STATE OF HAWAIʻI
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAIʻI 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543

February 13, 2023

The Honorable Senator Joy San Buenaventura, Chair
Senate Committee on Health and Human Services
The Thirty-Second Legislature
State Capitol
State of Hawaiʻi
Honolulu, Hawaiʻi 96813

Dear Senator Buenaventura 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 dianostic 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
Executive Administrator

JOSH GREEN, M.D.
GOVERNOR
KE KIA'ĀINA

CATHY BETTS
DIRECTOR
KA LUNA HO'OKELE

JOSEPH CAMPOS II
DEPUTY DIRECTOR
KA HOPE LUNA HO'OKELE

STATE OF HAWAII
KA MOKU'ĀINA O HAWAI'I
DEPARTMENT OF HUMAN SERVICES
KA 'OIHANA MĀLAMA LAWELAWE KANAKA
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February 11, 2023

TO: The Honorable Senator Joy A. San Buenaventura, Chair
Senate Committee on Health & Human Services

FROM: Cathy Betts, Director

SUBJECT: **SB 318 – FETAL ALCOHOL SPECTRUM DISORDERS.**

Hearing: February 13, 2023, 1:00 p.m.
Conference Room 225 & Videoconferencing, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) appreciates the intent of the measure, provides comments, requests an amendment, and defers to the Department of Health.

PURPOSE: This bill 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.

DHS recognizes that it can be very difficult and challenging for families struggling to find appropriate services for their children with a fetal alcohol spectrum disorder. There are a number of other measures proposing task forces to address services and processes for individuals with neurodevelopmental conditions, including fetal alcohol syndrome and autism. We respectfully recommend that as these various measures are considered by the Legislature, the task forces do not duplicate efforts. Regardless, DHS will participate.

DHS also notes on page 6, that healthcare professionals in Hawaii would need to follow U.S.-based screening tools and guidelines, which may differ from the Canadian guideline cited. However, the Canadian screening guidelines may provide relevant considerations that perhaps could be added to the US-based guidelines. Therefore, we propose the following amendment on page 6, lines 1-3,

"(3) A fetal alcohol spectrum disorders screening tool [~~with~~] considering relevant guidelines, including the Canada Fetal Alcohol Spectrum Disorder Research Network's diagnostic guidelines[.]"

Thank you for the opportunity to provide comments on this measure.

JOSH GREEN, M.D.
GOVERNOR OF HAWAI'I
KE KIA'ĀINA O KA MOKU'ĀINA 'O HAWAI'I

KENNETH S. FINK, M.D., M.G.A., M.P.H.
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Testimony COMMENTING on SB318
RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS.

SEN. JOY SAN BUENAVENTURA, CHAIR
SENATE COMMITTEE ON HEALTH & HUMAN SERVICES

Hearing Date: February 15, 2023 Room Number: 225

Fiscal Implications: Unspecified general fund appropriation.

Department Testimony: The Department of Health (DOH) recommends the proppsed task force be struck and SB318 amended to an appropriation only.

DOH published a report in 2009 identifying many of the issues that prevent wider recognition and diagnosis of FASD. The major findings were that private healthcare providers must organize differently, specifically that "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." A copy of this report is attached but is available onlin here:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3360082/

In lieu of a task force, DOH recommends apporpriations to commission a pilot project 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."

The proposed task force goals for recommendations for governmental support are premature until a more reliable prevalence rate is established. Concurrent work to develop teaching protocols may be conducted but is outside the scope of the Department of Health.

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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THE SENATE
KA ʻAHA KENEKOA

THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON HEALTH AND HUMAN SERVICES
Senator Joy A. San Buenaventura, Chair
Senator Henry J.C. Aquino, Vice Chair

NOTICE OF HEARING

DATE: Monday, February 13, 2023
TIME: 1:00 PM
PLACE: Conference Room 225 & Videoconference
State Capitol
415 South Beretania Street

LATE

POSITION: **STRONG SUPPORT SB 318**

Dearest Chair, Honorable Senator Joy San Buenaventura

and Vice Chair, Honorable Senator Henry JC Aquino and members of the Health and Human Services 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**

I am again pleading and humbly requesting for your VOTE, SUPPORT and to PASS SB 318 out of your committees. 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 periods. 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.** 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

Reference

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SB-318
Submitted on: 2/10/2023 6:31:52 PM
Testimony for HHS on 2/13/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Support	Remotely Via Zoom

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. Forming a Task Force would be a good way to bring stakeholders together to help develop a plan to put that in place.

SB-318
Submitted on: 2/10/2023 12:59:55 PM
Testimony for HHS on 2/13/2023 1:00:00 PM

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

Comments:

Dear Chair San Buenaventura and Vice Chair Aquino of the Senate Committee and Members of the Health and Human Services Committee,

The Hawai'i Fetal Alcohol Spectrum Disorders FASD Action Group a 501 c 3 with over 200 volunteer members, strongly supports SB 318.

Year after year we see our efforts to raise awareness, gain inclusion and support for FASD systems of care and diagnosis through legislation and negotiation with the State departments fall on deaf ears. We truly appreciate the intent of this legislation to establish the Fetal Alcohol Spectrum Disorders (FASD) Task Force with a required report to the Legislature in 2024.

FASD affects every sector of Hawai'i's society and the costs to society are immeasurable.

The estimated average annual cost to Hawai'i for FASD is over $876M – raising a child with FASD costs 30X more than the cost of successful prevention efforts. We've learned from our Parent & Caregiver Voices the significance of their struggles include:

(1) **Financial impact on family**- time to take off from work to attend appointments, to provide care as most daycare facilities are not trained to care for an infant or toddler with FASD and can become overwhelmed rejecting services. It was difficult to balance work and provide care for our son until he was placed into a FASD informed school.

