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# MENTAL HEALTH SERVICE AND PROVIDER PREFERENCES AMONG AMERICAN INDIANS WITH TYPE 2 DIABETES

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Abstract: In this study, we investigated mental health service and provider preferences of American Indian adults with type 2 diabetes from two tribes in the northern Midwest. Preferences were determined and compared by participant characteristics. After controlling for other factors, living on reservation lands was associated with increased odds of Native provider preference, and decreased odds of biomedical service preference. Anxiety also was associated with decreased odds of biomedical service preference. Spiritual activity engagement and past health care discrimination were associated with increased odds of traditional service preference. We discuss implications for the types of mental health services offered and characteristics of providers who are recruited for tribal communities.

## INTRODUCTION

American Indians and Alaska Natives (AI/ANs) experience disparities in diabetes and mental health compared to the general U.S. population. As a group, AI/ANs have the highest age-adjusted prevalence of diabetes of any racial/ethnic group in the U.S. (Blackwell, Lucas, & Clarke, 2014; Centers for Disease Control and Prevention, 2011), with higher rates of disease complications (e.g., hypertension, cerebrovascular disease, renal failure, lower-extremity amputations, and liver disease; Barnes, Adams, & Powell-Griner, 2010; O'Connell, Yi, Wilson, Manson, & Acton, 2010). AI/ANs also experience higher lifetime rates of post-traumatic stress disorder (Beals et al., 2005), and substance use disorders (Beals et al., 2005; Whitbeck, Hoyt, Johnson, & Chen, 2006; Whitbeck, ManSoo, Johnson, Hoyt, & Walls, 2008). AI/AN elders also have been found to report poorer mental health as compared to non-Hispanic Whites (Kim, Bryant, Goins, Worley, & Chiriboga, 2012). In a 2007 sample, AI/AN elders reported the highest rates of serious psychological distress of any ethnic

group (Kim, Bryant, & Parmelee, 2012). The risk for co-occurrence of substance abuse, depression, and diabetes is over 12 times higher for AI/ANs than for Whites (Tann, Yahiku, Okamoto, & Yanow, 2007). Prior literature has established the relationship between diabetes and mental health (e.g., depression, alcohol dependence, psychosocial stressors) among AIs (Jiang et al., 2007, 2008). Given the evident need for mental health services, this study aims to determine the preferences for mental and emotional health services and providers among AIs with type 2 diabetes.

For the general U.S. population, those with diabetes are more likely than those without to have depression and anxiety (Anderson, Freedland, Clouse, Lustman, 2001; Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002; Li et al., 2008; Lin & Korff, 2008). Individuals with diabetes and co-occurring depression have greater health care expenditures, more emergency room visits and hospitalizations, and poorer treatment adherence (Ciechanowski, Katon, & Russo, 2000; Egede, 2007; Egede, Zheng, & Simpson, 2002). Comorbid diabetes and mental health problems are associated with decreased quality of life, increased activity impairment (Egede, 2004; Goldney, Phillips, Fisher, & Wilson, 2004), and more complications from diabetes (De Groot, Anderson, Freedland, Clouse, & Lustman, 2001). Perhaps most alarming, individuals with diabetes and mental health problems experience higher rates of diabetes-related mortality compared to those without mental health problems (Egede, Nietert, & Zheng, 2005; Katon et al., 2005; Mai, Holman, Sanfilippo, Emery, & Preen, 2011). Literature evaluating co-occurring mental health problems among AI/ ANs with diabetes similarly suggests worse diabetes-related outcomes compared to those without mental health problems (Calhoun et al., 2010; Knaster, Fretts, & Phillips, 2015; Sahota, Knowler, & Looker, 2008; Singh et al., 2004; Walls, Aronson, Soper, & Johnson-Jennings, 2014). Due to the importance of emotional well-being for diabetes care, the American Diabetes Association (2015) recommends assessment and appropriate referral for psychosocial problems such as depression, diabetes-related distress, and anxiety. For individuals with co-occurring diabetes and mental illness, mental health treatment is important for diabetes management.

Among AI/ANs, poor treatment outcomes, limited use of services, and higher dropout from mental health treatment may be due to inadequate options matching their service preferences (Coyhis & Simonelli, 2008; Gone, 2004; Gone & Trimble, 2012; Johnson & Cameron, 2001; LaFromboise, 1988; Rodenhauser, 1994). Preferences for both service and provider influence the decision to initiate treatment (King et al., 2005), and can affect dropout and overall treatment outcomes (Swift & Callahan, 2009; Swift, Callahan, & Vollmer, 2011). As such, it is important to investigate the preferences for service and provider in order to improve the design and delivery of mental health services.

#### **Mental Health Service Preference**

We use the term *biomedical services* to refer to institutionalized biomedical and psychiatric services, sometimes referred to as 'Western' medicine. Despite an established need for mental health services, Indian Health Service physicians perceive low rates of access to high-quality, biomedical outpatient mental health services for their patients (Sequist et al., 2011). We use the term *traditional services* to refer to AI/AN traditional cultural outlets, such as talking with elders, offering tobacco and praying, consulting traditional healers, and participating in traditional ceremonies.

Prior work suggests AI/ANs may prefer Indigenous-based traditional services as opposed to biomedical services (Beals et al., 2005; Gone, 2004; Hodge, Limb, & Cross, 2009; Thomason, 2011; Walls, Johnson, Whitbeck, & Hoyt, 2006). In a community sample of reservation-dwelling AIs, more endorsed traditional services as very or extremely effective as compared to biomedical services located both off and on the reservation. After controlling for demographic factors, higher levels of enculturation and discrimination were significantly associated with perceived effectiveness of traditional services (Walls et al., 2006). Over 38% of an urban AI sample used a healer (including spiritual healer, herbalist, medicine woman or man, and elder) in addition to care from a biomedical health care provider, and the overwhelming majority of those who did not would consider seeing a healer in the future (Marbella, Harris, Diehr, Ignace, & Ignace, 1998). For those who had used a healer and obtained advice that differed from their biomedical health care provider, 61.4% rated their healer's advice as more important (Marbella et al., 1998). In a study of college students' treatment preferences, AN students were more likely to endorse community elder, and less likely to endorse psychiatrist, compared to Caucasian students (Stewart, Swift, Freitas-Murrell, & Whipple, 2013). Among AI college students, those strongly committed to tribal culture had more negative attitudes toward seeking counseling, compared to those weakly committed to tribal culture (Price & McNeill, 1992). The American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project examined rates of service utilization for biomedical and traditional services among a tribally enrolled sample of AIs from a Southwest tribe and a Northern Plains tribe. Use of traditional services was prevalent for physical and psychiatric problems, and was associated with traditional spirituality and AI identity (Novins, Beals, Moore, Spicer, & Manson, 2004). For individuals from the Northern Plains tribe, use of traditional services for psychiatric problems was associated with living on reservation for a longer percentage of life (Novins et al., 2004). Among those from the Southwest tribe, more had used traditional or spiritual healers for psychiatric and substance abuse in their life than had used biomedical providers (Beals et al., 2005). Of participants in the study, 50% had used biomedical services in the past year for substance use problems, 42% had used traditional

services, and 39% had used 12-step programs (Beals et al., 2006). Those who had used traditional services were more likely to identify with AI/AN culture than were those who used biomedical services only (Beals et al., 2006).

## **Provider Preference: Patient-provider Concordance**

Another important element of provider preference is concordance between the patient/ client and the psychotherapist/counselor, or the degree of similarity between the two. While some past results have called into question the clinical relevance of racial/ethnic matching (Maramba & Nagayama-Hall, 2002; Presnell, Harris, & Scogin, 2012; Shin et al., 2005), others have shown positive outcomes from racially concordant psychotherapy pairs compared to dissimilar pairs (Rickler, Nystul, & Waldo, 1999). When clients' preferences are met, dropout is lower and greater improvements in outcomes are made (Swift et al., 2011). This finding may be due to race serving as a proxy for cultural concordance (Moscou, 2008). A wealth of literature suggests that individuals prefer mental health providers with similar characteristics, including similar personality, values, and attitudes (Atkinson, Furlong & Poston, 1986; Atkinson, Poston, Furlong, & Mercado, 1989; Atkinson, Wampold, Lowe, Matthews, & Ahn, 1998; Ponterotto, Alexander, & Hinkston, 1988).

A meta-analysis of client-psychotherapist racial/ethnic concordance reported a moderately strong effect size for racial/ethnic concordance (Cabral & Smith, 2011). Another meta-analysis intimated ethnic minorities' preference for a racially/ethnically concordant psychotherapist, and suggested that cultural affiliation influences preference for a concordant provider (i.e., those with higher ethnic identity, cultural commitment, or cultural identification were more likely to prefer a provider of the same racial/ethnic background; Coleman, Wampold, & Casali, 1995). Indeed, other studies have shown that cultural factors strengthen the preference for racial/ethnic concordance (Coleman et al., 1995; Helms & Carter, 1991; Sanchez & Atkinson, 1983). In a study with AI/AN college students, participants indicated a preference for a psychotherapist with attitudes and values that matched their own; this finding was particularly true for individuals with a stronger sense of cultural involvement (Bennett & BigFoot-Sipes, 1991; BigFoot-Sipes, Dauphinais, LaFromboise, Bennett, & Rowe, 1992). AN college students demonstrated a stronger preference for a provider with a similar ethnicity compared to Caucasian students (Stewart et al., 2013). Those AN students with higher cultural identification had a greater preference for a provider of similar religious background and socioeconomic status compared to AN students with lower cultural identification (Stewart et al., 2013). Like race/ethnicity preference, gender preference may correlate with presumed similarities of gender concordant psychotherapists. AI/AN female college students strongly preferred a female AI/AN psychotherapist (BigFoot-Sipes et al., 1992).

In summary, both service type and provider characteristics are important considerations in providing mental health services. Frequently, prior research examined service and provider preferences in isolation of one another. In addition, studies with AI/ANs have focused largely on college student and community-based samples. We build upon prior research by surveying both service and provider preference in tandem in a population of AIs with a chronic disease, type 2 diabetes. Given the documented influence of mental health on diabetes outcomes, understanding and responding to the mental health treatment preferences of AIs with diabetes has the potential to improve care and outcomes for both diabetes and mental health.

#### **METHODS**

#### **Study Design**

The Mino Gizhigad (A Good Day) Study is a community-based participatory research project with the Lac Courte Oreilles and Bois Forte Bands of Chippewa and the University of Minnesota Medical School, Duluth campus. Both tribal communities consented to be named in public dissemination of research findings. The purpose of the overall study was to identify and describe the impact of mental and behavioral health factors on diabetes treatment and outcomes among Ojibwe adults with type 2 diabetes. Tribal resolutions from both communities were obtained prior to submission of the application for funding. The project began with community feasts and forums to discuss the study goals, obtain community feedback, and establish Community Research Councils. Community Research Council and University team members were active participants in the entire research process, from methodological planning to final data collection and analysis. The University of Minnesota and Indian Health Service National Institutional Review Boards reviewed and approved the methodology included in this study.

#### Sample

Potential participants were randomly selected from each reservation's health clinic records. Inclusion criteria were patients 18 years or older, type 2 diabetes diagnosis, and self-identified as AI. Clinic partners were trained on probability sampling methods to generate a random sample of 150 patients from their lists. Selected patients were mailed a welcome letter, an informational project brochure, and a contact information card with mail and phone-in options to decline participation. After allowing time for declined notices, trained community interviewers contacted remaining recruits to schedule interviews. Consenting participants were given a pound of locally cultivated wild rice

and a \$30 cash incentive. Paper-and-pencil, interviewer-administered surveys were completed in participants' location of choice, most often in private spaces within homes. The time to complete each survey ranged between approximately 1.5-3 hours.

Prior to sending to the university-based team, the on-site project coordinator coded and removed all participant identifying information from the survey. All survey data were entered and verified in electronic format by university research assistants. Of the participants, 218 out of 289 sampled individuals agreed to participate and completed surveys, with a final study response rate of 75.4%.

#### Measures

#### **Service Preference**

Perceived effectiveness of mental health services was assessed with the question: "Do you feel that [service type] can be of great help with an emotional or personal problem?" with three response options: 1 = Yes, 0 = No, and 0 = Don't know. "Don't know" was included as a negative response because it is a valuable piece of information: a disconfirmation of perceived efficacy of the service. The service types that were asked about were: family doctor, mental health professional, tribal elder, traditional healer, family member, pastor/priest/minister, 12-step meetings, and Internet. Comfort was addressed by asking, "How comfortable would you feel [talking/going to this service] about problems like these?" Response categories consisted of a 3-point Likert scale with response options of Very comfortable, Somewhat comfortable, and Not at all comfortable, as well as Don't know. We collapsed these response categories into a dichotomous variable (1 = Very comfortable, 0 = Somewhat comfortable, Not at all comfortable, and Don't know). We created a new dichotomous variable, service preference, to describe those who perceived a service as effective and were very comfortable with it (Perceived effectiveness = 1 and Comfort = 1), and those who did not (Perceived effectiveness = 0 and/or Comfort = 0).

We computed two new variables by grouping together service preferences to understand how individuals who preferred bundles of similar services compared to those who did not. *Traditional service preference* was composed of participants who indicated a service preference for both traditional healer and tribal elder. *Formal service preference* was composed of those who indicated a service preference for both mental health professional and family doctor.

## **Provider Preference**

Provider Gender Preference was assessed with an item asking participants, "If you went for counseling, would you prefer a male or female counselor?" Response categories consisted of Male, Female, and No preference. Native Provider Preference was assessed by asking participants

"If you went for counseling, would you prefer speaking to an American Indian/Native counselor?" with a *Yes/No* response. We also asked "Do you know the proper way to ask a traditional healer for help?" with a *Yes/No* response.

## **Independent Variables**

Depressive symptoms were measured using the Patient Health Questionnaire (PHQ-9), a 9-item instrument assessing depressive symptoms in the previous 2 weeks (Kroenke, Spitzer, & Williams, 2001; Spitzer & Kroenke, 1999). Responses range from 0 to 3 (0 = Not at all, 1 = several days, 2 = More than half the days, and 3 = Almost every day), with a possible range from 0 to 27. A score of 10 or higher was used as criterion of depression (Gilbody, Richards, Brealey, Hewitt, 2007). The PHQ-9 had an internal consistency of 0.90 in this sample. Anxiety was assessed using the 21-item Beck Anxiety Inventory (BAI), which quantifies the degree of impact of anxiety symptoms (Beck, Epstein, Brown, & Steer, 1988). Responses range from 0 to 3 (0 = Not at all, 1 = Mildly, 2 = Moderately, and 3 = Severely bothered), with a possible range from 0 to 63. A BAI score between 16 and 25 indicates moderate anxiety, and scores above 26 indicate severe anxiety. The BAI had an internal consistency of 0.95 in this sample.

Participation in *traditional spiritual activities* was assessed with nine Yes/No format questions assessing engagement in a variety of traditional spiritual activities (e.g., offered tobacco, used traditional medicine, smudged or saged). Responses were coded as 0 = No, and 1 = Yes, with a summed range of responses from 0 to 9. The internal consistency of this measure was 0.79 in this sample.

Health care discrimination was assessed by asking participants if there was a time they felt they would have received better care if they belonged to a different race/ethnic group, coded as  $0 = N_0$ ,  $1 = Y_{es}$ .

## **Demographic Variables**

Gender was coded as 0 = Male, 1 = Female. Although participants utilized care at medical clinics located on the reservation, not all lived on reservation lands. This difference was controlled for with a variable, where 0 = Off reservation, and 1 = On reservation. We controlled for potential differences between the two locations with a dummy variable (0 = Location 1; 1 = Location 2). Respondents reported *per capita household income* as \$10,000 ranges; the midpoint of these ranges divided by the number of people living in the household was used as the final measure. Participants were asked to self-report their *number of years with diabetes* and *age* in years.

#### Statistical methods

We analyzed data using SPSS, version 20. Descriptive statistics summarized service and provider preferences, depressive and anxiety symptoms, traditional spiritual activities, health care discrimination, and other demographic characteristics. To investigate the relation between service and provider preferences, we calculated phi coefficients, a measure of association between dichotomous variables. We used chi-square tests to determine the bivariate relationship between preferences and gender, living on reservation lands, traditional spirituality, depressive symptoms, anxiety, and health care discrimination, and logistic regression to investigate the multivariate relationship between these participant characteristics and traditional service preference, formal service preference, and preference for a Native provider. Multiple imputation of missing values was performed for predictor variables, with missing values ranging from 0% to 4.13% per variable. We generated five imputed datasets using fully conditional specification with logistic or linear regression where appropriate, and used the pooled data for regression analyses. Three participants had missing values on outcome variables (service and provider preferences); thus, a total of 215 cases were included in the final multivariate models.

#### **RESULTS**

Participants were, on average, 57 years old and reported having had type 2 diabetes for 15 years. Approximately 78% lived on reservation lands, 56% were female, and the mean annual per capita household income was \$10,331. Using a cutoff score of 10 or higher on the PHQ-9, 17.1% of the participants met criteria for depression. Nearly one quarter of those participating in this study met criteria for moderate (12.9%) or severe anxiety (12%), based upon BAI scores of 16-25 and 26 and above, respectively. The mean score for traditional spiritual activities was 2.71, with 51.4% participating in two or fewer activities and 48.6% participating in three or more activities. Seventy-nine percent of participants indicated they would prefer a Native provider (i.e., a counselor with similar race/ethnicity) if they needed counseling. Just over half (60.2%) knew the proper way to ask a traditional healer for help.

Perceived effectiveness of, comfort with, and overall preference for traditional, biomedical, and other mental health services are displayed in Figure 1. All services were deemed effective by over half of participants (56.3%-69%), except the Internet, which was perceived effective by only 22.7%. The percentage of participants reporting that they were very comfortable with the services ranged from approximately 20% for 12-step meetings, Internet, and pastor/priest/minister, to approximately 40% for family members, traditional healers, family doctors, and tribal elders. When both effectiveness and comfort were taken into account, family members were the most preferred service (41.7%), while the Internet was least preferred (13.9%).

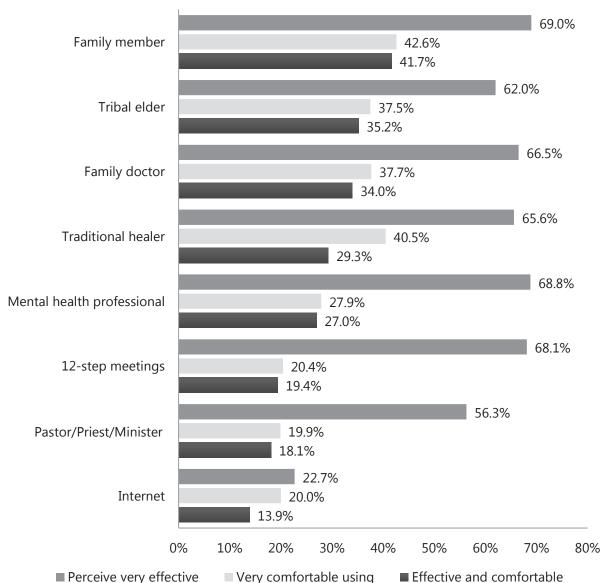


Figure 1
Service preference for help with emotional or personal problems

Table 1 shows the Phi coefficients for the dichotomous service and provider preferences. In general, preference for one service was correlated with most other services. Preference for a tribal elder was highly correlated with preference for a traditional healer. Native provider preference was associated only with preference for a tribal elder, a traditional healer, and a family member.

	1	2	3	4	5	6	7	8	9
1. Tribal Elder	1								
2. Traditional Healer	.858***	1							
3. Family Member	.269***	.282***	1						
4. Mental Health Professional	.215**	.230**	.206**	1					
5. Family Doctor	.238***	.207**	.168*	.383***	1				
6. Pastor, Priest, or Minister	.086	.015	.163*	.231**	.198**	1			
7. Internet	.240***	.213**	.148*	.058	.136*	.054	1		
8. 12-Step Meetings	.206**	.250***	.153*	.414***	.192**	.164*	.039	1	
9. Native Provider Preference	.152*	.155*	.147*	015	014	.009	001	.057	1

Table 1
Phi coefficients for Service and Provider Preference

Table 2 shows the differences between service and provider preferences based upon participant characteristics. Significant gender differences existed for provider gender preference, with women having a higher proportional preference for a female counselor (p < 0.001). A higher proportion of those living on reservation lands preferred a Native provider compared to those living off reservation (p = 0.001), and fewer living on reservation indicated a formal service preference (p = 0.016). More of those with higher traditional spirituality, defined as three or more traditional spiritual activities, indicated both a traditional service preference (p < 0.001) and Native provider preference (p = 0.010). No significant differences were detected between those with or without depressive symptoms; however, fewer of those with moderate or severe anxiety indicated a preference for biomedical services (p = 0.017). Significant differences emerged for anxiety status and provider gender preference, with a numerically higher proportion of those with anxiety symptoms preferring a female counselor (p = 0.033). Due to the high rate of anxiety in females in this study and the strong preference for a female provider among females, a post hoc chi-square test on anxiety and provider gender preference was performed separately for males and females, with non-significant results (male, p = 0.133; female, p = 0.371). Lastly, more of those who had experienced health care discrimination preferred traditional services (p = 0.006).

The results of logistic regressions for Native provider preference, traditional service preference, and biomedical service preference are shown in Table 3. We conducted multivariate analyses adjusting for gender, location, on reservation, per capita annual income in thousands, years with diabetes, and age. After controlling for other factors, summed spiritual activities was not significantly associated with Native provider preference (OR, 1.16; 95% CI, 0.99-1.36), and living on reservation was associated with increased odds of preferring a Native provider (OR, 3.32; 95%

<sup>\*</sup> p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001

CI, 1.49-7.40). Both summed spiritual activities (OR, 1.30; 95% CI, 1.12-1.52) and health care discrimination (OR, 2.59; 95% CI 1.24-5.39) were associated with increased odds of traditional service preference. Moderate and severe anxiety were associated with decreased odds (OR, 0.24; 95% CI, 0.06-0.91) of biomedical service preference, as was living on reservation lands (OR, 0.35; 95% CI, 0.05-0.80).

Table 2
Chi-Square Tests for Service and Provider Preference by Participant Characteristics

		Ser	tional vice rence	Biomedical Service Preference		Native Provider Preference		Provider Gender Preference			
	_	%	р	%	р	%	р	No Pref %	Male %	Female %	р
Candan	Male	29.5	0.5.5	12.6	111	75.8	400	64.9	23.4	11.7	.000
Gender	Female	28.3	.855	20.8	.114	71.7	.496	50.8	5.1	44.1	
Reservation	Off	26.5	.685	28.6	.016	55.1	.001	65.3	14.3	20.4	.263
Reservation	On	29.5	.003	13.9	.010	78.9		54.6	12.9	13.2	
Traditional	Low	17.0	.000	14.3	226	66.1	.010	57.1	14.3	28.6	.855
Spirituality <sup>a</sup>	High	41.7	.000	20.4	.236	81.6		57.0	12.0	31.0	
Depressive	No	28.9	.970	17.8	617	72.8	F02	60.1	12.9	27.0	.096
Symptoms <sup>b</sup>	Yes	28.6	.970	14.3	.617	77.1	77.1	41.2	14.7	44.1	
American	No	29.5	0.40	20.5	017	72.4 76.0 .620	57.4	16.1	26.5	.033	
Anxiety <sup>c</sup>	Yes	28.0	.840	6.0	.017		54.2	4.2	41.7		
Health Care	No	24.2	006	16.1	400	70.8	150	58.2	15.2	26.6	.110
Discrimination	<sup>d</sup> Yes	44.2	.006	21.2	.408	80.8	.158	51.9	7.7	40.4	

<sup>&</sup>lt;sup>a</sup> High participation in traditional spiritual activities defined by three or more activities. <sup>b</sup> Depressive symptoms defined by a score of 10 or higher on the Patient Health Questionnaire 9-item. <sup>c</sup> Anxiety defined by a score of 16 or higher on the Beck Anxiety Inventory. <sup>d</sup> Participants indicating there was a time they felt they would have received better care if they belonged to a different race/ethnic group.

