann, Castagno, & Solyom, 2012). Retention of AI/AN students often suffers due to a sense that their cultures are out of place in higher education. Challenges to Indigenous education include

"culture shock" when moving to an urban setting to complete a degree, cultural incompatibility with Western-style education programs, and financial concerns (Braun, Browne, Ka'opua, Kim, & Mokuau, 2014; Brayboy et al., 2012; Gracey & King, 2009; Martin & Seguire, 2013; Thornton & Sanchez, 2010). These students often come from families where they are the first generation to attend college.

The Great Lakes Native American Research Center for Health (GLNARCH) program draws upon a coalition of tribal and academic organizations to improve health research and AI/AN education. GLNARCH is based at the Great Lakes Inter-Tribal Council located on the Lac du Flambeau reservation in northern Wisconsin and operates within the tristate (Michigan, Minnesota, and Wisconsin) Indian Health Service (IHS) Bemidji Area. Through a unique blend of education, research, and storytelling, the program has experienced great success. In this paper, we report how storytelling promotes self-determination for participants in a health sciences pipeline program, as well as provide qualitative data outlining strengths of the program. The stories provided an opportunity for an informal analysis as well as insights into different ways of knowing.

# Health and Higher Education in the Bemidji Region

The Bemidji Region is the most underfunded of the 13 IHS areas (Great Lakes Inter-Tribal Epidemiology Center [GLITEC], 2011). AI/AN health in the U.S. and the tristate area has improved since the 1950s (e.g., precipitous drops in infant mortality due to treatments for infectious diseases like tuberculosis; (U.S. Department of Health and Human Services, 1999). In spite of this progress, health disparities persist for AI/ANs. Nationally, the risk of obesity is 49% higher for AI/AN children (Pan, May, Wethington, Dalenius, & Grummer-Strawn, 2013). In the Bemidji Region, AI/AN mortality rates are higher than those of the total population after accounting for differences in population age (GLITEC, 2011). Furthermore, the Native population in Wisconsin demonstrates elevated morbidity rates for diseases such as heart disease and diabetes (Wisconsin Department of Health Services, 2005), and AI/AN mortality rates are significantly higher for all cancers, chronic liver disease and cirrhosis, diabetes, heart disease, influenza and pneumonia, nephrotic syndromes, suicide, and unintentional injury in the Bemidji Region (GLITEC, 2011). Native students continue to be underrepresented in higher education. In the Bemidji Region, only 6.8% of the AI/AN population holds a bachelor's degree, compared to 16% of the general population, and only 3% hold a graduate degree, compared to 7.8% in the general population (GLITEC, 2011). GLNARCH grew from the realization that innovative approaches building upon the importance of relationships in AI/AN cultures are required to attract, foster, and maintain these students in research careers (Demmert, 2001). In addition to supporting research, GLNARCH boasts a strong Student Development Program to address these disparities.

Mainstream epistemology can lead to problematic interpretations of Indigenous educational outcomes (Kitchen, Cherubini, Trudeau, & Hodson, 2010). Non-Native researchers must walk a fine line when attempting to promote successful programs from a Western point of view. Not only should indicators of success incorporate AI/AN perspectives, but these indicators also must be constructed from participatory methods to honor the value of self-determination. This "decolonizing" of research methodologies (Braun et al., 2013) aims to empower Indigenous participants as researchers. Such methods are attractive to programs like NARCH because they acknowledge historical trauma, life-course perspectives, and phenomenology.

One of the challenges for Indigenous students in North America is that unexamined racial and cultural assumptions are endemic to society and are ingrained in contemporary views of education (Brayboy, 2005; Demmert, 2001; Kitchen et al., 2010). Tribal critical race theory outlines many challenges with research and education in Indian Country. Historical distrust resulting from dispossession, threats to sovereignty, liminal societal space, and threat of assimilation exert social forces on tribes (Burger & Gochfeld, 2011; Hoover et al., 2012; Tobias & Richmond, 2014) that can interfere with cooperative progress. Tribal critical race theory seeks to construct an interpretation of reality by helping individuals to name their reality through storytelling and counterstorytelling (narratives; Haynes Writer, 2008). This process provides a framework by which a culture (AI/AN) may represent itself in a self-determined manner. These theories, in which the effectiveness of programs and interventions is augmented by matching the process onto cultural patterns, provide useful principles to guide programs such as NARCH. As the program evolves, improved methods of evaluation and understanding will emerge. Building narratives via digital storytelling is a part of this evolution. Cultural compatibility theories manifest in a variety of forms throughout the literature (Demmert, McCardle, Mele-McCarthy, & Leos, 2006).

Health research has seen an increased demand for practices that promote creative, narrativebased approaches. One example is digital storytelling. The digital storytelling method emulates oral traditions in sharing experiences and transferring information, and provides a medium for participants to contribute directly to knowledge production (Cameron, Crane, Ings, & Taylor, 2013). GLNARCH has used this model in the past to engage interns in the process of sharing and presenting their projects; it allows them to contextualize their work within their personal lives and culture. Digital storytelling, therefore, is a culturally responsive tool for research and health promotion programs, due to its emphasis on narratives. Other programs have used digital stories effectively to increase participation, promote healthy behaviors, and report the associated successes in Native populations (Cueva, Cueva, Dignan, Lanier, & Kuhnley, 2014; Cueva et al., 2013; Wexler, Gubrium, Griffin, & DiFulvio, 2013). Digital storytelling is similar to documentary filmmaking in that they both focus on narratives to convey information. Documentary films and other mass media have been demonstrated to reduce stigma and bias, facilitate discussion of difficult topics between health care providers and patients, and add societal context to educational efforts (Anderson & Austin, 2012; Clement et al., 2013; Ebor, Murray, Gaul, & Sutton, 2015; Jordan & Bonds, 2015; Thonon, Pletinx, Grandjean, Billieux, & Laroi, 2016). This paper presents evidence that these two processes (digital storytelling and documentary filmmaking) may be blended to create powerful inquiries regarding AI/AN health as well as culturally compatible educational programs.

# **GLNARCH Origins and Goals**

GLNARCH developed from interest in tribally driven health research programming. Tribal health leaders and health professionals possess knowledge of community health priorities, and are familiar with local culture, traditions, and concerns. They also seek relevant community health data. GLNARCH brings these professionals together with academic partners. This need was first identified during a strategic planning session held between the Wisconsin Tribal Health Directors Association and the Great Lakes Inter-Tribal Council Indian Health Program in the fall of 1999. GLNARCH focuses on interdisciplinary collaborations between academic and tribal communities to improve AI/AN health and ameliorate health disparities.

GLNARCH activities are designed to ensure multigenerational success in tribal student/professional development and health research. The GLNARCH program combines research and training to achieve the following program outcomes: 1) Provide infrastructure for community-based participatory research (CBPR) on AI/AN health disparities; 2) Implement a

student development pipeline programs to increase AI/AN student/professional leadership in the areas of biomedical, clinical, and behavioral research; and 3) Implement an evaluation process of GLNARCH efficacy and disseminate this knowledge. Researchers at GLNARCH have taken the unique step of filming documentary-style interviews on participants' experiences with the program to showcase the accomplishments to date.

The third GLNARCH goal—evaluation, dissemination, and reporting—has proven elusive for NARCH programs throughout the country (Caldwell & Hernes, 2014). Though the successes of NARCH are evident to the community, the most powerful benchmarks are difficult to portray adequately in the format of scientific writing. Narratives presented in digital film format are an increasingly popular tool, yet programs that use this method for reporting may experience complications. Gubrium and colleagues (2014), for example, identified a number of ethical challenges, including: fuzzy boundaries between public health practice, research, and advocacy, as well as issues regarding consent and inadvertent exposures to harm from sharing sensitive information. From a practical standpoint, it is challenging to integrate filmmaking and other digital arts with more analytical disciplines. Doing so requires adaptation of different forms of evidence to programmatic evaluation while maintaining a standard of rigor that matches scientific research.

The video production described herein presents an effort to explore these challenges. The narratives that emerged demonstrate clear progress toward the stated GLNARCH goals, reported by participants in their own words. The best practices and challenges shared here will help to guide other researchers as they strive to adapt to an ever-changing atmosphere that intersects the arts, community, public health, and academic research.

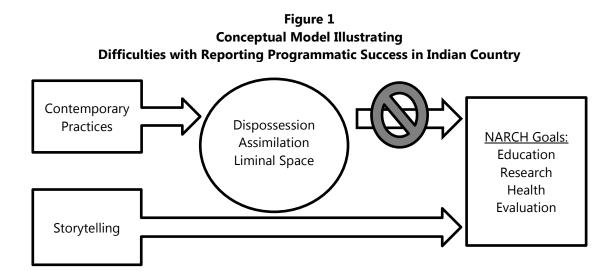
# **METHODS**

## Sampling Framework: Description of Student Development Program (SDP)

A key element of the GLNARCH SDP is to help students recognize the importance and feasibility of advanced education, as well as to develop the skills and academic background needed to do so. GLNARCH partners with the Mayo Clinic, Marquette University, University of Minnesota-Duluth, Concordia University of Wisconsin, University of Wisconsin (UW) campuses, and Medical College of Wisconsin to provide diverse opportunities for students in the GLNARCH SDP program. Over the years, GLNARCH has developed methodology for AI/AN student and professional development based on experience and a growing body of literature

(Jackson, Dellinger, Tornes, Poupart, & Dellinger, in press). This literature provides general recommendations for mentorship programs, as well as AI/AN-specific mentorship best practices. Key concepts include: service learning and student placement, mentorship, cultural congruence, epistemology, structured support, and community building (both cultural and professional).

Overall, the GLNARCH SDP follows a cultural compatibility framework as it applies to modern Indigenous perspectives (Demmert et al., 2006). The SDP program is implemented in four phases. Each phase provides hands-on experiences, networking, guidance, and financial support, depending on the age group (Figure 1). In the first phase, AI/AN students are invited to UW-Madison to participate in hands-on activities, meet faculty, and attend presentations from academic role models. In Phase II, approximately 20 students enroll in "The American Indian Student Scholars Program." This summer program allows students to explore UW-Milwaukee, Concordia University, Medical College of Wisconsin, and Marquette University campuses to learn about college application processes and health science careers and to participate in hands-on science and cultural activities. In Phases III and IV, approximately 12 selected undergraduate students (sophomore through senior standing) and 8 graduate students enter a period of academic mentoring and summer research experience under GLNARCH. The students are paired with research mentors based on locations, shared student/researcher interests, and student career paths. For a more detailed description of the GLNARCH SDP, see Jackson and colleagues 2015.



#### **Data Collection: Promotional Video Interviews**

This project was declared exempt from 45 CFR Part 46 under the provisions of 45 CFR 46.102(d) by the IHS National Internal Review Board. During the summer of 2010, 1 GLNARCH mentor and 10 GLNARCH interns were interviewed and filmed for participation in a promotional video. The students are paid GLNARCH interns who volunteered to discuss their experiences. These 11 participants are registered tribal members. The current analysis includes statements from the 10 students. The video production team consisted of the current authors. Mr. Jackson served as the interviewer and producer, and Mrs. Poupart served as producer both by coordinating the interviews and in her capacity as the GLNARCH SDP coordinator. Dr. Dellinger served as cinematographer, editor, and writer. Post processing (conducted by Dr. Dellinger) was guided by the entire production team with input from the GLNARCH Community Scientific Advisory Committee and Wisconsin Tribal Health Directors.

Distinct from the digital storytelling process, these interviews followed a documentary filmmaking procedure in which the director/producer asked leading and open questions. Other interviewing techniques can appear analyzed and dissected, which conflicts with storytelling values (Simonds & Christopher 2013). Interviewees in a documentary are termed "the talent," and are treated as such, which creates an empowering atmosphere for the storyteller. The students were encouraged to present an earnest expression of their personal experiences and to feel ownership of their stories. Powerful narratives that are relevant to participatory research emerged from the interviews. The GLNARCH video production 1) produced a form of participatory outreach (Dellinger, Jackson, & Poupart, 2015) that could be shared with tribal and academic leaders who then provided input on future iterations, and 2) provided qualitative data that bears relevance to NARCH program best practices. During the interviews, the interns were asked the following questions:

- 1. What are your experiences with the program?
- 2. Please describe your research project and the challenges that you encountered.
- 3. How did NARCH influence your journey through education?
- 4. How did it influence your professional development?
- 5. Please describe your feelings regarding the mentorship component.
- 6. Do you have any general comments and feedback on the program?

#### **Data Management and Analysis**

The production team investigated all interviews for common themes and patterns. During the editing and transcription process, the production team noted interviewee responses for relevance to the theoretical frameworks that guided GLNARCH program design—cultural compatibility theory (Demmert, 2001; Demmert et al., 2006) and tribal critical race theory (Brayboy, 2005)—as well as general program strengths. This process was similar to a content analysis; the units of analysis are responses to the film director's questions during participant interviews. We transcribed quotations to illustrate each of the four identified themes. Though not intended as a formal qualitative analysis, these methods form a template for a reporting system that promotes storytelling perspectives, participatory practices, and narrative success.

Once the first cut of the video was completed, it was presented at the Wisconsin Tribal Health Directors meeting for feedback. These meetings occur biannually in northern Wisconsin. The video has been featured regularly at these meetings since 2011 with updates in each year. At each showing, the tribal health directors and the GLNARCH Community Scientific Advisory Committee provided feedback for video production. Feedback was noted, and the video went through five iterations before arriving at the most recent draft, which is considered final (Dellinger et al., 2015).

#### RESULTS

Participant responses may be categorized as the following main themes: 1) support for professional development via networking and mentoring, 2) participatory research that translates to community ("helping my people"), 3) self-determination and cultural solidarity through intergenerational success, and 4) validation and enhanced participation in education.

## **Theme 1: Networking and Support**

Student project topics included acculturation and identity in client/clinician relationships, community center development, diabetes, nutrition, and community/traditional gardening. All students indicated that participation in the NARCH program greatly enhanced their participation in school, as well as their professional development. The comments in this section all support the notion that GLNARCH has applied the Cultural Compatibility framework (as influenced by Tribal critical race theory) to its activities successfully. The intern responses demonstrate that GLNARCH provides social support, financial support, mentorship, and networking.

In all 10 cases, the interns affirmed the intended program benefits of mentorship, networking, and support. The mentor interview also conveyed these benefits. The students credited the mentors with promoting success in completing their degrees. In most cases, these mentors are themselves AI/ANs who provide examples of success in health research for the students:

I realize how important they [NARCH mentors] were in my life to guide me, to support me, to give me that wisdom and that love. And above all, that motivation to know that I can do it too. (Student 1)

What was most impressive to me was the mentoring process. I've always believed in the mentoring process, having mentors and mentees, working together for the benefit of everyone involved. (Student 2)

[My Mentor] has helped me gain perspective on where I want to go, not only as a culture teacher, but as someone who wants to support other educators that are Native and non-Native in integrating culture into the classroom. (Student 3)

It really gave us a way to connect to each other, to network, to see others, and to create that social support network. We all supported one another, looked out for one another, and wouldn't let each other fall. (Student 6)

In addition to linking Native students with Native mentors, GLNARCH provides regular access to health professional networks. The interns all acknowledged that the program gave them access to Native health professionals and networks that they otherwise would not have had.

I think it's really important that we have role models and we see people who are from our own background and share a history with us. And we see them in roles that we want to aspire to. And we see how they navigate those roles. Because it's not an easy thing because we're still a pretty [major] minority in academia, but for me it was really powerful making those relationships and continuing those relationships. (Student 1)

# 77 VOLUME 23, NUMBER 2

Through that [mentoring program] I gained a lot of supporting letters of recommendation to be admitted into medical school so those relationships there were very valuable. (Student 4)

I don't care what anybody says; every job I've gotten is from the connections I made with people [through NARCH]. (Student 5) It got me involved with other Native professionals in the area. It was a good

network for resources throughout tribal communities throughout the state and surrounding states. (Student 6)

The NARCH program kind of forced me to stepping into that world of research and connecting with people who were interested in the same things I was. (Student 7)

# Theme 2: "Helping My People"

Participants offered the following responses to the open-ended questions (i.e., general comments regarding the program). Though these benefits were assumed by the production team, the director did not necessarily seek these answers out. The comments were noted due to their relevance to Cultural Compatibility and Tribal critical race theory. Key aspects of these narratives include: benefiting the community, generational sacrifice, and self-determination. Indicating a common pattern, 8 of the 10 students expressed pride in the belief that their work with GLNARCH directly benefited their people. When later asked, the 2 who did not directly mention this theme acknowledged its importance.

So I feel that maybe I am coming to these points where I can begin to give back because I've had such wonderful examples to teach me what does that mean and what does that look like? (Student 1)

And for the most part I think that, at least for the two summers that I was in the program, the students conducted various forms of research within separate Native communities. So the research that they were doing often-times helped, directly helped, their community. (Student 4)

I could handle the classes and the other issues with the school because I had this job [NARCH intern] with other Indians and I was doing work that was meaningful for Native Americans. And so it wasn't like I was doing this assignment just to do an assignment, I knew that I was helping my people. (Student 5)

That gave me some real world experience and prompted me to get more involved in some science-based fields where Native Americans are needed. (Student 6)

I hope to go to public health school and become a nutritionist and work in a Native community somewhere. (Student 8)

I've presented at the Wisconsin Indian Education Association Conference and I've had the opportunity to present at the National Indian Education Association Conference, presenting the work that I've done through NARCH. (Student 3)

I became fluent in acculturation and identity and therapy, the types of things I think are important for Native American communities. (Student 7)

Most people in my family have diabetes so I wanted to see what could be done to include a diabetes education project in a community center. NARCH was able to provide me with that internship opportunity, something I probably wouldn't be able to get perhaps with another internship. (Student 9)

My internship project was through the department of public instruction. What I did was research how we are changing the social climate in the classroom for Native American youth... Through this program we were basically teaching teachers to work with Native American youth. (Student 10)

#### **Theme 3: Self-Determination**

Intergenerational progress, solidarity, and self-determination emerged in various forms throughout the interview process. The students provided examples of sacrifices to promote economic mobility in the next generation and emphasized the importance of support from other Native people in their efforts:

My parents sacrificed so much to help us get where we are. They didn't have the kind of opportunities that we have. They didn't have the grants and the scholarships. (Student 1)

For me it was a real natural fit, kind of a Native style, being flexible, available, and honest. (Student 2)

My daughter also did the summer program at UW-Milwaukee in July, and she loved it. It gave her a lot of opportunities that she wouldn't have experienced otherwise. My daughter now is going to be taking her CNA class to become a certified nursing assistant and use that certificate to be able to work while she's going through college. (Student 9)

## **Theme 4: Validation and Enhanced Participation in Education**

In keeping with the programmatic goals of the GLNARCH SDP, we observed a theme of enhanced school participation. The enhanced participation seemed mostly to stem from validation of the idea that higher education was an achievable, worthy goal for AI/AN people. The students emphasized the empowerment that came from the realization that their efforts were supported and encouraged by programs such as GLNARCH and by the mentors.

I realize how important they [NARCH mentors] were in my life to guide me, to support me, to give me that wisdom and that love. And above all, that motivation to know that I can do it to. I come from a reservation and my background is humble but, I am a powerful person and each person is powerful and has something to teach and something to give. And so, to this day, going through difficult challenges and times I remember the things that they taught me. I take those skills with me, the research skills, as much as the personal skills. (Student 1)

Another thing that I wanted to say was just how import NARCH is in validating me and the degree that I was seeking. And that, when I'd look around and didn't see any Indians [at my university] they'd be the ones to say "No we need you here, it's that much more important." And I'd hear that from the other NARCH interns and from my NARCH mentor as well as the NARCH staff. I felt like that validation was so important in making sure that I finished school and felt like what I was doing was important. (Student 5)

## DISCUSSION

## Implications

All students interviewed during filming reported favorable perceptions of the GLNARCH programs. The nature of the responses matched established theoretical frameworks that highlight cultural compatibility and Indigenous epistemology. The themes conveyed through these narratives match a priori assumptions that theoretical frameworks on mentorship and AI/AN perspectives (Brayboy, 2005; Demmert et al., 2006; Jackson et al., in press) could guide NARCH activities and help NARCH to achieve its goals. Interview questions were designed to report programmatic success. It was noteworthy that the students offered evidence that the underlying theoretical frameworks of GLNARCH were operating in their experiences. These narratives, therefore, provide unique evidence supporting the value of cultural compatibility and tribal critical race theory in planning GLNARCH programming and research.

Contemporary practices in academic science tend to follow an analytic style of epistemology that emphasizes process. In these practices, the primary method of reporting requires a peer review. Though this process does not necessarily contradict Indigenous epistemology, it is not representational due to a paucity of AI/AN peer reviewers who can offer a non-Western perspective. Through storytelling, tribal perspectives may be integrated into the academic process, without assimilating the Western culture itself. Figure 1 conceptualizes how

contemporary practices are impeded by challenges unique to working in Indian Country. Using storytelling as a narrative reporting tool can transcend the boundaries, allowing programs such as GLNARCH to report success in a participatory manner.

Through these narratives, AI/AN participants in GLNARCH and other programs may define their own experiences with health sciences. A process that incorporates storytelling is better equipped to address the sometimes paradoxical issues of assimilation when attempting to provide health science capacity to tribal populations. Though the resources associated with health research funding are desired, some tribal/cultural leaders fear the potential of cultural assimilation as a result of adopting Western practices. The narratives of the students, in their own words, simultaneously ameliorate these anxieties while expanding the role of Indigenous epistemology in health science. Perhaps most importantly, the documentary atmosphere instilled the students with the sense that they had a venue to express themselves. They therefore offered sincere narratives freely and emphatically. Filling the role of "the talent" rather than "study subject" matches the goals of tribal critical race theory, in which subjects characterize their experiences in their own words. They believe, correctly, that their personal message will have impact because documentary fillmmaking is self-expression at its core.

# Limitations

The information presented here does not constitute a qualitative analysis. The themes are intuitively representative of attitudes in the population, but no quantitative estimate of generalizability is possible. The intent of this article is to demonstrate the value of blending assessment efforts with documentary filmmaking. We hypothesize that the process presented here could be leveraged to provide empowering and participatory data for future scientific inquiry.

## CONCLUSION

GLNARCH has demonstrated consistent success in promoting health sciences careers and research within the Bemidji Region since 2003. GLNARCH has placed 130 AI/AN students in research internships at both undergraduate and graduate levels, and Phase II has been implemented successfully with at least 20 AI/AN students annually since 2003 (Jackson et al., in press). Regarding research, previous NARCH projects (which include NARCH interns) have produced 20 accepted or published manuscripts, and 52 scientific presentations and/or posters. These achievements have led to six non-NARCH grants totaling approximately \$4.1 million (Jackson et al., in press). This evidence of success is complemented by the qualitative information gained during the GLNARCH participatory filmmaking project.

To better understand methods for conducting research that center on Indigenous ways of knowing and self-determination, innovative forms of evidence must be considered. The incorporation of Indigenous epistemology has demonstrated success in other health science educational efforts (Dickerson et al., 2014; Martin & Seguire, 2013). Similarly, other efforts to employ cultural compatibility in AI/AN education have determined that participatory evaluation practices are necessary (Curran, Solberg, LeFort, Fleet, & Hollett, 2008; Martin & Kipling, 2006). It is clear that the interviews discussed here provide a unique and powerful insight into the strengths of NARCH programs that use Tribal critical race theory and Cultural Compatibility frameworks to guide design and implementation. With the recent center renewal (NARCH VIII, September 2014-August 2018), the above information has led the team to updated efforts. Moving forward, the GLNARCH team plans to design and support research that will identify best practices for promoting narratives as evaluation and intervention tools. This work will include a new online digital story series where participants can publicly share their experiences in a documentary-style format using GLNARCH equipment and expertise. New GLNARCH film projects are also planned based on the best practices learned from the current results. These results highlight the importance of building theory and identifying the synergies between Western-style scientific inquiry and AI/AN storytelling.

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# EGO STRENGTHS, RACIAL/ETHNIC IDENTITY, AND WELL-BEING AMONG NORTH AMERICAN INDIAN/FIRST NATIONS ADOLESCENTS

Barbara M. Gfellner, PhD

Abstract: This study investigated associations between ego strengths (psychosocial development), racial/ethnic identity using Multi-Ethnic Identity Measure-Revised (exploration, commitment) and Multidimensional Measure of Racial Identity (centrality, private regard, public regard) dimensions, and personal adjustment/well-being among 178 North American Indian/First Nations adolescents who resided and attended school on reserves. As predicted, ego strengths related directly with centrality, private regard, and the adjustment measures; the moderation of ego strengths for exploration, commitment, and private regard reflected adverse functioning for those with less than advanced ego strengths. As well, ego strengths mediated associations between centrality and private regard with several measures of personal well-being. Practical and theoretical implications are considered.

Identity construction is the major developmental task for adolescents. According to Eriksonian theory, this process is predicated by successful resolution of earlier psychosocial stages, which also provide the foundation for negotiating subsequent lifespan concerns. The adolescent period is considered more complicated and challenging for minority youth who also must incorporate their racial, ethnic, or cultural background into their self-definition (Phinney, 1992). Research indicates that racial and ethnic identity (REI) functions as a protective resource to offset adversity among many disadvantaged minority groups (e.g., Chao & Otsuki-Cutter, 2011; Rivas-Drake, Seaton, et al., 2014; Rivas-Drake, Syed, et al., 2014; Smith & Silva, 2011). However, minimal research has focused on how psychosocial development is associated with REI to facilitate optimal well-being. In this study, psychosocial development, conceptualized as ego strengths (i.e., the outcomes, values, or assets that result from resolving lifespan developmental tasks), was examined in relation to various components of REI and adjustment, and as a potential moderator and a mediator for the dimensions of REI and well-being.

The sample, Indigenous adolescents, is an understudied group considered the most disadvantaged in terms of overall physical and mental well-being (e.g., Bramley, Herbert, Tuzzio, & Chassin, 2005; Frohlich, Ross, & Richmond, 2006). In Canada, Indigenous people are a prominent minority. More than 16% of the population in the prairie provinces self-identifies as Aboriginal; that is, North American Indian/First Nations (NAI/FN), including Status and Non-status Indian, Metis, and Inuit; 58% live on reserves, and 61% are less than 30 years of age—the most rapidly growing demographic in the country (Statistics Canada, 2013).

As with American Indian/Alaska Natives in the U.S., NAI/FN people in Canada experience higher rates of physical, social, and mental health problems in comparison with other minority groups (Comeau & Santin, 1995; Pavkov, Travis, Fox, King, & Cross, 2010; Townsend & Wernick, 2008), including increased psychological distress (Bratter & Eschbach, 2005; Campbell & Evans-Campbell, 2011; Walls & Whitbeck, 2011), greater challenges in terms of identity development (Arnett, 2006) and lower ethnic identity scores (Martinez & Dukes, 1997). These disparities have been linked with the historical trauma experienced by colonized Indigenous people (Evans-Campbell (2008) due to government assimilation policies (including the establishment of reservations, removal of children from their parents to attend residential schools) and a legacy of discrimination and racism (Kirmayer, Simpson, & Cargo, 2003). These practices have systematically undermined protective cultural factors, socialization, cultural values, ceremony, language, and tradition (Duran, Duran, & Brave Heart, 1998) and have continuing multigenerational impacts (Bombay, Matheson, & Anisman, 2014; Tafoya & Del Vecchio, 1996; Weaver & Brave Heart, 1999).

Research has shown that REI is viewed as a resource for optimal development among NAI/FN adolescents (Buruch, Bombay, Flores, Stewart, & Ponizovsky, 2014; Gfellner & Armstrong, 2012; 2013; Jones & Galliher, 2007; Martinez & Dukes, 1997; Whitesell, Mitchell, Kaufman, & Spicer, 2006; Whitesell, Mitchell, Spicer, & the Voices of Indian Teens Project Team, 2009); although often inconsistently, depending on the measure of ethnic identity used (Markstrom, Whitesell, & Galliher, 2011). The protective role of REI is reflected in the Native revitalization movement that typically includes traditional healing concepts (e.g., Garrett et al., 2014; Gone, 2009; Goodkind et al., 2010; Iwasaki, Bartlett, & O'Neill, 2005; Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011; LaFromboise, Hoyt, Oliver, & Whitbeck, 2006).

#### Ego Strengths and Psychosocial Development

From the Eriksonian perspective, ego strengths reflect the outcomes, values, or assets that emerge as a person negotiates and integrates the tasks associated with the eight psychosocial stages over the lifespan (Erikson, 1969). The first four of the developmental stages (trust vs. mistrust, autonomy vs. doubt and shame, initiative vs. guilt, competence vs. inferiority) occur from birth to age 12; these provide the foundation for identity versus role confusion, the fifth stage associated with adolescence and youth. The final three stages (intimacy vs. isolation, generativity vs. stagnation, integrity vs. despair) refer to the young, middle, and late adult years, respectively. Erikson's model is consistent with lifecycle epochs in Aboriginal cultures (cf., Reichard, 1977; Slobodin, 1981); and his field work included the Oglala Sioux in South Dakota and the Yurok tribe of Northern California.

According to Erikson's theory (1969), positive resolution of a psychosocial stage is associated with optimal adjustment; conversely, difficulties with earlier psychosocial phases have a negative impact on subsequent functioning and development. Indeed, psychosocial development or ego strengths would be expected to be an important precursor of REI development among NAI/FN adolescents and other minorities.

Ego strengths has been positively associated with identity achievement among youth and adolescents (Markstrom & Marshall, 2007; Markstrom, Sabino, Turner, & Berman, 1997) as well as with fidelity, the emergent value associated with personal identity (Markstrom & Hunter, 1999), and career identity (Anthis, 2014), and have been inversely associated with identity distress (Gfellner & Cordoba, 2011). Gfellner and Armstrong (2012) found significantly higher ego strengths among NAI/FN adolescents who strongly self-identified with Indigenous culture in comparison with those who self-identified as bicultural (both their own and mainstream culture). As with personal identity (achievement), ego strengths has been associated with other indicators of psychosocial maturity and adjustment, including self-esteem, social-cognitive ego development, locus of control, coping styles, empathetic concern, positive affect, personal distress, social support, academic adjustment, externalizing (e.g., acting out/behavioral) and internalizing (e.g., anxiety, depression) problems, and stress (Gfellner & Armstrong; 2012; Gfellner & Cordoba, 2011; Markstrom et al. 1997; Markstrom & Marshall, 2007). The present study extended the evaluation of ego strengths with well-being and as a predictor of REI among NAI/FN adolescents.

## **REI and Adjustment**

REI is a component of one's identity that develops as a function of one's group membership. It is a multifaceted construct that varies in complexity as well as salience, or importance to an individual's sense of self. REI models focus on identification and feelings of belongingness and attachment to one's group and the meaning attributed to this association (Phinney, 1992; Sellers, Rowley, & Chavous, 1997). From a developmental perspective, ethnic identity includes the processes of exploration and commitment (Phinney, 1992). Exploration involves actively seeking out and examining one's ethnicity and its meaning, while commitment refers to allegiance to one's group by incorporating or adhering to its values and ideology. Sellers and colleagues (1997) considered racial identity to encompass both the significance and qualitative meaning of one's background in terms of three components: centrality, or the extent to which race/ethnicity is salient to one's self-concept; private regard, which refers to the value one feels about one's background; and public regard, which is how one feels that others view one's group. These processes become increasingly important during adolescence, when individuals are undergoing dramatic physical, cognitive, and social changes (Phinney, 1993). REI is an important aspect of identity among members of minorities in comparison with those in the majority or dominant groups in society (Phinney, 1992); it has been associated with personal identity development (identity achievement) among minority but not among non-minority individuals (St. Louis & Liem, 2005).

According to social identity theory, individuals maintain self-esteem through identification with their group (Tajfel & Turner, 1986). Indeed, REI is viewed as an important predictor of positive adjustment, so that a strong REI contributes to personal well-being among ethnic group members (e.g., Rivas-Drake, Syed, et al., 2014; Smith & Silva, 2011). As a pivotal aspect of identity for some minorities, REI has been associated with positive outcomes; this result is not found among non-minority youth (St. Louis & Liem, 2005). Given the salience of REI for minority group members and its association with adjustment in general, ego strengths was predicted to moderate the linkages between REI and well-being. In other words, elevated ego strengths in conjunction with a robust REI were expected to be associated with adjustment. At the same time, ego strengths was examined as a mediator in the relationship between REI and psychological functioning; that is, ego strengths was predicted to REI, which, in turn, would be associated with personal well-being.

Several recent reviews of REI and positive development for minority youth (Chao & Otsuki-Clutter, 2011; Rivas-Drake, Syed, et al., 2014; Umana-Taylor, 2011) noted differences in: 1) the strength and direction for effects of REI among various groups, 2) the use of specific components versus global REI measures, 3) confounding of developmental effects, and 4) contextual factors. In a meta-analysis of acculturation/enculturation and mental health, Yoon et al. (2013) reported that REI (enculturation) related solely with positive mental health and anxiety. They indicated that REI was a more important predictor for African Americans than for Asian Americans, and suggested a focus on potential differences among various minority groups along with differential effects of age and social roles in relation to REI and contextual factors.

Similar concerns were echoed in a review of ethnic identity and mental health of American Indian/Alaska Natives by Markstrom, Whitesell, and Galliher (2011). Although less research is available for Indigenous youth in comparison with other minorities, a lack of consistent findings was attributed to variations in the ethnic identity measures used, including a greater reliance on acculturation (identification with mainstream society) rather than enculturation (REI) in some studies. These authors called for careful attention by investigators to the operationalization of ethnic identity and how it may be appropriate for Indigenous samples.

Taken together, these reviews, along with the work of other scholars (e.g., Casey-Cannon, Coleman, Knudson, & Valezquez, 2011; Cokley, 2007; Ong, Fuller-Rowell, & Phinney, 2010; Quintana, 2007) caution against the use of aggregate measures of REI as potential confounds that obfuscate findings. They emphasize the need to focus on discrete components of REI and how these may align differentially in relation to relevant outcome variables as well as across minority groups.

The present study measured REI with the two most frequently used indices: the Multigroup Ethnic Identity Measure-Revised (MEIM-R; Phinney & Ong, 2007) and the Multidimensional Measure of Racial Identity (MMRI; Sellers, Smith, Sheldon, Rowley, & Chavous, 1998). These instruments have been examined widely across different minority groups, including NAI/FN adolescents, although research with the latter group is scant. The MEIM-R assesses ethnic exploration and commitment; the MMRI includes scales for centrality, private regard, and public regard. Together, the scales may be considered to reflect two dimensions of REI: the affective/emotional, including attachment, belonging, in-group affect and pride (i.e., private regard, commitment, public regard); and the cognitive/evaluative consisting of awareness and meaning of group membership and importance to one's self-concept (i.e., exploration, centrality). As indicated previously, the affective components tend to be associated with selfesteem, positive well-being, and supportive resources (e.g., Rivas-Drake, Syed, et al., 2014; Smith & Silva, 2011). Despite limited evidence, these trends have been found with NAI/FN adolescents (Galliher, Jones, & Dahl, 2011; Gfellner & Armstrong, 2012; Jones & Galliher, 2007; Kenyon & Carter, 2010; Newman, 2005).

Given the multidimensionality of REI, the objective of this study was to investigate aspects of the construct rather than using a global configuration. Well-being was indexed by self-esteem (Rosenberg, 1979), superior adjustment, mastery and coping, and emotional tone (Offer, Ostrov, & Howard, 1982). The current study extended the evaluation of ego strengths as a predictor of the REI dimensions and a moderator and a mediator for the REI components with well-being. Developmental and gender differences were tested but predictions were not proposed, as an earlier study with the same population did not support these effects among adolescents. The hypotheses were as follows:

- Ego strengths was predicted to positively relate with the dimensions of REI and with well-being of NAI/FN adolescents.
- 2) The dimensions of REI were predicted to positively relate to well-being.
- 3) Ego strengths was expected to moderate the linkage between the REI variables and well-being.
- 4) Ego strengths was expected to mediate the association between REI and well-being.

