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:
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Prepared by: Amanda Luning, LMHC, IECMH-E®, Executive Director
Completed: December 2025

CONTENTS:

ATTACHMENTS:

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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CDC (2024) Alcohol Use During Pregnancy, https://www.cdc.gov/alcohol-pregnancy/about/index.html

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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

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Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. *Canadian journal of public health = Revue canadienne de sante publique*, *102*(5), 336–340. https://doi.org/10.1007/BF03404172

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HI FASD Action Group-Advisory Council Interest Form

We are looking for a multi-disciplinary group of folks to make up our Advisory Council for the "Exploring an Appropriate Brain-Based Fetal Alcohol Spectrum Disorder (FASD)-Informed Services Infrastructure" in Hawai‘i Project (please see flyer for dates and scope).

We will be responding to applicants with confirmation by January 8th, 2025. Mahalo nui for your interest!

* Indicates required question

1. First/Last Name: *

2. Best contact email: *

3. Best contact phone number:

4. What best describes your background (please check all that apply): *

Check all that apply.

- [ ] Parent/Family/Self Advocacy
- [ ] Government/Public Health Leadership
- [ ] Community or Non-Profit Leadership
- [ ] Physician
- [ ] Psychologist
- [ ] Mental Health Clinician (LMFT, LMHC, LCSW, etc.)
- [ ] Other Direct Service Provider
- [ ] Other: _____

5. Please briefly share with us your personal and/or professional background and interest in working in Fetal Alcohol Spectrum Disorders:

_____

_____

_____

_____

_____

6. Please share briefly your connections with Hawai‘i (ex: how long you have lived/worked here, your family, community, and/or cultural connections, etc.): *

_____

_____

_____

_____

_____

7. I am a not located on Oʻahu and will need scholarship support for travel for in-person convening.

   Mark only one oval.

   - ◯ YES
   - ◯ NO

8. I am able to attend the majority of the meetings as scheduled and willing to support in no less than two (2) small work group meetings in March and/or May of 2025: *

   January 27th, 2025-12:30pm-2:30pm (Zoom)

   February 24th, 2025-12:30pm-2:30pm (Zoom)

   March 2025-Small Working Groups (TBD/Remote)

   April 28th, 2025-12:30pm-2:30pm

   May 2025-Small Working Groups (TBD/Remote)

   June 30th, 2025 (In-Person-Oʻahu)

   Mark only one oval.

   - ◯ YES
   - ◯ NO
   - ◯ UNSURE

Hawai‘i FASD Action Group

TENET AGREEMENT

Working in Fetal Alcohol Spectrum Disorders (FASD) is, to say the least, ***complicated.***

Our work may discuss:
Families, babies, children…relationships, sex, pregnancy…culture, history, environments…government, politics, systems…communities, education, clinical care…values, trauma, and choices…*human beings*.

We will be talking a lot about human beings. *Ourselves included*.

Compassionate and holistic FASD work asks us to open our minds to what we believe about human behavior and to suspend our assumptions to imagine new and creative strength-based solutions…together.

With that said, the Hawai‘i FASD Action Group hopes that all our volunteers, advisors, subcontractors, staff, and Board members can work together under the following tenets:

- This work is very important, AND it is only one of many kinds of important work that aims to better health and balanced wellbeing for all.
- We are all people, with our own collection of lived-experiences, knowledge, strengths, vulnerabilities, and perspectives, none more valuable than the other, simply diverse and unique.
- Because we are a diverse group, this work may very well find us feeling frustrated, offended, hurt, or confused. This may be with processes, information, or even one another.
- As a collective we commit to giving the benefit-of-the-doubt that each of us here to be of help and service and is doing the best we can with what we have.
- We will remain open to taking deep breaths, asking kind and curious questions, following up, and doing what we need to do for ourselves and each other to continue our place in this complex and important work, with fullness of attention and compassion.
- Minutes or notes may be taken during group meetings, and unless explicitly informed ***(such as for reporting purposes, or aggregate community recommendations, of which you will be informed***), they will not be shared outside of the group(s). Please keep in mind that private information may be shared during these meetings and an expectation of confidentiality will be maintained.

I, _____, agree to work under the above tenets to the best of my ability.
(NAME)

Signature: _____ Date: _____

FASD is a kākou thing

ATTACHMENT C

FASD is a Kākou Thing

Exploring an Appropriate Brain-Based Fetal Alcohol Spectrum Disorder (FASD)-Informed Services Infrastructure

2025 *Advisory Council* RECRUITMENT

The effects of prenatal alcohol exposure, often known as Fetal Alcohol Spectrum Disorders (FASD) are complicated, and sometimes very challenging to clearly identify.

While it is always best for our communities to support healthy pregnancies and families, there are likely many people in our community affected by FASDs, that might be struggling with this often "invisible disability."

We'd like to help, and we need you.

Public health, community, and government leadership, physicians/clinicians, human services providers, and anyone who has any experience, including families and self-advocates, with FASDs, please consider joining us...

your mana'o has the power to change lives!

SCAN HERE TO APPLY FROM YOUR MOBILE DEVICE

CLICK HERE TO APPLY!

Jan 27th Meeting (Remote)

- Introductions and Connections
- FASD in Hawai'i -Background Presentation
- Advisory Council Scope and Goals

Feb 24th Meeting (Remote)

- Kuleana Review
- Large Group Discussion *(Moderated)*
- Development of Work Group Scopes

March 2025 Work Groups*

- General Public Awareness
- Screening, Assessment, and Diagnosis for Hawai'i
- Systems of Care and Service Eligibility

April 28th Meeting (Remote)

- Evaluation and Data Collection
- FASD Lōkahi Framework
- Making Collective "Good Trouble"

May 2025 Work Groups*

- Workforce and Training Needs
- Strength-Based Individual and Family Supports
- Systems, Policy, and Advocacy Considerations

June 30th In-Person Convening

- Work Group Presentations
- Advisory Council Pa'ina
- Next Steps

**Work Groups will be schedule in accordance with participant availability*

Meeting Topics/Schedules are Subject to Change

In-Person Convening will be on O'ahu, neighbor island friends, please inquire about travel scholarships.

