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Testimony COMMENTING on SB318 SD1
RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS.

SEN. DONOVAN DELA CRUZ, CHAIR
SENATE COMMITTEE ON WAYS AND MEAS

Hearing Date: February 22, 2023 Room Number: 211

Fiscal Implications: Unspecified general fund appropriation.

Department Testimony: The Department of Health (DOH) published a report in 2009 identifying many of the issues that prevent wider recognition and diagnosis of FASD. After many years of proposed task forces and working groups, the department recommends moving forward with a pilot to implement the findings of the 2009 paper.

A copy of this report is available online here and is attached to this document: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3360082/

The major findings were that private healthcare providers must organize differently, specifically that "Hawaiʻi does not yet have the type of multi-disciplinary team described in the Canadian literature set up to assess and diagnose FAS cases."

If appropriated, DOH will issue a request for proposal to implement the recommended co-management system where the "Primary Care Provider (PCP), the Behavioral Health Provider (BHP), and FASD specialist (Genetics, Pediatric Neurology, Developmental-Behavioral, other) each plays a specific role. The PCP will refer a patient who screens positive to an FASD specialist;

1. One or more FASD specialists will make the diagnosis, establish a treatment plan, and refer the patient back to the PCP (with the assessment and written treatment plan);

2. The PCP will refer the patient to BHPs in accord with the treatment plan; appropriate information, including the FASD specialist(s) assessment and treatment plan, will be sent;
3. The PCP and/or BHP will involve the patient's family and school as recommended in the treatment plan;
4. The BHPs will provide the treatment (medication and other modalities); the BHP will provide periodic reports to the PCP;
5. The PCP will monitor the patient's progress from patient contact and communication from the family, school, and BHPs, as indicated;
6. If the patient's progress is not satisfactory, the PCP will refer the patient back to the FASD specialist;
7. The FASD specialist will reassess the patient, modify the treatment plan as necessary with input from the PCP and BHP, and refer the patient back to the PCP."

Thank you for the opportunity to testify.

Offered Amendments: N/A.

PUBLIC HEALTH HOTLINE

JAY MADDOCK PHD AND DONALD HAYES MD, MPH, ASSOCIATE EDITORS
TONYA LOWERY ST. JOHN MPH AND RANJANI RAJAN MPH, MANUSCRIPT EDITORS

A Proposal for Achieving Health Equity for Fetal Alcohol Spectrum Disorders

David T. Sakamoto MD; Deputy Director, Hawai‘i State Department of Health

At an intuitive level Health Equity (HE) is a straightforward concept — everyone should have good health and have access to quality healthcare services. Yet, when looking at groups within the United States — and within Hawai‘i — clearly there are differences in health status, access to care, and the quality of care available. And when the differences are significant and fall along dimensions that have usually reflected discrimination, these differences can become disparities, and a sense of injustice arises.

The Centers for Disease Control & Prevention (CDC) is one of the principal governmental institutions charged with promoting HE. They see the inequalities in health status in the United States as “large, persistent and growing.” The main risk factors cited in a recent monograph are: poverty, income and wealth inequalities, poor quality of life, racism, sex discrimination, and low socioeconomic conditions. Their goal, then, is to ensure that everyone has the opportunity to attain his or her full health potential, as measured by length of life, quality of life, rates of disease, disability and death, severity of disease, and access to treatment.[1]

An aspect of healthcare that can also create access barriers is the stigma carried by certain diagnoses, such as Hansen’s at one time and more recently, HIV/AIDS. The CDC accepts that negative attitudes can pose barriers for persons needing treatment for a mental illness, as well. To understand, quantify, and trend attitudes towards mental illness, two questions were recently added to their Behavioral Risk Factor Surveillance System (BRFSS). The results showed that most adults (89%) agreed that treatment is effective. But fewer (57%) agreed that “other people are caring and sympathetic toward those with mental illness.” The most revealing statistic concerns the responses of people with mental health symptoms: fewer than one in four (24.6%) agreed that “other people are caring and sympathetic toward those with mental illness.”[2]

The health equity issues regarding behavioral health have been known (and tacitly accepted) forever. They deservedly will be explored in much greater detail later this year. The remedy, though, involves the “integration” of behavioral health and primary care, which will take a substantial modification of the cultures of these specialties and professions. Because of the size and complexity of the task, a useful approach might be to target one specific behavioral health diagnosis, improve the way the condition is managed, then scale up. This paper will discuss the Fetal Alcohol Spectrum Disorders (FASD) and outline the steps needed to move toward this “integrated” model.

Note that FASD is not a mental illness like schizophrenia or Attention Deficit Hyperactivity Disorder (ADHD), but 96% of the individuals with Fetal Alcohol Syndrome (FAS) in one study had a comorbid mental health diagnosis.[3] And many of the manifestations of FAS are behavioral in nature, so that patients become subjected to the same negative attitudes. Thus, changing the system of care for FASD is an appropriate starting point.

Proposal for a New System of Care for a Very Old Disease

“Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus,” the Institute of Medicine noted in their report to Congress in 1996.[4] The consequences of prenatal exposure to alcohol on the developing brain were described by the Greek philosopher, Aristotle, who wrote, “Foolish, drunken and harebrained women, most often bring forth children like unto themselves, morose and languid.”[5] The first description of the teratogenic effects of alcohol in the medical literature appeared more than four decades ago, but for many reasons getting affected children into an appropriate treatment program has remained stubbornly elusive. Considering that the prevalence of Fetal Alcohol Spectrum Disorders (FASD) is at least as frequent as the autism spectrum disorders and the estimated lifetime cost to society of each case exceeds $2 million,[6] this disorder has received surprisingly little attention.

What is FASD?