# METHOD

# **Participants and Procedure**

There were 178 NAI/FN adolescents in grades 7 to 12 (M = 14.2 years, SD = 2.0; 50% female) who resided and attended school in their FN communities (reserves) located in the southern midwest of Canada. The breakdown by grade level was:

- grades 7 and 8: M = 12.4 years, SD = .65; 39 females; 42 males
- grades 9 to 12: M = 15.6 years, SD = 1.6; 50 females; 47 males.

Students participated in this study in conjunction with the evaluation component of a cultural curriculum program operating in their band schools in 5 FN communities; the populations ranged from 871 to 4,302 (M = 1,962; Mdn = 1,394) persons. The Community Well-Being Index (a measure of socioeconomic well-being based on income, education, housing, and employment information from Statistics Canada) for these reserves ranged from 50 to 69, compared with the range of 66 to 89 for non-Aboriginal communities in the province (Aboriginal Affairs and Northern Development Canada, 2015).

The project was a collaborative process among community organizations and members, Aboriginal groups, and university researchers in all phases: initiation, proposal writing, program development, maintenance, and evaluation. The inclusion of communities was based on interest and commitment. The team developed, applied for, and received a Social Sciences and Humanities Research Council of Canada: Community-University Research Alliance (SSHRC-CURA) Grant for the project entitled "Community-Based Aboriginal Curriculum Initiatives: Implementation and Evaluation." The program consisted of integrating Aboriginal culture into all components of the school curriculum. It involved the use of Aboriginal artist-educators, teachers, and elders in ongoing course development and evaluation along with community members, educators/teachers, and researchers. The project was vetted by the University Research Ethics Board in accordance with the Tri-council Policy Guidelines (TCPG) for research with Indigenous people and by the respective Band Councils (Thompson, Whitesell, Galliher, & Gfellner, 2012).

Students' participation in this study required consent from parents or guardians, and student assent. Students took home consent forms that were signed by parents or guardians, and subsequently returned to teachers and collected by school-based community project coordinators prior to data collection. Survey administration was conducted by NAI/FN research assistants; students completed the surveys in their classrooms or in a larger group setting. Participants received gel pens as a gratuity during the survey administration. The survey took approximately 30 to 40 minutes to complete.

Overall, 68% of students registered in the schools completed the survey. Another 27% were absent on the survey administration occasions or had incomplete data, and 5% refused consent.

#### Measures

The Psychological Inventory of Ego Strengths (PIES; Markstrom et al., 1997) was used to assess ego strengths. It indexes progressive functioning in terms of Erikson's stages. The short form consists of 32 items, 4 for each of the eight ego strengths associated with the psychosocial stages (hope, will, purpose, competence, fidelity, love, care, and wisdom), which are rated on a 5-point Likert scale from 1 (*Does not describe me well*) to 5 (*Describes me very well*). Item scores may be summed for each scale as well as for a composite score. The composite score was

used in this study. Psychometric properties are given by Markstrom and Marshall (2007); the PIES has been used with African American adolescents (Markstrom & Hunter, 1999) and NAI/FN adolescents and adults (Gfellner, 2015; Gfellner & Armstrong, 2012).

The Multi-group Ethnic Identity Measure-Revised (MEIM-R; Phinney & Ong, 2007) is the most extensively used measure of REI; it is a global index that has been found to be valid and reliable with a number of ethnic groups. The MEIM-R includes two scales: Exploration refers to the extent to which one has examined one's ethnicity; and Commitment measures the extent to which one has affirmed one's ethnicity. Each scale includes three items that are rated on a 4point response scale that ranges from 1 (*Strongly disagree*) to 4 (*Strongly agree*.)

The Multidimensional Measure of Racial Identity (MMRI; Sellers et al., 1998), originally developed for use with African Americans and adapted for use with other minorities (e.g., Rivas-Drake, 2011), was modified for use with NAI/FN adolescents. Three scales were used. Centrality (eight items) refers to the extent to which one's ethnic identity is focal to one's life, or how one defines the self in terms of race and ethnicity. Private Regard (six items) measures the extent to which one feels positively or negatively toward Indigenous people and how one feels about being an Indigenous person. Public Regard (five items) measures how one feels that others view Indigenous people, and how one perceives that their group is viewed or valued by mainstream society. Items are rated on a 7-point scale from 1 (*Strongly disagree*) to 7 (*Strongly agree*). Mean scores were computed for each scale.

Self-esteem was indexed by Rosenberg's (1979) 10-item global self-image measure. Statements are rated on a 4-point scale from 1 (*Does not describe me at all*) to 4 (*Describes me very well*). Psychometric properties are well established; the measure is the most frequently used index of self-image, and it has been used in recent studies with Indigenous adolescents (e.g., Jones & Galliher, 2007; Whitbeck, Hartshorn & Walls, 2014; Whitesell et al., 2006; Whitesell et al., 2009).

Adjustment was indexed by three scales from the Self-image Questionnaire for Young Adolescents (SIQYA; Offer et al., 1982; Petersen, Schulenberg, Abramowitz, Offer, & Jarcho, 1984). The SIQYA involves scales that depict specific aspects of self-image. Statements about the self are rated using a 6-point scale from 1 (*Describes me very well*) to 6 (*Does not describe me at all*). Half of the items are reversed; scale scores are summed to reflect a positive value. Emotional Tone includes 11 items that refers to the psychological self. Examples include: "My feelings are easily hurt," "I am often nervous," and "I frequently feel bad." The other two scales are measures of the coping self. Superior Adjustment consists of 10 items such as "I am popular

at school," "New situations are often difficult for me to cope with," "I am worried I will not be able to make decisions for myself in the future." Mastery and Coping is measured by 10 items including, "When I decide to do something I do it," and "I am not afraid of competing to succeed." The SIQYA has well-established reliability and validity for normal, delinquent, and emotionally disturbed adolescents (Offer, Marohn, & Ostrov, 1979); it has been used extensively, including in a major study that compared the self-image of adolescents in 10 countries (Offer, Ostrov, Howard, & Atkinson, 1988).

A power analysis (typical of large scale survey research) refers to the sample size required to insure that findings are reliable. As noted above, this was not necessary as every student in the schools that participated in the curriculum initiatives project was targeted to partake in this study.

#### **Data Analysis**

Descriptive statistics included Sex by Age-group MANOVAs for the variables in the study. Correlations were computed between the predictor and moderator variables with the adjustment measures. A series of regressions analyses were run with age-group, sex, ego strengths, the respective REI dimensions (n = 5), and, subsequently, the ego strengths by REI-dimension interactions (n = 5) for each of the adjustment variables (n = 4), respectively. Slopes were plotted for significant interactions with the moderator and independent variables centered at the mean and  $\pm$  one standard deviation. Mediation was tested using Baron and Kenny's (1986) criteria followed by a Sobel test.

## **RESULTS**

Most students lived with both natural parents (21%) or mother (21%); followed by grandparents (15.3%), mother and stepfather (14.8%), father (8%), father and stepmother (7.4%), part-time with mother and father (4.6%), other (6%), adopted (1.7%), and court-appointed guardian or foster home (1.2%). The average educational attainment was high school for both fathers and mothers. The breakdown for fathers was: junior high or less (9.5%); some high school (29.7%); completed high school (34.5%); some post-secondary (16.9%); university degree (7.4%); and post-graduate school (2%). Similarly, the distribution for mothers was: junior high or less (9%); some high school (32.3%); completed high school (24.5%); some post-secondary (20.7%); university degree (10.3%); and post graduate school (3.2%). The majority of

fathers were employed in skilled (27.6%) and unskilled (31%) jobs, followed by professional/white collar positions (11.2%); one was a student, and 29.3% were unemployed. Students described most mothers as homemakers (50.4%), followed by employed in skilled (16.8%), professional (10.4%), and unskilled (16%) work; one was a student, and 5.6% were unemployed.

# **Preliminary Analyses**

A summary of the grade-level by sex ANOVAS for the variables in the study are given in Table 1. The significant main effects of grade-level for age, ego strengths, exploration, and commitment indicated higher scores for middle school than high school students apart from age. Sex differences for public regard and emotional tone reflected elevated scores for males. A significant grade-level by sex interaction for ego strengths, F(1, 172) = 6.08, p < .02,  $\eta = .034$ , showed lower psychosocial development among younger females (M = 3.22, SD = .44) in comparison with male cohorts (M = 3.47, SD = .43), and older female (M = 3.53, SD = .46) and male (M = 3.45, SD = .43) adolescents.

Means (SD) by Grade-level and Sex for the Variables in the Study											
<u>Variables</u>	Grade Level		F-Value	<u>Sex</u>		F-Value					
	Middle School <sup>a</sup>	High School <sup>b</sup>		Females	Males						
Age	12.4 (.65)	15.6 (1.6)	275.39***	14.2 (2.0)	14.1 (2.0)	0.04					
Ego Strengths	3.3 (0.45)	3.5 (0.44)	5.09*	3.4 (0.47)	3.5 (0.42)	1.63					
Centrality	6.0 (0.91)	6.2 (1.1)	1.41	6.1 (0.87)	6.1 (1.11)	0.00					
Private Regard	5.5 (1.4)	5.4 (1.8)	0.16	5.3 (1.3)	5.6 (1.2)	3.07					
Public Regard	4.5 (1.0)	4.2 (1.2)	2.88	4.0 (1.1)	4.7 (1.0)	20.68***					
Exploration	10.2 (2.3)	9.5 (2.1)	4.93*	9.9 (2.1)	9.7 (2.4)	0.22					
Commitment	11.9 (2.8)	10.7 (2.8)	7.58**	11.1 (3.0)	11.4 (2.8)	0.19					
Self-esteem	27.6 (5.3)	27.7 (5.2)	0.03	27.3 (5.3)	28.0 (5.2)	0.67					
Mastery &	4.10 (0.73)	4.3 (0.70)	2.57	4.2 (0.74)	4.2 (0.69)	0.89					
Coping Superior Adjustment	3.7 (0.80)	3.9 (0.77)	2.22	3.7 (0.78)	3.9 (0.78)	2.99					
Emotional Tone	3.6 (0.85)	3.5 (0.60)	0.12	3.4 (0.70)	3.7 (0.72)	4.15*					

Table 1 (SD) by Grade-level and Say for the Variables in the Study

<sup>a</sup> Middle school = grades 7 and 8; <sup>b</sup> High school = grades 9-12

\* = p < .05; \*\* = p < .01; \*\*\* = p <.0001

# **Correlational Analyses**

The zero-order correlations between the predictors and outcome variables, and the means, standard deviations, ranges, and alpha coefficients for all variables, are given in Table 2. As predicted in the first hypothesis, correlations supported associations between ego strengths, the REI dimensions of centrality and private regard, and all the adjustment measures. As indicated in the second hypothesis, each REI dimension correlated significantly with self-esteem and superior adjustment; centrality, private regard, and commitment correlated with mastery and coping.

Table 2           Correlations Between the Predictor, Moderator, and Outcome Variables in the Study												
	Ego Strengths	Self- esteem	Superior Adjustment	Mastery and Coping	Emotional Tone	M(SD)	Range	alpha				
Ego Strengths	-					3.4 (0.45)	2.2-4.7	.79				
MMRI												
Centrality	.24***	.15*	.19**	.24***	02	6.1 (2.0)	3.5-8.8	.57				
Private Regard	.28***	.25***	.18*	.18**	.10	5.4 (1.3)	2-7	.82				
Public Regard	.12	.24***	.16*	.07	.03	4.3 (1.1)	1.3-7.0	.61				
MEIM-R												
Exploration	.13	.16*	.15*	.06	10	9.8 (2.2)	3-15	.61				
Commitment	.14	.20**	.28***	.22**	10	11.3 (2.9)	2-15	.63				
Adjustment Variables												
Self-esteem	.41****	-				27.6 (5.3)	14-40	.77				
Superior Adjustment	.46****	.37****	-			3.8 (.79)	1.5-5.6	.66				
Mastery and Coping	.60****	.32****	.52****	-		4.2 (.71)	2.7-5.9	.71				
Emotional Tone	.27***	.11	13	.26***	-	3.6 (.72)	1.7-6.0	.79				

\* = p < .05; \*\* = p < .01; \*\*\* = p < .001; \*\*\*\* = p < .0001;

# **Regression Analyses**

The regression analyses for the MEIM-R and MMRI scales are summarized in Table 3 and Table 4. Consistent with the correlations, ego strengths was a significant predictors for each of the adjustment measures in the first set of regression analyses. Similarly commitment predicted self-esteem and superior adjustment. In contrast to the correlations, exploration and commitment related inversely with emotional tone, and public regard predicted self-esteem in the first set of the regression equations.

for MEIM-R Scales as Predictors of the Adjustment Variables								
MEIM-R <sup>a</sup>	Self- esteem		Superior Adjustment		Mastery and Coping		Emotional Tone	
	Beta(SE)	R <sup>2</sup>	Beta(SE)	R <sup>2</sup>	Beta(SE)	R <sup>2</sup>	Beta(SE)	R <sup>2</sup>
Exploration								
Grade	26 (.76)		.09 (.11)		.04 (.09)		13 (.11)	
Sex	.16 (.73)		.11 (.11)		.00 (.09)		.20 (.11)	
Ego Strengths	.16 (.03)****		.03(.00)****		.03 (.00)****		.02 (.00)****	
Exploration	.23 (.17)	.182	.03 (.03)	.226	00 (.02)	.360	05 (.02)*	.117
Grade	24 (.76)		.09 (.11)		.04 (.09)		13 (.11)	
Sex	.08 (.73)		.10 (.11)		.01 (.09)		.22 (.10)d	
Ego Strengths	.34 (.12)***		.05(.02)***		.01 (.02)		62 (.54)	
Exploration	.24 (.13)		.30 (.19)		23 (.16)		42(.18)*	
Ego Strengths X Exploration	58 (.37)	.194	08 (.05)	.235	.06 (.05)	.368	.11 (.05)*	.139
<u>Commitment</u>								
Grade	14 (.76)		.15 (11)		.11 (.09)		16 (.11)	
Sex	.11 (.73)		.12 (.10)		.02 (.09)		.20 (.10)	
Ego Strengths	.15 (.03)****		.02 (.00)****		.030 (.00)****		.02 (.00)****	
X Commitment	2.4 (.13)	.190	.06 (.018)**	.277	.04 (.02)**	.396	04 (.02)*	.118
Grade	34 (.74)		.13 (.11)		.11 (.09)		16 (.11)	
Sex	.28 (.71)		.13 (.10)		.09 (.09)		.20 (.11)	
Ego Strengths	.52 (.11)****		.06 (.02)***		.04 (.01)**		.02 (.02)	
Commitment	3.67(.97)***		.36 (.14)**		.11 (.12)		01 (.14)	
Ego Strengths	-1.00 (.28)***	.248	09 (.04)*	.296	02 (.03)	.397	01 (.04)	.118
X Commitment								

 Table 3

 Beta Coefficients, Error Terms, and Size Effects from the Multiple Regression Analyses

 for MEIM-R Scales as Predictors of the Adjustment Variables

<sup>a</sup> MEIM-R = Multi-group Ethic Identity Measure-Revised

\* = p < .05; \*\* = p < .01; \*\*\* = p < .001; \*\*\*\* = p < .001; \*\*\*\*

for MMRI Scales as Predictors of the Adjustment Variables								
MMRI <sup>a</sup>	Self- esteem		Superior Adjustment		Mastery and Coping		Emotional Tone	
	Beta (SE)	R <sup>2</sup>	Beta (SE)	R <sup>2</sup>	Beta (SE)	R <sup>2</sup>	Beta (SE)	R <sup>2</sup>
<u>Centrality</u>								
Grade	61 (.75)		.039 (.11)		.02 (.09)		11 (.11)	
Sex	.10 (.74)		.095 (.11)		04 (.09)		.18 (.11)	
Ego Strengths	.16 (.03)****		.026(.00)****		.03(.00)****		.02 (.01)****	
Centrality	.27(.38)	.173	.062 (.06)	.227	.07 (.04)	.419	06 (.06)	.121
Grade	52 (.75)		.04 (.11)		.01 (.08)		11 (.11)	
Sex	.01 (.74)		.11 (.11)		03 (.09)		.18 (.11)	
Ego Strengths	.13 (.04)***		.00 (.02)		.02 (.02)		.03 (.02)	
Centrality	.03 (.42)		34 (.42)		24 (.33)		.11 (.41)	
Ego Strengths X Centrality	.13 (.10)	.182	.12 (.12)	.232	.09 (.09)	.422	05 (.12)	.122
Private Regard								
Grade	50 (.75)		.048 (.11)		.02 (.09)		12 (.11)	
Sex	03 (.74)		.09 (.11)		04 (.09)		.19 (.11)	
Ego Strengths	.15 (.03)****		.03 (.00)****		.03 (.00)****		.00 (.02)***	
Private Regard	.55(.30)	.187	.00(.01)	.223	.00 (.04)	.409	.01 (.11)	.115
Grade	55(.74)		.05 (.11)		.02 (.09)		12 (.11)	
Sex	22 (.73)		.08 (.11)		04 (.09)		.19 (.11)	
Ego Strengths	.46 (.14)****		.03 (.02)		.03 (.02)		.02 (.00)	
Private Regard	1.04 (.40)**		.02 (.06)		06 (.29)		21 (.35)	
Ego Strengths X Private Regard	-1.72(.72)*	.214	03 (.11)	.223	.02 (.09)	.409	.07 (.11)	.117
Public Regard								
Grade	28 (.75)		.08 (.11)		.04(.09)		15 (.11)	
Sex	53 (.77)		.07 (.11)		02 (.09)		.20 (.11)	
Ego Strengths	.15 (.03)****		.03 (.00)****		.04 (.00)****		.02 (.00)****	
Public Regard	.95 (.35)***	.206	.01 (.01)	.243	00 (.01)	.423	04 (.05)	.113
Grade	29 (.750)		.08 (.11)		.04 (.09)		14 (.11)	
Sex	53 (.77)		.07 (.11)		02 (.09)		.20 (.11)	
Ego Strengths	.22 (.11)*		.03 (.02)		.03 (.01 )*		.01 (.02)	
Public Regard	2.59 (2.1)		.03 (.08)		05 (.06)		28 (.38)	
Ego Strengths	48 (.77)	.208	02 (.11)	.243	.07 (.09)	.426	.07 (.11)	.116
X Public Regard								

Table 4 Beta Coefficients, Error Terms, and Size Effects from the Multiple Regression Analyses for MMRI Scales as Predictors of the Adjustment Variables

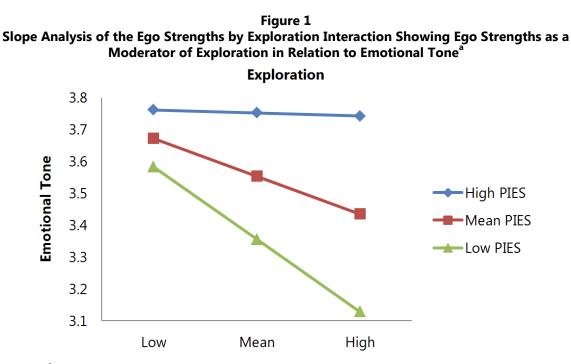
<sup>a</sup> MMRI = Multidimensional Model of Racial Identity

\*\*\*\* = p < .0001, \*\*\* = p < .001, \*\* = p < .01, \* = p < .05

### Ego Strengths as a Moderator of REI and Adjustment

To test for moderation (hypothesis 3), the interaction terms for ego strengths with each of the REI variables (n = 20) were entered in the second set of regression equations. Tables 3 and 4 show the results; the following four interactions attained significance.

The ego strengths by exploration interaction for emotional tone was significant (p < .0001). Following the work of Aiken and West (1991), slopes were plotted with ego strengths and exploration standardized at the mean and ±1 standard deviation. As seen in Figure 1, low ego strengths exacerbated the negative effect of exploration on emotional tone; the slope, t = -2.85, p < .01, was significant. A similar trend was seen for mean ego strengths with a significant slope, t = -2.20, p < .05. However, moderation was not found for those with high ego strengths, indicating that advanced ego strengths was protective regardless of level of exploration, while average and low ego strengths augmented the negative effect of exploration on emotional tone.





The interaction of ego strengths by commitment for self-esteem achieved significance (p < .0001). Figure 2 shows the slopes; for low ego strengths the significant slope, t = 3.92, p > .0001, indicated that deficient ego strengths in conjunction with commitment circumvented self-esteem. This effect was mirrored for mean ego strengths with a significant slope, t = 2.05, p < .0001

.01. Conversely, the gradient for high ego strengths did not achieve significance. In other words, low and mean ego strengths reversed the linkage between commitment and self-esteem; advanced ego strengths enhanced self-esteem regardless of level of commitment.

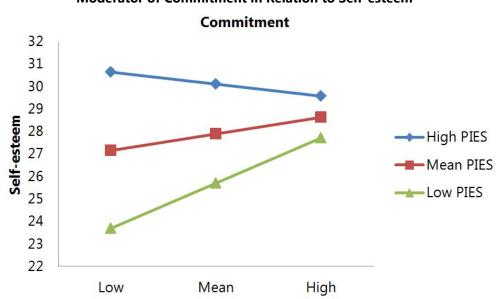


Figure 2 Slope Analysis of the Ego Strengths by Commitment Interaction Showing Ego Strengths as a Moderator of Commitment in Relation to Self-esteem<sup>a</sup>

<sup>a</sup> Ego strengths and commitment are centered at the mean;  $\pm 1$  standard deviation

Also significant was the ego strengths by commitment interaction for superior adjustment (p < .0001). As seen in Figure 3, low ego strengths depressed the effect of commitment on selfesteem; the slope, t = 3.65, p < .0005, was significant, and the trend was similar for mean ego strengths, t = 3.08, p < .005. The slope was not significant for high ego strengths, indicating augmentation of ego strengths as an indicator of superior adjustment, while low and mean ego strengths negatively moderated the effect of commitment on superior adjustment.

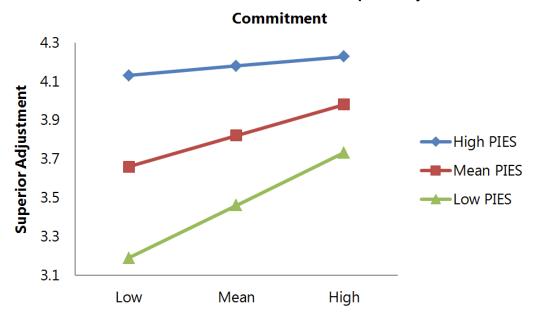


Figure 3 Slope Analysis of the Ego Strengths by Commitment Interaction Showing Ego Strengths as a Moderator of Commitment in Relation to Superior Adjustment<sup>a</sup>

<sup>a</sup> Ego strengths and commitment are centered at the mean; ± 1 standard deviation

Finally, as shown in Table 4, on the MMRI, the ego strengths by private regard interaction was significant for self-esteem (p < .0001). Figure 4 illustrates the slopes. The slope was significant for low ego strengths, t = 2.98, p < .005, revealing that low ego strengths negatively moderated private regard on self-esteem. The slopes did not achieve significance at the mean or high levels of ego strengths, reflecting that they independently contributed to self-esteem. However, deficient ego strengths negatively moderated the linkage of private regard with self-esteem.

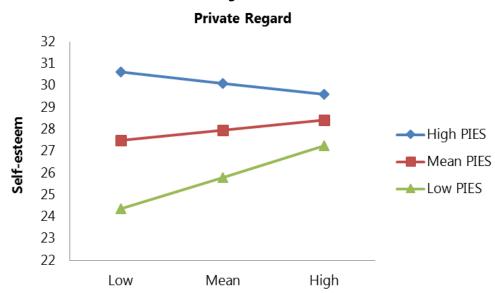


Figure 4 Slope Analysis of the Ego Strengths by Private Regard Interaction Showing Ego Strengths as a Moderator of Private Regard in Relation to Self-esteem<sup>a</sup>

<sup>a</sup> Ego strengths and private regard are centered at the mean; ± 1 standard deviation

#### Ego Strengths as a Mediator of REI and Adjustment

Following Hypothesis 4, ego strengths was examined as a mediator for the REI dimensions with the adjustment variables using the criteria outlined by Baron and Kenny (1986). The preconditions for mediation were the presence of correlations between 1) the REI dimensions and the adjustment measures, 2) ego strengths and the REI variables, and 3) ego strengths and the adjustment variables. As seen in Table 2, these correlations were significant, indicating potential mediation of ego strengths for centrality with mastery and coping; and private regard with self-esteem, superior adjustment, and mastery and coping, respectively. Testing the models involved generating three sets of regression analyses for each case (n = 4). First the REI dimension was regressed on the relevant outcome variable; the next step involved the regression of ego strengths on the appropriate REI variable; and finally, both ego strengths and the respective REI variable were regressed on the adjustment variable. Ego strengths was considered to function as a mediator if the REI dimension was mitigated or reduced in variance when included with the mediator in the regression analysis. A Sobel test of indirect effect was used to confirm mediation. The results of the regression analyses for the conditions that met the screening criteria were as follows.

In the first case, centrality was significant when regressed on mastery and coping ( $R^2 = .059$ ), and subsequently, when it was regressed on ego strengths ( $R^2 = .057$ ). For step 3, when

centrality and ego strengths were regressed on mastery and coping, ego strengths retained significance and centrality was mitigated (see Table 4). This drop in significance of centrality indicated that ego strengths functioned as a mediator; the significant Sobel test, z = 2.29, p < .02, substantiated this result. Thus, ego strengths related to centrality which in turn was associated with mastery and coping.

Following the same procedure, ego strengths was examined as a mediator for private regard and self-esteem. Private regard was significant when regressed on self-esteem ( $R^2 = .061$ ). Next, it was significant when regressed on ego strengths ( $R^2 = .080$ ); and, in the last model with both private regard and ego strengths regressed on self-esteem, ego strengths retained significance and private regard was mitigated (see Table 4). Mediation was supported by the Sobel test, z = 2.58, p < .01. In other words, ego strengths indirectly related to self-esteem through its association with private regard.

Ego strengths was tested as a mediator for private regard with superior adjustment. Significant effects were found with private regard regressed on superior adjustment ( $R^2 = .031$ ), showing that private regard was significant; and on ego strengths (shown above). In the third step, with private regard and ego strengths regressed on superior adjustment, ego strengths was significant and private regard was mitigated (see Table 4). The Sobel test, z = 2.03, p < .04, corroborated ego strengths as a mediator of private regard with superior adjustment.

Finally, ego strengths was examined as a mediator between private regard and mastery and coping. The effects attained significance for private regard regressed on mastery and coping  $(R^2 = .032)$ , and on ego strengths (shown above). When both private regard and ego strengths were regressed on mastery and coping, ego strengths retained significance and private regard was mitigated (see Table 4). The significant Sobel test, z = 2.03, p < .04, supported mediation. Ego strengths related to private regard, which subsequently was associated with mastery and coping.

### DISCUSSION

Ego strengths, REI as measured on the MEIM-R and MMRI, and positive well-being were examined among NAI/FN adolescents who resided and attended school in their reserve/FN communities. The results extended research on ego strengths (Anthis, 2014; Gfellner & Armstrong, 2012; Gfellner & Cordoba, 2011; Markstrom & Marshall, 2007; Markstrom et al., 1997) in relation to self-esteem, superior adjustment, mastery and coping, emotional tone, and

the affective REI dimensions of private regard and centrality that reflect belonging or attachment to one's group and its salience to one's sense of self.

The findings are consistent with a comprehensive review of research (Rivas-Drake, Seaton, et al., 2014) and meta-analysis (Rivas-Drake, Syed, et al., 2014) among pan-American minority adolescents using the same affective measures. Direct associations for centrality, private regard, and commitment (affirmation) with personal well-being underscore the protective function of these dimensions among NAI/FN adolescents. Similar relationships were reported for ethnic affirmation and belonging with self-esteem among Navajo (Galliher et al., 2011; Jones & Galliher, 2007) and general positive affect among Lumbee (Newman, 2005) adolescents.

In contrast to these affective components, exploration and commitment inversely predicted emotional tone in the regression analysis. Low emotional tone was an indicator of anxiety and distress for those involved in the process of exploring and examining their heritage, as well as those indicating commitment to their culture and its ideology, as reported on the MEIM-R. Unlike the affective dimensions, exploration is a cognitive component in which one actively questions issues relevant to one's self-definition while moving toward establishing an integrated sense of self. Considerable research shows that identity exploration tends to be associated with less stable functioning and well-being (Kroger & Marcia, 2011; Marcia, 1980). This involvement in searching and questioning may be a temporary phase in the process of identity formation for most young people, as the issues involved in active evaluating, rather than the process itself, may be the cause of anxiety and distress (Arnett, 2006). The negative association with commitment is less clear, although exploration is subsumed under commitment in consolidated identity achievement (Phinney, 1993). Recent revisions to the identity status paradigm extend commitment so that it may involve revisiting decisions and thereby aligns more closely with exploration (Luyckx, Goossens, & Soenens, 2006; Luyckx, Goossens, Soenens, & Beyers, 2006). From this perspective, both exploration and commitment reflect a state of flux that may account for these adolescents' depressed emotional tone scores.

The inverse relationship between exploration (and commitment) with emotional tone may reflect enhanced progress in establishing a coherent ethnic identity rather than unequivocal disruption. As NAI/FN adolescents advance in their REI development, they may be more responsive to the impact of negative nuances associated with their race, ethnicity, and culture, so that ethnic exploration is a source of uneasiness and anxiety, as indicated in the depressed scores for emotional tone. It also may reflect an awareness of the background of historical trauma, racism, and discrimination experienced by their group. Such an interpretation resonates with recent models of NAI/FN identity in which this legacy is a backdrop for REI that includes other aspects across many contexts (Markstrom, 2011; Whitbeck et al., 2014). The present findings may reflect a developmental unfolding of REI (Umana-Taylor et al., 2014); further research is needed to unravel the complexities of this process, including consideration of alternate dimensions of ethnic exploration (Syed et al., 2013) and commitment (Luyckx, Goossens, Soenens, & Beyers, 2006) and how they may change over time.

As well, anxiety was the sole outcome that was not associated with the affective components of REI in the Rivas-Drake, Syed, et al. (2014) meta-analysis of well-being among adolescents; exploration was not included in their computations. Other recent meta-analyses extending into the adult years with aggregated measures (Smith & Silva, 2011; Yoon et al., 2013) reported higher REI (enculturation) associated with anxiety and other negative as well as positive aspects of mental health. This finding was considered to be due to external factors, such as concerns over how one is viewed or accepted, fear of rejection, or a sense of insecurity in the context of mainstream society (Lau, Fung, Wang, & Kang, 2009). According to Chandler, Lalonde, Sokol, and Hallett (2003), socio-environmental factors, including the resilience that may be available through assets in one's reserve/FN community (e.g., economic opportunities, housing, and other community resources), require consideration as they are related to REI (cultural continuity) and well-being.

Ego strengths moderated the linkages for private regard, commitment, and exploration with several indicators of well-being (i.e., self-esteem, superior adjustment, emotional tone). In each case, those with less than optimal ego strengths demonstrated depressed personal well-being in these aspects as a function of REI. Given the associations between ego strengths and positive adaptation (e.g., Markstrom & Marshall, 2007), adolescents operating with low and mean levels of ego strengths may be delayed in social perspective taking and formal-operational skills that may not be available until later adolescence for some individuals (Berman, Schwartz, Kurtines, & Berman, 2001). As such, these components of well-being may be challenged for those who confront REI and a myriad of other developmental issues with insufficient personal resources. Indeed, focused approaches to intervention and support within the family and the community are needed to address these incapacities.

Ego strengths was supported as a mediator for centrality and private regard. In other words, the indirect effect of personal development (ego strengths) on well-being was through these REI dimensions. These findings highlight the importance of psychosocial stage development in providing the foundation for centrality, the integrating aspect of REI, in conjunction with active coping; and for private regard, an affective sense of attachment, with global as well as specific aspects of well-being. The results offer directions for intervention for those lagging behind in their psychosocial development, as well as for those experiencing challenges with REI, and suggest targeting positive feelings; belonging; and the relevance of one's race, ethnicity, and culture to one's sense of self (private regard and centrality) in educational programs and interventions with NAI/FN adolescents to facilitate REI development and to promote functional well-being.

These results contribute to the ongoing discourse concerning the interface of REI processes within the broader context of personal identity development (e.g., Schwartz et al., 2013; Schwartz, Zamboanga, Weisskirch, & Rodriguerz, 2009; Syed, 2010) and its importance for well-being (Syed et al., 2013). Careful elucidation of these relationships is warranted given the role of centrality (the prominence of REI in self-concept) as a moderator for negative consequences of discrimination among NAI/FN adults (Bombay, Matheson, & Anisman, 2010); it is unclear how the salience of race, ethnicity, or culture to one's self-definition may differ among adolescents, those in different contexts, or other minorities.

The present findings indicate the need for more nuanced study of racial/ethnic exploration and other aspects of REI in terms of their development and function, and how they are related to positive adjustment among NAI/FN adolescents. As well, it is important to extend the study of disaggregated REI to other areas of adaptive functioning for a better understanding of the role of REI among NAI/FN adolescents and how it may change over time. At the community level, findings from the school-based cultural curriculum project have been used to inform, advance, and extend program initiatives in terms of educational components and resources. Information is shared in a variety of venues, including student activities, workshops, websites, and discussion sessions. To protect the identity of the communities, data are always presented in aggregate. Long-term outcomes related to positive youth development are anticipated; further investigation will address longitudinal associations of the components of REI and additional areas of adjustment (e.g., school achievement, retention, and completion; mental health). At a subjective level, short-term progress has been observed in students' enthusiasm and accomplishments with cultural knowledge, and involvement in activities including art, stories, history, music, dance, tradition, ceremony, and celebratory events (e.g., cultural camps and projects, exhibitions of their work). Positive affirmations from teachers, parents, community members, and elders underscore the supportive function of the program at school and in the community.

Several limitations of the study warrant consideration. It was cross sectional, which precludes any notion of causality. Longitudinal investigation is essential to infer the ordering of changes in the association of ego strengths, various aspects of REI, and outcome behaviors. The findings provide important information about adolescents on reserves attending nonintegrated band schools. However, generalizability may be restricted, as NAI/FN adolescents in urban settings, those living off-reserve in towns or in other rural and remote regions, those attending integrated schools, and those with other tribal or band affiliation may differ. Nevertheless, given the complexities of NAI/FN peoples and commonalities of historical and political significance, it is important to piece together some comprehensive narrative about developmental risk and resilience from specific individuals and locales to glean some universal implications (Burach et al., 2014).

In summary, the results of this study provide empirical support for the theoretical relevance of ego strengths in REI development among NAI/FN adolescents, and indicate the need to enhance competence in the formative years of psychosocial stage development in tandem with a focus on racial/ethnic socialization to insure optimal personal growth and well-being. At the same time, further research is required to determine how these associations unfold among NAI/FN young people in different settings, as well as adolescents in other minorities.

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# AMERICAN INDIAN ELDERS' RESILIENCE: SOURCES OF STRENGTH FOR BUILDING A HEALTHY FUTURE FOR YOUTH

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> Abstract: This study examined American Indian (AI) elders' resilience to support an intervention to build resilience among AI urban youth. A literature review of peer-reviewed articles that address resilience in AI and other Indigenous elders yielded six studies that focused on intergenerational relationships, culture, and self-identity. In addition, a qualitative research project collected narratives with urban AI elders to document perceptions of resilience and resilience strategies. The combined outcomes of the literature search and research project revealed how resilience is exemplified in elders' lives and how resilience strategies are linked to cultural teachings and values, youth activities, and education.