Table 3
Results of Logistic Regression of Service and Provider Preference

	Native F Prefe		Traditiona Prefer		Biomedical Service Preference		
	Odds Ratio 95% CI		Odds Ratio 95% CI		Odds Ratio 95% C		
Gender (1 = female)	0.70	0.36-1.34	0.91	0.47-1.75	1.81	0.80-4.10	
Location	1.04	0.52-2.08	1.09	0.56-2.12	1.08	0.47-2.46	
On Reservation (1 = yes)	2.99***	1.37-6.54	1.23	0.54-2.82	0.35**	0.14-0.85	
Per capita income (thousands)	0.98	0.95-1.02	1.00	0.96-1.03	0.98	0.94-1.03	
Years with diabetes	1.01	0.98-1.04	0.99	0.96-1.02	1.00	0.96-1.03	

continued on next page

	Native F Prefe		Traditiona Prefer		Biomedical Service Preference		
	Odds Ratio 95% CI		Odds Ratio 95% CI		Odds Ratio	95% CI	
Age	1.01	0.98-1.03	0.98	0.95-1.01	1.03*	1.00-1.07	
Spiritual activities summed score	1.15*	0.98-1.34	1.29***	1.11-1.50	1.12	0.94-1.32	
Depressive symptoms (1 = yes)	1.10	0.42-2.90	0.68	0.27-1.72	1.05	0.33-3.36	
Moderate/severe anxiety (1 = yes)	1.01	0.44-2.31	0.59	0.25-1.38	0.21**	0.05-0.80	
Health care discrimination (1 = yes)	1.80	0.78-4.14	2.72***	1.33-5.58	1.67	0.69-4.08	
Constant	0.74		0.59		0.05		

Table 3, Continued
Results of Logistic Regression of Service and Provider Preference

#### **DISCUSSION**

This study illuminates the mental health treatment preferences among AIs with type 2 diabetes from two northern Midwest tribal communities. Given the high rates of mental health conditions among those with diabetes (Anderson et al., 2001; Grigsby et al., 2002; Li et al., 2008; Lin & Korff, 2008) and the negative consequences of mental health conditions on diabetes outcomes among AI/ANs (Knaster et al., 2015; Sahota et al., 2008; Singh et al., 2004; Walls et al., 2014), the investigation of mental health treatment preferences has great importance. We investigated the rates of perceived effectiveness of and comfort with multiple mental health services, and created a composite service preference for those services that were endorsed as both effective and very comfortable. We explored how service and provider preferences were related, and investigated the bivariate and multivariate relationships among traditional service preferences, biomedical service preference, and provider preferences with several participant characteristics.

We found that the majority of participants in this study perceived all but the Internet as effective for help with an emotional or personal problem; however, fewer felt very comfortable using the services (Figure 1). Family members were perceived as the most effective and most comfortable preferred service. There was no clear distinction between biomedical service preference (i.e., mental health professional and family doctor), and traditional service preference (i.e., tribal elder and traditional healer), in contrast with a prior community-based sample of AI/ANs, where more individuals perceived traditional services as effective compared to biomedical services (Walls et al., 2006). Much of the prior research has utilized probability or convenience samples with entire communities/tribal rolls serving as sampling frames. Notably, our sample included only individuals

p < 0.10; p < 0.05; p < 0.01

who were identified through medical records, meaning they had used the biomedical health system. As such, our sample may be biased to prefer biomedical services or blended care for mental and emotional health problems compared to those who have not used biomedical services. Additionally, differences in measurement of effectiveness may explain some differences between our results and those of prior work. Walls and colleagues (2006) measured effectiveness on a scale from *Not at all effective* to *Extremely effective*, and collapsed "Very" or "Extremely" effective to ascertain the perceived effectiveness of services; our measure of effectiveness was either yes or no, failing to capture varying levels of effectiveness across services.

Bivariate phi coefficients provide a picture of the relationship between different service and provider preferences (Table 1). For instance, preference for a mental health professional was most strongly correlated with preference for a family doctor and 12-step meetings, while preference for traditional healer was most strongly correlated with preference for a tribal elder. On the other hand, Native provider preference was associated only with service preference for a tribal elder, a traditional healer, and a family member. These results hint that different clusters of patients may exist, with some preferring traditional, some preferring biomedical, some open to both, and some not endorsing either. Further research is needed to characterize these groups and evaluate their patterns of service utilization.

#### Service Preference

In Table 2 and Table 3, we evaluated the impact of various participant characteristics on both service and provider preferences. More of those with higher traditional spirituality, and more of those having an instance of health care discrimination, preferred traditional services (i.e., tribal elder and traditional healer), even after controlling for other factors. Each additional spiritual activity was associated with 1.29 times higher odds of traditional service preference, and having a past incident of health care discrimination was associated with 2.72 higher odds of traditional service preference, consistent with prior literature (Beals et al., 2006; Novins et al., 2004; Walls et al., 2006). A recent study investigating potential differences between younger-old AI adults (ages 50-64 years) and older-old AI adults (ages 65 years and older) identified important predictors of attitudes toward mental health services (Roh et al., 2015). For the younger group, being female and having more social support were associated with better attitudes, while perceptions of the stigma associated with mental health service use were associated with worse attitudes (Roh et al., 2015). For the older group, having health insurance was associated with better attitudes, while age and each additional chronic disease were associated with worse attitudes (Roh et al., 2015). While this study did not measure cultural identity, it elucidated several other important correlates that can impact mental health attitudes, and showed that these may differ by age cohort.

After controlling for other factors, we found those with anxiety had 79% lower odds of biomedical service preference compared to those without, suggesting that those with a demonstrated need for mental health treatment are less open, or more averse, to formal care. Those living on reservation lands had 65% lower odds of preferring biomedical services compared to those living off reservation. This is an important consideration for health clinics on reservation lands; those who live on the reservation and have used the clinic for diabetes management in the past may not find the customary medical services offered acceptable for mental and emotional problems. These findings in tandem underscore the need to provide acceptable alternatives and access points for mental health treatment, reaching and caring for patients in ways and places they want.

#### **Provider Preference**

Significant gender differences existed in regards to provider gender concordance, with females demonstrating a preference for a female provider. This finding mirrors prior literature (BigFoot-Sipes et al., 1992). Significant differences in provider gender preference also were seen for those with and without anxiety. Results of our initial bivariate analysis seem to suggest that a higher proportion of those with anxiety preferred a female provider than did those without anxiety, but no differences were found between anxiety and provider gender preference when males and females were analyzed separately. The difference in provider gender preference by anxiety in this study appears to be an artifact of the difference between genders.

The overwhelming majority (79%) of participants in this study indicated they would prefer a Native provider. More participants living on reservation, and more of those with higher traditional spirituality, preferred a Native provider should they need to use one. This finding mirrors research among AI/AN college students; those who had stronger Indigenous cultural affiliation preferred counselors who shared similar cultural attitudes and values (Bennett & BigFoot-Sipes, 1991; BigFoot-Sipes et al, 1992; Johnson & Lashley, 1989; Stewart et al., 2013). After controlling for other factors, higher participation in spiritual activities had a non-significant odds of 1.15, while living on reservation was associated with 2.99 times higher odds of preferring a Native provider. This finding implies the need to support efforts to train and supply AI/AN reservation communities with Native providers.

Racial concordance often has been proposed as a proxy for culturally sensitive care (van Ryn & Burke, 2000), and could prove vital for decreasing co-occurring mental health and diabetes disparities among AIs. Prior research suggests that AI patients with higher self-reported ethnic identity rated racially different providers lower for several aspects of the medical interaction (Garroutte, Sarkisian, Goldberg, Buchwald, & Beals, 2008). When the provider and patient are racially concordant, the quality of the provider-patient interaction and the patient health outcomes

are positively impacted (Powe & Cooper, 2004; Saha, Taggart, Komaromy, & Bindman, 2000). Increasing the availability of AI mental health providers may enable AIs with type 2 diabetes and mental health problems to have a more positive view of treatment and to benefit from improved outcomes. In addition, racial concordance may significantly positively influence patients' perceptions of health care relationships (Blanchard, Navar, & Lurie, 2007) and, given that effective mental health services rely on building the therapeutic alliance and interpersonal relationship (Allen, Lewis, & Johnson-Jennings, 2016; Wampold, 2001; Wampold, Imel, Bhati, & Johnson-Jennings, 2006), it may positively influence mental health service outcomes (Green et al., 2003), especially among tribal members. Racial concordance also has been seen to significantly influence important health care satisfaction factors in the patient-provider relationship (Saha, Komaromy, Koepsell, & Bindman 1999). Hence, racial concordance in mental health treatment may be of high importance among Als who have type 2 diabetes and mental health needs. The Institute of Medicine has suggested increasing the percentage of racial/ethnic minority providers, including AI/ANs, to decrease health disparities. Racially concordant relationships are argued to improve provider-patient communication, improve patient adherence, and, ultimately, improve health care outcomes based on shared cultural values, beliefs, and experiences (Betancourt, Green, & Carrillo, 2002; Institute of Medicine, 2003).

## Limitations

The results of this study must be interpreted in light of the limitations and context of the study design. Our cross-sectional study design precludes temporal inferences, making it difficult to declare causality. Given the diversity that exists among tribal groups across the U.S., this study may not generalize to other AI/AN communities. While 22% of our participants did not live on reservation lands, they were sampled from a reservation clinic and lived near the reservation. As such, urban AI/ANs and those attending urban Indian Health Service facilities are not fully represented in this study. This research assessed comfort with and perceived efficacy of services, but failed to capture actual utilization of these services; there may be differences between subjective reports of preference and actual use.

#### CONCLUSIONS AND FUTURE DIRECTIONS

This study addressed an important area of mental health service preference and patient-provider concordance among AIs with type 2 diabetes. Overall, these findings suggest that AI/ANs with type 2 diabetes who have utilized biomedical services may prefer racially concordant providers and traditional services for mental health problems. We also found a strong preference for family members for help with an emotional or personal problem (regarding both perceived efficacy and

comfort level). Thus, racial concordance, traditional forms of healing, and familial preference are important constructs to examine while conducting mental health research among AI/ANs. A need exists for increasing promotion and training of AI/AN mental health providers in educational settings, and for training family members to provide informal mental health support. Furthermore, given it is unlikely that racially concordant providers could serve all AI/AN patients, cultural training for non-AI/AN providers and integration of traditional healing practices into the clinic setting could improve care. In doing so, tribally provided health services may work congruently and complimentarily with the health beliefs of patients whose culture may differ from conventional biomedical health care.

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# NATIVE VOICES: ADAPTING A VIDEO-BASED SEXUAL HEALTH INTERVENTION FOR AMERICAN INDIAN TEENS AND YOUNG ADULTS USING THE ADAPT-ITT MODEL

Stephanie Craig Rushing, PhD, MPH and Wendee Gardner, MPH

Abstract: American Indian and Alaska Native (AI/AN) youth experience disproportionate rates of sexually transmitted infections (STIs). Despite their need for culturally appropriate sexual health interventions, few evidence-based programs have been designed for or rigorously evaluated with AI/AN youth. The primary goal of this study was to adapt a videobased HIV/STI intervention for AI/AN teens and young adults (15-24 years old) living in urban and reservation settings. To capture the heterogeneous experience of AI/AN youth, as well as the viewpoints of adult stakeholders, formative research activities were carried out in collaboration with three geographically dispersed communities in the Pacific Northwest using focus groups and key informant interviews, following the ADAPT-ITT model. Based on participants' feedback, the team produced a culturally tailored intervention toolkit containing a Users Guide, the Native VOICES video, condom and dental dam demonstration videos, and a selection of condoms and dental dams. Forthcoming analyses are evaluating the effectiveness of the Native VOICES intervention with AI/AN youth living across the U.S.

## **INTRODUCTION**

Health issues that affect teens and young adults are particularly relevant in Indian Country. Youth are torchbearers of tradition and the future leaders of our communities. They are also a relatively large portion of the American Indian and Alaska Native (AI/AN or Native) population. Notably, roughly one-third of Native persons are 18 years or younger, compared to 24% of the total U.S. population, and as of 2015, 1.5 million AI/AN youth reside across Indian Country (Office of Minority Health, 2015).

Of particular importance are inequities related to sexual health. Stemming in part from a younger than average sexual début and lower rates of consistent condom use (de Ravello, Tulloch, & Taylor, 2012; Hellerstedt, 2004; Kaufman, Beals, Mitchell, LeMaster, &

Fickenscher, 2004), AI/AN youth experience disproportionate rates of sexually transmitted infections (STIs; de Ravello et al., 2012). In 2009, AI/ANs had the second highest rate of chlamydia reported among all races and ethnicities, with the highest rates occurring among young people ages 15-24 years (Centers for Disease Control and Prevention [CDC] & Indian Health Service [IHS], 2012). Sexually active youth are particularly vulnerable to Human Immunodeficiency Virus (HIV) transmission; nearly one-quarter of new HIV infections in the U.S. occur among teens and young adults (CDC, 2015).

The sexual health of Native youth is influenced by a number of socioecological factors, including high levels of poverty and substance use, insufficient sex education, poor access to reproductive health services, stigma, sexual violence, and historical trauma (de Ravello et al., 2012). Each of these important contributing factors have been discussed in greater detail by Walters and Simoni (2002) and de Ravello (2012).

Native young people's reproductive decisions also are shaped by unique social norms and sexual contexts that include both traditional and contemporary cultural values (Kaufman et al., 2007). Sexual health messaging is highly nuanced in AI/AN communities (Craig Rushing & Stephens, 2011; Gilley, 2006). As a result, mainstream sexual health campaigns and curricula frequently are inappropriate and ineffective for these populations.

Integrating cultural values into health interventions has been shown to enhance their appeal and effectiveness in diverse populations (Gilley, 2006; Kreuter, Oswald, Bull, & Clark, 2000; Kreuter et al., 2004; Kreuter et al., 2005). Resnicow (1999) first described cultural sensitivity as containing two dimensions: surface and deep structures. "Surface structure involves matching intervention materials and messages to observable, 'superficial' characteristics of a target population," including preferred people, places, language, music, food, locations, and clothing (Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999, p. 11). Deep structures, on the other hand, "involve incorporating the cultural, social, historical, environmental, and psychological forces that influence the target health behavior in the proposed target population" (Resnicow et al., 1999, p. 12). Incorporating this level of cultural sensitivity ensures that the intervention is grounded in the population's core health epistemology, values, and beliefs. Furthermore, subsequent research has found that messages tailored to the culture of the recipients are more likely to be retained, discussed with others, and perceived as relevant to the recipients (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003). Cultural tailoring is particularly important when addressing sensitive topics, like sexual health.

Similarly, interventions must align with organizational capacity and community readiness in order to be implemented sustainably and disseminated broadly (Peters, Adam, Alonge, Agyepong, & Tran, 2013). Misalignment can create irrelevant programs or unsustainable

services, and can negate the effectiveness of an intervention altogether (Chinman et al., 2005; Chinman, Imm, & Wandersman, 2004; Wandersman, Imm, Chinman, & Kaftarian, 2000). Aligning interventions to community needs can be particularly challenging in Indian Country, where readiness levels differ from tribe to tribe and health services vary from clinic to clinic (IHS, 2015).

#### THE NATIVE VOICES STUDY

The primary goal of this study was to design a video-based HIV/STI intervention for heterosexual and lesbian, gay, bisexual, trans, and two spirit (LGBT-TS) AI/AN teens and young adults ages 15-24 years, living in urban and reservation communities. The intervention was adapted from two evidence-based interventions (EBIs) included in the CDC's compendium of high-impact HIV prevention interventions: *Video Opportunities for Innovative Condom Education and Safer Sex (VOICES)* and *Safe in the City*. Given the substantial time and cost associated with designing effective interventions, the CDC strongly encourages communities to adapt EBIs to better reflect their own social and cultural contexts, without altering the interventions' core elements (Wingood & DiClemente, 2008). Prior to this study, none of the EBIs recognized by the CDC were designed for or rigorously evaluated with AI/AN youth (see <a href="https://www.effectiveinterventions.org">www.effectiveinterventions.org</a>).

## **Video-based Interventions**

VOICES is a single-session, HIV/STI prevention intervention in which condom use and negotiation skills are modeled in a video and then role-played and practiced by participants (O'Donnell, O'Donnell, San Doval, Duran, & Labes, 1998). The original intervention consisted of two culturally tailored videos, one for heterosexual African American adults and one for Latino adults visiting an STI clinic. In a randomized controlled trial involving 2,004 participants, those who viewed the VOICES videos had significantly fewer repeat STI infections (O'Donnell et al., 1998).

The CDC allows other culturally tailored videos to be used in the *VOICES* intervention, as long as they meet the inclusion criteria outlined by the intervention package. Thus far, seven supplemental videos have been approved by the CDC for use as alternatives, including *Safe in the City*. *Safe in the City* is a 23-minute looping video designed for STI clinic waiting rooms that requires no counseling or small-group facilitation (Myint-U et al., 2010). The video was designed for heterosexual and LGBT patients from diverse cultural backgrounds. A large-scale two-arm controlled trial, involving over 40,000 patients over 24 months, found a 9% reduction in

STIs among patients exposed to the video in the clinic's waiting room, compared with those who were not—likely a conservative estimate of intervention's potential impact, given that up to 20% of the patients did not see the entire video while in the waiting room (Warner et al., 2008).

#### **METHODS**

## **Native VOICES Adaptation Process**

Formed in 1972, the Northwest Portland Area Indian Health Board (NPAIHB) is a tribal organization that represents 43 federally recognized tribes in Washington, Oregon, and Idaho (NW). The mission of the NPAIHB is to "eliminate health disparities and improve the quality of life of American Indians and Alaska Natives by supporting Northwest Tribes in their delivery of culturally appropriate, high quality health care." The NPAIHB's governing board meets quarterly and is composed of one delegate from each member tribe, selected by the individual tribal governments.

The NPAIHB runs the Northwest Tribal Epidemiology Center (NW TEC), which carries out research, surveillance, and public health capacity building in partnership with the NW tribes. Within the NW TEC, several projects address adolescent sexual health, including Project Red Talon, which has provided training and technical assistance to tribes throughout the U.S. on implementing culturally appropriate sexual health programs for over 25 years. Two Project Red Talon staff—a Project Director and a Project Coordinator—oversaw the *Native VOICES* adaption process at the NPAIHB.

Staff from the NW TEC also facilitate the Adolescent Health Alliance, an inclusive, multifunctional group that meets quarterly in OR, WA, and ID to discuss cross-cutting planning and prevention strategies targeting AI/AN teens and young adults (addressing commercial tobacco use, substance abuse, HIV/STIs, teen pregnancy, and suicide). The Adolescent Health Alliance and the NPAIHB's Behavioral Health Committee (which meets quarterly) served as regional advisors for the *Native VOICES* study. Both bodies provided general guidance on the overall study design, and reviewed and interpreted study findings.

The *Native VOICES* study protocol was reviewed and approved by the Portland Area Indian Health Service Institutional Review Board (333712-1) and the Northwest Indian College Institutional Review Board. NW TEC staff recruited two NW tribes and one urban Indian health clinic to participate in the study by sending an informational letter to NPAIHB tribal delegates

and giving a presentation at an NPAIHB quarterly board meeting. Each study site submitted a letter of agreement signed by the tribe's Health Director, the clinic's Executive Director, or the tribe's governing council, as deemed appropriate by the site.

## The ADAPT-ITT Model

Designed by Wingood and DiClemente (2008), the ADAPT-ITT Model is a theoretical framework used to guide the adaptation of evidence-based HIV prevention interventions. The model consists of eight phases:

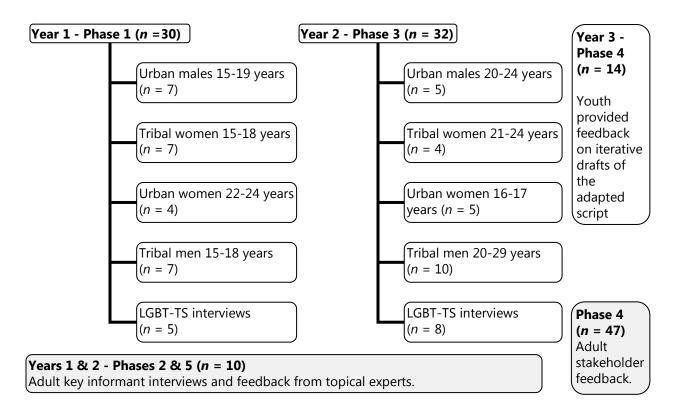
- Phase 1 Assessment: focus groups, interviews, or needs assessments are done with the target audience to better understand their informational needs.
- Phase 2 Decision: a literature review is used to identify EBIs, an EBI is selected that aligns with the needs and capacity of the target population, and community partners determine whether the EBI can be adopted or adapted.
- Phase 3 Adaptation: the original intervention is reviewed and tested by the target audience.
- Phase 4 Production: a first draft of the adapted EBI is developed for iterative review.
- Phase 5 Topical Experts: the draft is reviewed by consultants with expertise in topics covered by the intervention.
- Phase 6 Integration: the experts' feedback is incorporated into draft 2.
- Phase 7 Training: facilitators are trained to recruit participants and implement the intervention.
- Phase 8 Testing: two steps are required; the first involves a pilot test of the adapted EBI, and the second involves a randomized controlled trial to assess the efficacy of the adapted intervention (e.g., looking for changes in knowledge, attitudes, beliefs, and relevant behaviors; Wingood & DiClemente, 2008). This paper will describe the process used by Project Red Talon to adapt the *Native VOICES* intervention, covering Phases 1-7 and the first half of Phase 8.

#### Phase 1 – Assessment

Using an emergent study design, the research team collected a rich body of qualitative data over a 3-year period (2011-2013), to inform the adaptation process (Figure 1). As described by Morgan (2008), emergent data collection is purposefully designed to evolve over the course of a study. Emergent study designs provide flexibility to investigators, allowing them to adjust

the number of focus groups needed during each phase of the study, the segmentation of focus groups by age and gender, and the list of focus group questions, to best achieve study aims (Morgan, 2008).

Figure 1
Emergent Study Design Applied to the ADAPT-ITT Model



A local site coordinator from each of the three partnering Tribes/clinics was actively involved in planning the focus groups, selecting dates, locations, participant meals, and incentives. They circulated recruitment materials (letters and fliers), and reached out to youth eligible to participate in upcoming focus groups and interviews.

In accordance with human protection standards, a signed consent form was obtained from all participants. For youth ages 15-17 years, a parent/guardian consent form also was collected. Participants were given a \$20 gift card in appreciation for their time and involvement.

The Project Director and Project Coordinator purposely designed the study's focus group and key informant interview guides to protect the privacy of participants by enquiring about community norms and perceived behaviors among friends rather than about individual behaviors and beliefs. Additionally, focus groups were segmented by age and gender and welcomed both straight and LGBT-TS participants. The age and gender groupings were purposely distributed across the three study sites to obtain a range of younger and older perspectives, male and female perspectives, and urban and rural perspectives.

When possible, male focus groups were facilitated by a male AI/AN NPAIHB colleague who had experience facilitating focus groups. All female focus groups were led by the Project Coordinator, who had experience in sex education and focus group facilitation. The same set of questions was used for all four focus groups in Year 1, and a second series of standardized questions was used in Year 2.

Due to the sensitive nature of the topic, and to respect the privacy of participants, focus groups were deemed an inappropriate method for collecting sensitive sexual health information from young men who have sex with men (MSM) or women who have sex with women (WSW), many of whom are not "out" to their family and friends, and might not have felt comfortable providing honest feedback in front of their peers. To include these youth in the adaptation process and to elicit group-specific information, the Project Coordinator asked them a subset of the focus group questions in private, one-on-one key informant interviews, at times and locations selected by the participants (n = 13).

During Phase 1 – Assessment, the focus groups and key informant interviews were designed to identify:

- important cultural reproductive health values
- condom communication and negotiation skills
- social norms around contraception and condom use
- socioecological factors that might affect condom use in urban and rural communities

Four focus groups were held with AI/AN youth (n = 25), including 7 urban-based young men ages 15-19 years, 7 tribal-based young women ages 15-18 years, 4 urban-based young women ages 22-24 years, and 7 tribal-based young men ages 15-18 years. Also, five one-on-one interviews were carried out with youth who identified as LGBT-TS.

#### Phase 2 – Decision

To identify an appropriate EBI for adaptation, the NPAIHB worked with the Red Talon HIV/STI Coalition, which was formed in 2005 to reduce the prevalence of STIs among NW AI/ANs. NW tribal health representatives, teen pregnancy prevention staff, tribal leaders, and other community stakeholders attended quarterly Coalition meetings. In January 2009, an intertribal HIV/STI Action Plan was written by the Coalition and approved by the NW tribes (Project Red Talon, 2009). As a component of the plan, the Project Director conducted a literature review to identify technology-based HIV/STI prevention programs that might be

appropriate for AI/AN youth (Craig Rushing, 2010). During subsequent Coalition meetings, participants selected *VOICES* and *Safe in the City*, as they were deemed to be: (a) community centered, (b) culturally relevant, (c) adaptable, and (d) capable of being disseminated easily across the Indian healthcare system. Coalition members felt the video-based interventions would be well received by youth, and could be used flexibly in a variety of settings by a variety of staff. After reviewing national data on STI incidence reported by the CDC, the research team targeted the adapted *Native VOICES* intervention to the age range with the highest HIV/STI incidence rates for AI/ANs—youth ages 15-24 years.

