NCAI’s 12th Annual Tribal Leader/Scholar Forum
Narragansett Room
1:30pm-4:00pm

Building Tribal Data Infrastructure
Moderated by Chief Lynn Malerba, Mohegan Tribe

What does culturally-driven, data-informed decision-making look like? How is research inherently connected to the exercise of sovereignty? To argue the case for decolonizing data and driving research agendas for your community, a panel of researchers and practitioners from diverse but intersecting fields of knowledge has been assembled. By demonstrating the impact of their work—how it has supported those citizens often most vulnerable or invisible within or without the tribal community—great lessons will be shared and new methodologies gleaned.

Presenters:

Laying the Groundwork: Why Tribes Need Data & Research
Desi Rodriguez-Lonebear, University of Arizona & University of Waikato
Dr. Stephanie C. Rainie, University of Arizona Native Nations Institute

Culturally-Grounded Research to Guide Substance Abuse and Violence Prevention
Shanondora Billiot, Yale University

Tracking Victims of Sex Trafficking
Jim Walters, AMBER Alert Training & Technical Assistance Program
Dr. Dominique Roe-Sepowitz, Arizona State University School of Social Work

Decolonizing Data
Abigail Echo-Hawk, Urban Indian Health Institute
Community engaged research methods to develop interventions promoting wellness among Indigenous Peoples

Shanondora Billiot, MSW
Doctoral Candidate, Washington University in St. Louis
PI: Catherine Burnette, Ph.D.
Assistant Professor, Tulane University

June 12, 2017
Funding Acknowledgements

- This research has been supported by the Fahs-Beck Fund for Research and Experimentation Faculty Grant Program #552745
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- Newcomb College Institute of Tulane University
- University Senate Committee on Research Grant Program, Tulane University
- Carol Lavin Bernick Research Grant, Tulane University
Presentation Objectives

1. Describe a research methodology, which is used to inform community based and culturally relevant interventions (Burnette, Sanders, Butcher, & Rand, 2014) to address disparities and disproportionate rates of violence among Indigenous peoples.

2. Explain how this inductive, community based method addresses gaps in existing interventions and knowledge regarding violence and health disparities.

3. Conclude how culturally relevant research methodologies (Burnette, Sanders, Butcher, & Rand, 2014) and intervention development can be connected to provide meaningful and effective services to those populations most impacted by such development.
Framework of historical oppression, resilience, and transcendence
Historical Oppression, Resilience, and Transcendence

- Historical oppression has severely undermined Indigenous families
- Given rise to Indigenous peoples experiencing co-occurring and elevated rates of alcohol abuse and family violence. Drive heightened mortality
  - mental health disparities, such as post-traumatic stress disorder (PTSD), depression, and suicide
- Age-adjusted mortality rates for Indigenous peoples for alcohol, chronic liver disease and cirrhosis, and drug use are 6.2, 4.2, and 1.5 times that of the general population, respectively.
- Rates of IPV are 1.7 times higher for women, 4.5 times higher for men, and 1.5 times higher for child maltreatment for AI/ANs compared to Whites.
- Alcohol and other drugs (AOD) are a factor in approximately two-thirds of homicides involving intimate partners, and the murder rate of some AI/AN women is tenfold higher than for non-AI/AN women.
Addressing violence and disparities

• Culturally specific interventions are needed to address the pervasive violence and mental health disparities experienced by Indigenous populations:
  • Experience serious psychological distress at 1.5 times the general population
  • Twice the risk for posttraumatic stress disorder (PTSD) (American Psychological Association, 2010)
  • 368% more likely to die from alcohol related deaths, 138% more likely to die from unintentional injuries, and 54% more likely to die from suicide than the general population (Indian Health Service, 2014).
• Disproportionately high levels of violent crime victimizations (Greenfield & Perry, 2004).
  • Experience intimate partner violence (IPV) at approximately 2.5 times the rate of all women in the general population (Greenfield & Perry, 2004; Tjaden & Thoennes, 2000)
  • 46% experience rape, physical violence, or stalking (Black, Basile, Breiding, Smith, Walters, Merrick, Chen, & Stevens, 2011).
• Consequences of IPV parallel the mental health disparities such as, PTSD, suicide, depression, and substance abuse, disproportionately experienced by Indigenous populations, (Lawrence, Orengo-Aguayo, Langer, & Brock, 2012).
• Addressing IPV in Indigenous populations is imperative to ameliorating these disparities.