## INTRODUCTION

American Indian, Alaska Native, and Native Hawaiian (AI/AN/NH) elders are the keepers and transmitters of knowledge that can build healthy futures for generations (Garrett et al., 2014; Ka'opua, Braun, Browne, Mokuau, & Park, 2011; Wexler, 2011). Their life stories hold rich lessons and foundational knowledge that can be key to developing positive AI/AN/NH youth cultural identity and life skills (Garrett et al., 2014; Sarche & Whitesell, 2012; Wexler, 2011). AI/AN/NH elders survived and even thrived by developing resilience strategies in response to adverse situations, including historical trauma, social and political injustice, and discriminatory practices of the U.S. government (Brave Heart & DeBruyn, 1998; Grandbois & Sanders, 2009; Masten, 1994). In this context, resilience among elders is defined as adaptation in the face of risk and adversity (Grandbois & Sanders, 2009; Masten, 1994). The knowledge and experiences of elders can inform culturally centered public health approaches that nurture and support the well-being of AI/AN/NH youth. This study combines a literature review of studies exploring AI/AN/NH elder resilience with results from a qualitative research project that

documented AI urban elders' stories of resilience. The purpose of integrating the outcomes of a literature review and primary data collection was to identify the range of protective strategies of AI/AN/NH elders to inform the design of resilience education for urban AI youth.

Existing studies have identified a current and growing disconnect between AI/AN/NH generations, prompting a movement among AI/AN/NH communities to reconnect elders with youth (Goodkind, Hess, Gorman, & Parker, 2012; Tyer, 2015; Wexler, 2011). Transmitting knowledge and life lessons intergenerationally may help youth overcome their own adversities (Wexler, 2011; Goodkind et al., 2012). Cultural engagement, social support, and strong cultural identity have been identified as important protective strategies for AI/AN/NH youth development and resilience (EchoHawk, 1997; LaFromboise, Hoyt, Oliver, & Whitbeck, 2006; Wexler, 2014; Wexler, DiFluvio, & Burke, 2009). Additional strategies contributing to AI/AN/NH resilience in general include spirituality, ceremonies, oral tradition, tribal identity, humor, elders, and family relationships (HeavyRunner & Morris, 1997). Research that investigates whether these strategies protect urban AI populations is limited.

AI/AN youth in urban settings may face even greater challenges in developing strategies to build resilience. They may have fewer opportunities to connect with AI/AN elders, as they have limited cultural and community engagement and less access to tribal resources (Stumblingbear-Riddle & Romans, 2012). Urban AI/AN youth also experience a high prevalence of risk behaviors compared to White youth in urban areas for indicators related to unintentional injury, safety, violence, and drug use (Urban Indian Health Institute [UIHI], 2009). For example, urban AI/AN youth reported three times higher rates of attempted suicide and five times rates of injury resulting from a suicide attempt than urban White youth (UIHI, 2009). Reports of being hurt by a boy/girlfriend and carrying a gun within the past 30 days were twice as high, and reports of not attending school because of feeling unsafe were three times higher among urban AI/AN youth (UIHI, 2009). Compared to White youth, initiation of marijuana use before age 13 and use of it on school property within the past 30 days were two-fold higher for AI/AN youth. These disparities in health risk behaviors call for interventions aimed at improving AI/AN youth resilience.

### METHODS

# **Review of Literature**

A review of the literature was conducted following procedures from the Cochrane Collaboration (Higgins & Green, 2011) using three databases: Medline/PubMed, Web of Science, and Education Resource Information Center. The review used the following inclusion criteria: (1) peer-reviewed articles available in English; (2) available online and published from January 1, 1980 to December 31, 2013; (3) identified U.S.-based Indigenous elders as the primary target populations by using the terms *AI*, *Native American*, *AN*, and/or *NH*, and *elders*; (4) described non clinical-based studies; and (5) made specific reference to one or more of the following search terms: *resilience* (or sociocultural characteristics linked to resilience), *culture*, *intergenerational*, and *community*. The research team identified these search terms based on the main themes identified from the Urban AI Elders' Research Project, described below.

Data for the review were abstracted using a standard format. The results were organized by author, publication year, participant information, and study design, with a summary of results and discussion.

### **Urban AI Elders' Research Project**

Team members from a research partnership between the Tucson Indian Center (TIC) and the University of Arizona's Center for American Indian Resilience (CAIR) interviewed 13 AI urban elders to document narratives of resilience. The inclusion criteria were self-identification as AI, ages 55 years and older, residence in Tucson, AZ, and willingness to provide written consent for recording personal life stories for research purposes. The university-based research team, made up of three Native and two non-Native investigators, initially developed an openended, semi-structured 16-question interview guide.

Fifteen self-selected AI elders participated in a consensus panel, in which they facilitated a group decision process and modified, then finalized, the interview guide (for full details on how a consensus panel is conducted, see Coreil, 1995). The format yielded a 25-question interview guide designed to document elders' experiences and perceptions of historical trauma and resilience, as well as recommendations for youth navigating today's world. The modified interview guide was used in individual, face-to-face, video- and/or audio-recorded interviews with 13 AI/AN elders, each lasting 1-3 hours.

The study was designed to learn about resilience and resilience strategies from the elders' points of view. The research team thus did not use a resilience scale to determine whether the elders' in the study were resilient. Instead, the research team listened to their stories and qualitatively identified strategies elders had used to overcome adversities in their lifetime.

All interviews were transcribed verbatim. Six research team members each read two to four interviews to identify themes and to develop a codebook containing both inductive and deductive thematic codes and associated pattern codes (Patton, 2014). A thematic analysis was conducted using NVivo, a qualitative data analysis program. Two researchers applied the codes to all interviews independently and used intercoder-reliability scores, a function of NVivo, to guide consensus-building discussions. The research team and elders at the TIC offered feedback for the resulting thematic analysis. The data coded for the theme "youth resilience" were compiled and analyzed in a search for themes and patterns from the elders' narratives.

### RESULTS

# **Literature Review**

The initial search yielded a total of 138 potential articles. A total of 92 abstracts were reviewed initially; 46 abstracts did not actually address resilience strategies and 58 did not discuss resilience in the target populations. The process yielded seven articles that described elder resilience in relation to intergenerational and interpersonal relationships and/or cultural strengths. One of the seven articles was removed because it did not specifically discuss resilience factors as an outcome.

Of the six articles included in the review (Table 1), four (Browne, Mokuau, & Braun, 2009; Grandbois & Sanders, 2009, 2012; Schure, Odden, & Goins, 2013) directly investigated or measured resilience through narration, historical events, or standardized scales. The other two articles (Wexler, 2011, 2014) described the same study, which investigated intergenerational dialogue as a method to bridge the gap between AN elders and youth and to support cultural transmission to build resilience among youth.

	-		Native Hawaiian Elders' Resilience Strategies
Authors	Participants	Design	Outcomes and Application
Grandbois & Sanders, 2009	8 AI elders, ages 57-83 years	Storytelling used to explore AI elder resilience. Outcomes of thematic analysis of interviews cross-checked with respondents.	Themes identified: strategies of resilience are grounded in AI identity and connection felt with creation. Recommendations for mental health services are: offer culture-based online materials for elders, establish a "cultural consultant" network to answer questions, collaborate with AI communities to develop mental health services, train more AI mental health professionals, and include resilience strategies into mental health services.
Grandbois & Sanders, 2012	8 AI elders, ages 57-83 years	Storytelling used to examine AI elders' experiences with stereotypes and resilience.	Themes identified: culture and strong self-identity supported resilience relative to stereotyping. Recommendation for mental and physical health services to reinforce culture in the care of AI elders.
Browne, Mokuau, & Braun, 2009	Not applicable	Developed a model to investigate social and health disparities among NH elders by using a literature review of life course and resilience theories to develop a timeline with cultural and historical markers within the lives of NH elders. The timeline is linked to social/health delivery strategies.	Key historical events identified pre-1915 to post- 1975. Loss of culture has impacted the health of the older cohort of elders, but cultural renaissance may be beneficial in restoring health. Recommendation for social work practice to include culturally appropriate services that consider historical and cultural markers as well as resilience strategies within the lives of NH elders.
Schure, Odden, & Goins, 2013	185 AI elders, ages 55 years and older	Assessed association of resilience with mental health (using depression and mental health scales) and physical health (using physical health and chronic pain scales).	Demonstrated attenuated associations between resilience and physical health when adjusted for all physical health measures. Higher levels of resilience were associated with decreased odds of depressive symptomology, measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977).
Wexler, 2011	3 AN cohort groups: 7 AN elders, ages 60 years and older; 7 AN adults, ages 33-50 years; and 9 youth, ages 14-21 years.	Used Intergenerational Dialogue Exchange and Action (IDEA), an interview format. Focus groups (for youth and elders) and open- ended interviews were conducted.	IDEA offered opportunity for elder/adult/youth communication, and cross-age connections, supporting cultural knowledge transmission. Format allowed adults/elders to reflect on memories and choose stories, summarize key lessons, and give advice to the youth. Youth expressed sense of cultural identity as "learning about what the Elders have been through" (Wexler, 2011, p. 259).
Wexler, 2014	3 AN cohort groups: 7 AN elders, 60 years and older; 7 AN adults, 33- 50 years; and 9 youth, 14-21 years.	2 focus groups and 19 structured interviews conducted to investigate cultural strengths to identify ways to enhance resilience among Indigenous youth	Determined sources of strength for 3 generations to investigate how culture is shaped by past experiences and changed over time. Culture can support the people's sense of identity, feeling of commitment to "their people," and purpose in life. Youth were less clear about identity, and showed limited ability to use cultural strengths to overcome challenges.

Table 1 Articles Addressing American Indian, Alaska Native, and Native Hawaiian Elders' Resilience Strategies

American Indian and Alaska Native Mental Health Research Copyright: Centers for American Indian and Alaska Native Health Colorado School of Public Health/University of Colorado Anschutz Medical Campus (<u>www.ucdenver.edu/caianh</u>)

Grandbois and Sanders's (2009) work with eight AI elders revealed that resilience is grounded in culture, inter and intra relationships (i.e., families and communities), and the stories of survival by ancestors; the authors concluded that, to understand and study AI resilience, future work should be approached in context of an AI worldview (a shared perspective that includes beliefs, values, and assumptions that shapes the lives and very identity of AI people; Cross, 1998; Grandbois & Sanders, 2009). The scientific method alone may not capture the full meaning of resilience in Native cultures, requiring researchers to consider a more inclusive perspective of the multifaceted aspects of AI life philosophy (Grandbois & Sanders, 2009).

A second study by Grandbois and Sanders (2012) was based on the same project data, but focused on resilience and stereotyping; the authors assessed the elders' narratives relative to overcoming stereotyping, through acculturation and traversing two worlds (AI and dominant society). Elders reported that they ignored stereotypes and hostile groups, and resisted internalizing these encounters (Grandbois & Sanders, 2012). Additional findings from the narratives indicated that resilience was reinforced by attaining education and employment (Grandbois & Sanders, 2012). The elders' narratives expressed the importance of bridging dominant culture and traditional cultures to develop resilience and self-confidence to participate in both worlds. Elders were taught by their parents to be responsible, accountable, and strong, instilling a sense of pride that provided strength to face challenges. Based on the findings, the authors recommended that resilience strategies gleaned from the narratives should be used as a foundation to address health disparities.

The study by Browne, Mokuau, and Braun (2009) demonstrated that resilience is gained through culture and reaffirming cultural practices in daily living. The study showed that policies to return federal land and to promote cultural renaissance (i.e., NH culture, language, and religious practices) have been at the forefront in enhancing resilience from the individual to the community level for current and future NH populations.

Schure et al. (2013) measured resilience with the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) to determine potential associations with other physical and mental health measures. Schure et al. (2013) found associations between resilience and increased mental and physical health when unadjusted for all associations. However, the cross-sectional design of the study prevented meant that the direction of causality could not be determined, indicating a need for future research to use other robust designs to test resilience and its impact on mental and physical health outcomes.

Wexler (2011, 2014) described an intergenerational exchange study using a communitybased participatory research approach with AN youth, adult, and elder participants. The themes that emerged from the stories included maintaining family relationships and feeling a commitment to "their people," believing in themselves, relying on others, and feeling pride in culture (Wexler, 2011). Wexler (2014) used the same data to further investigate how resilience is enhanced by culture, and examined the association among resilience, well-being, and culture by identifying the ways in which culture offers protection and fortitude. The narratives revealed how the different generations accessed and used cultural understanding when facing challenges. While youth needed support to form cultural identity and an understanding of group membership, adults and elders were more likely to identify cultural-based strengths through a situated perspective, which helped them face challenges by using intergenerational strengths, being grounded in traditions and culture, and feeling part of something larger than themselves. Cultural identity is a key strategy in providing a sense of belonging and the resources needed to overcome challenges (Wexler, 2014).

# Urban AI Elders' Research Project

The elders' narratives yielded the themes of culture, youth activities, and education to support resilience for youth (see Table 2).

Relating to Youth Resilience				
Theme	Patterns	Examples of Patterns		
Culture	Know tribal roots and history	Teach historical events (e.g., AI children sent to boarding school) and share family stories (e.g., grandparents as role models, reservation living) to help youth reflect on the past to build identity for the future		
	Value intergenerational relationships	Build connection between youth and elders through cultural activities (e.g., farm with grandparents) and strengthen family networks (i.e introduce children to relatives) to help youth understand family lineage		
	Engage in cultural activities	Engage youth by sharing cultural teachings, connecting them to the land (e.g., care for yard and garden) and have them take part in sweat lodge or talking circles		
	Draw personal strength from cultural teachings and values	Teach youth they can use personal strength from positive thinking and spiritual faith (e.g., prayer) to get through challenges		

Table 2				
<b>Description of American Indian Elder Resilience Themes and Patterns</b>				
Relating to Youth Resilience				
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Relating to Fouri Resilience				
Theme	Patterns	Examples of Patterns		
Culture, continued	Build character traits from cultural teachings	Encourage positive character traits in youth to build their personal character (e.g., respect body, enjoy life even with limited income) and how they interact with others (i.e., respect women)		
Youth Activities	Engage in traditional activities	Engage youth in traditional activities (e.g., drum circles, dancing, powwow) to expose youth to activities not often experienced in urban settings		
	Engage in contemporary activities	Engage youth in contemporary activities in urban settings that are low cost (e.g., free community events) and activities that are family based (i.e. traveling, camping, grandparents taking grandkids on educational trips)		
Education	Support for education	Support education through community programs (e.g.,, clothing bank helping youth meet basic needs, TIC offering tutoring and helping youth apply for college)		
	Take responsibility for own education	Teach youth personal responsibility for reaching educational goals by sharing personal experiences and lessons learned (e.g., high school dropouts can get GEDs)		
	Value parental involvement	Parents support and influence youth to pursue and complete school by offering means and resources to increase exposure to educational opportunities (e.g., parents enroll youth in after- school programs such as YMCA)		
	Enhance motivation for education	Build motivation in youth to reach educational goals by offering positive reinforcement (e.g., higher education helps youth have a job they really like)		

Table 2, Continued Description of American Indian Elder Resilience Themes and Patterns Relating to Youth Resilience

# Culture

The elders defined culture as teachings and values centered on knowing one's tribal roots and history, understanding intergenerational relationships, and engaging in cultural activities. The use of fundamental cultural values and teachings emerged as a resilience strategy for building personal strength and character traits, such as generosity, responsibility, and a strong work ethic.

Knowing roots and history emerged as a key concept for culture. Understanding history and historical trauma, and sharing stories of the past, helps children understand their identity and honor the past. The elders shared that it was important for parents to teach children about their roots and history so they can understand who they are as AIs. One elder shared how people from his tribe had experienced historical racism and discrimination from the nearby city as an example of historical trauma. He wanted youth to know what their ancestors had faced so they could be proud of their heritage and honor the past. Another elder stressed that the wounds of historical trauma should not be forgotten because past trauma has contributed to loss of identity.

Establishing and maintaining intergenerational relationships was another key concept identified in the culture theme. Elders stated that connecting youth with elders and teaching kinship ties was needed so children know their relatives within the tribe. Nurturing intergenerational relationships was recommended to provide an opportunity for elders to teach youth about cultural beliefs and practices, language, and traditional roles. The elders also stressed that engaging in cultural activities, such as planting or making baskets, help children understand their roles in life and the connection between people and nature, the animate and inanimate.

Among the fundamental cultural teachings and values was the importance of having personal strength to overcome challenges. Elders stated strength can be accessed by praying to a higher power, identified as the Creator, a great one, and God. Strength, according to the elders, also is found in knowing that good is at the end of a hardship, that experiencing hardship is necessary to become strong, and that their ancestors overcame hardship.

The culture theme also included the importance of building positive character traits, such as sharing, being responsible, having a good work ethic, and not being jealous. Elders stressed having a voice and standing up for oneself, and respecting oneself and others.

### **Youth Activities**

Elders talked about traditional and contemporary activities that build resilience among youth. They suggested that traditional activities be added to school curricula as a way to bridge the gap between youth and elders; in particular, they suggested incorporating elders and their teachings into the classroom. One elder suggested forming AI clubs, such as a Boys and Girls Club, where youth could be engaged in cultural activities in urban settings. These urban AI elders thought teaching youth about local food systems would create awareness of local resources, even if they had limited access to the natural environment. They suggested teaching youth to collect food such as saguaro fruit (local to the Tucson desert environment) and to grow fruit and vegetables in the city, to reinforce cultural strengths and, in turn, support resilience. Other elders suggested teaching youth about ranch life, including raising and butchering cows.

The contemporary activities mentioned by the elders included involving youth in programs, such as the youth coalition at the TIC, summer camps, and reading and writing programs. Elders advocated that youth stay physically active through a variety of sports and activities such as volleyball, basketball, biking, walking, and dancing. Elders felt youth should get involved in community service and volunteer work, such as trash pickup, to build responsibility and a sense of community connection. Other suggested contemporary activities included mental health programs to address depression and thoughts of suicide, money management, and gun safety workshops for youth.

# Education

Elders stressed the importance of formal education and taking responsibility for one's education, having parental involvement, and enhancing motivation for education.

Elders encouraged youth to pursue higher education or vocational training after college to compete successfully in the world. They shared that growing up in challenging conditions, such as poverty, taught them important values of working hard, staying in school despite the odds, getting more education beyond high school, and making sure to work toward getting a good job or career. Elders stated that students need to feel responsible getting an education and persevering despite hardship.

Elders identified parental involvement as an important component of education and youth resilience. Parental support helps youth finish school and meet educational and career goals. Elders stated that parents can show their support by visiting their children's school and talking to teachers about their children's academic performance or school behavior. Elders also suggested that parents teach their children to be responsible with money and set high expectations for their children to attend college.

The elders expressed that motivation could be instilled by teaching youth not to take things for granted and to know their purpose for existing so that they understand the importance of getting an education. They also shared that youth also can be motivated to use their education to work with and help AI communities. Other motivators include grandparents encouraging their grandchildren to stay in school, make the right choices, and use their education to make a good living. The TIC was identified as a key resource to support education, particularly by offering a place for youth new to Tucson to begin to fit in and feel comfortable in a new city. While elders identified education as important, they also felt youth should return to their families' home reservation-based communities to help their people, no matter how long or far their schooling took them away from home.

### DISCUSSION

The three themes linked to resilience identified in the interviews with the TIC elders culture, youth activities, and education—are echoed in the literature reporting resilience narratives collected from non-urban AI elders (Browne, Mokuau, & Braun, 2009; Grandbois & Sanders, 2009, 2012; Wexler, 2011, 2014). These parallel themes indicate that AI/AN/NH elders draw strength from a shared cultural identity to be proactive in engaging in traditional and contemporary activities and achieving educational goals. AI/AN/NH elders' wisdom, drawn from their experiences, transcends the urban/reservation dichotomy and is applicable to today's AI/AN/NH youth. Similarities between the research project results and the literature review illustrate that elders identified culture-based strategies used throughout their lifetimes to overcome hardship, and offered these strategies for youth to build their resilience.

## **Culture-based Strategies**

TIC elders asserted that building resilience in youth is tied to knowing their cultural identity, and to understanding history and stories of the past. This finding is supported in Grandbois and Sanders' work (2009, 2012), which reports that elders stated children should learn about and apply strengths drawn from their culture, history, heritage, and traditional lifestyle. TIC participants shared that building inter- and intrapersonal relationships among family, community, and, especially, elders, would help youth build a sense of connection and belonging. These important networks would provide needed opportunities to teach and share cultural beliefs and practices. Similarly, Grandbois and Sanders (2009) found that elders valued interpersonal relationships and connection to their family, tribal groups, and clanship, and expressed the importance of having a "community identity" rather than a sole identity as an individual. Wexler's (2011) intergenerational study similarly revealed the importance of family relationships and having a sense of commitment to people in one's family and community.

According to the elders' narratives, youth resilience is influenced by gaining strength to overcome challenges, which can be done by calling on a higher power or listening to stories about survival. A similar belief was shared by elders in the Grandbois and Sanders (2009) study, who identified that shared history and survival of historical atrocities sustained the people's resolve. This research warrants further work to understand the role of history in building resilience strategies. Correspondingly, Wexler (2014) reported that AN elders and adults gained strength from their ancestors and felt grounded through their connection to traditions and culture.

TIC elders linked resilience to positive character traits, including being responsible and being a dedicated worker to support oneself and one's family. The Grandbois and Sanders (2012) study also found that elders thought being taught responsibility and a sense of pride by their own parents contributed to their raising their children as survivors.

### **Activity-based Strategies**

TIC elders suggested youth participate in traditional activities to enhance their sense of cultural belonging and identity as a resilience strategy to face challenges associated with living in an urban environment (e.g., prejudice, stereotyping, depression, substance use). Grandbois and Sanders (2012) similarly described cultural strengths drawn from traditional practices such as making music, dancing, building relationships by visiting family and friends, and storytelling to teach life lessons and bring comfort.

TIC elders also acknowledged the role of contemporary activities to enhance urban youth resilience and build positive life skills to avoid negative situations. Contemporary activities such as sports and behavioral health programs (e.g., suicide and depression prevention) were suggested to support youth resilience. Connection between health and resilience is supported by the work of Schure et al. (2013) who found an association between resilience and improved mental and physical health among AI elders.

### **Education-based Strategies**

TIC AI elders identified education as a strategy for building urban AI youth resilience. Elders stressed the importance of youth obtaining an education in order to successfully compete in the White world. The elders in the Grandbois and Sanders (2012) study similarly expressed that it was important to achieve educational goals and gainful employment, repeating the adage that knowledge fostered power. This literature review had a few notable differences from the research project. Browne, Mokuau, and Sanders (2012) studied policy change to build resilience and identified the Native Hawaiian Health Care Improvement Act as a policy that has promoted social justice in the health care system. The TIC elders did not directly propose policy changes, but did suggest potential areas for program and policy development by proposing that elders share knowledge and teachings as part of school curricula. Elders' knowledge for culture-based strategies also suggests potential policy implications for future public health interventions directed towards urban AI/AN youth. Funding mechanisms could support interventions that incorporate ways to enhance cultural understanding and strengths, build stronger intergenerational relationships, and increase participation in cultural activities.

### **Limitations of This Study**

This study did not survey all social science databases, or any unpublished work. Additionally, there were limitations pertaining to the research project that collected TIC elders' narratives. Only elders affiliated with the TIC were recruited; female participants dominated the sample. Most of the participating elders had actually grown up on rural reservations or outside of Tucson and were drawing on those early life experiences and projecting to urban AI youth.

### CONCLUSION

Based on results from the literature review and research project, public health efforts designed to enhance AI youth resilience should include building intergenerational communication strategies, promoting cultural strengths among youth, and supporting contemporary youth activities and education. Intergenerational communication and connection can help youth learn and understand elders' stories and strategies of resilience when faced with past adversities, thus reinforcing resilience through cultural identity. Promoting cultural knowledge and identity further draws on culture as a sustaining force offering inter- and intrapersonal strengths to youth as they build a foundation into adulthood. Intergenerational relationships allow youth to understand that culture is more than just engaging in cultural activities; it offers deeper meaning and values for creating life philosophy and understanding the purpose of life. Contemporary activities and education can guide youth through challenges

presented by the urban setting. Support for intergenerational relationships, such as involving elders in school or afterschool programs may be an effective strategy to integrate strengths offered by both culture and education.

The project with TIC elders solicited in-depth and complex life narratives to yield culturally relevant assets applicable to public health efforts to promote resilience strategies. Understanding the similarities and differences among AIs and other Indigenous groups can inform resilience research to build collective strengths. Resilience research offers an innovative path to guide policy development to shape determinants of health for future generations.

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# AMERICAN INDIAN AND ALASKA NATIVE RESILIENCE ALONG THE LIFE COURSE AND ACROSS GENERATIONS: A LITERATURE REVIEW

# Christina E. Oré, MPH, Nicolette I. Teufel-Shone, PhD, and Tara M. Chico-Jarillo, MPH

Abstract: Examining American Indian and Alaska Native (AI/AN) resilience using the life course framework could inform public health strategies that support favorable health outcomes, despite adversity (e.g., discrimination, historical loss, comorbidity). A systematic review of peer-reviewed literature published from 1970 to 2015 yielded eight articles on AI/AN life course and resilience. A content analysis identified three themes. AI/AN resilience is 1) an ongoing, dynamic process, 2) evident within linked lives and life transitions, and 3) accessed through cultural knowledge and practice. Resilience research could change the paradigm of AI/AN health research to guide asset-based approaches across the life course.

# **INTRODUCTION**

Despite decades of American Indian and Alaska Native (AI/AN) health disparities research, morbidity and mortality rates related to chronic disease, poor mental health, and comorbidity remain high among AI/AN peoples (Espey et al., 2014; Gone & Trimble, 2012; O'Connell, Yi, Wilson, Manson, & Acton, 2010). A shift in health disparities research approach is needed. AI/AN health disparities are associated with the interplay of biopsychosocial and cultural factors within a socioecological system influenced by detrimental historical and contemporary social determinants (e.g., colonization, assimilation policies, discrimination; Beckfield & Kreiger, 2009; Braveman, 2014; Cobb, Espey, & King, 2014; Marmot, 2005; Marmot & Bell, 2011; Walls & Whitbeck, 2011; Wexler, DiFluvio, & Burke, 2009). In the face of these inequities, many AI/AN individuals and communities continue to resist, to be resilient, and to thrive (Gone, 2013; Wexler et al., 2009). The resilience of AI/AN people has not been examined adequately as a process that could inform public health efforts to

address health disparities and inequities. The purpose of this literature review is to explore AI/AN resilience from the life course framework and highlight an alternate approach to achieve health equity.

## **Resilience: An Evolving Concept**

Resilience has evolved as a concept from an individual trait to a developmental process that varies depending on worldview, context, shared experiences, and timing of life events (Kirmayer, Sehdev, Whitley, Dandeneau, & Isaac, 2009; Wexler et al., 2009). Individual resilience is defined as the ability to adapt or respond positively (i.e., to exhibit growth and transformation) to stress and adversity (Norris, Stevens, Pfefferbaum, Wyche, & Pfefferbaum, 2008; Ungar, 2011; Wexler et al., 2009). This ability comes from an interaction of internal and external risk and protective factors derived from individuals, family, community, culture, and environment (Bunch, 2011; Fleming & Ledogar, 2008a; Kirmayer et al., 2009; Norris et al., 2008; Poortinga, 2012; Ungar, 2011). These factors are not discrete, but are processes that affect "trajectories of development" throughout a lifetime (Kirmayer et al., 2009, p. 69).

Resilience does not occur in isolation. From a socioecological perspective, individuals, family, community, culture, and environment are interconnected, and their interactions contribute to resilience at all levels (Kirmayer et al., 2009; Wexler et al., 2009). Communities as well as individuals can display resilience; community resilience is often interpreted as a collective process whose resources and strategies for adaption and transformation come from social networks and relationships, cultural beliefs and practices, and availability of material necessities (Kirmayer et al., 2009).

Resilience research has shifted away from an individualistic, deficit orientation toward the study of individual and collective processes, strengths, and assets within a complex adaptive system (Kirmayer et al., 2009; Stumblingbear-Riddle & Romans, 2012; Ungar, 2011). This perspective resonates culturally with the value placed on collective identity and processes within many AI/AN communities.

## **Reframing AI/AN Resilience: Cultural Resilience**

AI/AN health resilience research is nascent. Over the past 10 years, such research has focused on AI/AN adolescents (LaFromboise, Hoyt, Oliver, & Whitbeck, 2006; Stumblingbear-Riddle & Romans, 2012; Wexler, 2014; Whitbeck, Walls, Johnson, Morrisseau, & McDougall,

2009) and elders (Grandbois & Sanders, 2009, 2012). The work of LaFromboise et al. (2006) was seminal for identifying factors (specifically, family, community, and cultural factors) associated with adolescent resilience. In Grandbois and Sanders' (2012) study, elders identified the unifying theme of culture as a resource they accessed to overcome hardship in their lives.

Studies by Grandbois and Sanders (2009, 2012) and Wexler (2014) reframe AI/AN resilience as synonymous with cultural resilience. Cultural resilience is often equated with community resilience (Fleming & Ledogar, 2008a; Kirmayer et al., 2009). According to Healy (2006, p. 12, as cited in Fleming & Ledogar, 2008a, p. 10), "[indigenous] community or cultural resilience is the capacity of a distinct community or cultural system to absorb disturbance and reorganize while undergoing change as to retain key elements of structure and identity that preserve its distinctness." Therefore, AI/AN resilience is interpreted as the distinct AI/AN worldviews, beliefs, values, and practices that support individual and community resistance and positive transformation (Gone, 2013; Grandbois & Sanders, 2009; HeavyRunner & Sebastian Morris, 1997; Wexler, 2014). For this literature review, AI/AN resilience encompasses individual, community, and cultural resilience.

# **Critique of AI/AN Health Resilience Research**

Despite the evolution of resilience as a concept, some researchers express concern that resilience implies acceptance of the historical and contemporary structural inequalities (e.g., socioeconomic, political, environmental conditions) that contribute to persistent health disparities in Indigenous communities, including AI/AN communities (Boulton & Gifford, 2014; Kirmayer et al., 2009; Lavallee & Clearsky, 2006; Penehira, Green, Smith, & Aspin, 2014; Wexler et al., 2009). Another concern is that resilience studied as a linear causal process that consists of accumulating strengths, may stigmatize individuals and communities that appear to lack these strengths (Kirmayer et al., 2009; Wexler et al., 2009). The life course framework may assuage these criticisms; it is a nonlinear, nondeterministic, health equity theoretical approach.

#### Life Course Framework: Theory, Approach, and Perspective

The life course theory, attributed to sociologist Elder (1998), is used as a framework in gerontology, social work, and maternal child health research (Braveman & Barclay, 2009; Browne et al., 2014). Central to the life course framework is consideration of the social, cultural, economic, and political factors that impact human development and health (Elder, 1998; Fine &

Kotelchuck, 2010). This consideration situates the life course framework among research paradigms (e.g., critical theory, decolonizing methodologies) used to achieve social and health equity (Braun, Browne, Ka'opua, Kim, & Mokuau, 2013; Braveman & Barclay, 2009). The key constructs of the life course framework are lives embedded in historical context (i.e., cohorts), timing of life transitions (i.e., changing roles and life stages), linked lives (i.e., interdependence, intergenerational connections), and human agency within socioecological context (Elder, 1998). The life course framework defines health development as a nonlinear process, not a series of life stages. This process may be affected by exposure to stressors during crucial times from gestation through adulthood, which can shape responses and impact health and well-being later in life (Braveman & Barclay, 2009; Halfon, Larson, Lu, Tullis, & Russ, 2014).

The life course framework's emphasis on the continuum of life recognizes the potential influence of previous life experiences on current and future responses to adversity. This approach is well suited for resilience research because it considers how life experiences can contribute resilience strategies. Although influenced by personal history, the life course framework is not deterministic but acknowledges that pathways or trajectories can be changed to improve and maintain health and well-being (Fine & Kotelchuck, 2010).

The life course framework was chosen for this literature review as a culturally appropriate approach to study AI/AN resilience. Its constructs align with shared AI/AN worldviews that life is cyclical and that all beings are connected and in relation to each other across time and place (Deloria, 1994; Kirmayer, Marshall, & Phillips, 2011).

AI/AN health resilience research is often framed by historical trauma theory. "Historical trauma...is defined as cumulative emotional and psychological wounding across generations, including the lifespan, which emanates from massive group trauma" (Brave Heart, Chase, Elkins, & Altschul, 2011, p. 283). Within this theory, the AI/AN communal and collective experience of historical adverse events (e.g., colonization, removal, relocation, assimilation) is the cause of such trauma (Brave Heart et al., 2011); collective grieving or bereavement is the response, and is associated with poor mental and behavioral health among AI/ANs (Brave Heart et al., 2011). Assumptions that all historical adverse events were experienced as traumatic and lead to only pathological responses are being challenged (Denham, 2008; Gone, 2013). The life course framework provides a supplemental approach to study AI/AN resilience, a salutogenic response, within the context of historical adverse events that may or may not have been traumatic.

#### **METHOD**

This systematic review used guidelines and checklists from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Group and University of North Carolina Writing Center (UNCWC; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009; UNCWC, 2014). The reviewers used the following steps: 1) identified articles that fit the inclusion criteria (described below) for both topics (i.e., AI/AN resilience and life course framework), as shown in Table 1, 2) conducted descriptive and content analyses of selected articles, as shown in Tables 1 and 2, and 3) synthesized findings (Moher et al., 2009; Patton, 2002; UNCWC, 2014).

	Descriptive Overview of Selected Articles (N = 8)					
	Authors	Field	<b>Concepts and Theories</b>	Participants	Method	
1	Denham (2008)	Health Sciences/ Behavioral	Implied life course – Historical trauma and resilience	Four generations within one family	Qualitative	
2	Jackson & Chapleski (2000)	Social Sciences/ Gerontology & Anthropology	Life course theory – Cohort & Native American Ethnicity	Elders	Mixed	
3	McCloskey (1998)	Social Sciences/ Anthropology	Life course theory – Cohort & cultural resilience-persistence	Three generations of women	Qualitative	
4	Mohatt, Rasmus, Thomas, Allen, Hazel, & Marlatt (2008)	Health Sciences/ Behavioral	Implied life course – recovery process and resilience	Three generations	Qualitative	
5	Quintero (2000)	Social Sciences/ Behavioral	Life course theory, recovery process and resilience	Adult men	Qualitative	
6	Walls & Whitbeck (2012)	Health Sciences/ Behavioral	Life course theory and Historical trauma	Three generations within families	Quantitative	
7	Weibel-Orlando (1988)	Social Sciences/ Gerontology	Implied life course – Ethnicity, aging and culture	Elders	Qualitative	
8	Wexler (2014)	Health Sciences/ Behavioral	Implied life course – Historical trauma and resilience theory	Three generations	Qualitative	

Table 1 escriptive Overview of Selected Articles (N = 8)

	Resilience		Practice of Resilience Along the Life Course		Accessing Resilience	
Author/Publication Date	A dynamic developmental process	Lives embedded in historical context and contemporary times	Linked lives: Intergenerational connection	Timing of life transitions: Social/cultural roles	Cultural and traditional, beliefs, values and practices	Story, narratives, and lived experiences
Denham (2008)	Х	Х	Х		Х	Х
Jackson & Chapleski (2000)	Х	х			х	
McCloskey (1998).	Х	Х	Х		Х	Х
Mohatt, Rasmus, Thomas, Allen, Hazel, & Marlatt (2008)				х	х	х
Quintero (2000)				Х	Х	Х
Walls & Whitbeck (2012)		Х	Х			
Weibel-Orlando (1988)	Х	Х			Х	Х
Wexler (2014)		Х	Х		Х	Х

Table 2Themes From Selected AI/AN Life Course and Resilience Articles (N = 8)

# **Inclusion and Exclusion Criteria**

To be included in the literature review, articles had to 1) be peer-reviewed and available in English; 2) be published from January 1, 1970 to December 31, 2015; 3) identify AIs and/or ANs as the focus group; 4) identify the life course as an approach, perspective, theory, framework, or life history; 5) discuss historical or contemporary sociocultural and political determinants of health (e.g., historical adverse events, assimilation policies); and 6) use the term resilience or reference asset-based factors (e.g., social and cultural support). Articles that exclusively focused on 1) secondary analysis of national data sets, 2) biological pathways, or 3) clinical encounter descriptions were excluded.

