

Hawai'i FASD Action Group Executive Summary

"FASD Social Laboratory Project"

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Our Mission

The Hawai'i FASD Action Group's (HIFASDAG) primary mission is to raise awareness through education, advocacy, and research on the impact of Fetal Alcohol Spectrum Disorder (FASD) on individuals, their families, and the communities of Hawai'i.

About FASD

Fetal Alcohol Spectrum Disorders (FASD) are a spectrum of diagnosable conditions, ranging from the most serious Fetal Alcohol Syndrome (FAS), with a range of health conditions such as heart defects and visual and hearing impairments, to the often "hidden" lifelong neurological and neurodevelopmental disorders due to prenatal alcohol exposure. These can cause more subtle issues such as sensory sensitivities and other functional, social, memory, and communication impairments. **FASD is often undiagnosed or misdiagnosed.**¹

The effects of an FASD, especially when unidentified, significantly increase:

- School, behavioral, and learning challenges
- The likelihood of mental and health and substance use disorders
- Involvement in public safety and our court systems
- Vulnerability in unsafe situations and with unsafe people²

Our Project

Highly ambitious and the first of its kind in Hawai'i, the Action Group received a Grant-In-Aid (GIA) from the Hawai'i State Legislature through the Office of Community Services (OCS) in 2023, to explore the creation of a sustainable infrastructure for persons at-risk for FASDs.

After many years as an all-volunteer advocacy organization, the Action Group was looking to increase FASD knowledge, awareness, and support services in Hawai'i, and set out to explore screening, local data collection, and strength-based service modifications for providers. This summary includes data from the Final Report for OCS-GIA-23-87 to the State of Hawai'i and from the Evaluation Report prepared by The Catalyst Group.

What We Achieved

Objective 1: Train 100 Individuals in Hawai'i in FASD Awareness

210

Individuals
Trained

More than 210 individuals across the state were trained in general FASD awareness, and strength-based considerations for support services and care delivery.

Participants included:

- Staff from the Department of Education (DOE)
- Community Based Family Support and Employment Services
- Physicians, Substance Abuse Treatment Services, and other health service providers

Objective 2: Specialized Training and Screening

Because FASD screening is so complex, the Action Group contracted the former Substance Abuse and Mental Health Services Administration (SAMHSA) Center of Excellence specialist to train providers in the Life History Screen (LHS). This screen considers many factors of risk, including family, school, and employment as well as current and historical factors in daily functioning. Screeners and agencies also received ongoing consultation support from the trainer.

44

Trained in
Specialized
Screening Tool

129

Individuals
Screened

Two direct services agencies in Hawai'i participated in screening adults at potential risk for prenatal alcohol exposure:

- **Ages 17-61**
- **95% Female**
- **Pregnant/Parenting Women (PPW) Treatment Program:** 122
- **Employment Support Program:** 7

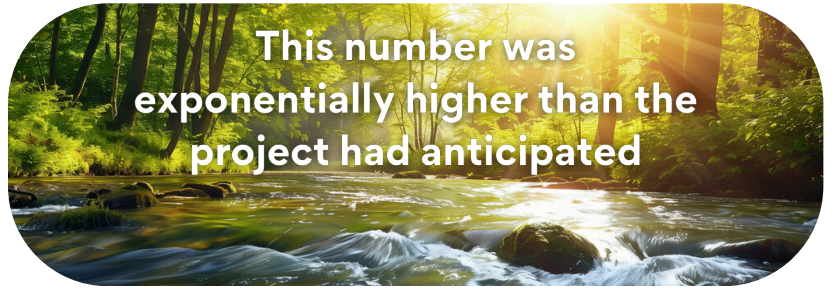


Objective 3: Support and Collect Data (...and pivot)

76%

Of Individuals Screened

Eligible for Modifications



With extremely high percentages of risk demonstrated *from the first month* of screening planned case-management services, care planning, and data collection were **OVERWHELMING**

The partners convened and decided to...

HO'ONALU

"go with the flow"

FASD informed-services were shifted directly into provider agencies

Individual level data collection was suspended due to limited infrastructure

Agencies began advocating for their clients long-term needs in the community

"The project has significantly influenced staff, increased their awareness and understanding of FASD."



"They now understand that FASD clients are not bad or broken, but that their brain works differently, and that their needs are different."

Focus Group Evaluation

What We Learned

Quality Relationships, Perverserance, and Flexibility are Key

Improved Client Relationships: Increased efforts, such as frequent check-ins and continuous follow-up supports with clients and employers, have strengthened relationships with FASD clients and the employers, leading to better retention. One staff noted, “it takes about 3 or 4 months to follow-up with them to see if they can stabilize in their job.”

Focus Group Respondent

“project staff learned to tailor their approaches, offering more detailed and supportive services to FASD clients, including breaking down tasks and solving problems step-by-step, therefore leading to more effective intervention strategies. Also learned the importance of extensive case coordination with various agencies and resources needed by FASD clients (e.g., adult mental health services, financial resources, etc.).”

Focus Group Evaluation



Experience, Expertise, and Ongoing Support are Critical



Dan Dubovsky, MSW
FASD Trainer/Specialist

“FASD: Issues to Consider”
4.0 out 4.0

Training Evaluation Score

The trainer “was a true expert on the topic, both from lived experience and from his professional work. I appreciate the concrete and clear examples he provided which made this presentation clear and easy to understand. I went away feeling that I had new information I could apply to my work immediately.”

Training Evaluation Feedback

Better Understanding: Training has helped staff understand FASD behaviors better (“better able to help clients feel safer and less judged”), resulting in improved therapeutic bonding and reduced client dropouts. One of the agency partners observed, “staff seem to be less likely to discharge clients due to noncompliance with their better understanding of FASD.”

Focus Group Evaluation

Moving Forward

Support Early Intervention and Community Awareness

“follow up with more on how to assist providers (pediatricians, social workers, therapists) with early identification.”

Training Evaluation Feedback

Expand Systemic Supports

“start with building a foundation, creating the ground work first. Advocate with social security, disability departments, human services, police department, probation and any agencies that FASD individuals need to interface with to establish relationships and convince why and how they need to work with and help FASD individuals.”

Focus Group Evaluation

“The partners also wished that they had more time and resource to advocate for FASD issues at the macro level and described how they ran into restrictive policies that they wished they had more time to address and advocate for the clients.”

Focus Group Evaluation

FASD IS A KĀKOU THING

Providers did the best they could and:

highlighted the need for extensive community involvement for the success of each FASD client and the challenges of getting everyone “on the same page.”

Focus Group Evaluation

MAHALO TO OUR PARTNERS

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Please go to: <https://fasdhawaii.org/resources/> (Hawai'i Based Resources and Information) for downloadable PDF



1 National Institute of Alcohol Abuse and Alcoholism (2023) Alcohol's Affect on Health-Fetal Alcohol Exposure; <https://www.niaaa.nih.gov/publications/brochures-and-fact-sheets/understanding-fetal-alcohol-spectrum-disorders>

2 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>

3 Grant, T. M., Novick Brown, N., Graham, J. C., Whitney, N., Dubovsky, D., & Nelson, L. A. (2013). Screening in treatment programs for Fetal Alcohol Spectrum Disorders that could affect therapeutic progress. *International Journal of Alcohol and Drug Research*, 2(3), 37–49. <https://doi.org/10.7895/ijadr.v2i3.116>