(2) **Untrained staff**- when educators, healthcare providers and service providers are not trained, they place a negative label on the child with the direction of services for the child becoming negative because staff don't understand the "Won't vs. Can't". They view the child as defiant, a conduct problem etc. These students can be placed in ILC or disciplined for their brain based disability.

(3) **Adults with FASD in the prison** who possibly were not identified at a young age, and not appropriately supported in the schools and home settings, that may have created the negative stigma for them growing up has led to incarceration (not identifying FASD to understand and provide the right supports in place, DOH referrals, supervision, appropriate supervision) added to recidivism in the prison.

We offer our voices at anytime to educate members of the HHS Committee and the Hawaii State Legislature on fetal alcohol spectrum disorders, also known as the "invisble disability".

We strongly support the passage of this bill and we appreciate the opportunity to submit legislation for SB 318.

Sincerely yours,

Cleota G. Brown, President

Hawaiii FASD Action Group

HAWAII SUBSTANCE ABUSE COALITION

SB318 FSAD Task Force and Funding
COMMITTEE ON HEALTH AND HUMAN SERVICES
Senator Joy A. San Buenaventura, Chair
Senator Henry J.C. Aquino, Vice Chair
Monday, Feb. 13, 2023: 1:00 : Room 225 Videoconference

Hawaii Substance Abuse Coalition supports SB318

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.

SB-318
Submitted on: 2/10/2023 2:19:29 PM
Testimony for HHS on 2/13/2023 1:00:00 PM

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

Comments:

Dear Members of the Senate's Health and Human Services Committee:

I fully support SB318, which establishes a Task Force within the Department of Health to implement and distribute funds for the purposes of supporting those affected by Fetal Alcohol Spectrum Disorder (FASD). FASD Is a life-long permanent brain condition when a human fetus is exposed to the harmful metabolites of alcohol during pregnancy. Ever since the DOH terminated funding for its FASD Task Force, the State of Hawaii has never resurrected such an important entity. Close to 900 individuals are affected by FASD yearly in the State of Hawaii (based on 18,000 births in Hawaii and the finding that one in every 20 1st-grade children has an FASD via a National Study). To no fault of their own, individuals affected by an FASD are born into an impossible world. It is our responsibility in a society where the consumption of alcohol is a living issue that we support those affected by an FASD so they don't end up homeless, in prison, or in a mental health institution. In the cases of Ariel Kalua, Peter Boy, Kaniala Rapoza, and the list goes on, never has FASD been ruled out. Instead, Autism is always mentioned, but not FASD. Please pass SB318 for the people of Hawaii with FASD.

Sincerely,

Kenichi Yabusaki, Ph.D.

Dear Senator San Buenaventura, Chair, Senator Aquino, Vice Chair, and members of the Health and Human Services Committee:

I am writing in full support of SB318.

Individuals and families affected by fetal alcohol spectrum disorders (FASD) are often unseen and unheard because people with FASD often do not qualify for services under the current guidelines of the developmentally disabled. Hawaii has no surveillance system for FASD and we do not know how many people in Hawaii may be affected by an FASD. A significant national research project estimated that one in twenty first graders may be affected by an FASD (May, et. al, 2018), suggesting that because FASDs are difficult to assess, more individuals may be affected by an FASD than currently identified.

I am a psychologist with clients and families affected by the effects of prenatal alcohol exposure. Many have difficulties with memory, learning, understanding language, executive functioning, behavioral challenges, and other brain-related (hidden) disabilities. These challenges are often misdiagnosed and without FASD-informed interventions, many people with an FASD can never reach their potential. Some of my clients are homeless, in the criminal justice system, have been expelled from multiple schools, and have mental health and substance abuse issues. Yet, with proper support including supportive families, I have witnessed successful, happy, and productive individuals with FASD.

I urge the committee to pass this bill to create a task force that investigates, documents, and recommends ways to track the prevalence of FASD, suggest best practice prevention methods, and create FASD-informed assessment and intervention strategies in Hawaii for people with FASD.

I appreciate your consideration.

Ann S. Yabusaki, PhD

References:

May, P., et al. (2/6/2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities, *Journal of the American Medical Association.* JAMA. 2018;319(5):474-482. doi:10.1001/jama.2017.21896

February 10, 2023

To: HHS Chair and Committee

RE: SB 318

Aloha Legislators,

The statistics on Fetal Alcohol Spectrum Disorders (FASD) are jarring. Let's not pretend like they aren't.

Alcohol is an integrated part of our lives and cultures, and until recently there was no specific spotlight on these long-term effects.

As a clinician that has worked for many years in intergenerational trauma, I can tell you that about five or so years ago when I really started learning about what FASD looked like in behavioral presentation, I was absolutely ***ravaged.***

I am currently the Clinical Director at Women's Way (*the only residential level SUD treatment program for pregnant and parenting women and their babies in the state of Hawai'i*), and I KNOW this issue like not many do. I have seen total ***intergenerational devastation*** from the invisibility of this problem.

I urge you please:

We need to STOP PUNISHING people for having a disability they were born with.

We need to STOP SHAMING people who are suffering from trauma, disorder, and disease.

We need to STOP IGNORING the fact that WE are fearful of what acknowledging this will do to our systems and be brave in taking the first steps.

We need to BELIEVE that we can do right by those who have suffered for too long in the dark and provide HOPE that we can stop the cycle through prevention, education, and ***careful listening*** around the complexities that this presents.

A task force is one of many very wise and meaningful steps in moving this forward and I fully support SB318.

Mahalo nui,

Amanda M. Luning, LMHC, IECM-E®