## Phase 3 – Adaptation

During Phase 3 – Adaptation, a second round of focus groups and interviews was designed to elicit feedback on the original *VOICES* intervention; test the relevance of possible "sexual health scenarios" that could appear in a revised script; and gather feedback on important components of the video, including plausible dialogue, styles of communication, and locations, as well as social, environmental, and psychological factors influencing characters' behaviors. During the feedback sessions, participants watched segments of the original *VOICES* video and the *Safe in the City* video, and discussed content, relevance, and tone. The Project Coordinator facilitated four focus groups with AI/AN youth (n = 24), and conducted eight one-on-one interviews with youth who identified as LGBT-TS. The groups included 5 urban-based young men ages 20-24 years, 4 tribal-based young women ages 21-24 years, 5 urban-based young women ages 16-17 years, and 10 tribal-based young men ages 20-29 years.

#### Phase 4 – Production

Informed by the focus group and interview findings (described in the Results section of this paper), the Project Coordinator drafted initial changes to the original VOICES script. To get diverse youth perspectives on the adapted script, 14 AI/AN teens and young adults from communities across the U.S. read or reenacted iterative drafts of the adapted script and provided feedback on the characters, scenes, tone, and dialogue. These participants were recruited from AI/AN theater clubs, a two spirit youth group, and a summer youth leadership conference, and were compensated for their time. The script was then reviewed and refined by the Project Director and the topical and community experts described below in Phase 5.

## **Phase 5 – Topical (and Community) Experts**

Altogether, 47 adult clinicians, tribal health advocates, teachers, parents, and elders from across the NW were consulted during the 3-year project. The Project Director or Project Coordinator visited each study site once or twice per year to meet with the site coordinator and

other community stakeholders. Site visits were used to support local recruitment efforts, conduct focus groups and interviews, review and discuss study progress and findings, and offer showings of the adapted video to the community at large.

In addition to these informal gatherings, the Project Coordinator conducted 10 scripted key informant interviews in Years 1 and 2 of the project with clinicians and prevention specialists from the three study sites, to identify features that would affect the usability and acceptability of the adapted intervention within the Indian health care system and in other tribal settings.

The research team also consulted subject matter experts and communicated with the original *VOICES* investigators and staff at the CDC to ensure core elements of the intervention were retained. Prior to production, the final script was reviewed and approved by the CDC *VOICES* diffusion team—the body responsible for determining whether new videos meet the inclusion criteria outlined by the *VOICES* intervention package.

# **Phase 6 – Integration**

Following edits to the video script recommended by topical experts, the research team hired a media firm with extensive experience in AI/AN health marketing. After weighing various options, the research team and media firm chose to shoot the *Native VOICES* video in Oklahoma City, OK (rather than in the Pacific Northwest), where the media firm had an existing network of Native actors, film production houses, and other community ties. This decision reduced the cost to produce the video and kept production within the desired timeframe.

In preparation for shooting the video, the study team collaborated with the media firm to select actors based on short video clips of the actors reading portions of the script, and selected set locations based on photos and recommendations from a location scout hired by the media firm. Finally, in collaboration with study staff, the media firm identified a Native director and film crew, and acquired the necessary filming permits.

The final *Native VOICES* video was shot over a 3-day period in August 2013. During filming, an NPAIHB staff member was present at all times for consultation, acting as the cultural content expert to ensure the integrity of the adaptations made to the script; appropriateness of site locations; and the quality of acting, filming, and treatment of youth actors. The *Native VOICES* video can be viewed on YouTube at <a href="https://youtu.be/xaBxwUg\_gxU">https://youtu.be/xaBxwUg\_gxU</a>.

## Phase 7 – Training

In response to adult stakeholder feedback (collected during study site visits, Adolescent Health Alliance meetings, and NPAIHB quarterly board meetings), NPAIHB staff created a *Native VOICES* toolkit to help support the intervention's dissemination and implementation in diverse urban and tribal settings. The toolkit includes a DVD containing the culturally tailored *Native VOICES* video (23 minutes), a condom demonstration video (1:40 minutes), and a dental dam demonstration video (1:08 minutes) given by a Native health educator; an intervention Users Guide; and a selection of condoms and dental dams. The toolkit can be ordered free of charge by emailing <a href="mailto:native@npaihb.org">native@npaihb.org</a>.

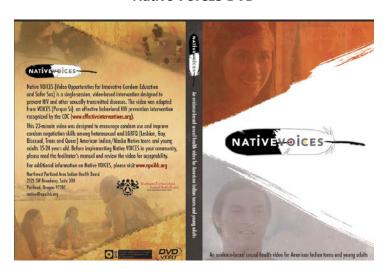


Image 1
Native *VOICES* DVD

Modeled after the original *VOICES* Video Guide, the *Native VOICES* Users Guide encourages users to facilitate a 30- to 45-minute, small-group discussion after watching the video. The video also can be used independently in settings or situations where the small-group discussion is not practical or appropriate, per *Safe in the City's* implementation guidance.

#### Phase 8 – Testing

To assess the acceptability, relevance, and cultural appropriateness of the adapted video, the film was premiered at tribal sites involved in the study (at Red Carpet showings open to the public), and at several subsequent Native youth conferences. A brief <u>satisfaction survey</u> (see

Appendix A) was collected from 67 consenting viewers, including youth, parents, and tribal health educators. The survey was based on a questionnaire included in the CDC's *VOICES* Implementation Kit, and was approved during the study's IRB review process.

## **Data Management and Analysis**

All focus groups and key informant interviews conducted during the study were audio recorded and transcribed, and detailed notes were taken at community meetings where the intervention was discussed. Reflecting the emergent study design, qualitative data were analyzed systematically by a single NPAIHB staff member using MAXQDA software (MAXQDA Software, 2014) after each phase of the study, to determine whether thematic saturation had been reached and to adjust study questions for subsequent phases of the study.

Where appropriate, content analyses were used to identify the presence, intensity, and frequency of topics and themes generated by groups and individuals; however, a grounded theory approach was utilized primarily, allowing themes to emerge from the data, prior to the development of the code book (Creswell, 2006).

To ensure the resultant findings resonated with the lived experiences of AI/AN youth and NW tribal members, all study reports were reviewed and discussed with study partners, and with youth during subsequent rounds of focus groups and interviews conducted in Year 2. All script and intervention changes were grounded in data collected by the research team.

## **RESULTS**

#### Phase 1 – AI/AN Youth Sexual Health Knowledge and Attitudes

The focus groups and key informant interviews provided useful information regarding the unique values and perspectives of AI/AN youth, including their understanding of sexual health, and common questions, misconceptions, and concerns. Data from this phase of the study informed the surface and deep cultural changes that were made to the *Native VOICES* script.

#### **Condom Use**

The majority of participants felt that youth in their communities seldom used condoms. If condom use were to occur, most felt it would be likely to happen at the beginning of a relationship, during the first few sexual encounters, or with a short-term sexual partner. Most

youth indicated that they do not feel comfortable initiating conversations about protection with potential sexual partners, and, as a result, condoms and other forms of birth control usually are not discussed prior to sex.

#### **Youth Access to Condoms**

Youths' perceptions about low condom use among peers in their community had little to do with physical access to condoms. Youth universally reported a multitude of locations where condoms were available. When asked further about this discrepancy, both tribal- and urban-based young people reported feeling uncomfortable being seen taking condoms in public spaces, like clinic waiting rooms or tribal health pharmacy counters, which made it challenging for youth to access condoms. In addition, young people were reluctant to ask teachers or nurses for condoms, because they feared others finding out that they were sexually active. Some young people reported stealing condoms from stores due to embarrassment or fear of being seen.

### **Barriers to the Use of Condoms and Other Methods to Protect Against STIs**

The majority of participants felt that condoms take away from the pleasure of sex and that is why young people choose not to use them. This viewpoint often was expressed to explain low rates of condom use among youth. Other common explanations included impairment by drugs or alcohol, the desire to not ruin the moment, a preference for "hidden" forms of birth control (like birth control pills), and a strong social stigma against youth carrying condoms around daily, to a party, or on a date. The research team also observed a general lack of knowledge about different ways to prevent pregnancy and STIs, as well as a lack of knowledge about the potential consequences of acquiring STIs.

#### LGBT-TS Youth: access to condoms and dental dams

LGBT-TS youth reported that accessing condoms was relatively easy and free at clinics, nonprofit organizations, and events for queer youth; however, those seeking dental dams and gloves were often hard pressed to find these forms of protection. Additionally, not all youth felt comfortable accessing protection from mainstream "queer" spaces, like LGBT student centers, because they felt these places did not acknowledge their Native cultural identity adequately.

#### **Native Youth: Oral Sex and Personal Risk**

Although several WSW identified dental dams as a way to prevent STIs, none reported having used them. Many expressed a belief that dental dams were "silly" and that they couldn't imagine asking a sexual partner to use one. WSW commonly expressed a belief that WSW are more "clean" than male partners and are thus less likely to spread STIs. Several asserted that STIs are not able to spread between women and that sex between women is less risky.

Notably, youth in focus groups also reported that unprotected oral sex was commonplace. In fact, during every focus group (n = 49 youth) and LGBT-TS interview (n = 13 youth), no participants said that they or anyone else they know use protection during oral sex. This finding is worth highlighting, given that oral sex poses some risk for transmitting STIs, including HIV.

# Phase 2 – Results are discussed after Phase 3, along with results from Phases 4-5

# Phase 3 – Changes to improve age and cultural appropriateness, and LGBT-TS inclusivity

Youth recommended topics that should be included in a successful sexual health video for Native teens, including: ways to prevent STIs and pregnancy, the consequences of getting an STI, situations that are relatable to youth on the reservation, positive portrayals of LGBT-TS youth, and how to talk to a sexual partner about protection. They also requested that the video not include romanticized Native imagery or make it seem like everyone who has sex gets a disease. They suggested using humor to intiate conversations about sex, and to keep the conversations between characters light and lively.

Focus groups and interview participants were especially insightful when reviewing the original *VOICES* video. During these sessions, youth voiced a great deal of awareness about the importance of cultural relevance, age appropriateness, and video quality. Table 1 shows a list of changes that were made to the *Native VOICES* script, based on feedback from AI/AN youth.

Table 1
Changes to Improve Age and Cultural Appropriateness, and LGBT-TS Inclusivity

Level	Original	Native VOICES	Youth Rationale
Surface <sup>a</sup>	When Eddie and Joanna meet, Joanna is alone reading in a park. She and Eddie flirt and make plans to meet again.	When Jamie and Christina meet, both are with friends. They indicate their interest through body language and text message, and chat online before making plans to meet again.	AI teens don't flirt as openly and as confidently as adults. Characters should meet when they are with friends, because that is less intimidating.
Surface/ Deep <sup>b</sup>	Major scene locations include a bar, upscale restaurant, pharmacy, and a hair salon.	Major scene locations include a basketball court, private homes, and a supermarket.	Scene locations need to better reflect the spaces occupied by Native youth.

# Table 1, Continued Changes to Improve Age and Cultural Appropriateness, and LGBT-TS Inclusivity

Level	Original	Native VOICES	<b>Youth Rationale</b>	
Deep	Major characters include friends, sexual partners, and healthcare providers.	Trusted family members (an auntie, an elder, and a brother) impart important health messages.	New characters reflect the sources that AI youth typically turn to to get health information.	
Surface/ Deep	No out LGBT-TS characters.	Several LGBT-TS characters, including one of the main characters. The message that "two girls - or two guys - can give each other STIs" is featured.	Must include LGBT-TS characters to be more realistic, and reflect a diversity of perspectives.	
Surface/ Deep	No LGBT-TS positive role models.	Tyler, Christina's friend who is living with his male partner, is respected in the community, successful, and connected. He participates in safer sex behavior and is in a healthy, happy same-sex relationship.	Need to include positive role models who can inspire LGBT-TS youth to protect themselves and model healthy same-sex relationships. Must be involved, tied to their culture, and valued by their community.	
Surface	Discussions about STIs and safer sex occur in public spaces.	Discussions about STIs and safer sex occur in private spaces or public spaces where characters are alone.	It would be "awkward" to have this conversation about sex in public where others might overhear you.	
Surface	Promoted condoms as a safer sex tool.	Promotes both condoms <u>and</u> dental dams.	Needed to better meet the sexual health needs of youth.	
Surface	After performing a condom demonstration on a beer bottle, the character shakes his friends' hands before leaving the scene.	After performing a condom demonstration on a soda bottle, the character wipes his hands on his shorts, and shakes his friends' hands before leaving the scene.	It bothered several participants that the character shook hands after touching a lubricated condom. They thought it was "gross."	
Surface	Characters openly discuss the pleasure of sex.	Specific lines regarding sexual pleasure were removed and conversations were softened regarding sexual desire.	Men and women discussing the pleasure of sex made several teens feel uncomfortable.	
Deep	Dialogue between friends discussing safer sex are at times serious and weighty.	When youth talk with each other about sex, they use humor. Dialogue is generally light, interspersed with depth.	Use humor to intiate conversations about sex and keep them lively. Intense conversation about safer sex between youth is unrealistic.	

Table 1, Continued
Changes to Improve Age and Cultural Appropriateness, and LGBT-TS Inclusivity

Level	Original	Native VOICES	Youth Rationale
Deep	Carmen, Joanna's cousin, shares a story about how she contracted chlamydia and as a consequence has problems getting pregnant. She quickly advances the dialogue forward.	Christina's Auntie Amanda shares her experience contracting an STI. Unlike Carmen, Amanda is more reluctant to tell Christina about her former infection. She pauses and shows signs of distress, clearly indiating that this is a difficult subject.	In a reservation setting, rumors may spread regarding STI infection, which could impact someone's social standing. Someone would be more guarded and emotional disclosing a past STI, especially if it impacted fertility, because children are highly valued in AI/AN communities.
Surface Deep	Eddie's friend brings him to a drug store to show him the different kinds of condoms and encourages him to buy condoms.  Eddie and Joanna have	Jamie, along with his brother and a friend, goes to a large urban supermarket to buy condoms using self-checkout.  Jamie and Christina have	Participants recommended that the characters use self-checkout, a less intimidating option than buying condoms from a cashier or being seen getting them at a free clinic or pharmacy.  Need to demonstrate the effect
Эсер	unprotected sex after their first date at a restaurant.	unprotected sex after drinking at a house party.	of drinking and drugs on decision-making.
Surface	No comparable element in original video.	Jamie is tested for STIs and is positive. He discloses this to his girlfriend, and he tells the viewer they now use condoms. Jamie advises the viewer to "embrace the awkward - even if you're scared. Things can happen to you. They happened to me."	Young people almost universally expressed a fear of bringing up protection with long- and short-term partners because they feared being judged or rejected, and potentially losing the opportunity to have sex. Several said you just "have to do it," even though it may be difficult.

<sup>&</sup>lt;sup>a</sup> **Surface** – Match intervention materials to observable, 'superficial' characteristics of the target population: people, places, language, music, food, clothing (Resnicow et al., 1999, p. 11). <sup>b</sup> **Deep** – Incorporate the cultural, social, historical, environmental, and psychological forces that influence the health behavior of the target population (Resnicow et al., 1999, p. 12).

### Phases 2, 4, and 5 – Adult Stakeholder Recommendations for Intervention Design

In addition to the feedback obtained from youth, key informant interviews and periodic meetings with adult community stakeholders provided valuable feedback on components of the *Native VOICES* script. Adults echoed the desires expressed by youth to include humor in discussions about sexual health, demonstrate the effects of drugs and alcohol on decision making, and interweave cultural references and values. They envisioned using the video to spark youth engagement in local history, traditions, and health resources.

# **Phase 7 – Intervention Training and Dissemination**

Staff at Native youth-serving organizations offered suggestions to improve the usability of the intervention in various settings, and brainstormed resources and tools that would facilitate the program's implementation. They recommended that:

- the intervention offer more than one format for implementation, to accommodate different settings and different sized groups;
- the intervention include time for reflection and group discussion, so the facilitator could gauge comprehension, answer questions, and address misconceptions;
- mini-episodes be relatively short, about 4-8 minutes long; and that
- supplemental activities range from 30-60 minutes.

# Phase 8 – Video Acceptability, Relevance, and Cultural Appropriateness

Positive reactions to the video at Red Carpet showings suggest promise for the intervention's acceptability, relevance, and appropriateness for AI/AN youth in diverse urban and rural settings. Sixty-seven AI/AN youth, parents, and tribal health educators returned satisfaction surveys after watching the video. Over 98% thought the video was culturally appropriate for AI people, and 98% felt the information could be trusted. Additionally, 95% thought what the actors did and said about condom use and negotiating safe sex would work for them and 91% thought the video showed real-life situations with characters to whom they could relate. After watching the video, 73% felt more likely to get tested for HIV/STIs and 66% felt more likely to use condoms. These findings support the need for rigorous evaluation of the intervention's effectiveness, as recommended in Phase 8 of the ADAPT-ITT model.

#### DISCUSSION

This paper describes the study used to adapt the *VOICES* intervention for AI/AN youth (*Native VOICES*), using the ADAPT-ITT model (Wingood & DiClemente, 2008). The emergent study design provided flexibility to refine research questions over the course of the study, based on insights acquired during the process. These data informed the selection of surface and deep cultural changes to the intervention (Kreuter et al., 2003). Surface-level adaptations included changing the intervention's name and logo. The scenes in the video were shifted to those more commonly experienced by AI/AN youth in their day-to-day lives. Deep cultural adaptations included the inclusion of trusted family members (notably an auntie, an elder, and a brother) who imparted important health messages; an LGBT-TS character who was influential and respected

in his community to reinforce positive representations of AI/AN LGBT-TS young people; humor to initiate and forward conversations about sex; and relevant cultural nuances, including the fear of private information becoming public in tight-knit reservation communities.

Because the original VOICES videos were designed for adult audiences, many script and setting changes were made to improve age appropriateness. Youthful slang and come-backs were incorporated throughout, and character interactions were relocated to homes, schools, and outdoor basketball courts. Intentional effort was made to include the needs and perspectives of LGTB-TS young people, a group at heightened risk for HIV/STIs but often overlooked by sexual health programs. To better reflect the current social and cultural contexts of Native youth, characters in *Native VOICES* were placed in multicultural communities, moved seamlessly between urban and rural environments, and blended Western and traditional perspectives and values—all common occurrences in tribal communities.

Despite the persistent need, few evidence-based interventions promoted by state or federal agencies have emerged from, been tested with, or been adapted to the unique social, economic, demographic, and cultural contexts that surround rural and urban AI/ANs (Spence, 2007). To be truly effective, sexual health interventions must build upon existing community strengths and resources, fit sustainably into local health care systems, and, most importantly, be congruent with the cultural values of the population (Mohatt et al., 2008; Walters & Simoni, 2002). By collecting data from diverse AI/AN youth and multiple urban and tribal communities over a 3-year period, the resulting intervention reflects a wide spectrum of perspectives and experiences.

### **Strengths and Limitations**

Due to staffing and budget limitations, only one member of the research team analyzed data collected from interviews and focus group discussions. Because multiple researchers were not available to develop consensus or verify interpretations of the textual data, the researcher identified emergent themes that arose using a grounded theory approach. To identify and limit potential biases, the research team asked participants in subsequent phases of the study clarifying questions to explore areas where a high degree of understanding and interpretation was required.

While the *Native VOICES* intervention was culturally adapted to reflect the informational needs and sexual norms of Native youth living in the Pacific Northwest, the final script was reviewed by young people and adult stakeholders across Indian Country. This decision reflected

a deep desire by the study team to design a sexual health intervention that could be utilized by Native youth both within and beyond the Pacific Northwest. Based on preliminary satisfaction surveys gathered from youth, parents, and tribal health educators, the study team anticipates the intervention will have relevance in other regions and settings. Given that most of the formative research took place in the Pacific Northwest, we concede that a more rigorous evaluation of the intervention is needed to determine its transferability to AI/AN youth in other regions of the U.S.

# **Next Steps**

To fulfill the second step of Phase 8 – Testing (Wingood & DiClemente, 2008), the team conducted a three-armed randomized controlled trial of the *Native VOICES* intervention in partnership with nine tribal sites located throughout the U.S. Pre-, post-, and 6-month follow-up surveys were used to assess changes in sexual health knowledge, attitudes, self-efficacy, and behavior among nearly 800 AI/AN youth ages 15-24 years. If the *Native VOICES* intervention demonstrates positive change, it is positioned to be the first evidence-based HIV/STI intervention for AI/AN youth widely promoted and distributed by the CDC.

#### **CONCLUSION**

*Native VOICES* fills a significant need for evidence-based, sexual health interventions purposefully designed for heterosexual and LGBT-TS AI/AN youth living in reservation and urban settings. The development of *Native VOICES* using a community-based, phased, emergent study design offers a useful model for future research adapting evidence-based interventions for diverse populations.

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# Appendix A Native VOICES Satisfaction Survey



#### **Instructions:**

Please take a few minutes to answer the following questions about the Native VOICES video. Please answer as truthfully as possible. There is no right or wrong answer. Your answers will help us improve the video's use for other AI/AN youth in the future. Thank you.

1.	Mat is your sex?  Male Female Other (please describe):
2.	w old are you? (Please check one.) Younger than 15 years old 15 -17 years old 18 - 24 years old I am older than 24 years old

Please circle the answer in each row to describe how you feel about the Native VOICES video.

3	Did you <u>enjoy</u> watching the Native VOICES video?	Yes	No	Don't know
4	The <u>quality</u> of the video's actors, editing, and music were:	Excellent	Average	Poor
5	Would you <u>recommend</u> this video to a friend?	Yes	No	Don't know
6	I think the information I got from this video was:	Right	Wrong	Don't know
7	I think the information I got from this video:	Can be trusted	Can't be trusted	Don't know
8	I think the information I got from this video will help me make healthy life choices.	Yes	No	Don't know
9	How does this video compare to other sexual health lessons that you've had?	Better	About the same	Worse

# Appendix A, Continued Native VOICES Satisfaction Survey

Do you agree or disagree with the following statements about the Native VOICES video. The video showed real-life situations with characters 10 Agree Disagree that I could relate to. The video showed both partners (men and women) 11 Agree Disagree taking responsibility for negotiating condom use. I could see myself or my friends in the same 12 Agree Disagree situations that were presented in the video. Some of the things the actors did and said in the 13 video about condoms and negotiating safer sex Agree Disagree would work for me. 14. Do you think the Native VOICES video is culturally appropriate for American Indian people? ☐ Yes □ No Comments: 15. Did the Native VOICES video change your views about using condoms? ☐ Yes, I am more likely to use condoms ☐ Yes, I am <u>less</u> likely to use condoms □ No, my opinion did not change 16. Did the Native VOICES video change your views about using dental dams? ☐ Yes, I am more likely to use dental dams ☐ Yes, I am <u>less</u> likely to use dental dams ☐ No, my opinion did not change 17. Did the Native VOICES video change your views about getting tested for STDs/HIV? ☐ Yes, I am more likely to get tested for STDs/HIV ☐ Yes, I am less likely to get tested for STDs/HIV ☐ No, my opinion did not change

18. Do you have any other comments that you would like to share with the video's developers?

Thank you for your time!

# PARTICIPATORY VISUAL METHODS FOR AMERICAN INDIAN COMMUNITIES AND MENTAL HEALTH CONVERSATIONS

Allyson Kelley, DrPH, MPH, CHES, LaDawn Kay Medicine Bull, BA, and Gary LaFranier, BA

Abstract: Visual methods serve a unique purpose in that they help generate data that uncover experiences, knowledge, and contextual factors that lead to a greater shared understanding about a topic. We describe the process and results of one American Indian community-based organization's success using visual methods to prompt community conversations about mental health and substance abuse. We uncovered community members' mental health perspectives and experiences through visual vignettes. Our hope is that other communities and funding agencies see the value and promise of visual methods as a valid approach that promotes shared dialogue, decision making, and conversations for future generations.