“FASD” is an umbrella term that encompasses the wide array of abnormalities caused by in utero exposure to alcohol. These developmental disorders are physical as well as neurobehavioral and can affect each person in different ways, such that there is no typical “FASD profile.” The Fetal Alcohol Syndrome (FAS) is the best known variant of FASD (the only one that is an ICD-9, 10 diagnosis) and often manifests more severe signs and symptoms. FAS children tend to present with distinct facial characteristics, cognitive impairment (low IQ), growth deficiency, poor memory, coordination difficulties, learning disabilities, attention deficits, hyperactivity, and problems with impulse control, language, memory, and social skills. The heart, kidneys, eyes, ears, and limbs may be involved.[7]

Prevalence

The prevalence of FASD has been thought to be about 1% of live births. But in May, 2009 the US Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA) estimated that the real rate could be five times that. To illustrate this point, in a year-long study of youths remanded for a forensic psychiatric assessment in Canada 23.3% were diagnosed with FASD, whereas only 1% carried the diagnosis pre-study.[8] Each year in Hawai'i there are around 18,500 live births. Applying the national statistics, conservatively, there are 185 new cases of FASD each year, but the number could be much higher.

Diagnosis of FAS and Related Considerations

Part of the reason for the wide range in the prevalence estimate is the difficulty in making a firm diagnosis. Unfortunately, there is no specific test for FAS. And other disorders, such as attention-deficit/hyperactivity disorder and Williams Syndrome, share some of the same features. The anomalies seen on neuroimaging studies, such as MRI, are not specific to FAS because the developing brain may be susceptible to alcohol throughout gestation; thus the structural part of the brain that is being formed at the time of exposure sustains the injury.[9] Three highly regarded organizations have developed diagnostic criteria for FAS; each requires the presence of specific facial abnormalities, lower than average height/weight, neuro-behavioral deficits, and prenatal alcohol exposure (confirmation is not an absolute requirement). The neuro-behavioral criteria can be difficult to appraise, prompting a Canadian group to recommend the use of a multidisciplinary team (psychologist, occupational & physical therapists, speech pathologist, social worker, and physician) to assess each child — at substantial cost.[10]

FAS falls on the severe end of the Fetal Alcohol spectrum. Many cases will fall short of the FAS criteria, but nevertheless should be considered alcohol-related neurodevelopmental disorders or birth defects. The prevalence of these less-severe cases may be 3 to 10 times higher than FAS. Presently no consensus has been reached on FASD criteria.[11]

Beyond these clinical issues, primary care providers (PCP) may be reluctant to make the diagnosis for non-technical reasons. The stigmatization issue is a factor for the child and the mother, which may affect the provider/patient relationship. Concerns about a "safe environment" may arise because of substance abuse, and these concerns can be an indication to involve social services. Hence, side-stepping these issues with an alternative diagnosis might have advantages, but there also can be consequences. Table 1 points out how the treatment of different conditions with similar manifestations can diverge markedly.

Treatment

The damage to the central nervous system caused by alcohol is irreversible and has lifelong implications. The natural history of FAS has shown that these patients are at great risk for "adverse life outcomes," such as encounters with the criminal justice system, substance abuse, and inappropriate sexual behavior. These risks can be significantly reduced by families, communities, and healthcare providers working together to create a stable environment with enduring relationships and an appropriate treatment regimen. Early diagnosis and intervention (before 6 years of age) appears to be the key.[13]

Table 1. (Source: Dan Dubovsky, SAMHSA FASD Center for Excellence)[12]

Behavior: Takes risks	**Core Cause of Behavior**	**Intervention**
Fetal Alcohol Spectrum Disorders	• Does not perceive danger	Provide mentor; utilize a lot of repeated role playing
Attention Deficit Hyperactivity Disorder	• Acts impulsively	Utilize behavioral approaches (eg, stop and count to 10)
Oppositional Defiant Disorder	• Pushes the envelope; feels omnipotent	Psychotherapy to address issues; protect from harm
Behavior: Does not complete tasks	**Core Cause of Behavior**	**Intervention**
Fetal Alcohol Spectrum Disorders	• May or may not take in information • Cannot recall information when needed • Cannot remember what to do	Provide one direction at a time
Attention Deficit with Hyperactivity Disorder	• Takes in information • Can recall information when needed • Gets distracted	Limit stimuli and provide cues
Oppositional Defiant Disorder	• Takes in information • Can recall information when needed • Choose not to do what they are told	Provide positive sense of control; limits and consequences
Behavior: Hits others	**Core Cause of Behavior**	**Intervention**
Fetal Alcohol Spectrum Disorders	• Someone told them to • Misinterprets intentions of others • May sense bump as attack • May respond from history of abuse	Deal with misinterpretations at the time; one-to-one support
Attention Deficit Hyperactivity Disorder	• Frequently an impulsive act	Behavioral approaches to address impulsivity
Oppositional Defiant Disorder	• Plans to hurt others • Misinterprets intentions of others as attack or impending attack	Consequences; cognitive behavioral approaches

While there is no specific cure for FASD, medication may be used to mitigate some of the symptoms. Additionally, a number of treatment approaches have shown positive results. These include education therapy directed at specific skill-building, parent training, and behavior therapy.[14]

Total FASD Patient Care Requirements

A complete FASD program must take a multi-factorial approach that includes the primary prevention of this 100% preventable diagnosis, the screening of infants and children, and the provision of diagnostic and therapeutic services. Although each of these areas needs expansion, the lack of an available FASD "track" is, with some possible exceptions, the glaringly omitted piece.