# **Data Extraction**

Four databases were searched: ERIC, JSTOR, Ovid, and PubMed. Search terms were: life course OR life span OR life stage AND American Indian(s), OR Alaska Native(s), OR North American Indian(s), OR Native American(s). Citations, including abstracts and full text, were imported into EndNote 7.2. The citations then were imported into Microsoft Excel in order to categorize and group them. Findings from descriptive and content analyses are found in Tables 1 and 2.

# Analyses

Descriptive and content analyses were conducted to provide the reviewers' interpretation of findings on AI/AN resilience within the life course framework (Denzin & Lincoln, 2005; Patton, 2002; UNCWC, 2014).

## **Descriptive Analysis**

The descriptive analysis provides an overview of the use of life course framework to study AI/AN resilience. The reviewers grouped the selected articles by author, publication date, field, concepts/theoretical framework, participants, and methods (Table 1). The implicit and explicit use of the life course framework was identified and described (Table 1 and Findings).

#### **Content Analysis**

A content analysis provides insight into the concept of AI/AN resilience from within the life course framework. It is an inductive and iterative process (Creswell, 2012; Patton, 2002); articles are reviewed repeatedly to identify emerging ideas, patterns, and themes that relate to the topic(s) (Patton, 2002). In this study, the reviewers 1) identified and labeled shared ideas and patterns, 2) used the labels to identify unifying themes, 3) revisited the content of each article to confirm themes, and 4) provided in-depth description of themes (Creswell, 2012; Patton, 2002). The following labels were used: historical adverse events, story/narrative/lived experience, sociocultural roles and responsibilities, inter- and intragenerational connection, identity/ethnicity, strength based, and transformative potential.

#### FINDINGS

#### **Descriptive Analysis**

A total of 231 articles were retrieved from the databases; 26 article abstracts met the inclusion criteria, and 8 full articles were included in this review. The eight articles were in social and health sciences: anthropology (1), gerontology (2), and mental and behavioral health (5). Five had intergenerational participation across three or four generations, two focused on elders, and one on adults. Six used qualitative methods, collecting narratives, responses to semi-structured interview questions, and observational data. One used closed-ended questionnaires that incorporated structured instruments validated in non-AI/AN populations, and one used mixed methods (Table 1).

## Life Course Framework: Explicit and Implicit

All eight selected articles used two or more constructs from Elder's (1998) life course framework (e.g., lives embedded in historical context, timing of life transitions, linked lives, human agency). Only three of the selected articles explicitly used the life course framework to study AI/AN resilience. Jackson and Chapleski (2000), McCloskey (1998), and Walls and Whitbeck (2012) used the framework as the theoretical underpinning for their studies. Jackson and Chapleski (2000) and McCloskey (1998) grouped their participants into age cohorts to study the impact of historical adverse events on cultural identity and life course patterns such as education, employment, and childbearing. Walls and Whitbeck (2012) exemplified how the concepts of lives embedded in historical context and linked lives can provide a theoretical framework for AI/AN health research. Their study found an association between historical adverse events (i.e., relocation) and poor intergenerational health outcomes (i.e., substance abuse, depression).

Denham (2008), Mohatt et al. (2008), Quintero (2000), Weibel-Orlando (1988), and Wexler (2014) did not explicitly use the life course framework; life course constructs were inferred in their theoretical approaches and use of life histories as a data collection tool. These researchers implicitly used the construct of lives embedded in historical context to study individual and cultural resilience. They collected intergenerational life histories of participants who experienced historical adverse events and contemporary hardships. For example, the impact of lives embedded in historical context is implicit in Weibel-Orlando's (1988) study on ethnicity and aging among elders who participated in the Bureau of Indian Affairs relocation and

vocational assistance programs of the 1950s, and Quintero (2000) implicitly used the life course framework to interpret the life histories of problem drinkers by exploring motivators for dramatic behavior change (i.e., cessation).

# **Content Analysis**

Three themes that provide insight into AI/AN resilience emerged from the content analysis. AI/AN resilience is 1) an ongoing, dynamic process that responds to a changing environment, 2) evident within the life course framework (e.g., lives embedded in historical context, linked lives, timing of life transitions), and 3) accessed through culture (e.g., origin-creation stories, lived experiences). See Table 2.

# **AI/AN Resilience is a Dynamic Process**

Studies by Denham (2008), Jackson and Chapleski (2000), McCloskey (1998), and Weibel-Orlando (1988) illustrate how resilience is not a trait; rather, it is a non-linear process that varies along the life course and across generations. For example, Weibel-Orlando (1988) studied the interaction of ethnicity and aging in life histories collected from 28 AI elders. The participants were born on tribal lands, lived and worked in urban areas for at least 20 years, and returned to their tribal lands after retirement. They experienced adversity, stress, and vulnerability upon returning to reintegrate into their tribal communities. Their resilience was an ongoing process of reconnecting and investing in regular and ceremonial displays of ethnic group membership. Kirmayer et al. (2009) describes this process as tapping into multiple resources along the life course, depending on context. Findings revealed ethnicity and aging to be resources for resilience, and, subsequently, for well-being, cultural continuity, and community connection.

# AI/AN Resilience Within the Life Course Framework

# Lives Embedded in Historical Context and Linked Lives

McCloskey (1998), Jackson and Chapleski (2000), and Walls and Whitbeck (2012) studied the impact of rapid sociocultural and environmental changes associated with historical and contemporary events on individual lives and on communities. McCloskey's (1998) study is an early work that used the life course approach by studying resilience in the life histories of three generations (cohorts) of Navajo women (N = 77): grandmothers, midlife mothers, and young mothers. McCloskey (1998) explored the resources and strategies for resilience accessed by participants in each cohort during changing and adverse historical and contemporary contexts

(e.g., the boarding school era, changes in agricultural and livestock policies, the relocation era), and identified Navajo culture, values, and beliefs as the resilient core that informed the women's life course patterns. The author identified the principles of the resilient core as: 1) an egalitarian perspective that fostered complementary relationships between men and women, 2) a matrilineal legacy and clan membership, and 3) value placed on motherhood and childbearing. These shared sociocultural principles in turn informed each cohort's life course patterns of education, work, marriage, and childbearing.

Jackson and Chapleski's (2000) study is seminal for its use of cohorts and life histories to study ethnic identity among AI elders. This synthesis study combined findings from two respective studies: one, a quantitative longitudinal study with data collection at baseline (N = 309) and 18 months later (N = 253); and the other, a qualitative study with a low number of participants (N = 24) designed to collect in-depth and nuanced life histories. Participants were placed into cohorts based on the time period of their birth. The conditions experienced by each cohort along the life cycle from birth to middle age (e.g., poverty, prejudice, boarding schools, self-determination era policies), and their impact, were examined. The elder cohort experienced the adverse conditions of poverty, boarding schools, termination, and relocation. In contrast, the middle-age cohort experienced adverse conditions during early childhood that shifted toward supportive conditions associated with self-determination, tuition waivers, and hunting and fishing rights from later childhood through their mid-adult years.

These findings demonstrate that adversity had a differential impact on each age cohort. Jackson and Chapleski (2000) found a seemingly paradoxical reversal between older and middleaged AIs with regard to participation in traditional cultural activities. The middle-aged cohort had the highest rate of participation in traditional practices and displayed more traditional AI styles and behaviors than their elders. This open expression of cultural engagement was adaptive in an evolving society increasingly tolerant of cultural diversity. In contrast, elders who experienced the oppression of boarding school policies that forbade cultural expression kept their cultural knowledge and practices concealed and appeared acculturated. The elders' response may not have been overtly resilient, yet their strategy of concealing their culture allowed that culture to survive. Jackson and Chapleski (2000) referred to the elder cohort as bicultural, neither assimilated nor acculturated. Bicultural identity is the ability to shift between two cultures' norms, traditions, and styles, and is a strategy of resilience. Examination of the cohorts' differential experiences revealed the dynamic, subtle, complex, context-specific, and time-sensitive nature of cultural resilience (i.e., ethnic identity; Jackson & Chapleski 2000). Walls and Whitbeck's (2012) study regarding the intergenerational effects of relocation on health behaviors (i.e., substance misuse/abuse, depressive symptoms, parenting style) within AI and First Nations (FN) families in the U.S. and Canada exemplifies the use of the life course framework. Walls and Whitbeck (2012) collected responses from AI and FN youth and their biological mothers, whose parents had participated in urban relocation programs initiated in the 1950s. The results indicated transmission of problem behaviors across three generations. For example, grandparents' drinking problems had a significant indirect effect on their grandchildren's delinquency by way of their parents' deviant and negative parenting behavior. The emphasis placed on lives embedded in historical context in the life course framework guided this study to find an association between cumulative adversity and cumulative poor health and well-being. The findings of Walls and Whitbeck (2012) imply that resilience lies in breaking the cyclical effects of historical adverse events that result in cultural losses by reconnecting generations and educating parents and children about cultural values, spirituality, and practices.

# Timing of Life Transitions: Roles, Responsibilities, and Relationships

From the life course perspective, three studies examined resilience responses to stressors and adverse conditions during life transitions (i.e., becoming a parent or grandparent; Mohatt et al., 2008; Quintero, 2000). These studies demonstrate how culturally defined roles, responsibilities, and relationships in parenthood may be a resource for individual, community, or cultural resilience. In these studies, the adversity faced by participants was substance misuse/abuse, and the resilience response was "natural recovery" or "aging out." Mohatt et al. (2008) and Quintero (2000) identified an individual's desire to parent from within his or her traditional culture as a strategy for cessation of problem drinking. Factors associated with natural recovery (e.g., social pressure, time, priorities) are not usually considered resilient (Kunitz, 2006); they are considered the natural life course of the behavior. Yet, in these studies, parenting was considered part of cultural resilience (Mohatt et al., 2008; Quintero, 2000). This transition is a point during the life course where culturally and socially defined roles become a resource to support natural recovery.

Mohatt et al. (2008) collected life histories from 57 AN participants representing three transition periods during the life course: youth, middle age, and elders. These narratives were used to develop a heuristic model of recovery from alcohol dependence. In this study, individuals exhibited resilience through self-reflection and action. Recovery motivators were cultural values and practices that highlight cultural resilience via family and kinship responsibilities and

interconnection. For example, participants shared that they were motivated by their realization of the impact their drinking had on their family and by their desire to fulfill their responsibilities as fathers, mothers, and grandparents.

Quintero (2000) collected 48 life histories from AI men, former problem drinkers, who shared that their primary motivator for alcohol cessation was to fulfill their role as responsible Navajo fathers, to raise their children, and support a good life for their families. This responsibility extended beyond themselves and had implications for the tribe as a whole. For these men, aging out of alcohol abuse meant following cultural teachings and sharing cultural knowledge with their children. For example, they noted that sharing and reflecting on origin-creation stories was a strategy for cultural resilience. These stories describe the cultural and social expectations that shape and guide good thought and behavior, in order to live "the good life" (Quintero, 2000, p. 1042).

# AI/AN Resilience is Accessed Through Worldviews, Beliefs, Values, Practices, and Lived Experiences

All eight studies identified cultural values, beliefs, and practices as essential resources for AI/AN resilience along the life course and across generations. Denham (2008), Quintero (2000), and Wexler (2014) specifically explored the use of narratives, lived experiences, and traditional stories as a cultural resource and strategy. Sharing narratives and life histories (i.e., storytelling) is a practice within many AI/AN communities that supports an individual's position, sense of self, collective identity, while reinforcing connections to family, community, and environment (Denham, 2008; Gone, 2013).

Denham's (2008) study used life histories to examine the resilience responses of a multigenerational AI family to historical adverse events. Resilience came from sharing "narratives, metaphors, and strategies of resistance" within the family circle, from one generation to another (p. 405). The stories of resilience and survival were transformed into lessons and teachings with their delivery and interpretation, in addition to their content. For example, the father used a power song passed down from one of his ancestors killed during the wars of colonization to get through his service in Vietnam. Resilience capabilities are revisited in the story to reinforce that the family has the same strong blood as its ancestors. The family circle and narratives provide a space to retain family members' sense of self as well as their connection to one another, their community, and their environment. Resilience was interpreted as maintaining balance in the chaos of life.

Quintero's (2000) study identified traditional stories as an important resource for AI resilience. In this case, the stories supported Navajo men's aging out of problem drinking because of family responsibilities and their desire to live by traditional Navajo values. Establishing and maintaining harmony (in Navajo, *hózhó*) in family relationships was important to this process of resilience.

Wexler's (2014) study used life histories of three generations of ANs to understand the process of cultural resilience. The narratives collected from adults and elders demonstrated "collective suffering and cultural fortitude" in the face of adversity (p. 88). The older generations were grounded in their cultural identity and affiliation, and had a resource with which to confront adversity. Their identity gave them a sense of self-worth, social belonging, and purpose throughout their lives. Youth had less understanding of how their cultural identity and affiliation was a source of strength. As a result, they were less able to access cultural resources that could give them a similar sense of belonging, connection, and purpose. Denham (2008), Quintero (2000), and Wexler et al. (2009) demonstrate how narratives and stories (e.g., origin-creation stories, life histories, lived experiences) are a resource for cultural resilience, and a potential strategy for intergenerational transmission.

## DISCUSSION

In this literature review, the use of the life course framework provides insight into AI/AN resilience. Findings reveal that the AI/AN resilience process is relative to age and sociocultural context, is collective and intergenerational, and is derived from AI/AN worldviews, beliefs, values, and practices (Table 2). Combining the life course framework with the study of AI/AN resilience is synergistic and represents a new asset-based, culturally grounded approach to AI/AN health research and efforts to achieve health equity.

# AI/AN Resilience is Relative to Age and Sociocultural Context

There are 562 AI/AN tribes, nations, villages, and consortia, each with its own history, language, culture, practices, and, in some cases, tribal lands; over 60% of AI/ANs live in urban areas (National Congress of American Indians, n.d.; Stumblingbear-Riddle & Romans, 2012). Within this diversity are shared adverse experiences of colonization and assimilation that are

considered distal contributors to present-day social inequities (e.g., discrimination, marginalization; Gone & Trimble, 2012). AI/AN resilience is affected by historical and contemporary contexts, life transitions, and lived experiences.

The work of Denham (2008), Jackson and Chapleski (2000), McCloskey (1998), Mohatt et al. (2008), Quintero (2000), Walls and Whitbeck (2012), Weibel-Orlando (1988), and Wexler (2014) shows that AI/AN resilience is a dynamic process that manifests itself differently for each generation. In some situations, AI/AN resilience may be expressed as acculturation, while actually serving as a strategy to protect and sustain culture within the context of assimilation policies. In other cases, cultural beliefs and practices may need to be reclaimed through enculturation practices (Denham, 2008; Jackson & Chapleski, 2000; McCloskey, 1998; Wexler, 2014). This finding is consistent with current resilience research. Ungar (2011) writes of the complexity of understanding resilience as an adaptive response to varying sociocultural contexts, structural conditions, and life events. The life course framework adds the constructs of lives embedded in historical context and differential generational (i.e., linked lives) impact to this concept of resilience, furthering its applicability to the study of AI/AN resilience.

#### AI/AN Resilience is Collective and Intergenerational

Findings gained from use of the life course framework support AI/AN resilience as a collective and intergenerational process that relies on cultural continuity through shared values and practices (Denham, 2008; McCloskey, 1998; Walls & Whitbeck, 2012; Weibel-Orlando, 1988; Wexler, 2014). These characteristics of AI/AN resilience are consistent with findings from Fleming and Ledogar (2008a), Grandbois and Sanders (2012), Kirmayer et al. (2011), and Stumblingbear-Riddle and Romans (2012) that make the argument for synonymous use of community, collective, and cultural resilience within Indigenous communities. AI/AN resilience is considered a process where traditional community structure and social relationships, cultural identity and practices, spirituality, relationship to place and environment, and lived experiences of adversity are protective (Fleming & Ledogar, 2008b; Grandbois & Sanders, 2012; Torres-Stone, Whitbeck, Chen, Johnson, & Olsen, 2006). The life course framework adds the construct of linked lives, interdependent and interconnected, supporting this evolving concept of resilience, particularly for culturally grounded and nuanced resilience research.

## AI/AN Resilience is Derived from Worldviews, Beliefs, Values, and Practices

In the studies in this literature review, participants accessed their AI/AN worldviews, beliefs, values, and practices when faced with stress, adversity, or hardship along their life course (Denham, 2008; Jackson & Chapleski, 2000; McCloskey, 1998; Mohatt et al., 2008; Quintero, 2000; Weibel-Orlando, 1988; Wexler, 2014). For many AI/AN communities, cultural values, beliefs, and practices are a source of strength, power, medicine, and healing (Brave Heart et al., 2011; Denham, 2008; HeavyRunner & Sebastian Morris, 1997; Mohatt et al., 2008; Torres-Stone et al., 2006). Shared cultural values and beliefs include respect, responsibility, reciprocity, spirituality, connectedness, collective memory, and collective identity. Practices include language acquisition or maintenance, storytelling, sharing lived experiences, traditional parenting, participating in traditional and social activities, and developing intergenerational connections. These resources and strategies inform and guide the thought, speech, and behavior of individuals throughout their lives, regardless of exposure to adversity (Kahn-John & Koithan, 2015). In this way, the findings from this literature review equate AI/AN resilience with cultural continuity, health, and well-being.

#### Mechanism and Strategies of AI/AN Resilience: Narrative and Story Sharing

Within AI/AN concepts of health and well-being, reciprocal knowledge sharing based on historical and contemporary stories and on cultural and lived experiences, and maintenance of relationships and connections, are central. Sharing narratives within a family circle is a cyclical process that informs both individual and collective understanding and action (Denham, 2008; Kirmayer et al., 2011). Denham (2008) describes the family culture and stories that are passed from one generation to another as a cumulative strategy of resilience, but notes that the inability to maintain family or cultural continuity is not a barrier to accessing cultural resilience. At any point in an individual's life course, he/she may begin his/her own family circle and fill it with stories, songs, and teachings that are passed down from generation to generation.

Wexler et al. (2009) considered life histories or narratives important tools for understanding the continuum of resilient responses throughout a lifetime. The AI/AN resilience literature has identified three AI/AN resilience responses: adapting, growing, and awakening (Fleming, 2008a; HeavyRunner & Sebastian Morris, 1997; Kirmayer, 2009; Ungar, 2011). Such responses may be adaptive (positive or negative) or regenerative (i.e., growth; Fleming & Ledogar, 2008a; Richardson, 2002). The third response, awakening, is not predicated on

exposure to substantial adversity (HeavyRunner & Sebastian Morris, 1997). This type of response is considered a state of individual and collective well-being that exists within everyone, regardless of exposure to adversity (HeavyRunner & Sebastian Morris, 1997). Sharing narratives and stories is both a strategy to respond to adversity and a mechanism for passing along or maintaining positive health practices within a group.

# LIMITATIONS/CONSIDERATIONS

#### Few Studies Use the Life Course Framework to Study AI/AN Resilience

The life course framework is primarily used to study the negative impact of adversity, hardship, and stress, both in early life development and at life transitions, on AI/AN adult and elder health and well-being (Burnette & Cannon, 2014; Roh et al., 2015). There were a limited number of articles that focused on AI/AN resilience as an asset-based process across the life course. This literature review used an expanded concept of the life course framework to consider the impact of historical and contemporary sociocultural and political context on cohorts, rather than on individuals, and potential intergenerational responses.

## Limited Diversity of Responses for AI/AN Resilience Intervention Development

While there are shared historical adverse events that support AI/AN resilience research, these events may lead to diverse responses within AI/AN communities. Researchers must consider the following when developing interventions based on AI/AN resilience research: diversity of culture, definition of community, tribal government relationship to the federal government, and potential disconnection between generations when accessing resources for cultural resilience.

#### Limited Evaluation of Resilience Strategy: Sharing Narratives and Stories

The selected studies did not incorporate narrative and story sharing as a strategy within specific interventions; rather, they identified narratives and stories as cultural resources for AI/AN resilience, or used them to study AI/AN resilience. Therefore, it was not possible to evaluate the value or effectiveness of specific narratives or stories.

#### **Challenges for Measuring Community and Cultural Resilience**

Researchers are challenged to define, operationalize, and measure community and cultural resilience. Community resilience is currently measured by aggregating individual proxy psychosocial or sociological measures (e.g., sense of self or coherence; social cohesion, social capital, social networks; Goodkind, Hess, Gorman, & Parker, 2012; Wexler, 2014). For example, in the studies included in this literature review, data from narratives or participant interviews were compiled to yield a picture of resilient people. To date, only Kirmayer et al. (2009) have explored other determinants that might reflect community and cultural resilience. They identified several dimensions of cultural resilience, including family and community connectedness, oral traditions and storytelling, and collective knowledge and identity. The challenge offered by their work is quantifying these proposed dimensions of cultural resilience.

# IMPLICATIONS

The need to address inequities in AI/AN health and well-being drives a downstream and shortsighted approach in public health research and intervention development. Public health is dominated by a deficit-oriented, individual-focused, and decontextualized approach that aims to identify specific risk and protective factors that affect individual health behavior and to improve health outcomes (Braveman & Barclay, 2009). Yet, the persistence of health disparities requires a change in paradigm.

#### (Re)naissance: AI/AN Resilience Research Along the Life Course

Using the life course framework to study AI/AN resilience is an innovative approach that can inform asset-based resilience research for intervention and policy development. This framework supports needed structural analyses of the socioecological impact of historical and contemporary events and conditions on the collective health of Indigenous peoples (Boulton & Gifford, 2014; Braveman, 2014; Estey, Kmetic, & Reading, 2007; Kirmayer et al., 2009; Lavallee & Clearsky, 2006). For example, within the life course framework, the link between assimilation policies and contemporary social inequities and health disparities may be studied and findings used for policy and advocacy efforts (Braveman, 2014; Estey et al., 2007; McCloskey, 1998). Additionally, the life course framework provides an umbrella under which intergenerational responses associated with historical trauma, resilience, vulnerability, and negative social determinants may be studied to understand individual and collective pathways, mechanisms, and strategies (Denham, 2008; Gone, 2013).

AI/AN health research and intervention science is enhanced by use of the life course framework to identify resilience strategies. These strategies are used over time and in changing circumstances, and can be applied to prevent or manage chronic illness and conditions. Narratives and life histories are relevant strategies, as they contain lessons and teachings gained through traditional storytelling and lived experience. Reviewing and analyzing narratives to identify protective factors and processes can inform asset-based interventions. Such knowledge can guide the development of resilience-informed public health prevention interventions. For example, to explore AI resilience and resilience. Content analysis of the elders' narratives identified themes that were used to guide 12 modules for an AI youth resilience program. In addition, the narratives were used as prompts for discussion and self-reflection. The curriculum is designed around three resilience strategies expressed by the elders: culture, activity, and education.

Resilience is a poorly understood and underused resource in AI/AN health research and practice (i.e., program and policy development). Applying resilience strategies could redirect and enhance the effectiveness of public health efforts in AI/AN communities. A life course-resilience research paradigm is an innovative approach to understanding both AI/AN individual and collective health behaviors within context, and the determinants that impact health outcomes. It provides a means for understanding the mechanisms and strategies used for AI/AN resilience. This shift in approach is needed within AI/AN health research to eliminate disparities and achieve health equity.

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# NATIVE TRANSFORMATIONS IN THE PACIFIC NORTHWEST: A STRENGTH-BASED MODEL OF PROTECTION AGAINST SUBSTANCE USE DISORDER

Stacy Rasmus, PhD, James Allen, PhD, William Connor, PhD, William Freeman, PhD, Native Transformations Community Action Board, and Monica Skewes, PhD

Abstract: This paper presents findings from the Native Transformations Project, an exploratory community-based participatory research study that aims to identify sources of strength and protection against substance use disorder in three tribal communities in the coastal Pacific Northwest. Preliminary results from the study describe the specific settings, acts, and behaviors that build strengths and provide protection at the family, community, individual, and spiritual levels within coastal Pacific Northwest local tribal cultures. Findings from this study give voice to stated community preferences for grassroots Native intervention programs based in local cultural knowledge, worldviews, values, and theories of change, that operate at the local level on their own terms.

*"What generation of our people is going to not have alcohol or alcoholism in their family or home? I want it to be in mine."* 

The quotation above comes from a participant interviewed for the Native Transformations Project (NTP), which explores strengths, protections, and resilience against substance use disorder (SUD) in three tribal communities in the coastal Pacific Northwest, hereafter called Coast Salish. While the devastating impacts of drugs and alcohol for American Indian and Alaska Native (hereafter collectively referred to as Native) people and communities are well known (Substance Abuse and Mental Health Services Administration [SAMHSA], Center for Behavioral Health Statistics and Quality, 2011; SAMHSA, Office of Applied Studies, 2012), we know significantly less about the lives of those Native people doing well and living strong in their communities (Mohatt, Rasmus, et al., 2004). There is broad understanding of the

critical need for more effective, culturally grounded prevention and intervention strategies to increase resilience and recovery from SUD in Native communities (Allen, Mohatt, Beehler, & Rowe, 2014; Gone & Calf Looking, 2011; Hawkins, Cummings & Marlatt, 2004). How to devise, develop, and deliver effective treatment and prevention services to meet tribal community-specific cultural needs is considerably less well understood.

Coast Salish tribal people continue to suffer disproportionately from SUD relative to other ethnic minority and non-minority groups (Akins, Mosher, Rotolo, & Griffin, 2003). In particular, opioid (e.g., heroin, prescription painkillers) dependence and overdose among Coast Salish people has increased dramatically since 2000, emerging as a current top tribal health priority in Washington State (Radin, Banta-Green, Thomas, Kutz, & Donovan, 2012; Radin et al., 2015). While these studies generally reveal higher levels of SUD among Native people in Washington State, they also show that differences may be lessened when individual-, community-, and cultural-level risk and protective factors are taken into account (Akins et al., 2003).

This study takes place within three rural, reservation Coast Salish communities located in Washington State. The study was initiated in response to tribal community requests for research to increase understanding about Coast Salish strengths and well-being to identify factors that facilitate recovery from, and protect against the development of, SUD. The study was engaged with the goal that tribes could use its findings to develop, enhance, and evaluate tribal community prevention, intervention, and recovery services by building Coast Salish strengths and protections against SUD.

#### SUD Intervention Grounded in Native Culture, Worldview, and Theory of Change

A recent review of Native SUD prevention efforts found a fundamental disconnect across a majority of the programs described, between "the theories used to guide development of prevention programs in AI/AN [American Indian/Alaska Native] communities and culturally appropriate theoretical constructs of AI/AN worldviews" (Walsh & Baldwin, 2015, p. 41). The most prominent theories guiding contemporary and available substance abuse interventions come from Western psychology (e.g., Transtheoretical Model, Prochaska & DiClemente, 1983; Social Cognitive Theory, Bandura, 2001) and biomedical models (e.g., Dole, 1988). Most studies testing the effectiveness of these SUD interventions are conducted predominately among the majority Euro-American population, with generally little or no representation from minority populations, and Native populations in particular (Gone & Alcantara, 2007).

The prominent SUD interventions (Botvin, Griffin, & Nichols, 2006; Kazdin, 2008) most widely used in Native communities often focus solely on the individual and emphasize factors such as personal agency (i.e., the individual's autonomous decision making; Bandura, 2001), individual motivation to change (Prochaska & DiClemente, 1983), and cognitive appraisal of the pros and cons of changing (Prochaska et al., 1994). While these may be important factors to consider for people from various cultures, these models neglect to consider the influences of family, community, cultural and spiritual factors, all of which are central to the experiences of tribal community members. When factors key to the experience of Native people are not addressed in theories or interventions, it is not surprising that prevention and treatment programs often fail to demonstrate their desired outcomes in these populations (Casey, Rawson, Li, & Hser, 2011; Dickerson et al., 2011; Evans, Spear, Huang, & Hser, 2006).

Increasingly, Native community members are advocating for cultural approaches to addressing SUD on their own terms. Whitbeck, Walls, and Welch (2012) note broad-based efforts composed of grassroots Native intervention programs, operating in parallel to these more limited research efforts with Native populations described in the existing literature. These Native programs, instead of adapting existing programs, are based in local cultural knowledge, worldviews, values, and theories of change, and operate at the local level. These local initiatives are often only informally evaluated; as a result, they are rarely, if ever, reported in the SUD research literature. These grassroots efforts sometimes are portrayed as arising out of a clash between Western and Native clinical paradigms (Calabrese, 2008); however, their absence from the SUD research literature also reflects broader tensions between the cultural worldview of Native communities and the theories, worldviews, and cultural assumptions of Western social and biomedical health science research (Gone, 2012).

There are several important drivers to the development of local cultural interventions in tribal communities. Foremost is a broad motivation to address SUD within many Native populations, coupled with an apparent divergence in the match of the predominant intervention programs to Native clients. Beals et al. (2006) reported that 13.3% of participants in the American Indian and Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors

Project (AI-SUPERPFP) sought help for substance use problems during the year prior to assessment. Of those with past-year SUD, 38.9% had sought help. Of this group, 52% sought Western professional services; 41%, Alcoholics Anonymous 12-step support groups; and 40%, traditional healers. Strikingly, in comparison to National Comorbidity Survey (NCS) data, the Native populations in the study cited above were slightly more likely to actively seek out help than were those in the U.S. general population. However, the existing research (Dickerson et al., 2011; Evans et al., 2006) suggests that despite this interest in participation in programs to address SUD, when Native people do seek treatment, the types of treatments currently offered by Western model programs result in lower treatment retention and utilization rates, in contrast to non-Native matched controls. Also of note in the AI-SUPERPFP findings was the substantial proportion of Native people with SUD who consulted traditional healers to address their SUD problems. This finding is again reflective of the consistent interest among Native people in cultural approaches to address SUD. This combination of research findings fuels the growing argument for SUD interventions based in or more oriented toward Native theories of change and grounded in local Indigenous culture (Gone & Calf Looking, 2011).

## **People Awakening: Beginnings of a Translational Pathway**

Important steps toward the goal of developing Native theory-driven SUD interventions have been taken, with significant gains over the last decade (Allen et al., 2006; Donovan et al., 2015; Mullany et al., 2009; Rasmus, Charles, & Mohatt, 2014). Of greatest relevance to the current study are efforts of the People Awakening Project (Allen, Mohatt, Beehler, & Rowe, 2014; Mohatt, Rasmus et al., 2004; Mohatt et al., 2008), a community-based participatory research (CBPR) study that has spanned nearly 20 years. The collaborative work began when a group of Alaska Native (AN) leaders requested that university researchers assist them in a project to explore AN pathways to sobriety and wellness. Dr. Gerald Mohatt at the University of Alaska Fairbanks helped answer this call to action, and the People Awakening Project was proposed with the aims of portraying another, unheard side of the Alaska Native story (Mohatt, Hazel et al., 2004), profiling sobriety, well-being, and strengths, in contrast to the often negative public attention on AN communities (Weaver, 1988). The People Awakening Project focused on often overlooked stories of strength, hope, and positive identity and identified indicators of AN protection and well-being that are enduring parts of the culture and its Aboriginal way of life.

The People Awakening Project began by collecting 101 life history interviews from AN people who had never developed an alcohol use disorder (AUD), or had successfully recovered from AUD and maintained their wellness for 5 or more years. Their life histories revealed key protective factors that might help assist these research participants with recovery from AUD (Mohatt, Rasmus, et al., 2004), and suggested protective factors that might help prevent the development of AUD. These protective factors identified in the People Awakening Project became the building blocks for an AN theory-driven intervention to reduce youth suicide and AUD that was focused in the Central Yup'ik communities of Alaska (Allen, Mohatt, Beehler & Rowe, 2014; Rasmus et al., 2014).

A key tenet that permeates the ongoing efforts of the People Awakening Project is its strength-based approach (Allen, Mohatt, Beehler, & Rowe, 2014). This strength-based approach focuses on building protection, rather than reducing risk. As a result, the approach requires researchers to ask intriguing questions, such as: What is protective against SUD? What factors mediate pre-existing risk factors? Which are most amenable to intervention? Strength-based approaches direct inquiry to identify specific factors within a community, family, individual, and culture that build well-being by providing protection.

The People Awakening Project began as a discovery-based CBPR qualitative study. The initial study evolved into a program of CBPR intervention research with direct treatment and prevention applications. NTP seeks to replicate the successes of People Awakening in building a translational research pathway from basic, descriptive research to intervention development. The current study, as the first study in a planned program of research, is discovery based, and, through qualitative inquiry, aims to identify Coast Salish tribal-specific sources of strength and protection, and strategies for achieving and maintaining wellness. The study is conceived as a first step in initiating a program of CBPR intervention research to develop a strength-based, Indigenous theory-driven intervention to prevent SUD among the NTP partnering tribes.

# **METHODS**

# **Tribal Context and CBPR Process**

The NTP brought together local representatives from three Coast Salish tribal communities with researchers from the Northwest Indian College and the University of Alaska Fairbanks as part of a CBPR (Minkler & Wallerstein, 2008) initiative to reduce disparities in SUD.

Two of the primary researchers on the team have developed long-term relationships with Coast Salish communities, having worked in various capacities in health, social service, and education for the tribes for almost 20 and 40 years, respectively. Tribal representatives from the three study communities approached the researchers in 2011 to undertake a project to identify Coast Salish strengths that were protective against SUD, and that could ultimately be used to improve existing SUD treatment services, as well as to develop community-based prevention services.

The three participating tribal communities were engaged both separately, through a local process, and together, through the development of the Native Transformations Community Action Board (CAB).

Each tribal community has its own system of governance, and a local oversight group was established at each site to guide the project through the appropriate local channels. The research was approved and implemented at each site according to its own tribal-specific decision-making process. Each tribe selected representatives to be members of the cross-site CAB that would meet monthly for the duration of the project. The resulting CAB consisted of 11 tribal representatives from the three communities, along with Tribal College/University project staff. The CAB has met monthly (29 times) since the project began and continues to meet as needed. The CAB has been active in guiding and contributing substantially within all stages of the research, including development of the research questions and data collection tools, recruitment and interviewing, analysis of the data, and interpretation and sharing of the results.

# **Participants**

Our original goal was to recruit and interview 60 adults (ages 21 years and older) from the three tribal communities, proportional to the size of each community and stratified per CAB recommendations by age group (21-35 years, 36-55 years, 55 years and older), gender, and sobriety category (lifetime wellness and secure wellness, defined below). The CAB chose the two categories of wellness as being more holistic and better representing the reality as lived in the three Coast Salish communities than sobriety. *Lifetime wellness* was defined as individuals who may have experienced other hardships and challenges, but had not had a problem with drugs and/or alcohol, and were considered good role models of resilience. *Secure wellness* was defined as those individuals who did at one time in their lives have a problem with drugs and/or alcohol, but had changed their lives and had not had a problem with drugs and/or alcohol for 3 or more years and were at the current time considered good role models of recovery. We interviewed 62 adults from the three communities, exceeding our recruitment goals, and could have interviewed many more interested participants but were constrained by timeline and budget. As can be seen in Table 1, there were 26 individuals in the Lifetime Wellness group and 36 individuals in the Secure Wellness group, with age group and gender represented fairly equally across each of the wellness categories and tribal communities.