#### **BACKGROUND**

Participatory research methods engage diverse groups in discussions and collaborations that often result in social change and improved health (Jason et.al, 2004). Visual images (e.g., photographs, drawings, paintings) are tools used in participatory research methods to prompt dialogue between researchers and community members. In American Indian (AI) communities marginalized by colonization and dominant Western research paradigms and worldviews (Kelley et.al, 2013), participatory research methods and visual images are appropriate. Images can help communities think critically about sensitive and highly personal issues like substance abuse or mental health challenges, while creating opportunities for in-depth discussions and exploration in a variety of community settings. In contrast, traditional Western research uses written reports, statistics, and sophisticated language to convey information—such approaches often alienate community members. Funding agencies and federal programs often prefer Western research approaches, yet these approaches may fail to demonstrate cultural sensitivity or in-depth understanding about the economic, social, cultural, and contextual differences that define communities. This lack of understanding ultimately

leads to flawed program approaches promoted by federal agencies and unrealistic expectations for communities and community-based programs (Gone, 2004; Gray, de Boehm, Farnsworth, & Wolf, 2010).

There is a disconnect between funding agencies and communities where Western psychology, ideologies, and epistemologies are often deeply rooted in program approaches and funding streams that do not work for AI communities. The power, control, and economic interests of federal agencies may unknowingly subjugate culturally marginalized groups, like AI communities to harm. Evidence of hegemony can be found in federal funding agency protocols and demands based on Western ideals and infrastructure, including extensive data collection, evaluation, clinical resources, and sophisticated studies that promote Western definitions and concepts of mental health systems and needs.

There are fundamental differences in how some AI communities view mental health systems and needs compared to federal agency definitions. For example, funding agencies like the Substance Abuse and Mental Health Services Administration (SAMHSA) often define a mental health system of care as:

A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community and throughout life. (Stroul, Blau, & Friedman, 2010, p. 1)

It could be argued that this federal agency definition tries to be broad-based, inclusive, and respectful of cultural differences. However, many AI communities are disaffected by the terms *mental health* and *system of care* because of (1) the oppression and colonization they have experienced, and (2) the fact that these concepts are foreign to many communities. AI communities may view mental health systems and needs as one part of the broader social, cultural, and spiritual context. In fact, some AI communities historically did not have a word for "mental health needs," and, according to a tribal elder (tribal elder/advisor, personal communication, March 15, 2013), the closest term for mental health needs in one Native language would translate to "those who could not listen." Prevention efforts in reservation communities may be complicated by the fact that, under the federal agency definition of mental health, individuals are assigned labels or diagnoses that historically had no meaning or relevance, and therefore do not exist based on AI community standards and worldviews.

### **New Methods for Prompting Mental Health Conversations**

New methods that give voice to historically marginalized populations through a common language and shared dialogue are needed to promote a shared understanding of mental health systems and needs as well as solutions in AI community settings. This paper describes the use of visual methods (vignettes) to engage AI community members in conversations about mental health systems and needs for families and youth.

# VISUAL METHODS AND INDIGENOUS INQUIRY

Arts, imagery, crafts, oral traditions (e.g., storytelling), and painting are part of the unique history of all cultural and ethnic groups (Gray et. al, 2010). For early AIs, drawings served as visual depictions (stories) of events that happened in their lives, including battles, ceremonies, and everyday living. Among Indigenous groups, '...story and knowing cannot be traced back to any specific starting time within tribal societies, for they have been tightly bound since time immemorial as a legitimate form of understanding' (Kovach, 2010, p. 95). Visualization and imagery remain an important part of AI cultures and knowledge transmission in the present day. Visual methods serve a unique purpose in that they help generate data that uncover experiences, knowledge, and contextual factors that lead to a greater shared understanding about a topic (Baker & Wang, 2006). They are used most appropriately to 1) convey information about a given community's strengths and challenges; 2) prompt sharing of information that often is sensitive in nature; and 3) elicit responses, experiences, and perceptions about sensitive topics that are not conveyed through more traditional means. Visual methods also allow for artistic expression that is universal and does not depend on language or education level. In addition, these methods are appropriate for cultivating relationships among community-based program personnel and their fellow community members, consultants, and federal program officers (Gray et.al, 2010). Visual methods are an effective way to reach youth, young adults, and individuals with lower literacy levels or those who would not be reached through traditional data collection efforts (e.g., surveys, key informant interviews, focus groups), and to encourage community participation, dialogue, and engagement (Freire, 1970; Wallerstein & Bernstein, 1988). Such methods can be used to confirm or validate the experiences and needs of community members without making people feel defensive, which is critical when topics like mental health systems and needs are discussed.

Indeed, the use of visual methods can prompt social action by helping community members prioritize concerns, build on strengths of culture, and advocate for improvements (Gray et.al, 2010). In research, visual methods are particularly useful when community-based programs already have a general idea about the needs, experiences, and beliefs of individuals based on formative data like that gained from focus groups, surveys, community reports, and presentations.

#### **THEORY**

The theoretical underpinnings of visual methods come from the work of Paulo Freire (1970), a Brazilian educator who conceived much of what is written about empowerment education theory and critical consciousness. Building on Frantz Fannon's (1965) psychiatric and psychologic analysis of the dehumanizing effects of colonization, Freire's work sought decolonization of all people, including Indigenous populations throughout the world. Critical consciousness is based on achieving an in-depth understanding of the world while taking action against oppression that comes from a lack of understanding (Wallerstein & Bernstein, 1988). Although critical consciousness first started in education, much of Freire's work extended into health education, research, and policy and program implementation in community-based settings (Bernstein et al., 1994; Wiggins, 2012). Visual methods are theoretically driven and are based on empowerment and social action processes that call for community participation, identifying a problem, solving a problem, and giving voice to people and experiences that often are ignored or not reached through traditional research or data collection methods (Davis & Harrison, 2013). In light of this illuminating power, authors and communities have built on Freire's work and described their successes with visual methods in communities where populations have a distrust of Western research approaches and dominant worldviews (Banks, 2001; Bernstein et al., 1994; Thomson, 2009).

# **Objectives**

This case study describes how one AI community-based organization (CBO) developed a culturally relevant visual methods data collection strategy to document and confirm mental health systems and needs, resources, and perceptions of community members. The overall purpose of the 3-year project, funded by SAMHSA, was to plan and develop a system of care on the reservation for children and families with serious mental health needs. In the first 2 years of the project, the project team used traditional methods like surveys, focus groups, and community gatherings to collect information from the community on mental health systems and needs and substance abuse; however, this case study describes how visual methods were used later to uncover the contextual, cultural, and community factors related to mental health systems and needs on the reservation. This approach was more culturally relevant and sensitive to the experiences of community members.

#### **METHODS**

The project team, which consists of the CBO's chief professional officer, the grant project director, a data coordinator, four program partners, two cultural consultants, and an evaluation scientist, followed a three-step process based on the early work and recommendations of Freire (1970). First, they listened to understand the mental health concerns and issues of youth and families. Second, the team created what Freire called "codes" (here called visual vignettes) that illustrated community-identified issues. Last, the team recorded and shared information from community members about what they wanted to see change in the community that would help improve mental health systems and access to resources.

The team submitted the protocol for this study to the executive board of the CBO, which gave the team final approval. The team followed the local tribal protocol; because tribal protocols vary, teams in other communities may need to submit visual data collection methods to an IRB of record prior to collecting information.

## **Community Context and Setting**

The AI community is located in Montana and is home to one federally recognized tribe. The location is rural and designated as a medically underserved area. Mental health services are offered through the tribe, and limited substance abuse treatment options are available.

### The Project Team's Partnership

The partnership started in 2010 when members of the CBO attended a workshop taught by the evaluation scientist to learn more about resource coordination and support for tribal mental health programs. Together, the team developed a plan to address unmet mental health needs for children and youth in the community; one goal was to secure funding to support planning for a mental health system of care. The evaluation scientist was not affiliated with an academic institution, allowing for more flexibility and trust building in the partnership process.

#### **Program**

The team received funding from SAMHSA in 2011 and worked closely with other tribal health programs, including behavioral health, recovery, Bureau of Indian Affairs, social services, and schools. Cultural leaders, elders, and natural helpers also supported the program as advisors and cultural resources. (Natural helpers are individuals from the community with traditional and spiritual gifts who do not fill traditional 'helping' roles or professions as defined by Western standards,

but nonetheless provide essential advice and assistance.) A community advisory board provided oversight and included representatives from youth- and family-supporting organizations, cultural programs, public and tribal schools, social service organizations, law enforcement, juvenile justice, and CBOs, as well as traditional knowledge keepers and elders.

In the first 2 years of the project, the team tried traditional data collection methods to gather information about mental health systems and needs, including a 19-question paper-and-pen survey sent to providers that asked questions about the kinds of mental health resources available, client demographics, and provider demographics. This needs assessment was the first step in the 3-year planning process of documenting the existing mental health services that would later be used to create a system of care on the reservation. After the needs assessment, the team conducted focus groups with community members to document their perspectives about gaps in existing mental health services. The team also tried to gather information via surveys, interviews, community gatherings, and secondary data analysis. However, many community members were reluctant to talk about mental health, and these traditional data collection methods resulted in data that were difficult to link with mental health systems and needs. For example, widespread poverty and a lack of community activities were common responses to mental health-related questions. In the 3rd year of the grant, the team decided to try a different approach and developed a data collection strategy that was relational and intuitive. Ultimately, the team wanted to explore and confirm the issues, barriers, and resources on the reservation. Over several months, the team developed visual vignettes of different scenarios people may experience as they navigate the mental health system on the reservation (e.g., cutting behavior, prescription drug and alcohol abuse, mother addicted to drugs wanting to get her kids back). These were vetted by the team and various stakeholders using the following process: The evaluation scientist sent electronic copies of the vignettes to the data coordinator, project director, and CBO for review and comment. After the evaluation scientist incorporated their comments, the data coordinator and project director asked several community advisory board members to review the revised vignettes which served as a pilot process. This process resulted in two additional visual vignettes: a veteran and a transgendered youth. A total of six vignettes were used in the participatory data collection process.

It is important to note that, within this method, story and drawings make more sense to those who have experienced or seen the events occur in their community—these vignettes are very specific to what happens in this reservation community. Someone without knowledge of the context, history, location, and norms may not understand or benefit as much from this method. However, the scenarios created by the team may help those without knowledge to gain understanding about the unique community context. For example, professionals working with Native veterans returning to their reservation may not be aware of how veterans access resources in their communities, or

of the strong kinship systems and family support that help veterans when they return home. Some professionals may not understand, for example, the distrust of Western behavioral health providers, the use of pills to treat anxiety, or the limited employment opportunities on reservations. The veteran vignette outlines this process and lists other resources that are available on the reservation, many of which are available in other reservation communities as well. See Appendix A for all vignettes.

### **Participatory Visual Data Collection**

Informants were identified using a convenience sampling method, where the data coordinator, trained by the evaluation scientist, approached people in a variety of community settings and asked them to look at 8.5" x 11" color printouts of the visual vignettes and answer questions about them. (Note: The vignettes were referred to as *diagrams* during these interviews because *visual vignette* is not a commonly used term on the reservation.) The data coordinator also went to all five districts on the reservation and approached people outside community locations (e.g., post office, community meeting hall). The data coordinator gained verbal informed consent for all participants interviewed, and the team followed local protocols for data collection, analysis, dissemination, and reporting, as well as ethical standards of research for the community. Participants did not receive compensation. No participants mentioned privacy concerns, although it is possible that some individuals approached were not comfortable talking about mental health on the reservation and therefore declined to participate. The majority of people asked by the data coordinator agreed to participate in the interviews; however, the team did not record the number of people asked and the number of people who refused.

# **Participants**

Interviews were conducted in March and April 2014 with community members over 18 years of age (N = 25) who represented various perspectives, ages, and genders, as well as all districts in the community. The team decided that 25 responses were sufficient based on the resources and time available, and on similarities in experiences shared by community members.

# Questions

Community members were asked a series of open-ended questions, including:

- 1. What do you think about these stories/experiences illustrated in the diagrams?
- 2. Are these situations similar to what people on the reservation experience?
- 3. What other mental health resources are available in the community?

In some cases, community members looked at the diagrams and wrote directly on them; sometimes they used lines to show how they felt the experiences did not reflect what actually happens in the community, and they redirected the arrows and order of events (see Figure 1). With other informants, the data coordinator wrote down information using a paper and pen. All paper documents were converted to electronic format either by scanning or by typing responses into Microsoft Word; the electronic versions then were sent to the evaluation scientist for analysis.

Jane is 14. Her mom noticed she has Cutting marks on her arms. A week goes by and Jane Her mom Calls Jane has been depressed continues to Cut. Her mom Calls Behavioral and she recently broke up the BIA police Health for an with her boyfriend. She appointment, usually gets high before they Can see she Cuts and has a history her in 4 of past suicidal ideation weeks... and attempts... The psychiatric Her mom is still Jane is placed in jail hospital admits Concerned and for observation.. Jane... drives Jane to And released the Billings for next day .. treatment.. Therapy does not help... Conditions at home have not Changed.. Cutting conti**ble** What other resources might be available for Jane? But.. 3 days later Natural Helpers Jane is sent home... Elders Jane goes to her Sweats appointment at Talking Circles behavioral health Alta Care and begins Honor Your therapy... Life MSPI Youth Family Services Recovery THE CONTROL OF THE PROPERTY OF

Figure 1

Example of Visual Vignette Presented to Community Member to Prompt Dialogue

#### **Analysis**

The team was most interested in a visual representation of themes and the relationships between them; therefore, they selected a thematic network analysis approach (Attride-Stirling, 2001). All data were uploaded into ATLAS.ti by the evaluation scientist (Muhr & Friese, 2004) to ensure the themes illustrated were supported by the responses and to see how they were related. Themes then were reviewed by the team, community members, and program personnel to ensure they

represented the actual experiences and perceptions of people in the community. The team followed an Indigenous research approach that allowed for inquiry and exploration of the dominant and traditional research paradigm of mental health systems and needs on the reservation. This approach was most appropriate for the community and included a participatory decolonizing framework designed to promote self-determination and cultural autonomy with the goal of justice and equity (Denzin, Lincoln, & Smith, 2008).

The analysis process required several steps. The first step was to devise a coding framework and then to open code text. Next, themes were abstracted from coded text segments and refined. Thematic networks were created by arranging basic and organizing themes and extrapolating global themes. These networks then were illustrated and refined based on the project team's review and consensus. Networks then were examined to find meaning between themes and patterns that emerged from the process.

In the last step of the analytic process, the team organized the themes based on the following categories: strengths, challenges, recommendations, culture and spirituality, access and quality, and general statements. Data generated from visual methods then were used to refine diagrams describing the mental health systems and needs on the reservation.

#### **RESULTS**

Visual methods helped the team elucidate concepts, stories, and experiences related to the mental health systems and needs on the reservation.

The global theme that emerged was expanding the use of culture and existing cultural resources for youth and families with various unmet mental health needs. This theme was linked with other organizing themes, including the community history and context, where strengths and challenges were described by community members. Another organizing theme was recommendations about how to improve mental health and substance abuse resources with regard to access and quality (see Figure 2). (Most participants did not distinguish substance abuse from mental health needs. For example, some people talked about wanting to get help for their family members who struggle with substance abuse and depression.)

Many community members talked about the use of spiritual leaders, the connection to cultural resources, and the use of elders to teach and reinforce culture. This finding was documented by the team early on, but not in the context of specific mental health needs. Community members voiced specific recommendations based on the circumstances outlined in the visual vignettes. Several conversations related to the need for improved law enforcement response to mental health crisis situations, improved clinical care, and challenges within the family environment where drinking and

drugs are present. Also, many community members talked about the need for better access to and quality of mental health services (e.g., lack of culturally competent providers). Community assets and strengths were echoed in many conversations, where the Boys and Girls Club was mentioned as a positive place for community activities and leadership building in youth. Other conversations related to using existing mental health resources in the community, and many recommended efforts to increase community awareness about mental health resources on the reservation. Due to the sensitive nature of mental health conversations in the community, specific statements are not included in this paper.

Strengths **Challenges**  Kinship system Jails • Club leadership Clinic History and • Club activities/access Substance abuse • Several mental health **Community Context** common resources available in Lack of trust in mental community health providers and systems **Use of Existing Cultural** Resources **Access and Quality General Statements**  Shelters • Elders teach about Recommendations Culturally competent culture clinicians Activities reinforce • Increase use of culture spiritual leaders Basic needs must be met Church Reach out and care

Figure 2
Thematic Analysis: History, Cultural Resources, and Recommendations

In summary, this process uncovered both strengths and challenges related to the current mental health system of care on the reservation. The team hopes to focus on the challenges uncovered through this process to improve conditions and access. For example, to address the lack of culturally competent mental health providers and the differing views about the definition of mental health

needs, the CBO plans to promote mental health awareness through CBO staff trainings, professional development opportunities, partnerships with behavioral health programs, and continuing mental health conversations in the community.

#### Limitations

Visual methods in research present limitations, mainly because the process is subjective and there are limits to what one can observe in a drawing. Words were used in the visual vignettes to tell stories about how individuals accessed different mental health systems on the reservation. Not all stories were captured through this time-intensive process; therefore, the results and feedback provided by participants may not represent the entire community or the experiences of all community members. The results of this effort are not generalizable to other tribes or communities; however, the team feels the approach is transferable to other communities. To this end, the team created a blank visual vignette that could be used by other tribes; it includes areas for need, context, resources, and discussions. However, the use of visual methods requires an initial understanding about context and needs—if communities do not have preliminary data or information, visual methods may not be appropriate. Also, the participants' responses and openness rely heavily on the individual leading the discussion. The data coordinator in this study was comfortable with these conversations and was well respected in the community, so trust was already established and the information shared was honest and open.

For nearly 3 years, the team, advisory board members, and grant project officers used a variety of words to define mental health system and needs. These words meant different things to different people, which created confusion and feelings of inadequacy among team members. The team learned two lessons from this experience. First, it's important to think creatively when traditional research approaches fail to deliver needed information. Second, dialogue about mental health systems and needs must begin with the people. Visual methods served as the most effective approach to these conversations.

# **Next Steps**

In the future, communities and funding agencies must consider the reasons information is requested by funding agencies and generated in communities. The project team learned early in the 3-year process that the generation of information without a clear purpose is not always valuable to community members and rarely improves the conditions for which the information is requested. In the first 2 years of the project, the team tried traditional data collection methods and found that community members were reluctant to talk about mental health; yet, in the 3rd year of the project, when the team started using visual methods—people started to talk, and the team listened.

Several lasting effects came from the insights gained through the team's use of participatory visual research methods. First, the team developed a deeper understanding of how the community views and experiences the mental health system of care on the reservation. This understanding pointed to the unique strengths and challenges in the community. The CBO plans to build future programs and services using the strengths identified through this process, including community awareness and resources such as strong kinship systems, existing mental health providers, spiritual leaders, and elders. Second, a drug task force coalition was revitalized in the community, supported by the stories and experiences shared by community members through visual vignettes. Third, leadership in the community for mental health-related training and capacity increased. Both a community and a youth advisory board met every month to discuss the mental health needs of youth and families on the reservation. In sum, this process increased mental health awareness in the community and translates to improved screening, identification, and referral for individuals in need.

In closing, visual data collection methods as a research strategy worked to instill trust between the community and the research team. Visual vignettes were more effective in reaching community members than were traditional approaches, and served as a common ground that uncovered community members' perspectives about and experiences with mental health systems and needs, as well as substance abuse. The relationships developed through this process helped community members share their experiences and knowledge in a manner that was safe and relevant to the community. This knowledge, in turn, helped the team understand and document community voices regarding mental health systems and needs on the reservation, and to integrate findings from across demographics, reservation districts, genders, and age groups. Ultimately, the visual data collection process was effective and promoted community ownership, engagement, and feedback.

In the future, the team plans to continue using visual methods for information and data gathering—especially when sensitive and highly personal topics are discussed. In doing so, the team hopes to empower community members as advocates of social change while promoting the rich history, language, values, arts, and aspirations of community members for healthy future generations.

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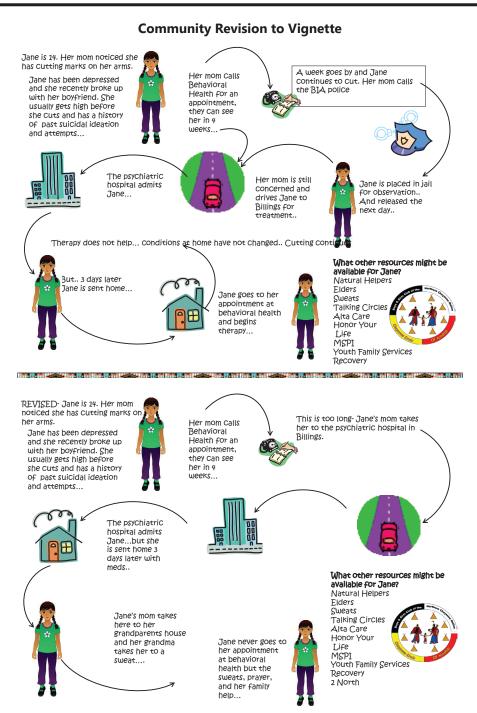
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# Appendix A Visual Vignettes

**Blank Vignette** 

# 

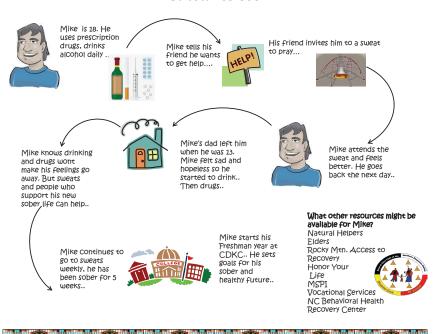
# Appendix A, Continued Visual Vignettes



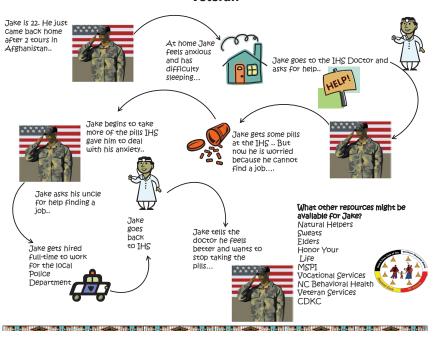
These two vignettes show how a community member changed the process from the first to the revised/second. During an interview, the community member suggested removing the step where BIA police are called and Jane is placed under observation.

# Appendix A, Continued Visual Vignettes

#### **Substance Use**

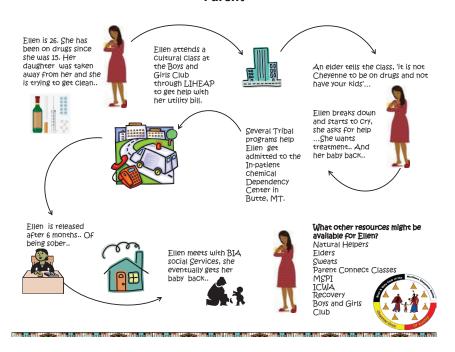


#### Veteran

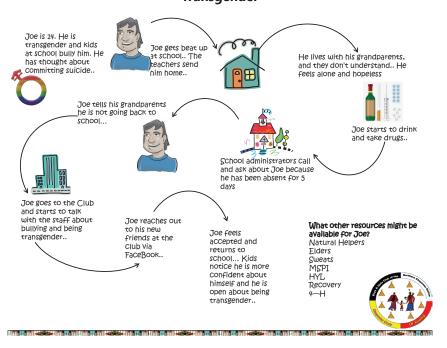


# Appendix A, Continued Visual Vignettes

#### **Parent**



# Transgender



# Appendix A, Continued **Visual Vignettes**

# **Systems of Care**

# Systems of Care Northern Cheyenne



Educational Support

Materials and supplies for low income families Parent Connect Classes Schools



FOOD
WIC, TANF, SNAP for Low Income
Commodity Food Program



Mental Health

Youth and Family Services Counseling Youth Dynamics-C Behavioral Health Alta Care

Dept. Health & Human Services Psychiatric Hospitalization-B



Shetter & Housing Support
Rose Bud Lodge Shetter for Children
ICWA, Housing Authority, LIHEAP
Housing Assistance Council
Priendship House B
St. Labre Family Services-Child Residential
Care and Clothing Youth Dynamics for Emergency Shelter Tumbleweed Runaway Program-B



Blessed Sacrament Catholic Biessed Sacrament Catholic Church Morning Star Baptist Christ the King Catholic Church Latter Day Saints Prayer Lodge



Recreation & Activities
Boys and Girls Clubs
Circle of Life Youth Group



Juvenile Justice

Second Season Tribal Courts BIA Healing Hearts



Medical Services
IHS Clinic
Sheridan Memorial Hospital St. Vincent Hospital Billings Clinic





Substance Abuse Help
Meth Suicide Prevention for Support
Recovery Center for Treatment
Behavioral Health for Counseling Youth Dynamics for Counseling-C
Rocky Mountain Tribal Access to Recovery for In Patient Chemical Dependency Center <18 years
Biessed Sacrament Church 12 Step Program

\*C=Colstrip, B=Billings

# THE PROSTITUTION AND TRAFFICKING OF AMERICAN INDIAN/ALASKA NATIVE WOMEN IN MINNESOTA

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Abstract: We examined social and physical violence experienced by American Indian/Alaska Native (AI/AN) women in prostitution and their impacts on the mental and physical health of 105 women (81% Anishinaabe, mean age = 35 years) recruited through service agencies in three Minnesota cities. In childhood, abuse, foster care, arrests, and prostitution were typical. Homelessness, rape, assault, racism, and pimping were common. The women's most prevalent physical symptoms included muscle pain, impaired memory or concentration, and headaches. Symptoms of post-traumatic stress disorder and dissociation were common, with more severe psychological symptoms associated with worse health. Most of the women wanted to leave prostitution and they most often identified counseling and peer support as necessary to accomplish this. Most saw colonization and prostitution of AI/AN women as connected.