Please contact Amanda at *amanda@fasdhawaii.org* for any questions or more information.
Mahalo nui!

fasdhawaii.org

Hawai'i FASD (Fetal Alcohol Spectrum Disorders) Action Group

grove insight

Views of Fetal Alcohol Spectrum Disorders Among Health Care Professionals in Hawaii

Analysis of Findings from a Survey of 210 Primary Care and Behavioral Health Providers conducted by Grove Insight for the FASD Action Group

March 2025

Methodology

- ✓ This analysis is based on findings from an online survey of 210 health care professionals and those working in youth services.
- ✓ A survey link was provided through professional networks across Hawai‘i and respondents were reminded to take the survey at regular intervals. There was a “lucky drawing” gift card enticement to increase participation. The survey, which averaged 13 minutes in length, was conducted from February 5 to March 5, 2025.

Report notes:

- ✓ Due to rounding, displayed answer choices may not always add up to 100%.
- ✓ Verbatim responses from the open-ended questions are used in this report. In a few cases, they have been lightly edited for readability.
- ✓ Primary health providers are referred to this way or as “PCPs” in the analysis; mental health care providers are also referred to as “behavioral health” professionals.

Demographics of the sample universe: predominantly women, majority Caucasian, and a mix of professions, length of service, and years of residency in Hawai‘i

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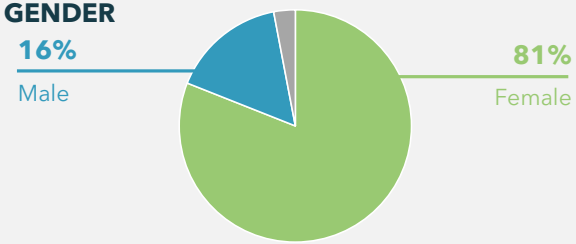
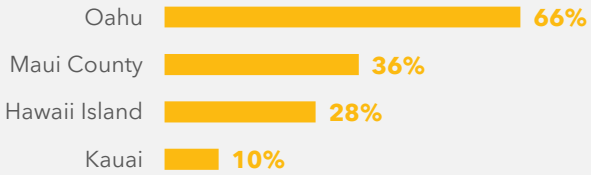
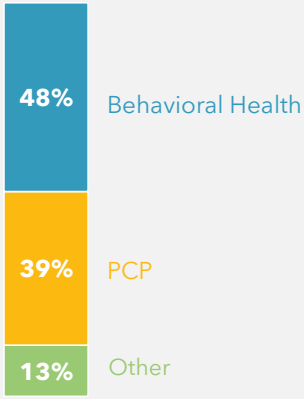
GENDER



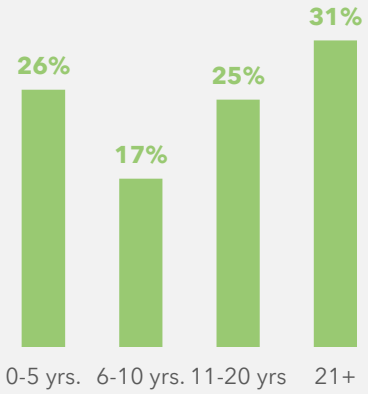
ISLAND(S) WHERE THEY PROVIDE CARE



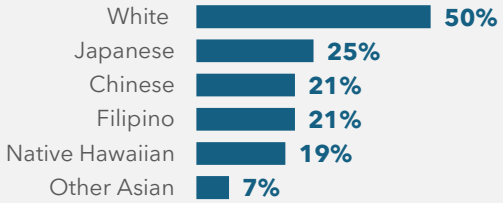
PROFESSION



YEARS WORKING IN FIELD



RACE/ETHNICITY



Hawai'i FASD (Fetal Alcohol Spectrum Disorders) Action Group

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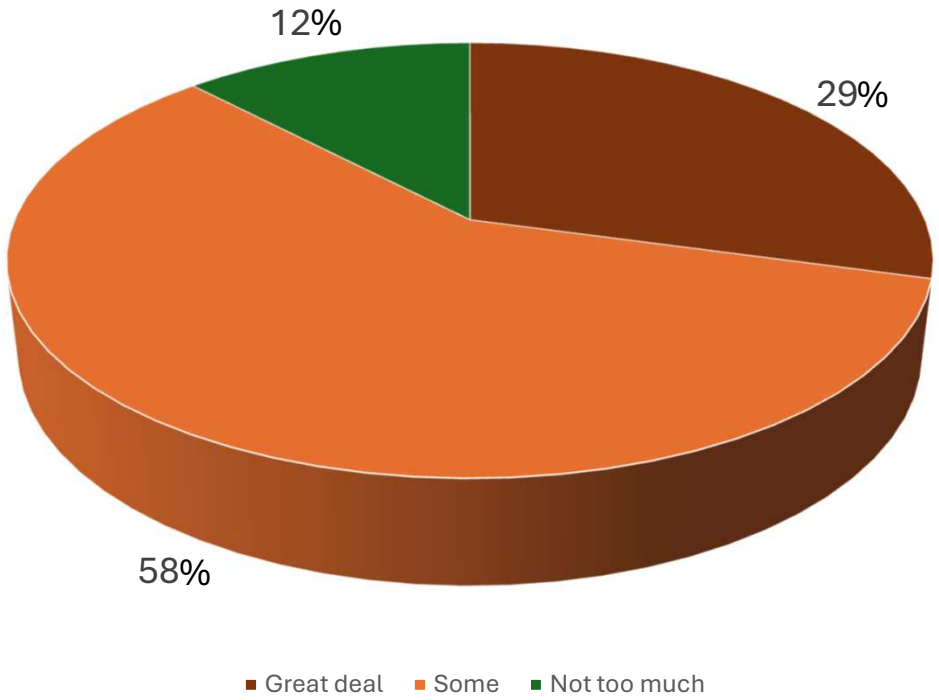
General Views of Fetal Alcohol Spectrum Disorders

