

# Why does diagnosis matter?

The Hawai'i FASD Action Group  
[www.fasdhawaii.org](http://www.fasdhawaii.org)

# FASD

(fetal alcohol spectrum disorders)

## The Science and The Stigma

**ATTITUDES**...when a brain-based difference is well understood, it can **change the response of others, and therefore outcomes.** Perceptions of “won’t” in behavior can create responses that are not considerate of unique needs and can exacerbate challenges.<sup>4</sup>

**APPROACHES**...“treatment” implies progression, remission, and/or cure. **FASDs are not acute conditions,** the affects are teratogenic and part of a persons functioning and development from birth and across the lifespan.

**ACCOMMODATIONS**...understanding the environment and supports needed to change or adapt, not necessarily the person, is crucial. Although often “invisible” and harder to understand, **FASDs are just like other disabilities.**

**ACCEPTANCE**...all behavior is brain-based and knowledge is power. Understanding ones own strengths and needs can support both self and family advocacy and **significantly reduce comorbidities.**

“Expert consensus suggests that treatment approaches that rely on an assumption of ‘normal’ functioning of [these] cognitive processes are likely to be less effective with individuals with an FASD. This appears to be true for both mental health and substance abuse treatment settings.”<sup>1</sup>

## Different is just...DIFFERENT

Mental Health Conditions

Fetal Alcohol Spectrum Disorders

### BASIC FRAMEWORK

Disorders that affect mood, thinking, and behavior, including considerations in brain chemistry, environment, genetics, and trauma.

Diagnostic assessments can include presenting symptoms, history, and ruling out of bio-medical causes via exams and lab testing.

### INTERVENTION APPROACH

Provide therapies, structure, and/or medications that support changes in regulatory/behavioral responses and functioning.

### BASIC FRAMEWORK

Damage to structural parts of the brain, body, and/or central nervous system **a person is born with** that are responsible for managing different bodily and behavioral functions, often permanently affecting **executive capacity, memory, and insight.**<sup>2</sup>

Diagnostic assessments can include cross-systems teams and specialists, early family inclusion and support, neuropsychological testing, brain imaging and mapping, complex biomarker examination, and **iterative personal and family history.**

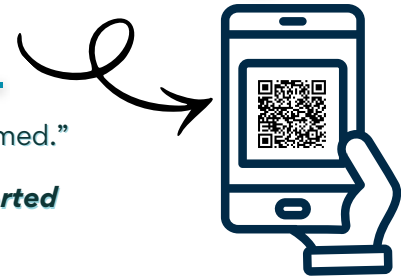
### INTERVENTION APPROACH

**Create adaptations and/or accommodations, including to the environment and social supports, across systems and throughout the lifespan.**

**Change the approach to support success.**

# FASD is a Kākou Thing

## TRAINING OPPORTUNITIES



**ASSESSMENT IS CRITICAL**...FASD screening and assessment have to be “FASD-informed.” FASDs are a complicated set of conditions that can be confusing in their presentation. Clinicians and **care providers across systems need to be properly trained and supported** to explore distinct tools and provisions of care.

**ACCESS IS KEY**...FASD specialization is currently very limited in Hawai'i, and brain-imaging and neuropsychological testing are not always considered or covered by health plans. **Many adolescents and adults have gone without an early diagnosis.** When we accept there is a need, we can develop this capacity together.

**ALOHA IS AN ANSWER**...while Hawai'i may still be developing some new capacities, we have the “Aloha Spirit” that allows us to uniquely hold **compassion, curiosity, and community** at the center of our focus in caring for one another. When people get what they NEED they can THRIVE. → **NEXT PAGE**



1-Center for Substance Abuse Prevention (US). Addressing Fetal Alcohol Spectrum Disorders (FASD). Rockville (MD): Substance Abuse and Mental Health Services Administration (US); 2014. (Treatment Improvement Protocol (TIP) Series, No. 58.) Executive Summary. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK344248/>

2-Chung, D. D., Pinson, M. R., Bhenderu, L. S., Lai, M. S., Patel, R. A., & Miranda, R. C. (2021). Toxic and Teratogenic Effects of Prenatal Alcohol Exposure on Fetal Development, Adolescence, and Adulthood. International journal of molecular sciences, 22(16), 8785. <https://doi.org/10.3390/ijms22168785>

3-Hawai'i FASD Action Group. (2025). Hawai'i FASD Action 2025 Advisory Council Report: A Co-Managed System of Care for People with Fetal Alcohol Spectrum Disorders (January-June 2025). Prepared by Amanda Luning, LMHC, IECMH-E®, Executive Director. December 2025. Retrieved from [fasdhawaii.org](http://fasdhawaii.org).