1. Prevention: identify women at risk for binge drinking; provide an effective intervention to stop alcohol use; public education on the effects of alcohol during pregnancy
2. Screening of infants, toddlers and children
3. Referral to appropriate healthcare providers
4. Entry into an FASD "track" with a preplanned set of diagnostic and therapeutic steps

Government's Role: the Hawai'i Department of Health has had a multi-pronged public health strategy for its FASD program that includes, alcohol prevention programs, social service interventions, screening clinics, the development of screening tools, data-gathering through the CDC's Pregnancy Risk Assessment Monitoring System, the development of family education material, support for provider education, and efforts to improve communication and collaboration among the different disciplines. The state will strive to maintain and expand its programs over the coming years.

A full treatment of FASD is beyond the scope of this paper. Because Health Equity is a central theme in the care of FASD patients, the remainder of this paper will be devoted to the development of a model of care that improves outcomes and increases HE. To accomplish this, a system of care has to be created that leverages existing resources to make a definitive diagnosis, to provide appropriate therapy, and to modify the treatment plan depending on reassessment results. Ultimately, at least in this context, primary care and behavioral health have to move into a more coordinated relationship, which will help reduce mental health stigma and discrimination.

Clinical experts in Hawai'i relate that currently, behavioral health and primary care providers generally continue to operate in separate silos with minimal sharing of information. From the standpoint of many (if not most) of the PCPs in Hawai'i, behavioral health services are obtained from a specialist through a formal consultation.

General Constraints Within the Hawai'i Delivery System

- A majority of PCPs practice in solo or small group practices (<5 providers)
- Many of the PCPs and Behavioral Health Providers are early in the implementation of electronic health records and are generally not able to share information electronically
- PCPs are often not comfortable in making the diagnosis of FAS
- PCPs often will not provide an extensive range of behavioral health treatment services
- Hawai'i does not yet have the type of multi-disciplinary team described in the Canadian literature set up to assess and diagnose FAS cases
- Hawai'i has a small number of FASD specialists

System of Care After Screening of a Pediatric Patient

This proposal is for a co-management system where the PCP, the Behavioral Health Provider (BHP), and FASD specialist (Genetics, Pediatric Neurology, Developmental-Behavioral, other) each plays a specific role. There will be a single treatment plan and appropriate sharing of information.

1. The PCP will refer a patient who screens positive to an FASD specialist;
2. One or more FASD specialists will make the diagnosis, establish a treatment plan, and refer the patient back to the PCP (with the assessment and written treatment plan);
3. The PCP will refer the patient to BHPs in accord with the treatment plan; appropriate information, including the FASD specialist(s) assessment and treatment plan, will be sent;
4. The PCP and/or BHP will involve the patient's family and school as recommended in the treatment plan;
5. The BHPs will provide the treatment (medication and other modalities); the BHP will provide periodic reports to the PCP;
6. The PCP will monitor the patient's progress from patient contact and communication from the family, school, and BHPs, as indicated;
7. If the patient's progress is not satisfactory, the PCP will refer the patient back to the FASD specialist;
8. The FASD specialist will reassess the patient, modify the treatment plan as necessary with input from the PCP and BHP, and refer the patient back to the PCP.

There are two caveats. This proposed "system of care" is just a set of guidelines. To get the desired outcomes, the providers will have to consciously agree to assume specific duties that they perhaps have not performed in the past. Some of the new responsibilities, such as more frequent and detailed communication or participation in case conferences, may have no additional reimbursement.

Although this proposal represents a significant change from current practice, it only creates a "collaborative model." The providers work together, but from the patient's point of view the behavioral health treatment is still a separate service that comes from a specialist so that some of the stigma may yet remain. This undertaking, however, is a necessary first step toward an "integrated model," where behavioral health is part of primary care, and patients perceive it as a routine part of their health care.[15]

Change in the system of care doesn't happen overnight, as least not in healthcare. But providers should begin to think about the issues presented in this paper, FASD, health disparities surrounding behavioral health, and the possibility of a more integrated delivery system. And that is the purpose of this paper.

Providers will have to be given more information, such that they have a clear understanding of their roles, what to expect from their clinical colleagues, and the risks and benefits to all parties, particularly the child and his or her family. Free and open dialogue will be a critical part of the change process; for this reason co-located providers (same practice setting) should have an easier time moving forward. Perhaps early adoption of this change should be done in a more controlled environment with external support and data-gathering capability. Regardless, it's time to make the CDC's measures of health equity in this area trend upward. A new system of care for a very old disease seems like a good place to start.

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February 22, 2023

The Honorable Senator Donovan M. Dela Cruz, Chair
Senate Committee on Ways and Means
The Thirty-Second Legislature
State Capitol
State of Hawaiʻi
Honolulu, Hawaiʻi 96813

Dear Senator Dela Cruz and Committee Members:

SUBJECT: SB318 Related to Fetal Alcohol Spectrum Disorders

The Hawaii State Council on Developmental Disabilities **Supports SB318,** which establishes the Fetal Alcohol Spectrum Disorders Task Force within the Department of Health. Requires a report to the Legislature. Dissolves the task force on 7/1/2024. Appropriates moneys to the Department of Health to establish and support the work of the task force. Authorizes the Department of Health to contract with a third party to assist the task force..

Fetal Alcohol Spectrum Disorder (FASD) is an underdiagnosed and underrepresented developmental disability in our state. There is no concrete way to make a diagnosis and FASD can share symptoms with other developmental disabilities and learning disabilities. From a 2012 study looking at the prevalence of FASD a conservative estimate was 1% of our population. However, the study noted that this estimate is most likely on the low end, and the real rate could be up to 5%. For perspective, the current prevalence rate for all intellectual/developmental disabilities is 1.58 percent of our population. Even at 1% prevalence rate FASD would make up a significant portion of our I/DD community.