A majority say they know "some" about the effects of alcohol during pregnancy

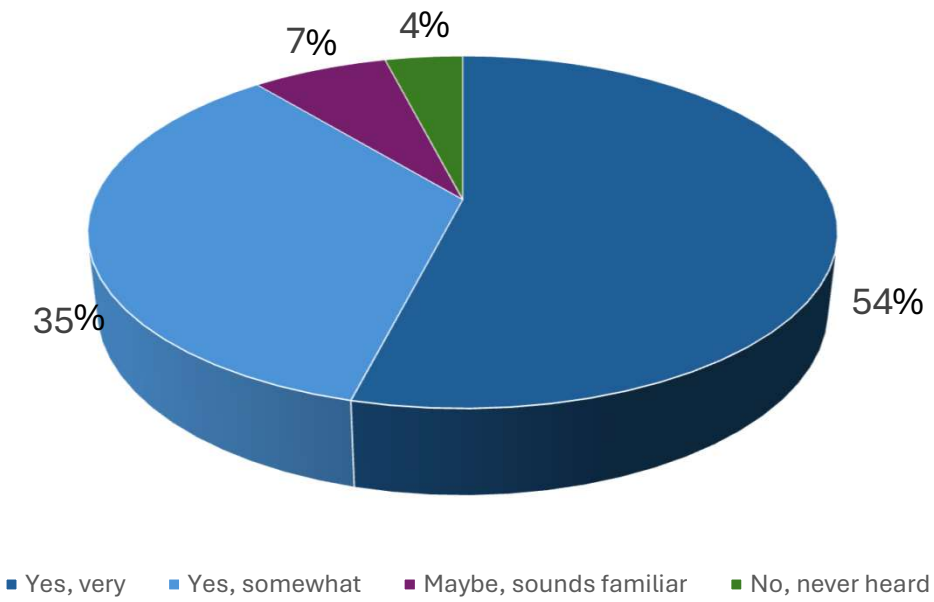
Slightly more than one in four know about the potential effects "a great deal."

How much would you say you know about the potential effects of alcohol use on a fetus during gestation/pregnancy?



A majority contend that Fetal Alcohol Spectrum Disorders is a “very familiar” term

Have you ever heard of the term "Fetal Alcohol Spectrum Disorders" or "FASD"?

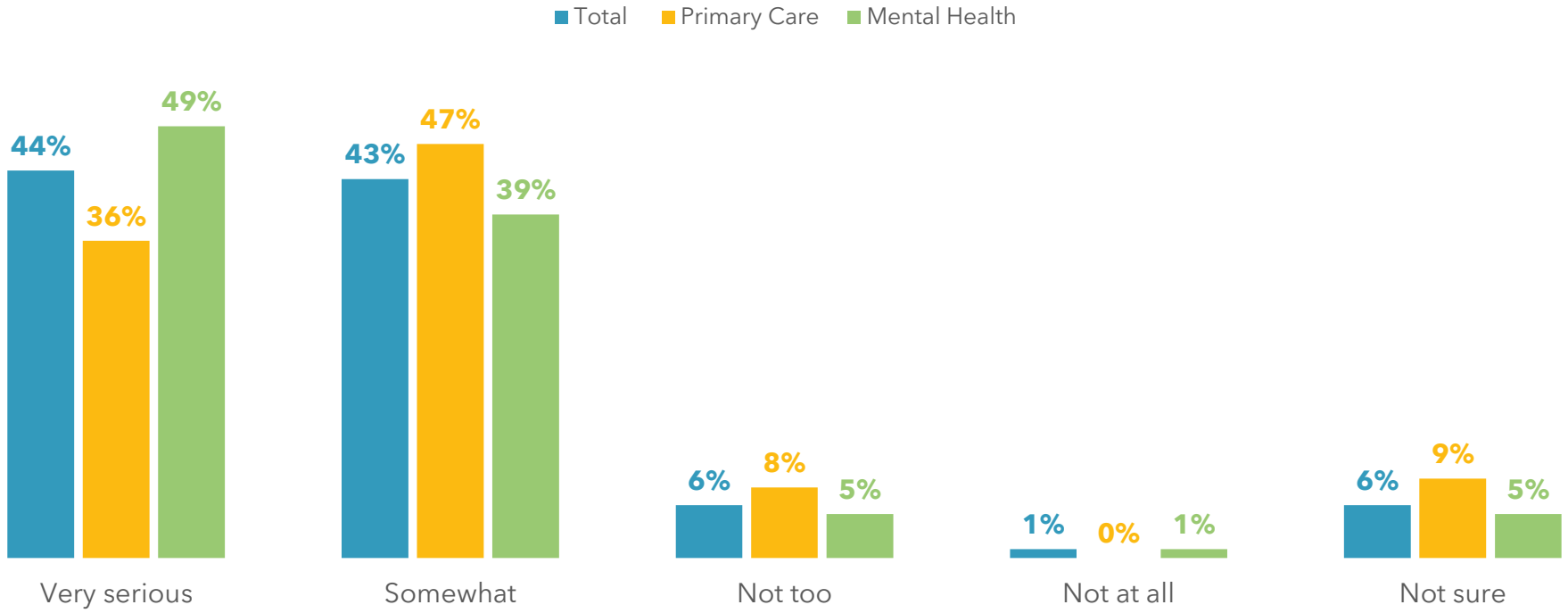


At least “somewhat familiar” 89%
Less certain, know nothing 11%

Nearly nine in 10 consider FASD to be a serious issue in Hawai‘i

Though only a plurality consider the problem “very serious” with a lower number among PCPs