Source: APA, 2010
Methods: Mixed methods—Ethnographic and follow-up survey

- What are the culture and context of Indigenous mental health disparities, family violence, and resilience in the Southeast?
  1. Compiling the primary record (participant observation, field notes, existing records)
  2. Reconstructive analysis (data analysis used throughout stages)
  3. Dialogic data generation (individual focused interviews, family interviews, focus groups)
  4. Discovering system relations (comparing results across tribes and sub-samples)
  5. System relations as explanations of findings (discussion and interpretation)
Data collection and analysis with standards for rigor

- Adhere to methodology in prior stages
- Compare results with extant research

- Triangulation across recording devices
- Low inference vocabulary
- Flexible observation schedule
- Prolonged engagement

- Consistency Checks
- Encourage explanation by participants
- Interview repeated times
- Member checks
- Peer debriefing (Throughout)

Compiling the Primary Record

Dialogic Data Generation

Discovering System relations

System relations to explain findings

Arrows depict reconstructive analysis (Negative Case Analysis, Expert Checking coding, Audit trial, Checking findings with data)
Data Collection & Analysis Stages

1. Primary Record/Quantitative Data
2. Dialogic/Qualitative Data
3. Reconstructive Analysis
4. Determining System Relations (Follow-up Survey)
5. System Relations Explains Findings
Sampling Overview: Mississippi and Louisiana Tribal Settings

- >10,000 MS members
- >17,000 LA members

436 participants
- MS (N=228)
- LA (N=208)

127 completed surveys
- MS (N=80)
- LA (N=47)
Qualitative Interviews (Dialogic Data)

Participants by Tribe and Interview Type.

<table>
<thead>
<tr>
<th>Individually-focused</th>
<th>Focus Group</th>
<th>Family-focused</th>
</tr>
</thead>
<tbody>
<tr>
<td>$N=254$</td>
<td>$N=217$ participants across 27 groups</td>
<td>$N=163$ across 64 family interviews</td>
</tr>
<tr>
<td>MS</td>
<td>LA</td>
<td>MS</td>
</tr>
<tr>
<td>$n=145$</td>
<td>$n=109$</td>
<td>$n=13$ (range 3-17, $m=9$)</td>
</tr>
<tr>
<td></td>
<td>$n=14$ (range 2-14, $m=8$)</td>
<td>$n=34$</td>
</tr>
<tr>
<td>Total participants for group interviews</td>
<td>$n=113$ participants</td>
<td>$n=104$ participants</td>
</tr>
<tr>
<td></td>
<td>$n=80$ participants</td>
<td>$n=83$ participants</td>
</tr>
</tbody>
</table>

Note. For group-based interviews (i.e., focus group and family interviews), total participants for each respective groups are displayed in the row below total number of group interviews.
Purposive Sampling and Recruitment: Categories of participants

<table>
<thead>
<tr>
<th>Category</th>
<th>MS (n, %)</th>
<th>LA (n, %)</th>
<th>Total (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional (18+)</td>
<td>47, 20.6%</td>
<td>23, 11.1%</td>
<td>70, 16.1%</td>
</tr>
<tr>
<td>Elder (56+)</td>
<td>44, 19.3%</td>
<td>61, 29.3%</td>
<td>105, 24.1%</td>
</tr>
<tr>
<td>Adult (24-55)</td>
<td>76, 33.3%</td>
<td>71, 34.1%</td>
<td>147, 33.7%</td>
</tr>
<tr>
<td>Youth (11-23)</td>
<td>61, 28.8%</td>
<td>53, 25.5%</td>
<td>114, 26.1%</td>
</tr>
<tr>
<td>Total</td>
<td>228, 100%</td>
<td>208, 100%</td>
<td>436, 100%</td>
</tr>
</tbody>
</table>
Stage One

Primary Record/Quantitative Data

Participant observation: BEP groups
Existing Data:
- 206 Behavioral health intake forms (MS)
- 293 Needs assessments (LA)

Cultural sensitivity strategies—
(a) Use Appropriate methodology;
(b) Allow for fluidity and flexibility—available data varied by context;
(c) Enable Tribal Self-determination—work within protocols of tribe;
(d) Collaborate;
(e) Work with cultural insiders (hired 5 tribal RAs)

System Relations Explains Findings
Stage Two

A. Individually-focused interviews: $n=254$ participants completed ($n=145$ MS; $n=109$ LA); average lasted approximately 64 minutes (63.49)

