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**Exploring an Appropriate Brain-Based Fetal Alcohol Spectrum Disorder (FASD)  
Informed Services Infrastructure for Hawai'i**

**“FASD is a Kākou Thing”**

**Performance and Evaluation Report**

**Year One of Three: Oct. 2024 to Sept. 2025**

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Prepared for the **Hawai'i Fetal Alcohol Spectrum Disorders Action Group (HIFASDAG)**

O'ahu, HI

Submitted October 2025/Finalized December 2025

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## PREFACE

Leadership in Hawai'i understands interconnectivity in a different way than perhaps other places. We recognize that connection to source isn't to be taken lightly, as it is both powerful and fragile. We can have a mindset of abundance and generosity, whilst also respecting reciprocity and balance.

As a spectrum of conditions, Fetal Alcohol Spectrum Disorders (FASD) often present more questions than answers. Finding precision around diagnosis, clarity in need and care, and where appropriate resources might be sourced from, all while simultaneously supporting prevention, can feel like a monumental task. ***The question then begs, is the task worth the taking?***

When children are born exposed to alcohol...to illness, to stress, to poverty...not just their brain and bodies suffer...everyone suffers. FASD by nature of its complexity poses an existential question about the way that we "understand" behavior. We like to have "answers" to know in a way that we consider to be scientific and based on evidence and data, but even with what we believe these things to be, ***objectivity is never without underlying values.***

We are all living with the vulnerable brains and bodies we were born with and developed in our early childhood, yet NONE of us chose any of our exposures and experiences...so what then does that mean? For the Action Group it is from the premise of ***everyone deserves to have safety, belonging, and opportunity***, even if they don't know how on their own, that we develop our values.

The values of the people doing this work center around ***"compassion, curiosity, and community."*** Kindness is the basis for all our endeavors in combination with high-quality inquiry while holding that one is not more important than the other. This kindness extends to our colleagues, our partners, our families, our skeptics and, of course, each other, in our sincerely "kākou" effort.

The group of people that are involved in this work are extraordinary. In the true sense of "extraordinary." Our contractors, Board, volunteers, advocates, and champions, are some of the most fierce and brilliant folks around...and they are each humble enough to know they are all ***just people helping people.*** We are each just as vulnerable to the world around us as anyone else. We get sad and scared and confused, just like anyone else, and we are proud professionals who share this openly with one another. We commit to transparency, regular reflective practice, exploration of our biases, our fears, and our relationships, and to gracious celebration of the joys of doing good work together.

So, is it worth it? **We sure think so.**

Looking forward to you joining us next year, and on the journey ahead, for an exciting paradigm shift, and working towards a world that is kinder, more connected, and ***possible for everyone.***

Aloha nui,



Amanda

## EXECUTIVE SUMMARY

FASD is complicated, affecting the brain and other organ systems, leading to diverse and sometimes unpredictable combinations of physical, cognitive, and behavioral conditions and challenges. This complexity is compounded by the lack of a specific medical test for diagnosis, the hidden nature of many of the symptoms, the difficulty in confirming prenatal alcohol (and other substance) exposure, and high rates of co-occurring conditions persisting into adulthood, particularly among women (Flannigan et al., 2022). In addition, the stigma associated with FASD can prevent help-seeking or proper diagnosis and there remains a shortage of specialized professionals and clinics, especially in rural areas.

Given these complexities, the work to shed light on and respond to FASD has been slow and difficult, despite the commitment and expertise of those championing the issue in Hawai'i, at least since 2016--the time of initial convening of the Hawai'i Fetal Alcohol Spectrum Disorders Action Group (HIFASDAG). The passing of Act 192 in 2023, however, brought new energy to these efforts in the form of funding for a three-year project. Primary goals of this project as awarded to the HIFASDAG include **increasing public awareness, FASD diagnoses, and support of the FASD community and beginning the creation and development of a co-managed system of care.**

These project goals are consistent, not only with the aims of the State, but with the recommendations of the former National Organization on Fetal Alcohol Syndrome (NOFAS) Policy Center,<sup>1</sup> including:

- creation of a state FASD Task Force and state plan
- use of evidence-based FASD behavioral interventions
- provision of trained mentors, housing assistance, and vocational training and placement for adults with FASD
- provision of resources and supports for affected parents, caregivers, and professionals
- integration of FASD-informed care into existing programs and services
- decrease the recidivism rate for individuals with FASD in the justice system through regular screening and assessment, and the training of police, judges, and prison staff
- and reduce waste by increasing the effectiveness of FASD programming

It is this work, as conducted in the project's first year, that is under study here, with attention to alignment with the Goals and Evaluation Blueprint and adherence to the Projected Timeline. (See Appendix, pages 23 on.) Functionally, this includes the

- convening of an **advisory body**, comprised of diverse specialists and community representatives
- development and implementation of a non-stigmatizing **public campaign** (here, via digital platforms)

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<sup>1</sup> now the Policy and Training Center of FASD United, a nonprofit dedicated to FASD advocacy and policymaking

- implementation of a **statewide workforce survey** to advance screenings and the diagnostic process, critical for identification and response (via subcontract)
- provision of multiple **targeted trainings** to expand specialized education
- development of multiple **partnerships** in support of further training (here, including certification in infant mental health)
- and the **beginning development of inter-agency care teams** attentive to prevention, early identification, and lifelong support across various sectors.

Key metrics for this evaluation include

- general schedule compliance and task completion rates
- stakeholder satisfaction with deliverables
- and (though the responsibility of the Board and not a part of this study) budget compliance and resource efficiency.

Beyond these metrics for the functional deliverables, however, the project is ultimately one of shifting public perception--away from shame and blame and towards responsibility and compassionate response--so as to ready the State for a different system of care. In this sense, the state-wide survey results can be viewed as a sort of baseline for awareness and level of initiative, the public awareness campaign as a call for change and re-shaping of the FASD narrative, and the targeted trainings as a necessary step towards the skills that will be required for an informed and effective workforce.

**In this work, the project has met or exceeded its stated targets for year one and is on track for the same for the work ahead.**

## **RECOMMENDATIONS**

It is recommended that the project bolster its community representation, especially at the advisory level; better track the number of trainings provided and trainee feedback (necessary for identifying gaps); solicit additional presentation feedback; seek additional support to provide further FASD-informed specialist training; and consider the addition of cost and qualitative analyses to strengthen evaluation.

## **DISCLAIMER**

This report is for the intended purposes of use by HIFASDAG only. The views expressed are those of the evaluator, based on professional judgement and information made available at the time. While every effort was made to be accurate and complete, there may be errors or omissions.

## **ACKNOWLEDGMENTS**

Support for this project was supported by community donations, multiple grants and public partnerships, and primarily through the Office of Planning Policy and Program Development (OPPPD) with funding from legislation championed by Senator Joy San Buenaventura and Representative Terez Amato.

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## INTRODUCTION AND BACKGROUND

This project was developed in response to Hawai'i Act 192,<sup>2</sup> allocating funds to the Hawai'i State Department of Health to establish and administer a three-year pilot program to implement a co-managed system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders (FASD). Key components, as planned, include a public awareness campaign, cross-agency coordination for better response, and the eventual development of longer-term supports in the areas of FASD care, treatment, and prevention.

Key to implementation of Act 192 is the Hawai'i Fetal Alcohol Spectrum Disorders Action Group (HIFASDAG). This group was started in 2016 as a research and awareness collaborative, became a fiscally sponsored project of FASD Communities in 2018, and was officially incorporated as a 501(c)3 nonprofit in 2020.

### Mission and Vision:

- HIFASDAG Mission: 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 .
- HIFASDAG Vision: Fetal Alcohol Spectrum Disorder (FASD) invisible no more.

### Key Organizational Milestones:

- Hosting statewide conferences (e.g., "FASD: Interventions for an Invisible Disability" in 2017 and "FASD: Improving Outcomes Across Systems of Care" in 2019)
- Increasing its volunteer membership to over 200
- Receiving a state Grant-in-Aid to study FASD prevalence and needs in 2022, laying a foundation for future study
- Hiring of their first Executive Director in 2024--the person charged with coordination of this effort while continuing the group's work on policy, awareness, and support.

## RATIONALE & LOGIC

Fetal Alcohol Spectrum Disorders are highly prevalent in Hawai'i , with estimates suggesting that they affect 1:20 live births, similar to the national prevalence.<sup>3</sup> Currently, an estimated 70,793 people could be impacted, though just a minority are diagnosed.<sup>4</sup> The treatment and care of individuals with FASD can involve multiple systems on the federal, state, and local levels, including health (especially behavioral), child welfare, criminal justice, and disability care. The

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<sup>2</sup> SB318 2023: A Bill for an Act Relating to Fetal Alcohol Disorders was introduced on Jan. 19, 2023 and became Act 192 when signed into law on July 3, 2023.