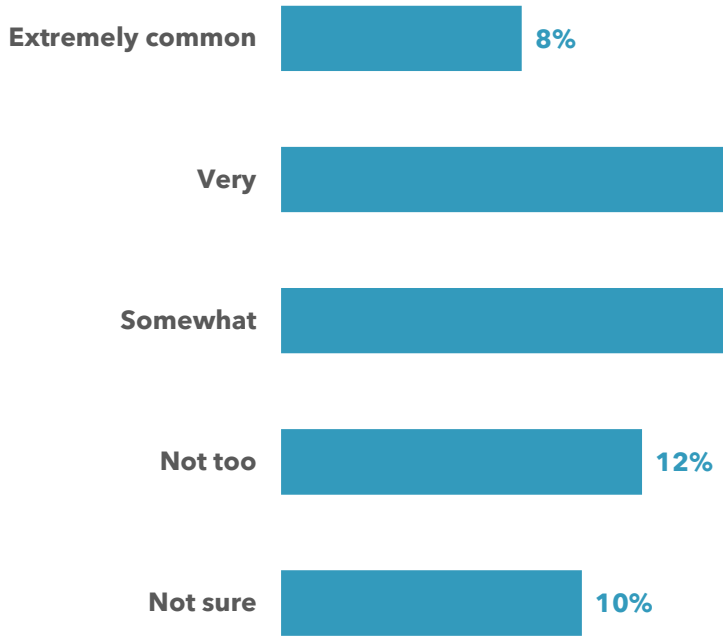
Based on what you know, how serious of an issue or problem do you think Fetal Alcohol Spectrum Disorders or “FASD” is in Hawai‘i? (Asked only among those who were familiar with FASD)



Nearly the same number who deem FASD to be "very serious" believe it is at least "very common" in Hawai'i

More than one in five believe it is "not too common" or are unsure

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? (Asked only among those who were familiar with FASD)



	Total	PCPs	Mental Health
Extremely/very	44%	46%	41%
Somewhat	35%	31%	37%

Providers are nearly unanimous that screening children for FASD is at least "somewhat" important; there are meaningful differences between PCPs and behavioral health pros

Three-quarters consider it to be "very" important, with behavioral health experts more likely to be in this camp than PCPs.

How important is it that children in Hawai'i be screened for FASD, Fetal Alcohol Spectrum Disorders?

	Total	Primary	Mental Health
Very important	77%	65%	86%
Somewhat important	18%	30%	9%
Total important	95%	95%	95%

Though respondents give lower priority to screening adults for FASD

By a margin of more than 20 points, providers are less inclined to see screening for adults as "very important" when compared to children

How important is it that children in Hawai'i be screened for FASD, Fetal Alcohol Spectrum Disorders?

IMPORTANCE OF SCREENING KEIKI FOR FASD:

	Total	Primary	Mental Health
Very important	77%	65%	86%
Somewhat important	18%	30%	9%
Total important	95%	95%	95%

IMPORTANCE OF SCREENING ADULTS FOR FASD

Very important	56%	44%	62%
Somewhat important	31%	37%	28%
Total important	87%	81%	90%

Hawai'i FASD (Fetal Alcohol Spectrum Disorders) Action Group

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Knowledge and Awareness of Screening Tools

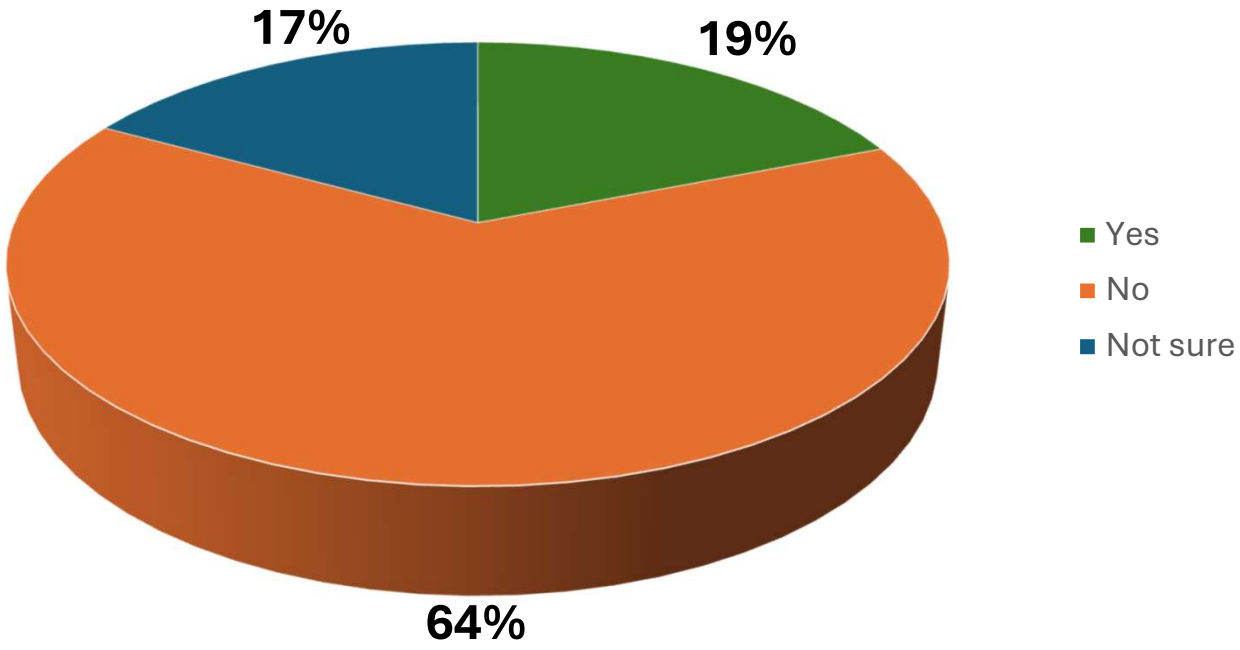
Nearly two-thirds are not familiar with screening and assessment tools used in FASD diagnosis

