

UC DAVIS HEALTH | **MIND INSTITUTE**

Fetal Alcohol Spectrum Disorders (FASD) – Learning from Living Experiences



Julie Mei Law, MD
Developmental-Behavioral Pediatrics Fellow
March 2026

1


Disclosure Statement

I have nothing to disclose.


UC DAVIS HEALTH | **MIND INSTITUTE**

2


Background



1-5% school children
Up to 1 in 20
1 child in every classroom



Nearly **2 million**
Californians with FASD




>80% undiagnosed

Lack of knowledge and stigma about FASD among **healthcare professionals (HCPs)** are important factors contributing to missed or late diagnoses.

UC DAVIS HEALTH | **MIND INSTITUTE** May, 2018
Chenault, 2015


3

Role of Healthcare Professionals (HCPs)



Lack of knowledge about FASD

- Limited training
- Limited awareness
- Discomfort, denial, avoidance



Stigma about FASD

- Pervasive
- Negative, lasting impacts
- Discomfort, assumptions, unconscious bias

Missed / delayed diagnosis
Lack of support

(Smith, 2017)
<https://fasdunited.org/stigma-language-guide/>
<https://doh.wa.gov/communities-and-development/health-equity/stigma>

UC DAVIS HEALTH | MIND INSTITUTE

4

Research Methods

Community-Based Participatory Research

A collaborative, equitable approach
Research benefits the community




Qualitative Research

Patients and families are experts through *lived / living experiences*

A different approach to medical learning

May lead to a quantitative study

<https://www.detroituz.org/about-us/what-is-cbpr/>
<https://fasdunited.org/land-empowerment/>

UC DAVIS HEALTH | MIND INSTITUTE


5


Study Aims & Design

Aim 1

How do healthcare professionals (HCPs) impact Californians with FASD?

Qualitative study






Aim 2

Will an educational intervention improve HCP knowledge, attitudes, and beliefs about FASD?

Quantitative study



UC DAVIS HEALTH | MIND INSTITUTE

6



UC DAVIS HEALTH | **MIND INSTITUTE**

Qualitative Study

Aim 1



7

Qualitative Study

Participants (n = 29)

- 5 Teens
- 9 Adults
- 15 Caregivers – 12 adoptive, 3 biological
- 7 families Northern CA, 7 Central/Southern CA
- 11 families Urban, 3 Rural


Interviews

- Lived / Living experiences

Focus Groups

- Interactions and experiences with HCPs
- Strategies for HCPs

Teens & Adults with FASD	
Race/ethnicity, %	
White	67%
Black	21%
Asian	7%
Age at diagnosis (median)	0-26 yrs (10)
Comorbid conditions, %	
Anxiety / mood disorders	93%
ADHD	50%
Learning disabilities	43%
Autism	29%
Education status, %	
School disruption	79%
Graduated HS (adults)	55%
Vocational / College (adults)	33%
Work status, %	
Unemployed (adults)	67%
Employed (adults)	33% (1 cannot work due to chronic health problems)



8



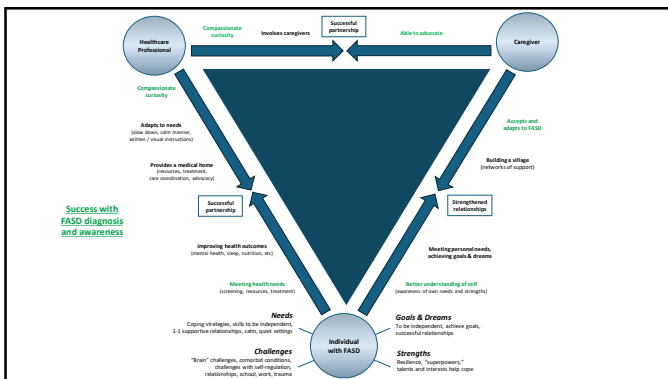
9



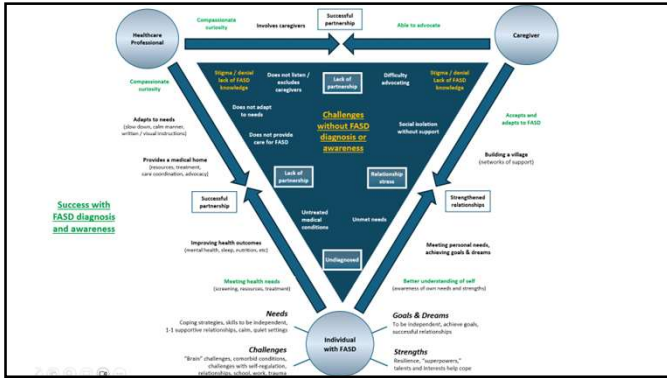
10



11



12



13



14

UC DAVIS HEALTH | **MIND INSTITUTE**

Quantitative Study


Aim 2

15

Educational Sessions for HCPs

Participants (n = 41 needed)

1. UC Davis Pediatric residents, attendings
2. UC Davis Internal Medicine primary-care residents, attendings
3. UC Davis MIND Institute
 - DBP, Psychology, Genetics, SW, staff
4. Community practice
 - General Pediatrics, staff



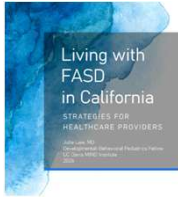
UC DAVIS HEALTH MIND INSTITUTE

16

Educational Sessions

Content

1. Pre-survey (5 min)
2. FASD Education (25 min)
 - Prevalence, risk factors, symptoms, comorbidities, diagnosis, management
 - Video clips
 - Strategies for HCPs
3. Panel Discussion (25 min)
 - Led by qualitative study participants
4. Post-survey (5 min)



UC DAVIS HEALTH MIND INSTITUTE

17

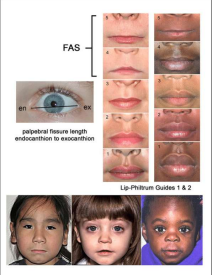
Facial Features

Only 10% of patients with FASD

- Smooth philtrum
- Thin upper lip
- Short palpebral fissures
- Epicanthal folds
- Railroad track ears (extra ridge on outer ears)
- Low nasal bridge
- Cleft lip/palate
- May / not change during puberty and persist into adulthood.