There is increasing awareness about violence perpetrated against American Indian and Alaska Native (AI/AN) women (LaPointe, 2008; Smith, 2005; Tjaden & Thoennes, 2000). AI/AN women today are vulnerable to sexual exploitation as a result of post-colonial homelessness, poverty, health problems (including mental disorders), and a lack of basic services to address these conditions. Like other women in military conflict zones, AI/AN women were at extreme risk for rape, prostitution, physical abuse, and racist verbal abuse during colonization (Hyman, 2009; Pretty Sounding Flute, 2000; Smith, 2005). During the boarding school era, an effort to force assimilation (Adams, 1997), U.S. policy required most AI/AN children to live in off-reservation boarding schools where physical and sexual abuse were common (Deer, 2004a; Perry, 2002). Colonial abuse aimed at destroying AI/AN cultures persisted throughout the 20th century and continues today.

As a result, many AI/AN people live in adverse social and physical environments that place them at high risk of exposure to traumatic events with rates of violent victimization more than twice the national average (Manson, Beals, Klein, & Croy, 2005). High rates of poverty, homelessness, and chronic health problems in AI/AN communities (Palacios & Portillo, 2009; Perry, 2008) create vulnerability to prostitution and trafficking among AI/AN women by increasing economic stress and decreasing the ability to resist predators (Bortel, Ellingen, Ellison, & Thomas, 2008; Deer, 2010). AI/AN women are subject to high rates of childhood sexual assaults, domestic violence, and rape both on and off reservations (Bachman, Zaykowski, Lanier, Poteyeva, & Kallmyer, 2010; Chenault, 2011; Clark & Johnson, 2008; Evans-Campbell, Lindhorst, Huang, & Walters, 2006; Saylors & Daliparthy, 2012). The vast majority of prostituted women were sexually assaulted as children, usually by multiple perpetrators, and were revictimized as adults in prostitution as they experienced being hunted, dominated, harassed, pimped, assaulted, battered, and sometimes murdered by sex buyers, pimps, and traffickers (Farley, Franzblau, & Kennedy, 2014).

We use the word *prostitution* to refer to the exchange of sex acts for money, food, shelter, and other needs; outcall/escort/cell phone prostitution; Internet prostitution; massage parlor and brothel prostitution; child and adult pornography; strip club prostitution; sauna- or nail parlor-based prostitution; live sex shows; street prostitution; peep shows; phone sex; servile marriages/"mail-order brides"; and prostitution tourism. *Trafficking* is prostitution under pimp control and can be domestic or international.

As noted above, homelessness is linked to the sexual abuse of prostitution and trafficking (Farley et al., 2003) and is a primary risk factor for prostitution (Boyer, Chapman, & Marshall, 1993; Louie, Luu, & Tong, 1991; Simons & Whitbeck, 1991). When state and private agencies fail to offer women and children shelter, pimps provide housing in exchange for prostitution. AI/AN people are overrepresented in the homeless population in the U.S. (Zerger, 2004). Housing instability on reservations sometimes results in migration to urban areas, leaving young women vulnerable to prostitution. Although AI/AN people constitute only 1% of adults and 2% of youth in Minnesota, they constitute 11% of homeless adults and 20% of homeless youth (Koepplinger, 2009; Minnesota Coalition for the Homeless, 2008; Wilder Research Foundation, 2010).

Prostitution is, unfortunately, excluded from some reports on violence against AI/AN women. Although both reports addressed sexual violence against AI/AN women, neither a 2007 Amnesty International report nor a 2010 article by Bachman et al. addressed prostitution or sex trafficking. AI/AN women and children are disproportionately represented in U.S. and Canadian

prostitution (Farley, Lynne & Cotton, 2005; Kingsley & Mark, 2000; McKeown, Reid, & Orr, 2004), just as Māori youth in New Zealand (Plumridge & Abel, 2001) and Atayal youth in Taiwan (Hwang & Bedford, 2003) are overrepresented in prostitution.

Most often entered into by those with a history of sexual, ethnic, and economic victimization, prostitution is a sexually exploitive, usually violent survival option that rarely has been included in discussions of sexual violence against Native women. Because Native women are at high risk for poverty, homelessness, and childhood sexual violence, which are risk factors for prostitution, and because prostituted women are at high risk for violence and emotional trauma, our goal was to learn more about the lives of Native women prostituted in Minnesota, a group of people whose experiences of violence, physical and emotional health, opinions about prostitution in a historical context of colonialism, and stated needs in order to exit prostitution have not been adequately studied in psychological research.

#### **METHOD**

# **Participants**

We interviewed 105 AI/AN women in prostitution who were in contact with supportive agencies in Minneapolis, Duluth, and Bemidji, Minnesota. Based on the empirical data in this study and others, the authors do not consider prostitution to be work in its positive meaning as legitimate commerce (Farley et al., 2005; Potterat et al., 2004; Silbert & Pines, 1983; Stark & Hodgson, 2003; Widom & Kuhns, 1996). We have come to understand prostitution as a form of violence against women and as a human rights violation; therefore, we avoid using the term "sex worker," which conceals and mainstreams these violations. Although referring to women as "sex workers" may be an attempt to dignify prostitution, after many interviews with prostituted women, we conclude that the expression fails to lend dignity to activities that are dehumanizing and degrading. Instead, we use the terms "woman in prostitution," "prostituting woman," or "prostituted woman," avoiding the transformation of women into the very harms perpetrated against them. In professional practice settings such as clinics or shelters, we use words that the women themselves use for prostitution, such as "in the life" or "dating." In conferences, staff meetings, or articles, we use the terms suggested above. <sup>1</sup>

The women volunteered for the study after seeing announcements posted at agencies or via snowball or chain referral sampling. We asked agencies that are members of the Minnesota Indian Women's Sexual Assault Coalition to help us identify women in their communities who might want to participate in this research project. Advocates at these agencies posted flyers at

food shelves, homeless shelters, and other locations in the community. We have conducted comparable research in nine other countries; in all locations, we sought at least 100 respondents because that number made it possible to conduct meaningful analyses and arrive at reasonable conclusions. A smaller number would not have permitted this. We interviewed 105 women because we anticipated having to discard some data, or that some data would be missing. Fortunately, this did not occur for most questionnaire items.

#### **Procedure**

We conducted research interviews consisting of six questionnaires that included both quantitative items and structured open-ended questions. The following questionnaires were read aloud to the women, and notes were taken on paper or on a computer because audio recording of illegal activity (prostitution) would likely have jeopardized rapport with the interviewees and resulted in less candid responses.

The Prostitution Questionnaire has been used previously in nine countries (Farley et al., 2003) and includes questions about age of entry into prostitution, number of sex buyers; experiences of sexual and physical violence in childhood and adulthood; use of pornography in prostitution; history of homelessness, physical health problems, alcohol and drug use; whether respondents wish to leave prostitution, and what they need in order to do so. Most of the questions are close-ended (requiring a response of *yes* or *no*, or using response categories specific to the question; e.g., *last week*, *last month*, or *last year*) and a few are open-ended (e.g., "Where were you born?").

We included six items from the Dissociation subscale of Briere's Trauma Symptom Checklist (TSC-40; Elliott & Briere, 1992), which was developed to assess trauma symptoms in survivors of childhood sexual abuse. On a Likert scale of 0 (*never*) to 3 (*often*), scores of 2 or 3 indicate a clinically significant frequency of dissociative symptoms. TSC-40 total scores yield an alpha of .90, and the mean internal consistency for the subscales is .69 (Elliott & Briere, 1992). Differences in dissociative symptoms among adults with different child abuse histories have been obtained with the TSC-40 (Briere & Runtz, 1990).

The women also completed the Post-traumatic Stress Disorder Checklist (PCL; Weathers, Litz, Herman, Huska, & Keane, 1993), a self-report research inventory for assessing the symptoms of post-traumatic stress disorder (PTSD), which are grouped into three categories: 1) traumatic re-experiencing of events or flashbacks; 2) avoidance of situations which are reminiscent of the traumatic events, and a protective emotional numbing of responsiveness; and 3) autonomic nervous system hyperarousal (such as jittery irritability, super-alertness, or

insomnia; American Psychiatric Association [APA], 2000). Respondents were asked to rate these symptoms on a 17-item, Likert-scored scale (1 = not at all, 5 = extremely) with test-retest reliability of .96. Internal consistency as measured by Cronbach's  $\alpha$  was .97. Validity of the scale is reflected in its strong correlations with the Mississippi Scale (.93), the Post-traumatic Stress Disorder-Keane scale of the Minnesota Multiphasic Personality Inventory-2 (.77), and the Impact of Events Scale (.90; Weathers et al., 1993). The PCL has functioned comparably across different ethnic cultures in the U.S. (Keane, Kaloupek, & Weathers, 1996). We measured symptoms of PTSD in two ways. First, using Weathers and colleagues' (1993) scoring suggestion, we considered a score of 3 or above on a given PCL item to be a symptom of PTSD. Scored in this way, these symptoms were used to estimate the presence or absence of a diagnosis of PTSD for each woman. Using DSM-IV criteria (APA, 2000), women who scored 3 or higher on at least one symptom of re-experiencing, three symptoms of avoidance, and two symptoms of hyperarousal met criteria for a diagnosis of PTSD. Second, using a procedure established by the authors of the scale, we generated a measure of overall PTSD symptom severity by summing respondents' ratings across all 17 items.

General health was measured using self-rating on a scale of 1 = poor to 5 = excellent. The validity of this method has been established through correlations with physician-assessed health and mortality (Idler & Angel, 1990; Kaplan & Camacho, 1983; Mossey & Shapiro, 1982). We also administered a Chronic Health Problems Questionnaire (Farley et al., 2005) that included items scored *true* or *false* and was developed from an earlier study of 854 people in prostitution in nine countries, which used an open-ended item to inquire about health problems (Farley et al., 2003). The most frequently mentioned health problems in that study were used as checklist items in the Chronic Health Problems Questionnaire for the present study; reliability data are not available.

We created a new questionnaire, the Native American Prostitution Questionnaire, to inquire about interviewees' understanding of prostitution in relation to their cultures, historical trauma, boarding school, foster care, adoption, tribal identity, and sexual violence, among other factors. The questionnaire contained open-ended questions to which verbatim responses were recorded. For example, questions included "What Nation/Tribe are you from?" and "Please explain how colonization of Native people and prostitution and trafficking of Native women are connected, in your own words." The latter question was asked only when the interviewee responded, "yes" to a previous question about whether she saw such a connection. The questionnaire also included close-ended questions (e.g., "Did any of your family members attend boarding schools?" which was coded *yes*, *no*, or *don't know*, and "Were you ever in foster care?" which was coded *yes* or *no*).

The study protocol was reviewed by Prostitution Research & Education's Ethics Review Committee. The interviews were conducted by 5 interviewers who had experience in sexual assault and domestic violence advocacy and were trained in interview techniques and questionnaire administration, including observed and practice interviews. Interviews lasted 1-2 hours. Advocates at Minnesota Indian Women's Sexual Assault Coalition member agencies took calls and scheduled interviews; provided transportation, sexual assault advocacy, and support during and after interviews; and provided interview space in their offices. Each woman signed an informed consent form and received a \$75 gift card in appreciation of her time.

#### **RESULTS**

# **Demographic Characteristics**

The mean age of the women was 35 years (range = 18-60 years, SD = 11). Ninety-eight percent of the women were currently or previously homeless.

# **National and Tribal Identities**<sup>3</sup>

The Bureau of Indian Affairs, operating as an arm of the U.S. government, defines "who is an Indian" in approximately 12 different ways for the purpose of determining eligibility for services. Yet identity among AI/AN people does not generally follow the federal government's model (Haozous, Strickland, Palacios, & Solomon, 2014). Most AI/ANs provide an identity connected to their reservation instead of their family ancestry identity. Many have multiple heritages and also have two or more reservation identities. It is possible, for example, for an AI/AN person to live on a reservation but not share the tribal identity of the majority on that reservation. In this study, we have done our best to stay as close as possible to the women's own categorizations, which are sometimes tribes or nations and sometimes reservations. The women were likely to self-identify based on which people in their family or community taught them about their ancestry.

A significant majority (81%, n = 85) of women identified as Anishinaabe, also known as Ojibwe or Chippewa. Of these women, 94% (n = 80) identified Anishinaabe as their only tribal affiliation, and 6% also identified with another nation. The remaining 19% (n = 16) of the women identified as coming from one or more other nations (e.g., Lakota/Dakota, Apache, Oneida, Menominee, Ho-Chunk, Blackfoot, Cherokee, Choctaw, Ponca, Cree, Sioux), or occasionally identified as Native American and did not specify national or tribal affiliation.

Of the 90 women who told us where they had grown up, the vast majority (91%, n = 82) had grown up in Minnesota. Nine percent (n = 8) had grown up in other states within the U.S., and 1% (n = 1) had grown up overseas. Of the 89 women who told us that they had grown up in the U.S., 44% (n = 39) indicated that they had grown up on a reservation. Reservations in Minnesota included Leech Lake, White Earth, Red Lake, Fond du Lac, Mille Lacs, Grand Portage, and Bois Forte. Reservations located outside Minnesota were in South Dakota (Pine Ridge, Rosebud, and Cheyenne River), Wisconsin (Menominee), and Oklahoma (Ponca).

At the time of the interview, most of the women lived in Duluth (49%) or Minneapolis (27%). Six percent currently lived on either Leech Lake or Fond du Lac reservation. The remaining 19% lived in other Minnesota cities.

## Antecedents to Prostitution in the Lives of AI/AN Women

# **Boarding School**

Nine percent of the women we interviewed had attended boarding school. More than two thirds (69%, n = 63) of the 105 women had family members who had attended boarding school. The relatives who attended boarding school were grandmothers (42%), mothers (35%), grandfathers (26%), sisters (17%), fathers (17%), or cousins (17%). Other relatives included brothers, great grandmothers, great grandfathers, aunts, uncles, and daughters. Boarding schools were located in a variety of states<sup>4</sup> and in Canada.

Of relatives who had attended boarding school, more than two thirds (69%) were known by the women to have been abused there. All of those relatives were verbally or mentally abused; most (94%) were spiritually, culturally, or physically abused; and 27% were sexually abused. The abuse was perpetrated by teachers, church officials, and government officials.

## **Foster Care and Adoption**

Forty-six percent (n = 48) of the women we interviewed had been in foster care, in an average of 5 foster homes (range = 1-20, median = 3, SD = 4.8). Before the age of 5 years, 34% of those who had been in foster care had been placed in an average of 3.7 foster homes (range = 1-10, median = 3, SD = 3.3). Between the ages of 6 and 10 years, 53% had been placed in an average of 3.4 foster homes (range = 0-14, median = 2, SD = 4.1). Between the ages of 11 and 18 years, 73% had been in an average of 2.8 foster homes (range = 0-16, median = 1, SD = 3.5). As children, the women were placed in AI/AN foster homes 36% of the time. Twenty percent of the women were living on reservations prior to being placed in foster care. The 87 foster care locations were most often in Duluth, St. Paul, or Minneapolis (38), other Minnesota locations (30), and less frequently on Minnesota or South Dakota reservations (8).

Several women spoke to interviewers about the reasons for their foster care placement. They were children of alcoholics or drug addicts and frequently ran away from home, almost always attempting to escape abuse from male relatives or neglect/abandonment. Some cared for mothers who were emotionally incapacitated, homeless, or addicted. Several were placed in foster care upon the death of grandparents.

Almost half (46%) of the women who had been in foster care had been abused in foster families, most often verbally (86%), spiritually (81%), culturally (76%), physically (67%), and/or sexually (38%). The abuser was most often the foster mother (57%), foster brother (52%), foster father (45%), foster sister (29%), or other person (29%). The five interviewees who were adopted reported similar abuse patterns.

One woman's story was illuminating. Violet (name changed) had been raised in several foster homes. In one, missionary foster parents called Violet and her sisters "little savages" and reminded them that they should be grateful to have a home. Violet was sexually abused as a child by adult male relatives and family friends. Kidnapped at age 12 and trafficked to a Midwest city, she was beaten, raped, forcibly addicted to drugs, and sold into prostitution. Until she found peer support and health care, she was not able to escape prostitution. She now connects her prostitution with a multigenerational history of injustice and abuse, including her mother's abuse in a boarding school and family members' alcoholism and prostitution. Finding her cultural identity, Violet explained, was part of the path of her escape from prostitution.

## Arrests as Children and as Adults

Police and social service agencies have only recently begun to understand prostitution of children as sexual assault against a child rather than a crime committed by a child. More than half (52%) of the women we interviewed were arrested during childhood on average 8 times (range = 1-60 times, median = 3, SD = 12). Several had been arrested for prostitution when they were children; other arrests were for assault and battery (17%), underage drinking (15%), truancy (14%), and theft (9%). Most of these juvenile arrests (84%) resulted in convictions.

Eighty-eight percent (n = 92) of the women had been arrested as adults. They had been arrested an average of 4 times during adulthood (range = 1-39, median = 2, SD = 6), most commonly for drunk driving (14%), prostitution (12%), theft (10%), and assault and battery (8%). Most of the women's arrests (84%) resulted in convictions.

# **History and Characteristics of Prostitution**

# **Extent and Types of Prostitution**

The women had been in prostitution, on average, 14 years (range = 0-43, SD = 11), and had begun prostituting, on average, at age 21 (range = 4-50 years, median = 18 years; SD = 8). Thirty-nine percent (n = 41) had been sold for sex when they were minors, i.e., younger than 18 years of age (see Table 1).

Table 1
Age, Age of Entry, and Length of Time in Prostitution of AI/AN Women Prostituted in Minnesota Compared to Prostituted Women in Nine Countries

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	AI/AN Women Prostituted in Minnesota (N = 105) <sup>a</sup>	Prostituted Women in Nine Countries (N = 854) <sup>b</sup>	
Mean age (SD)	35 (11)	28 (8)	
Age range	18-60	12-68	
Mean age of entry to prostitution (SD)	21 (8)	19 (6)	
Years in prostitution (SD)	14 (11)	9 (8)	
Percent younger than 18 when entered prostitution	39%	47% (353)	

<sup>&</sup>lt;sup>a</sup> Sample size varies somewhat depending on how many women answered a given question. <sup>b</sup> Reported in Farley et al., 2003.

One fourth (27%, n = 28) of the women had been used in prostitution by more than 500 men. Eleven percent (n = 12) had been used by 500-1,000 men; 16% (n = 17) of the women had been used in prostitution by more than 1,000 men.

A large majority (75%) of interviewees had engaged in prostitution in exchange for food, shelter, or drugs. Most (77%) had been prostituted in multiple locations in urban areas (see Table 2). The most common locations were street prostitution (85%); private residences (83%); private parties, hotels, or nightclubs (69%); and bars (68%).

Table 2
Locations where 105 Minnesota AI/AN Women Were Prostituted and Knew of Others Prostituting<sup>a</sup>

Location where prostituted	Self	Others
Street	85% (89)	77% (58)
Private Home or Apartment	83% (87)	77% (58)
Private Parties/Hotels/Nightclubs	69% (72)	73% (55)
Bar	68% (71)	67% (50)
Outcall/Escort	36% (38)	59% (44)
Internet or Live Video Chat	26% (27)	48% (36)
Phone Sex Line	26% (27)	43% (32)
Reservation	21% (22)	36% (27)
Strip Club	20% (21)	60% (45)
Casino	19% (20)	35% (26)
Sauna	16% (17)	37% (28)
Massage Parlor	14% (15)	35% (26)
Pornography	10% (11)	29% (22)
Peep Show	8% (8)	28% (21)
Brothel	8% (8)	31% (23)
Farm	8% (8)	13% (10)
Church	2% (2)	1% (1)
Cult	1% (1)	1% (1)
Ship in Duluth Harbor	1% (1)	-

<sup>&</sup>lt;sup>a</sup> Sample size varies somewhat depending on how many women answered a given question.

# The Role of Families

Of the 105 women we interviewed, 57% (n = 60) had family members also involved in prostitution, including cousins, sisters, mothers, aunts, nieces, and daughters. Brothers and fathers, possibly involved in pimping, also were mentioned. Fifty-eight percent of the women's families knew about their prostitution, and, in 43% of those instances, had tried to help them get out of prostitution.

# **Trafficking**

Forty-five percent of the women had been trafficked for the purpose of prostitution. Although they often assumed that trafficking occurred only if they were transported by pimps from one location to another, under the William Wilberforce Trafficking Victims Protection Reauthorization Act (TVPRA; 2008), no transportation is required to have been trafficked. Additionally, the TVPRA defines any child under the age of 18 years who is used in prostitution as a trafficking victim.

Prostitution often meets the legal definition of human trafficking, in that pimping or third-party control of a prostituted person cannot be distinguished from trafficking (Huda, 2006). Under many laws, consent is irrelevant in determining whether trafficking has occurred (United Nations, 2000). Eighty-six percent of interviewees believed that most women do not know what prostitution is really like when they begin prostituting. They reported that deception or trickery, which are critical elements in most definitions of trafficking, are almost always involved in prostitution.

Almost half (49%) of interviewees turned over most of their money from prostitution to pimps. Forty-two percent of the time, the woman's boyfriend or pimp was gang affiliated, and many women named the gangs with which their pimps were involved. The women's mothers, children, and other family members were also named as recipients of prostitution monies 27% of the time. Pimps' recruitment tactics included enticement at schools or bars or via the Internet, recruitment as dancers, hitchhiking, and gang coercion. "I wouldn't say there are pimps anymore," explained one woman we interviewed. "Now, they're all boyfriends." The women were often domestically trafficked under brutal pimp control. One woman told us,

My dad was very abusive to my mother and I ended up running away to Chicago. When I was 17 I was stranded in Chicago and had to get home to Wisconsin. I went to a party, there were lots of drugs, I got left there, and I was roaming around. A pimp was nice to me, he gave me this, gave me that. Then he took me to someone's place and he said this guy—age 40—he's interested in you. Then he started hitting me after I said no. I was so scared I just did it. After that I kept doing it because I was afraid to get hit.

Another woman described being prostituted and trafficked in Las Vegas by her pimp: "The men just kept coming and coming and I never slept or ate, I just had sex all the time. My pimp used the back of the van." Another woman described her prostitution on ships out of the port of Duluth, in international waters.

Many of the women we interviewed (74%) noted where trafficking of others for prostitution had occurred. The most common locations they mentioned were street prostitution (77%); private homes or apartments (77%); private parties, hotels, or nightclubs (73%); bars (67%); and strip clubs (60%).

While most of the women were transported for prostitution from Minneapolis/St. Paul or Duluth, they also were moved from the White Earth and Menominee reservations and from Chicago and Albuquerque. The women mentioned 32 states where they were transported for prostitution.

We asked the women about the ethnicity of the sex buyers. A majority of the men were European American (78%) or African American (65%), but also Latino (44%), AI/AN (24%), and, less frequently, Asian (9%). These percentages are consistent with other research on sexual violence against AI/AN women, documenting that a majority of perpetrators are not AI/AN (Perry, 2004).

#### Other Violence in the Lives of AI/AN Women in Prostitution

We asked the women about their experiences of four types of lifetime violence: childhood sexual abuse, childhood physical abuse, rape as adults, and physical assault as adults (see Table 3). Seventy-six percent of the women had experienced three or four of these types of violence (see Table 4).

