



Addressing FASDs: Lessons in Policy and Equity

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Background



- ▶ FASDs are a significant public health concern and a 100% preventable disorder.
- ▶ The cause is prenatal alcohol exposure (PAE) from maternal-fetal transfer.
- ▶ Pregnancy binge drinking (> or = four or more drinks on one occasion) is the highest risk of FASDs (May et al., 2018).

At-Risk



- ▶ Females aged 18-20 years make up the largest group of nonpregnant women who reported the highest frequency and intensity of binge drinking (May et al., 2014).
- ▶ Earlier studies report frequent heavy drinking among acculturated Hispanic women who are pregnant or of childbearing age, thus placing the offspring at increased risk for FASDs (Bakhireva et al., 2009; Chambers et al., 2005).

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What is FASD?

DEFINITION

Prenatal exposure to alcohol can damage the developing fetus and is the leading preventable cause of birth defects and neurodevelopmental disabilities.

Fetal alcohol spectrum disorders (FASD) is a non-diagnostic umbrella term that describes the range of effects that can occur as a result of prenatal alcohol exposure.

EFFECTS

These effects span across physical, mental, behavioral and learning disabilities that may be mild or severe, all with lifelong implications.



Alcohol use during pregnancy can lead to lifelong effects.

Up to **1 in 20** US school children may have FASDs.



People with FASDs can experience a mix of the following problems:

Physical issues

- low birth weight and growth
- problems with heart, kidneys, and other organs
- damage to parts of the brain



Which leads to...

Behavioral and intellectual disabilities

- learning disabilities and low IQ
- hyperactivity
- difficulty with attention
- poor ability to communicate in social situations
- poor reasoning and judgment skills



These can lead to...

Lifelong issues with

- school and social skills
- living independently
- mental health
- substance use
- keeping a job
- trouble with the law



Drinking while pregnant costs the US **\$5.5 billion** (2010).



The Randall Lewis Health Policy Fellowship (RLHPPF)

- ▶ Designed to engage local graduate students in health professions in making positive changes in public policy and systems, and thus impact the health of communities.
- ▶ Recently began taking graduate nursing students.
- ▶ Through this fellowship, assessment of educational policies and programs occurred related to the primary prevention and early detection of at-risk mothers for alcohol exposure in pregnancy, and prevention of FASDs in children residing in a medically underserved area (MUA) of Southern California.



Site: Institute for Fetal Alcohol Spectrum Disorders
Discovery

University of California, San Diego
Department of Pediatrics
Division of Dysmorphology and Teratology



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Purpose



- ▶ The purpose of this project is to describe the process and impact of a campus-community fellowship addressing health policy and equity, through the lens of an investigation on Fetal Alcohol Spectrum Disorder (FASD).

SCOPE OF WORK

Goal: Develop Culturally Competent Health Policies and Educational Tools to Address Fetal Alcohol Spectrum Disorders (FASD)				
Objectives	Activities	Start/End Date	Who is Responsible	Tracking Measures
1. Analyze the need for culturally competent health policies and educational tools to address issues surrounding Fetal Alcohol Spectrum Disorders (FASD) in Southern California, with a focus on the Inland Empire.	Meet with representatives of the community partnership: CSU San Bernardino, Azusa Pacific University, the University of California, San Diego Institute for Fetal Alcohol Spectrum Disorders, and maternal child health stakeholder agencies: Perinatal Mental Health Collaborative, San Bernardino Public Health Department, Riverside Public Health Department, Betty Ford Center, and other relevant agencies	9/17-12/17	Anne Lama	Document stakeholder meetings and input to create a strategic plan Track: Educational policies and practices for vulnerable populations regarding FASD and accessibility and availability of multi-cultural tools and policy considerations
2. Assess opportunities for addressing gaps, and/or providing for community needs, based on current initiatives	Review previous work done between CSU San Bernardino and the University of California, San Diego Institute for Fetal Alcohol Spectrum Disorders, Create a VMOSA and Logic Model with collaborators and community stakeholders to assess current FASD policies and information dissemination, including multicultural approaches and cultural competency.	1/18 –6/18	Anne Lama	Deliverables: Logic Model to include short, medium, and long term goals for policy, practice, and identifying gaps, needs, and strengths of policies regarding FASD in the Inland Empire and throughout Southern California
3. Assist with one - two areas of focus to expand on or address community initiatives.	Perform policy analysis and synthesis	2/18 –6/18	Anne Lama	Focus on identified priorities by community partners, such as educational approaches and policies for FASD in vulnerable populations in Southern California, especially in the Inland Empire.