[https://www.capitol.hawaii.gov/slh/Years/SLH2023/SLH2023\\_Act192](https://www.capitol.hawaii.gov/slh/Years/SLH2023/SLH2023_Act192)

<sup>3</sup> <https://nofaspolicycenter.org/wp-content/uploads/2023/06/FASD-in-Hawaii.pdf>

<sup>4</sup> *ibid*

total lifetime costs have been estimated to be over \$2 million per affected individual;<sup>5</sup> for Hawai'i , amounting to \$870 million annually when considering health care, special education, corrections, residential support, and lost productivity.<sup>6</sup>

FASD, however, is preventable and much of the associated costs--to systems, families, and individuals--can be reduced with the implementation of effective public health policies and programs. At the state level, these need to span prevention, early identification (screening, evaluation, and training), and intervention.

## INITIATIVE DESCRIPTION

The project has been charged with the creation, development, and testing of a co-management system for diagnosing and coordination of care provision for persons with FASD. Ultimately, this will be achieved by coordinated multidisciplinary response in the areas of prevention and intervention involving primary care providers, behavioral health specialists, and FASD specialists across the state. In accordance with Act 192, outcomes for an estimated 70,800 persons affected are thereby expected to be improved.

To achieve this, the project laid out five primary objectives.

- **Objective 1. Conduct a landscape assessment on existing FASD awareness, integration, and action nationally, internationally, and in Hawai'i .**
- **Objective 2. Perform comparative analysis on screening, assessment, identification and/or diagnostic protocols for FASD in Hawai'i .**
- Objective 3. Develop cross-sector entry points to screening and informed services for individuals affected by FASD.
- Objective 4. Prepare systems and policies to support care and informed adaptations to services.
- Objective 5. Determine a sample group to monitor and evaluate their experiences within their systems of care, including their primary care provider, FASD specialist and other service providers.

Of these, only the first two objectives apply to year one, though gains were made also in the area of objective three. (See *Appendix, Goals and Evaluation Blueprint and Projected Timeline, pages 23 on.*)

## EVALUATION FOCUS & METHODS

As a new project, there was much to be done--from management of legalities and creating a structure for board governance, to attending to resource development, strategic planning, and impact assessment--even as the project had yet to establish its identity. Though all these efforts are touched on here, the primary focus is on alignment of the work with the Goals and

<sup>5</sup> <https://aspe.hhs.gov/sites/default/files/documents/cc4124633f39ba9b707dcbcdc9725063/state-responses-to-fasd.pdf>

<sup>6</sup> <https://nofaspolicycenter.org/wp-content/uploads/2023/06/FASD-in-Hawaii.pdf>

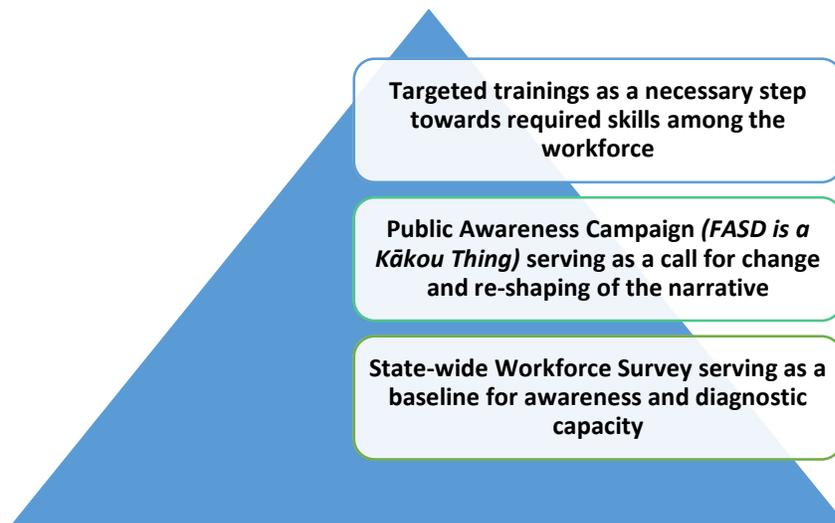
Evaluation Blueprint and adherence to the Projected Timeline (designed to flex, in response to anticipated change).

Functionally, this includes the

- convening of an **advisory body**, comprised of diverse specialists and community representatives (Objective 1)
- development and implementation of a non-stigmatizing **public campaign** (here, via digital platforms) (Objective 1)
- implementation of a **statewide workforce survey** to advance screenings and the diagnostic process, critical for identification and response (via subcontract) (Objective 1)
- provision of multiple **targeted trainings** to expand specialized education (Objective 2)
- development of multiple **partnerships** in support of further training (Objective 2)
- and the beginning development of **inter-agency care teams** attentive to prevention, early identification, and lifelong support across various sectors (Objective 3).

Key metrics include general schedule compliance and task completion rates, stakeholder satisfaction with deliverables, and (though the responsibility of the Board and not a part of this evaluation study) budget compliance and resource efficiency. *(Note: It is suggested that the project include some sort of fiscal analysis, e.g., cost-utility, to help provide a clear metrics of the project’s clear costs and facilitate future planning, as it is known that a lot of the work was completed with the support of uncompensated advocates and volunteers).*

Beyond these metrics and the functional deliverables, however, **the project is ultimately one of shifting public perception--away from shame and blame and towards responsibility and compassionate response--so as to ready the state for a different system of care.** In this sense, the state-wide survey results can be viewed as a sort of baseline for awareness and level of initiative, the public campaign as a call for change and re-shaping of the FASD narrative, and the targeted trainings as a necessary step towards the skills that will be required for an effective workforce.



Conceptualization: Key components

## OBJECTIVE 1. ADVISORY COUNCIL

One of the first tasks was the convening of a high-level Advisory body, comprised of experts in the fields of behavioral and developmental disabilities, FASD, social services, business, law, and community organizing. *This included support from the Board of the HIFASDAG and a specially recruited Advisory Council.*

### HIFASDAG Board of Directors (2025):

- Alan H. Shinn, MSW; former Executive Director for Coalition for Drug-Free Hawai'i
- Kenichi "Ken" Yabusaki, PhD; retired biochemist and author
- Stephanie W. Batzer, Esq., LSW; former Court Appointed Special Advocate and Volunteer Guardian Ad Litem
- Jane Onoye, PhD; Associate Professor, Research Division of the University of Hawai'i JABSOM Department of Psychiatry
- William "Bill" Kumagai; Public Sector Strategist/Consultant
- Ginny Wright; Family and Community Advocate
- Arlina J. Wong; Acumen Fiscal Agent

### Advisory Council (January 2025-June 2025):

- Amelia Kyewich-Kaneholani, M.Ed; Program Specialist, Hawai'i State Council on Developmental Disabilities
- Darlyn Chen Scovell, CSAC, MA; FASD Advocate
- Eri Rodrigues, LCSW, IMH-E®; Behavioral Health Specialist with Kokua Kalihi Valley Comprehensive Family Services
- Miki Kiyokawa, MD; addictions medical specialist, Queens Medical Center
- Nia Alfulaij, PhD, MS, MACP; neuroscientist, University of Hawai'i at Manoa Associate Researcher
- Valerie Rose, MPH, RDN; Program Specialist, Hawai'i State Office in Primary Care and Rural Health.
- Ann Yabusaki, PhD, LMFT; HIFASDG founder, psychologist and FASD specialist

**ORGANIZATIONAL DEVELOPMENT:** In this first year, the Board responsibilities included re-defining the organization's mission and vision, deciding on primary goals, managing resources (e.g., funds, commitments, and partnerships), overseeing operations, and developing and approving the overall Strategic Plan. Towards these ends, the Advisory Council met monthly from January 2025 on, excluding March (allowing for the Seattle conference), with committees convening in between. All members played vital roles in getting the project up and running and positioned for success (*the Advisory Council Report, without attachments, begins on page 36*).

Full 2025 Advisory Council Report available at <https://fasdhawaii.org/fasd-resources/>



*Dr. Ann Yabusaki, HIFASDAG Founder and Project Advisory Council member  
and Amanda Luning, Executive Director (Feb. 2025)*