Seventy-nine percent of the women had been sexually assaulted as children, by an average of 4 perpetrators (range = 1-40, median = 2, SD = 6.3). Childhood sexual abuse was a critical factor in these women's later prostitution; in some women's lives, this early abuse was prostitution or pimping by family members. "My dad sold us to his friends when I was younger," said one woman. Another woman's father offered her up for sexual abuse when she was 4 years old in exchange for his receiving a tattoo. As children, more than half of respondents (56%) had been physically abused by caregivers.

Table 3
Violence Perpetrated Against AI/AN Women Prostituted in Minnesota Compared to Violence
Against Women Prostituted in Nine Countries

	AI/AN Women Prostituted in Minnesota (N = 105) <sup>a</sup>	Prostituted Women in Nine Countries (N = 854) <sup>b</sup>
Threatened with a weapon in prostitution	78% (73)	64% (503)
Physically assaulted in prostitution	84% (85)	73% (595)
Raped in prostitution	92% (92)	57% (483)
(Of those raped) raped more than five times in prostitution	68% (50)	59% (286)
Current or past homelessness	98% (97)	75% (571)
As a child, was hit or beaten by caregiver until injured or bruised	56% (55)	59% (448)
Sexual abuse as a child	79% (78)	63% (508)
Mean number of childhood sexual abuse perpetrators	4	4
Median number of childhood sexual abuse perpetrators	2	1

<sup>&</sup>lt;sup>a</sup> Sample size varies somewhat depending on how many women answered a given question. <sup>b</sup> Reported in Farley et al., 2003.

Table 4
Number of Types of Lifetime Violence Among AI/AN Women Prostituted in Minnesota
Compared to Women Prostituted in Nine Countries

Number of types of Lifetime Violence	AI/AN Women Prostituted in Minnesota (N = 101) <sup>a</sup>	Prostituted Women in Nine Countries (N = 854) <sup>b</sup>
None	2% (2)	13% (110)
1 Type of Violence	4% (4)	16% (133)
2 Types of Violence	29% (19)	20% (171)
3 Types of Violence	36% (36)	26% (222)
4 Types of Violence	40% (40)	25% (218)

<sup>&</sup>lt;sup>a</sup> Sample size varies somewhat depending on how many women answered a given question. <sup>b</sup> Reported in Farley et al., 2003.

Ninety-two percent (n = 92) of the women had been raped in prostitution. More than half (53%, n = 56) had been raped five to 10 times, and 15% had been raped more than 20 times in prostitution. Rape as adults contributed to the women's entry into prostitution. After one

respondent was raped, she acceded to prostitution: "I figured why not get paid for acting out, it's being taken anyway." Another interviewee explained that being sexually assaulted numbed her to prostitution: "It was easier to prostitute after the sexual assault."

Eighty-four percent (n=88) of the women had been physically assaulted while prostituting. Most often the person who assaulted them was a man who bought sex (44%, n=46), but the batterers also were pimps (15%) or someone else who was neither sex buyer nor pimp (27%). More than half (52%) of the women had been physically threatened in the month prior to our interviewing them. Of those, 87% had been threatened with a gun, knife, or other weapon.

# **Physical Health Problems**

When asked about chronic health problems (see Table 5), more than half of the women reported muscle aches or pains (72%), memory problems (69%), trouble concentrating (69%), headaches or migraines (57%), vision problems (55%), and joint pain (52%). Many of the women experienced stomach pain or bloating (48%), neck pain (44%), shortness of breath (39%), allergies (38%), nausea (35%), pain or numbness in hands or feet (33%), asthma (32%), and dizziness (30%).

Table 5
Chronic Health Problems of 105 AI/AN Women
Prostituted in Minnesota

Chronic Health Problem	Percent (n)		
Muscle aches or pains	72% (76)		
Memory problems	69% (72)		
Trouble concentrating	69% (72)		
Headaches or Migraine	57% (60)		
Vision problems	55% (58)		
Joint pain	52% (52)		
Stomach ache or upset stomach or bloating	48% (50)		
Neck pain	44% (44)		
Shortness of breath	39% (41)		
Allergies	38% (40)		
Nausea	36% (36)		
Pain or numbness in hands or feet	33% (34)		
Asthma	32% (33)		
Dizziness	30% (31)		

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Table 5, Continued
Chronic Health Problems of 105 AI/AN Women
Prostituted in Minnesota

Chronic Health Problem	Percent (n)
Constipation or diarrhea	28% (29)
Rapid or irregular heart beat	28% (29)
Trouble with balance or walking	27% (28)
Swelling of arms, hands, legs, or feet	27% (28)
Carpal tunnel	27% (26)
Painful menstruation	25% (26)
Muscle weakness or paralysis	25% (25)
Chest pain	24% (25)
Vomiting	24% (25)
Hearing problems	23% (24)
Trembling	22% (23)
Sweaty hands	22% (23)
Skin problems	20% (21)
Jaw or throat pain	19% (20)
Cold or flu-like symptoms	19% (20)
Vaginal pain	13% (14)
Loss of feeling on skin	13% (14)
Pain in breasts	12% (13)
Pelvic pain	10% (10)
Difficulty swallowing	6% (6)

Almost three fourths of the women (72%) had suffered traumatic brain injury. Assaults to the head included the following symptoms and sequelae: broken jaws, fractured cheekbones, missing teeth, punched lips, black eyes, blood clots in the head, hearing loss, memory loss, headaches, and neck problems. Other violent injuries suffered by the women included flesh wounds; broken bones; arm/shoulder injuries; scars or bruises; knee/ankle injuries; and being raped, kicked, strangled, burned, or shot. One woman said, "I had a broken nose from being beaten by a pimp. [I experienced] sexual torture from my boyfriend so I have problems in my left hip. How do you tell a doctor about this?"

More than half (51%) of the women we interviewed had been diagnosed with a physical health problem, most frequently diabetes (13%), asthma (7%) or high blood pressure (7%). They also reported back injuries; hepatitis A and hepatitis C; heart disease; fibromyalgia; kidney disease; incontinence; pancreatitis; and neck, knee, and heel injuries.

#### **Medication Use**

Fifty-six percent of the women were taking medications at the time of their interviews. Of these women, 80% were prescribed medication to manage a psychological condition. Fourteen percent took sleeping pills regularly, and 11% were medicated for chronic pain. Medications for chronic disease such as diabetes or high blood pressure were used by 61% of respondents.

## **Mental Health Problems**

Sixty-five percent of the women had been diagnosed with a mental health problem. The most common diagnoses were depression (78%) and anxiety disorders (71%). The latter included generalized anxiety, panic attacks, phobias, PTSD (28%), and obsessive compulsive disorder. Another 33% had been diagnosed with bipolar disorder. Less common, but also reported, were attention-deficit/hyperactivity disorder, learning disorders, sleep problems, schizophrenia, and dissociative identity disorder. Forty percent of the women had been psychiatrically hospitalized, and 49% had family members who had been psychiatrically hospitalized.

#### **PTSD**

Most prostitution includes the kinds of traumatic stressors that are required for a diagnosis of PTSD, such as witnessing violent abuse and experiencing fear, horror, and powerlessness in response. PTSD is characterized by an oscillation between re-experiencing the event (flashbacks and autonomic nervous system hyperarousal) and emotional numbing (avoidance and numbing symptoms). In this study, 70% of the women met criteria for flashbacks, 61% met criteria for avoidance and numbing, and 74% met criteria for autonomic nervous system hyperarousal. Fifty-two percent met all criteria for a diagnosis of PTSD; their mean PTSD severity score was 51 (SD = 19).

We estimated the association of PTSD with the women's physical health using the Pearson correlation coefficient. The more severe the interviewees' symptoms of PTSD, the poorer their health ratings, r = .22, p = .024, N = 101. Women with PTSD were more likely to report poor or fair health, and much less likely to report very good or excellent health, than women without PTSD,  $\chi^2$  (2, N = 103) = 8.244, p = .016 (see Table 6). When we separately explored the individual components of PTSD, re-experiencing traumatic memories/flashbacks was not significantly associated with self-rated health. However, women with avoidance symptoms were more likely to report poor/fair health, and less likely to report good/excellent

health, than women without PTSD,  $\chi^2$  (2, N=103) = 6.508, p=.039. Women who reported autonomic nervous system hyperarousal were more likely to report poor/fair health, and less likely to report good/excellent health, than women without PTSD,  $\chi^2$  (2, N=103) = 7.362, p=.025.

Table 6
Post-traumatic Stress Disorder Diagnosis and Self-Rated Health of AI/AN Women
Prostituted in Minnesota

Health Rating	Women with PTSD (n = 54) <sup>a</sup>	Women without PTSD (n = 49)
Poor/Fair	48%	31%
Good	39%	33%
Very good/Excellent	13%	37%

## **Dissociation**

Dissociation is an escape and avoidance strategy in which deliberate human cruelty results in fragmentation of the mind into different parts of the self that observe, experience, and react, as well as parts that do not know about the harm (Ross, Farley, & Schwartz, 2003). The primary functions of dissociation are to handle overwhelming fear and pain and to help one deal with the experience of traumatic abuse. Table 7 indicates the percentages of women who had clinically significant symptoms of dissociation according to the Dissociation subscale of the TSC-40. Almost three fourths (71%) experienced "spacing out," a colloquial description of dissociation. "After you get into prostitution, you get used to it. It's like using the bathroom. You don't think about it after a while." More than two thirds of the women reported memory problems (68%), which are normative among those with symptoms of dissociation (APA, 2000). More than half of the women reported flashbacks (64%) and derealization (59%), which is the feeling that the world has changed, that one is observing herself from outside the body and/or that things in the world are not real. Half of the women felt that they were not in their bodies. Twenty-eight percent reported clinically significant dizziness.

The more severe the women's dissociative symptoms, the more likely they were to report fair or poor health, r = .35, p = .0003, N = 102. Some of the women explained how dissociation helped them survive prostitution. "It's a way of blocking memories...leading a double life within." "When the johns were sexually assaulting me," said another woman, "I could be in England or somewhere else until they were done." Several women spoke of learning to dissociate during sexual assaults when they were children. When she was "9 years old and being raped," one of the interviewees disclosed, "my mind left my body and was looking down from

the ceiling. I don't want to be that person on the streets worrying about where the next hit is coming from, losing my kids, hurting them..."

Table 7
Symptoms of Dissociation in 102<sup>a</sup> AI/AN Women Prostituted in Minnesota

Symptom	Mean	SD	Range	Percentage (n) Rating Symptom at Clinical Level
Flashbacks	1.8	1.0	0 - 3	65% (65)
Spacing Out	2.0	1.0	0 - 3	71% (72)
Dizziness	0.9	1.0	0 - 3	28% (29)
Memory Problems	1.9	1.1	0 - 3	68% (69)
Derealization	1.7	1.0	0 - 3	59% (60)
Not in Your Body	1.4	1.1	0 - 3	50% (51)

<sup>&</sup>lt;sup>a</sup> Sample size varies somewhat depending on how many women answered a given question.

#### **Substance Abuse**

Three fourths (77%) of the respondents used drugs or alcohol, with 67% reporting alcohol use and 59% reporting drug use. The women had used drugs or alcohol, on average, for 18 years (range = 2-57 years, median = 15, SD =12). Crack/cocaine was the drug of choice for 35% of the women, and marijuana was drug of choice for 28%. Methamphetamine/speed was used by 9% of the women, and pain pills/Vicodin/Lortab by 7%. Heroin, OxyContin, MDMA (ecstasy), LSD, morphine, PCP, Xanax, downers, nicotine, and methadone also were mentioned as preferred drugs.

A majority of the women who used drugs or alcohol (61%) described the need to "chemically dissociate" from the physical and emotional pain during prostitution. One woman explained that she used drugs "so it can numb me, so I can do what they want me to do." Another stated "...That's why I did a lot of drugs—to numb myself—so I didn't know what was going on and I could just leave my body." Many women (43%) used drugs or alcohol after prostituting in order to block traumatic flashbacks or memories of prostitution. "I guess I use drugs to make my body not care so much about what I did." Some women described how drugs and alcohol helped them cope with other traumatic events in their lives, such as loss of child custody, loss of a relationship, and physical and sexual violence. Others began using drugs or alcohol in childhood.

Several interviewees stated that substance abuse affected their psychosocial development; for example, one woman noted, "My thought process really came to a halt at the age I started using. I started smoking marijuana at age 10, and started cocaine at age 15."

More than half (61%) of the women had been introduced to drugs and alcohol by family members. Sometimes parents gave them drugs or alcohol as entertainment or as a sedative. Substance abuse sometimes was considered a normal part of family life. "My grandfather gave me Crown Royal when I was two." More than one fourth (27%) of interviewees had been deliberately addicted by a pimp, boyfriend, or husband in order to coerce them into prostitution.

# The Emotional Reality of Prostitution

"It's like incest—no one wants to talk about it."

"As far as I'm concerned, all prostitution is rape."

The Prostitution Questionnaire asked interviewees to list five words that described their feelings during prostitution. Of the 456 responses, 90% (412) were negative words, 7% (32) were positive, and the remaining 3% (12) were neutral. Some words were more frequently used than others. The word *dirty* was used by more than one third of the women (36%) to indicate how they felt during prostitution. Other commonly used words were *sad*, *lonely*, *scared*, *disgusted*, *angry*, *numb*, *ashamed*, *guilty*, *nasty*, *ugly*, *depressed*, and *used*.

#### **Racism**

Race and ethnic prejudice is integral to prostitution. Most sex buyers employ ethnic stereotypes—in this study, stereotypes about AI/AN women (Dworkin, 1997). As one of the interviewees explained, "When a man looks at a prostitute and a Native woman, he looks at them the same: 'dirty.'" For some women, the prejudicial words caused greater pain than the physical assaults and rapes, and they explained that damage lasts longer. "You can get over the hit, the pain, but the words keep lingering on."

Forty-two percent of the women had been racially insulted by sex buyers or pimps. The racist verbal abuse (e.g., savage, squaw) was linked to sexist verbal abuse (e.g., whore, slut) when sex buyers used both types of words in the same phrase as part of the abuse. Racist generalizations about alcohol abuse were common. Hatred of the women's skin color was reflected in comments such as "Why don't you go back to the rez—go wash the brown off you." Other racist remarks by sex buyers were homicidal: "I thought we killed all of you." Some of the racist verbal attacks were unprintable. For some sex buyers, the racist degradation was sexually arousing and was integral to their sexual use of AI/AN women. The women were expected to

tolerate racism and sexism: "You don't get paid if you talk back." AI/AN women were fetishized as exotic others. In some cases, sex buyers demanded that the women role-play colonist and colonized as part of prostitution: "He likes my hair down and sometimes he calls me Pocahontas. He likes to role-play like that. He wants me to call him John."

Several women also experienced racism within their own communities. For example, some communities rejected women because they were "mixed race" and not full-blooded AI/AN. One woman who sought help on her reservation was rejected because her daughter appeared "too White." A woman whose family included both AI/AN and African American ancestors explained her sense of disempowerment in the community. "I'm just as much this part as that part, even though I'm separated out as African or Black. Don't cut me up and divide me in half."

# **Connecting Colonization and Prostitution**

A majority of the women we interviewed (62%, n = 65) saw connections between colonization and prostitution of AI/AN women. Some observed the profound inequality of both institutions. One way of understanding colonization is that it removed AI/AN peoples' options. "I'm doing what I can to survive, just the way Native Americans did what they could to survive with what was given to them by the government: disease, alcohol, violence." Others described the common losses of basic human rights resulting from colonization and from prostitution: loss of traditional ways of living, loss of social status, and loss of self-respect. "The living conditions. I see a connection to poverty and public housing. I'm put down anyway, so why not prostitution? I'm called a 'squaw', so why not?" The devaluation of women in prostitution was often seen by these interviewees as identical to devaluation of colonized AI/AN people. "Back then they treated us like nothing. And when I was out there [prostituting] I felt like nothing."

Several women explained that the concepts of sexism and prostitution were unfamiliar to AI/AN people until contact with colonists. For example, "Our Native people weren't aware of anything about prostitution until the British came and started raping our Native women and had them as slaves and using them for sex." Another woman saw the sexism of colonists toward their own women and compared it to prostitution. "The way that the White people treated their women is the same way that pimps treat their hoes. And then Native men started treating us like that." Expanding the colonist/pimp analogy, another woman said that the U.S. "was the pimp to the Indians."

Others saw the commonality between colonization and prostitution of AI/AN women in the desire to subordinate another person. "It's how they treat you. Like cowboys and Indians. They'd rape the women and take them and sell them. Just like Black people and slavery. We're not supposed to have anything. Not supposed to say anything. Not supposed to look them in the eye or be disrespectful." Another woman saw that both colonists and sex buyers "have to have somebody to make feel inferior. To make themselves feel better." The process of colonization, one woman said, reduced AI/AN women to commodities.

## **Connections and Disconnections with Cultural Identities**

Many women felt disconnected from Native cultures, sometimes as a result of feeling shame. One woman explained, "I'm such an embarrassment to my race. A lot of people know what I do, so I stay away." Several women were denied enrollment in their communities. One sought help from her tribe but was rejected because, she said, "people from the reservation don't support people like me."

Many of the women spoke of a desire to connect or reconnect with their cultures. "I'm still trying to find myself...being more connected to my cultural identity would help me find my path." Some women felt that being more connected with their cultures would help them discover ways of healing from prostitution. Indeed, others credited their survival to their cultural identity. One third (32%) of the women described specific AI/AN cultural or spiritual practices, including sweats, smudging, pow wows, dancing, using tobacco, and praying, as an important part of their identities. One woman incorporated cultural practices into substance abuse treatment that ultimately helped her escape prostitution: "When I got into treatment I went through a pipe ceremony and sought to find myself again ... From the treatment center, I entered my first sweat lodge. That's what opened my eyes. I made it all the way through. I knew I wasn't alone." Another woman explained, "My spirituality helped me survive. If I didn't have that I wouldn't have had anything to fall on to keep me sane and give me hope that tomorrow is going to be a better day."

Connections with their own cultural identities and connections with and support from other AI/AN people were often cited as ways of surviving prostitution. "Pray together, burn sage, pray. Confide in one another and embrace each other." Others spoke of the importance of having AI/AN people that they could look up to and from whom they could seek advice: "Just knowing that there's healthy Native ladies out here that I can talk to." "I see a Native therapist and she helps me." "I've had to go to medicine men to get doctored because the White field cannot help you. Because they cannot see it." Some women told us how important it was for them to share history and strength with other AI/AN people. "Just believing, and knowing that our people had made it before, through everything."

# Urgent Needs of AI/AN Women Who Seek to Escape Prostitution

Ninety-two percent of the interviewees wanted to escape prostitution. We asked the women what they needed in order to accomplish this (see Table 8). They mentioned individual counseling (endorsed by 75%) and peer support (73%) most frequently. Other frequently mentioned needs were vocational training (68%), housing (67%), substance abuse treatment (58%), and self-defense training (50%). They also expressed a need for health care (48%), legal assistance (34%), physical protection from a pimp (26%), and child care (26%).

Table 8
Needs of AI/AN Women Prostituted in Minnesota Compared to
Women Prostituted in Nine Countries

Need	AI/AN Women Prostituted in Minnesota (N = 106) <sup>a</sup>	Women Prostituted in Nine Countries (N = 854) <sup>b</sup>
Individual Counseling	75% (79)	56%(431)
Peer Support	73% (77)	51%(393)
Vocational Training	68% (72)	76% (600)
Home or Safe Place	67% (71)	75%(618)
Substance Abuse Treatment	58% (62)	47%(356)
Self-Defense Training	50% (53)	45%(340)
Health Care	48% (51)	61%(480)
Legal Assistance	34% (36)	51%(366)
Physical Protection From a Pimp	26% (28)	23%(157)
Child Care	26% (28)	44%(335)
Legalized Prostitution	10% (11)	34%(251)

<sup>&</sup>lt;sup>a</sup> Sample size varies somewhat depending on how many women answered a given question. <sup>b</sup> Reported in Farley et al., 2003.

Because it is sometimes assumed that legalizing prostitution would decrease its violence, we asked the women about this. Only 17% of the 105 women thought that legal prostitution would increase their safety.

A number of the women said that if they were out of prostitution, they would like to work in a helping profession such as nursing or social work. Many wanted to help other women get out of prostitution; for example, one woman said, "At the hotel there were other women in prostitution. A vice officer who knew my younger daughter said, 'You are so much better than this'. I told him I was in it for my kids. He didn't arrest me, he referred me to Breaking Free. I would love to go with the police when they go to bust these girls and talk to them about a better way."

#### DISCUSSION

The unique contribution of this article lies in its documentation of the relationships among prostitution, violence, traumatic stress, and a plethora of resulting adverse symptoms in a population of AI/AN women in Minnesota. Sexual violence against AI/AN women, including prostitution and trafficking, is a deeply rooted phenomenon. To better understand this violence and its consequences, we interviewed 105 AI/AN (primarily Anishinaabe) women in prostitution about their lives, using both standardized and open-ended questionnaires. Through these interviews, we identified important aspects of the women's experiences of prostitution, the contexts that led to it, their experiences of violence and traumatic stress, and their survival skills.

# **Experiences of Prostitution**

The women's descriptions of prostitution were overwhelmingly negative. Many of the words they used to describe these experiences are the same words used by incest and rape survivors (Herman, 1992). More than one third of the women used the word *dirty* to describe how they felt during prostitution, which reflects their internalization of the toxic sexism and racism of those paying for sex toward the women they buy (Poupart, 2003). Some viewed their oppression as AI/AN women in and of itself as a primary reason they were targeted by sexually predatory johns, pimps, and traffickers. The racist and sexist verbal abuse described here confirms this violent predation of AI/AN women as hated/eroticized objects.

Given the prevalence of violence and these negative descriptions, it is not surprising that almost all of the women we interviewed wanted to escape prostitution. Despite their poverty, lack of stable housing, and need for medical care (including substance abuse treatment), they most frequently endorsed needs for individual counseling and peer support, indicative of the importance of relationship to them. Family members attempted to interrupt the women's prostitution in a variety of ways—urging them to quit, offering housing, moving them out of town, providing money, and encouraging them to break up with pimps/boyfriends. They also took the women to sweats and sought out supportive women's groups and agencies offering addiction treatment.

#### **Context of Prostitution**

The women entered prostitution with a background of cultural, family, and personal trauma. The almost universal history of homelessness among them (98%) provides compelling evidence for their lack of alternatives for survival, and also for the association between

prostitution and poverty. Many of the women's parents or grandparents had been removed from their families and placed in boarding schools. Most of these relatives were known by the women to have been abused there. The majority of the women had family members who also were involved in prostitution. A fourth-generation survivor of prostitution spoke about the rapes of women in her family and her resignation to the sexual violence in her community. Nearly half the women had been in foster care, and of those, nearly half had been abused in care. We suggest that a history of colonization increases the vulnerability of AI/AN women to poverty, prostitution, and other sexual violence.

The women we interviewed often had had multiple arrests, starting in childhood. These arrests reflect their lack of security and alternatives to prostitution, their homelessness, and their substance abuse. The women had committed almost as many crimes in childhood as in adulthood, suggesting that early in their lives they may have lacked access to adult protection, housing, and health care. Several of the women had been convicted of crimes that were probably committed while they were under the control of a pimp or dominant partner. The multiple arrests of these women prevented their escape from prostitution, because a criminal record was a barrier to obtaining affordable housing, employment, and frequently even essential social services.

The common assumption that women prostitute *either* indoors or outdoors is inaccurate. The women in this study had been prostituted in multiple settings: on the street, in private homes, hotels, nightclubs, bars, escort agencies, reservations, strip clubs and casinos. This and other studies find that women prostitute wherever sex buyers are located. Interviews with sex buyers confirm this (Farley, 2005; Farley, MacLeod, Anderson, & Golding, 2011; Kramer, 2003). Meaningful outreach to AI/AN prostituted women must consider these multiple locations where men pay for sex, which also are where the women are located.

Organized criminals play a significant role in the trafficking of AI/AN women both on and off reservations (Freng, Davis, McCord, & Roussell, 2012; Koepplinger, 2009; Pierce, 2009). Nearly half of the women we interviewed had been trafficked for the purpose of prostitution, and half surrendered most of their money from prostitution to pimps, of whom nearly half were gang affiliated. Pimps make it extremely dangerous for women to escape prostitution. Death threats are common. As a consequence of this danger, outreach to these women must be cautious and creative; for example, phone numbers for help could be placed on billboards and in restaurants where the women take breaks.