In Hawaii FASD's first hurdle is in screening and diagnostic tools. The Council appreciates this measure specifically having the task-force look at what screening tools are best for our state. Thank you for the opportunity to submit testimony in **support of SB318.**

Sincerely,

Daintry Bartoldus

Daintry Bartoldus
Executive Administrator

SB-318-SD-1
Submitted on: 2/20/2023 8:07:56 PM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Support	Written Testimony Only

Comments:

This is an issue that has been a high priority of ours for several years. Section 1 of the bill very aptly lays out the nature and extent of the problem. Individuals with FASD fall into a true gap group. Given the fairly restrictive eligibility criteria for mental health or developmental disabilities services they may well not qualify for either. Yet they exhibit behavior that might parallel those conditions and have needs that are just as significant. Efforts in the past have focused on education about the dangers of alcohol consumption while pregnant. However, much more is needed. These people really need services. The original version pf the bill proposed to form a Task Force which would be a good way to bring stakeholders together to help develop a plan to put that in place. We certainly support the SD1 version which goes further and sets up a pilot project to actually deliver the services. While we are a little unclear as to how this pilot project will work, we certainly appreciate the attitude of the Department of Health and the Senate Committe on Health and Human Services who both felt that it was time to go beyond a Task Force and "do more".

THE SENATE
KA ʻAHA KENEKOA

THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON WAYS AND MEANS
Senator Donovan M. Dela Cruz, Chair
Senator Gilbert S.C. Keith-Agaran, Vice Chair

NOTICE OF DECISION MAKING

DATE: Wednesday, February 22, 2023
TIME: 9:30 AM
PLACE: Conference Room 211 & Videoconference

State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT SB 318 SD1**

Dearest Chair, Honorable Senator Donovan M. Dela Cruz

and Vice Chair, Honorable Senator Gilbert S.C. Keith-Agaran and members of the Ways Means

Committee.

I am Darlyn Chen Scovell, a volunteer advocate for families and children with FASD (Fetal Alcohol Spectrum Disorder) and the Hawaii FASD Action Group. Being the voice of children who have none and individuals with FASD who have been marginalized, unrecognized, and without help, attention, and services for many, many years. I am writing in **STRONG SUPPORT of SB 318 SD1**

I am again pleading and humbly requesting for your VOTE, SUPPORT and to PASS SB 318 SD1 out of your committee. I am reaching out for your help in my fight for FASD Services and Community Awareness with a Noble Objective of *decreasing the number of babies born with FASD in Hawaii, spearheading the much-needed services and understanding of this invisible disability, FASD.*
FASD diagnosis is a processing disorder, learning disability, and attention-deficit/ hyperactivity disorder, similar to Autism Spectrum Disorders however distinctly VERY DIFFERENT. The NEURODEVELOPMENTAL IMPAIRMENTS associated with FASD came WITH SIGNIFICANT SOCIAL COST ACROSS THE LIFESPAN in increased medical, educational, and vocational support and lost productivity. I have worked with children with Autism as a Registered Behavioral Therapist under ABA Guidelines. In my observations, FASD is a Developmental Disability that is equally as severe as Autism, with the significant challenge that **FASD disability is NOT VISIBLE**; they look like you and me, and their IQ may pass as normal initially, but the damage is in the brain, neurological damage caused by ALCOHOL consumption during pregnancy. This is a CAUSE SPECIFIC AND PREVENTABLE.

Unfortunately, alcohol advertising fails to inform adequately about the dangers associated with alcohol use by childbearing-age consumers. The label adopted by the alcohol industry suggests that alcohol should be avoided during pregnancy because of the risk of birth defects, which may occur before a woman knows she is pregnant. Since many pregnancies are unplanned or mistimed, women may unintentionally expose their offspring to alcohol without realizing it. **Not all women have regular**

monthly menstrual cycle/periods and many do not know that they are pregnant thus consume alcohol without intentions to become pregnant. Multiple organs of the fetus are at risk of damage from the teratogenic effects of alcohol crossing the placenta. The trajectory and long-term outcomes of those with **Prenatal Alcohol exposure (PAE)** were initially shrouded in mystery. Practitioners in the field then adopted the term invisible disorder for the consequences of Prenatal Alcohol Exposure. According to the *DSM-5,* the diagnostic terms fetal alcohol spectrum disorder (FASD) or neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE) describes the combined challenges and strengths common in people whose mothers consumed sufficient alcohol at the threshold known to be associated with adverse neurobehavioral effects. Individuals diagnosed with Neuro Developmental-Prenatal Alcohol Exposure suffer primarily from cognitive and intellectual deficits, including the areas of learning and memory, language, attention, executive functioning, and adaptive and social functioning (Mela, 2023). Experts estimated that 2% to 5% of U.S. schoolchildren—as many as 1 in 20—are affected by prenatal alcohol exposure, which can cause complications with growth, behavior, and learning (APA, 2022). The prevalence of fetal alcohol spectrum disorder (FASD) in the United States may be much higher than previous estimates have indicated. Researchers reported in the February 6 JAMA that in four communities they studied, as much as 1.1 percent to 5 percent of first-grade children were affected, and those were conservative estimates (Moran, 2018).

