Initial Steps in Establishing Reservation and Urban Community Support/Resources for AIAN Families Dealing with FASD

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The 7th International Conference on Fetal Alcohol Spectrum Disorder Research: Results and Relevance 2017
Learning Objectives

• Describe our first steps in establishing support for those dealing with FASD in an American Indian Alaska Native (AIAN) reservation and urban setting

• Discuss lessons learned and approaches to challenges

• Explore how AIAN community priorities differ by location
California

- Largest number of Native Americans & most distinct tribes today
- ~1/3 of all Native Americans in U.S. pre-contact
- ~100 languages and >300 dialects pre-contact
- Varying times of contact and non-Native group
  - Spanish
  - British
  - Russian
Reservation vs. Urban
Project Locations

Two American Indian populations in Southern California:

Reservation

Urban
The prevalence of FASD is unknown in our community

A previous study found:

- Half of women of childbearing age do not consume alcohol
- Those who consume alcohol tend to do so in a heavy episodic manner
- A third of women of childbearing age may be vulnerable to having an alcohol-exposed pregnancy
What is NOFAS?

National Organization on Fetal Alcohol Syndrome

A non-profit network that works to prevent alcohol use during pregnancy and to support individuals and families living with FASD
Resource Assessment
Focus Groups & Interview
Pre-implementation survey
Create NOFAS
Post-implementation survey
Healthy Native Nation

We are the first AIAN NOFAS affiliate!

Our staff is local and primarily Native

Resource assessment found limited availability of services and no specific support for individuals and families dealing with FASD
Focus Groups and Interviews

Priorities:

• Educate professionals working with community about FASD

• Educate community groups

• Educate community members at events

45 participants

39 AIAN
## Community Survey

Demographics; n (%) or mean ± SE; Not statistically different

<table>
<thead>
<tr>
<th></th>
<th>Total Sample</th>
<th>Reservation</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants</strong></td>
<td>305</td>
<td>155</td>
<td>150</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>218 (72.4)</td>
<td>119 (76.8)</td>
<td>99 (67.8)</td>
</tr>
<tr>
<td><strong>Have a child</strong></td>
<td>229 (79)</td>
<td>112 (77.2)</td>
<td>117 (80.7)</td>
</tr>
<tr>
<td><strong>Age category</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24 years</td>
<td>50 (16.7)</td>
<td>19</td>
<td>31</td>
</tr>
<tr>
<td>25-45 years</td>
<td>146 (49)</td>
<td>80</td>
<td>66</td>
</tr>
<tr>
<td>46-64 years</td>
<td>80 (26.8)</td>
<td>41</td>
<td>39</td>
</tr>
<tr>
<td>&gt;64 years</td>
<td>22 (7.5)</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td><strong>Current drinker</strong></td>
<td>122 (41.5)</td>
<td>70 (45.8)</td>
<td>52 (36.9)</td>
</tr>
<tr>
<td><strong>Drinks /week</strong></td>
<td>3.70 ± 0.42</td>
<td>4.27 ± 0.63</td>
<td>2.97 ± 0.49</td>
</tr>
</tbody>
</table>

* n=102 (57/45)
Community Survey

Drinks per Week Among Current Drinkers; Mean ± SE; Not statistically different

<table>
<thead>
<tr>
<th>Age Categories</th>
<th>Reservation</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24 years</td>
<td>n=5</td>
<td>n=6</td>
</tr>
<tr>
<td>25-45 years</td>
<td>n=34</td>
<td>n=27</td>
</tr>
<tr>
<td>46-64 years</td>
<td>n=16</td>
<td>n=9</td>
</tr>
<tr>
<td>&gt;64 years</td>
<td>n=1</td>
<td>n=1</td>
</tr>
</tbody>
</table>
Community Survey

143 (48.6%) know someone in need of services

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Reservation</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not aware of anyone in need of services</td>
<td>151</td>
<td>68 (44.7)</td>
<td>83 (58.5)</td>
</tr>
<tr>
<td>Know someone in need of services</td>
<td>143</td>
<td>84 (55.3)</td>
<td>59 (41.5)</td>
</tr>
</tbody>
</table>

More participants were aware of someone in the community in need of developmental disability related services at the reservation site than the urban site (p=0.019; OR=1.33)
Community Survey
Can We Talk?