B. Focus groups: $n=217$ across 27 focus groups (14 MS focus groups, 13 LA focus groups; 57 minutes (57.18).

C. Family interviews: $n=163$ (34 MS family interviews; 30 LA family interviews); 70 minutes (69.69),

D. Total length interviews was about 89 minutes (88.99)

Cultural sensitivity strategies—

(a) Appropriate methodology  
(b) Cultural reader (interview guides)  
(c) Spend time in community  
(d) Use a tribal perspective (extensive member checks);  
(e) Allow for fluidity and flexibility (interview preferences)  
(f) Reciprocate and give back (compensation, results, on-going);  
(g) Enable Tribal Self-determination-work within protocols of tribe;  
(h) Collaborate;  
(i) Work with cultural insiders (hired 5 tribal RAs)  
(j) Honor confidentiality (group interviews)
Stage Three: Reconstructive analysis

Pragmatica Horizon analysis
Team based qualitative research (Guest and MacQueen, 2008)
Multiple coders analyzed the majority of data (74%).
66% of the MS data was analyzed by two or more coders and 86% of LA data was coded by multiple people (i.e., 51% =two analysts and 35% =three analysts).

- Interviews professionally transcribed
- PI created codebook based on aims across ecosystemic levels
- Completed several transcripts, creating coding scheme
- Team made up of PI, 2 non-Indigenous RAs and 2 Indigenous Ras (Cultural insiders, collaboration)

  - Rigorous training
  - Interrater reliability
  - Bi-monthly meetings, coding log
  - Extensive peer support
  - Expert coders independently reviewing coding
Follow up survey: 127 Participants

- Qualitative themes compared across tribes—universal and context specific themes
  - Hierarchical coding schemes exported from Nvivo to excel
- Scale to measure each overarching theme
- Scales created for those where no relevant scale exists (e.g., family resilience and historical oppression)
- Qualtrics survey--$50 gift card (55% received)

- Culturally sensitive strategies: Used culturally congruent scales where available, those used with focal tribes, used tribal perspective, reinforce strengths, use cultural reader, work with cultural insiders
### Highlights of predictors of key outcomes from follow-up survey data (n=127)

<table>
<thead>
<tr>
<th>IPV Perpetration: adverse childhood experiences (ACE), discrimination</th>
<th>Depression: historical oppression, family resilience, income, and daily hassles</th>
<th>Anxiety: historical oppression, daily hassles, beliefs in egalitarian gender roles (negative relationship)</th>
<th>Alcohol Abuse: daily hassles, life satisfaction, IPV</th>
<th>PTSD: stressful life events</th>
<th>Difference by tribe: alcohol abuse, drug abuse, IPV, and ACE all higher for MBCI</th>
</tr>
</thead>
</table>
Methodology to Intervention

- Most insidious themes included violence in families and substance abuse (primarily alcohol abuse) and the importance of families
- Marsiglia and Booth’s as well as Whitbeck’s frameworks to guide the cultural adaptation of intervention
  - Phase 1: Initial assessments—literature review and preliminary research
  - Phase 2: Selection of EBP
  - Phase 3: Design
  - Phase 4: Adaptation-community based participator research with a community advisory board, training community health representative to facilitate a community based and sustainable prevention program, focusing on substance abuse, violence in families, and bolstering family and community strengths.
  - Phase 5: Evaluating the intervention
Discussion

- Culturally relevant research works, it’s intensive at the beginning, but precise and robust
- Consistency of results across Primary record, dialogic data, samples, and sub-samples lead to the trustworthiness and credibility of findings
- Led to robust findings even with a relatively small sample size
- Directly informed the selection and adaptation of a culturally relevant evidenced based program, of which there are very few for Indigenous Americans.

• Questions?
References


References

- Green L. Review criteria and rating scale for community-based participatory research. .
SEX TRAFFICKING AND AMERICAN INDIAN PERSONS: PHOENIX ARIZONA, PILOT STUDY

Dominique Roe-Sepowitz, MSW, Ph.D.
Arizona State University, Office of Sex Trafficking Intervention Research
Pierce and Koepplinger (2011) Native American women are the most frequent victims of physical and sexual violence in the US when compared to other racial and ethnic groups.