Just one in five are familiar with FASD tools; roughly the same number (19%) know colleagues who use a FASD screening tool.

Are you familiar with any screening/assessment tools that are used for the identification or diagnosis of FASD?

"I believe that many individuals get misdiagnosed. I also have seen people with FASD appear to have other disabilities and not get diagnosed properly."

"This was part of my formal training as a Developmental Behavioral Pediatrician. However, I was trained in a very interdisciplinary model which is not currently available to me in my place of employment, which makes it more challenging to feel confident in my diagnosis."

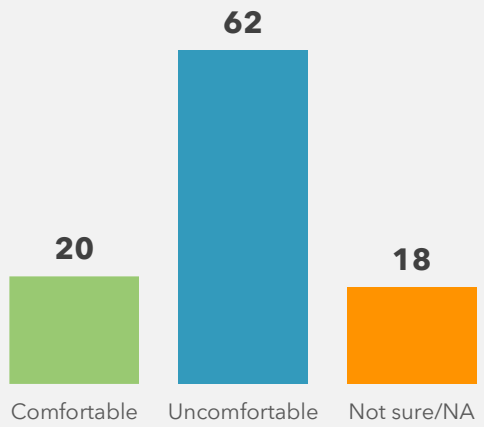


Unsurprisingly, given lack of familiarity, a majority do not feel comfortable screening, assessing and/or diagnosing FASD – and the discomfort is higher among PCPs

Just five percent said they are "very comfortable" screening and diagnosing FASD

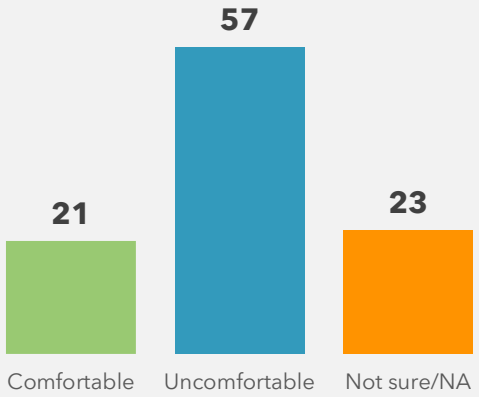
How comfortable are you in **screening, assessing, and/or diagnosing FASD?**

Total Sample



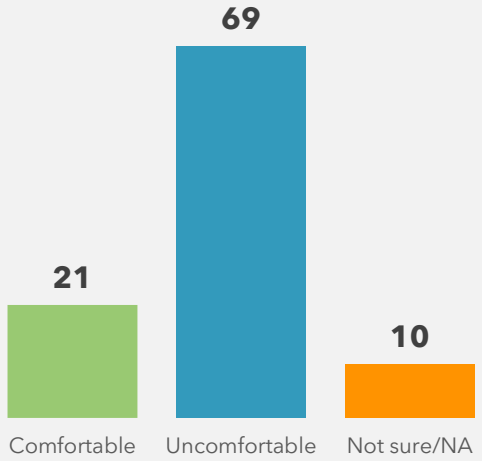
"Very comfortable" 5%

Mental Health Providers



"Very comfortable" 5%

Primary Health Providers



"Very comfortable" 5%

Those familiar with FASD attribute awareness to formal schooling

Workplace and community training were also cited and over one in 10 said personal experience

Where did you learn about Fetal Alcohol Spectrum Disorders (FASD)? (Choose all that apply)
(Asked only among those who were familiar with FASD)

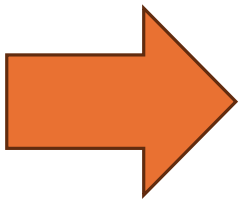
Formal schooling (high school, community college, university, medical school, etc.)	68%
Training in the community (outside of my school/employer)	34%
In-service training at my place of employment	29%
Personal experience (friend, family)	15%
Can't recall	6%

For six in 10, the formal schooling where they learned about FASD was in Hawai‘i

Few report of continuing education or access to resources from these institutions

Was your learning connected to an institution or organization based in Hawai‘i or in another location? (please select all that apply)
(Asked only among those who were familiar with FASD)