## **History of Trauma and its Consequences**

Frequent and extreme violence was committed against these AI/AN women over the course of their lives. Surrounded by predators, three fourths had been sexually abused as children by an average of four perpetrators. A history of sexual assault preceding prostitution has been noted by others. One young woman told Silbert and Pines (1982, p. 488), "I started turning tricks to show my father what he made me." Dworkin (1997, p. 143) described incest as "boot camp" for prostitution.

Our interviewees were in an almost constant state of revictimization. The assaults against them were part of a lifetime of exploitation and abuse. The vast majority of the women had been raped in prostitution, typically multiple times, and most had been physically abused in adulthood, most often by a man who paid for sex. Half had been threatened, usually with a weapon, during the month before we interviewed them. Stable housing and protection from domestic and sexual violence are crucial for the women we interviewed. Most of the women also expressed a need for individual counseling and peer support, reflecting a desire for their unique experiences as AI/AN women in prostitution to be heard and seen by people who care about them. Other frequently mentioned needs were vocational training, housing, substance abuse treatment, and self-defense training, which was likely a result of the frequent violent assaults in prostitution.

## **Health Problems**

A history of violent victimization is associated with physical health problems (Golding, 1999b), which were common among these women. More than half reported physical pain, vision problems, or cognitive problems. Almost three fourths had experienced a traumatic brain injury, which has been associated with chronic illness (Langlois, Rutland-Brown, & Wald, 2006), other disabilities (Langlois et al., 2006), unemployment (Doctor et al., 2005), and early death (Langlois et al., 2006; Vaaramo, Puljula, Tetri, Juvela, & Hillbom, 2015), including death specifically caused by traumatic events (Vaaramo et al., 2015). We recommend a medical evaluation for women in or escaping prostitution. Readers may contact the first author regarding use of questionnaires for assessing adverse health consequences of prostitution in this study.

#### **PTSD**

Rape and other sexual violence—whether paid for or not—may result in symptoms of PTSD. Given the prevalence of trauma in their lives, it is not surprising that 52% of the women in this study met diagnostic criteria for PTSD (Robin, Chester, & Goldman, 1996). This rate compares to an 8% prevalence rate in the general U.S. population (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995), and to the 54-86% prevalence seen among prostituted people from

nine countries (Farley et al., 2003). The prevalence of PTSD in battered women ranges from 31% to 84% (Golding, 1999a) and in combat veterans PTSD ranges from 2% to 17% (Richardson, Frueh, & Acierno, 2010).

Experiences of violence over the course of one's lifetime, as well as intergenerational trauma, have a cumulative effect on PTSD symptoms (Follette, Polusny, Bechtle, & Naugle, 1996). Historical trauma as experienced by AI/AN peoples—both in the form of prostitution and more generally as colonization—has caused PTSD and other mental disorders such as depression (Cole, 2006). The insidious trauma of racism as documented in these interviews is another cause of emotional distress and disorders (Root, 1996). The high prevalence of PTSD in the women we interviewed is consistent with past research that found that AI/AN children and adolescents who experience sexual trauma and multiple traumas are likely to be at high risk for developing PTSD (Gnanadesikan, Novins, & Beals, 2005). We recommend culturally appropriate treatment that specifically includes a decolonizing perspective (Goodman & Gorski, 2015; Marsella, Friedman, Gerrity, & Scurfield, 1996).

## **Dissociation**

Previous research has established a strong association between trauma history and dissociation (Mulder, Beautrais, Joyce, & Fergusson, 1998). We found high rates of dissociation among the women we interviewed, who told us that it was essential to their survival during prostitution. The same dissociative response that women develop to survive the trauma of rapes in childhood and adulthood is used to survive the paid rapes of prostitution. Consistent with others' findings (Dobie et al., 2004; Schnurr & Green, 2004; Zatzick et al., 1997), both PTSD and dissociation were associated with poorer general health among the women we interviewed. On the other hand, dissociative phenomena that result from interaction between psychological and culturally based social processes, such as shamanism, can be positive (Kirmayer, 1994). The voluntary use of dissociation can enhance artistic creativity (Ross, 1991). Among the interviewees in this study, some experiences of dissociation promoted spiritual healing. For example, one woman explained that when she dissociated, she went to the spirit world, where healing occurred (Pierce, 2009).

Symptoms from recent traumatic experiences may not only cause distress in and of themselves, but may amplify symptoms from earlier violence and abuse (Follette et al., 1996). Numbing symptoms typical of both PTSD and dissociation increase the risk of revictimization (Ullman, Najdowski, & Filipas, 2009) because more adaptive survival responses are not

employed by the victim of violence. Because AI/AN survivors of prostitution have high rates of dissociation, it is important for health care and social service workers to assess carefully for any history of revictimization when clients seek services.

Three fourths of the women we interviewed used drugs or alcohol, which is common in traumatized populations, including combat veterans and survivors of sexual and domestic violence (McFarlane, 2001; Norris, Foster & Weishaar, 2002; Stewart, Ouimette, & Brown, 2002). The majority of these women described their substance use as a form of chemical dissociation. More than half of those we interviewed voiced a need for alcohol and drug addiction treatment. The literature on drug and alcohol treatment for traumatized populations suggests an integrated treatment protocol for those with both substance abuse and PTSD, such as the cognitive-behavioral approach developed by Najavits (2001; Najavits & Johnson, 2014). Given the high risk for PTSD in this population, mitigation of traumatic stress (e.g., by providing secure housing, protection from pimps, food, and health care), coupled with appropriate treatments for PTSD, is highly recommended (see below).

# Recommendations for Policy, Treatment, and Research

# **Policy**

To address the harms of prostitution, it is necessary to use education, prevention, and intervention strategies similar to those dedicated to other forms of gender-based abuse such as rape and domestic violence. This understanding of prostitution as violence against women must then become a part of public policy and must be structurally implemented in health care, mental health services, substance abuse treatment, homeless shelters, rape crisis centers, and battered women's shelters (Stark & Hodgson, 2003). Health care practitioners must become acquainted with community services, antiviolence resources, and agencies dedicated to offering services to women in prostitution (Polacca, 2003). As with battered women, physical safety is a critical concern. It is essential that health care practitioners and victim advocates receive specialized training in both traditional and Western approaches, and that they understand women in prostitution as victims of violence, not as criminals. Program development and implementation by survivors of prostitution, both AI/AN and non-Native, are essential. Two-thirds of the women we interviewed expressed a need for vocational training, which requires specialized programs. Vocational training or rehabilitation must address prostitution survivors' extensive trauma history and also their history of domination and abuse. For example, Baldwin (2003, pp. 313-314) suggested that survivors of prostitution should not be required to work in service

occupations that require the display of female submission, citing a case in which a survivor refused a job that required her to clean beds in the same hotels where she had prostituted for many years. Yet this refusal jeopardized her receipt of public assistance benefits.

Most of the women we interviewed would benefit from legal services, including family law (divorce and child custody), criminal record expungement, disability law, and benefits law. Policy reform recommendations, such as decriminalizing victims of prostitution so they do not have to fear arrest, would ensure that AI/AN women who have been domestically trafficked receive the same access to services as do international victims of trafficking (Johnson, 2012). Tribal officials should be trained to recognize domestic trafficking and pimping as a first step in overcoming silence and denial regarding these issues. Jurisdictional disputes with respect to tribal, state, and federal laws regarding arrests of sex buyers and pimps on tribal lands have hindered policy reforms that would support AI/AN women in prostitution. Cross-deputization agreements among tribal, state, and federal law enforcement agents that would allow them to respond to crimes outside their jurisdictions would increase arrests and prosecutions of pimps and traffickers, as well as rapists (Deer, 2004b; Johnson, 2012).

#### **Treatment**

A general health strategy for AI/AN women should involve equitable access to health services, AI/AN control of services, and diverse approaches that respond to cultural priorities and community needs (Denham, 2008; Royal Commission on Aboriginal Peoples, 1996). Models for healing of AI/AN women in prostitution would include a decolonizing perspective that acknowledges and analyzes historical trauma, violent crimes, family violence, child abuse and neglect, discrimination, and unresolved grief and mourning. Cultural moderators of these traumatic experiences that would promote healing include family/community support, traditional spiritual practices and medicine, and a positive AI/AN identity (Walters, Simoni, & Evans-Campbell, 2002).

Cultural competence in mental health care of AI/AN people includes recognition of a) the asymmetrical power relationship between counselor and client; b) the ways that Eurocentric professional values may conflict with the needs of AI/AN people seeking mental health treatment; c) differences in symptom expression, symptom language, and symptomatic patterns in AI/AN people with mental illness or emotional disturbance; and d) differences in thresholds of individual and social distress (i.e., differences between AI/AN individuals/groups and European Americans with respect to what upsets them, based on culture and history, and also differences in tolerance of symptoms by support systems (Goodman & Gorski, 2015; Western Interstate Commission for Higher Education, 1998). Health care practitioners, especially those in the field

of mental health, as well as advocates in related fields, need to apply a holistic healing approach to AI/AN women that embraces traditional healing (Fadiman, 1997; Hodge, Limb, & Cross, 2009). Native cultural and spiritual traditions should be made available to AI/AN women in prostitution by nonjudgmental people who are educated about prostitution's devastating impact. A study of the needs of Vancouver prostituted women underscores these recommendations (Benoit, Carroll, & Chaudhry, 2003). Willmon-Haque and Bigfoot (2008) and Gone (2004) describe several culturally relevant trauma treatment programs for AI/ANs that are based on Native perspectives about wellness, and that also include the decolonizing and culturally relevant factors mentioned above. The Peguis AI/AN community in Manitoba, for example, found that a combination of traditional and Western healing approaches was especially effective for people who suffer from emotional problems, including those related to alcohol and drug abuse, violence, and suicide (Cohen, cited in Royal Commission on Aboriginal Peoples, 1996). In our opinion, Western medical treatment of PTSD and dissociation is best combined with traditional healing for AI/AN women who want to escape prostitution. 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 (Grandbois, 2005). For example, several women we interviewed had struggled to use traditional spiritual healing practices for their mental health problems, but their physicians had objected to these practices. "I was in the hospital. I was unstable depression. It was a bad spirit. I wanted to smudge and was not allowed to." Another woman told her physicians that she suffered from bad dreams and was subsequently diagnosed with schizophrenia. Her doctor prescribed medicine to stop the bad dreams, she said, but "I know that our dreams mean something so I don't take the meds. I need those dreams."

Although most women in this study wanted the opportunity to use traditional healing methods, some women did not. Practitioners should respect both preferences. It is extremely important that no woman be pressured to participate in any spiritual practice if she is uncomfortable. Women in prostitution have been manipulated, coerced, and betrayed by johns and pimps, sometimes by government agencies and health care practitioners. They must be fully accepted as AI/AN women whose choice not to participate in traditional cultural practices is honored.

## **Limitations and Future Research**

This study was limited to AI/AN women currently living in Minnesota. There is a great need for research on the prostitution and trafficking of Indigenous women in other regions and for careful study of what kinds of interventions help them to exit prostitution. Research in New Zealand, Australia, Canada, and Taiwan has found that Indigenous women are at highest risk for

prostitution because of their history of oppression and colonization, poverty, and sexual violence (Sethi, 2007). The triple force of race, sex, and class inequality disparately impacts Indigenous women. Another limitation of this study was sampling strategy. Given the illegality of prostitution, researchers have found that a representative sample of women sold for sex is not possible (McKeganey & Barnard, 1996). We interviewed those people to whom we had access and who themselves had access to some social supports. Because the women were recruited through their contacts with service agencies, they may not be representative of prostituted AI/AN women who do not contact service agencies for support. Other studies of traumatized people have found that survivors minimize the intensity and the extent of sexual violence and other abuse (e.g., Van der Kolk & McFarlane, 2006); therefore, we estimate that, as high as some of the numbers are in this study, the trauma and resulting symptoms of distress are in reality likely to be even more prevalent and severe. The use of some open-ended questions occasionally reduced the clarity of the data. However, this limitation was balanced by the use of standardized measures to assess attributes such as PTSD, dissociation, and general health, as well as the use of close-ended questions about a range of experiences in prostitution. Despite these limitations, we are confident that this study of the experiences of prostituting AI/AN women contributes significant new information.

It is crucial to understand the sexual exploitation of AI/AN women in prostitution today in the historical context of colonial violence against nations (Frideres, 1996; Ryser, 1995; Waldram, 1997). Women who are marginalized because of colonialism's devastating historical impact, because of their lack of opportunities and education, because of racial and ethnic discrimination, poverty, previous physical and emotional harm, and abandonment *are* the people bought in prostitution. Women who have the fewest real choices available to them are those who are in prostitution. The critical question to ask with respect to the women we interviewed is not "Did she consent?" but "Has she been offered the choice to exist *without* prostituting?"

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## **ENDNOTES**

- For further analysis regarding use of the terms "sex work" and "sex worker" please see *Letter to David Minthorn*, *Stylebook Editor of The Associated Press*, October 31, 2014, with 301 signatories at <a href="http://catwinternational.org/Home/Article/587-over-300-human-rights-groups-and-antitrafficking-advocates-worldwide-weigh-in-on-sex-work-terminology-in-media.">http://catwinternational.org/Home/Article/587-over-300-human-rights-groups-and-antitrafficking-advocates-worldwide-weigh-in-on-sex-work-terminology-in-media.</a> See also Robert Brannon (2013) *Women and Girls Used in Prostitution are Not "Sex-Workers"* (unpublished paper, on file with first author). See also *Prostitution is not 'sex work'* by Coalition Against Trafficking in Women at <a href="http://www.catwinternational.org/Content/Images/Article/253/attachment.pdf">http://www.catwinternational.org/Content/Images/Article/253/attachment.pdf</a>.
- <sup>2</sup> In Duluth, we worked with Mending the Sacred Hoop Coalition, Domestic Abuse Intervention Project, American Indian Community Housing Organization, Dabinoo'igan Shelter, Min-No-

Aya-Win Human Services, a Fond Du Lac sexual assault advocate, and Program for Aid to Victims of Sexual Assault (PAVSA). In Duluth, American Indian Community Housing Organization reached out to the community to let them know about the research, posting flyers at food shelves, homeless shelters, and other locations. Mending the Sacred Hoop provided interview rooms and a welcoming atmosphere with refreshments and a smudge bowl for interviewees and interviewers. Dabinoo'igan Shelter provided transportation for the women and also were available to the women post-interview if they needed support. PAVSA and Min-No-Aya-Win offered sexual assault advocacy. The Domestic Abuse Intervention Project provided an advocate who was available to the women during the interviews and as a support resource after the interviews. In Minneapolis, we reached out to Breaking Free and Minnesota Indian Women's Resource Center. Some of our interviewees participated in Breaking Free's support programs. In the Bemidji area, an advocate at the Anishinaabe Equay program put up flyers in the community, received calls from women who wished to participate in the research, and scheduled the interviews. She also served as a resource for the women in the event of emotional distress and provided ongoing support to several of the women. We also worked with the Anishinaabe Equay program of the Sexual Assault Program of Beltrami, Cass & Hubbard Counties and the Nokimagiizis Program of the Northwoods Coalition for Family Safety. Each organization provided interview space in their offices.

- <sup>3</sup> Rudolph Ryser, Center for World Indigenous Studies (<u>www.cwis.org</u>) contributed this description of how Native people self-identify based on family versus reservation heritage.
- <sup>4</sup> Boarding schools were located in South Dakota (Flandreau Industrial School, Marty Mission, St. Francis, Stephan), Minnesota (Mission School, Red Lake School, Shattuck), Oklahoma (Riverside, Oaks Mission School, Chilocco Indian School, River), North Dakota (Wahpeton), California (Sherman), Kansas (Haskell Indian Junior College), Arizona (GMA), in Idaho, and in Wisconsin.
- <sup>5</sup> Frequently mentioned were Gangster Disciples, Black Gangsters, Four Corner Hustlers, Stone Gang, and Vice Lords (all Chicago-based gangs), as well as Bloods, Sureños, and Native Mob.

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(MIWSAC) and other groups who provide services and referrals to victims of violence assisted in recruitment of participants. These agencies and groups include Breaking Free, Minnesota Indian Women's Resource Center, Mending the Sacred Hoop Coalition, Domestic Abuse Intervention Project, American Indian Community Housing Organization, Dabinoo'igan Shelter, Min-No-Aya-Win Human Services, Fond Du Lac sexual assault advocate, and Program for Aid to Victims of Sexual Assault (PAVSA).

The Anishinaabe Equay program of the Sexual Assault Program of Beltrami, Cass, and Hubbard Counties and the Nokimagiizis Program of the Northwoods Coalition for Family Safety provided space for the research interviews. An advocate at Anishinaabe Equay coordinated the research in the Bemidji area and offered post-interview resources to the women. Prostitution Research & Education staff members Angel Daniels and Emily Inouye Butler made important contributions to this research, as did William Mitchell College of Law students Sara Marie Campbell and Heather Monasky. Vednita Carter of Breaking Free helped with the first interviewees. Alice Vachss provided valuable consultation regarding the crimes committed by the women. Sarah Curtiss and Paula Morton at Mending the Sacred Hoop in Duluth helped to make the interviews possible in that city. Miriam Sosa, Katrina Crenshaw, Jo Wang, Olivia Hanning, Sister John Paul at PRE and Elizabeth Fuerst at Native American Youth and Family Center entered data and transcribed narrative questions.

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# DEVELOPMENT AND PILOTING OF A BRIEF INTERVENTION FOR SUICIDAL AMERICAN INDIAN ADOLESCENTS

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Abstract: American Indian (AI) adolescents have the highest suicide death and attempt rates of any U.S. group, yet few interventions have been developed or evaluated for this population. This paper presents the first adaptation of a brief evidence-based intervention for AI adolescents from one reservation who made a suicide attempt. We describe our community-driven approach to intervention development and a small pilot study (n = 13). Preliminary findings indicate reductions in adolescents 'negative thinking, depression, and suicidal ideation, and an increase in psychological service utilization. Key innovations include delivery by AI paraprofessionals and potential to strengthen the continuum of care between emergency department and outpatient settings.

#### INTRODUCTION

Suicide deaths and attempts are a major source of morbidity, mortality, and health care costs in the U.S., with the highest rates among American Indian and Alaska Native (AI/AN) youth. According to Center for Disease Control and Prevention (CDC) data, the suicide rate among (AI/ANs) ages 15-24 years is 51.93/100,000 and 16.74/100,000 for males and females, respectively (3-4 times higher than that of other U.S. youth), and suicide is the second leading cause of death for AI/ANs in this age group (Suicide Prevention Resource Center, 2013). While the majority of individuals who attempt suicide do not die, a suicide attempt is one of the most well-established risk factors for suicide death (Bridge, Goldstein, & Brent, 2006; Prinstein et al., 2008); 14.7% of high-school AI/AN youth reported a suicide attempt and 6.1%, a medically serious suicide attempt, in the past 12 months on the CDC's Youth Risk Behavior Survey, nearly 2-3 times the rate of other U.S. youth (7.8% and 2.4%, respectively; Suicide Prevention Resource Center, 2013).

Suicide attempts often go unrecognized (Claassen & Larkin, 2005; Kemball, Gasgarth, Johnson, Patil, & Houry, 2008; King, O'Mara, Hayward, & Cunningham, 2009), and many individuals who do receive medical attention obtain little or no follow-up treatment (Bridge, Marcus, & Olfson, 2012; Knesper & American Association of Suicidology, & Suicide Prevention Resource Center, 2010). This problem is compounded further in rural, reservation-based settings with significant barriers to care, including stigma, lack of available services, long wait lists, poor access to transportation, and lengthy travel distances (Freedenthal & Stiffman, 2007; Novins, 2009; Probst et al., 2006; Pullmann, VanHooser, Hoffman, & Heflinger, 2010). Only 24% of individuals who died from suicide on one reservation used IHS services in the 6 months prior to their death, versus 50% of controls (Mock, Grossman, Mulder, Stewart, & Koepsell, 1996), and over half of those who died from suicide or attempted suicide in one region of Alaska discontinued psychological care (Wexler, Silveira, & Bertone-Johnson, 2012). On the other hand, data from adolescent medical records in the study community indicate substantial contact (82%) with the local emergency department (ED) for any reason in the year before a suicide attempt with 26% for psychiatric reasons (Ballard et al., 2014). In one region of Alaska, 40% of those who died by suicide came into the ED for an alcohol-related accident in the year prior to their death (Hill, Perkins, & Wexler, 2007). Therefore, the central role of the ED in mental health triage on reservations provides a unique opportunity for developing and evaluating ED or ED-linked mental health interventions to address current service delivery gaps in these communities.

The National Strategy for Suicide Prevention calls for effective identification, assessment, and treatment of suicidal patients in the ED as a critical prevention strategy (U.S. Department of Health and Human Services [US DHHS], 1999; US DHHS Office of the Surgeon General & National Action Alliance for Suicide Prevention, 2012). For adolescents who attempt suicide, a brief ED-based intervention developed by Rotheram-Borus et al. (1996) might currently be considered the gold standard. The intervention has been empirically validated (Rotheram-Borus et al., 1996; Rotheram-Borus, Piacentini, Cantwell, Belin, & Song, 2000), recognized by the Suicide Prevention Resource Center's Best Practices Registry, and successfully adapted cross-culturally, but until now, not in a Native community (Asarnow, Armm, & McGrath, 2002; Asarnow et al., 2011; Donaldson, Spirito, Arrigan, & Weiner Aspel, 1997). The intervention includes a workshop for ED providers to improve their interactions with suicidal adolescents and their families, a video aimed at increasing families' treatment engagement, a crisis therapy session, an on-call therapist, and linkage to an existing outpatient therapy program (Rotheram-Borus et al., 1996). Significant outcomes have included positive maternal attitudes toward treatment, increased adolescent treatment adherence, decreased adolescent depression and suicidal ideation, and decreased maternal symptoms of depression (Rotheram-Borus et al., 1996, 2000). Because there is variable linkage to outpatient care in many community settings, Asarnow and colleagues (2011) further adapted this intervention to incorporate a compliance enhancement component (Spirito, Boergers, Donaldson, Bishop, & Lewander, 2002; Wells, Tang, Carlson, & Asarnow, 2012) and demonstrated improved follow-up with treatment (Asarnow et al., 2011). (See Hughes & Asarnow, 2013 for a full description of these interventions.)

This paper presents the first adaptation of the Rotheram-Borus intervention for AI adolescents, conducted by the Johns Hopkins Center for American Indian Health in partnership with the White Mountain Apache Tribe (Apache). We discuss: 1) our process for adapting the original ED intervention, 2) unique implementation challenges that were addressed and community assets that were applied to develop the intervention, and 3) preliminary results from 13 Apache adolescents and families who participated in a pilot study of the new intervention.

#### **METHODS**

## **Tribal Population**

The White Mountain Apache Tribe (~17,100 enrolled tribal members) resides on the Fort Apache Indian Reservation in northeastern Arizona. Data from the Apache Suicide Surveillance System, a community-mandated reporting and follow-up system for suicidal and non-suicidal self-injury, provides tribal-specific data from 2001-2006 for Apache youth ages 15-24 years (Mullany et al., 2009). The suicide rate was 128.5/100,000 (13 times the U.S. All Races and 7 times the overall AI/AN rates); the suicide attempt incidence rate of 3.5% was approximately 17 times rates from similar studies (~0.2%); and 76% of all Apache youth suicide attempters were brought to the ED, 59% were given a referral for treatment, and just 24% made contact with the agency to which they were referred.

#### **Phase I: Intervention Adaptation**

# **Community-driven Participatory Approach**

Johns Hopkins-Apache partners have refined a community-driven participatory approach to intervention development, where key stakeholders are actively involved from selection and adaptation to implementation and evaluation, which is necessary when partnering with AI/AN and other minority and disadvantaged populations (Barlow et al., 2006; Walkup et al., 2009). A participatory approach ensures interventions are culturally appropriate and facilitate community-level dissemination and sustainability. Johns Hopkins and Apache collaborators have an over 30-year trust relationship engaging in research aimed at addressing health disparities, and our current

Community Advisory Board (CAB) has many longstanding partners from earlier work, welcomes interested community members, and regularly selects new participants to meet the needs and content areas of new projects or to fill roles that have been vacated. Our CAB is comprised of tribal leaders, study staff, representatives from tribal agencies, ED providers, and Elders. Through a series of focus groups with the CAB, parents, and youth, the original intervention was adapted extensively for the Apache community in line with standard treatment development guidelines (Rounsaville, Carroll, & Onken, 2001).