Three research studies have looked at NA women, all in Minnesota.
Koepplinger & Pierce (2009)

- Explored 4 databases of AI and AN women in Minnesota.
  - 40% reported some involvement in commercial sexual exploitation.
  - 27% reported some involvement in what was defined as sex trafficking by the state of Minnesota.
Contributing factors in why American Indian and Alaskan Native women and girls were targeted by sex traffickers:

- Poverty
- Generational trauma
- Violence and victimization
- Depression and mental illness
- Suicide
- Drug and alcohol abuse
- Child abuse

Lacking cultural safety” as a critical factor in healing, defined as an environment that is spiritually, socially, emotionally, and physically safe.
Farley et al (2011) Garden of Truth

- Interviewed 105 AI and AN women in Minnesota
- Explored the experiences that led to their sexual exploitation, their sex trafficking experiences, and the effect of the sex trafficking on their ability to heal.
- Reported life histories
  - 80% sexual abuse
  - 2/3 had a member of their family attend a state run boarding school for AI persons
  - 92% had been raped
  - 98% had been homeless
  - 80% had received some substance abuse treatment
  - 52% had a PTSD diagnosis
No published research in Arizona

- For services and previous research, American Indian and Alaskan Native persons are mixed in with all other racial and ethnic groups of known sex trafficked/prostituted persons.

- It is not clear if AI persons have unique experiences or treatment needs.

- Anecdotal evidence from 10 years of working with sex trafficked clients and trainings with tribal law enforcement, medical and mental health providers.
Study

- ASU IRB approved this study.
- Surveys were completed from January 2011 through May 2017 by 840 individuals participating in the DIGNITY Diversion program.
- 37 (4.4%) of the respondents identified as **American Indian**
  - 34 female
  - 2 male
  - 1 both genders
Survey at Prostitution Diversion Intake

- Academic history
- Social history
- Self-harm behaviors
- Alcohol and Drug use
- Information about sex exchange
- Age of first sex exchange
- Sell selling situations
- Involvement in sexual exploitation/pathways
- Readiness to leave situation
- Barriers to exiting
ACADEMIC & SOCIAL SERVICE HISTORY

- Expelled / Suspended: 51.4%
- Special Education Classes: 37.8%
- Social services involved: 56.8%
- Placed in foster care: 35.1%

Youngest age for foster care placement was 0, oldest age was 16 years (average age 8.6 years old).
Respondents reported having:

0-11 Children

45.9% reported their parents were never married

58.3% reported parent, step-parent or foster parent had a problem with alcohol/drugs

56.8% ran away from home before age 18

75.8% had a family member in jail

51.4% witnessed someone in home doing drugs

26.5% reported a family member involved with sex industry
ABUSE EXPERIENCES

- Molested as a child: 62.2%
- Raped before age 18: 44.4%
- Experienced emotional abuse as a child: 28.6%
- Food had been withheld as punishment: 13.5%
- Had someone do something to them on purpose to make them bleed: 10.8%

Youngest age reported for molestation was as an infant.
Youngest age reported for rape was 4 years old.
45.9% said yes to harming self in anyway

37.5% said yes to engaging in risk taking behaviors

21.6% engaged in binging/purging behaviors

43.2% attempted suicide

53.1% engaged in sex with a stranger

40.6% engaged in cutting/self-mutilation

34.4% responded yes to not eating for long periods of time

12.5% Have been involved with a gang
ALCOHOL & DRUGS

54.3% believed they are addicted to alcohol or drugs

88.6% had at some point in their life taken drugs

50% Believe they drink alcohol excessively
EXCHANGE OF SEX FOR SOMETHING OF VALUE

- Sex exchange
  - 91.9% Money
  - 16.2% Clothing
  - 5.9% Jewelry
  - 40% Drugs
  - 28.6% Place to Stay
  - 14.3% Protection
  - 22.9% Other
When asked if they had ever exchanged sex for something of value, 42.3% were under 18 (M = 15.6 years) the first time this happened.

The youngest age reported was 13 years old.

The oldest age reported was 42 years old.
SEX SELLING

60% STREET PROSTITUTION

18.2% STRIP/DANCE CLUB

44.8% INTERNET CALL GIRL

3.4% BROTHEL

17.2% PORNOGRAPHY

TELEPHONE CALL GIRL
Sex Traffickers/Pimps

- 29.6% reported having a pimp

Comments about pimps:

- I didn’t like it cause I was never given what I wanted with the money.
- He was lazy.
- It was a very bad situation.
- My pimp used to be my boyfriend. It was his idea for me to prostitute on the streets. He used to abuse me, hit me around if I didn’t do what he told me to do. He always made me work every night.
- It was really hard, you can never rest or sleep until you have his money.
How did you get involved?

**A friend**
- “A friend introduced me to it”
- “A friend was doing it. I wanted to make some extra money so I decided to try it.”

**Economics**
- “… I had lost my job and I had no place to live. I didn’t have no money to support myself, keep myself alive. I did it cause I needed a place to rest my head…”
- “Lived on the streets, had no other choice. The man I was with made no money so I had to provide for us.”