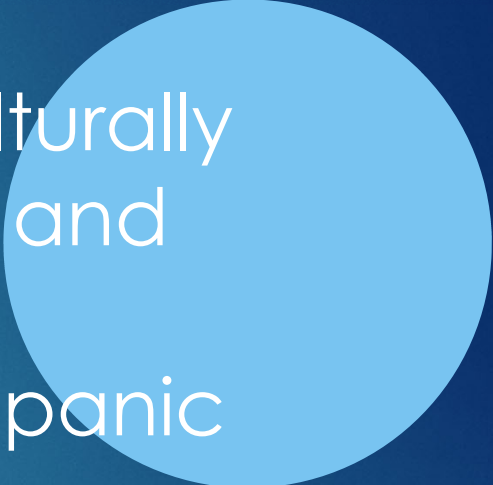
Aims



1. Describe the campus-community partnerships in a health policy fellowship in a MUA in Southern California.
2. Identify gaps in policy and educational programs for prevention of alcohol exposure during pregnancy and subsequent FASDs.

Problem



- ▶ Research identified a gap in culturally appropriate prevention policies and educational programs for reproductive age females of Hispanic background.
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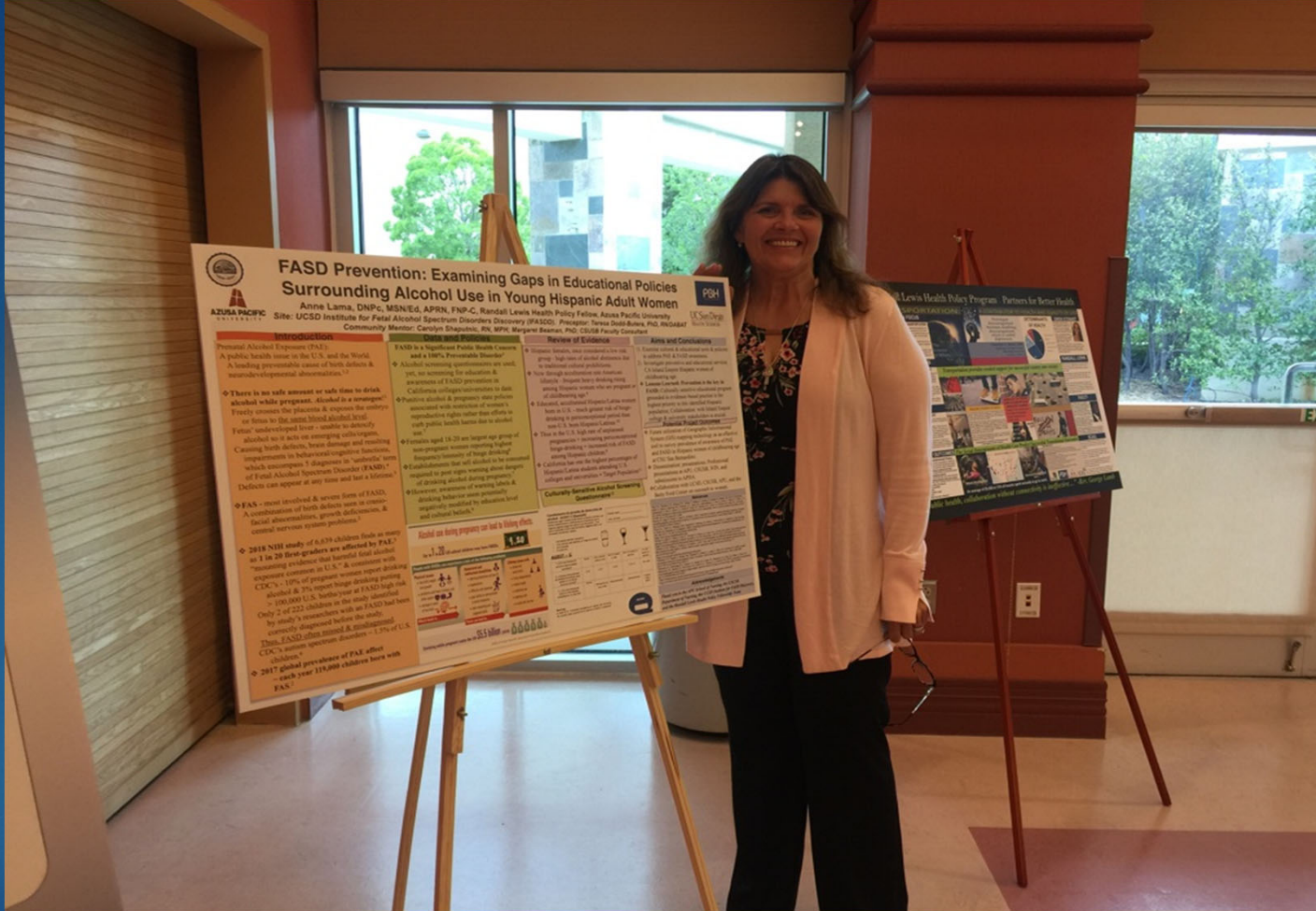
Methods