Table 1

Native Transformation Project Research Participant Age Group, Gender, Community and Wellness Group						
	Tribe A	( <i>n</i> = 27)	Tribe B (	(n = 21)	Tribe C (	(n = <b>1</b> 4)
Sobriety Status	Female	Male	Female	Male	Female	Male
Lifelong Wellness: 21-35	2	1	1	0	1	1
Lifelong Wellness: 36-55	1	3	1	2	1	1
Lifelong Wellness: 55+	2	2	2	1	4	0
Secure Wellness: 21-35	4	1	1	2	0	0
Secure Wellness: 36-55	1	2	2	3	1	2
Secure Wellness: 55+	4	4	1	5	2	1
Total	14	13	8	13	9	5

# Procedures

By recommendation of the CAB, two of the primary researchers conducted all of the interviews for the project. CAB members assisted with local recruitment, nominating individuals from their communities known to be role models of strength and wellness. CAB members assisted the interviewers in making contact with nominated individuals from their communities, and sometimes went with the interviewer to the interviews. In a few cases, they stayed for the duration of the interview, at the request of the interviewee. Volunteers also were sought through local advertisement of the research at community meetings and health forums held at each tribal site. Finally, a snowball recruitment approach was utilized, with each participant being asked to nominate another individual or individuals from their community who they considered to be positive examples of living well and being strong.

Each interview took place over the course of 1-2 days, and on average, lasted between 2 and 5 hours. Interviews were recorded using digital voice recorders, and all interviews were transcribed by a professional service. These interviews were conducted as part of a larger study of substance use and SUD histories using survey methodologies.

The transcribed life history interviews were uploaded into ATLAS.ti qualitative data management software, and analyzed by the entire project team. We used a constructivist grounded-theory approach (Charmaz, 2000) that incorporated a co-construction of the analytical process. The two interviewers coded the data using grounded-theory process steps that moved from memoing to open coding, and then to selective coding and theoretical coding (Glaser, 2005). The CAB reviewed memos and open coding lists, and then developed additional codes that were added at the selective and theoretical coding stage. A final code list was developed and approved by the CAB to answer the primary research questions of the study, which were to identify Coast Salish sources of strength and protection, and strategies for achieving and maintaining wellness.

The two interviewers coded the transcripts line by line. Each coder independently coded two randomly selected interviews to assess inter-rater agreement before the selective and theoretical coding stage began, and again at midpoint. First order agreement coefficients (AC1; Gwet, 2012) were computed to determine level of agreement. An ACI of .87 and .85 was obtained, respectively, indicating strong reliability.

#### RESULTS

Open coding of the life history interviews revealed sources of strength and strategies for wellness that were organized by the selective codes: family sources of strength, community sources of strength, individual sources of strength, and spiritual sources of strength. Family sources of strength include factors within Coast Salish lineage and family systems contributing to resilience and recovery, such as extended family, role and place in family, parenting and grandparenting strategies, and family traditions. Community sources of strength include references to community traditions and resources, opportunities to learn and participate in educational and wellness activities in the community, and environmental factors, such as having access to tidelands, hunting grounds, and sacred places. Individual sources of strength include references to personal strengths, and to strategies for being well and strong and for improving self-efficacy. Spiritual sources of strength include engagement in spiritual gatherings and activities in the community, personal spiritual engagement and beliefs, and prayer.

Family sources of strength were coded with highest frequency of any selective code on our code list, with 637 independent references. Code frequencies for community sources of strength, individual sources of strength, and spiritual sources of strength were 345, 501, and 241,

respectively. Narratives from these four code families were analyzed separately by our team to identify patterns of recurring or shared protective factors within each of these four domains. Results provide deep description of these protective factors and wellness strategies, summarized in Table 2, which emerged from our analysis of Coast Salish sources of strength.

<u>Family Sources of Strength</u> Teachings Family Roles, Rules, and Rituals Protective Parenting Ancestors "Uncles" Powerful Women Grandparents	Individual Sources of Strength Awareness Working on Living Helping Others Honoring Your Gift/Speaking from the Heart Power of Mind Indian Names/Being a Namesake			
<u>Community Sources of Strength</u> Opportunities for Learning and Healing Social Connections Strong Elders Traditional Laws Harvesting and Sharing Resources Healthy Connections to the Past	<u>Spiritual Sources of Strength</u> Welcoming in the Spirit Belief in Prayer Gatherings Warnings Rites of Passage Being on the Land/Water			

Table 2 Coast Salish Protective Factors

# **Family Sources of Strength**

# Teachings

Protective families generally pass on teachings. Teachings provide moral guidance and instruction on how to live well. In the words of an NTP participant, teachings can "shoot like arrows into a person," setting or righting a person on a path toward wellness.

The teachings that my dad and my grandmother and my mom shared were a big part of making me who I am. Mom and dad taught me was when you talk or when you speak, speak from your heart and my dad always said use as little words as possible. So those were good teachings and even from childhood he always said use your ears first, you've got two ears, one mouth, listen and think before you speak. At funerals, me and my brother and younger brother when things were done and chairs needed to be put away, we were expected to do that. My aunt and her husband eventually, we call it stood me up, as a young man, and said, well they didn't say it but I knew that's what it was, you're going to be a cultural speaker. You're going to stand up and speak for people at our ceremonies, particularly at funerals. So they didn't ask me, they stood me up and it's just the way it happens and so those teachings about thinking before you talk were putting me on this path. I don't see those teachings anymore. I think all that leads into how you treat other people, how you treat yourself.

#### Family Roles, Rules, and Rituals

Families with clear roles for each member and rules to follow tend to be protective. Family rituals are activities that families do together on a regular basis, such as eating together, going to powwows, going out fishing, and helping at ceremonies and funerals. Family rituals provide stability and build cohesion.

My aunt had a huge part in my life. She was strict on rules, making sure of where I was at, what I was doing, when I was going to come back with limitations on when I could go places or who I can hang out with. A few times she did kind of loosen up, that's when I slipped a few times. It started in middle school thinking I was part of the cool group of kids and whatnot, claiming the one color and thinking I was a gang banger and smoked weed. Me and one of my friends got caught smoking weed on school campus and we got emergency expulsion for a week, and my aunt, she didn't like it at all. That's when everything got tightened back down and I just kind of became a homebody, cleaned up the house, chores, helped her. As I was growing up with her, she was one of the cooks for all the funerals and ceremonies, different types of ceremonies, whether it be funerals, powwows, marriages, namings, gatherings. I helped her out in the kitchen and out on the floor, setting up tables, placing things. I'm pretty sure that was a huge part too by keeping busy and helping out with the community.

#### **Protective Parenting**

Having strong parental role models is also a critically important source of strength and protection within families. Grandparents and extended family members have critical protective roles in Coast Salish families, but the presence of a healthy and strong parent in the lives of our participants was also a key recurring theme in stories of strength.

In retrospect though, looking back at the situation, I think the experience with my grandmother especially after everything I'd been through in my childhood just really finally clicked me into a mindset that really prepared me for today. It was a real melding of both worlds-kind of thinking. I grew up in the inner city and had parents that although they weren't together, and although they had their shortcomings, really instilled a lot in me as a young man. Then on top of that, being able to live with my grandmother, and just kind of learn from an Elder who grew up in that old-school time when Elders lived within the old teachings. It just really helped my way of thinking of things traditionally speaking.

#### Ancestors

Kinship knowledge (knowing who one's relatives are, and being an active part of one's lineage) is protective.

When you talk about the Indian culture, there's one thing that is predominant in all of it, is family is central. Family is central to everything. It begins and ends with your family. We're taught that our families go beyond first cousins and that we can claim a relationship in a lot of different ways and can go seven or eight or nine generations back. And you want to be related to families that have a lot of respect because you know if you claimed as a relationship, certain families, you get inherent respect that is shared by everyone because they do things in certain ways or they're very dedicated to the traditions and teachings. And when you're dedicated to teachings, you're doing things in a proper way and good things happen to you.

#### Uncles

Protective families have strong male role models who, like the watchmen on a reef net canoe, look after the younger members of their families. "Uncles," an English term closest to the Coast Salish meaning, play a key role in Coast Salish communities, providing guidance and discipline when needed. The role of uncle can be assumed by any of the older male relatives in an extended family system.

In our community a long time ago, the teachings to the kids came through stories, and the uncles. You see that a lot still. Boys who are misbehaving, their dads send them off to live with an uncle. And what I've observed from that is the uncle can be a little bit more strict and harder on a young man than a dad can be in teaching them how to follow the rules.

# **Powerful Women**

Protective families often have central female figures that provide the "glue" and the teachings that hold a family together and keep a family strong.

I think what brought me through all this was my grandfather's culture. He was raised by his mom, single parent, very strong, hard working woman. Our belief in our culture is something that's been handed down to my grandfather comes from the mother, his mother. It was always handed down to the female of the family because it's the female that's supposed to be the glue of the family. And that was drummed into my head, that if I get a family to be the glue.

#### Grandparents

Grandparents, like uncles, can be any Elder member in an extended family system. Grandparents have a critical role in the development of wellness. Protective families generally have at least one strong grandparent figure who takes an active role in the upbringing of the grandchildren.

My son, he's in sixth grade and he already says he's going to college and knows what he wants to do with his life. It was pretty comical because his soccer coach was talking about college and he popped up and he said yes, I'm going to college or my grandma will kill me if I don't go. And I looked at him because I was standing there and I said to him, and what will Mommy do? And he's like, I don't know. And he said I'm not worried about that, I'm worried what Grandma will do. It was like oh wow. It was pretty funny. He said Grandma's going to make sure I make myself a good life. So I mean we talk about college and stuff, but he's inseparable from Grandma and it doesn't matter what we talk about, but with Grandma it's like the law. If Grandma says something, that's what it is.

Sometimes I'll ask him why do you feel that way and he said because Grandma's your mom too and she's the boss. So can't argue with that I guess. She taught me well so I don't mind.

#### **Community Sources of Strength**

#### **Opportunities for Learning and Healing**

Protective communities generally include opportunities for learning new skills, gaining new knowledge, and healing. Opportunities include access to both Euro-American and Coast Salish learning and healing.

Probably one of the best things that happened here on the reservation is when they provided on the job training and we got some real special instructors that really supported us. Some of us were encouraged to go to college. That was a big change finding out I really could learn and finding out a direction to go in, finding out something I loved to do. I was nineteen and was already married and flunked out of college and then went to the aqua-culture training program and found out I really could learn and ended up graduating.

## **Social Connections**

Protective communities often build interdependence and provide emotional support. Social networks describe social connections in a community. Strong social networks create intergenerational interconnections. Social networks with strong, loving relationships, and those that include Elders, build resilience.

There was a sense of community then and there was a woman's circle that my mother had in that period of time, and the women were quite strong. They had something meaningful. The relationships were built. So those same aunties are my aunties today and those women are still important to me. I saw a woman the other day in the casino of all places and she looked at me like, 'I should know you but who are you.' She didn't say anything, it was on her face. I told her my name and then my parent's names and she goes, 'Oh I should love you.' Now for me I thought it's not me she's talking to about that love; it was the love of everything. I can see her going back in time and connecting because there were all those kinds

of pieces. I think for most of the people that I grew up with at that time will tell you some of the same things, that there was some structure, there was some community, there was these aunties and uncles that were watching and looking, and as we've grown, I've noticed that my children don't have that sense of community. They don't have that sense of the strengths of aunts and uncles in the same way.

#### **Strong Elders**

Strong Elders direct a path for learning and wellness for the people, family, and community. Strong Elders have the respect of the community and recognize their role and power to help the community heal.

Okay so sometimes on Facebook it can get kind of dramatic. One time when I actually put my feelings out, and I didn't even make it really strong out there, I just made like a small comment and an Elder responded to my post. She said let's have lunch and lets talk about this, and she had no idea what it was and I couldn't say no because she's an Elder, and so I went and had lunch with her and I think that is huge. I felt really, really supported because a lot of times... I actually worked for the Elders and a lot of them are going through their own struggles and don't know how to interact with the younger generation. I mean I loved them and I cared for them, but it was so hard sometimes to always respect them just because of how they treated you as a young person. But then when that Elder reached out to me, it put a huge different twist on it. I'm like okay there are Elders out there that care and I feel like that's really important in Native communities across the board is that they have that support from the Elders.

#### **Traditional Laws**

Protective communities guide themselves, enacting local rules and standards from within and teaching inherent rights.

It's important that we continue to carry out these traditional laws. And they said if we talk long enough we can find out how we're all related and we may have to go back to seven, eight, nine generations but we can all tie ourselves together. So we try to work that way. We try to think that way that when there's something that happens in this community, it's part of our family. So we act appropriately.

## Harvesting and Sharing of Resources

Protective communities engage in traditional subsistence practices, including fishing, hunting, and gathering, with the sharing of resources among their members.

In a bigger sense, there's work that keeps us together as a community and a meal is always there. Resources are always to share, there's always food at the table spread, people are giving a meal and sometimes other resources are shared and traded and it's all driven by resources. It's all driven by what you're harvesting. I call it the harvesting and gathering. You harvest the resources and you gather as a people. So during the time of harvesting, there's the values and respect that's shared between the family and then there's bigger sets of traditions that are shared during the larger gatherings and I really believe it all resolves around resources, fish and animals and everything that kept our culture alive since we can remember.

## **Healthy Connections to the Past**

Being part of a community's success story is often protective. Recognizing the historical strengths of one's community and the strengths of one's ancestry also builds resilience.

In growing up with my grandparents, we always had to be proud of our coat as Native people. Don't ever, ever take your coat off. The coat meaning our Indian heritage, our pride in our being a Native. Don't ever take your coat off. You take your coat off and you're open for everybody to hurt you. I kept my coat on though. I had to protect myself. Again protecting myself because nobody else will. My grandchildren, my granddaughters don't believe that there was a time when people treated Indians so badly. I told them don't ever, ever let anybody call you a dirty little Indian. You stand up, you show them your coat. You show them your knowledge of being who you are because I've already put names on my children, their cultural names. And mine was put on me when I was younger. You're then taught to learn where that comes from, who had that name before you, how were they. And I say to my children that's part of that coat. With that coat you're carrying with you all that past.

## **Individual Sources of Strength**

#### Awareness

Opening up to learning and healing can build strength and resilience. Gaining awareness is a key part of the process of awakening and transformation.

I realized that I had this whole pathway to follow. There was a great deal of reflection on what my mother did for our Nation, what my father did and what my grandparents did and my great parents did for us as a people and it was kind of like this spiritual thing. It was so strong in me that I was coming home from the smokehouse and I came to a stop light there outside the reservation and I started crying uncontrollably. It was like one in the morning, just all by myself and it was just so overwhelming and it was about my failures, it was about what was right, it was about my kids and like I was just blowing it. So I had to figure out what I am going to do then.

## Working on Living

Individual contributions to family survival and success are often protective.

We had our duties to do, chores to do and it was nothing for me to get up at 6:30 in the morning and do something. Like I said my mom and dad taught us how to do that kind of stuff, I mean get up and go to work, get up and go to work whether

it's picking berries or whatever. And the hours of work at home was nothing compared to the ten hour days we spent in the berry patches and cucumbers and stuff. So it was easy duty for me and we just enjoyed it. It was really a rewarding thing. I still thank my dad and my mom for doing that survival mode with me.

#### **Helping Others**

Doing and caring for others, especially Elders, helps build resilience.

When I was really young my mom would take me to Grandma's quite a bit. So my Grandma was another support for me, but she died when I was ten or eleven. I can remember cooking and cleaning a lot. She showed me how to crochet, how to manually do quite a bit with the home. Then when I got older into my teenage years, she had me babysit for some of my aunts and uncles and she'd also send me to the Elders houses' that lived by us and she'd have me go sit and talk to them or help clean their houses. So if their dishes needed to be done, I'd go and do their dishes. If their bathroom needed to be cleaned, things like that. So I learned how to cook and clean at a young age but then when she'd send me to go help cook and clean for the Elders I never looked at it like a chore, it was just something that we did because it was something that they needed help with. But I remember just being so interested because they always had cool stories to tell, funny stories and tribal stories and I really took a big interest in learning about my family tree.

#### Honoring One's Gift and Speaking from the Heart

Gaining knowledge of one's own personal strengths and special abilities contributes to protection. Honoring oneself, as one is, and learning to speak from the heart, build resilience.

So within the community, everybody's got a gift and we're taught that you need to honor that gift. If you don't use it, the Creator's going to take that gift away. Whether it's your voice, or speaking from the heart, or whether you're a cook or a hunter, those are gifts that God gave you to help your people.

## **Power of Mind**

Individual spiritual power was seen as protecting bodies and minds. Individuals with power of mind believe in themselves and demonstrate strong self-efficacy.

Even at childhood I said when I have my kids, my kids will never, ever go through this. So I remember very, very young saying never again. When I'm old enough and on my own and I'm able to change my life, none of that will be in my life. So it's kind of weird and you know I never really talked about that but I mean, that was some pretty big feelings to have as a child. Most kids are worried about watching TV and running to get their bike or whatever, but I was thinking about... I was always thinking about even as young as elementary school, I was always thinking about my life as an adult and how different it would be then when I was a child and how those bad things scared me.

## Indian Name and Being a Namesake

Having an Indian name and knowing about the relative for whom one was named build strengths.

Native pride isn't a tattoo, it's how you live. It's the humbleness you have about where you come from, the family that you come from, the Elders that came before and that's my grandmas, my grandpas, my uncles. It's that pride that you have and where you come from. That was one of the things that dad said is to be proud to have your family name. Be proud of the people that you come from. You come from strong people. Strong beliefs. Don't do things to drag that name through the mud.

## **Spiritual Sources of Strength**

#### Welcoming the Spirit

An important protective factor is recognizing the spirit that lives within, and knowing how to engage in a healthy spiritual relationship.

As an alcoholic I think we've lost our spirituality. We lost our spiritual connection through our alcoholism and our drug addiction. I don't think our spirit wants to be in our body as long as it's being abused by alcohol and drugs, so it leaves. So when I sobered up, it was like the spirit came back in and it wants to live in this house again, but I don't know who he is. So through this, I'm learning my spirituality, my culture. I have a higher power. I have God. And it feels so good to have that feeling of wholeness. It's comfortable. It's a warm feeling. I don't know how to explain it, but it was somebody that wasn't there while I was using. It takes a while to understand it. It takes a while to understand the spirituality. That's what's really lonely I think when we're using, is there's not a spirit living inside of you and we're more spirit driven people than we are human driven people. This human life is just what we have. The spiritual is going to live forever. So it feels good to welcome that spirit back in.

### **Belief in Prayer**

Similarly, believing in and accepting the power of prayer, and knowing how to pray, were seen as protective and strengthening.

Creator first. If you don't do that then you won't have a fighting chance. That's the way I look at it. Because if you got nothing to believe in at the start and then it's going to be a tough battle because you're going to get knocked down and the Creator's going to be the one picking you back up. It's why the beliefs. Like I said I got my Native culture and my powwow culture and Shaker, everything that I've learned tells me it wasn't that bottle that made me feel better. It wasn't the counselor that made me feel better. It was the prayer that I had when I was at my worst. If people can remember that then they can get through it as long as they believe. You're always Indian and all Indians have always known how to pray. It's just that they need to practice it more to be better people, be stronger people, to be proud.

## Gatherings

Protection is often created by engaging in ceremonial and spiritual activities, together with other members of the family and community.

So a lot of the Tribes have ceremonies. We've been taught that if you thank salmon for giving up its life to you, you thank the deer, the elk, for giving its life so you could survive you'll always be successful because that resource it allows itself to be caught so that we can be successful but only when we pay our respect. So a lot of us when we go fishing, we thank salmon, we thank the water, we thank the resource itself for being good to us.

## Warnings

Giving verbal and nonverbal signs of acknowledgment and respect for the spirits and the spiritual life was frequently described as protective.

Well she taught me respect yourself, of course. You're Native. You walk tall. You're the first people that ever walked in this country and don't let anybody put you down because of that. And so I always remember that. And then she would teach me things like—well first of all always respect your Elders no matter who it is. Always respect your Elders and I've always done that. I could just see my mom turning in her grave if I ever didn't do that and things like; you don't eat food in a cemetery, you don't drink in a cemetery, you don't step on graves, things like that. You don't whistle after dark. I remember all the little things. You don't cry outside after dark. You don't hoot and holler after dark unless it's in a ceremony and you don't sleep with your curtains open or your blinds open.

## **Rites of Passage**

Events marking an important stage in a person's life often protect by building a sense of purpose and place as part of a community. Rites of passage can include receiving an Indian name, receiving a song, receiving first Communion, and hunting one's first animal.

He'd walk me through sticker bushes. He says those are people's words. If they sting, it just goes away. That's another thing. The stinging nettles, they sting just for a little while and they'll go away. Those are people's words. Don't let them hurt you. I think we as grandparents need to be teachers again and not be so darned busy. I hear people talk about their culture but they don't live it. Words are cheap. You got to feel it. You got to walk it and I do now. Like even helping somebody with their funeral, there's a protocol. Like I just came from one yesterday. I had my granddaughter walking with me, I'm teaching her. I told her you're going to be my legs. I just told her what she had to do and she did it. You're grandma's legs. She went and did it and I feel my grandfather, like he's channeling me to teach her now using his tools. I don't see very much of that. I don't. I don't see that in our community very much at all. You got to do it. The way they did me, I'm doing it to my granddaughter. She's going to go for the walk in the sticker bushes too.

#### Being on the Land and Water

Being out in the forest, in the mountains, and out on the sea are generally protective because those activities strengthen one's spirit.

My Papa was a fisherman, he was a commercial fisherman. There would be a lot of times where he'd just take mamma and I out in the boat with him, out in the open ocean and I was a little kid, okay. You're wondering, how the heck did she stay on the boat? Because those are high waves half the time. Well, they tied me to the boat. So if I fell over and they don't see me on the boat, they just pull me back in. Now Papa, when I was a teenager, he says there's a reason I did that to you if you really think about it. The waves are the things in life. I've tied you to my boat. You fall off, I'm always going to be there. That's family. So I told my kids I don't have a boat but I'll share my story. I got a Suzuki... But I've never, ever forgotten it. I'm still tied to the boat. I'll always be tied to the boat. But being tied to that boat is I'm tied to my culture. I'm tied to my heritage. That's where our strengths have to come from. That's where our teachings and everything comes from, from our family boats.

## DISCUSSION

The NTP described a rich array of Coast Salish cultural strengths. These strengths can be used as the building blocks to a cultural theory of protection from SUD in this tribal setting. These results convey a detailed, deep description of the specific settings, acts, and behaviors that generally provide protection on the family, community, individual, and spiritual levels within Coast Salish local tribal cultures.

The People Awakening Project offers a blueprint for how this type of protective factors model (Allen, Mohatt, Fok et al., 2014) can be used to guide culturally grounded intervention development (Rasmus et al., 2014). The People Awakening work also provides an example of how protective factors can be used as tribal-specific behavioral health indicators that can be measured (Mohatt et al., 2014).

The descriptions of protection emerging from the NTP findings also suggest why importing mainstream treatment and prevention models into this cultural context may not be the most effective approach. Similar to the People Awakening findings (Mohatt, Rasmus et al., 2004), NTP identified a number of distinctive, tribal-specific protective factors unaddressed by existing mainstream intervention. For example, the culturally distinctive protective factor of "powerful women" aligns with Coast Salish Indigenous social orientation through the mother's lineage (Suttles, 1987). Also distinctive is "honoring one's gift and speaking from the heart," which aligns with Coast Salish values of public speechmaking and oral exposition (McHalsie, 2007).

In addition, a number of the NTP findings overlap to a significant degree with similar, but not entirely identical, concepts mapped by the People Awakening protective model and by researches working within other tribal settings. Examples of this overlap include the Coast Salish protective factor "power of mind," which displays a number of parallels to "*ellangneq* (awareness)" in the Yup'ik context (Allen et al., 2006). Similarly, "helping others" in the Coast Salish context bears a number of similarities to "communal mastery" in Yup'ik settings (Fok, Allen, Henry, & Mohatt, 2012), which, in turn, was a variable originally studied with Northern

Plains American Indian women (Hobfoll et al., 2002). These and other findings of cultural distinctiveness and of overlap with other tribal settings suggest convergence with the translational CBPR intervention research pathway adopted by People Awakening (Allen, Mohatt, Beehler, & Rowe, 2014). They suggest the potential for broader and more generalizable applications of the NTP findings for community-based and culturally grounded efforts to create more effective substance abuse interventions for Native people.

Despite this promise, a number of limitations exist regarding the generalizability of the NTP findings. First, interpretations of the data may be generalizable only to the participants from the three Coast Salish tribal communities that took part in the NTP study. Additionally, participants in the study were all over the age of 21, and findings may not be generalizable to youth in the communities. Finally, the study looked broadly at resilience from SUD, but the majority of participants described wellness from AUD or polysubstance use disorder that involved alcohol. Currently, the three tribes participating in the study all report rising incidence in opioid misuse and overdose. Findings from the NTP study may not be generalizable across all types of SUD. More research is needed to ascertain the relevance of our findings to other Coast Salish individuals and communities, and the degree to which the results generalize across other tribal cultures, age groups and SUD experiences.

The next steps in a program of CBPR intervention research involves a crossing of paths with the roadmap provided by the People Awakening Project (Allen, Mohatt, Beehler, & Rowe, 2014). Similar to the People Awakening translational pathway, our next step with Native Transformations is the development of a Coast Salish Wellness and Protective Factors Model that could be tested using measures developed from the People Awakening work along with new measures specific to the Coast Salish American Indian community context (Allen, Fok, Henry, Skewes, & People Awakening Team, 2012; Allen, Mohatt, Fok, et al., 2014; Fok et al., 2012; Fok, Allen, Henry, & People Awakening Team, 2014; Mohatt, Fok, Burket, Henry, & Allen, 2011). Such efforts have the potential to address a number of key Coast Salish elements in these communities left unaddressed in mainstream interventions.

The NTP findings describe key elements of what is lacking in conventional interventions as applied to tribal communities. The findings may provide explanations for 1) why outcomes for Native people treated with conventional interventions are not as positive as outcomes for the populations that comprise the evidence base of these interventions (Dickerson et al., 2011; Evans et al., 2006), 2) why minor adaptations of existing interventions may not be as effective with Native populations, and 3) why such adaptations, to be promising, must be extensive and based on a Native worldview (Venner, Feldstein, & Tafoya, 2007). These findings give voice to stated community preferences for grassroots Native intervention programs based in local cultural knowledge, worldviews, values, and theories of change, that operate at the local level on their own terms. However, at their heart, the NTP findings are a message of hope, and the strengths they portray provide an answer to the participant's question that opened our paper, "*What generation of our people is going to not have alcohol or alcoholism in their family or home?*" NTP provides the tools for "*it to be in mine*."

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## PARTNERING WITH AMERICAN INDIAN COMMUNITIES IN STRENGTH-BASED COLLABORATIVE HEALTH RESEARCH: GUIDING PRINCIPLES FROM THE FORT PECK CEREMONY OF RESEARCH PROJECT

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Abstract: Background: The Ceremony of Research Project was implemented to strengthen tribal communities' ability to harmonize Western research processes with Indigenous ways of knowing. Methods: Focus groups were conducted with tribal members to understand Indigenous processes, beliefs, and practices necessary to promote positive research experiences with tribal communities. Results: Findings address time; relationship building and maintenance; inclusion of diverse tribal members in the research design, as well as American Indian epistemology; respect for tribal values, beliefs, and customs throughout the research process; and the reciprocity of research. Conclusions: Our study has important implications for how researchers can take a strengthbased approach to conducting research with tribal communities.

## **INTRODUCTION**

In the U.S., American Indians and Alaska Natives (AI/ANs) are at highest risk for a myriad of adverse health outcomes such as heart disease, obesity, cancer, diabetes, suicide, and sexually transmitted infections (Centers for Disease Control and Prevention, 2011a, b). Recognizing the persistence of health disparities in Indigenous populations as a serious issue in the U.S., the *Healthy People 2020* report calls for collaborative strength-based strategies in health research to further investigate the causes of disease and prevention strategies for underserved and at-risk populations (U.S. Department of Health and Human Services, 2008). Despite this recommendation, there remains a lack of awareness regarding what is required to

develop strength-based collaborative research to address health disparities—particularly for health research with Indigenous communities (Tobias, Richmond, & Luginaah, 2013).

Previous work suggests that research with Indigenous communities has a relational focus: One must understand and respect how tribal people form and maintain relationships with others, the land, and the spirits and how these relationships in turn influence ideas and ways of perceiving the world (Kovach, 2012; Wilson, 2008). This paradigm shifts the focus from oneway transfers of information to open, bidirectional exchanges that include sharing Indigenous and academic perspectives, as well as exposure of the personal self (Castleden, Morgan, & Lamb, 2012). This exchange requires establishing and maintaining trust as a foundation for any research conducted with tribal communities (Christopher, Watts, Knows His Gun McCormick, & Young, 2008). Emerging from the literature discussing collaborative strength-based research partnerships with Indigenous communities are the following understandings: 1) the need for knowledge of language, culture, place, and spirituality, their interconnectedness, and how these concepts may affect attitudes, beliefs, and behaviors among a group of people; 2) the need for expertise in a variety of research methodologies; and 3) the need for researcher awareness of self and a willingness to share self in the research process (Chilisa, 2012). These understandings call for new schemas in research on health disparities with Indigenous peoples that entail personal disclosure and presence, the melding of Indigenous knowledge with academic training, the utilization of innovative intervention frameworks and interdisciplinary approaches, and, perhaps most importantly, a focus on solutions instead of problems.

The *Ceremony of Research Project* (CRP) was conceived in light of this complexity of issues facing Indigenous communities in the U.S. and outside researchers (i.e., researchers who are primarily non-Indigenous, and not from the Indigenous communities in which the research is taking place). CRP built upon a longstanding partnership between Fort Peck Community College and Fort Peck Tribal Health Department in Poplar, Montana and Montana State University (MSU) in Bozeman, Montana. CRP's core purpose was to increase the research capacity of the Fort Peck Tribes in a way that built upon their strengths and respected tribal beliefs and values, while incorporating Western research processes. CRP was conducted within a community-based participatory research framework, in keeping with other examples of proactive Indigenous nations overseeing production of their knowledge (Christopher et al., 2011; Koster, Baccar, & Lenrelin, 2012; Salois, Holkup, Fripp-Rumer, & Weinrent, 2006). A project advisory board (PAB) was formed to work in partnership with researchers at MSU to provide direction and guidance for the project. The PAB was made up of five tribal members who were selected by

Fort Peck Community College and the Fort Peck Tribal Health Department and approved by the Fort Peck Tribal Executive Board, the governing body of the Fort Peck Tribes.

CRP conducted a series of focus groups to gain insights about the Fort Peck peoples' Indigenous processes of knowledge acquisition and transmission, the cultural and traditional beliefs or practices that are key to these, principles to guide research projects, and how an outside researcher can best establish relationships and conduct research with the Fort Peck Tribes that is empowering and useful to the people of Fort Peck. The focus groups sought to learn directly from the people of the Fort Peck Tribes what kind of research they wanted, how they wanted research to be conducted on their reservation, and what they expected of researchers coming to the reservation. The results of the focus groups are discussed in this paper as a set of principles that may guide researchers in developing strength-based collaborative research projects with Indigenous populations.

#### METHODS

#### **Study Site**

The focus groups took place on the Fort Peck Reservation in northeastern Montana, a Northern Plains prairie, frontier environment that spans approximately 2.1 million acres. There are nearly 12,000 enrolled members of the Fort Peck Tribes, about half of whom currently live on or near the reservation. There are two nations enrolled at Fort Peck: the Assiniboine and Sioux tribes. The Assiniboine and Sioux are descendants of the Lakota, Dakota, and Nakoda/Nakona nations of the Great Plains tribes, which have the largest geographical land base of any of the federally recognized tribes in the U.S. The Fort Peck Tribes are some of the poorest in the U.S. (U.S. Census Bureau, 2014).

#### **Participants**

To gain a representative range of perspectives, the focus group participants were selected by CRP staff and approved by the PAB based on the following criteria: age, gender, knowledge of tribal history and cultural ways of life, leadership within the college and tribal governance, and geographic distribution on the reservation. Thirty-eight tribal members representing Assiniboine and Sioux cultural heritage or clan groups participated in the focus groups. The focus group participants ranged from young people to elders, and were from the six primary communities across the reservation.

## Procedures

CRP staff, all members of the Fort Peck Tribes trained in Western qualitative research methods, conducted the focus groups. Each focus group lasted 1.5 hours. The focus group procedure followed tribal protocol and recommendations as set forth by the Fort Peck PAB: each focus group began and ended with a prayer, participants were provided with meals and gifts to thank them for their time and participation, and, when first invited, elders were given a special gift of tobacco as a sign of appreciation for their wisdom. Transportation was provided for participants if necessary.

The focus group interview guide was developed in partnership with the PAB, CRP staff, and the researchers from MSU. The PAB and CRP staff felt strongly that, because of the history of research abuses experienced by the Fort Peck Tribes in the past, as well as the collective history of research misconduct with tribal communities, the focus group interview guide should not directly reference "research." Rather, the questions were designed to better understand the gathering and sharing of knowledge. Questions included:

- 1) What is your philosophy or beliefs about how knowledge is gained or learned at Fort Peck?
- 2) What cultural and traditional beliefs or practices do you think are important to include in how knowledge is gained or learned with the Fort Peck Tribes?
- 3) What are some examples of your cultural and traditional beliefs that might influence how a project or study is conducted here?
- 4) What general principles should guide projects or studies that involve acquiring knowledge about the people of Fort Peck?
- 5) What do you think is important for an outsider to do and know when he or she comes to Fort Peck to learn about us? In other words what do you need or want to see from an outsider before you would feel comfortable telling them something about yourself or your opinions or beliefs about something?

CRP staff leading the focus groups at times elaborated on the questions, especially for youth and elder participants, by rephrasing the questions or providing examples to participants. All focus group interviews were audio recorded and transcribed. Audio files were erased following transcription.

The study protocol was reviewed and approved by the Institutional Review Board (IRB) at MSU and by the Fort Peck Tribal Council Executive Board, which at the time CRP began was the ethical review board for the Fort Peck Tribes. Since then, an independent IRB has been established by the Fort Peck Tribes. This manuscript was reviewed and approved for publication by the Fort Peck IRB.

## **Data Analysis**

The research team examined the focus group transcripts to identify major themes. Transcripts then were examined line by line using Atlas.ti qualitative analytic software, and were assigned "open codes" to categorize data and identify emergent themes following the guidelines of a grounded theory analysis. As described by Strauss and Corbin (2008), grounded theory is an inductive approach to data analysis that "allows the theory to emerge from the data." Related codes were identified and linked according to broader analytic categories or "axial codes." These categories were organized according to how they addressed CRP's overall goal of building research capacity within the Fort Peck Tribes. The categories then were shared with the PAB for discussion, clarification, and approval. Few changes were made to the categories when reviewed with the PAB members also selected concepts and quotations they wanted highlighted in the presentation of the focus group findings in this manuscript.

## RESULTS

Through qualitative analysis of focus group data, six themes emerged as important principles of collaborative strength-based research with the Fort Peck Tribes. Broadly, these themes speak to the importance of a researcher spending time on the reservation with tribal members; inclusion and respect for diversity among tribal members in the research process; respect for tribal history; respect for tribal customs throughout the research process; respect for AI epistemology; and giving back to tribal communities through the research process. A number of subthemes were related to each of the overarching themes. Table 1 summarizes the themes and related subthemes that emerged from the qualitative analysis.