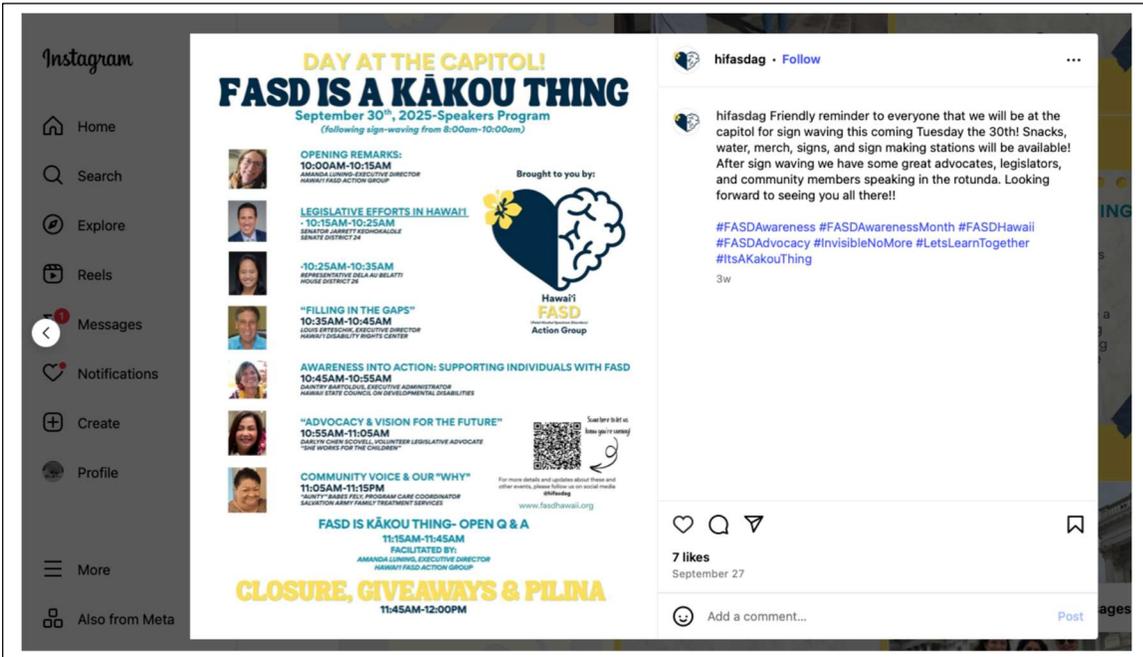
### **OBJECTIVE 1. PUBLIC AWARENESS CAMPAIGN (YEAR ONE)**

The project wasted no time in creating newsletters, publicizing events (*e.g., awareness sign waving, particularly during September, International FASD awareness month*), updating their website (themed “FASD is a Kākou Thing”), updating social media sites, and pulling these together by way of Linktree ([linktree.com/hifasdag](http://linktree.com/hifasdag)).

This ongoing theme, of FASD being a “**kākou thing**,” emphasized community and shared responsibility as an **antidote to stigma**--an idea that was promoted by both the HIFASDAG and the state Department of Health and that characterized all communication and materials. To facilitate access to information and needed linkages, the website (<https://fasdHawai'i.org>) included dropdowns for issue involvement, community and professional resources (*e.g., legal and advocacy, perinatal supports, parenting resources, reading materials, etc.*), contact information, and ways to donate to the cause.

Through these platforms and with this messaging, the project provided targeted public awareness and a steady supply of professional educational materials about FASD, while at the same time facilitating connection to developing state and community resources to assist affected individuals and families. Not only did this promote interchange among providers, persons affected, and policy-makers; this campaign served also to pave the way for greater attention to FASD prevention, identification, diagnosis, intervention, and treatment services.

This was achieved, in part, through messaging intended to 1) help shift the focus from blame (particularly of birth mothers) towards support and understanding of those affected and 2) from preoccupation with diagnosis (though critical) to the more pressing matter of attention and care. (See event promotion example below.)



Instagram promotion of a “Day at the Capitol” held during FASD Awareness month, Sept. 2025

**CAMPAIGN PARTNERS:** To better reach key demographics, partnerships were developed with

- the Hawai’i State Department of Health (DOH)
- Papa Ola Lokahi (*assisted with campaign approach, language, and content and with sharing of posts*)
- Maui Behavioral Health Resources (MBHR) (*assisted with neighbor island public awareness*)
- Hawai’i Community Foundation (*provided seed grant to help reduce mental and behavioral health stigma*)
- and Harvard College (*provided a small grant supporting media*).

**Additionally, Crystal Clear Communications and Pacific Media Group** were contracted to support with the website, marketing, media opportunities, and communication.

**CAMPAIGN EVALUATION:** Though the influence or impact of this aspect of the project are still to be measure (i.e. particular outcomes) the project did have mechanisms in place for estimating interest in the digital content (i.e., audience reach and engagement). This was tracked by way of “views” and “likes”—topping 4K in September 2025 alone—the month of state-wide, national, and international FASD Awareness.



Example of tracking of views and likes

**OBJECTIVE 1. STATEWIDE WORKFORCE SURVEY (YEAR ONE)**

In early 2025, the project took its first steps to assess the readiness of providers to screen for and/or diagnose FASD--this, by way of a landscape survey. This involved planning for the survey scope, preparation of a tentative list of professional networks so as to reach key provider groups, and the hiring of an independent surveyor, Grove Insight--eventually charged with the goal of reaching over 200 providers from across the state, including Lāna`i and Molokai.

Titled "Views of FASD among Healthcare Professionals in Hawai'i ," Grove Insight released a 36-item on-line survey to professional networks across the state. This survey was accessible, with reminders, from Feb. 5 to March 5, 2025. Response time was stated at an average of 13 minutes and, to incentivize participation, a "lucky drawing" was offered (with \$100 gift cards later provided to four randomly selected winners).

## SURVEY INSTRUMENT & RESPONSES

The following provides the Statewide Workforce Survey narrative and the 36 items (minus the response options), followed by key responses (in blue).

Aloha! To better understand the professional knowledge and education in prenatal alcohol exposure in Hawai'i, we are asking you to complete this short, confidential survey. We are specifically asking to hear from providers, including social workers and community health workers, either in primary care or mental health. We also invite providers who focus on families including child welfare and public safety workers. All individual responses will remain confidential.

Qualified respondents who complete the survey will have the opportunity to enter a lucky drawing to win one of four \$100 gift cards. Your kōkua is important and valued. We would appreciate it if you would pass this survey link on to others who meet the definition above, so they can take this survey, too.

1. Please choose the area or areas that best define where you deliver services.  
Predominantly Oahu-greater Honolulu area followed by Oahu-rural (Westside/North Shore)
2. Please share your most current professional field of practice.  
Predominantly MD/DD/APRN followed by licensed master's level Mental Health
3. How many years have you have been working in your field?  
Predominantly 21+ years followed by 0-5 years and 11-20 years
4. Tell us a little about the individuals and/or families that you serve.  
Predominantly adolescents (ages 13-17) and young adults (ages 18-25)
5. How much would you say you know about the potential effects of alcohol use on a fetus during gestation/pregnancy?  
Predominantly Some followed by A great deal
6. Have you ever heard of the term "Fetal Alcohol Spectrum Disorders" or "FASD"?  
Yes (89%)
7. Based on what you know, how serious of an issue or problem do you think Fetal Alcohol Spectrum Disorders or "FASD" is in Hawai'i?  
Very (44%) followed by Somewhat (43%) serious
8. Based on what you know, how prevalent or common do you think Fetal Alcohol Spectrum Disorders or "FASD" are in Hawai'i that are either diagnosed or undiagnosed?  
Very (36%) followed by Somewhat (35%) common
9. Where did you learn about Fetal Alcohol Spectrum Disorders (FASD)?  
Mainly Formal schooling (68%) followed by Training in the community (34%)
10. Was your learning connected to an institution or organization based in Hawai'i or in another location?  
Mainly Hawai'i-based (60%)

11. If your learning was Hawai`i-based, has there been continuing education or resources available from that source?  
 Not sure (40%) followed by No (36%)
12. If applicable, how often do you apply your knowledge of FASD to your direct practice with individuals and families?  
 Predominantly rarely (49%)
13. How important is it that children in Hawai`i be screened for FASD, Fetal Alcohol Syndrome Disorders?  
 Very important (77%)
14. How important is it that adults in Hawai`i be screened for FASD, Fetal Alcohol Syndrome Disorders?  
 Very (56%) followed by Somewhat (31%) important
15. Are you familiar with any screening/assessment tools that are used for the identification or diagnosis of FASD?  
 No (64%)
16. How comfortable are you in screening, assessing, and/or diagnosing FASD?  
 Not comfortable at all (35%)
17. What, if anything, about your education, training, or personal experience makes you feel comfortable screening and/or diagnosing FASD?  
 Mainly formal training and work experience with affected populations
18. What education, training, resources or support would make you feel more comfortable screening, assessing and/or diagnosing FASD?  
 Training, both basic and specialized, particularly on use of screening tools; updated tools; webinars, workshops, certification programs--hybrid or virtual; specialty clinics and resources; and preferably free CEU and CME training
19. Have you ever administered a tool to screen for Fetal Alcohol Spectrum Disorders (FASD)?  
 No (63%)
20. If you have ever administered a screening tool, have you done so while working in Hawai`i?  
 Yes (65%)
21. If you have ever administered a screening tool, please share the name(s) of the screening tool(s) either you have administered or are familiar with.  
 BRAIN, LHS, SBIRT, 4Ps, others
22. Have you ever diagnosed or participated in a team diagnostic evaluation for an individual with an FASD? (Please check all that apply)  
 No (70%)
23. If you diagnosed or participated in a diagnostic team process, have you done so while working in Hawai`i?  
 Yes (63%), No (37%)
24. If, you have participated in a FASD diagnostic evaluation for an individual in Hawai`i with FASD (for any age group), please share the name of the team/practice and/or organization where you did so.  
 Queens, Kapiolani, DOH CAMHD, DOE, PATH Clinic, others