4-McLachlan, K., Flannigan, K., Temple, V., Unsworth, K., & Cook, J. L. (2020). Difficulties in Daily Living Experienced by Adolescents, Transition-Aged Youth, and Adults With Fetal Alcohol Spectrum Disorder. Alcoholism, clinical and experimental research, 44(8), 1609-1624. <https://doi.org/10.1111/acer.14385>

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## When we ALL get what we NEED we can all THRIVE

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### WHY USE THE RIGHT DIAGNOSTIC FRAMEWORK?

**EARLY INTERVENTION**-the sooner intentional support happens, the better. Parent and family education can reduce shame and stigma and help families to accept and understand potentially needed supports. Healthy early relationships, quality nutrition, various therapies, and family care all create better long-term outcomes. Diagnosing clinicians can work closely with **Part C-Early Intervention** providers to support quality and appropriately tailored Individualized Family Service Plans that transition children with FASDs into lifespan supports.

SCAN ME!



**DISABILITY PROTECTIONS**-the provision under **HI Rev Stat § 333F-1 (2024)** holds that “an individual from birth to age nine who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described above, if the individual, without services and supports, has a high probability of meeting those criteria later in life”, supporting the importance of documenting prenatal alcohol exposure and fetal alcohol spectrum disorders even if not initially presenting as a developmental disability.

SCAN ME!



**MEDICAID WAIVER SERVICES**-a diagnosis later on in life can support “Complex Behavioral Health” and “Developmental Disability” needs that might not have been identified earlier in life, including services and provisions of care covered by the **Hawai'i QUEST Integration Section 1115(a) Demonstration**, meant to “enable the state to offer demonstration benefits that may not be available to all categorically eligible or other individuals.”

SCAN ME!



**CONNECT WITH YOUR LOCAL ADVOCATES TODAY**

### BREAK THE CYCLE

“Fetal alcohol spectrum disorders represent the intersection of complicated biological, family, community, and societal circumstances that increase risk for social inequity, intergenerational trauma, and health disparity.”<sup>3</sup>

### BUT THEY DON'T HAVE TO

Thriving happens when we change attitudes, use right approaches, make accommodations, and support **ACCEPTANCE**.

Shame and stigma have **NO PLACE...**

normalizing diagnosis supports earlier identification and better outcomes.

**ACCEPTANCE**  **ADVOCACY**

# FASD is a Kākou Thing

**HOLISTIC & SPECIFIC**-brain-based disorders are very complex, so quality and iterative assessment really help. Knowing how to approach development, daily living, education, financial management, employment, family and social **supports based on accepted functioning and needs**, changes outcomes across the lifespan.

**COST EFFICIENT**-while high-quality public awareness messaging can support healthier pregnancies, getting an early diagnosis also **reduces costly complex comorbidities** and can increase family involvement and self-advocacy.

**KEIKI TO KUPUNA**-we know FASD is a lifespan condition, but Hawai'i based projects suggests that FASD is multigenerational, especially when not diagnosed. Women with undiagnosed FASDs are at an **exponentially increased likelihood** of having a child with an FASD due to complex social and biological risk-factors.

**COMMUNITY-BASED**-nearly half of pregnancies in Hawai'i are unplanned<sup>2</sup> and national data suggests that one in twenty people could be affected.<sup>1</sup> **FASDs are not “going away” anytime soon.** Accurate epidemiological data on FASD diagnosis helps everyone to better understand how to develop education, care, and resources that **increase intentional focus across our communities** in different areas of health and wellness.



1-Centers for Disease Control (2024), Fetal Alcohol Spectrum Disorders (FASDs)-Data and Statistics on FASD, retrieved from: <https://www.cdc.gov/fasd/data/index.html>

2-Hawai'i Department of Health (2020) PRAMS-Unintended Pregnancy Fact Sheet, [https://health.hawaii.gov/fhsd/files/2020/10/Unintended-Pregnancy-Fact-Sheet\\_2020.pdf](https://health.hawaii.gov/fhsd/files/2020/10/Unintended-Pregnancy-Fact-Sheet_2020.pdf)

3-Flannigan, K., Pei, J., McLachlan, K., Harding, K., Mela, M., Cook, J., Badry, D., & McFarlane, A. (2022). Responding to the Unique Complexities of Fetal Alcohol Spectrum Disorder. *Frontiers in psychology*, 12, 778471. <https://doi.org/10.3389/fpsyg.2021.778471>

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