# Table 1Summary of Themes and Subthemes

## Theme 1. Spending Time in the Community Prior to Research

**Subthemes:** Becoming familiar with tribal history, customs, beliefs; building relationships/trust with community members; ensuring proposed research is in alignment with/ relevant to community needs/interests

#### Theme 2. Respect for Diversity of Community Views

**Subthemes:** Community is not monolithic; need to develop novel, innovative strategies to engage community members; show deference when engaging certain community members (especially to elders)

#### Theme 3. Respect for Tribal History

**Subthemes:** Historical link between institutional research and oppression of tribal communities; mistrust of outside, non-Native researchers; need for researchers to demonstrate their commitment to use research for benefit of community

## Theme 4. Respect for Community Customs and Practices

**Subthemes:** Providing food or meals to participants; showing appreciation for community members' time through gifts; showing appreciation for/deference towards community elders through giving tobacco; understanding humor/teasing as a way to build relationships

#### **Theme 5. Respect for American Indian Epistemology**

**Subthemes:** Knowledge is gained through spiritual insight; knowledge is gained through experience; knowledge is gained through participation; knowledge is gained through listening; knowledge is shared from one generation to the next; knowledge is shared between families and community members

#### Theme 6. Ensuring Reciprocity Throughout the Research Process

**Subthemes:** Build reciprocity into all phases of research; research products should benefit the community; research can benefit future generations of community members

## Spending Time in the Community Prior to Research

Participants emphasized that, prior to implementing a study, outside researchers must ensure that a proposed study is relevant to Fort Peck's needs and interests. Participants suggested that researchers conduct "background research" on Fort Peck's history and customs, which would include engaging a diverse representation of Fort Peck tribal members in preliminary discussions to identify research topics of interest and importance to Fort Peck. Participants explained that this immersion is necessary to ensure that researchers are familiar with practices and values of the Fort Peck peoples, and do not misinterpret and/or misrepresent what they learn through the research process. If you were going to come here and you want someone to tell you things about their life, about where they live, you need to immerse yourself with the people you want to know. That's the only way you're going to learn.... You have to come here and you have to be with us. You have to be a part of our lives as often and as long as you can. Because we can tell you stories, but it doesn't mean you're going to understand the meaning behind them.

This comment is emblematic of an epistemology whereby knowledge is acquired by "being with," watching, and listening.

Taken together, the collaborative development of research questions and time spent in the community can support the design and implementation of a study, build upon community strengths, and ensure outcomes are relevant to tribal members and researchers alike. This approach contrasts with past studies in which researchers came to Fort Peck for a brief period of time to get approval for their research and collect data, and then left when the research was finished—without coming back to the Tribes to interpret the research findings, share the results with the Tribes, or collaborate with the Tribes to determine how the findings should be shared and with whom.

Additionally, time spent with the community may facilitate research that is respectful of the values and practices of the Fort Peck Tribes, and relevant to tribal needs and interests.

[Research] needs to be respectful and relevant. And even if it's embarrassing that shouldn't be a reason to not do it. But I think...putting more than one person in to debate it and to discuss it and to say, "Okay. Can we see a good outcome for this? Will there be help? Will it help strengthen and keep our culture and our people alive?" So, I think those are things. Respectful and relevant.

According to participants, the ideal mark of "relevance" is translating research results into effective practices that can be sustained in the community beyond the funding period of a project. Researchers' commitment to stay with the community over time, endeavoring to perpetuate or institutionalize the programs and practices that show promise to address tribal interests and needs, additionally may help ensure sustainability of practices developed as a result of the collaborative research project.

#### **Respect for Diversity of Community Views**

Participants emphasized the necessity of collaboration between outside researchers and community members in the development of research questions and study design. Of importance is engaging a diverse representation of community members—not only a select handful of key informants. This step also is important for a cultural epistemology in which knowledge is distributed—each person holds a different piece.

When people come here and they want to learn about our culture and all this stuff, they always go to the same people.... And those same people necessarily don't represent all of our views.... I think there just needs to be a broader selection of people.... So, you know, we're all represented. It's not just one certain way of things.

The diversity of beliefs, values, and practices within and across Fort Peck communities emphasizes the importance for outside researchers to develop novel and innovative strategies to engage a wide representation of community members so that studies capture and reflect this diversity.

<u>We</u> were raised to get out and speak our minds. But there are so many people who won't...there has to be a variety of ways where you can get information you need from the people you need it [from]...find different ways to reach everybody, not just certain people.

While participants noted the importance of engaging a diversity of community members in research, they also emphasized the cultural importance of showing deference toward community elders:

Well, there're certain things [researchers] need to understand, [with] the older ladies, and even the men...when you're doing surveys...there're certain things that you won't ask them, because they won't do it. And you already know that, so don't ask.

Overall, participants felt that understanding and respecting the balance between engagement of and deference toward community members was an important component of collaborative strength-based research with tribal communities.

## **Respect for Tribal History**

The history of exploitation, misrepresentation, and/or suppression of Indigenous culture by outside (White) educational institutions and researchers emerged as a central theme of focus group narratives. Participants explained that the relationship between tribal communities and researchers has been strained, to say the least, due in large part to the role of institutional research in oppressing Indigenous communities.

...the worst enemy was not the [cavalry]. It was the anthropologists that were supposed to be experts on Indians.... Those are the ones that said, 'Yes, I'm an expert on the Indian.... They're Pagan. Yes, they're heathen. And yes, they have no belief system. So, we've got to save them.' That's what [the anthropologists] told [the politicians] because that's what they wanted to hear.... So, as much as the cavalry did to us, they weren't our worst enemy. It was those White anthropologist experts on Indians that hurt us more than anybody because our culture was so devastated.

Participants explained that researchers should take this history into account in the design and implementation of studies with Indigenous communities, and take extra measures (e.g., cross-validating study findings with community members) to avoid misrepresenting communities and perpetuating harmful cultural stereotypes.

#### **Respect for Tribal Customs and Practices**

Participants emphasized the importance of researchers demonstrating an understanding and respect for tribal customs and practices throughout the research process. Within Fort Peck, the practices of gift-giving and using humorous teasing as a way to build relationships are positively influential during the research process. As participants explained, providing gifts or food during research activities aligns with community principles of reciprocity, and can be important for engaging community members in research: You got to give them a special invitation, or take them tobacco, then they'll come and gladly do it. But, they will sit back and wait, and you've got to approach them...welcome them to come and participate.

If [the researchers] want to meet with the community, it might sound funny, but in order to get to know the community you have to have food. That's the number one thing is you have to have something for them....

Participants noted that, after engaging community members, researchers should be aware of different community practices or customs used to build relationships. Within Fort Peck, humor and friendly teasing are common. It is important for outsiders to be aware of this practice:

...it should be discussed with [researchers] before [they] go out, because [with] Indian humor, they're going get teased, and [may] take offense...

## **Respect for AI Epistemology**

Key to respect for Indigenous beliefs is an understanding of and appreciation for AI epistemology—the many different ways that knowledge is gained or shared within tribal communities. According to participants, knowledge may be gained through spiritual insight, observation and experience.

Now, when you're talking about general principles that should guide projects and studies that involve acquiring knowledge, I think you have to understand the levels of cosmos as it pertains to tribal knowledge. Like, we have four levels of understanding. And those four levels of understanding represent four times, the different stages of the Creator himself.

Spiritual insight, the influence of the metaphysical world, and belief in the Creator may profoundly impact how tribal members believe research should be conducted with their people.

In addition to direct learning through spiritual insight or experience, participants also noted that sharing knowledge within and across families is common, and an important way of not only learning, but maintaining community cohesion and solidarity: [A]ll kinds of generational relationships...are really important to Native people... grandparents, kids, everybody's important.... We gain a lot of knowledge that way, through those relationships we can have with all of our family. It's not just our immediate family...it's more seamless for Native Americans.

Central to this process of sharing knowledge is the practice of attentive listening to both speech and silence, which participants also indicated researchers should model when interviewing community members.

You need to be open but also listen to people. Listen. We have people that have come in and...they hear what they want to hear.... But I think that's one of the things that Indians do [is listen].

According to participants, demonstrating an understanding and respect for AI epistemology is necessary for researchers, to ensure they fully appreciate the meaning of research findings and do not misinterpret or misrepresent them. The demonstrating of understanding and respect is done through listening.

## **Giving Back: Ensuring Reciprocity Throughout the Research Process**

The practice of reciprocity is highly valued among the Fort Peck Tribes, and participants indicated it should be incorporated into any research project involving Fort Peck. This point is particularly salient given the history of exploitation of Indigenous communities by outside researchers, as one participant explained:

That's the most important thing, how're you sharing with your people...Our people are built on that type of friendship, and giving away, people just gave up everything they had, at times. It was [our] nature. But we gave away so much to the non-Indian, nothing in equal amount has ever returned to us, nothing. An equal amount. That includes goods, that includes land, that includes friendship—nothing has ever returned in equal amount.... And so [researchers who are welcome] don't just take, and take, and take, and take—they replenish.

Above all, participants indicated that reciprocity must entail using the research process and findings to benefit communities.

I think that if we're looking at developing research to overcome social problems ...associated with poverty and despair, suffered by our people today research itself is an empty bottle, unless you've got some action-oriented strategy that would come as a result of research. That's the benefit that I'm talking about. What would be that action results strategy to overcome whatever dilemma, whatever ill that we have.

#### DISCUSSION

Effectively addressing health disparities and achieving health equity—as laid out in *Healthy People 2020*—requires close collaboration between health researchers, practitioners, and the populations most at risk of poor health outcomes (U.S. Department of Health and Human Services, 2008). It requires that researchers and practitioners have a realistic understanding for what such collaboration might entail as well as how to work with Indigenous communities from a place of empowerment, resiliency, and strength. This article reports on a set of guiding principles for conducting research *with* members of the Fork Peck AI community, principles that were outlined by tribal members themselves. As tribal members indicated, any research that is carried out in their community should be relevant to Indigenous community needs and interests; respectful of community history, customs, members, and ways of knowing; and in alignment with community ethics of reciprocity.

Researchers must maintain perpetual understanding of tribal history and culture at the forefront of their research process because the abuses, atrocities, and injustices experienced by tribal communities, no matter how long ago, are continually part of the present. As profoundly stated by one participant, it was academics, with their presumed knowledge of tribal beliefs and practices, that created the most destruction for Indigenous people. Indigenous communities' history of colonization is living memory at the individual and collective levels as people's life stories have been shaped significantly by loss, trauma, and grief (Geia, Hayes, & Usher, 2013). Thus, the very act of conducting research in Indigenous communities has the real potential to retraumatize individuals and communities. For example, traditional knowledge that might be shared with an outside researcher may not be considered valid and reliable by academic

colleagues because the information ("the data") was not collected using a standard Western research methodology. This attitude demeans and minimizes the importance of this knowledge, which is considered sacred by the carriers of such wisdom. As another example, the terminology of the questions used in the focus groups for this study perplexed some participants because the questions were general, overarching inquiries related to how knowledge is acquired and how to implement a research study. These types of questions are not connected with tribal members' daily life on the reservation and, therefore, at times it was difficult for the participants to respond unless further explanation or examples were given. As one counter, Lambert (2013a) asserts that an "Indigenous" approach to research will pose questions in terms of the resilience of tribal communities and their traditional knowledge, beliefs, and practices as distinct from Western research questions aimed at theoretical frameworks aimed at measuring and analyzing problems.

Moreover, the wounding experienced by tribal communities in the name of research can be mitigated: Community-based participatory research methods have made major progress in establishing trust between Indigenous people and researchers to assist in the healing of tribalacademic partnerships (Christopher et al., 2008). We suggest that researchers in the health arena who work with Indigenous communities maintain a historical, cultural, environmental, and present-time perspective grounded in respect and reciprocity when conducting research. Elston et al. (2013) describes this as "holding space" for both the Indigenous research collaborators and academic partners in which the research process is allowed to unfold without judgment or fear of betrayal. In particular, we emphasize the highly critical necessity of listening, not just listening to words that are being spoken but listening to nonverbal communication, listening to the silences between words or conversations, and paying attention to what has happened and what is happening in the physical environment in which research within a tribal community is taking place (Duran, 2006; Richmond, Elliott, Matthews, & Elliott, 2005; Wilson, 2003). Furthermore, we highlight the need to be aware of and respectful toward spirituality and the connection to a universal cosmology that is central to AI belief systems and ways of life, and to how AI peoples perceive, experience, and understand the world around them (Marks, 2007).

Awareness of Indigenous epistemologies also is needed in order to create a holistic strength-based research process with Indigenous populations (Lambert, 2013b). More and more Western scientists who work with Indigenous communities are calling for the integration of Indigenous epistemologies with standard Western research methodologies (McDonald, Priest, Doyle, Bailie, & Waters, 2010). For example, researchers working with Indigenous communities in New Zealand and Australia discuss the use of storytelling with Maori communities in New

Zealand, or "yarning" as it is referred to in Australia, as a legitimate research methodology (Clandinin, 2006; Geia et al., 2013; Suaalii-Sauni & Fulu-Aiolupotea, 2014). Similarly, AI communities in the U.S. use storytelling as a way to transmit and share knowledge (Cajete, 2000). Other work on Indigenous epistemologies presents Indigenous concepts of knowledge gathering through empirical observation, traditional teachings, revelation (i.e., dreams and interactions with the spirit world), and relationality (Lavalee, 2009). This literature supports the weaving together of Indigenous and Western science. Royce-Botha (2011) presents Engestrom's concept of "knotworking" as a potential template for the mixing of Western and Indigenous methods. Knotworking depicts a tribal community and a researcher in a constant sequence of research based on past actions, present-time behaviors, and their respective knowledge; in doing so they create an authentic research process that is meaningful and relevant for Indigenous communities and researchers.

Belief systems among Indigenous populations also emphasize the importance of interdependence and reciprocity. Our focus group results highlight the Fort Peck Tribes' core philosophies related to reciprocity, sharing, and giving back, and may be generalizable to other tribal-academic partnerships because, despite the growing body of knowledge in recent years related to conducting research with Indigenous communities, challenges still remain for outside researchers in understanding how to be authentic in a research partnership with Indigenous peoples (Jagosh et al., 2015; Mosavel, Ahmed, Daniels, & Simon, 2011). Salois and colleagues (2006) present a conceptual model grounded in spirituality, reciprocity, and harmony that emphasizes the importance of sharing from the heart to build relationships during research with tribal communities. Further, there is a foundational belief among Indigenous communities in maintaining social, cultural, and interpersonal balance among people in that, when one is given something, one must give something back (Dieter & Otway, 2002). Nicholls et al. (2009) developed the concept of reflexivity for researchers working with Indigenous communities, meaning that researchers must not come to Indigenous communities with the intention of being emotionally detached and personally withdrawn, with rigid definitions of research processes and goals, or with expectations of research participant homogeneity. Rather, strength-based collaborative research with Indigenous populations is fostered through researchers' ability to be transparent about themselves on a personal level, to engage in meaningful interpersonal relationships with community members, and to work toward the highest good for the collective.

Finally, avoiding further exploitation—which can come in the form of conducting research to get grants to fund research and publish, but not to ultimately solve problems—means that researchers must commit to project sustainability and solution-focused processes. This mindset is a challenge for the health research system, for which successful research projects or successful intervention strategies may stop after the funding has ended. Few health research dollars, currently, can be translated into perpetual programming, and funding in the social services sphere is insufficient to implement all the useful interventions that researchers may develop. One of the keys to giving back to tribal communities is building structures that ensure health intervention sustainability over time.

#### **CONCLUSION**

In this paper we present a set of principles that can guide researchers in developing strength-based collaborative research projects with Indigenous populations. Our findings are grounded in: 1) spending time with the community prior to the research taking place; 2) respect for the diversity of community values, perspective, and knowledge; 3) respect for the history of the community; 4) respect for tribal customs and practices; 5) respect for Native epistemology; and 6) giving back and reciprocity. Furthermore, despite more than a decade of efforts to improve health research with Indigenous communities through the implementation of community-based participatory research projects, our findings indicate a continued need for vigilance in understanding the profound impact of colonization on the individual- and community-level lived experience for Indigenous communities. We also found that strengthbased collaborative research with Indigenous communities must embrace an Indigenous worldview and incorporate those beliefs and practices as part of the core research process, not just as something else to be studied. Finally, it is necessary to create community-academic partnerships that support both the researched and researcher in a mutually respectful and nonjudgmental manner and that allow for mutual giving, receiving, and sharing. By approaching community-academic relationships in this way, strength-based collaborative research is as much about the journey of the relationship between Indigenous communities and academics, as it is about promoting health equality.

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# STRENGTH-BASED WELL-BEING INDICATORS FOR INDIGENOUS CHILDREN AND FAMILIES: A LITERATURE REVIEW OF INDIGENOUS COMMUNITIES' IDENTIFIED WELL-BEING INDICATORS

# Jennifer Rountree, PhD and Addie Smith, MSW, JD

Abstract: Mainstream child and family well-being indicators frequently are based on measuring health, economic, and social deficits, and do not reflect Indigenous holistic and strength-based definitions of health and well-being. The present article is a review of literature that features Indigenous communities' self-identified strength-based indicators of child and family well-being. The literature search included Indigenous communities from across the world, incorporating findings from American Indians and Alaska Natives, First Nations, Native Hawaiians, Māori, Aboriginal Australians, and Sámi communities. Sorting the identified indicators into the quadrants of the Relational Worldview, an Indigenous framework for well-being based on medicine wheel teachings that views health and well-being as a balance among physical, mental, contextual, and spiritual factors, the authors discuss the findings.

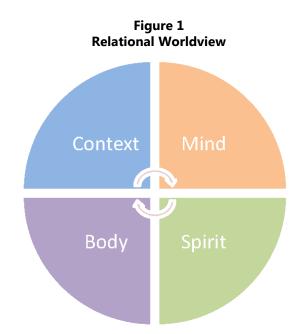
Mainstream child and family well-being indicators continue to reflect the Western framework of illness and disease. These indicators are almost universally used to describe the physical, social, and economic welfare of children. Their use is of particular concern in communities facing social inequities that are largely driven by structural or systemic, institutionalized bias, because the Western framework underlying these indicators assumes that the means to improving child well-being is to treat "symptoms" with an individual "cure," and does not acknowledge that well-being is also a product of social inequities. For example, economic indicators focus on poverty and parental/caregiver unemployment; health indicators measure deaths and substance abuse; family and community indicators focus on single-parent families, teen birth rates, and the number of children living in families where the head of household lacks a high school diploma. While the Social Determinants of Health movement has

helped to shift some of the "blame" off individuals to political and economic systems, the focus is still on what is deficient—what is missing or wrong with the community and how those deficiencies negatively affect children and families.

Fundamentally, deficit-based measures focused on disease and illness do not reflect Indigenous worldviews of well-being, which are not based on the Western medical model framework of illness and disease, but are holistic and grounded in balance and harmony in human relationships and the natural and spiritual world. Indigenous worldviews require a description of child well-being based on strengths, reflecting the web of connections among the child, family, and community; cultural and spiritual practices; and individual health and stability. When working with American Indian and Alaska Native (AI/AN) families, well-being indicators should include meaningful measures that reflect these perspectives when describing the status of children.

# FRAMEWORK FOR INDIGENOUS WELL-BEING: THE RELATIONAL WORLDVIEW AND STRENGTH-BASED INDICATORS

The Relational Worldview (RWV; Cross, 1997) provides a framework for Indigenous well-being. It is "shared by many Indigenous people throughout the world because of common values such as the importance of the extended family, the meaning of land, and spiritual elements" (Goodluck, 2002, p. 22). Based on traditional medicine wheel teachings, well-being occurs when balance and harmony exists in relationships among multiple variables, including spiritual forces. Whereas the Western framework is a linear model based on cause and effect, intervention in the RWV does not target symptoms or causes, but focuses on returning the individual or system (family, community, organization, etc.) back into balance (Limb, Hodge, & Panos, 2008). The four quadrants making up the wheel or circle represent four sets of elements that impact well-being, which, together, must come into balance. These quadrants are context (family, culture, community, environment, history), mind (cognition, emotion, identity), body (physical needs and genetic makeup, practical needs—including financial needs), and spirit (spiritual practices and teachings, dreams, stories; Friesen et al., 2014).



Returning to well-being does not occur through the eradication of negative symptoms or root causes, but through the coordinated, balanced development of essential elements across the four quadrants (Cross, 1997). These essential elements, or indicators, are the subject of the present literature review. Goodluck (2002) describes how deficit- and strength-based approaches are opposite in focus; one favors the individual in an individualistic society, and the other, collective tribal society, as represented by different norms, beliefs, and values that support each model's perspective. While it is beyond the scope of this paper to review the history of strength-based approaches, it is notable that the strengths approach is one that has been utilized in mainstream institutions and numerous disciplines to improve outcomes in the general population.

#### THE PURPOSE OF THIS LITERATURE REVIEW

This literature review is based on a project in partnership among the Annie E. Casey Foundation, the National Congress of American Indians, and the National Indian Child Welfare Association. The goal of this project is to develop a guide to understanding mainstream child well-being indicators that reflect the Indigenous worldview and the realities of tribal and urban Indian communities and to identify the indicators that meaningfully describe, measure, and quantify the numerous strengths AI/AN children find within their families, communities, cultures, and traditions. The purpose of the current literature review is to identify a set of strength-based indicators self-identified by Indigenous communities through research partnerships and to vet the most common indicators with AI/AN audiences through focus groups and survey research. Our longer-term goal is to propose a set of widely embraced strength-based measures to complement mainstream health-oriented, deficit-based measures to create a more accurate and meaningful picture of well-being for children and families in Indigenous communities.

Researchers working in Native communities have been constrained by existing measures that do not reflect cultural values; further, measures necessarily focus on certain data elements to the exclusion of others. As one researcher put it, "measure what you value or you'll only value what you measure" (Donaldson, in Cross, Fox, Becker-Green, Smith, & Willeto, 2004). Our broader intention is to claim the values and worldviews of Indigenous communities as legitimate and representative of well-being for Indigenous children and families.

#### METHODS

The present review focused on peer-reviewed literature sourced from five databases: PsychINFO, Academic Search Premier, Social Services Abstracts, ERIC, and Sociological Abstracts. Search terms included strength-based, indicators, health, well-being, American Indian, Alaska Native, and Native American. Inclusion criteria were: AI/AN as the target population and indicators identified by community members. Articles that were theoretical or not based directly on original qualitative data collected from community members were excluded. Due to the limited number of articles found based on the above criteria, the search was extended beyond AI/AN to Indigenous and Aboriginal communities; thus, the resulting findings include well-being indicators identified by First Nations, Native Hawaiians, Māori, Aboriginal Australians, and Sámi communities. The search was restricted to the years 2010-2015, resulting in eight articles. Using qualitative content analysis (Krippendorff, 2012), community definitions of well-being indicators were coded to identify descriptive themes. In some cases, very specific indicators (e.g., types of ceremonies or traditional practices) were grouped into more general themes. To frame this work in Indigenous ways of thinking and knowing, the resulting themes were sorted based on the corresponding elements of the four quadrants of the RWV. This organization allowed the authors to describe well-being as a state of balance and emphasize the relational nature of these indicators. The findings are presented using the RWV quadrant.

#### SUMMARY OF ARTICLES REVIEWED

**Boulton and Gifford (2014).** The authors summarize the findings of their qualitative studies (Boulton & Gifford, 2010, 2011a, 2011b; Boulton, Gifford, & Tamehana, 2010), gathered through semi-structured interviews that asked Māori participants to define *whānau ora* (family well-being). Optimum well-being for Māori includes the well-being of not only the individual's immediate family but also of the *whānau* (extended family), sub-tribe, and tribe. Proponents emphasize that whānau ora "can only be determined by ascertaining the health of a person across a number of indicators, many of which lie outside of the health sector," and are not limited to biological factors (Boulton & Gifford, 2014, p. 2).

**Cross, Friesen, Jivanjee, Gowan, Bandurraga, Matthew, & Maher (2011).** In a series of focus groups in an urban AI/AN community agency, Cross and colleagues (2011) asked elders, youth, parents and caregivers, and agency board and staff members, "What does success look like for Native youth?" The study was designed in collaboration with urban agency and university partners with two goals: 1) to create a culturally grounded participatory method to document the effectiveness of culturally specific services, and 2) to develop a process within community-based programs for conducting evaluations based on "good outcomes," as defined by the cultural community served.

Kant, Vertinsky, Zheng, & Smith (2013). Through the public health lens, Kant et al. (2013) explored social, cultural, and land use factors related to Canadian Aboriginal well-being. Surveys were developed in partnership with two First Nations communities (one in Ontario and one in British Columbia) to identify key domains that characterize well-being and the factors that influence these domains. Domains included Education, Employment, Health, Housing, Income, Sociocultural, and Land Use. Based on a preliminary analysis of over 300 surveys, Kant and colleagues (2013) combined the highly correlated domains of Sociocultural and Land Use into one domain (SCLU), determining "social, cultural, and land use (SCLU) factors are the essential foundation of Aboriginal well-being and health" (Kant et al., 2013, p. 463).

**Kral, Idlout, Minore, Dyck, and Kirmayer (2011).** To gain insight into the high suicide rates among Inuit youth, Kral and colleagues (2011), guided by a steering committee of Inuit youth and elders, conducted open-ended interviews with 50 Inuit participants between the ages of 14 and 94 years and surveyed 66 Inuit high school and college students with the same open-ended questions about the meanings of happiness, health and healing, sadness, and social change. As the authors describe, a primary goal of the project was to convey Inuit perspectives on well-being through *unikkaartuit* (the people's stories; Kral et al., 2011, p. 429).

**Mark and Lyons (2010).** Mark and Lyons' (2010) qualitative study composed of indepth semi-structured interviews with six Māori spiritual healers in New Zealand provides a conceptual model of Māori health and illness—*Te Whetu* (the star). Similar to the RWV model, Te Whetu is comprised of five interconnected aspects: mind, body, spirit, family, and land.

McCubbin, McCubbin, Zhang, Kehl, and Strom (2013). McCubbin et al. (2013), utilizing the RWV framework to define well-being as a relational construct, created the Relational Well-being (RWBII) tool, a culturally based, 14-item measure rooted in beliefs and values emphasizing family, ancestors, culture, and harmony with nature, developed and tested with a sample (N = 810) of Native Hawaiians in Hawai'i.

Nystad, Spein, and Ingstad (2014). In their qualitative study exploring community resilience and well-being within an indigenous Sámi community in Northern Norway, Nystad and colleagues (2014) conducted semi-structured interviews with 22 informants ranging in age from 13 to 19 years. The authors found that cultural factors, including Sámi language competence, use of natural resources, and traditional ecological knowledge—such as reindeer husbandry-related activities—strengthen Sami adolescents' ethnic identity and pride, "which in turn act as potential resilience mechanisms" (Nystad et al., 2014, p. 651). Interconnectedness among community members and with the environment promoted resilience and well-being.

**Priest, Mackean, Davis, Briggs, and Waters (2012).** Priest and colleagues (2012) conducted qualitative interviews with 25 caregivers of Aboriginal children living in Melbourne, Australia. In these interviews with parents, grandparents, aunties, uncles, and/or Aboriginal child care or health workers and foster parents, researchers asked key questions: "What is well-being for an Aboriginal child? How would you describe a healthy Aboriginal child? How do you know an Aboriginal child is developing well?" Based on their findings, the researchers developed a conceptual framework of Aboriginal child well-being comprised of four themes: Strong Culture, Strong Child (which includes individual child characteristics), Strong Environment (including safety and material needs, as well as access to services), and Strengths and Challenges (the historical, social, and political context in which Aboriginal children are living and growing up).

# RESULTS

# Context

The context quadrant of the RWV includes the social supports of family, community, and the land itself, as well as the surrounding socioeconomic and political climate—both current factors and historical antecedents that continue to impact the present (Cross, 1997).

Table 1 Context Indicator Find	ngs							
Context	Boulton & Gifford (2014)	Cross et al. (2011)	Kant et al. (2013)	Kral et al. (2011)	Mark & Lyons (2010)	McCubbin et al. (2013)	Nystad et al. (2014)	Priest et al. (2012)
Support (family, friends, community)/interdependence	Х							Х
Connection to land					Х		Х	Х
Community involvement/participation/contribution	Х	Х				Х		
Family commitment						Х		
Kinship/elders/community connection/ties			Х	Х			Х	Х
Life cycle events/traditional activities/practices				Х		Х	Х	Х
Healthy relationships		Х		Х				
Safety		Х						Х
Connecting with resources		Х						
Access to cultural sites			Х					

Within the context quadrant, the themes identified by Cross et al. (2011) were categorized as *healthy relationships*, in which Native youth follow and/or serve as positive Native role models; *positive community relationships and contributions*, allowing youth to feel a sense of purpose and participation in one's community; *connecting with resources* (e.g., health care); and *safety*.

Priest et al. (2012) identified context-related indicators predominately in the thematic areas of Strong Environment and Strengths and Challenges. *Kinship and family connection* was emphasized, particularly the extended nature of Aboriginal kinship networks beyond blood relations—with "aunties" and "uncles" including community members and family friends other than direct relatives. These structures provided children with strong *support networks*, which were seen as particularly important during challenging times when responsibility for ensuring the child's needs were met could be shared. *Elders* played a significant role within these kinship networks, particularly because of their role in sharing *cultural knowledge* and *traditional practices*. Being closely connected to community was considered critical to remaining connected to culture and requisite to maintaining well-being. As one participant described:

You can't become disconnected from community and yeah it's when you become disconnected from your cultural background I think you become disconnected with yourself and that's impossible so you can't really be a sick individual. In order to stay well you need that connectedness. (Susie [pseudonym]; Priest et al., 2012, p. 185)

It is notable that *safety* was the only identified (and only shared) indicator between the two urban Indigenous communities (Cross et al., 2011; Priest et al., 2012), and that there were no other broad differences or similarities between rural or reservation and urban Indigenous communities.

# Mind

In the RWV, the mind quadrant represents the internal constructs that orient the individual toward the path of health and healing and the mental and emotional capacity to thrive (Cross, 1997). Using this framework, these internal constructs may be learned through cultural teachings or may be innate personal qualities. These essential elements of well-being may manifest in educational achievement and employment.

Mind	Boulton & Gifford (2014)	Cross et al. (2011)	Kant et al. (2013)	Kral et al. (2011)	Mark & Lyons (2010)	McCubbin et al. (2013)	Nystad et al. (2014)	Priest et al. (2012)
Cultural identity/sense of belonging to cultural group	Х	Х	Х					Х
Ethnic pride							Х	Х
Self-esteem								Х
Happiness	Х							Х
Focus/determination		Х						
Hope/looking forward/optimism	Х							
Hinengaro (mind)					Х			
Educational enrollment/achievement		Х						
Resilience						Х		Х
Speaks Native language						Х	Х	
Cultural teachings/knowledge		Х						Х
Coping skills		Х						
Personal qualities/capacities		Х						Х
Employment/employability		Х						

Table 2 Mind Quadrant Indicator Findings

Having a *sense of belonging or identity and active participation* was described as engagement of community members, being part of a place and having a greater purpose, and contributing to the community. One participant noted that a family that exhibited or had achieved a state of whānau ora was "peopled by those who make contributions" (Boulton & Gifford, 2014, p. 6). This example shows the highly interactive workings of indicators across quadrants of the RWV, with cultural identity (mind) influencing and being influenced by active participation (context) with and contributions to the community.

Sámi participants (Nystad et al., 2014) reported a high level of *ethnic pride*. In connection to Native language, while all participants considered themselves Sámi regardless of their level of Sámi language competence, two respondents who did not speak Sámi also reported

high levels of *ethnic pride*. However, some youth did not feel accepted as Sámi due to their poor Sámi language skills or multiethnic background. In short, the authors concluded, Sámi language provides a sense of belonging and is needed for full membership in the community (Nystad et al, 2014, p. 659).

As noted in the above matrix, the most frequently cited indicator among these sources was *cultural identity or sense of belonging to a cultural group*.

#### Body

The body quadrant of the RWV represents the essential physical and economic building blocks that support well-being (Cross, 1997).

Body Quadrant Indicator F	indin	igs						
Body	Boulton & Gifford (2014)	Cross et al. (2011)	Kant et al. (2013)	Kral et al. (2011)	Mark & Lyons (2010)	McCubbin et al. (2013)	Nystad et al. (2014)	Priest et al. (2012)
Financial security/stability/income	Х	Х				Х		
Tinana (body)					Х			
Adequate food/good nutrition					Х			Х
Traditional foods			Х					
Housing/homeownership		Х						Х
Access to health care		Х				Х		Х
Access to services						Х		Х
Healthy lifestyles/activities		Х						
Physical health/fitness		Х						Х
Traditional healing practices			Х					

Table 3 Body Quadrant Indicator Findings

Three articles identified *financial security/stability/income* and three articles identified *access to health care* as indicators of well-being (two of the three identified both of these indicators) to make them the most frequently cited indicators in this RWV quadrant.

# **Spirit**

The spirit quadrant of the RWV represents the spiritual forces and beliefs that promote well-being and are maintained through practice and ceremonies (Cross, 1997). Along with the context indicators, these sources of well-being often are overlooked in mainstream approaches to well-being assessment.

Spirit Quadrant Indica	or Fi	nding	gs					
Body	Boulton & Gifford (2014)	Cross et al. (2011)	Kant et al. (2013)	Kral et al. (2011)	Mark & Lyons (2010)	McCubbin et al. (2013)	Nystad et al. (2014)	Priest et al. (2012)
Spiritual values/well-being	Х							
<i>Wairua</i> (spirit)					Х			
Spiritual practice/knowledge/ceremony		Х	Х			Х		Х
Expressing Native identity		Х						
Balance	Х							
Ancestry/Whānau/Whakapapa (family genealogy)		Х			Х			

Table 4

Spiritual practice/knowledge/ceremony was most commonly cited among the eight studies. Compared to other quadrants of the RWV, the spirit quadrant contains the fewest indicator findings. While spiritual values, practices, and belief systems are integral to Indigenous perspectives of well-being, this finding indicates that they are perhaps the most difficult to explain or put into mainstream languages.

#### DISCUSSION

Cross (1997) defines well-being as a relational construct. Other researchers have used a similar construct to understand and examine Indigenous well-being (McCubbin et al., 2013). Because they do not take contextual and spiritual indicators into account, mainstream well-being indicators miss "half of the picture" when it comes to the well-being of Indigenous children and families. Kingsley et al. (2013) argue that academics and governments struggle to describe

Aboriginal well-being, "reducing it to a matrix of standard socio-economic indicators and biomedical measures rather than complex Aboriginal concepts which include issues like kinship, connection to Country [land] and the like" (Kingsley et al., 2013, p. 679). Implicit in the tension between the continuity of Indigenous culture and the achievement of socioeconomic equity is the view that "attachment to traditional cultures and lifestyles is a hindrance to achieving mainstream economic goals" (Dockery, 2010, p. 315). However, the eradication of poverty alone does not address nor develop the well-being of Indigenous communities, nor are traditional cultures and lifestyles an obstacle to achieving economic needs. As described by community members in the literature referenced here, instilling cultural values and positive cultural identity is requisite to well-being as much as economic security or physical health.

The strength-based perspective has been utilized in the helping fields of counseling psychology, social work, and nursing for some time. More recently, "positive" indicators also have been used in the international development field by the United Nations Children's Fund (Lippman, Moore, & McIntosh, 2009). Central to this approach is the empowerment of the patient or client by focusing on inherent strengths, including both internal and external resources, rather than problems to be overcome. In the context of Indigenous communities, problems to be overcome often are the result of centuries of violent and oppressive policies and practices and may represent political and structural issues that children and families cannot solve on their own. This history includes the extreme losses experienced by tribally centered and child-focused people who were rooted to their land, values, religions, languages, and traditions (Goodluck & Willeto, 2000).