25. Do you know of any colleagues/team members in Hawai'i who administer screenings and/or assessment/diagnostic tools for FASD?  
No (42%)
26. Have you ever referred any individual you have worked with for FASD screening or diagnosis in Hawai'i?  
No (73%)
27. Have you ever worked with any individuals who have received a screening for FASD from an entity/provider outside of Hawai'i?  
No (58%)
28. Have you ever worked with any individuals in Hawai'i who have received a formal diagnosis of Fetal Alcohol Syndrome (FAS) or Alcohol Related Birth Defects (ARBD)?  
No, not to my knowledge (67%)
29. If, yes, did that person receive this diagnosis in Hawai'i (FAS/ARBD)?  
Not sure (72%)
30. What are some of the barriers or challenges that you believe could prevent people from getting screened for Fetal Alcohol Syndrome in Hawai'i?  
Lack of familiarity, rare application of FASD knowledge, inadequate or dated training, lack of attention to the benefits of screening
31. How interested are you in receiving more training or resources to help screen and diagnose Fetal Alcohol Syndrome?  
Somewhat (32%), Very (30%), Extremely (28%) interested
32. Is there anything you would like to add about increasing training, education, and professional awareness in prenatal alcohol exposure and/or screening, identifying and diagnosing FASDs in Hawai'i?  
Need good, evidence-based assessments, credit to the Action Group
33. Gender  
Predominantly female (81%)
34. Race/Ethnicity (Check all that apply)  
Predominantly White, followed by Asian and Native Hawai'i an
35. If you are interested in being part of the conversation on how to increase awareness and training around Fetal Alcohol Syndrome in Hawai'i, please provide your contact information below.  
77 replied
36. To be entered in the drawings for a gift card, please provide your email address and phone number so we can reach you if you are a winner of the lucky drawing for a \$100 gift card!  
131 replied

Thank you for taking the time to share your voice and experience with us. Your feedback is incredibly valuable. All responses will be kept confidential and analyzed only in the aggregate for research purposes. Mahalo for your kōkua!

**DEMOGRAPHICS:** Respondents were predominantly white or Asian, female, and professionals in either behavioral health (48%) or primary care (39%), with over half reporting 11 to 21 or more years of work in their respective fields. Though Maui/Moloka`i/Lāna`i, Hawai`i Island, and Kauai were represented, most respondents were providing care on Oahu.

**PRIMARY FINDINGS:** Results from the 210 providers who responded revealed that

- many believed that FASD was extremely or very common in Hawai`i (44%), particularly those working in behavioral health
- and the majority thought that screening for FASD was very important for children (77%), as well as adults (56%), suggesting that they recognized the negative consequences of FASD under-identification and misdiagnosis.
- Still, only 34% of respondents described themselves as “familiar” with screening tools and only 5% as “very comfortable” with screening or diagnosis.

Overall, these findings suggest significant structural barriers to maternal and child healthcare access across the state, with stigma preventing help-seeking and hindering or delaying treatment (Luning, 2025)<sup>7,8</sup> and likely complicating providers’ interest in and ability to secure training and supports.

This information was disseminated by way of special presentation by Lisa Grove to the Advisory Council (March and April 2025) and later more widely (May 2025), alongside an analytic report drafted for internal use.

## **OBJECTIVE 2. COLLABORATIONS & PARTNERSHIPS (YEAR ONE)**

Training has been a primary focus of year one, alongside resource development in support of this training. Beyond the Office of Planning, Policy & Program Development (OPPPD) grant, covering daily operations and implementation of the state-wide survey, the project additionally entered into contract with:

- the State Department of Health, Maternal and Child Health Branch, for the provision of a three-session Home Visiting FASD Training Series (July through Aug. 2025; now completed)
- and Maui Youth & Family Services, Sentry Malama Na Keiki Initiative, to support the mental health needs of children directly impacted by the Aug. 2023 wildfires (May 2025 through April 2026; providing four in-person and four virtual sessions with open consultation follow-up).

Though tailored to organization and participant needs, these “FASD is a Kākou Thing” trainings generally covered

- the basics of prenatal alcohol exposure (PAE), fetal alcohol spectrum disorders (FASD), and the lifespan effects on individuals and their families

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<sup>7</sup> unpublished manuscript

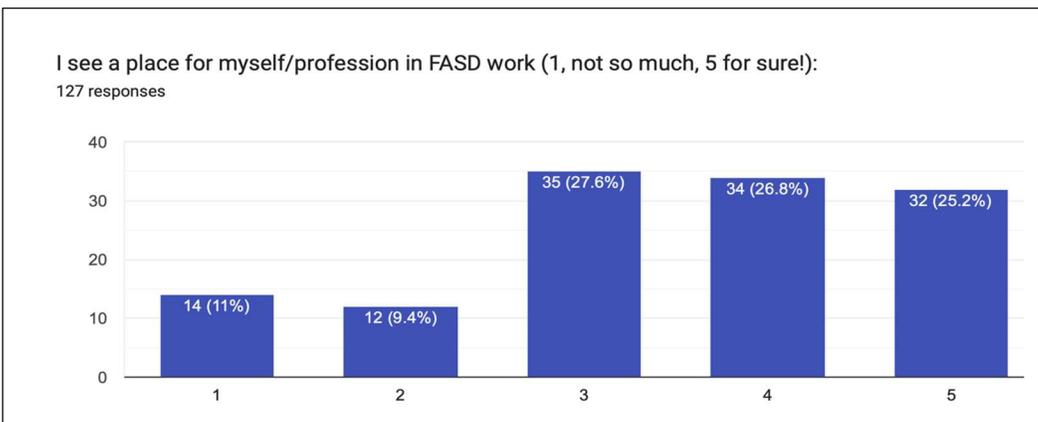
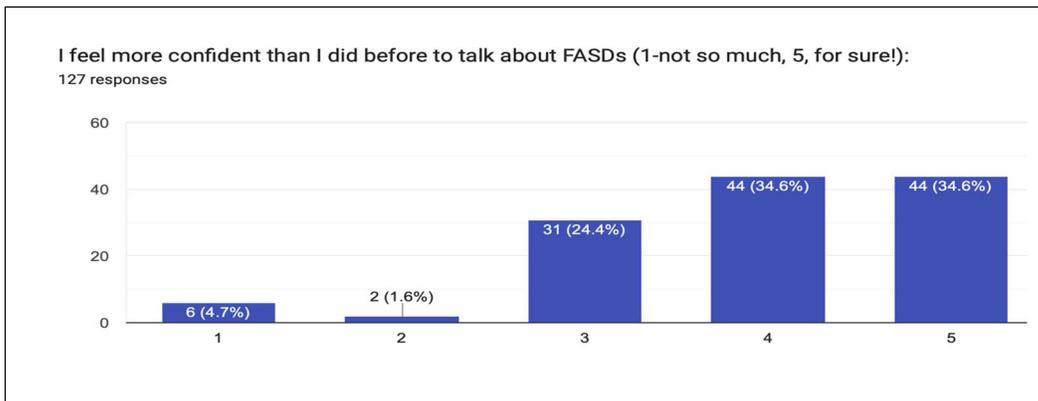
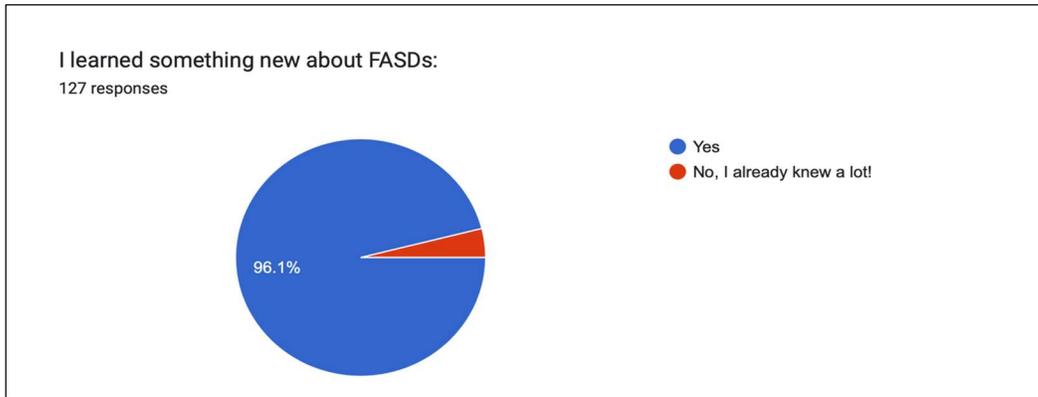
<sup>8</sup> A full copy of the Grove Insight survey report may be made available upon request.

- the typical behavioral presentations of people affected by FASDs and how these intersect with systemic response to those behaviors in the community (“DSW Continuing Education and Professional Development”)
- and systemic considerations that are unique to Hawai‘i around screening, assessment, diagnosis, and FASD-informed care and service delivery.

In addition to these trainings, the project and its representatives were involved in an array of conferences and gatherings--sometimes for the purpose of delivering presentations, often for the purpose of building relationships and for the “kākou” coalition (See table below for a sampling [not comprehensive] of FASD community engagement over the year.)