Numerous scientific studies have shown that early diagnosis prevents secondary disabilities, such as school failure, juvenile delinquency, mental health problems, homelessness, and unemployability. Individuals with undiagnosed FASD often end up as recidivist clients in institutional settings, including jails, mental health programs, psychiatric hospitals, and homeless shelters. Do you know that we send our FASD Students needing care to the mainland, which costs us $18,000.00 monthly, paid by the Hawaii Department of Education? Our very own Hawaii family is willing to come forward to provide details of this information. According to the Hawaii Department of Public Safety, the state spends about **$140 per inmate per day**, which includes program services, food, health care, and administrative costs. When you add it up, that amounts to $51,100 per year per prisoner locked up in Hawaii. This data was dated in 2016, and I am sure it is much more now. Our Hawaii State records show the cost to transport prisoners to and from the mainland **—** and to house them **—** have grown tremendously. In 2016, the state flew a total of 650 inmates to or from Saguaro at the cost of $871,213, which works out to about **$1,300 each way per inmate. There are current indicators that most of our inmates have FASD, most especially repeat offenders.**

The support for FASD research and services is limited. The National Institute on Alcohol Abuse and Alcoholism funds innovative research on FASD, said Christie Petrenko, Ph.D., a clinical psychologist and research associate professor at Mt. Hope Family Center, University of Rochester, and co-director of the FASD Diagnostic and Evaluation Clinic. Despite everything, the Substance Abuse and Mental Health Services Administration (SAMHSA)–funded FASD Center for Excellence program was shuttered in 2016, leaving a big gap between research and practical solutions for children and families affected by FASD. Currently, a bipartisan bill before Congress, the FASD Respect Act, would support FASD research, surveillance, and activities related to diagnosis, prevention, and treatment. (APA has endorsed this bill.) Our legislators have fully supported the FASD Respect Act from Hawaii to Washington, DC, which I was also involved in.

I am fortunate to have letters to the Congressional Delegation to Capitol Hill to seek all our Washington, DC representatives to Co-Sponsor the FASD Respect Act. ALL of our representatives in Washington DC signed and Co-Sponsored S.2238 — 117th Congress (2021-2022) and H.R.4151 - FASD Respect Act - 17th Congress (2021-2022) Advancing FASD Research, Services, and Prevention Act or the FASD Respect Act. With this in line, we need to have an action plan and services for our families and children with FASD in Hawaii. **Our nation and the world now recognize this is an existing problem that needs action and support.** I hope you will be another Champion for this invisible disability population clouded by the stigma that their own mothers with guilt, shame, and fear of being judged, refuse to come forward to fight for these children. These children were said to have fallen into the cracks of our society, and I begged to disagree; they have fallen over the cliff and were forgotten.

Please help me help these children and families impacted with FASD. Please **VOTE to PASS SB 318 SD1.** Thank you so much. Please do let me know if there is anything else I can do to help this population who they say have fallen into the crack of our society and in my opinion, they fallen on the cliff and have been forgotten. FASD children who have an invisible disability – INVISIBLE NO MORE!

These children are born in an impossible world ~ Please let us make this world possible for them.

Thank you so much for your kind consideration.

Always with Gratitude.
Respectfully yours,
Darlyn Chen Scovell

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FASD United
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS

On behalf of FASD United, I am pleased to submit written testimony expressing wholehearted support for S.B. No. 318 entitled: "A BILL FOR AN ACT RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS."

FASD United is a public health nonprofit organization and the national voice on fetal alcohol spectrum disorders (FASDs) dedicated to supporting individuals and families living with FASDs and preventing the harmful effects of prenatal alcohol exposure.

Studies supported by the Centers for Disease Control and Prevention and the National Institutes of Health show that at least 1 in 7 newborns are prenatally exposed to alcohol that can impair human development and as many as 1 in 20 adolescents have identifiable developmental disabilities associated with prenatal alcohol exposure.

Despite alarming rates that make FASDs more pervasive than autism spectrum disorders, numerous factors have hindered clinical, legislative, and public recognition of FASDs. Individuals with FASDs have a comparatively unique constellation of diseases and conditions complicating universal clinical recognition of the disorders. Published research has identified 428 medical diseases, congenital malformations, deformities, chromosomal abnormalities, and mental and behavioral disorders that can occur in individuals with FASDs. A lack of FASD-informed practitioners and systems of care, public, institutional and self-stigma surrounding FASDs, and resistance to public health messages to abstain from alcohol during pregnancy, have also hindered appropriate recognition and investment in FASDs.

FASD United strongly supports the approach proposed in S.B. No. 318 requiring the Department of Health to establish and administer a five-year pilot program to implement a co-management system of care for the diagnosis and treatment of FASDs that specifies the operational procedures of the co-management system of care, including the responsibilities of the primary care provider, FASD specialist, and behavioral health provider.

S.B. No. 318 is a thoughtful and essential step toward understanding the significance of FASDs, assessing the needs of affected children and adults, and integrating FASD services into systems of care. The successful implementation of the pilot program will bring FASDs out of the shadows, establish the protocol for the management of FASDs, fulfill the promise to support disadvantaged populations, save taxpayer resources, and serve as a model for other states.

Hawaii FASD Action Group is a vital leader on behalf of individuals, their families, and the communities of Hawaii and an important contributor to the FASD global community. FASD United is pleased to collaborate with the Hawaii FASD Action Group team as a member of the FASD United Affiliate Network—and all agencies, professionals, and advocates across the state—to ensure that individuals affected by FASDs receive the support and services they deserve.

FASD United is grateful to the Hawaii State Legislature, Hawaii State Senate, Senate Committee on Health and Human Services, State Council on Developmental Disabilities, Hawaii Disability Rights Center, Hawaii Fetal Alcohol Spectrum Disorders Action Group, Hawaii Substance Abuse Coalition, and the Hawaii Department of Human Services and Department of Health, for their commitment and actions to address FASDs. FASD United strongly urges passage of S.B. No. 318 and the appropriation of funds necessary to fully carry out its provisions.

SB-318-SD-1

Submitted on: 2/21/2023 8:35:32 AM

Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Cleota Brown	Testifying for Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group	Support	Written Testimony Only

Comments:

Dear Senator Dela Cruz, Chair, Senator Keith-Agaran, Vice Chair and Members of the Senate Ways and Means Committee:

On behalf of Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group, our Board of Directors and 200+ volunteers, **we strongly support SB 318 SD1, Relating to Fetal Alcohol Spectrum Disorders.** Requires the Department of Health to establish and administer a five-year pilot program to implement a co-management system of care for the diagnosis and treatment of individuals with fetal alcohol spectrum disorders, with funds appropriation approvals. (SD1).