Other physical findings:

- Clinodactyly
- Hockey stick palmar crease



UC DAVIS HEALTH MIND INSTITUTE

<https://depts.washington.edu/fasdp/hmh/fas-face.htm>
<https://www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorder/screening-assessment/>

18

Successful Strategies for HCPs	
Brain challenges	<ul style="list-style-type: none"> Slow down! Be patient. Check for understanding. Extra appointment reminders Involve caregivers (with patient permission)
Difficulty with self-regulation	<ul style="list-style-type: none"> Speak calmly, provide a calm, quiet setting. Provide clear written / visual instructions
Primary symptoms & co-morbid conditions	<ul style="list-style-type: none"> Be willing to learn about FASD Universal screening for prenatal alcohol exposure Recognize risk factors and symptoms that may be consistent with FASD – it is a spectrum. Provide a medical home (guidance, treatment, referrals, care coordination).
Relationship challenges & trauma	<ul style="list-style-type: none"> Screen for adverse experiences Provide support during medical appointments / procedures Provide family resources for caregiver and family support Refer to individual or family counseling
Social, school & work challenges	<ul style="list-style-type: none"> Recognize potential for masking and mismatch between verbal ability and level of functioning. Allow caregivers to be present to help patients self-advocate. Understand what patients need to succeed in school or work
Lack of FASD supports or services	<ul style="list-style-type: none"> Advocate for patients to access educational and Regional Center services

19

Demographics

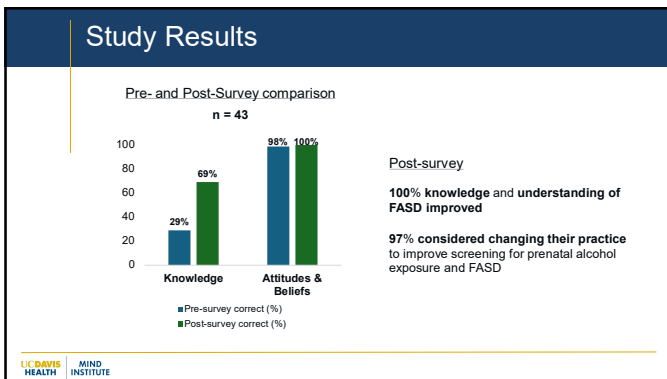
48 completed pre-survey

- 20 Physician trainees
 - 13 Pediatric residents
 - 4 Internal Medicine residents
 - 3 DBP fellows
- 15 Physicians
 - 11 Pediatrics
 - 3 Internal Medicine
 - 1 Psychiatry
- 13 Other HCPs
 - 4 Psychology
 - 3 Social Work
 - 2 Genetics Counselors
 - 1 each Nurse, Medical Assistant, Patient Navigator, Care Coordinator

Participants	
Familiarity with FASD	
Not familiar	15%
A little (lectures only)	29%
Some knowledge	20%
Care for patients with FASD	27%
Expert	8%
Preparedness	
1 – Not at all	Mean 1.8 (not at all / somewhat)
2 – Somewhat	
3 – Neutral	
4 – Moderately	
5 – Very	

UC DAVIS HEALTH | MIND INSTITUTE

20



21

Work Products

Resource Toolkit For Families

- MIND Institute
- FASD Network of Northern California
- FASD Network of Southern California

FASD Educational Video

- 20-minute video
- Pediatric residents and other learners

22

Conclusion

1. **FASD diagnosis and awareness** are key to successful interactions and outcomes for individuals with FASD, their caregivers and HCPs.
2. A brief educational intervention **significantly improves knowledge about FASD** among HCPs. Attitudes and beliefs were highly positive and did not change.
3. Further research is needed to determine how knowledge and practice change can be sustained over time.

23

With gratitude to our team, sponsors & participants

Julie Law, MD
DBP Fellow, UC Davis MIND Institute

Annette Kunzman, MBA
Mother and President of the FASD Network of Southern California
Executive Director of FASDNow!

Anne Lindsay Dahl
Mother and Vice President of the FASD Network of Northern California

Peggy Black, MA
Mother and President of the FASD Network of Northern California

Rebecca Tillou, BS
Interviewer and Adult living with FASD

Danielle Vakutin
Qualitative Research Assistant

Narueporn Likhitweerawong, MD PhD
Qualitative Research Assistant

Melissa Gosdin, PhD
Qualitative Research Advisor, UC Davis Center for Healthcare Policy & Research

Susan Timmer, PhD
Research Advisor, UC Davis Department of Pediatrics

Tanaporn Jasmine Wilaisakditipakorn, MD
Primary Mentor, UC Davis MIND Institute
Division of Developmental Behavioral Pediatrics

Grant Funding

American Academy of Pediatrics
CATCH Implementation Grant (2024-25)

UC Davis Department of Pediatrics
Fellow Grant (2025-26)

Maternal Child Health Bureau
HRSA Grant # T77MC25733

24