<b>Conferences. Trainings</b>				
Month/Year	Event	Organization.Sponsor/Location	Purpose	Numbers reached/Worker type
Aug-24	AANHPI Trauma Informed Care & Other Services**	Univ Hawaii, Lotus Project (O‘ahu)	Advocacy/Public Awareness	40+ registered attendees
Oct-24	AEPS Early Childhood Conference (2 days)***	DOE/DOH (statewide)	Public Awareness	100+ registered attendees
Nov-24	Training on Historical and Systemic Trauma/Oppression (2 days)**	Racial Equality Institute, Maui	Relationship Development	25+ participants
Jan-25	State of Reform Health Policy Conference**	Statewide	Relationship Development/Public Awareness	100+ registered attendees
Feb-25	Annual Conference (2 days)***	American Academy of Family Medicine-Hawaii Chapter (statewide)	presentation, networking	60+ physicians
Mar-25	9th Annual FASD Research Conference (3 days)***	FASD United, Seattle, WA	Abstract Presentation/Relationship Development	400+ registered attendees
Apr-25	Addictions Conference*	UH Manoa, School of Medicine, Dept. of Psychiatry (statewide)	Relationship Development	50+ registered attendees
25-Apr	Hawaii Disability Rights Center*		Training	15+ disability rights advocates
25-Apr	Transitional Family Homes Program*	Child and Family Services	Training	8+ foster family couples
Jul-25	Children with Special Healthcare Needs Branch Strategic Planning***	DOH (statewide)	Advocacy/Public Awareness	60+ systems leaders
Jul-25	'Aha Wellbeing Summit (2 days)***	Papa Ola Lokahi (statwide)	Public Awareness/Relationship Development (500+ in attendance)	400+ registered attendees
Jul-25	Annual Probation Conference***	First Circuit Court (statewide)	Training (120+ in attendance)	120+ probation officers, judges, attorneys
Aug-25	Stakeholders Meeting - Early & Periodic Screening, Diagnostic, & Tx***	MedQuest/DOH (statewide)	Presentation	25+ early intervention providers
Aug-25	Hawaii Pacific University***	Undergraduate programs (O‘ahu)	Guest Lectures	12+ SUD, mental health, public safety providers
Sep-25	Pūkūkahī Recovery Conference***	Windward Community College (O‘ahu)	Public Awareness	100+ registered attendees
Sep-25	FASD United Impact Week (3 days)***	FASD United, Washington, DC	Legislative Advocacy/Relationship Development	25+ states represented
Sep-25	Ola Pono o Kaua‘i: An Exploration of Rural Mental Health Through the Lifespan***	Kaua‘i Rural Health Association, Kaua‘i	Public Awareness	50+ registered attendees
Sep-25	Ho‘ohana: Hawaii Island Early Childhood Conference***	Multiple Sponsors, Hawaii Island	Public Awareness	150+ registered attendees
Sep-25	Day at the Capital***	Hawaii State Capital Building (O‘ahu-neighbor island representation)	Rally, Advocacy, Press Conference/Public Awareness	20+ advocates attended
<b>Partnerships</b>				
Oct 2024 to Mar 2026	Mālama Na Keiki*	Maui United Way Sentry (Maui)	*FASD is a Kākou Thing* online/in-person Training Series	8 trainees
July to Aug 2025	Maternal Infant/Early Childhood Home Visiting (MIECHV) Series*	DOH (statewide)	*FASD is a Kākou Thing* Training Series for Homevisitors	22 participants x 3 trainings (series)
Ongoing	JABSOM/Project ECHO*	Univ Hawaii at Manoa (O‘ahu)	Guest Lectures (Child & Adolescent Psychiatry, Pediatrics, Family Medicine)	Ongoing (avg. 10 attendees/per)
	*Online **In-Person ***In-Person w/materials distributed			

**TRAINING EVALUATION:** Feedback was gathered on trainings delivered April through Oct. 2025 by way of a 6-item on-line questionnaire, capturing responses from 127 trainees. (Note: The number of trainees opting to forgo the questionnaire is unknown.) This feedback shows **high satisfaction** with the training content with 96% of respondents reporting having learned something new, 69% reporting increased confidence to talk about FASD, and 52% stating that they saw a place for themselves in FASD work. (See ratings below.)



### HIGHLIGHTS



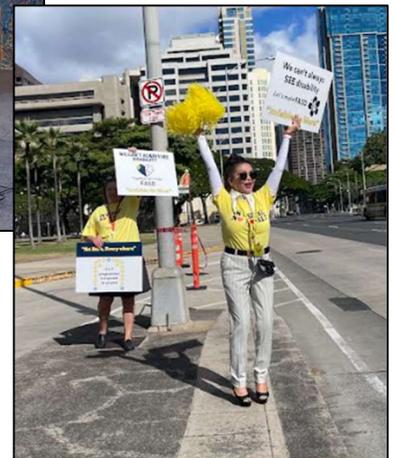
ABOVE: Amanda Luning, Executive Director  
Hawai'i Academy of Family Physicians Annual Conference



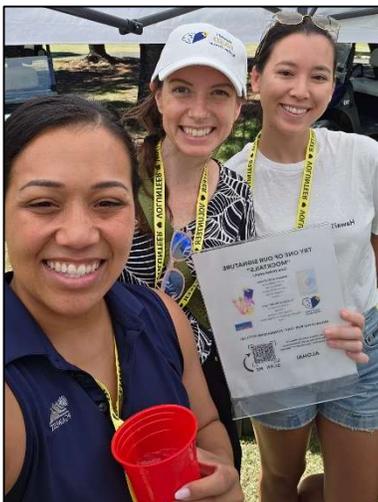
LEFT/BELOW: Advisory Council Members Darlyn Chen Scovell, Dr. Nia Alfulaij, and Amanda Luning, FASD United Impact Week Conference, Washington DC, FASD



LEFT: FASD Action Group members and Micheal "Keawe" Anderson, current Board Chair of FASD United, FASD Awareness Month



ABOVE: FASD Awareness "Day at the Capital" activities Daintry Bartoldus of the Hawai'i State Council on Developmental Disabilities and Darlyn Chen Scovell participate in sign waving.



LEFT: Charlee Tanuvasa (FASD Community Trainer), Amanda Luning (ED), and Erin Rupert (HI FASD Action-Executive Assistant) at the "Celebration of Aloha" (Dry Fundraiser)

Lastly, community work included the organization’s involvement in the 13<sup>th</sup> annual “Celebration of Aloha” golf tournament and concert held in Sept. 2025 at the Mid-Pac Country Club, with proceeds benefiting Malama O Nā Keiki (Care for Hawai’i Neonates). This partnership supported ‘dry’ fundraising and socialization with the Action Group participating as the “mocktail” and alcohol-free beverage sponsor, to begin to explore community-based attitudes about complex alcohol use and support future public awareness focus efforts.

### **OBJECTIVE 3. COLLABORATIONS & PARTNERSHIPS (Starting Year Two)**

Though in advance of timeline expectations, the project has been working also to establish Hawai’i 's first Certified FASD Specialist (C-FASDS) credential designed to 1) set professional standards across disciplines for work in prevention, screening, diagnosis, and FASD-informed care and 2) create a registry of trained specialists for system-wide referral and public access (this, to fulfill mandates under Act 192). This proposed plan includes three months of curriculum design and recruitment followed by two rounds of nine-month cohort training, concluding with three months of evaluation and administrative state-integration work.

The current plan for this training includes reliance on a three-tiered model for clinical, community, or education/justice tracks. Core content will include FASD science and stigma, FASD-informed care, cultural implications for Hawai’i , prevention and screening, diagnostic training (in-depth for the clinical team track), and case management and interprofessional referral. Benchmarks for credentialing will be developed based upon completion of training, case application, and mentorship (Luning, 2025).<sup>9</sup>

In concert with other efforts, this plan will result in expanded availability of needed specialty expertise. The greater goal, however, is one of ensuring that the project is sufficiently developed prior to hand off to the State (as mandated by Act 192)--a goal that will require collaboration and networking with community partners to continue and expand this work (Luning, 2025).<sup>10</sup>

### **DISCUSSION/RECOMMENDATIONS:**

Consistent with the recommendations of the former National Organization on Fetal Alcohol Syndrome (NOFAS) Policy Center,<sup>11</sup> the project has made initial gains in its work to

- support the creation of a state FASD Task Force and state plan
- support the use of evidence-based FASD behavioral interventions
- supply trained mentors, housing assistance, and vocational training and placement for adults with FASD

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<sup>9</sup> unpublished manuscript/proposal

<sup>10</sup> unpublished manuscript/proposal

<sup>11</sup> now the Policy and Training Center of FASD United, a nonprofit dedicated to FASD advocacy and policymaking

- provide resources and support for affected individuals, parents, caregivers, and professionals
- integrate FASD informed care into existing programs and services
- decrease the recidivism rate for individuals with FASD in the justice system through regular screening and assessment, and the training of police, judges, and prison staff
- and reduce waste by increasing the effectiveness of FASD programming

Closer to home, the project is additionally in alignment with the Goals and Evaluation Blueprint and Projected Timeline for Completion, having **met or exceeding its stated targets** and **within the timeframes established** (notably, with reliance on a single staff person, before bringing in additional part-time support six months into the year).