Hawaii-based	60%
Elsewhere	40%



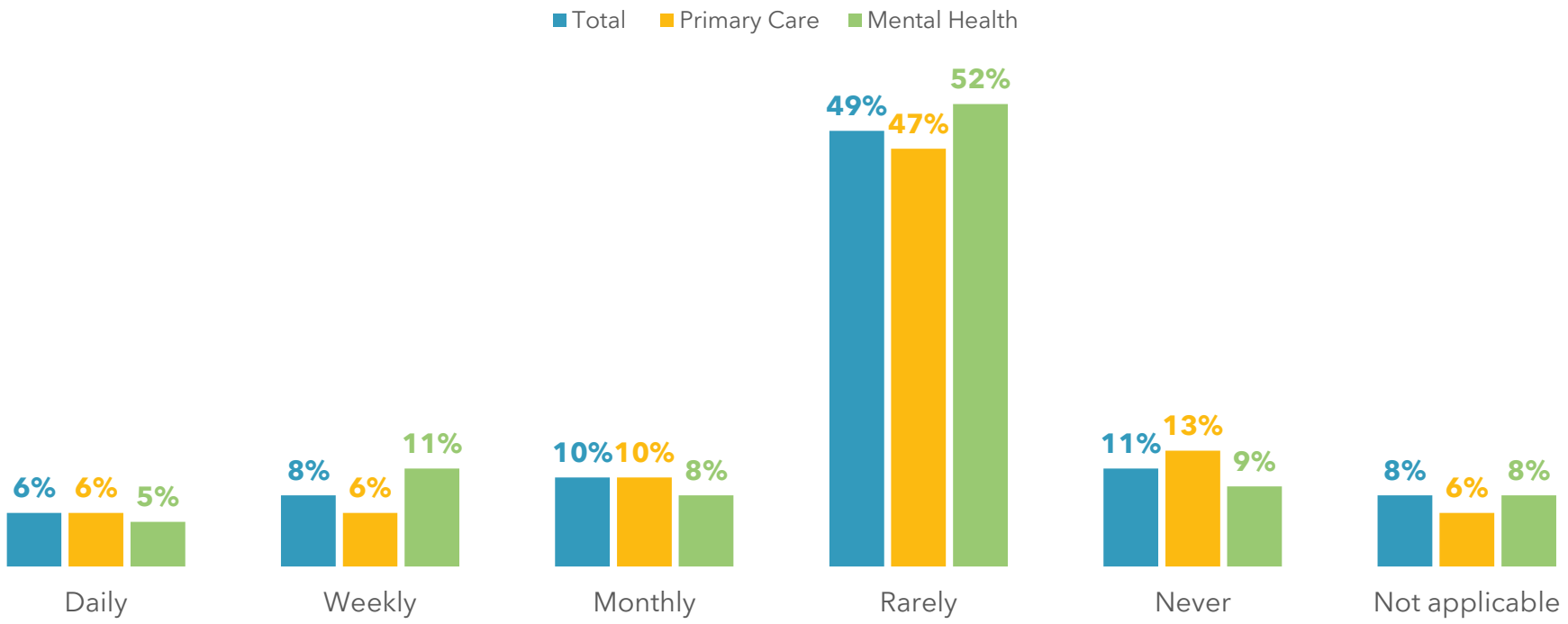
If your learning was Hawai‘i-based, has there been continuing education or resources available from that source?

Yes	24%
No	36%
Not sure	40%

The vast majority say they rarely, if ever, apply their FASD knowledge to their practice

One-quarter draw upon this knowledge at least monthly.

If applicable, how often do you apply your knowledge of FASD to your direct practice with individuals and families?
(Asked only among those who were familiar with FASD)



More have worked with individuals who have been diagnosed than have screening or diagnostic experience

Rank ordered by "very often"	Yes*	No**	If yes, was done while working in Hawai'i
Administered a tool to screen for FASD	21%	63%	65%
Diagnosed or participated in a team diagnostic evaluation	21%	70%	63%
Worked with individuals in HI who have received a formal FAS or ARBC diagnosis	33%	67%	19%

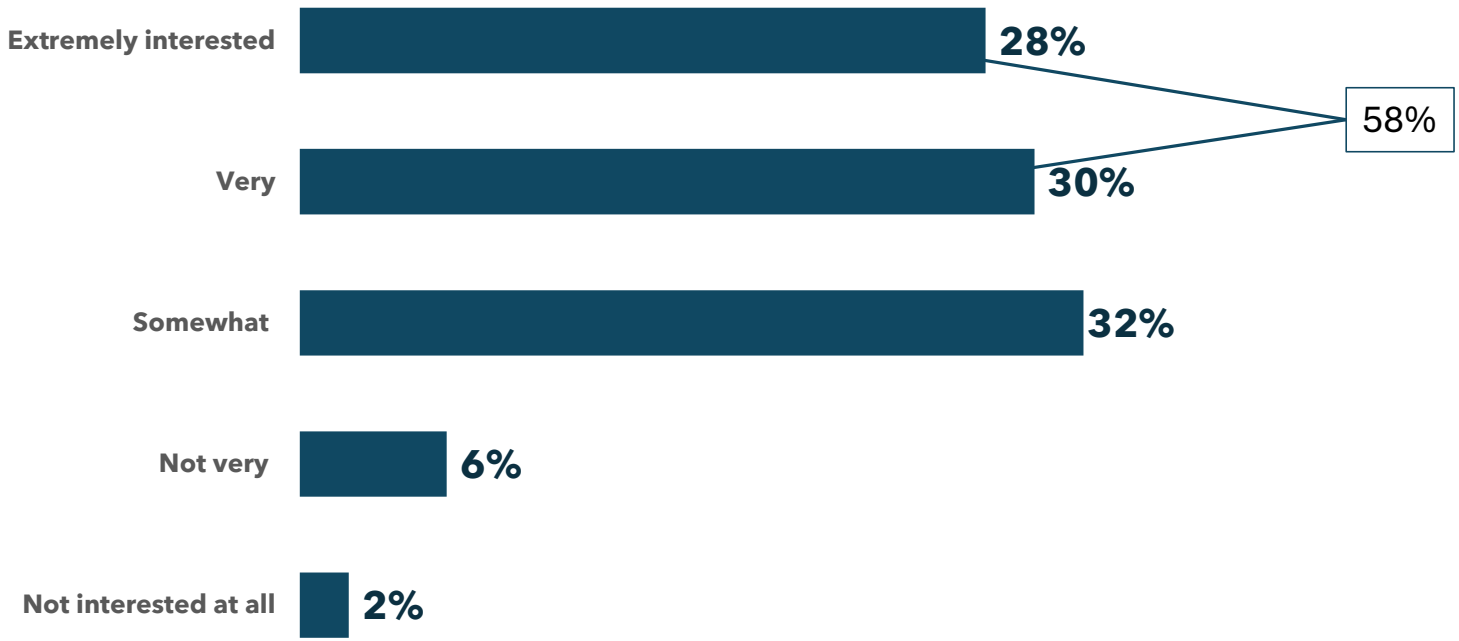
Name of screening tool:
SBRIT (3 mentions)
FASD Best (2 mentions)
NIDA
NST
4P's Plus (2 mentions)
LHS
Familydoctor.org