Indicators of child well-being drive important policy and funding decisions at the federal, state, and tribal/local levels. Mainstream researchers and organizations in the U.S. have a longstanding history of collecting and reporting deficit-based well-being indicators that describe the status of Indigenous children as a product of causes and effects. This process has led to ineffective policies and practices that do not account for the interconnectedness of Indigenous well-being and the numerous Indigenous strengths that must be cultivated to promote well-being. The use of the RWV and those strength-based indicators identified by Indigenous communities will promote more accurate and complete reporting on the status of Indigenous youth which will, in turn, drive policymakers toward more effective and meaningful solutions.

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# PERCEPTIONS AND USE OF COMMUNITY- AND SCHOOL-BASED BEHAVIORAL HEALTH SERVICES AMONG URBAN AMERICAN INDIAN/ALASKA NATIVE YOUTH AND FAMILIES

Julie Salvador, PhD, Jessica Goodkind, PhD, and Sarah Feldstein Ewing, PhD

Abstract: Understanding youths' awareness and use of behavioral health services is important for improving services and engagement. Interviews and focus groups were conducted with students, parents, and teachers/staff in an urban area to understand awareness and use of a school's Native-tailored and -staffed school-based behavioral health center (NT-BHC) and community-based services. Results showed overwhelmingly positive responses regarding NT-BHC staff and services, with concerns focused on too few staff and services, and on privacy and confidentiality, as well as important differences in awareness and use of behavioral health services among youth, parents, and teachers/staff, valuable for improving engagement with and services for AI/AN youth.

There are significant health disparities between American Indian and Alaska Native (AI/AN) populations and the general U.S. population, including, but not limited to, cardiovascular disease, tuberculosis, infectious diseases, diabetes, substance use disorders (SUD), homicide, and suicide (Grim, 2003; Holman et al., 2011; O'Connell, Rong, Wilson, Manson, & Acton, 2010). While much has been done to elucidate the existence of these disparities in health for AI/AN communities, more research is needed to understand the contributing factors and how to address them (Manson, 2000). Culturally appropriate and accessible services for AI/AN populations, including adolescents, still lag behind Western practices (Gone & Trimble, 2012). This disparity matters because AI/AN communities have stressed the need for behavioral health services that are culturally congruent (Gone & Trimble, 2012).

Regarding mental health, rates of suicide are higher for AI/AN youth versus all other youth (Centers for Disease Control and Prevention, 2013), and AI/AN youth are more likely to experience SUD and psychiatric disorders (Beals et al., 2002; Beals, Novins, Mitchell, Shore &

Manson, 2002). In addition, according to the Urban Indian Health Commission (UIHC, 2007), urban AI/AN populations face challenges, including high rates of poverty and depression, limited culturally appropriate health services, and ineligibility for or inability to utilize health services offered through the Indian Health Service or tribes.

Specifically, many AI/ANs, like those families and youth that are the focus of this study, live in urban areas, while many of the federally funded health care services are provided on reservations. Time constraints, transportation issues, cost of traveling, and distrust of government programs are some of the issues that AI/AN youth and families face in accessing behavioral health services (Kaiser Family Foundation, 2004). Furthermore, for AI/AN persons accessing services in urban clinics, Medicaid pays only part of the cost of service, which, with the high rates of poverty among many AI/ANs, creates additional barriers to receiving care (UIHC, 2007).

One place where urban AI/AN youth can access treatment without many of the above barriers is school. Schools are the major providers of mental health services for children (Burns et al., 1995; Costello et al., 1996; Leaf et al., 1996). In fact, 75% of children who receive mental health services receive this care through the education sector, with schools as the most common point of entry (Farmer, Burns, Phillips, Angold, & Costello, 2003). Providing mental health services within schools can also support improved school outcomes, as children whose emotional, behavioral, or social difficulties are not addressed have a reduced capacity to learn (Rones & Hoagwood, 2000) and are more likely to drop out of school (Kerns et al., 2011). Thus, making services accessible at schools may be key to successfully serving otherwise hard-to-reach urban AI/AN youth. The fact that school-based services increase access to and use of behavioral health services is a critical foundation from which additional and rigorous effectiveness and implementation research can lead to positive outcomes for youth.

Research has emphasized that, while basing health services in schools is an important step to ensure access for youth, it is not sufficient. For AI/AN youth, of equal importance is collaboration with AI/AN communities to support services that are culturally sensitive and meet the needs defined by the consumers and communities themselves (Ball & Pence, 1999; Sarche & Spicer, 2008). Researchers have examined many school-based interventions and programs developed for AI/AN youth (Brown & Summerbell, 2009; Caballero et al., 2003; May, Serna, Hurt, & DeBruyn, 2005; Sharma, 2006), including attitudes toward school-based health centers and reviews of existing programs (Guo, Wade, Pan, & Keller, 2010; Rones & Hoagwood, 2000). However, among these studies, there are almost no data on school-based centers that have been

tailored specifically for Native adolescents and operated by Native counselors/staff. Native tailoring and staffing may be an important combination for enhancing engagement, use, and successful outcomes for AI/AN youth.

Partnership approaches to research, such as the community-based participatory research (CBPR) approach (Wallerstein & Duran, 2008) used in this study, help place community perspectives and needs at the forefront of the research endeavor. This study also used a qualitative approach to help ensure that the views, opinions, and experiences of AI/AN youth and parents informed our understanding of how people perceive and use services, as well as how to tailor existing behavioral health services to fit the needs of this important and underserved population. Because qualitative methods focus on describing how people understand and give meaning to their experiences, they are different in key ways from quantitative methods. For instance, while quantitative researchers often apply random sampling techniques in order to conduct statistical analyses that will allow generalizations to be made about a population, qualitative research methods use non-random "purposeful" sampling where the aim is to select information-rich cases for in-depth study (Rice & Ezzy, 1999). Qualitative research, therefore, does not aim to generalize; rather it specifies and provides a view of meanings and interpretations of a small group of persons with shared experiences.

The current study follows in the footsteps of previous research with Indigenous communities that used a partnership model (Daley et al., 2010; Jernigan, 2010; Wallerstein & Duran, 2010) or qualitative research methods to better understand and improve current health services (Baldwin, Johnson, & Benally, 2009; Dickerson & Johnson, 2011; Leston, Jessen, & Simons, 2012). The existing research base indicates that comprehensive efforts are needed to improve the effectiveness of school-based services (Atkins, Hoagwood, Kutash, & Seidman, 2010), and more studies on effectiveness are needed (Kutash, Duchnowski, & Lynn, 2006). This study focused on awareness, utilization, and perceptions of a Native-tailored behavioral health center (NT-BHC) by urban AI/AN youth, a population for whom there has been limited clinical research and particularly high treatment need (West, Willians, Suzukovich, Strangeman, & Novins, 2012). This study used a qualitative CBPR approach to 1) learn about perceptions of the NT-BHC and 2) understand awareness and use of school- and community-based behavioral health services/supports, including the NT-BHC.

# **METHODS**

#### The Community-based Participatory Research Partnership

This research project was developed in partnership with an NT-BHC implemented by mostly AI/AN staff in a Southwestern city and with the local university's Department of Psychiatry. The NT-BHC is located on a charter school campus that serves mainly AI/AN youth (referred to here as the Native American Charter School, or NACS). NACS had approximately 350 students in 6th through 12th grades from more than 37 tribal nations during the course of this study.

The NT-BHC focuses on providing behavioral health support to students, including case management, education, crisis intervention, individual and family counseling, group therapy, and referrals for medication management, as well as other, more general support services, such as providing bus passes to students to get to after-school jobs. However, the foundation and approach to services is what makes the center tailored for AI/AN youth and families. The NT-BHC is grounded in their traditions and in elements of traditional healing, and seeks to improve well-being by building upon each youth's personal strengths. Key elements of the center include Indigenous wellness promotion that is provided by and for the AI/AN community. Most staff members are AI/ANs who have trained under AI/AN mentors and clinical supervisors in AI/AN service agencies or with traditional cultural and spiritual leaders. Both the NACS and the NT-BHC use a wellness wheel that approaches students' health from a holistic perspective and is grounded in respect for Indigenous knowledge. The wheel is interactive and includes wellness goals in the following areas: 1) intellectual, 2) physical, 3) social/emotional, and 4) community/relationships. The NT-BHC also has a private space called the Bison room that is a culturally based area for all students, families, and even school staff to use for meditation and prayer honoring AI/AN traditions. It is a private room with pillows and items associated with AI/AN traditions and healing, including flute music, posters, sage, and eagle feathers, and also is used as a space for youth to sit alone quietly when they want to do so.

The CBPR partnership upon which this study is based started when clinical staff at the NT-BHC contacted the local university partner, wanting to learn about the aspects of the NT-BHC and other behavioral health services/supports noted earlier. The university had an existing relationship with the NT-BHC, having provided ongoing behavioral health-related consultation as the NT-BHC was developed; therefore, the partnership was a logical and important next step to help ensure the program was meeting the needs of youth and families. The university and

NACS partners held collaborative research team meetings and determined that interviews and focus groups would be the best methods for understanding these questions. All procedures were approved by the university Institutional Review Board. To provide confidentiality, the lead author, who was unknown to the youth and was not a member of the school or the NT-BHC staff, conducted interviews with youth who had used NT-BHC services. AI/AN students from the university were hired to conduct focus groups with youth to determine what services/supports they were aware of and might use in their school and in the larger community. Parents and teachers/staff participated in separate focus groups about these topics. Because the two qualitative methods followed distinct procedures, participant selection, data collection, analysis, and results, they are each described below in detail. Interviews are discussed first, followed by the focus groups.

#### Interviews

# **Participants and Procedure**

Between September 1, 2010 and January 31, 2011, 17 youth (9 female, 8 male; age range, 11-19 years) participated in one-on-one interviews (n = 17). This number is 10% of the 170 students who used NT-BHC services at the school that year. Youth received a \$15 gift card for their participation.

#### **Process, Measures and Data Collection**

All middle and high school youth who used the NT-BHC during the September 2010-January 2011 timeframe (170 out of the total school population of 350) were asked by staff after their appointment if they would be interested in participating in a confidential interview to provide feedback about NT-BHC services. This qualitative sampling process is called criterion sampling (Rice & Ezzy, 1999). Youth were asked the following questions: "What did you like best about the services you received at the NT-BHC?" "What didn't you like about the services you received?" and "What would you like to see changed or done differently to provide better services?" Youth were told that the interviews would be conducted by a researcher from outside the NT-BHC to encourage open feedback. Interested youth were asked to let NT-BHC staff know a good time to complete the interview to avoid conflict with classes (e.g., at lunch, after school, or during school hours with permission from a teacher). NT-BHC staff scheduled the interview times. Youth ages 14 years and older provided informed, written consent. In the setting for this study, youth 14 and older are allowed to consent for behavioral health services without parental/legal guardian consent; therefore, the NT-BHC research team believed that asking for adult consent for these students to participate in research about their services might violate their privacy and possibly put them at risk. Self-consent for these youth was approved by the university IRB and is a common practice with studies presenting minimal risk to youth. Youth under the age of 14 years needed parental/legal guardian consent to participate.

The university researcher (and lead author) met the students at the NT-BHC in a private room to conduct the interviews. Interviews addressed the three questions of interest to the NT-BHC (see Table 1). The lead author, who is an intensively trained qualitative researcher with over 20 years of experience documenting interview and focus group responses, recorded interview responses in detailed notes on paper and reflected them back to participants to confirm accuracy and meaning.

Interview	Questions, Themes, and Examples (	N=17)
<ol> <li>What did you like best about the s</li> <li>What didn't you like about the served.</li> <li>What would you like to see change</li> </ol>		r services?
<ul> <li>Supportive staff to listen:</li> <li>Liked that staff were supportive, had time for them, would listen to them when feeling down</li> <li>Staff described as cool, flexible, nice, open</li> <li>Hard when staff were not there (not enough staff), hard when you need to talk</li> <li>A place to be alone:</li> <li>Liked the NT-BHC Bison Room, a place to be alone, to reflect</li> </ul>	<ul> <li>Confidentiality and privacy:</li> <li>Being checked up on at school: <ul> <li>Liked that staff gave notes in class, pulling youth out of class to talk</li> <li>Did not like being pulled out of favorite class to go to NT-BHC<sup>b</sup></li> <li>Embarrassing to be checked up on</li> </ul> </li> <li>Talking to parents <ul> <li>Liked that staff only told parents about serious issues</li> <li>Sometimes told them things they did not need to know (e.g., cutting)</li> </ul> </li> </ul>	<ul> <li><u>NT-BHC to talk to staff</u></li> <li><u>Did not like being pulled out</u> of favorite class to go to NT-</li> </ul>

 Table 1

 Interview Questions, Themes, and Examples (N=17)

<sup>a</sup> Negative comments underlined. <sup>b</sup> Cross coded under two themes

# **Data Analysis**

Responses for each of the three questions were coded to identify the main categories and themes. Given the brief interview responses, this process was done by hand by the lead author.

#### **Interview Results**

The interviews did not have a predetermined time limit, but youth tended to be brief and completed the interview in approximately 10-15 minutes. Interview themes and examples are presented in Table 1. The vast majority of the youth interviewed (n = 16) had positive things to say about the NT-BHC (one youth said that she had not used the NT-BHC enough to make a comment). These positive comments cut across three of the four themes listed in Table 1 (and listed here in italics). One interview theme was that the NT-BHC had *Supportive Staff to Listen* to the youth. Youth described the staff as flexible and "cool." The only negative issue around talking with staff was that sometimes a counselor was not available when youth wanted to talk. Wanting more staff and greater availability of staff was one of the main concerns of the youth. A second and related theme was that youth liked having *A Place to be Alone*. This opportunity was provided by the Bison room of the NT-BHC. Youth said that they liked this space because it gave them a place to be by themselves and think.

A third interview theme, Confidentiality and Privacy, had two sub-themes. One subtheme related to being checked up on at school by NT-BHC staff. Some youth said they liked when staff checked on them. Examples included having a personal note delivered to them in class from the NT-BHC staff asking about how they were doing, or a note delivered to the teacher that called them out of class to come to the NT-BHC to talk. However, other youth said they did not like this practice or were embarrassed by it. These youth said they did not like to be pulled out of a favorite class or "followed" in the lunch line (this theme is also coded under a second theme regarding initiation of services). A second sub-theme under Confidentiality and Privacy was NT-BHC staff talking to parents about concerns with the youths' behavioral health. While some youth said that staff were very careful about keeping issues private and would only talk to parents if an issue was "serious," other youth said that staff told parents things that were not serious and should not have been reported. Specifically, one youth mentioned cutting behavior, but said it was not serious and should not have been reported to the parent. The reporting led to the youth being removed from the home for a period of time, which the youth said was upsetting. A fourth theme, Initiation of Services at the NT-BHC, included comments from youth who did not like being told to go to the NT-BHC by someone else, such as a parent or school staff member.

The final interview question asked youth for suggestions for improving services. This theme focused on wanting more of what the NT-BHC had to offer. Youth wanted a bigger space that was less "cramped" and wanted more counselors and services. In particular, youth mentioned wanting programs on anger management, and a space to do art or play music. They also wanted the NT-BHC to have food/drinks, or to allow students to bring them in. One youth suggested NT-BHC give bus passes to help students get to after-school and weekend jobs. (The youth understood that passes currently were given only to low-income students).

# **Focus Groups**

# **Participants and Procedure**

Four focus groups were conducted between September 2010 and March 2011. A total of 26 people participated in the focus groups. Six youth participated in a middle school focus group (4 male, 2 female) and six in a high school focus group (2 male, 4 female). All youth in the middle and high school focus groups were under the age of 18 years. Five parents (all female) and 9 teachers/staff (5 male, 4 female) also participated.

# **Data Collection**

While the lead author was able to both conduct the brief interviews in a one-on-one format with youth and take detailed notes, the research team agreed that a separate facilitator would be needed for the focus groups so that the lead author could concentrate on documenting the responses. Responses were documented using word processing software on a computer for rapid note taking, active listening, and clarifying responses, and were reviewed with the facilitator directly after the focus group. The research team recruited two college-age AI/AN youth to facilitate the groups. They had experience working with youth and were trained by the lead author in focus group facilitation.

NACS students were invited to participate via fliers posted around the school and read aloud in class by teachers and during school-wide announcements. The fliers asked any interested youth to call the NT-BHC or stop by to pick up a consent or consent/assent form. The lead author completed the consent process, reviewed completed consent forms, and answered questions prior to starting each focus group. Parents were recruited during a school open house event via an information table, where NT-BHC staff provided fliers about the focus groups, as well as by announcements at parent-teacher association meetings over the course of 2 months. Teachers/staff were invited through fliers placed in their mailboxes at school and were asked to contact the NT-BHC to sign up. All participants received a \$15 gift card for their time.

Focus group questions are listed in Table 2. All youth were asked the same questions. Some parent and teacher/staff questions were slightly modified to ask about behaviors of the youth (rather than their own behaviors) and relevant information about one's child (for parents) and for students generally (for teachers/staff).

		Focus Group Questions
High School and Middle School	2. 3.	Where do people in your community go for help when they are having emotional problems, like feeling sad or angry, and stuff like that? Where do people in your community go for help if they have a problem with drugs and alcohol? What services are available at your school for kids who are having problems emotionally, like feeling sad or angry? What about substance abuse problems? Do you know about the NT-BHC? Have you ever thought about using these services?
	5.	What culturally based services do you use to remain healthy?
	6.	What kinds of services or things could be provided at NACS to help students?
Parents	1.	What mental health and substance abuse services are available for your family/child in the community?
	2.	What mental health and substance abuse services are available for your family/child at school (NACS)?
	3.	What services have your family/child used at the NT-BHC at NACS?
	4.	What do you like about the NT-BHC? What does your child like about the NT-BHC? What could be improved?
	5.	What culturally based services do you need to keep your family healthy?
Teachers/Staff	1.	What mental health and substance abuse services are currently available in this community?
	2.	What mental health/substance abuse services are currently available at this school?
	3.	Do you think NACS students use the NT-BHC? (if yes, for what?)
	4.	What do you like about the NT-BHC? What could be improved?
	5.	What culturally based services are needed at the school/at the NT-BHC?

Table 2 Focus Group Questions

#### **Data Analysis**

Typed responses for each focus group were entered into the NVivo qualitative software program. Responses initially were open coded by the lead author to establish a general range and to list themes and examples from each focus group. Responses were then coded using a thematic analysis approach, with the initial coded responses grouped into broader overarching themes (Liamputtong, 2013). Both initial codes and larger theme areas were reviewed and finalized by the research team to ensure coding accuracy and agreement of final themes and appropriate

examples. The coded responses under each question, and themes developed from the responses, were reviewed by the research team for differences and similarities across the four focus groups (middle school, high school, parents, and teachers/staff).

# **Focus Group Results**

<u>Overall Focus Group Themes</u>: Overall themes and examples from each focus group (middle school youth, high school youth, parents, and teachers/staff) are presented in Table 3 and cover focus group questions 1-5. The table then describes the themes from each focus group for these five questions and progressively displays similarities and differences across them. This table is designed to help readers quickly visualize the similarities and differences among the focus group responses from different focus group participants.

Focus Group Themes								
Middle School	Friends and Family (No specifics	<b>NT-BHC</b> Bison Room, NT-BHC	<b>Professional Services</b> Rehab	Traditional Activities Healing ceremonies				
<i>N</i> = 6	mentioned)	<b>Go to place alone</b> Bedroom Garage (to play drums) Park/lie in grass		Medicine men Sweat lodges				
High School N = 6	GrandparentsTalking groupsRParentsCounselingJElders(substance abuse,PTeachers they liked/ trustedBison Room (has sage		<b>Professional Services</b> Rehab Jail Police Therapy	<b>Traditional Activities</b> Ceremonies Traditional activities (No specifics mentioned)				
	Sometimes better <u>not</u> to share problems with community members	—used to cleanse oneself; music; feathers)						
Parents N = 5	Family and People they Trust Other parents Community members Healers School staff	<b>NACS</b> Families share similar	Professional Services Counseling Therapy (Covered by Medicaid; <u>not</u> always culturally sensitive) Would not use services	<b>Traditional Activities</b> Traditional healers Ceremonies Services in their home or tribal community Feel whole, rejuvenated				
	backgrou Supportiv		offered in city					
Teachers <i>N</i> = 9	Trusted Adults Teachers Parents NACS Student alliance Student council	NT-BHC Counseling Talking circles Talk box Always someone available	<b>Professional Services</b> Counseling Therapy Substance abuse services	<b>Culturally Based</b> <b>Education</b> Professional development to learn more about other AI/AN cultures				

Table 3 Focus Group Themes

American Indian and Alaska Native Mental Health Research

Copyright: Centers for American Indian and Alaska Native Health Colorado School of Public Health/University of Colorado Anschutz Medical Campus (<u>www.ucdenver.edu/caianh</u>) <u>Middle School Youth</u>: Middle school youth said they would talk with family and friends when they needed help, as well as teachers they trusted and liked. Middle school youth mentioned almost no professional services/supports. Only "rehab" was mentioned, with no further discussion. One youth said he did not know where to get help. Middle school youth responses were unique in that the youth talked about various *places* they would go when they felt sad or needed help. For example, things like going to the park to sit in the grass were mentioned, as well as going to their room, or going to their garage to play music (drums mentioned specifically). Spending time outdoors has been demonstrated as an important coping strategy for AI/AN youth that provides a sense of connection to the land (Goodkind, Gorman, Hess, Parker, & Hough, 2014), and appears to be valuable to youth even when the land is in an urban area rather than their home or tribal community. When asked about services at their school, middle school youth said they knew of the NT-BHC and knew that it helped students, but did not elaborate further. When asked about traditional activities in which they participated to stay healthy, middle school youth mentioned ceremonies, songs and dances, powwows, feast days, making/eating traditional foods, painting, weaving, hunting, and making pottery.

*High School Youth:* High school youth primarily talked about going to family and friends when they needed help, as well as talking with teachers that they liked and trusted. One youth mentioned talking with grandparents because they were wiser "and know what they are talking about." However, some youth said that they would avoid talking with someone in their community about personal issues because they did not want community members to know about their problems. The high school youth were the only focus group participants to mention this concern. (However, interview respondents also raised the issue of confidentiality and privacy, suggesting such concerns were more widespread, particularly if youth had received services.) High school youth said they were aware of the NT-BHC and the therapy and counseling services it provided, including "talking groups" where youth met with an adult staff member to discuss issues together after school. However, none of these youth were certain of the exact days when the groups met. High school youth who mentioned using the NT-BHC services said that the services helped students with substance abuse and anger issues. Youth were not asked directly about personal use of services, for privacy reasons, but could discuss this if they chose. High school youth also mentioned a few services that they were aware of in the larger community, such as "rehab" and "jail," but did not elaborate further. When asked specifically about

traditional practices related to their cultural background that they used to stay healthy, high school youth said that they participated in ceremonies and traditional activities, but did not go into further detail or provide examples when prompted.

<u>Parents</u>: Parents mentioned talking with family when they needed help or support, but did not specifically mention talking with friends in these situations. Rather, they identified talking to a person that they trusted, which could be a friend, family member, or other person. Parents said that when they (and their youth) needed help, they could talk with some of the teachers at the school as well as other parents and staff at the NT-BHC. When asked about services at the school, most parents knew about the NT-BHC and that it offered counseling and mediation. Parents said that they found services helpful and convenient; they also reported that staff were caring, established one-on-one relationships with youth, and were responsive to parents. One unique theme in the parent focus group included comments that the NACS itself was supportive. Parents explained that the NACS helped them and their youth because it was made up of other families similar to their own, where people knew each other and youth shared similar backgrounds.

When asked about behavioral health services available in the larger community, parents mentioned professional services/supports, such as counseling and therapy, and mentioned by name specific clinics that were aimed at serving AI/AN people. They mentioned the Indian Health Service and said that they were aware that the cost of their services could be covered in part by Medicaid. However, despite this awareness, parents expressed a preference for services provided in their home or tribal community, or offered at the NT-BHC, which they contrasted with culturally insensitive services that they or their children received in the local urban area. It is important to note that many parents preferred to get wellness services/supports in their home or tribal community, even though it required travel ranging from 20 minutes to several hours each way. Parents' discussion about dissatisfaction with services in the local urban area included an example from a health center in a nearby public school available to NACS students. Some parents said that this health center was not culturally sensitive like the NT-BHC and, therefore, their youth did not use it much. One parent said that her son, who had used this health center, felt judged by staff members' questions regarding drinking in the home. The parent said that these questions seemed to define problems in advance, make assumptions about the family and its problems, and endorse only one view of how families should be.

Parents also provided examples of traditional practices they and their families used to stay healthy or when they needed help. They reported that ceremonies, sweat lodges, and medicine men in their home or tribal community helped them to feel "whole" and "rejuvenated." One parent said she trusted her medicine people because they could see things that others could not.

<u>Teachers/Staff</u>: Themes in the teacher/staff focus group centered largely on professional services and supports, such as treatment and counseling available at the NT-BHC and in the larger community. These responses contrasted with those from the other focus groups that first mentioned family and friends, use of spaces (e.g., parks, garage), music, and traditional services. Teachers/staff mentioned a wide range of school services/supports, including the NT-BHC, talking circles, the talk box (where youth could ask questions anonymously), the student alliance, and the Student Council. They also knew of many clinics in the area that primarily served AI/AN people, the Indian Health Service, local hospitals, substance abuse treatment centers, and inschool behavioral health services provided by external personnel. Teachers/staff also mentioned that youth would talk with teachers, school staff, and parents to get help they needed, which was common across all the focus groups.

Teacher/staff responses about what students did when they needed help or support focused on talking to adults at the school (like teachers and other staff), talking with parents, and using professional (paid) services like counseling and therapy. While teachers/staff were not asked specifically to talk about students' use of traditional services, this theme did not emerge during the discussion about available services/supports for youth. Teachers/staff expressed interest in learning more about different AI/AN cultures and having further professional development in this area.

<u>What could be provided to help students? Youth Responses</u>: Youth only (middle and high school) were asked one additional question about what services and other things could be provided at NACS to help students (Question 6). Results are presented in Table 4 on the next page.

	What Could be Provided at NACS to Help Students
Middle School	<ul> <li>More activities:</li> <li>Activities; clubs; play instruments</li> <li>When I play drums, it helps me feel better</li> </ul>
	<ul> <li>Help with schoolwork:</li> <li>Helping us with our homework, having an older person or teacher tutor us</li> </ul>
High School	<ul> <li>Other:</li> <li>Game Stop cards, new shoes; Need more sleep.</li> <li>More activities:</li> <li>Activities, field trips, dances, fun stuff</li> </ul>
	<ul> <li>Student apathy or disengagement:</li> <li>Activities, being open (to new things), doing things, like going to the park. That keeps people on their feet and taking everything in. Less sitting around. [Some kids] don't care.</li> <li>Keep the kids that care in school, and let the others stay home</li> </ul>
	<ul> <li>More health services:</li> <li>Classes on being healthy (examples: sex education, self-defense)</li> </ul>
	<ul> <li>More behavioral health services:</li> <li>Counselors for drugs</li> <li>Counselors/programs for emotional wellness/dealing with abuse, suicide, grief For example: <ul> <li>To learn what is bothering you and how to help yourself feel better</li> <li>When someone passes away, how to deal with it</li> </ul> </li> </ul>
	<ul> <li>School safety:</li> <li>A lot of kids that have drugs, alcohol, and weapons they bring to school. It is scary.</li> </ul>
	<ul> <li>School campus: [Note: classes held in metal trailers instead of permanent buildings]</li> <li>School is not ready yet. Completing the school first would have provided more student support services.</li> <li>If our school was done the teachers would be more prepared.</li> <li>We don't need a big school [completed buildings] to learn.</li> </ul>

Table 4 What Could be Provided at NACS to Help Students

Themes from the middle school youth responses included *More Activities*, such as clubs or playing drums, *Help with School*, including tutoring, and basic items such as gift cards to a game shop, shoes, and sleep. Themes from the high school youth responses covered a wider range of topics. As with the middle school youth, high school youth also wanted *More Activities*, and expressed frustration with *Student Apathy or Disengagement* in participating in school and related activities. One youth said that students who are not interested in participating in things should just "stay home." Another theme was wanting more *Health Services*, which included sex education and self-defense classes. But the majority of the discussion focused on *Behavioral Health Services*, including counselors for drugs, but in particular focused on emotional pain and grief, often in response to losing a relative or close friend: "Losing someone …drastically

changes your life 'til you can't deal with it." Students discussed wanting to improve the school environment, including the themes School Safety and the School Campus. Regarding safety, students wanted police to protect youth from those who bring weapons to school. Discussion about the School Campus focused on the belief that the school was not fully ready in terms of buildings and space to provide for the students adequately: "They should have made the school first and then they would have more student support services." One youth, however, disagreed, explaining that the portables which made up the majority of classrooms at the school were not a negative aspect, as least in terms of supporting learning: "We can learn behind a trash can."

Loss/Lack of Cultural Knowledge and Ways to Strengthen: The high school focus group alone had an important, impromptu discussion in relation to the question "What culturally based services do you use to remain healthy?" While direct responses to this question are included in Table 3, the additional conversation this question inspired warrants a separate table, presented below (Table 5). The conversation revolved around two main themes: Loss/Lack of Cultural Knowledge students experienced and How School can Support Strengthening Cultural Knowledge.

	Table 5
	Loss/Lack of Cultural Knowledge and Suggestions for Strengthening
High School	<ul> <li>Expressing loss of/lack of cultural knowledge:</li> <li>[Used to] go to my aunt's house and dance fancy shawl. Used to do a lot of traditional things, and then went to public school.</li> <li>Don't know our traditions, we are raised in [City], and we would likelike me and my sister, we don't really know our background and traditions. We were born and raised in [City]. We don't have family to teach us.</li> <li>[Don't know] culturally sensitive information, cultural protocols.</li> <li>Don't know my background.</li> <li>As a child, used to be traditional and dance back home on the reservation. But then went to elementary school and forgotlike dissecting a frog. Didn't know I wasn't supposed to do that and had to have a ceremony.</li> <li>Lady brought an anaconda into the school and that was wrong but I didn't know it.</li> <li>One time in history [class] my sister she was asked to bless and feed a tree. She didn't know what to do.</li> </ul>
	<ul> <li>How school can support strengthening cultural knowledge</li> <li>Activities: Indian dances; pottery making; cutting trees for firewood; planting trees; harvesting</li> <li>Learn language [3 Southwestern languages mentioned specifically]</li> <li>Bad thinking about my family know more Spanish than Navajo kind of weird.</li> <li>If students don't know their own culture, then maybe they could meet someone from where they are from to help them learn. Rights and wrongs of what to do.</li> <li>A younger person coming in, like a parent to help teach.</li> <li>Bringing in people to teach us about our culture.</li> </ul>

# Tabla F

In the first theme area, *Loss/Lack of Cultural Knowledge*, students gave examples, often based in school settings, where they became aware of their lack of cultural knowledge in relation to their AI/AN heritage. Examples from the high school youth include dissecting a frog in class and viewing a snake at school. In both cases the youth did not realize until later that these practices were against traditional beliefs and cultural norms. Another student mentioned being asked to bless and feed a tree at school and not knowing how to do it. Many students noted that they had been more involved with cultural practices when they were younger, and felt that being in the urban area made them more disconnected from their cultural practices and beliefs. This unique discussion among the high school youth, and the range of examples, suggest that these moments when they became aware of their limited cultural knowledge and skills were emotionally powerful and created lasting memories. It is also important to note that some examples (e.g., frog dissection, viewing a snake) likely occurred at other public middle or high schools before the youth transferred to NACS.

The second theme was *How School can Help Support Strengthening Cultural Knowledge*. Examples included having cultural activities at school, such as traditional dances and AI languages, cutting firewood, and making pottery. With regard to language loss, one youth described feeling it was a "bad thing" and that it was "kinda weird" to know more Spanish than one's own AI/AN language. Youth suggested having someone come to the school to help teach them about cultural practices and beliefs, with one youth suggesting that someone "young…like a parent" would be a good fit.

# DISCUSSION

# Effect of Cultural Tailoring on Service Utilization

The study findings above demonstrate the importance of culturally appropriate services for AI/AN youth and families. The interviews with both middle and high school youth who had used the services demonstrated showed positive views of the NT-BHC staff, with negative comments focused on wanting more services. In the parent focus group, cultural tailoring of services was an important theme. Some parents talked about a nearby school health center that was lacking in culturally appropriate services and that, therefore, their youth did not like to use. Such experiences were likely a driving force in parents' stated preference for getting services/supports in their home or tribal community, even though it entailed traveling, sometimes great distances. This finding is supported by studies that show AI/AN underutilization of biomedical services offered by mainstream providers (Beals et al., 2005; Novins, Beals, Moore, Spicer, & Manson, 2004), and a preference among some AI/ANs for traditional healing practices to meet behavioral health needs (Gone, 2008; Gurley, et al, 2001). For further rich discussion concerning the use of and preference for traditional healing among urban AI/ANs and related cultural considerations, see Hartmann and Gone, 2012. Despite the availability of health services in urban areas, this study and related literature suggests that cultural tailoring and service provision by AI/AN staff may be important factors in encouraging the use of behavioral health services for AI/ANs. The only urban services the parents reported liking were the services at the NT-BHC that their youth sometimes used. This finding is important because it suggests that culturally tailored services for AI/AN youth, such as those offered at the NT-BHC, may be more important than convenience and location for improving service utilization.

Another valuable finding was the fact that teachers/staff focused on the availability of services/supports in the urban area, and did not discuss use of traditional services (or informal supports from family and friends). This finding suggests an opportunity to raise awareness about preferences and actual use of services that can help teachers/staff better understand and support students and families.

# Native-tailored and Native-staffed: Improving Utilization Rates

In this study, we found that 170 out of a total of 350 students had used the NT-BHC (49%) during the 2010-2011 school year. While this percentage is comparable to utilization rates for other mainstream school-based health centers (Anglin, Naylor & Kaplan, 1996), it is important to remember that utilization rates of AI/ANs and other ethnic minority groups are often *lower* than those of White youth (Farmer et al., 2003; Shim, Compton, Rust, Druss, & Kaslow, 2009). Thus, the nearly 50% utilization rate in this study provides support for the practice of providing culturally appropriate services to encourage behavioral health service utilization (Evaneshko, 1999) with numerous challenges in accessing quality health care services (Brown, Ojeda, Wyn, & Levan, 2000; UIHC, 2007). One study of foster care-placed youth found that AIs were significantly less likely to receive school services than were White children of the same gender with similar social service experiences and mental health problems (Farmer et al., 2001). Other studies have found that, while attitudes about services may be positive initially among ethnic minority groups, use often declines after services are begun,

possibly because services are not culturally sensitive (Diala et al., 2000). Therefore, offering culturally appropriate and tailored services may be an important factor in raising AI/AN utilization rates.

#### Variations in Awareness of School and Community-based Services/Supports

While there was overall general awareness of the NT-BHC, an important study finding was the variation in awareness of behavioral health services among the participating groups. Understanding this variation can be important in the design and marketing of services in both schools and the larger community. The middle school youth demonstrated very limited awareness of any services, school or community based. Largely, their responses including things like going to the park or their room, playing music, and talking to friends and family. These findings are particularly interesting when contrasted with teacher/staff responses about services available to youth, which reflected mainly services that were professional in nature (e.g., agencies, clinics). Understanding this apparent disconnect can help to develop appropriate services and strategies to engage youth. Such strategies might include holding a clinic or support center "open house" which younger youth can attend with friends or family, increasing their comfort and familiarity. Other efforts might include focused, age-appropriate marketing and education to encourage younger youth to become more aware of and to use professional services (e.g., therapy).

# **Privacy and Confidentiality**

Another important study finding was that youth were concerned about privacy and confidentiality. Being pulled out of class or checked on by NT-BHC staff at school was embarrassing. Some youth also were upset that their parents were told about problems they had discussed in confidence with NT-BHC therapists. Many youth are very concerned in general with being embarrassed in front of friends, especially in school. However, because some youth in this study liked being checked on by staff, the recommendation for school-based health centers in general is to ask youth if they would like to be contacted during school regarding their wellbeing. If so, the youth and staff should agree on a format that feels safe and private for the youth (e.g., youth who do not want to be contacted at school could set up a time to call or come by the health center). Also, staff should work with youth to clarify the limits of confidentiality and the kinds of things that need to be shared with parents.