Prenatal alcohol exposure (PAE) is the most commonly known cause of developmental disabilities in the United States and is a significan public health issue, exasperated by the COVID-19 crisis causing increased mental health issues and the targeted advertising and social media campaigns to increase the use of alcohol by women. There is no safe amount, type of alcohol or time during pregnancy that is safe for a fetus. In Hawai'i of the almost 17,000 babies born annually, as many as 840 are estimated to have a FASD.

The estimated average annual cost to Hawai'i from FASD is over $876M - while raising a child with FASD costs 30X more than the cost of successful prevention efforts.

This five year pilot program is a step towards protecting innocent children from lifelong brain damage and providing informed diagnosis and support services for young children to possibly live a meaningful and productive life.

We encourage and plead with all of you on Hawaii's Senate Ways and Means Committee to support and approve SB 318 SD1 and the funding necessary to support the Department of Health in developing a meaningful program for this invisible disability. We believe the funding costs for this program will be a small portion of the total costs today if the State of Hawaii, Department of Health continue to exclude FASD from it's support.

We wish to thank Senator Joy San Buenaventura and the Members of the Health and Human Services Committee for SB318 and their support in moving it forward.

We hope everyone on the Senate Ways and Means Committee will see this legislation for what it represents - **saving lives and protecting innocent children.**

Sincerely yours,

Cleota G. Brown, President

FASDHawaii.org

808-258-5874

HSAC
HAWAII SUBSTANCE ABUSE COALITION

LATE

SB318 SD1 FSAD Task Force and Funding

COMMITTEE ON WAYS AND MEANS
Senator Donovan M. Dela Cruz, Chair
Senator Gilbert S.C. Keith-Agaran, Vice Chair
Wednesday, Feb. 22, 2023: 9:35 : Room 211 Videoconference

Hawaii Substance Abuse Coalition supports SB318 SD1

ALOHA CHAIR, VICE CHAIR AND DISTINGUISHED COMMITTEE MEMBERS. My name is Alan Johnson. I am the current chair of the Hawaii Substance Abuse Coalition (HSAC), a statewide organization for substance use disorder and co-occurring mental health disorder treatment and prevention agencies and recovery services.

FASD is a preventable and treatable disability.

There are significant and increasingly improved interventions that are available for mental health issues such as Fetal Alcohol Spectrum Disorder and other disorders.

With home-based and community-based healthcare supported by a Task Force to improve access to essential services, we can make a difference.

FASD is a problem in Hawaii and efforts can be made to prevent this devastating condition as well as to treat children and adults that would increase their functioning:

- FASD is a range of neurodevelopmental (brain-based) disabilities that can affect any person exposed to alcohol before birth.
- FASD effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications that often co-occur with substance abuse and mental health issues.
- Proactive health care programs and interventions can help people develop new learning and coping skills to help them improve functioning. Modifications to existing treatment models can be very effective.
- FASD is very expensive to healthcare with estimates that the lifetime costs for each person is estimated to be over $2M.
- Individuals with FASD are involved with the criminal justice system at an alarming rate. Youth and young adults with FASD have a form of brain damage that may make it difficult for them to stay out of trouble with the law. Without the aid of proper treatment, they do not know how to deal with police, attorneys, judges, social workers, psychiatrists, corrections and probation officers, and others they may encounter.

We can make a difference:

- Understand the disorder and reshape some of our interventions to change a child's behavior and improve functionality.
- Reduce the prevalence of FASD.
- Empower care givers to help FASD people reach their full potential.
- Address stigma by educating our communities to understand the complexities of this disability while promoting a more inclusive culture.
- Greatly improve upon outcomes through measurement brought about by Medicaid funding.
- Reduce childhood trauma by increasing supports for high-risk families, building resilience, and improving access to treatment.

Working together, we can join the growing number of states that claim to be a "FASD-Informed State."

We appreciate the opportunity to provide testimony and are available for questions.

LATE

SB-318-SD-1
Submitted on: 2/22/2023 12:27:36 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Kristine Altwies, MA/LMFT	Testifying for A Family Tree/Pono Roots Counseling Center	Support	Written Testimony Only

Comments:

SB 318 RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS.

Aloha,

I am in support of SB 318, relating to Fetal Alcohol Spectrum Disorders and respectfully ask this committee to pass this bill. This proposal would bring long overdue attention, support, diagnosis, and most importantly action to one of the State's most invisible but nonetheless harmful disorders. Based on my 30 years work in child welfare and mental health in Hawai'i, I am confident that undiagnosed FASDs are rampant within the population in our prison and juvenille justice systems.

As someone who has worked with families in adoption and foster care for my entire career, I have witnessed first hand the destruction and devestation of families who adopt or foster children with undiagnosed and therefore untreated FASDs. Because FASDs are predominantly formed during the first trimester of pregnancy, a time when many women do not even know they are pregnant, the risk of exposing an unborn child to alcohol in utero is extremely high. This is tragically true for many communities that are already at risk in other ways.

This bill represnts a long overdue course correction in our communal relationship to a disorder that can have life-long, pervasive, and wide-spread effects.

Thank you for your consideration!

Kristine Altwies, MA/LMFT

Director of Hawaii International Child, DBA A Family Tree and Pono Roots Counseling Center

SB-318-SD-1
Submitted on: 2/17/2023 3:53:34 PM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Caroline Azelski	Individual	Support	Written Testimony Only

Comments:

In support of SD1. Thank you.