There are, however, some recommendations looking forward. These include

- Community representation
  - To better respond to the particular interests and needs of those affected by FASD, it is recommended that the project bolster its community representation, especially at the advisory level.
- Data collection/record keeping
  - Existing data do not capture the number of trainees, just data from those who elect to provide feedback. To more accurately assess participant response, it is recommended that effort be made to track all trainees.
  - Existing data do not capture feedback on presentations. It would be helpful to have some sort of mechanism in place for this, possibly similar to the brief survey used for feedback on trainings.
- Resource development
  - Increased requests and demand for further FASD-informed specialist training, as a result of heightened awareness, may require additional funding and related support. (This is not a recommendation so much as it is a factor to consider in planning.)
- Project evaluation/additional measures
  - In support of evidence-based decision-making with regard to resource allocation, it might be useful to include some sort of fiscal analysis (e.g., cost-utility). This can be conducted at project end or after, though ideally before wider-scale implementation.
  - To better understand shifts in public perception (i.e., away from shame and blame and towards compassionate response and care), it might be helpful to include some form of qualitative analysis (e.g., narrative or thematic). Though difficult to capture, this change in perception is (theorized to be) key to the project's success.

According to the Strategic Plan 2025 (see Appendix, page 32), some of these efforts are likely already underway.

## CONCLUSION

Beyond the **deliverables**, however (the “what” of the Project), it may be important to say a bit about the **approach** (the “how”). Reflecting back on the Executive Director’s comments (see Preface regarding the importance of compassion, curiosity, and community) alongside the Workforce Survey findings, it seems the deficit-oriented narratives around PAE and FASD have not only delayed treatment; they have also undermined the capacity of health professionals to provide meaningful knowledge and appropriate response (Hewlett & Lyall et al., 2025). This has resulted in a situation of provider lack of confidence, knowledge, and skills; compounding the unrecognized wellbeing needs of affected individuals already faced with collective trauma and deep mistrust.

The rebuilding of trust, then, and the centering of a strength-based wellbeing approach are not only culturally appropriate for Hawai’i; they are essential to the dismantling of the colonial and paternalistic dynamics embedded in mainstream service delivery (Hewlett & Lyall et al., 2025), resulting in maternal stigma and stigma by association and made visible by their effects (e.g., over-representation of FASD affected individuals in the criminal justice and child welfare systems and the development of “secondary disabilities” such as homelessness, unemployment, and mental health issues).

This is not to say that a shift in the narrative will remedy FASD or all its related problems, but the raising of awareness could surely serve as a key element in FASD prevention and the promotion of maternal and fetal health. In this sense, the Project’s offerings of targeted trainings and the early steps to develop a FASD Certification Credential program in Hawai’i could effectively serve to break down the barriers of stigma, inattention to cultural context, and knowledge gaps feeding the problem. Attention to these matters could, at the same time, help to address the problem of underdeveloped interdisciplinary response on the part of providers--now established, despite good intention, as commonplace.

From an evaluation standpoint, this relational approach seems a fitting, if not necessary, way to tackle deeply entrenched and largely unexamined perspectives on FASD, particularly in Hawai’i where so many already marginalized people remain vulnerable to further harm. Even more, this approach can be useful in helping to shape understandings (e.g., about the role of stigma by association) that should prove useful in the development of provider-focused organization-level policy, *thereby laying a foundation for the greater goal of broader systems change.*

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**APPENDIX**

Goals and Evaluation Blueprint..... 23

Projected Timeline ..... 29

Strategic Plan 2025 ..... 32

Hawai'i FASD Action 2025 Advisory Council Report (Jan. to June 2025) .... 34

Partnerships/collaborations.....

### Goals and Evaluation Blueprint

***“It is not possible to consider FASD messaging as separate from the shame, guilt, and stigma experienced by those diagnosed with the disorder or for the mothers who have delivered a child alcohol exposed. The prominent messaging that FASD is a ‘100% preventable disorder’ acts as a foundational message that by just not drinking during pregnancy, the disorder can be prevented, but this does not account for the complexities of women’s lives.”***  
*(Chaote, 2019)*

**GOAL #1: Conduct a landscape assessment on existing FASD awareness, integration, and action nationally, internationally, and in Hawai’i .**

**Literature Basis:** *“FASD diagnosis and management have not been sufficiently established and tailored. Stigma, cultural contexts, knowledge gaps, and the heterogeneity of clinical manifestations are significant barriers to an accurate diagnostic process” (Lesinskienė, 2024).*

Evaluation Questions	Outcome Indicators Measured	Expected Outcomes/Activities	Expected Methods of Measurement	Data Collector/ Frequency
<p><b><i>What do providers and systems in Hawai’i know about FASD? What information is lacking?</i></b></p> <p><b><i>What screenings, assessments, and/or diagnostic protocols are used and in what settings?</i></b></p>	<p># of providers with knowledge, training, and/or protocols on FASD screening, assessment and/or diagnosis; % of those surveyed</p> <p>Data collection on:</p> <ul style="list-style-type: none"> <li>• Availability of screening, assessment, and diagnostic protocols</li> <li>• Types of providers who use them</li> <li>• Settings where they are administered</li> <li>• Availability of informed services</li> </ul>	<p>Work towards gauging realistic provider and structural readiness to support a co-managed system of care for individuals affected by an FASD.</p> <p>Estimate/determine training and workforce needs.</p> <p>Partner with training, pre-service, and professional development organizations in accordance with needs.</p>	<p>Online/email provider awareness surveys</p> <p>On-site/in-person provider interviews</p> <p>Provider follow-up by phone</p> <p>Public awareness baseline surveys</p>	<p>Project Coordinator</p> <p>Contracted Project Evaluator</p> <p>Within first 6 months of Project</p>

**Goals and Evaluation Blueprint**

**GOAL #2: Perform comparative analysis on screening, assessment, identification and/or diagnostic protocols for FASD in Hawai‘i .**

**Literature Basis:** “Effective and ethical implementation of FASD screening practices requires consideration of several factors for success, ensuring that resulting benefits outweigh potential harms” (McLachlan, 2022).

Evaluation Questions	Outcome Indicators Measured	Expected Outcomes/ Activities	Expected Methods of Measurement	Data Collector/ Frequency
<p><b><i>What unique considerations might be made for protocols to accommodate the demographics and populations in Hawai‘i ?</i></b></p>	<p>Currently available/locally utilized tools/protocols and/or lack thereof</p>	<p>Develop consensus on “high-quality” screenings, assessments, protocols for diagnosis for Hawai‘i</p> <p>Adjust goals and evaluation methods considering formative outcomes</p> <p>Comprehensive report with recommendations</p>	<p>Research (<i>catalog, academic, conferences, interviews, etc.</i>)</p> <p>Data synthesis and analysis</p>	<p>Project Coordinator</p> <p>Contracted Project Evaluator</p> <p>First year of Project</p>

### Goals and Evaluation Blueprint

**GOAL # 3: Develop cross-sector entry points to screening and informed services for individuals affected by FASD.**

**Literature Basis:** “It is critical ... to recognize patterns of presentation of FASD at all ages from infancy to adulthood and refer for appropriate diagnostic assessment in order to advocate for individual, family, and community understanding of behavior and establish comprehensive and appropriate supports for the affected individual” (Hanlon-Dearman, 2021).

<b>Evaluation Questions</b>	<b>Outcome Indicators Measured</b>	<b>Expected Outcomes/Activities</b>	<b>Expected Methods of Measurement</b>	<b>Data Collector/Frequency</b>
<p><b><i>Are people with historical, functional, and behavioral challenges screened for FASD in all appropriate settings/populations ?</i></b></p> <p><b><i>Are those who are identified as being at-risk provided appropriate and affordable informed services based on their identified needs?</i></b></p>	<p>Identification of potential priority demographic/ population and service providers for monitoring</p>	<p>Deliver data presentations, recommendations, and intensive trainings and consultation to identified sectors.</p> <p>Adjust goals and evaluation methods in light of formative outcomes.</p>	<p>Consumer and family feedback</p> <p>Training surveys and evaluation reports</p>	<p>Project Coordinator</p> <p>Contracted Project Evaluator</p> <p>Within first 18 months of Project</p>

**Goals and Evaluation Blueprint**

**GOAL #4: Prepare systems and policies to support care and informed adaptations to services.**

**Literature Basis:** “Although community ownership of a program is critical to ensuring local capacity and longevity, it is also necessary for states to commit resources and improve policies to building and fortifying multiple systems for more integrated and comprehensive prevention and care” (Onoye, 2017).