More than half, thought the community would be willing to talk about alcohol in pregnancy or about children affected by alcohol

83 (56.5%) Reservation; 86 (60.6%) Urban

Community is ready to address this “hidden disability”
Community Survey
Things pregnant women can do to have a healthy baby

The 3 most important things:

- Stop taking drugs
- Stop drinking alcohol
- Stop smoking

>95% agree
Community Survey
Things pregnant women can do to have a healthy baby

Most likely to be rated “not important”:

**Reservation**
1. Follow traditional ways
2. Avoid stress

**Urban**
1. Take vitamins
2. Go to the dentist
Community Survey

True or False?

• Almost everyone knew that drinking alcohol during pregnancy can lead to disabilities in the baby (99%)
• More than 1 in 4 believed a child can grow out of the effects of prenatal alcohol exposure (26.6%)
• More than 1 in 8 believed prenatal alcohol exposure cannot hurt the baby before the mother knows she is pregnant
• More than 9 in 10 agreed that being affected by prenatal alcohol exposure makes your life and the life of your family more difficult and that treatment and services help
• More than 3 in 4 believed some services and treatment options were available in the community (Reservation 77%, Urban 86%)
Importantly

Nearly everyone agreed that if services were available, they would use them (or recommend them to friends)
Community Survey

**Availability** of Services for People With Developmental Problems

- Perception of availability of services ranged from 28% (speech and language therapy) to 69% (individual counseling)

- Perception of slightly fewer services available on reservation:
  - Less vocational job training
  - Fewer addiction services
  - Less support for teens
Community Survey

Prioritization of Services and Support

- Individual counseling
- Family/parent counseling
- Family support network
- Parenting classes
- Addiction services
- Anger management
- Speech & language therapy
- Social skills training
- Legal services
- Physical therapy
- Educational support
- Teen support network
Suggestions from Comment Section

- Raise awareness
- Provide education/training on an ongoing basis
- Lower stigma / lower shame
- Foster open discussion
- Talk to Elders
- Support talking circles
- Public events
- Radio messages and public service announcements
- Workshops
- Continuing community outreach
- Advocates for affected families
- Parents and others willing to talk about how their lives were affected
- Home visits
- Strong community connection with people from each tribe
What do you do if people don’t know they are affected?

Problem:
If diagnosis is unavailable few people are aware of their status

Solution:
– Ready, Set, Go!
– Raising awareness
– Providing referrals
Lessons Learned

- **Cultural congruency**: modify surveys, measures, interventions
- **Local Staff**: hire and train local trusted community members
- **Partnerships**: community groups, Tribal IRB, programs that synergize
- **Space**: testing and interview rooms; confidential quiet area; welcoming
- **Transportation**: for participants and staff
- **Food**: culturally expected and crucial to project completion
- **To encourage completion of project**:
  - Create a sense of urgency
  - Make it convenient for participants
  - Multiple means of contact

*Solutions come from within the community*
Currently ongoing

- Implementation of prioritized strategies is proceeding as assessment continues
- Training of professionals dealing with community
- Education of community groups
- Raising awareness through presentations, tabling, and modest media campaign
- Creation of a community FASD resource center
- Connecting community with diagnostic services
- Connecting community to treatment outside community until local capacity can be expanded
Conclusions

• Community input into the structure of the NOFAS affiliate has been informative and has identified priorities and gaps

• Differences are emerging between reservation and urban communities
  – Risk and protective factors
  – Attitudes toward healthy pregnancies
  – Needs relating to developmental disabilities
  – Availability of services
  But prioritization of initial desired services and support are similar

• Crucial to involve local Native community members in all aspects of study
We are grateful for support from Native American Research Centers for Health (NARCH VII) funding from the NIH National Institute of General Medical Sciences grant #GM106376 and Indian Health Service grant #U261IHS0081, Christina Chambers PI.

This research is also informed by data obtained through the NARCH V grant #GM087518 / U26IHS300292, and the NIAAA grant #U01AA019879.