Name of team/practice//organization:
CAMHD (3 mentions)
DOE (2 mentions)
Residency training in HI (2 mentions)
Imua Services
Waikiki Health Women's PATH Clinic
East Hawai'i Family Guidance Center
Dr. Bridget Rovner, Molokai

*Yes responses were asked the age of the patients they conducted a FASD for, allowing for multiple responses. Most of the "yes" responses were for pregnant/postpartum individuals and keiki.
**Question was not applicable to 18-25% of respondents depending on the question.

Nearly six in 10 are at least “very interested” in receiving more FASD screening and diagnosis training, resources

How interested are you in receiving more training or resources to help screen and diagnose Fetal Alcohol Syndrome?



Comfort comes from specific trainings – and necessity due to patient type

Many admit that their training may be inadequate but also see it as a key to comfort.

What, if anything, about your education, training, or personal experience makes you feel comfortable screening and/or diagnosing FASD?

"Prevalence of FASD in some of the populations I have cared for."
"ASAM training programs for OUD and addiction medicine overview."
"I've researched this myself and also provided in-depth trainings to other professionals. I understand that this is pretty rare, however.."
"I feel comfortable using SBIRT, but leave diagnosing to medical providers."
"Trainings around general Alcohol or SUD screenings were helpful when there was **actual scenarios and/or role play opportunities** provided."

"Previous trainings attended were thorough and provided a lot of psychoeducation."
"I can recognize symptoms and how these effect individuals behavior and functioning."
"When I worked as a drug and alcohol counselor, we had several patients who had children with FASD. It was also covered in my nursing program and during my first hospital job."
"Lived experience. CSAC for over 20 years."
"Medical school and resident training on FASD."

When asked what would make them more comfortable, more than a third of respondents specifically mentioned the word "training" as key to comfort.

What education, training, resources, or supports would make you feel more comfortable screening, assessing and/or diagnosing FASD?

"Training specifically on screening tools, assessment tools, and/or diagnosing FASD."
"Open to all trainings for FASD"
"Learning more about the screening tools and ways to get an individual properly diagnosed yearly trainings on FASD."
"Training on the specific symptoms, diagnostic criteria, testing tools."
"I've only received basic training on symptoms, facial features, and mother's hc to help assess for FASD. Would like more in depth training on diagnosis and treatment, as well as community and school supports."

"Relearning what FASD is, the effect of FAS to persons from birth to adulthood, education on screening tools, and management for person(s) with FASD."
"I would like more trainings about warning signs and symptoms of FASD."
"Including screening questions and flagging the potential of FASD is something that I do but I am still uncomfortable with giving a formal diagnoses without confirmation of use by the mother and without full comprehensive psychological/neurological testing."
"Assessment training and education on warning signs of FASD"
"Workshops, training programs towards a certification, clinical experience, etc"

Barriers to FASD screening center on stigma along with a lack of awareness and lack of resources more broadly

It was also suggested that the benefits of screening are not touted enough

What are some of the barriers or challenges that you believe could prevent people from getting screened for Fetal Alcohol Syndrome in Hawai‘i?

“Shame, knowledge, time, accessibility to local testing centers or hospitals.”
“They do not know it exists; lack of knowledge of where to go for testing; what are the signs to look out for.”
“Stigma. Being ashamed; labeled as a "bad parent" Don't want their child to be labeled Does not think screening applies to them.”
“Stigma, doesn’t have health insurance, afraid, transportation or people feeling shame or embarrassment.”
“If youth is with bio-family, discomfort around disclosure of pre-natal alcohol consumption. If in foster care, incomplete history/unable to verify in-utero consumption.”
“Mostly suspicion of FASD, lack of awareness of this as a possibility in children with developmental delays”

“Discomfort with talking about Substance Use Disorders.”
“Fear; not knowing how to access; denial of exposure or use of alcohol.”
“Biggest barrier: Professionals are not sufficiently trained to understand FASD and don't know how to diagnose or intervene appropriately.”
“Shame; they don't know this resource is available to them; they don't know what FAS is.”
“Lack of education on the utility of doing this.”
“Availability/accessibility of resources on Molokai.”

Respondents gave kudos to the FASD Action Group, called for greater public awareness, and expressed interest in more training, including on neighbor islands

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?

"With all the competing diagnoses and a prevalence rate of 5% that sounds like an uphill battle for mostly anybody outside of pediatrics. Maybe more awareness, but for who? Providers or for parents? Adoptive parents may be more interested In learning about childhood diagnoses. I'm not sure they are told about RAD. Both FASD and RAD seem like they might be important to adoptive parents, even fosters."

"Screening and diagnosis are challenging to perform in busy clinical practices and resources to serve these individuals are extremely limited. Adding FASD as a qualifying diagnosis for services for the Developmentally Disabled would facilitate access to some services."

"Providing more education to the judiciary where it can be a struggle to work with FASD clients and complying with court orders they may or may not fully understand."