**Force, Fraud, Coercion**
- “My boyfriend. He’s very manipulative with his words, and he very quickly made me feel worthless and made me feel like I couldn’t do anything so he pushed me in that direction. Saying it was my way to help out to pay bills.”

**Strip Club**
- “Bartending and dancing eventually became an opportunity to escort.”
- “Started working at the strip club and wanted more money. Talked to a few of the girls I worked with and decided to get more money.”
Avoid Jail

• “I was homeless, had a warrant in Alaska and was 18 years old. I didn’t want to go to jail”.

Pimp/boyfriend

• “My boyfriend, he is very manipulating with his words and he very quickly over time made me feel worthless and made me feel like I couldn’t do anything so he pushed me in to that direction. Saying it was my way to help out and pay bills. I went along with it to make him happy with me.”

Drugs/alcohol

• “I needed a place to lay my head and to get the drugs I needed.”
• “My addiction to drugs and alcohol led me to prostitution.”

Family

• “My Dad told me to go make his money.”
• “My sister taught me.”
# Vulnerabilities

<table>
<thead>
<tr>
<th>People</th>
<th>Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friends</td>
<td>Addicted to alcohol/drugs</td>
</tr>
<tr>
<td>Family members</td>
<td>Previous abuse</td>
</tr>
<tr>
<td>Pimps</td>
<td>Needed money</td>
</tr>
<tr>
<td>Boyfriends</td>
<td>Loss</td>
</tr>
</tbody>
</table>
84.4% Stated they **are ready** to stop sex exchanging
What prevents you from leaving?

“Nowhere to live. Feel a lack of support.”

“No other income.”

“Finding a job.”

“I need the money, I can’t find another job. Once I get back to school or find another job, I will stop doing this.”

“Sometimes making a right way of living doesn’t always keep you sheltered.”
What has led to the decision to leave?

"Because I am **tired of it** and I’m not only **hurting myself** but family and friends who **care** about me, plus I just want to now go and live a **normal life again**. Making money the right way."

"I have **nothing** to show for my life. **I want something better.**"

"I never wanted this life. It’s **risky** and **scary** and **I love living** and I want to continue my **life successfully.**"

"Decided **college could be better** for a **job** and getting money."
What we don’t know:

- Are these respondents unique when compared to the other participants in the DIGNITY Diversion program?
- Do they have specific treatment needs?
- Are there unique ways of supporting their exiting experiences?
- Where is the sex trafficking being initiated?
- Tribal land or urban setting (where arrested)?
- How are casino’s involved?
- Is technology/internet being used as part of the recruitment and exploitation of these victims?
Next Steps

- Partnerships
- Exploring the research plan/methodology
Questions?

Dominique.roe@asu.edu
Decolonizing Data

Abigail Echo–Hawk, MA (Pawnee)
Director
Urban Indian Health Institute
32 Urban Indian Health Organizations (UIHPs)
- 19 states representing 100 counties
- 1.2 million AI/ANs reside in service areas

3 UIHP Types
- Outreach and Referral Programs
- Limited Ambulatory Programs
- Full Ambulatory Programs
Spiritual Self Esteem

Emotional Self Love

Physical Self Image

Mental Self Concept

Adapted and developed by Vivette Jeffries Logan & Jackie Goodwyn from Four Worlds Development Project & Raul Quinones Rosado, PhD
We tend to **think** our way through life, forgetting that to **feel** is an important part of being human. Our disciplines tell us that in order to be fair, we must learn to be **objective**, but objectivity is the absence of compassion and humanity. To think without feeling is to sacrifice our bodies and our spirits, and to cease to be whole.

“Many ills of Western society can be traced to a disconnect between head and heart, which manifests culturally as a schism between science and religion.”
#DecolonizeData

- **Love**
  - Why do we need data? Why do we gather data?

- **Feel**
  - What does it mean to be objective?

- **Create with intent**
  - Prayer

- **Give**
  - Gifting the best that we have for the benefit of the people.
Maternal and Child Health

Prenatal Care by Trimester, UIHO Service Areas, 2008-2012

NATIVE WOMEN LIVING IN URBAN AREAS ARE 4.5 TIMES MORE LIKELY TO DIE FROM PREGNANCY RELATED COMPLICATIONS THAN WHITE WOMEN. #decolonizedata
Urban Native moms are 14% LESS likely to have a c-section than white women #decolonizedata
Contact Information

- Abigail Echo-Hawk, MA (Pawnee)
  Director, Urban Indian Health Institute
  abigaile@uihi.org