This ethnographic study focused on program and policy analysis regarding FASDs.

Tools for assessment included:

- ▶ the use of geographic information systems (GIS)
- ▶ community walk-throughs
- ▶ engagement with residents
- ▶ partnership with national CDC initiatives, and
- ▶ dialogue with regional public officials in monthly fellowship meetings, coupled with weekly preceptor guidance.



FASD Prevention: Examining Gaps in Educational Policies Surrounding Alcohol Use in Young Hispanic Adult Women

Anne Lama, DNPc, MSNEd, APRN, FNP-C, Rosalind Lewis Health Policy Fellow, Azusa Pacific University
 Site: UCSD Institute for Fetal Alcohol Spectrum Disorders Discovery (FASDC), Professor, Santa Rosa-Buena, PhD, PhDc
 Community Mentor: Carolyn Sheehy, RN, MPH, Margaret Swann, PhD, CSUB Faculty Consultant

Introduction

Personal Alcohol Exposure (PAE)
 A public health issue in the U.S. and the World. A leading preventable cause of birth defects & neurodevelopmental abnormalities.

- There is no safe amount or safe time to drink alcohol while pregnant. Alcohol is a teratogen. Freely crosses the placenta & exposes the embryo or fetus to the same blood alcohol level.
- Fetus' undeveloped liver - unable to detoxify alcohol so it acts on emerging cell organs. Causing birth defects, brain damage and resulting impairments in behavioral/cognitive functions, which encompasses 1 diagnosis in "subclinical" form of Fetal Alcohol Spectrum Disorder (FASD)*.
- Deficits can appear at any time and last a lifetime.

FAS - most involved & severe form of FASD.
 A combination of birth defects seen in craniofacial abnormalities, growth deficiencies, & central nervous system problems.

- 2018 NIH study of 6,779 children finds as many as 1 in 20 first-graders are affected by PAE.2
- Researcher indicates that harmful fetal alcohol exposure common in U.S. & consistent with CDC's - 10% of pregnant women report drinking alcohol & 3% report binge drinking posing ~100,000 U.S. babies/year at FASD high risk.
- Only 2 of 222 children in the study identified by study's researchers with an FASD had been correctly diagnosed before the study.
- Though FASD often missed & undiagnosed, CDC's national spectrum disorders - 1.3% of U.S. children.
- 2017 global prevalence of PAE affect children* - each year 110,000 children born with FAS.

FASD is a Significant Public Health Concern and a 100% Preventable Disorder!
 Alcohol screening interventions are used, however, the education & awareness of FASD prevention in California colleges continues to date.

- Positive alcohol & pregnancy awareness associated with restriction of women's reproductive rights rather than efforts to curb public health harms due to alcohol use!
- Females aged 18-20 are target age group of non-pregnant women reporting higher frequency history of binge drinking!
- Establishments that sell alcohol to be consumed of drinking alcohol during pregnancy, "I support 'Let's Get Pregnant' - 100% 'Pregnant' college students reported 'not' frequent drinking behavior when pregnancy indicated by education level and cultural beliefs."