The Action Group does an amazing job educating, informing and raising awareness about the issue. Would it be possible to partner with the DOH, hospitals, AMA, JABSOM, etc to do a public service announcement to raise awareness about prevention and screening?

"Training on neighbor islands"

"There used to be a team that focused on this in Hawai'i (even on Moku o Keawe) and I haven't heard of another team being re-established in years."

"The Action Group has done such a wonderful job with putting in efforts to bring about awareness and legislation. It seems like time is still needed for more providers being able/willing to diagnose and treat."

"Resources to give to people who are interested or even contact information or help line people can call if they have questions."

"Training and education would be great if it was available here on Lānaʻi."

Any increased awareness and education is helpful, in my opinion.

A couple health care pros questioned the need for FAS diagnoses, or at least what is currently offered

Hawai'i FASD (Fetal Alcohol Spectrum Disorders) Action Group

grove insight

Summary of Findings

Summary of Findings

Providers are at least somewhat familiar with the effects of alcohol during pregnancy and Fetal Alcohol Spectrum Disorder (FASD).

- Though less than 30% say they know "a great deal" about alcohol impacts during pregnancy with just slightly more contending they are "very familiar with Fetal alcohol Spectrum Disorders.

Most agree that FASD is a serious issue with some prevalence in Hawai‘i.

- While most say FASD is a serious issue, there is division over the extent to which it is seen as a "very" or "somewhat" serious issue here. By a margin of 13 percentage points, mental health professionals are more likely than their primary care counterparts to consider FASD to be "very serious."
- FASD is considered to be at least "very" common in Hawaii, suggesting that it warrants more attention by the medical community.
- Moreover, nearly all Providers agree that screening of keiki for FASD is important. They are less adamant when it comes to the importance of FASD screening in adults.

Despite its importance, most are not familiar with the screening tools at their disposal and therefore not comfortable screening and diagnosing FASD.

- Roughly half of those with knowledge of FASD say they rarely if ever apply their knowledge of FASD to their practice.

Summary of Findings

- Relatively few have administered a screening tool or have been part of a diagnostic evaluation. Despite this, one-third have worked with patients with FASD diagnoses.
- Those who feel capable of screening and diagnosing FASD are comfortable mostly because of training, schooling, or necessity due to prevalence of FASD in their patient demographics. Those who aren't point to a lack of training and unfamiliarity with screening tools.
- With near unanimity, survey respondents agree that screening, assessing, and diagnosing these young patients is critical, rendering it unnecessary to convince providers of the importance. What they may not fully understand, however, is how to use current screening tools.

When questioned about barriers, many point to lacking expertise with screening and diagnostic tools. Stigma, lack of resources, and lack of public awareness are also important factors.

- While considered essential, many don't know how to screen, assess, and diagnose infants and young children, let alone treat and manage these patients. The good news is that a plurality wants to better understand, diagnose, and treat their patients. **"Training"** was the word mentioned most often in the open-ended questions.
- Most providers are at least "very interested" in receiving more training, including on neighbor islands.

Mahalo!

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Hawai'i FASD (Fetal Alcohol Spectrum Disorders) Action Group

ALOHA FRIENDS AND MAHALO FOR YOUR INTEREST IN PARTNERING ON PUBLIC AWARENESS AROUND THIS IMPORTANT PUBLIC HEALTH ISSUE!

PLEASE READ CAREFULLY:

OUR CRITICAL POINTS OF "PUBLIC AWARENESS" FOCUS:

"FASD is a Kākou Thing"-because alcohol is legal and holds nearly ubiquitous/wide-spread use in our communities we acknowledge ***we all have a part*** in educating, raising awareness and supporting healthy and alcohol-free pregnancies (localized SERIES-general public)

"Let's Learn Together"-because ***FASD is a really complex public health issu***e that ***affects people across the lifespan***, there is SO much we still need to learn and understand across systems of care (localized SERIES-providers)

"Compassion, Curiosity, Community"-because ***alcohol use and pregnancy are both really complicated*** we can work reduce shame, stigma, and perceptions around "poor choices" or neglectful systems, so ***we must commit to nonjudgement and collective action***.

"Invisible No More"-***screening, assessment, and diagnosis can be challenging, and neurological effects often present as "behavioral."*** When our communities feel comfortable being honest, helpful, and kind, more pregnancies will be healthier, more people will talk about it and advocate, and ***those who may be affected will get the support they need.***

"From FASD-Informed to Thriving"-just like all of us, individuals affected by FASDs can live full and amazing lives. When strengths are the primary point of focus and ***systems, relationships, and support are FASD-Informed***, life can be filled with joy, creativity, and purpose.

Please visit this site to read stories of FASD Changemakers around the world: https://alcfasdchangemakers.org/alc/

While it is correct that "no amount" of alcohol is safe to consume during pregnancy, we are asking that our public awareness partners avoid any oversimplified language that doesn't include complex considerations of social and environmental drivers of health and behavior.

"100% Preventable" messaging, implications around maternal behavior, or fetal imagery, can be inadvertently shaming and we are consciously choosing not to use them in our messaging. *This is in alignment with both our National Affiliate's recommendations and our Values.*

www.fasdunited.org/stamp-out-stigma

We realize that this is a complicated, sensitive, and nuanced issue, and hope to approach it as such, please do contact us directly if you have any questions or input.

If you choose to partner with us, we will provide you with guidance, and as many direct materials (media and printed) as we're able to, however, we encourage you to truly make "FASD a Kākou Thing" and include elements you feel are relevant to your community and organizations.

Mahalo again... together we can make FASD "Invisible No More"!

Sincerely,

Amanda, Erin & the FASD Action Group

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SAMPLE