SB-318-SD-1
Submitted on: 2/19/2023 4:22:53 PM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Lea Minton	Individual	Support	Written Testimony Only

Comments:

I support SB318SD1 please pass this measure.

SB-318-SD-1
Submitted on: 2/19/2023 9:47:08 PM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Kenichi Yabusaki	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Dela Cruz, Vice-chair Keith-Agaran, and Members of the Ways and Means Committee:

I strongly support the passage of SB318 relating to the creation of s Task Force within the Department of Health to help those affected by Fetal Alcohol Spectrum Disorders (FASD). Previously, this Task Force was to be created for an infrastructure to receive when and if Federal monies were to be distributed by the passage of the FASD Respect Act in Washington. To this end, Hawaii's delegation unanimously supported the FASD Respect Act in the House and Senate in 2022. This same Bill will be reintroduced in Congress again.

The current SB318 is defective because it involves a five (5) year pilot program to find the prevalence of FASD in Hawaii. With Hawaii's 50% unintended pregnancy rate, increased binge drinking (alcohol), and a robust nationwide study on FASD that has already shown one in twenty (5%) first-grade children (conservative estimate) having an FASD, by extrapolation via Hawaii's 18,000 annual birthrates, nearly 900 individuals will be affected by FASD yearly. Thus, in five years, over 4,500 individuals will be affected by an FASD. There is no need for a prevalence study. FASD is here and now in Hawaii. What is needed is to develop a multidisciplinary infrastructure of FASD informed professionals (psychologists, occupational therapists, speech and language specialists, and the like) coupled with early solid intervention programs to address those affected by FASD and their caregivers (parents, foster care, etc.). How many more Parkland, FL mass killings (Nicolas Cruz who has FASD and killed 17 people), Ariel Kalua (Waimanalo), Kaniala Rapoza, Peter Boy, etc.) are needed (FASD never ruled out only given diagnoses of Autism spectrum disorders) must we witness to convince Hawaii that it has a huge FASD problem now? I strongly urge you to consider eliminating the five-year pilot study for prevalence and immediately build an infrastructure of professionals that can help those with FASDs and their families with early childhood interventions to prevent the problems in teenagers and adults who enter the prisons and homeless populations to no fault of their own. A five-year prevalence study is geared for "It's already late, then it's later, then it's too late." Thousands of individuals affected by an FASD live in Hawaii and can't receive services because our society does not understand FASD as a permanent lifetime brain condition. With approx 900 people affected each year. year it costs Hawaii millions of dollars. Please reconsider eliminating the five-year prevalence study and change it to using the five years to build an infrastructure of FASD-informed professionals with early intervention programs.

Thank you.

Kenichi Yabusaki, Ph.D.

SB-318-SD-1
Submitted on: 2/20/2023 2:19:49 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
mark matsushita	Individual	Support	Written Testimony Only

Comments:

As a Licensed Marriage and Family Therapist and a Certified Substance Abuse Couselor in Hawaii I fully support this bill. Fetal Alcohol Syndrome affects us at so many levels. Not only does it affect the individual famiolies but it also comes at a cost to society as well

SB-318-SD-1
Submitted on: 2/20/2023 9:47:26 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Jeremy Daniel	Individual	Support	Written Testimony Only

Comments:

I am in full support of SB 318. FASD is rampant in the state of Hawaii. Studies show that 1 in 20 kindergartners have it. That's 5% of the population! But there are currently no measures in place to support the diagnosis and treatment of individuals with an FASD. If we continue to ignore this population, we will continue to see an increase in crime, homelessness, and other social/economic issues that impact all of us.

To do nothing (as we have been doing) is completely irresponsible and lives are at stake.

Date: February 20, 2023

To: Senator Dela Cruz, Chair, Ways and Means Committee

Senator Keith—Aragan, Vice Chair

Members of the Senate Ways and Means Committee

From: Ann S. Yabusaki, Ph.D., LMFT

RE: Strong support of SB No. 318 (SD 1)

I am writing in strong support of SB 318 (SD 1) for several reasons:

1. The national statistics show that one in twenty first graders are affected by Fetal Alcohol Spectrum Disorders (FASD). (May, et. al, 2018).
2. Hawaii lacks a model of FASD-informed care to assess, diagnose, intervene, or prevent FASD.
3. Because FASD, a brain disorder due to drinking during pregnancy, is challenging to diagnose, many individuals are misdiagnosed and often enter into our criminal justice system, homeless population, substance abuse and mental health systems.
4. FASD is a life-long brain disorder and requires lifelong interventions.
5. Hawaii lacks a statewide system to track the number of people affected by prenatal exposure to alcohol.

FASD impacts so many of our systems of care and with lifelong intervention, affected individuals can be productive and live meaningful lives. There are many barriers to care—among others, providers who do not understand FASD, lack of an FASD-informed multidisciplinary assessment center, lack of continuum of care in our community for people and families affected by FASD.

I am a psychologist who has tried to steer families and individuals with high risk for FASD to resources in the community, only to find there are few, if any. The need for a multidisciplinary approach to assessing and diagnosing FASD includes a FASD-informed speech therapist, occupational therapist, physician, social worker, and others.

SB318 (SD 1) is a major first step in trying to address the complexities of FASD. Only through proper assessment can a diagnosis be reached and the number of affected individuals tracked.

I urge the committee to please consider how this bill could improve and save lives as well as reduce the cost for incarceration, homelessness, treatment for substance abuse or mental health.

Thank you for your consideration.

SB-318-SD-1
Submitted on: 2/21/2023 5:09:44 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Cheryl Harris	Individual	Support	Written Testimony Only

Comments:

I support this bill.