Review of Educational Policies

- Systems, however, that considered core college group, had more alcohol drinking than other college cultural problems.
- Very high alcohol consumption and binge drinking - began being drinking only during college years rather than in preparation of college age!
- Education, developmental stages of late women in U.S. - much greater self-identification of a common cultural group than seen in U.S. born Hispanic/Latina*.
- This is the U.S. high use of pregnant women's - drinking environmental changes - including the higher percentage of young Hispanic/Latina*.
- California has the highest percentage of Hispanic/Latina students attending 2- & 4-year colleges and universities "not" frequent drinking behavior when pregnancy indicated by education level and cultural beliefs."

Culturally Specific Alcohol Drinking Practices

- Students, however, that considered core college group, had more alcohol drinking than other college cultural problems.
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Key Findings and Conclusions

- Students, however, that considered core college group, had more alcohol drinking than other college cultural problems.
- Very high alcohol consumption and binge drinking - began being drinking only during college years rather than in preparation of college age!
- Education, developmental stages of late women in U.S. - much greater self-identification of a common cultural group than seen in U.S. born Hispanic/Latina*.
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Recommendations

- Students, however, that considered core college group, had more alcohol drinking than other college cultural problems.
- Very high alcohol consumption and binge drinking - began being drinking only during college years rather than in preparation of college age!
- Education, developmental stages of late women in U.S. - much greater self-identification of a common cultural group than seen in U.S. born Hispanic/Latina*.
- This is the U.S. high use of pregnant women's - drinking environmental changes - including the higher percentage of young Hispanic/Latina*.
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Results



- ▶ The experience as an RLHPF fellow for the 2017-2018 year was life-changing as both participant and observer.
- ▶ As an observer, my contextual lens for community is forever changed beyond a narrow definition as partner.
- ▶ As a participant, the community lens has expanded for understanding the capabilities and possibilities of utilizing nurses as advocates for health policy and equity.
- ▶ The research and activities uncovered inequity in a MUA regarding issues of prevention and education for FASDs.


Implications



- ▶ To address health disparities, advanced practice nurses must serve as advocates for health and educational policies to ensure professional education, prevention and treatment regarding FASDs.
- ▶ The significance of this fellowship resulted in the identification of gaps in professional education and patient care policies as a perfect fit for nurse educator initiatives to make curriculum changes and create student nurse champions leading the way in addressing PAE & FASD.

Lessons Learned



- ▶ Prevention is the key in FASD; and culturally sensitive educational programs grounded in evidence-based practice is the highest priority in this identified Hispanic population.
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A woman in a red dress is shown from the waist up, holding her belly. The image is overlaid with a semi-transparent dark grey rectangle containing the title text. The background is a soft-focus indoor setting with light-colored walls and a window with blinds. A small green square is visible in the top right corner of the image.

FETAL ALCOHOL SPECTRUM DISORDERS

A Toolkit for Nurse Champions

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Who is a Champion?

DEFINITION

Champions enthusiastically support an increase awareness and prevention of FASD through alcohol screening and brief intervention (Alcohol SBI) training for nurses and all health professionals. Additionally, Champions facilitate educational messaging to professionals and the public whenever and wherever possible within their sphere of professional influence.



EXECUTIVE CHAMPION

Administrative nurses who advocate and influence other nurses and organizations about FASD prevention and who encourage the dissemination of information about FASD.



NURSE LEADER CHAMPION

Clinical nurses who support the principle of FASD prevention, promote knowledge and skill development, and facilitate dissemination.



STUDENT CHAMPION

Student ambassadors who are the proponent and cheerleader of the FASD cause, while still in school.



Champion Role and Impact

ROLE

- + Promote educational materials and trainings on Alcohol SBI and other evidence-based practices to prevent FASD.
- + Facilitate dissemination of Alcohol SBI and FASD training, practice guidelines, and related resources.
- + Advocate for evidence-based trainings and the adoption of USPSTF recommendations to make Alcohol SBI a Standard of care in clinical settings.
- + Survey your membership and/or practice setting to assess need for further training and support for nurses implementing Alcohol SBI as a routine practice.

IMPACT

- + Increase the number of nurses who are skilled in Alcohol SBI and understand its importance in relation to FASD prevention.
- + Improve consistent, science-based messaging about risky drinking and alcohol use during pregnancy.
- + Influence practice change among nurses and other healthcare professionals in the areas of prevention, identification, and treatment of FASD.
- + Sustain implementation of Alcohol SBI toward the elimination of FASD and Alcohol Exposed Pregnancies (AEP).

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