Evaluation Questions	Outcome Indicators Measured	Expected Outcomes/Activities	Expected Methods of Measurement	Data Collector/Frequency
<p><b><i>What services/adaptations are currently offered to/missing for people affected by FASD or persons most at-risk, and in what systems?</i></b></p> <p><b><i>Are current systems appropriately adjusting practices to be informed for persons affected or at risk of having been affected by an FASD?</i></b></p>	<p>Develop a comprehensive list of social services, health care systems with/without existing FASD protocols/adaptations/services.</p> <p>Reporting on: Service coverage from Medicaid/MCO's, private insurers.</p> <p>Specific and/or FASD-informed services offered by social services and/or healthcare organizations.</p>	<p>Support the update of protocols, procedures, policies and clarification of eligibility criteria.</p> <p>Track before and after changes at organizational level via policies and procedures.</p> <p>Train towards a brain-based FASD-informed workforce that better supports all persons at risk.</p>	<p>Online/email surveys</p> <p>Provider follow-up by phone</p> <p>Service sector research</p>	<p>Project Coordinator</p> <p>Contracted Project Evaluator</p> <p>Consultants/Advisory Council</p> <p>Upon collection, within first 18 months of Project</p>

**Goals and Evaluation Blueprint**

**GOAL #5: Determine a sample group to monitor and evaluate their experiences within their systems of care, including their primary care provider, FASD specialist, and other service providers.**

**Literature Basis:** “Robust measures of coordination processes will be essential tools to evaluate, guide and support efforts to understand and improve consequential deficits in care coordination. In addition to evaluating the effectiveness of improvement initiatives, such measures are important to identify deficiencies addressable by quality improvement efforts, may be used for comparative reporting or accountability and recognition purposes, and are essential for evaluating how care coordination is related to patient outcomes” (Shultz, 2013).

<b>Evaluation Questions</b>	<b>Outcome Indicators Measured</b>	<b>Expected Outcomes/Activities</b>	<b>Expected Methods of Measurement</b>	<b>Data Collector/ Frequency</b>
<p><b><i>Are people with historical, functional, and behavioral challenges screened for FASD in all appropriate settings/populations?</i></b></p> <p><b><i>Are those who are identified as being at risk provided appropriate and affordable informed services based on their identified needs?</i></b></p>	<p>Identify # of at-risk persons screened.</p> <p>Identify # of persons who screen positive for a possible FASD.</p> <p>Identify # of persons referred for further assessment.</p> <p>Identify # of persons receiving informed-services.</p> <p>Preliminarily identify/assess gaps and ongoing needs.</p>	<p>Assess informed service delivery in relationship to developed metrics for participating individuals and families.</p> <p>Further determine service and support navigation and real experiences of persons with FASD and their families within systems.</p>	<p>FASD Informed/adapted interviews and surveys with participants</p> <p>Family and service provider surveys</p> <p>Qualitative interviews and/or focus groups</p>	<p>Project Coordinator</p> <p>Contracted Project Evaluator</p> <p>Consultants/ Advisory Council</p> <p>3 and 6 months from beginning of monitoring period</p>

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**Project Timeline:**

<b>When</b>	<b>Primary Evaluation Concerns</b>	<b>Tasks</b>	<b>Tools (to be developed)</b>	<b>Persons Responsible</b>
<b>Year One/ First Half</b>	<i>What do providers and systems in Hawai'i know about FASD?</i>	Develop advisory groups, determine sub-contractors, and trainers	Advisory Council Structure & Purpose Outline  Landscape Survey Report	Project Coordinator  Consultants/ Sub-Contractors
	<i>What screenings, assessments, and/or diagnostic protocols are used and in what settings?</i>	Develop and disseminate provider awareness surveys, conduct provider and systems interviews.  Disseminate public awareness baseline surveys  Begin engaging cross-sector policy partners and providers	Baseline FASD Public Awareness Report	BOD
<b>Year One/ Second Half</b>	<i>What do providers and systems in Hawai'i know about FASD?</i>	Hire additional staff as designated; develop advisory groups, determine contractors, and trainers	Advisory Council Structure & Purpose Outline  Landscape Survey Report	Project Coordinator  Consultants/ Sub-Contractors
	<i>What screenings, assessments, and/or diagnostic protocols are used and in what settings?</i>  <i>What training is needed to support appropriate screening, referrals and service adaptations across sectors?</i>	Develop and disseminate provider awareness surveys, conduct provider and systems interviews.  Disseminate public awareness baseline surveys  Begin engaging cross-sector policy partners and providers  Conduct open/cross-sector trainings	Baseline FASD Public Awareness Report & Training Recommendations	BOD

<b>Year Two/First Half</b>	<p><i>What sectors and providers might disproportionately be serving at-risk individuals and families?</i></p> <p><i>What unique considerations might be made for these protocols for Hawai'i ? For different demographics and populations?</i></p>	<p>Conduct research and develop recommendations for screening, assessment and/or diagnostic protocols</p> <p>Engage providers, universities (pre-service), government, NGOs, and potential servicing systems and providers (<i>ongoing</i>) to look at sector specific considerations</p> <p>Conduct targeted provider/systems trainings</p>	<p>Screening, Identification, and Diagnostic Team/Mechanism Recommendation Report for Hawai'i</p> <p>Develop Basic Standardized Cross-Sector Training Curriculum Outline for Hawai'i</p> <p>Training Evaluation Reporting</p>	<p>Project Coordinator</p> <p>Advisory Council/Consultants</p> <p>Trainers</p> <p>Primary Evaluator</p>
<b>Year Two/Second Half</b>	<p><i>What services or adaptations are currently offered or missing, and in what systems, to people affected by FASD or persons most at-risk?</i></p> <p><i>Are current systems appropriately adjusting practices to be informed for persons affected or at-risk of having been affected by an FASD?</i></p>	<p>Determine assessment and diagnostic team(s) and potential FASD specialist(s)</p> <p>Determine sample size and partner providers</p> <p>Develop evaluation protocol and metrics for services, individuals and families</p>	<p>Develop FASD Specialist Certification for Hawai'i</p> <p>Training Evaluation Reporting</p>	<p>Project Coordinator</p> <p>Advisory Council/Consultants</p> <p>Primary Evaluator</p>

<p><b>Year Three/First Half</b></p>	<p><i>What services or adaptations are currently offered or missing, and in what systems, to people affected by FASD or persons most at-risk?</i></p> <p><i>Are current systems appropriately adjusting practices to be informed for persons affected or at-risk of having been affected by a FASD?</i></p>	<p>Monitor participants</p> <p>Continue to conduct targeted provider/systems trainings</p>	<p>Service/Funding Gap Report for Hawai'i</p> <p>Training Evaluation Reporting</p> <p>Develop Population Recommendation and Evaluation Plan</p>	<p>Project Coordinator</p> <p>Advisory Council/Consultants</p> <p>Primary Evaluator</p>
<p><b>Year Three/Second Half</b></p>	<p><i>Are people with historical, functional, and behavioral challenges screened for a possible FASD in all appropriate settings/population?</i></p> <p><i>Are those who are identified as being at-risk provided appropriate and affordable informed services based on their identified needs?</i></p>	<p>Evaluation reporting of system of care for chosen population</p> <p>Exploration of long-term sustainability and systemic integration</p> <p>Continue to engage providers, universities (pre-service), government, NGOs, and potential servicing systems and providers (ongoing)</p>	<p>Initial and Follow-up Reporting on Participants</p>	<p>Project Coordinator</p> <p>Advisory Council/Consultants</p> <p>Primary Evaluator</p>



The Hawai'i FASD Action Group

Mission

Our Mission is to raise awareness and build coalitions through education, advocacy, and data collection on **Fetal Alcohol Spectrum Disorders (FASD)** to make a positive impact on individuals, their families, and the communities of Hawai'i.

Vision

Our Vision is to make FASD **Invisible No More**

Our Values

CURIOSITY

Brain-based and trauma-informed approaches can be considered and implemented even before a formal diagnosis. It's **okay to wonder about how to be helpful** and supportive. Asking curious and kind questions is a good way to learn together.

COMPASSION

Working in a complex public health issue requires **nuance, thoughtfulness, and trust**. No amount is safe to consume during pregnancy and alcohol use is complicated. Families and parenting are complicated, too. **Let's be gentle with ourselves and one another** as we work in both community awareness for prevention and in getting people the support they need to thrive.

COMMUNITY

We believe that in Hawai'i we are all a part of one lāhui **doing good work together**. Our organization is committed to openness, cooperation, and our community...first.

Our Team

**Amanda Luning**  
Executive Director

**Erin Rupert**  
Executive Assistant

Board of Directors

The Action Group

To meet the strategic goals of the HI FASD Action Group, our organizational infrastructure includes a mix of staff, an advisory council, volunteers, and a Board of Directors.

We also strategically contract and partner with specialists, professionals, and key stakeholders, and engage and support our community champions.

In keeping our work agile and transparent, we can do integrative work with our partners without competition, for the collective benefit of our Mission.



FASD IS A KĀKOU THING

Hawai'i FASD Action Group  
P.O. Box 6611, Kaneohe, HI 96744 • info@fasdhawaii.org • Phone: (808) 460-8353



# Our Strategy

**PUBLIC AWARENESS CAMPAIGNING**  
The more knowledge in the community the better... less judgement, less stigma, more support, more success.

**COALITION BUILDING**  
You and me, and everyone in between, have a place in supporting the healthy pregnancies, child development, and the overall wellness of our next generations.

**TRAINING AND CONSULTATION**  
Never a "one and done." A complex public-health issue like FASD will always keep us on our toes. Let's commit to KEEP learning together.