## **Formative Development**

Focus group participants discussed implementation considerations and adaptations to intervention content. Implementation considerations included: 1) the local Indian Health Service ED staff were overburdened to deliver the intervention; 2) the ED lacked mental health care providers and space to deliver the intervention; 3) the ED providers faced interpersonal challenges when establishing rapport with families, who were seen as central to the prevention of youth suicide; and 4) concurrent substance use precluded clinical evaluation until adolescents were sober again and limited intervention engagement during an ED visit. Content concerns included: 5) the intervention content did not emphasize the central role of family, Elders, and Apache cultural assets, and 6) the original video featured non-AI actors, thereby decreasing empathy and trust in intervention messages.

#### **Implementation Adaptations**

Based on the focus group feedback, the CAB and study team made the following changes to how the original intervention was implemented, corresponding to challenges 1-6 discussed above. The CAB and study team believed these adaptations were essential for establishing rapport and motivating behavior change with at-risk participants and their families. To address 1, 2, and 4, the intervention was delivered in the home or another private setting outside the ED, soon after the index ED visit. The CAB indicated that adolescents and families would be more open and responsive to the intervention in a comfortable setting, and home-visiting approaches are not bound by clinic constraints, particularly long wait times and need for transportation. (The original ED staff training workshop focused on building rapport with suicidal youth and families was omitted, because the intervention was no longer taking place in the ED.) To address 1-3, locally trained Apache paraprofessional Community Mental Health Workers (CMHWs) delivered the intervention, addressing the gap in available mental health professionals and capitalizing on their ability to navigate: cultural considerations (because the CMHWs and participants were of the same culture), treatment access issues, and the relationship between participants and non-Native providers (Barlow & Walkup, 1998; Lancet Global Mental Health Group et al., 2007).

To address 3, parent/guardian participation was required and was expanded to include additional family members, reflecting cultural values in the strength of extended families and local preference for family-based interventions. This adaptation also provided an opportunity to address family-based conflict (identified in the literature as an important risk factor for suicide), and for family members to reinforce skills, including implementation of the youth's safety plan (Barlow & Walkup, 1998; Cross, 1997; Hill, 1989; Rotheram-Borus et al., 1996). To address 4, in the part of the intervention addressing risk situations, we discuss substance use as a potential facilitator for suicidal thoughts and behaviors. We also added elements based on motivational interviewing techniques: a readiness scale for seeking help through counseling, and emphasis on continuing treatment until both the therapist and participant jointly decide to stop. Because this intervention was intended to be brief and to transition youth into outpatient care, the study team decided to focus on treating suicidal thoughts and behaviors directly, as opposed to specific potential underlying factors such as substance use.

## **Content Adaptations**

To address 5, the study team created an enhanced participant workbook and corresponding CMHW manual that incorporated familiar Apache characters, environments, and cultural practices, as well as added places for family participation. For example, the original description of the relationship among thoughts, feelings, and behaviors was adapted to include a fourth component—spirituality reflecting Apache beliefs about the importance of spiritual balance in health and well-being. These elements were illustrated in a four-component circle, a familiar symbol to Apache and other AI groups. To address 6, a new video was produced with Native actors, dramatic vignettes specific to the characteristics of suicide attempts by male and female adolescents in this community, and added emphasis on connecting with local resources. To address 5, it also included testimonial messages from Elders who spoke in Apache and imparted messages about the seriousness of suicide, its impact on the community, their concern for the adolescent, and Apache beliefs about resilience and communal importance of each individual's life. The adaptation process for the video included drafting a script based on the original video; integrating Apache study staff and CAB feedback on the script; testing the revised messages in the script with youth, parents, and Elders in the community; finalizing the script, which was generally detailed and specific, but included only key points for the Elder portions so they could personalize their messages; and hiring an Apache producer to complete the video. All intervention materials were adapted in English, and CMHWs translated them orally into Apache as needed.

#### **Final Intervention**

The new intervention was named "New Hope" during a large community meeting led by the CAB, where the video component was previewed. New Hope was designed to be conducted over 1-2 visits in a family-preferred setting after discharge from the ED for a recent suicide attempt (2-4 hours total intervention time). New Hope emphasizes the seriousness of a suicide attempt; teaches coping skills to reduce risk, including emotion regulation, cognitive restructuring, social support, self-efficacy, and safety planning; and helps participants overcome barriers to treatment motivation, initiation, and adherence. CMHWs explain to participants and families that New Hope is psychoeducation designed to be adjunctive to clinical psychological services and to reinforce linkage to the local outpatient mental health center and other culturally acceptable care providers (e.g., church counselors, traditional healers).

#### Phase II: Pilot Evaluation

## **Study Design**

We selected an open trial design to evaluate the potential impact of New Hope with assessments delivered by CMHWs at baseline and 1, 2, and 3 months post-intervention, in addition to brief case management and support over the follow-up period.

## **Inclusion Criteria**

Eligible participants were Apaches ages 10 to 19 years who attempted suicide in the past 90 days.

## **Sampling Procedures**

A convenience sample was recruited and followed up through the tribally mandated Apache Suicide Surveillance System, described in detail elsewhere (Cwik et al., 2014), between April 2009 and June 2011. The Apache system receives reports on community members of all ages for a range of suicidal and related behaviors; the majority of reports for suicide attempts come from the ED. The pilot was described by CMHWs affiliated with the Suicide Surveillance System to youth who came through the system and met study inclusion criteria. For interested youth ages 10 to 17 years, different CMHWs who were study team members approached parents to provide consent; youth provided assent. Youth ages 18-19 years consented independently. If youth wanted a non-parent/guardian adult to participate with them, parents/guardians provided permission and the additional adult signed a separate consent. Intervention delivery and data collection occurred in the participant's home, Johns Hopkins office, or another private location of the participant's choice. Participants received a \$25 Wal-mart gift card at the completion of each study assessment visit. The

New Hope intervention was only available during this time period to study participants; however, all community members who were reported to the surveillance system received an assisted referral to the local community mental health center.

The pilot study protocol was approved by the White Mountain Apache Tribal Council and Phoenix Area Indian Health Service Institutional Review Boards, and the Apache Health Advisory Board and Tribal Council. The Apache Health Advisory Board and Tribal Council approved this manuscript.

#### **Quality Assurance**

Six part-time CMHWs were trained in New Hope delivery and the study protocol by clinical supervisors for a total of 40 hours each, including extensive role-playing. CMHWs were required to score 80% or higher (on a 100% scale) on a written exam prior to intervention delivery. Supervision was provided daily by a local Apache site coordinator, weekly by clinical supervisors via phone, and quarterly on site. Clinical supervisors assessed intervention mastery and fidelity by rating audio files of all completed sessions according to key intervention content and delivery criteria. Feedback was provided through individual coaching and additional training when necessary.

#### **Pilot Measures**

We used a comprehensive battery to assess participant characteristics and outcomes, focused on constructs that evidenced change in studies of the original intervention (e.g., depression), and that we believed were important to capture locally based on adaptations and previous research by the study team (e.g., family functioning). We prioritized standardized measures used in our population previously, with other AI samples, or in the suicide field. All measures were reviewed by our CAB and CMHWs for cultural acceptability and were edited to reflect syntax and semantic preferences without changing underlying meaning. Core assessments are described below. Because our sample was too small to examine reliability, estimates are presented from the general literature.

#### **Baseline Characteristics**

<u>Sociodemographics</u>: A 51-item structured interview adapted by the study team from the Voices of Indian Teens survey (Moran, Fleming, Somervell, & Manson, 1999) assessed socioeconomic status, household composition, maintenance of traditional Apache practices, school status, and leisure-time activities.

<u>Suicide History Screen</u>: A 38-item structured interview adapted from two standard assessments, the Columbia Suicide Screen (test-retest reliability, 0.48 to 0.58; Beck, Shuyler, & Herman, 1974) and the Suicide Intent Scale (internal consistency, 0.79 to 0.95; Shaffer et al., 2004), assessed the context of current and past suicide attempts and treatment history.

Youth Risk Behavior Survey (YRBS; Borowsky, Resnick, Ireland, & Blum, 1999; Brener et al., 2002): An 87-item self-report widely used among AI samples with a median Kappa of 60% and range of 24% -91%, assessed substance use, sexual behaviors, and unintentional injuries/violence.

Outcomes Assessed at Baseline and 1-, 2- and 3-Month Follow-ups

Knowledge, Attitudes and Behavior (KAB): A 24-item self-report questionnaire designed by the study team assessed key content, messages, and skills included in New Hope, as well as participant satisfaction. Items cover participants' report of what was learned, attitude change, and intended behavioral change as a result of the intervention. The questionnaire contained multiple-choice and 5-point Likert scale items. Likert scale items are generally positively scored, with higher scores representing stronger agreement with or endorsement of an item.

<u>Children's Negative Cognitive Errors Scale</u> (CNCES; Leitenberg, Yost, & Carroll-Wilson, 1986): A 17-item self-report, with Cronbach's alpha of 0.89, the CNCES assessed cognitions about social/peer rejection, group activity competence, and academic competence.

Center for Epidemiological Studies-Depression Scale (CES-D; Weissman, Pottenger, Kieber, Ruber, & Williams, 1977): The study team used the CES-D, a 20-item self-report with a large body of supportive psychometric data among adolescents and AI samples, to assess depressive symptoms (Cronbach's alpha = 0.88). The CES-D has a cutoff of  $\geq 28$  indicating clinical impairment.

<u>Children and Adolescent Services Assessment</u> (CASA; Angold et al., 1998): A 21-item structured interview assessed mental health services utilization (e.g., help seeking).

Intervention Fidelity and Safety

<u>Fidelity Rating Form</u>: CMHWs received a rating of "Needs Training," "Satisfactory," or "Excellent" on 27 items pertaining to key intervention content (i.e., correctly explaining the problem-solving tool and using the tool to address a problem identified by the participant) and 19 items pertaining to intervention delivery (i.e., establishing rapport and using age-appropriate examples) that were developed by the study team.

Suicide Ideation Questionnaire (SIQ/SIQ-JR; Reynolds, 1988): The SIQ/SIQ-JR is a 15-item, 7-point scale that analyzes frequency and severity of suicidal ideation over the past 6 months, and has been widely used among AI adolescents and other populations (Cronbach's alpha = 0.97). The clinical cutoffs, indicating severe suicidal ideation warranting clinical intervention, are 30 for the SIQ and 23 for the SIQ-JR.

## **Safety Assessment and Management**

CMHWs assessed the participant's current risk for suicide by completing the SIQ/SIQ-JR at the close of every intervention and assessment study visit. The study protocol for assessing suicide risk and corresponding safety procedures were reviewed with participants and parents at the time of informed consent by CMHWs. Based on the SIQ/SIQ-JR score and corresponding risk categories developed by the study team, in addition to other information shared during the visit, the participant's current level of suicide risk was classified as either: Does Not Appear at Risk, At Some Risk, At Medium to High Risk, or At Very High Risk. Study safety protocol dictated CMHWs respond in a graduated fashion and contact study clinicians based on assessed risk, which ranged from making a safety plan with the adolescent and parent (At Some Risk) to taking the youth to the ED (At Very High Risk).

## Participant Flow

Forty-seven youth (35 females and 12 males) were eligible and were approached during the recruitment period; 29 (22 females, 7 males) were interested and consented to study participation (61.7%). Eighteen youth completed the baseline assessment, conducted over 1-2 separate visits after consent (62.1% retention); of the 11 participants who did not complete the baseline, 4 were lost to follow-up, 4 were noncompliant with scheduled study visits, and 3 voluntarily withdrew. Thirteen of 18 completed New Hope, delivered over 1-2 separate visits after baseline completion (72.2% retention); 5 participants who did not complete New Hope due to scheduling difficulties or missed appointments. The majority (11/13) of those who received New Hope completed some portion of the follow-up visits (84.6% retention). There are no follow-up data on participants who did not complete the intervention. See Figure 1 for complete details.

### **Data Analysis**

First, means and standard deviations were calculated for the full sample (N=13) on sociodemographic and other baseline characteristics. Second, Kruskal Wallis tests were run, and the study team determined there were no differences between the full sample (N=13) and those who had at least one follow-up visit (N=11) on outcome measures at baseline; those with baseline data only were excluded from the rest of the analyses. Third, linear mixed model repeated measures analysis was conducted to examine cross-time changes in hypothesized outcomes for participants (N=11) with at least one follow-up visit; 63.6% (N=1) had all three follow-ups, 27.3% (N=1) had two follow-ups, and 9.1% (N=1) had only 1 follow-up. Analyses were conducted using the SPSS MIXED procedure utilizing restricted maximum likelihood estimation. Time was modeled as fixed effect (with subject as random). An autoregressive covariance structure (AR1) was specified to account for cross-time correlations of the repeated measures within subjects. Only significant findings are reported in the text (alpha level was set at N=1). We will briefly describe CMHW intervention mastery, sociodemegraphics, and baseline characteristics, but the main focus of reporting will be on preliminary intervention outcomes.

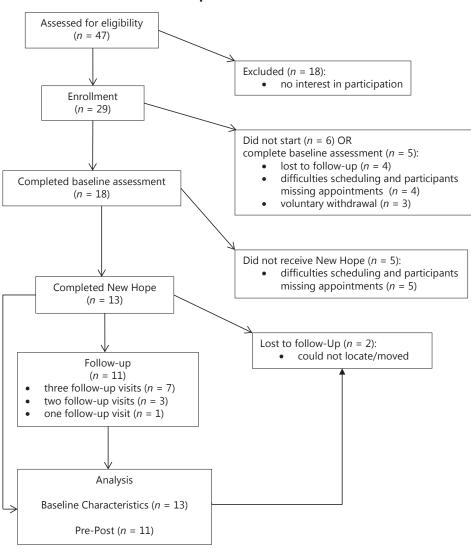


Figure 1
New Hope Enrollment Chart

**RESULTS** 

# **CMHW Intervention Mastery**

The mean exam score was 87%. Two of the audio files were not recorded properly. Of the scored audio files (n = 11), 10% of items received a grade of "Needs Training"; 38%, "Satisfactory"; and 52%, "Excellent."

# Sociodemographic Characteristics (n = 13)

Mean age was 14.3 years (SD = 2.2) and 92% were female (n = 12). Approximately half reported currently living with just one parent (54%, n = 7), and the other half with both parents (46%, n = 6); 46% (n = 6) also had one or more grandparents living in the home. On average, participants had moved 3.6 times (SD = 4.9) in the past year, and 85% (n = 11) received monetary assistance with groceries. The majority were currently in school (77%, n = 10).

## Baseline Characteristics (n = 13)

The average age of first suicide attempt was 13.5 years (SD = 2.3) and median number of attempts was two (SD = 7.1, mean = 5.5, range, 1-22). Laceration was the most common method (39%, n = 5). The majority (62%, n = 8) reported family conflict as the reason for their current attempt. Most adolescents reported lifetime alcohol (62%, n = 8) or marijuana (69%, n = 9) use. Less than half (46%, n = 6) reported being referred initially for treatment after their attempt. See Table 1 for complete information.

Table 1
Baseline Characteristics

	Total (n = 13)
Suicide History, M (SD)	
Age first attempt	13.5 (2.3)
Number attempts	5.5 (7.1)
Current Attempt, % (n)	
Method	
Hanging/asphyxiation	23.1 (3)
Alcohol/drug overdose	30.8 (4)
Laceration	38.5 (5)
Precipitating Event(s)	
Suicide/death	23.1 (3)
Relationship problems	7.7 (1)
Family problems	61.5 (8)
Anger/depression	38.5 (5)
Other/don't know	30.8 (4)
Referred for Treatment	46.1 (6)
Lifetime Substance Use, % (n)	
Alcohol	61.5 (8)
Marijuana	69.2 (9)
Cocaine	7.7 (1)
Methamphetamine	7.7 (1)
Other (glue, heroin, steroid)	30.8 (4)

## Pilot Outcome Evaluation (n = 11)

## **Knowledge and Satisfaction**

Participants reported knowledge about suicide risk and attitudes toward counseling in the desired direction. For example, 100% of participants reported "knowledge of situations that may cause them to hurt themselves" and 90% of participants endorsed "staying in counseling until the counselor and the individual agree it is time to stop" at 3 months. In addition, items pertaining to quality of CMHWs (i.e., respectful, knowledgeable, helpful, professional) and overall program satisfaction (i.e., helpful) were some of the highest rated items on the KAB questionnaire at each of the follow-up time points, with averages ranging from 4.13-4.75 (on a 5-point scale) at 3 months.

## **Intervention Targets**

Negative cognition scores improved significantly from baseline (M = 50.4; SD = 14.8) to 1 month (M = 48.2; SD = 15.7), 2 months (M = 39.5; SD = 14.5) and 3 months post-intervention (M = 36.1; SD = 17.2; F[3,19.6] = 3.807, p = .03). Depressive symptom scores also improved significantly from baseline (M = 33.3; SD = 15.3) to 1 month (M = 25.1; SD = 10.2), 2 months (M = 25.7; SD = 12.8), and 3 months follow-up (M = 21.0; SD = 12.7; F[3,21.5] = 4.794, p = .01)—representing a change from approximately 5 points above the CES-D clinical cutoff of  $\geq 28$  at baseline to 7 points below by 3 months. See Figures 2 and 3 for boxplots of these data.

The number of participants who scored above the clinical cutoff of 30 for the SIQ and 23 for the SIQ-JR seemed to decrease over the follow-up period, from 64% (n = 7/11) at baseline, to 11% (n = 2/11) at 1 month, to 9% (n = 1/11) at 2 months, and 10% (n = 1/10) at 3 months. In addition, participants appeared to utilize more outpatient care from a mental health provider at 1 month (M = 12.9 times) and 2 months (M = 10.2 times) in comparison to baseline (M = 3.6 times), but this increase attenuated by 3 months (M = 2.8 times). Conversely, visits to the ED for mental health reasons seemed to decrease during the study period: baseline (M = 9.0 times), 1 month (M = 0.9 times), 2 months (M = 0.3 times), and 3 months follow-up (M = 0.3 times).

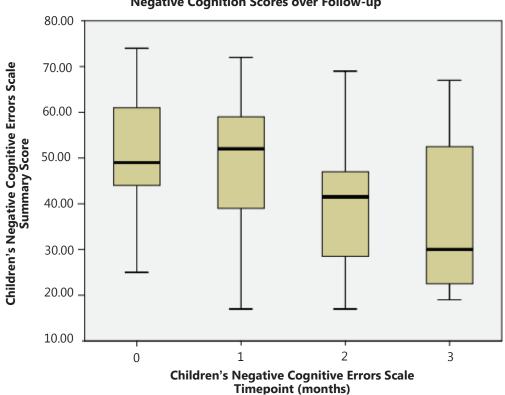
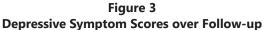
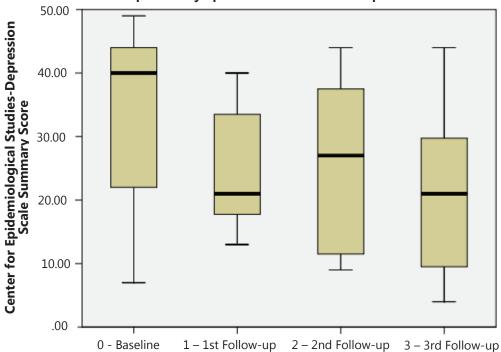


Figure 2
Negative Cognition Scores over Follow-up





Center for Epidemiological Studies-Depression Scale Timepoint (months)

#### **DISCUSSION**

Preliminary findings from this pilot evaluation of New Hope, a brief intervention for AI adolescents with a recent suicide attempt, are promising for younger adolescent females. Participants reported changes in the hypothesized direction on several intervention targets that are worthy of further study, including decreased negative thinking and depressive symptoms; improved suicide-related outcomes, including knowledge about how to reduce suicide risk, as well as scores below the clinical cutoff for suicidal ideation post-intervention; and changes in targeted service use outcomes, including improved attitudes toward counseling, increased outpatient treatment utilization, and decreased ED visits for mental health.

The most innovative aspects of this study are the relevant lessons learned for suicide prevention in AI/AN communities. First, the treatment development process, which can be replicated in other contexts, serves as an example of a community-driven participatory approach to culturally adapt an evidence-based intervention, including specific changes to the intervention that seemed to work well (i.e., changing who delivers the intervention) and others that might not have worked as well (i.e., removing from the ED setting). In this case, the tribal-academic partners created what might be considered a new intervention that was flexible in implementation, but had replicable goals and content to achieve desired outcomes. Second, the evaluation demonstrated that local paraprofessional CMHWs can be successful in delivering a brief intervention and providing follow up to adolescents with a recent suicide attempt, as evidenced by high intervention exam scores, quality assurance ratings, participant satisfaction ratings, and improved outcomes. Paraprofessionals have been trained in other settings to conduct a variety of psychoeducational interventions consisting of support, problem solving, and other skill development (Barlow et al., 2006; Bass et al., 2006; Bolton et al., 2007; Holden, 1996; Walkup et al., 2009), but this pilot may represent the first instance directly targeting adolescents with suicide attempts. Integrating paraprofessionals into Western medical settings to supplement limited psychological services in reservation-based and other rural and disadvantaged communities is an important mental health model that also increases capacity of the local workforce.

New Hope also responds to several objectives of the National Strategy for Suicide Prevention: it addresses the needs of a vulnerable group through intervention tailoring to a specific cultural and situational context;) promotes the safety and well-being of suicidal adolescents treated in the ED by providing them a brief intervention; coordinates with the existing Apache Suicide Surveillance System, local ED, and outpatient mental health center to ensure continuity of care, as fewer than half of those in the pilot sample reported being referred for treatment initially after their attempt; and establishes a unique link among the ED, CMHWs, and local mental health care providers to provide alternatives to ED-based care (US DHHS, 1999; US DHHS Office of the Surgeon General

& National Action Alliance for Suicide Prevention, 2012). Specifically, youth were connected at a high-risk time with CMHWs who could assess risk, teach them to use a safety plan and coping skills developed through the intervention, communicate with providers, and connect them with a counselor—perhaps providing enough support to avert ED visits for less severe crises.

This pilot study has several limitations. First, and most importantly, the subsample of participants with full participation was composed mostly of younger females (92%). While youth suicide intervention trials generally have underrepresentation of males, with samples ranging from 68-100% female (Asarnow et al., 2011; Diamond et al., 2010; King et al., 2006, 2009; Rotheram-Borus et al., 1996; Spirito et al., 2002; Wharff, Ginnis, & Ross, 2012), this challenge is still especially concerning, as the majority of suicide deaths are among older adolescent/young adult males and almost as many males as females attempt suicide among AIs (Mullany et al., 2009). Second, but equally important, retention was a critical issue; 29 youth were consented to achieve a sample of 13 youth who received the intervention. Closer examination of the participant flow illustrates that the greatest challenges were difficulty locating and contacting youth following their ED visit, and completing the baseline battery (62.1% retained); but, once youth started New Hope, the majority completed the intervention and follow-up visits (84.6%). The study's required parent participation in intervention visits may have been a barrier; CMHWs reported challenges finding a mutually agreeable time for parents and adolescents. We did provide flexibility by allowing an additional adult to participate, but none of the participants utilized this option. Third, there was no control group; it is possible that participants may have shown improvement in targeted domains without the intervention, or that we observed regression to the mean with a sample that was high risk from baseline. Findings should be considered within the context of these limitations.

The study team has planned future directions to increase participant retention and the target population reached: 1) utilize alternative strategies to reach males, such as more activities (and less didactic material) and delivery by male CMHWs; 2) provide flexibility (e.g., a separate family visit) and/or motivational enhancement to encourage (but not require) family participation, and widen criteria to include Elders and trusted friends as additional social supports; 3) incorporate part of the intervention back into the ED (as per the original model) or into other settings where at-risk adolescents can be identified, such as primary care, schools, churches, or other community-based locations; 4) better understand the need for the intervention to address co-morbid substance use; 5) minimize the number of assessments/visits prior to intervention delivery; and 6) review the findings with key stakeholders, including ED staff, to get their feedback on which adaptations worked and did not work, and on next steps.

Development and evaluation of interventions directly targeting AI/AN suicidal adolescents are important for several reasons. First, few interventions have been shown effective for suicidal adolescents in general and none have been developed or evaluated specifically with this population, the most at-risk group in this age range. Second, the use of a community-driven participatory process and study implementation render preliminary findings more transferable to a real-world setting and to other populations with similar risk profiles and barriers to care. Lastly, New Hope has the potential to fill one important gap in the continuum of care, the bridge between an ED visit and outpatient treatment, for Native suicidal adolescents by providing psychoeducation and connectedness to a trusted community resource and cultural mediator that safeguards this high-risk group and improves their engagement with mental health services.

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