

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

Annika Montag, Rhonda Romero, Toni Jensen, Ami Admire,
Amiyonette Goodblanket, Dan Calac, Christina Chambers

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

Learning Objectives

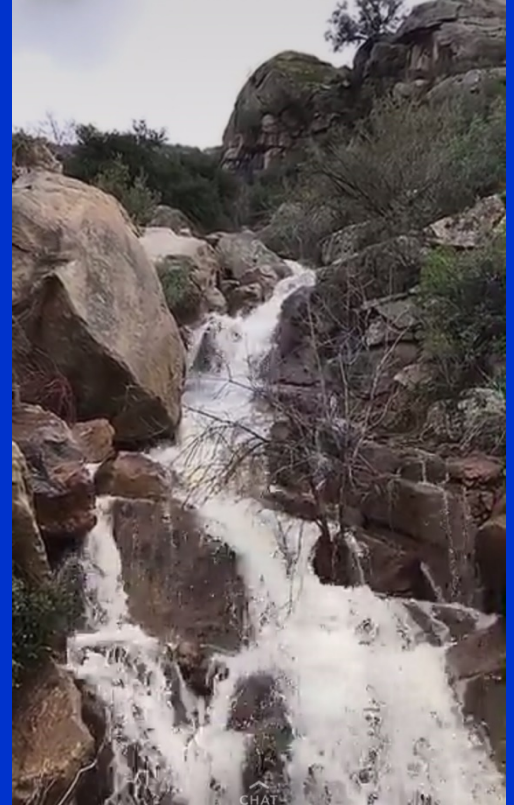
- Describe our first steps in establishing support for those dealing with FASD in an American Indian Alaska Native (AIAN) reservation and urban setting
- Discuss lessons learned and approaches to challenges
- Explore how AIAN community priorities differ by location

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



The Great Oak



Baskets by basketmaker Carmalita LaChappa, Kumeyaay. Source: Museum of Man

```
graph LR; A[Needs] --> B[Priorities]; B --> C[NOFAS Affiliate];
```

Needs

Priorities

NOFAS
Affiliate

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



Community Survey

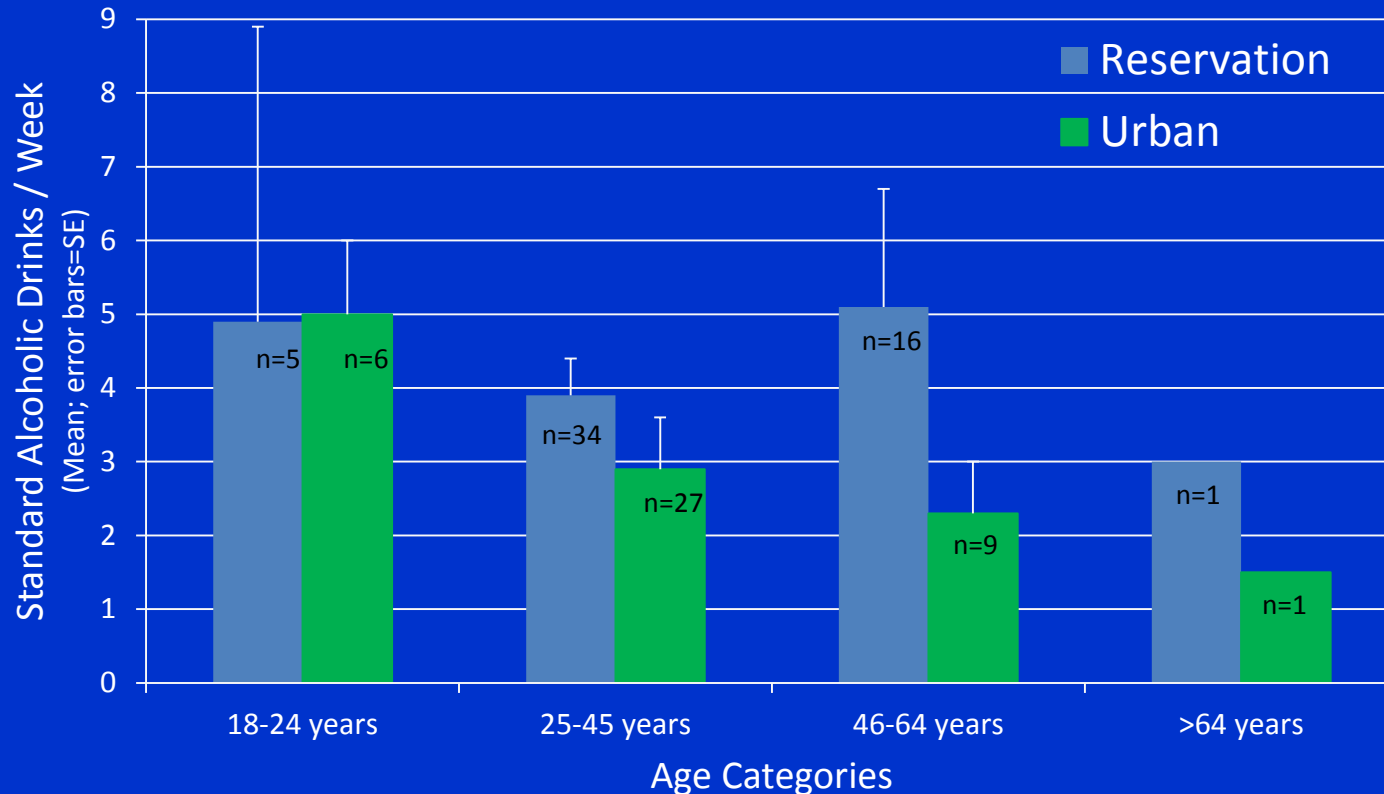
Demographics; n (%) or mean \pm SE; Not statistically different

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

*n=102 (57/45)

Community Survey

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



Community Survey

143 (48.6%) know someone in need of services

	Total	Reservation	Urban
Not aware of anyone in need of services	151	68 (44.7)	83 (58.5)
Know someone in need of services	143	84 (55.3)	59 (41.5)

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%)

Community Survey

True or False?

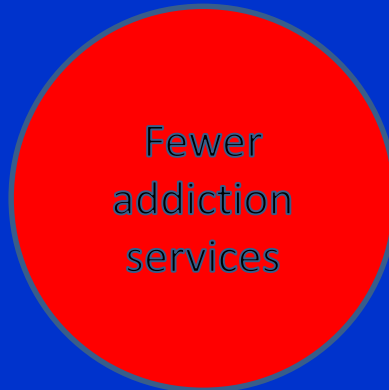
Importantly

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:



Community Survey

Prioritization of Services and Support



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.