**DATA COLLECTION**  
We want to gather information for and from our own communities. From numbers to stories, the more we understand, the better we can do.

**SYSTEMS COORDINATION**  
Across sectors, across the lifespan. It's when systems work together that they actually work... together.

**ORGANIZATIONAL DEVELOPMENT**  
What we do is who we are. We aim to work ourselves out of a job, so we transform and stay nimble as the work moves forward.

## Help FASD become *Invisible No More!*



- Tell **Everyone** You Know
- Share a Handout or Brochure
- Join Social Media
- Subscribe to Newsletters
- Request Training and Information

- Advocate for Each Other
- Implement FASD Informed-Practices
- Become a Specialist
- Normalize Diagnosis and Support

- Volunteer/Connect People
- Fundraise/Donate
- Work in Systems Change
- Make FASD **Invisible No More**



### LET'S LEARN TOGETHER



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## **HAWAI‘I FASD ACTION 2025 ADVISORY COUNCIL REPORT**

**RE: Act 192 (2023)**

A Co-Managed System of Care for people with Fetal Alcohol Spectrum Disorders

**(January-June 2025)**

### **ADVISORY COUNCIL MEMBERS:**

*Amelia Kyewich-Kaneohelani, MEd, Ann Yabusaki, PhD, LMFT, Darlyn Chen Scovell, CSAC, MA,  
Eri Rodrigues, LCSW, IMH-E®, Miki Kiyokawa, MD, Naghum “Nia” Alfulaij, PhD, MS, MACP,  
Valerie Rose, MPD, RDN, supported by Linda Ikeda, PhD, MSW,*

**Prepared by: Amanda Luning, LMHC, IECMH-E®, Executive Director**

*Completed: December 2025*

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**ATTACHMENTS:\***

- A-Interest Form*
- B-Tenet Agreement*
- C-Roadmap (Recruitment)*
- D-FASD Health Care Professionals Survey Analysis*
- E-Public Awareness Campaign Partner Guide*

**\*NOT EMBEDDED HERE DUE TO LENGTH: Full Report Available at**  
**<https://fasdhawaii.org/fasd-resources/>**

**PURPOSE & RECRUITMENT:**

In response to a contract with the Office of Planning, Policy, and Program Development-OPPPD (ASO Log No. 25-191) funding for Act 192 (2023) in November of 2025, the Action Group began recruiting members to participate in an **Advisory Council** in accordance with the objectives and timeline of the project (*Exploring an Appropriate Brain-Based Fetal Alcohol Spectrum Disorder (FASD) Informed Services Infrastructure for Hawai'i*).

Recruitment materials went out to the Action Group listerv as well as to government partners in December of 2025. Public health, community, and government leadership, physicians/clinicians, human services providers, and anyone who has any experience, including families and self-advocates with FASD were encouraged to apply.

The interest form asked for contact information, professional and/or personal interest and/or background in FASD, and connection to Hawai'i.

Participants were asked to commit to a 6-month period including a minimum of 3 group meetings (on Zoom), 2 small working group meetings, and an in-person gathering in June at the end of the period. *Travel stipends were offered to neighbor island participants by the Action Group.*

A copy of the Interest Form (**Attachment A**) and Tenets/Agreements (**Attachment B**) are attached.

**ROADMAP OF FOCUS AREAS (see Attachment C):**

Meetings and Workgroups focused on the following content areas:

- **General Public Awareness**
- **Screening, Assessment, and Diagnosis for Hawai'i**
- **Systems of Care and Service Eligibility**
- **Workforce & Training Needs**
- **Strength-Based Individual & Family Supports**
- **Systems, Policy & Advocacy Considerations**

In addition to the above meeting focus areas Advisory Council Members participated in providing feedback on the following activities, some of which are further reported on the HI FASD Action Group 2025 Annual Report:

- **FASD Health Care Professionals Survey-2025** (*Hawai'i-based FASD Workforce and Diagnostic Capacity Survey with Grove Insight*). Analysis Attached (**Attachment D**)
- **“FASD is a Kākou Thing” Public Awareness Campaigns and Community Trainings**

**ADVISORY COUNCIL DISCOVERIES:**

**Act 192** (A Co-Managed System of Care for FASD) **was passed under several assumptions:**

- 1) That our health, social services, and education systems are regularly screening for FASD. **They are not.**
- 2) That we have FASD Specialist in Hawai'i **We do not.**

- 3) That we have diagnostic capacity in Hawai'i. **We do not.**
- 4) That we have designations (*such as clear eligibility criteria*) for service and care provision and FASD-Informed systems. **We do not.**
- 5) That it is safe for women, families, and people affected to talk about FASD in their communities. **It is not.**

It was discovered that currently, there is no epidemiological data on FASD in Hawai'i. PRAMS data (*Pregnancy Risk Assessment and Monitoring Systems*) continues to indicate that the unintended pregnancy rate remains at close to half, and that binge drinking prior to pregnancy, and drinking in the third trimester is still more than 15%.

National data indicates approximately 1 in 20 people to be affected, and special population data is much higher.

Our GIA 2023-24 training project-for clinicians to screen and adjust approaches to people with a high risk for FASD in special programs such as rehabilitation and youth programs, the risk rate increases to more than 75% (*GIA Project Executive Summary available at fasdhawaii.org*).

In early 2025 we conducted a **statewide FASD Health Care Professionals Survey** about provider confidence and knowledge of FASD. Responding physicians and providers openly admitted they were undertrained, not confident, and without support around diagnosis...and feel it is important but *are not doing it*.

There are significant cross-system implications for keiki and families when FASD screening and diagnosis are needed and do not happen and appropriate services are not provided (*including going to prison, having children removed and parental rights terminated, incorrect diagnoses and prescription medications, school suspension and expulsion, fired from employment, mandated over and over again to ineffective services, not to mention being ostracized from their own 'ohana*).

#### **ADVISORY COUNCIL RECOMMENDATIONS:**

- **Safe, stigma-free, non-judgmental messaging from our Public Health sector**
  - Partner Guidelines were created for the September 2025 Public Awareness campaign that can be utilized as a baseline (**Attachment E**).
- **FASD-Informed systems**
  - *Training Requirements for all clinical, public health, social services, education, and public safety professionals.*
  - *Consistent Guidance for "FASD-Informed" service provision, such as adaptations to provisions of service/care including environmental considerations and simple tools.*
  - *Education and on-going support for families and individuals, including support for self-advocacy.*
- **Cross sector, iterative, screening, and documentation requirements (not "one and done"), during pregnancy and throughout the lifespan**

- *Examples:*
  - *Early and Periodic Screening, Diagnostic and Treatment (EPSDT)*
  - *Early Intervention Services (Part C)*
  - *Child Find (IDEA)*
  - *Continued monitoring and sharing of information across systems as permitted by client*
- **Multidisciplinary assessment and diagnostic clinics**
  - *Examples:*
    - *University of Hawai'i-JABSOM*
    - *Kapi'olani Medical Center for Women and Children*
- **Clear guidance on functionality, diagnosis, and eligibility requirements across the lifespan for people at-risk, in a diagnostic process, and/or with a clear diagnosis**
  - **Examples:**
    - Developmental Disabilities Division (DDD)
    - Department of Education (DOE)
    - MedQuest Waiver Services
    - Managed Care Organization (MCO) Coverages

### **PATHWAY FORWARD:**

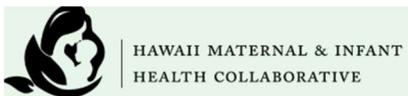
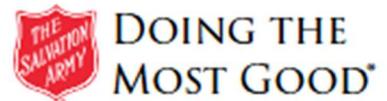
FASD is a too often “invisible” disability that effects our economy, our systems, and ultimately cause harm to the quality of life for our entire community. While the Advisory Council recognizes these to be “big” asks, we also come to the table with a sense of urgency around a critical paradigm shift in perceptions around brain-based behavior and how our social, educational, and clinical support systems respond.

- **Develop State Coordinator Position(s) to:**
  - Manage ongoing FASD Specific Multidisciplinary and Cross Sector Advising
  - Conduct Internal Administrative and Policy Reviews and Changes (State and City and County Levels)
  - Coordinate and/or Develop projects for families and individuals at risk or living with FASD.
  - Coordinate Funding for increased FASD-informed public health and awareness, direct care and services, family supports, supportive housing for people with or at risk for FASD ), including the funding from the FASD Respect Act under the reauthorization of the SUPPORT Act. <https://www.congress.gov/bill/119th-congress/house-bill/2483/text?s=4&r=1&q=%7B%22search%22%3A%22HR+2483+119th+Congress%22%7D#toc-HE71B38912F944EC28EA69B918AA9A3E2>
- **Develop multidisciplinary FASD Specialist Training/Credential Programs**
- **Legislation** (*as needed to support the above activities*)

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## THE ACTION GROUP WOULD LIKE TO MAHALO AMAZING 2025 COLLABORATORS



*To the too often unknown, unacknowledged, unrecognized volunteers, champions, caregivers, families, self-advocates, and people with living experience working tirelessly, every day to make FASD "Invisible No More" we send YOU our deepest RESPECT and gratitude.*