SB-318-SD-1
Submitted on: 2/21/2023 5:27:28 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Robert M Armstrong	Individual	Support	Written Testimony Only

Comments:

Aloha Senators,

As a concerned citizen and member of the Hawai`i Fetal Alcohol Spectrum Disorders Action Group, I stand in strong support of SB 318 SD1. Similar to our current understanding of autism, alcoholism and homelessness; fetal alcohol spectrum disorders (FASDs) may not be immediately obvious in society but is responsible for a long list of concerns for the individual, families and most importantly, our State.

SB 318 puts in place a reasonable and affordable multidisciplinary response to these concerns in order to identify, respond and treat those affected in our State. We need to begin to understand the complex and ellusive nature of this condition and its effects. In my opinion, SB 318 is that needed start.

It is also important to remind all that Hawai`i will diagnose more than 800 new individuals each year with this condition, joining the estimated 71,000 residents who already must contend with these symptoms. If left unaddressed, the problem will only grow in its magnitude and cost to society.

The proposed legislation is that response by providing for a five-year study to establish and administer a program of care with the Health Department. I have no doubt when implemented SB 318 will prove to be both cost-efficient and humane. Thank you for your affirmative vote and support.

Mahalo,

Robert M. Armstrong, Honolulu

(808) 859-4755

SB-318-SD-1
Submitted on: 2/21/2023 6:23:19 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Jamaal Wright	Individual	Support	Written Testimony Only

Comments:

I support this bill.

SB-318-SD-1
Submitted on: 2/21/2023 7:56:13 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Ken Farm	Individual	Support	Written Testimony Only

Comments:

Aloha Chair, Vice Chair, and Committee Members,

Position: STRONG SUPPORT

This is a prudent measure please allow for this to pass on to the House.

Mahalo,

Ken Farm

SB-318-SD-1
Submitted on: 2/21/2023 8:36:50 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Richard Ries	Individual	Support	Written Testimony Only

Comments:

I strongly support this compassionate and critical measure. I believe it to be our societal duty to provide care for those impacted and the pilot may assist with identifying how best to do so.

LATE

SB-318-SD-1
Submitted on: 2/21/2023 10:04:49 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Kaili	Individual	Support	Written Testimony Only

Comments:

i stand in support in Sb 318 Sd1.

LATE

SB-318-SD-1
Submitted on: 2/21/2023 12:24:41 PM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Joy Quick	Individual	Support	Written Testimony Only

Comments:

2/21/23

Senator Donovan M. Dela Cruz, Chair

Senator Gilbert S.C. Keith-Agaran, Vice-Chair

Members of the Senate Committee on Ways and Means

Re: SB318, SD1

I strongly support this bill and recognize the community's need to help children with FASD.

S. Joy Quick, MA, LMFT, CSAC

LATE

SB-318-SD-1
Submitted on: 2/21/2023 11:25:09 PM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Kelsi Yonting	Individual	Support	Written Testimony Only

Comments:

Being a voice for children and individuals with FASD, I am writing in STRONG SUPPORT of SB 318. I humbly ask that you VOTE, SUPPORT and PASS SB 318. Our future generations are depending on us to be intentional about their physical, emotional, and mental health.

LATE

SB-318-SD-1
Submitted on: 2/22/2023 12:04:17 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Amanda Luning	Individual	Support	Written Testimony Only

Comments:

I support this bill, please see previous testimony. Mahalo.

LATE

SB-318-SD-1
Submitted on: 2/22/2023 8:09:09 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Shaye Kimura	Individual	Support	Written Testimony Only

Comments:

This is a very important bill that will help with meeting the needs of a special population that often is underserved or unrecognized.

LATE

SB-318-SD-1
Submitted on: 2/22/2023 9:19:32 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Chelsea Gonzales	Individual	Support	Written Testimony Only

Comments:

FASD diagnosis is a processing disorder, learning disability, and attention-deficit/ hyperactivity disorder, similar to Autism Spectrum Disorders however distinctly very different. The Neurodevelopmental impairment associated with FASD came with significant social cost in increased medical, educational, and vocational support and lost productivity. FASD is a Developmental disability that is equally as severe as autism, with the significant challenge that **FASD disability is not visible**; they look like you and me, and their IQ may pass as normal initially, but the damage is in the brain, neurological damage caused by **alcohol consumption** during pregnancy. **This is a cause specific and preventable**.

LATE

SB-318-SD-1
Submitted on: 2/22/2023 10:42:38 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Dawn Morais Webster Ph.D.	Individual	Support	Written Testimony Only

Comments:

Why we have ignored this issue for so long defies belief. Please move this bill forward. Our children should not have to suffer the consequences of legislative inaction. Mahalo.

LATE

SB-318-SD-1
Submitted on: 2/22/2023 10:44:44 AM
Testimony for WAM on 2/22/2023 9:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Shaylah Nichols	Individual	Support	Written Testimony Only

Comments:

Aloha,

I am in support of SB 318, relating to Fetal Alcohol Spectrum Disorders and respectfully ask this committee to pass this bill. This proposal would bring long overdue attention, support, diagnosis, and most importantly action to one of the State's most invisible but nonetheless harmful disorders. Based on my years of work in child welfare and mental health in Hawai'i, I am confident that undiagnosed FASDs are rampant within the population in our prison and juvenille justice systems.

As someone who has worked as a social worker with families in adoption and foster care, I have witnessed first hand the destruction and devestation of families who adopt or foster children with undiagnosed and therefore untreated FASD. Because FASD is predominantly formed during the first trimester of pregnancy, a time when many women do not even know they are pregnant, the risk of exposing an unborn child to alcohol in utero is extremely high. This is tragically true for many communities that are already at risk in other ways.

This bill represnts a long overdue course correction in our communal relationship to a disorder that can have life-long, pervasive, and wide-spread effects.

Thank you for your consideration!