#### **Initiation of Services**

Youth expressed concern that they were not always in charge of initiating services on their own. Some were told they had to go by a parent, and, in some cases, NT-BHC staff members pulled youth from class when they did not want to go (as noted above, youth also believed that this practice limited their privacy). We recommend that student health center staff discuss with youth and parents the best way to involve youth in services that are initiated by a parent, so students can establish a role in the process. Increased student involvement may help build a trusting relationship and encourage future use. A youth-guided approach as to when, how, and what services are provided is a cornerstone of national Systems of Care principles and has been associated with positive youth outcomes (Substance Abuse and Mental Health Services Administration [SAMHSA], 2010).

#### **Importance of Informal Supports: Family and Friends**

This study also reflects another important finding in behavioral health research: that a main source of support for all youth is family and friends. Research with AI/AN youth has shown the value of talking with family and friends for helping them cope with stress (Goodkind et al., 2014). Therefore, providing education and training can help strengthen the capacity of family and friends to give support and offer referrals for services. Programs such as the Model Adolescent Suicide Prevention Program (MASPP) utilize the concept of "natural helpers," which is based on the premise that, when young people have problems, they most often turn to friends for help, and that schools have an informal helping network that can be enhanced to support youth. MASPP is listed on SAMHSA's National Registry of Evidence-Based Programs and Practices (SAMHSA, 2015). Another example is the Strengthening Families Program, which works to enhance families' capacity to support adolescents (Kumpfer, 1998). Programs that work to build up the natural support capacity of friends and families can be an effective approach for meeting the behavioral health needs of youth.

#### What Could be Provided at NACS to Help Students

Having the school provide support for some of the students' basic needs was another theme that emerged. Middle school youth mentioned shoes, sleep, tutoring, and more activities; for high school youth, the conversation touched on activities, but went more in depth regarding frustration about other youth who are not engaged at school. It would be important to explore some of these concerns, such as sleep, more in depth (perhaps in a short wellness survey or discussion with teachers about their perception of the concern in class) to understand how widespread these issues are, and then work to develop strategies to address them.

Importantly, there was significant focus among high school youth on the loss of family members and friends, especially their desire to have the school help them cope with their feelings of grief. This discussion highlights the trauma faced by many AI/AN youth and the need for behavioral health services related drugs, abuse, and suicide. The focus on this issue directly relates to the relatively high exposure of AI/AN peoples to a range of violent and traumatic events involving serious injury or threat of injury to oneself, or witnessing this threat or injury to others (Manson, Beals, Klein, Croy, & the AI-SUPERFP Team, 2005). Of all races, they have the highest per capita rate of violent victimization; children between the ages of 12 and 19 years, in particular, are more likely than their non-Native peers to be the victims of both serious violent crime and simple assault (Rennison, 2001). The positive impressions of the NT-BHC among youth who had used services provide support for the important role that this culturally appropriate school-based health center plays in the lives of these urban youth.

# Loss/Lack of Cultural Knowledge and Suggestions for Strengthening

High school youth were unique in having additional discussion about loss/lack of cultural practices and making suggestions for the school to help address this issue. Interestingly, when asked about cultural practices they used to stay healthy, middle school youth mentioned a number of activities, whereas high school youth mentioned a smaller range. This finding reflects their memories of being more culturally active and spending more time in their home or tribal community when they were younger: "When I was 3 or so I used to be traditional and dance back home on the reservation. But then when I went to elementary school I forgot..." High school youth provided very specific and memorable examples of violating cultural norms or forgetting cultural practices in a public context, revealing a shared experience that they wanted the school to help them address.

# Limitations

This study expands what is known about AI/AN student and parent awareness and use of school- and community-based services, and this information can be used to improve services and utilization and to inform future research. Participants demonstrated awareness of, positive

attitudes toward, and relatively high use of an NT-BHC; these findings may support the development of similar centers in other urban schools that serve AI/AN students. This study used mixed methods, including the collection of NT-BHC use rates, but was predominately qualitative. The qualitative approach provides important strengths as well as limitations. Qualitative research (e.g., interviews and focus groups) is not intended to be representative of an entire population, and, therefore, the results are not generalizable (Vogt, King, & King, 2004). However, these methods provide much-needed information—in this case, about how AI/AN youth and parents perceive and utilize available services, both in school and in the larger community. While not generalizable, this type of research can provide critical data to make practical improvements in existing services and approaches, as well as inform future mixed methods or quantitative studies. A second limitation was reliance on notes rather than recordings of the focus groups, which would have provided more quotations and is preferred with qualitative research, when appropriate. However, because this study was foremost a CBPR study, respecting the school's desire *not* to record respondents was paramount in the research team's methodological decisions.

#### CONCLUSION

Significant health disparities among AI/AN youth may be alleviated through use of behavioral health services. Ensuring that such services, like those provided at the NT-BHC, are culturally appropriate may be an important factor in increasing both first-time and repeated use of services/supports among urban Native youth and families. This study suggests that tailoring behavioral health services for AI/AN youth can lead to high satisfaction with services and high levels of use. It also highlights differential awareness and use of behavioral health services/supports among youth, parents, and teachers/staff. If utilized to improve behavioral health services for urban AI/AN youth, the findings from this study can contribute to improve health outcomes and reduced health disparities.

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# ENTREPRENEURSHIP EDUCATION: A STRENGTH-BASED APPROACH TO SUBSTANCE USE AND SUICIDE PREVENTION FOR AMERICAN INDIAN ADOLESCENTS

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> Abstract: American Indian (AI) adolescents suffer the largest disparities in substance use and suicide. Predominating prevention models focus primarily on risk and utilize deficit-based approaches. The fields of substance use and suicide prevention research urge for positive youth development frameworks that are strength based and target change at individual and community levels. Entrepreneurship education is an innovative approach that reflects the gap in available programs. This paper describes the development and evaluation of a youth entrepreneurship education program in partnership with one AI community. We detail the curriculum, process evaluation results, and the randomized controlled trial evaluating its efficacy for increasing protective factors. Lessons learned may be applicable to other AI communities.

# **INTRODUCTION**

Leading substance use and suicide prevention researchers working with North American Indigenous communities have issued a call to action: to develop prevention models targeting key determinants of mental health and well-being at the level of whole communities situated within their larger socioeconomic contexts (Chandler & Lalonde, 2008; Wexler et al., 2015). Past substance use and suicide prevention research has focused on problems and has been deficit based. Researchers urge for new initiatives that examine societal-level factors such as poverty and unemployment, and make an explicit commitment to local capacity building and community health, with an overarching emphasis on resilience (Allen, Mohatt, Fok, Henry, & Burkett, 2014; Wexler et al., 2015).

Toward this end, this paper describes an entrepreneurship education program for American Indian (AI) youth and the study design evaluating its efficacy, currently being conducted within a tribal reservation context. The entrepreneurship education program and evaluation plan were co-created through a tribal-university partnership targeting known protective factors for substance use and suicide at individual, peer, and community levels. First, we review the literature on targeted protective factors that form the rationale for utilizing an entrepreneurship education intervention for substance use and suicide prevention. Second, we describe the methods used to develop and implement the program, including process evaluation results, as well as those used to evaluate program impact on youths' psychosocial, behavioral health, educational and economic outcomes.

#### **Background on Protective Factors**

# Connectedness

Looking across well-supported theoretical and conceptual frameworks for substance use and suicide prevention, connectedness is a cross-cutting strength-based construct (Whitlock, Wyman, & Moore, 2014). Connectedness is the degree to which an individual or group possesses a subjective sense of emotional interrelatedness (belonging, caring, value and trust) and a willingness to share with and seek resources from the communities in which they are embedded (Whitlock et al., 2014). Connectedness is interactive; there are three pathways by which connectedness may protect against substance use and suicidal behaviors: 1) intrapersonal responses and processes, 2) collective responsibility and action, and 3) positive norms and expectations (Whitlock et al., 2014). Among Indigenous North American populations, adolescents are the most disproportionately affected by substance use and suicidal behaviors, which share similar risk profiles (Allen et al., 2014; Barlow et al., 2012; Borowsky, 2010; Tingey et al., 2012). Connectedness has been negatively correlated with suicidal thoughts and behaviors in a sample of Native youth (Borowsky, Resnick, Ireland, & Blum, 1999).

**Connectedness to Caring Adults.** For adolescents, connectedness to systems in which youth-adult relationships are developed may confer protection against suicide by increasing the likelihood that negative affect, distress, high-risk behavior and direct warning signs of suicide will be noticed and addressed proactively, and by facilitating connection to community resources (Whitlock et al., 2014). Adolescents also may be less at risk for suicide if they experience the

neurophysiological benefits of connectedness (i.e., believing one is of value and cared for) and are able to better regulate their emotions through social affiliation and attachment with caring adults (Whitlock et al., 2014).

School and Peer Connectedness. Connectedness to school may have unique import to AI adolescents who suffer high rates of school dropout and related unemployment and poverty. School connectedness, "the belief held by students that adults and peers in the school care about their learning as well as about them as individuals," has been associated with several positive outcomes (Centers for Disease Control and Prevention [CDC], 2009, p. 3). School connectedness improves school attendance, staying in school, grades, and test scores, and students who do well academically are less likely to engage in risky behaviors (CDC, 2009). School connectedness is one of the strongest protective factors against substance use, school absenteeism, early sexual initiation, violence, and risk of unintentional injury (Resnick et al., 1997). Furthermore, perceived closeness, feelings of belonging, and engagement with teachers and peers predict lower likelihood of suicide among students (O'Keefe & Wingate, 2013; Whitlock et al., 2014). Other studies with AI communities have found that school completion and a positive attitude towards education are protective against suicide (Alcantara & Gone, 2007; Whitbeck, Hoyt, Stubben, & LaFramboise, 2001).

# Hope, Mastery, and Self-control

Constructs related both to youths' sense of connectedness and lower risk for substance use and suicide are hope, mastery, and self-control (O'Keefe & Wingate, 2013). Hope has been defined as a positive motivational state based on being goal-directed and having pathways to meet those goals (O'Keefe & Wingate, 2013). Students who are connected to school possess a greater sense of self-efficacy and motivation to meet their academic goals; they are able to connect present and future behaviors regarding academic/career goals and generate plans to achieve those goals (Snyder, 2002). Hopelessness has been found to correlate positively with depression and negatively with self-esteem and prosocial behavior (Kazdin, Rodgers, & Colbus, 1986). Among a sample of AI/Alaska Native students from three universities representing 27 tribal communities, having hope and optimism were found to decrease suicidal ideation after controlling for age, sex, marital status, and household income (O'Keefe & Wingate, 2013).

Additional protective factors that reduce the effects of stress and adverse life events are especially important in tribal socioeconomic contexts (CDC, 2009; Substance Abuse and Mental Health Services Administration's Center for the Application of Prevention Technologies [SAMHSA CAPT], 2015). Unemployment, lack of social capital, and poverty are predisposing

risk factors for negative mental health outcomes, and rural AI communities with lower socioeconomic status have higher substance use and suicide rates (Alcantara & Gone, 2007; Allen et al., 2014). Protective factors identified as contributing to resiliency amidst socioecological risks for substance use and suicide include attachment, mastery, and self-control (SAMHSA CAPT, 2015).

# **Positive Youth Development**

A positive youth development framework posits that youth who develop mastery and are supported by caring adults and peers to cultivate new skills are more likely to exercise control over their lives by making healthy choices and withstanding external pressures (SAMHSA CAPT, 2015). Positive youth development approaches are designed to utilize and enhance youths' strengths, provide opportunities for skill building, and foster healthy peer and adult relationships (SAMHSA CAPT, 2015). Substance use and suicide prevention models reflective of this approach attempt to engage youth in prosocial activities across school, peer, and community contexts in a manner that is productive and constructive (SAMHSA CAPT, 2015).

# **Entrepreneurship Education**

Entrepreneurship education is a positive youth development approach with promise to promote protective factors identified as meaningful to AI adolescent substance use and suicide prevention at individual, peer, and community levels. Entrepreneurship education is the pursuit of opportunity beyond the resources currently controlled (Stevenson, 1983; Stevenson & Gumpert, 1985; Stevenson & Jarillo-Mossi, 1991). Entrepreneurship education increases motivation for under-resourced groups to complete formal education, promotes vocational and social skills, and enables youth to contribute to their community's economic development (Graig, Owen, & Ritter, 2012; Lee, Chang, & Lim, 2005; Youth Entrepreneurship Strategy Group, 2008).

Entrepreneurship education has been shown to increase youths' feelings of security, affiliation, autonomy, identity, and achievement, as well as to improve confidence, knowledge, and ability (Graig et al., 2012; Lee et al., 2005; Youth Entrepreneurship Strategy Group, 2008). Entrepreneurship education gives youth the opportunity to discover hidden talents and uncover capabilities and skills they did not know they had. Entrepreneurship education has a positive impact on students' lives, whether or not they become entrepreneurs (Cheung, 2008).

Impact evaluation of entrepreneurship education programs is growing (Charney & Libecap, 2000; Matlay, 2005; Mwasalwiba, 2010). Several studies indicate youth receiving entrepreneurship education are more likely to increase their occupational aspirations and to have higher standardized test scores, better school attendance, lower dropout rates, and higher overall educational attainment (Barnett, 1995; Durlak, 1997; Lifschitz, 2011; Reynolds, Temple, Robertson, & Mann, 2001; Temple, Reynolds, & Miedel, 2000). Youth receiving entrepreneurship education also are more likely to take initiative and lead in business, arts, and sports activities and to demonstrate increased locus of control (i.e., the belief that achievement and goal attainment is due to their own actions and decisions and not due to chance or luck; Barnett, 1995; Durlak, 1997; Lifschitz, 2011; Reynolds et al., 2001; Temple et al., 2000). Entrepreneurship education has been shown to build key assets for positive youth development, translating to reductions in substance use, depression, and violence (Karcher, 2002, 2005; Karcher, Davis, & Powell, 2002; Karcher & Finn, 2005; Karcher & Lee, 2002; Karcher & Lindwall, 2003).

This paper describes the development and evaluation of a youth entrepreneurship education program in partnership with one AI community. We detail the content and competencies of the entrepreneurship education curriculum, implementation schedule, and randomized controlled trial evaluating its efficacy for increasing protective factors for substance use and suicide prevention. Lessons learned will have application to other AI and underresourced Indigenous communities.

#### **METHODS**

# **Participating Tribal Community**

The entrepreneurship education program and evaluation design were developed by a partnership between the White Mountain Apache Tribe (Apache) and the Johns Hopkins Center for American Indian Health (JHU). The Apache reside on the Fort Apache Indian Reservation in Northeastern Arizona, which consists of 1.6 million acres and is geographically isolated from other population centers. The primary sources of industry include a tribally owned timber and sawmill, casino, ski resort, and historical museum, as well as agriculture and livestock enterprises. Other major employers are the tribal health, social service, and education departments, Indian Health Service, Johns Hopkins University, and local schools. Despite these

economic and employment assets, negative economic forces have increased the number of unemployment claimants living on the Apache reservation by 320% (First Things First White Mountain Apache Tribe Regional Partnership Council, 2012).

The Apache population is young; over half (54%) of Apache tribal members are less than 25 years old, compared to approximately 35% within the U.S. All Races population (Indian Health Service, 2009). School dropout is high: In 2009, only 41% of students completed high school in 4 years (First Things First White Mountain Apache Tribe Regional Partnership Council, 2012). Apache students are scoring lower in reading and math literacy than youth statewide and youth who belong to other tribes in Arizona. In 2010, approximately 40% of Apache third graders were proficient or advanced in reading, compared with 75% statewide (First Things First White Mountain Apache Tribe Regional Partnership Council, 2012). The young age of the population, coupled with school incompletion, has led to approximately 60% of the community either "Not in the labor force" or unemployed, and the majority of people live below the federal poverty level (First Things First White Mountain Apache Tribe Regional Partnership Council, 2012).

An under-resourced context has contributed to what Apache community leaders describe as a pervasive feeling of hopelessness among their youth, which may be a contributing factor to high rates of substance use and suicide (Cwik et al., 2011; Mullany et al., 2009). Among a sample of Apache youth who attempted suicide (n = 17), the average score on the Hopelessness Scale for Children was 8.77 (range 0-17; *SD*, 2.02). A score  $\geq 7$  is equal to "high hopelessness," and 88% of this sample scored  $\geq 7$  (Cwik et al., 2016; Kazdin et al., 1986).

Community leaders detail how youth struggle to see the practical side of what they learn in school and have little incentive to study and stay in school (Cheung, 2008). A qualitative casecontrol study with Apache teens comparing those who engaged in binge alcohol use (cases) versus youth with no lifetime binge alcohol use (controls) found that controls were strongly connected to school and understood how their educational accomplishments would impact longterm career goals (Tingey et al., in press). Cases who had engaged in binge alcohol use were not attached to school; they had poor attendance and low grades, often did not graduate, and rarely were involved in structured activities outside of school settings (Tingey et al., in press).

#### **Intervention Development**

Research partners agreed to explore a youth entrepreneurship education model to promote culturally based protective factors for substance use and suicide prevention. A participatory research approach shaped the exchange of ideas between community and academic partners and the structure of the resulting intervention (Fisher & Ball, 2005). A Community Advisory Board (CAB) of youth and adults was formed to explore avenues for intervention development. CAB members discussed how entrepreneurship is a well-established platform in the Apache community, from which individuals and families have filled current economic and employment opportunity gaps. For example, "Tailgate" is a community-based open-air daily market featuring local vendors selling food, goods, and services not offered through large-scale businesses on the reservation. Artisans crafting Apache beadwork, jewelry, burden baskets, moccasins, and clothing are well known and called upon for supplying community members with necessary items for traditional ceremonies and events. These activities are rooted in Apache traditions and values and serve as repertoires of behaviors that have buoyed the Apache people through generations of adversity.

Working from a positive youth development framework, the CAB and research partners established key goals for the intervention: 1) to teach entrepreneurship education blended with life skills, 2) to promote school connectedness (e.g., a commitment to school, attachment to prosocial peers, belief in schools norms about positive behavior), and 3) to foster supportive relationships between youth, positive peers, and caring adults (Dickens, Dieterich, Henry, & Beauvais, 2012). We culled existing best practices from both Native and non-Native youth entrepreneurship education (see programs "Making Waves" at http://fourbands.org/makingwaves/index.htm and "Network for Teaching Entrepreneurship" at www.nfte.com). Life skills content was drawn from previous curriculum materials and activities developed by tribal-academic partners targeting communication, social problem solving, and cognitive restructuring (Cwik et al., 2016; Barlow et al., 2012; Tingey, Mullany, Strom, Hastings, Lee, et al., 2015).

Research partners chose members of the Apache community to facilitate the entrepreneurship education intervention. Facilitators received rigorous training in the entrepreneurship curriculum and were required to pass competency exams prior to administration. This choice of interventionist broadens the pool of caring adults to which adolescents can connect. Enabling members of the Apache community to learn, practice, and teach entrepreneurship education also builds the local workforce and economy, which further strengthens the program's community-level impact and fosters sustainability.

Research partners and community collaborators embarked on a pilot implementation year to refine the entrepreneurship education program. A pilot cohort of youth participated in the program and provided feedback on curriculum content, method, and schedule of delivery. Together with CAB members, and community collaborators, the research team processed and interpreted this feedback via in-person and phone-based meetings, after which the program structure and curriculum were finalized for implementation and evaluation.

The resulting entrepreneurship education intervention, Arrowhead Business Group-Apache Youth Entrepreneurship Program (ABG), is a 16-lesson curriculum taught via discussion, games, hands-on learning, and multimedia. Approximately 60 hours of training over an 8-month period focus on entrepreneurship and business development, life skills self-efficacy, and finance. Basic math computation skills and literacy are reinforced by training. ABG has varying instructional levels to address literacy challenges and either delayed or advanced academic skills.

Each curriculum lesson is designed for delivery by two adult facilitators (one male, one female) to mixed-gender groups of youth. Many lessons also incorporate presentations by Apache entrepreneurs and community business leaders as well as Elders, who reinforce aspects of Apache culture that promote entrepreneurship and connectedness to positive Apache identity. The first 10 lessons are taught during a 5-day residential summer camp; the last 6 lessons are taught through workshops during the academic year. ABG curriculum is highly experiential and skills based. Youth practice public presentations and social networking skills. They map community assets with a focus on gaps in the local economy and identify opportunities for new businesses. Youth conduct market research and learn branding, marketing, and basic accounting concepts, which are then applied to a hands-on community-based selling event.

The six workshops focus on groups of youth developing small business plans. At the last lesson, youth present their business plans and can be awarded funding for small business startup. Youth who start businesses are then assigned a community-based mentor for continued support. Additional outside mentoring is provided by community volunteers who give ongoing startup advice to youth and their business groups (see Table 1).

Lessor	Lesson Name & Content	Timing
1	Getting Started with Goal Setting Personal strengths, values, goals, building a web of support	Camp
2	Effective Communication and Problem Solving Verbal and nonverbal communication, listening, problem solving	Camp
3	<b>Planning Ahead for a Great Future</b> Graduating high school, building a good resume	Camp
4	Jumpstart Your Savings, Grow a \$Million Saving money, small purchases add up	Camp
5	Basic Budgeting Budgeting, needs, wants, flexible expenses	Camp
6	Our Community Needs Community mapping, products/services, nonprofits, identifying needs	Camp
7	Entrepreneurship Say What? Introduction to entrepreneurship, characteristics of entrepreneurs	Camp
8	Get in the Game: Starting a Business Business opportunity identification, linking business ideas to personal interests/streng	Camp ths
9	<b>It's All in a Name</b> Business names, logos, slogans	Camp
10	The Nuts and Bolts of a Business Plan Components of a business plan	Camp
11	Economic Leaks in Our Community How money moves into and out of the community	Workshop 1
12	Hitting the Bull's Eye: Marketing for Success and Making Your Mark Target market, market research, marketing strategies	Workshop 2
13	<b>Be Yourself</b> Personal strengths, building confidence, resume writing, interview process	Workshop 3
14	<b>Smart Money</b> Personal finance, tracking money, cash flow (aka "business budget")	Workshop 4
15	<b>Community Selling Event</b> Practical application of learned content, community development	Workshop 5
16	The Final Countdown: Presentation Day Public speaking, communication, building confidence, business development	Workshop 6

Table 1 ABG Lessons and Schedule of Implementation

# **Evaluation Design**

The CAB and the Apache Tribal Council and Health Advisory Board endorsed using a 2:1 (intervention:control) randomized controlled design to evaluate ABG intervention impact on psychosocial, behavioral health, educational, and economic outcomes from baseline up to 24

months post-intervention. The study was approved by relevant tribal, Indian Health Service, and University research review boards. This manuscript was approved by the Apache Tribal Council and Health Advisory Board. There is no data safety and monitoring board for this study.

# Participants

Participants are AI adolescents ages 13-16 years who are members of the White Mountain Apache community and are enrolled in a local high school. We are recruiting participants using a nonprobability sampling frame and obtaining informed consent from parents/legal guardians and assent from youth for their study participation.

#### Randomization

A 2:1 allocation ratio is applied to yield twice as many participants in the intervention group as the control condition. While equal randomization (1:1) is the most statistically efficient model, unequal randomization was chosen because increasing the number of youth exposed to ABG's potential benefits was preferred by community leaders. The 2:1 ratio results in a modest loss of statistical power, but enables us to reduce the proportion of study funding spent on the control condition and increases our learning through secondary analyses within the intervention arm (Dumville, Hahn, Miles, & Torgerson, 2006).

# **Control Condition**

Youth randomized to the control condition will participate in simultaneous recreational and art activities held three times during the academic year. Youth randomized to receive the ABG intervention will also receive the control condition in order to attribute differences in outcomes to the ABG intervention. All recreational and art activities are led by Apache community members. All participating youth (intervention and control) will be divided into large mixed-gender groups of approximately 50, to receive the control condition.

# Sample Size

Using a repeated measures design (a minimum of one baseline and two follow-up measures per youth), the total target sample is 600 AI adolescents with 400 youth in the intervention arm and 200 youth in the control arm. This sample size will be sufficient to detect a shift of one fifth of a standard deviation in each of the study's psychosocial scale means with 80% power. Participating youth are being recruited annually in three cohorts (years 1, 2, and 3) with approximately 133 and 66 youth in the intervention and control cohorts each year. We anticipate that roughly 25% of the sample size will be lost to attrition at the final follow-up evaluation timepoint, resulting in a final sample size of 450 (300 intervention, 150 control).

### **Data Collection**

The assessment battery is a series of self-report measures administered via Audio Computer Assisted Self Interview (ACASI) delivered to all participants at baseline, immediately post-intervention, and 6 months, 12 months, and 24 months post-intervention. The assessment battery measures the following domains: 1) *psychosocial*: connectedness, hopefulness/ hopelessness, self-efficacy, locus of control, depressive symptoms; 2) *behavioral health*: alcohol and drug use, sexual risk taking, suicidal behavior, and violence; 3) *educational*: high school attendance, academic achievement (grades, standardized test scores), college and occupational interests; and 4) *economic*: entrepreneurial activity, economic advancement/empowerment, and small business knowledge, including overall intervention satisfaction. All assessments have been selected for their past use among AI populations, pilot tested with Apache youth, and revised to reflect local language, clarity, and flow (see Table 2).

ACASI technology allows participants to complete assessments on a computer with headphones and a corresponding voice reading questions. Research partners have found in the Apache population that self-reporting of sensitive behaviors is more reliable and valid when ACASI technologies are used compared to pencil-and-paper self- or interviewer-administered questionnaires (Mullany et al., 2013; Vereecken & Maes, 2006). ACASI's audio-based technology ensures privacy and confidentiality and also prevents low literacy from being a barrier to data collection. The baseline survey is administered at the time of consent. Local study staff members arrange a confidential location for administration of all remaining follow-up evaluation surveys. Participants receive Wal-mart gift cards (range, \$25-100) after completing each follow up (see Table 2).

Table 2           Data Collection Measures and Time Burden (in minutes)									
Outcome	Measure	Baseline	Post	6 Months	12 Months	24 Months			
<u>I. Psychosocial</u>									
Depressive symptoms	Patient Health Questionnaire 9- (PHQ-9) (Spitzer et al., 1999)	3	3	3	3	3			
Locus of control	Norwicki-Strickland Locus of Control (Nowicki et al., 1973)	10	10	10	10	10			
Social connectedness	Hemingway Measure of Adolescent Connectedness (Lohmeier et al., 2011)	15	15	15	15	15			

Continued on next page

Outcome	Measure	Baseline	Post	6 Months	12 Months	24 Months
Social connectedness, continued	Awareness of Connectedness Scale (Mohatt et al, 2011)	3	3	3	3	3
Life skills self-efficacy	Life Skills Self-Efficacy Scale (LaFromboise et al, 1995)	5	5	5	5	5
Hopelessness/hopefulness	Hopelessness Scale + Apache Hopefulness Scale (Hammond et al., 2009; Kazdin et al., 1986)	5	5	5	5	5
II. Behavioral Health						
Substance use	Youth Risk Behavior Survey (substance use subscales) (Brener et al., 2004)	5	5	5	5	5
Sexual and risk-taking behaviors; violence	Youth Risk Behavior Survey (various subscales) (Brener et al., 2004)	12	12	12	12	12
III. Educational						
School attendance (absenteeism, tardiness), and performance	School Records Review (no time burden)	0	0	0	0	0
College and occupational interest	Across Time Orientation Measure (ATOM) (Nakkula et al., 2003)	4	4	4	4	4
IV. Entrepreneurial and Econo	omic					
Entrepreneurial knowledge and activities	Investigator-developed survey items	3	3	3	3	3
Economic advancement and empowerment	Investigator-developed survey items	5	5	5	5	5
Participant program satisfaction	Investigator-developed survey items	0	10	10	0	0
Total Time Burden:		75	85	75	75	75

 Table 2, Continued

 Data Collection Measures and Time Burden (in minutes)

#### Analysis

Baseline characteristics will be summarized and compared across study groups to assess the success of randomization. Initial analyses will be conducted under an "intent-to-treat" model in which data are analyzed according to study group assignment at randomization (Lavori, 1992; Lavori, Dawson, & Shera, 1995). We will then conduct "completer analyses" on those participants completing at least 50% of intervention lessons. Dichotomous outcomes will be

American Indian and Alaska Native Mental Health Research

evaluated using Fisher's exact tests and logistic regression analysis at discrete timepoints. Some scale items may be assessed continuously; that is, continuous outcomes will be measured at multiple timepoints or accumulated over the course of the study, and evaluated using generalized linear mixed models (GLMM) or survival models (Breslow & Clayton, 1993; McCulloch & Searle, 2001). Model equations will include an indicator for study group (i.e., intervention or control) and a function of time to capture trajectories or thresholds.

Because temporal relationships are not known, exploratory analyses will be conducted to examine shapes of plotted means and confidence intervals for each assessment period. We will fit bivariate GLMMs with treatment and time in order to choose the specification of time with the best model fit, and explore simple and fractional polynomial time functions, categorical specifications and thresholds (Cui et al., 2009; Royston & Sauerbrei, 2008). All analyses will be conducted using STATA, Version 12 with statistical significance at p < 0.05.

#### **RESULTS: PROCESS EVALUATION**

#### **ABG Program Development**

ABG program development was iterative, as we adapted conventional entrepreneurial concepts for the Apache cultural context. Many existing youth entrepreneurship models we explored valued an individual approach to business development. However, in the participating and other AI communities, a collective approach is more appropriate. Thus, the ABG curriculum was designed to promote a cooperative methodology to entrepreneurship and to teach youth how the entire community benefits from business creation. For example, the ABG curriculum includes youth participation in a community-based selling event (i.e., at Tailgate or a basketball game). Profits from these selling events are given back to the community either via charitable contribution or donation to a local entrepreneur.

The ABG program also differs from existing entrepreneurship curricula because it prioritizes building life skills before teaching business and financial literacy. Life skills development is not explicitly included in other national entrepreneurship programs. The CAB stressed an immediate need to build the confidence and self-esteem of ABG program participants; reconnect them to personal, family, and community values; and teach related goal setting and attainment. The first three ABG lessons tie youth to their ancestral heritage as Apaches and AIs and teaches them how having self- and ethnic identity provides a strong foundation for being entrepreneurs. These concepts are expounded in subsequent lessons, which discuss how values and identity impact achievement of short- and long-term goals.

# **ABG Program Delivery**

During pilot implementation, a multipronged feedback process ensured continuous quality improvement of program delivery. Curriculum lesson structure and content were evaluated immediately upon completion of the summer camp and each follow-up workshop. Facilitators completed feedback forms after each lesson, answering questions about lesson timing, flow, content, and additional thoughts. Also, pilot youth participants completed informal feedback forms. Information from facilitator and pilot youth participant feedback forms was brought to group meetings of the research team, which was composed of the curriculum manager, project manager, project coordinator, and facilitators. The research team discussed feedback from youth and staff and identified items for which CAB input was required. Relevant feedback was brought to the CAB for reaching consensus in decision making and edits to the curriculum and its delivery. The following paragraphs highlight several key program changes that were made based on this feedback process.

# **Camp Length**

The first 10 ABG lessons are taught during the residential summer camp. Initially, the camp lasted 3 days and participants arrived on the morning of the first day. During the pilot implementation year, we determined (through the feedback process described above) that 3 days were insufficient to cover all curriculum content and allow enough time for skill building and free play. The camp is now nearly 5 full days, with participants arriving in the evening of the first day for a welcome dinner.

#### **Camp Location**

The camp location also changed from off-reservation in the pilot year to on-reservation at a tribally owned site. Program staff and community collaborators wanted to demonstrate firsthand how the community benefits from hosting the camp, while cultivating pride in the ABG program and connection to the local culture. However, because the camp was the first time many of the youth were away from home for multiple nights in a row, there were concerns before the move that youth might become homesick and would be picked up from the on-reservation site by their families on day 1 or 2, causing them to miss the rest of the experience. During pilot implementation, however, staff noticed homesick youth typically felt much better by midweek and wanted to stay at camp. Because these concerns were mitigated and the community would benefit from hosting the camp, we changed the camp location to be on the reservation.

# Academic Year Workshops

After camp, youth complete workshops. During pilot implementation, we encountered several challenges that led to changes in the workshop structure. Initially, workshop content was organized into 12 additional lessons. Each month for a year, groups of youth participated in one content-rich after-school lesson, after which they attended a hands-on weekend workshop. The after-school lessons and weekend workshops proved difficult to coordinate logistically. Because of extensive transportation needs, especially on weekends, lessons often started very late, not allowing time to complete lesson content and build relationships. In addition, many youth had competing activities (e.g., sports, family commitments). Youth also were not engaged in these workshops. Via feedback from pilot youth, we learned that content-heavy lessons taught after school felt too much like being in class. Program staff also realized that weekend lessons did not focus enough on the youths' own business plan development. Lesson content in general was not interactive enough to maintain youth interest.

Thus, the workshop curriculum was restructured into six lessons (3-4 hours each), delivered once per month and including a meal. Workshops have a flexible delivery structure and can be hosted after school, during the evenings, or on weekends, depending on the participating youth and co-occurring community events. ABG core curriculum content is taught at camp, allowing the six follow-up workshops to be tailored to the youth and their specific business plans. Workshop activities are hands-on, building on concepts taught at camp in a simulation context (youth work together to create a mock business to apply their new skills). Further support for business plan development was added to the curriculum in the form of business plan templates, which are highly visual, step-by-step guides that are broken down by business plan section to help youth develop a competitive plan.

# **Target Participant Age**

Existing youth entrepreneurship programs typically target older adolescents and young adults, as some curriculum concepts (e.g., finance, accounting) are advanced. During the pilot year, we found younger participants (~ages 13-16 years) were more engaged in the learning process than were older youth. Also, enrolling younger youth enables longer-term follow up and support during critical transition periods (middle school to high school and high school to

college). The Apache community suffers from high rates of school dropout; thus, shifting our target population to youth ages 13-16 years was endorsed by members of the CAB to promote school attendance and college matriculation.

## CONCLUSION

Entrepreneurship education is a promising model of positive youth development to promote life skills and school connectedness and to reduce high risk behaviors in AI communities. Evaluation of such a program is a highly innovative approach to substance use and suicide prevention with potential for replication in other Indigenous and similarly stressed communities. If study aims are achieved, the field will have a new strength-based strategy to reduce adolescent substance use and suicide, the largest health disparities faced by AI communities. Immediate impacts promoting educational and occupational aspirations will deepen understanding of employing strengths and resiliency factors in research, as well as support the health, well-being, and improvement of socioeconomic conditions in AI communities.

Many AI and Indigenous communities are dismayed by research that emphasizes negativity and problems, and evaluation of positive youth development interventions for impacts on substance use and suicide is rare (O'Keefe & Wingate, 2013; SAMHSA CAPT, 2015; Stiffman et al., 2007; Whitlock et al., 2014). Recognizing that connectedness is a fundamental focal point of Indigenous cultures and value systems, coupled with a simultaneous call to promote marginalized communities engaging in productive economic activities, investment in a groundbreaking approach such as entrepreneurship education for substance use and suicide prevention is justified (Allen, Mohatt, Fok, & Henry, 2009; Allen et al., 2006; Mohatt et al., 2004; Struthers et al., 2003).

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# 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 wellnesspromoting 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 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 coinvestigator 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			
	•	Men ( <i>n</i> = 12)	Women ( <i>n</i> = 12)
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%)

Tabla 1

<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, Hovt, & 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., mathrelated 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 colearn. 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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