



STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
Honolulu, HI 96801-3378
doh.testimony@doh.hawaii.gov

**Testimony in SUPPORT of SB318 SD2 HD1
RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS.**

REP. KYLE T. YAMASHITA, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: March 30, 2023

Room Number: 308

1 **Fiscal Implications:** An appropriation of \$150,000 for each of the three years, or \$450,000, is
2 recommended. The amount may be adjusted with the duration of the pilot.

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

7 A copy of this report is available online here and is attached to this document:

8 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3360082/>

9 The major findings were that private healthcare providers must organize differently, specifically
10 that “Hawai‘i does not yet have the type of multi-disciplinary team described in the Canadian
11 literature set up to assess and diagnose FAS cases.”

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

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

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

14 DOH has established contact with a potential partner to develop the concept further. An
15 appropriation of \$150,000 for each of the three years is recommended.

16 Thank you for the opportunity to testify.

17 **Offered Amendments:** DOH respectfully requests one amendment:

18 Lapsing

19 Since this measure proposes a three-year project window, DOH requests an amendment that
20 prevents lapsing of funds for the three-year period.



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

March 30, 2023

The Honorable Representative Kyle T. Yamashita, Chair
House Committee on Finance
The Thirty-Second Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Yamashita and Committee Members:

SUBJECT: SB318 SD2 HD1 Related to Fetal Alcohol Spectrum Disorders

The Hawaii State Council on Developmental Disabilities **Supports SB318 SD2 HD1**, which Requires the Department of Health to establish and administer a three-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders.

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.

Fetal Alcohol Spectrum Disorder is the number one Developmental Disability that can be prevented. The added appropriation to the State Council on Developmental Disabilities enables annual outreach for awareness events. The sum recommended for the appropriation is \$35,000 as this is the amount our Council currently spends on similar outreach events. This would ensure that an annual public awareness campaign preventing FASD can be established within our state. Awareness is the most effective way to create systems change to support this gap group in our community.

The Honorable Representative Kyle T. Yamashita, Chair
House Committee on Finance
SB318, SD2, HD1
March 30, 2023
Page 2

FASD has been a long-time gap group that has gone underserved in our state. We hope this measure can begin to address the needs of this population. Thank you for considering an appropriation of \$35,000 for our awareness campaign and for the opportunity to submit testimony in **support of SB318 SD2 HD1.**

Sincerely,

A handwritten signature in blue ink that reads "Daintry Bartoldus". The signature is written in a cursive, flowing style.

Daintry Bartoldus
Executive Administrator



SB318 SD2 HD1 FSAD Task Force and Funding

COMMITTEE ON FINANCE

Rep. Kyle T. Yamashita, Chair

Rep. Lisa Kitagawa, Vice Chair

Thursday, Mar 30, 2023: 3:00 : Room 308 Videoconference

Hawaii Substance Abuse Coalition supports SB318 SD2 HD1

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-HD-1

Submitted on: 3/28/2023 3:08:32 PM

Testimony for FIN on 3/30/2023 3:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	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 of 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 current version which goes further and sets up a pilot project to actually deliver the services. We very much appreciate the attitude of the Department of Health and the Legislature who both felt that it was time to go beyond a Task Force and "do more".

HOUSE OF REPRESENTATIVES
THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON FINANCE

Rep. Kyle T. Yamashita, Chair

Rep. Lisa Kitagawa, Vice Chair

Rep. Micah P.K. Aiu	Rep. Rachele F. Lamosao
Rep. Cory M. Chun	Rep. Dee Morikawa
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Rep. Kirstin Kahaloa	Rep. Jenna Takenouchi
Rep. Darius K. Kila	Rep. David Alcos III
Rep. Bertrand Kobayashi	Rep. Gene Ward

NOTICE OF HEARING

DATE: Thursday, March 30, 2023
TIME: 3:00 p.m.
PLACE: VIA VIDEOCONFERENCE
Conference Room 308
State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT SB 318 SD2 HD1**

Dearest Chair, Honorable Representative Kyle T. Yamashita and Vice Chair, Honorable Representative Lisa Kitagawa and members of the Committee on Finance,

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 SD2 HD1** - requiring the Department of Health to establish and administer a 3-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders **with amendment for this Bill to be effective upon approval.**

There are nearly seventeen thousand babies born annually in the State, as many as eight hundred forty are estimated to have fetal alcohol spectrum disorders. Even using best practices, few children in the State are diagnosed with fetal alcohol spectrum disorders, or are misdiagnosed with other developmental disorders, resulting in absence in appropriate treatment. This measure is intended to improve outcomes for individuals with fetal alcohol spectrum disorders and promote health equity by establishing a pilot program for a multidisciplinary co-management system of care for individuals with fetal alcohol spectrum disorders.

HONOLULU (KHON2) — The American Addiction Centers discovered a new finding about alcohol consumption from 2020 to 2021. Most states nationwide saw a dramatic decrease in alcohol consumption, between 10–20%. However, Hawaii saw the opposite. According to the study, from 2020 to 2021, Hawaii increased alcohol consumption by 23%. They broke down how many alcoholic drinks one person

estimated to have from 2020 to 2021. In Hawaii, they said the average drinker had 520 drinks in 2020 and 639 in 2021 (Hunt, 2022). The data also show that drinking in isolation found birthrates in 2021 to create a net increase of 46,000 births above the pre-pandemic trend across the two years combined.

I am again pleading and humbly requesting for your VOTE, SUPPORT and to PASS SB 318 SD2 HD1 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 become recidivist clients in institutional settings, including jails, mental health programs, psychiatric hospitals, and homeless shelters. Do you know 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. Adding it up 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, considering the seven years of inflation from 2016 to 2023. 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 SD2 HD1.** 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 for many many years. 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

American Psychological Association. (n.d.). *A hidden epidemic of fetal alcohol syndrome*. Monitor on Psychology. Retrieved January 14, 2023, from <https://www.apa.org/monitor/2022/07/news-fetal-alcohol-syndrome#:~:text=Experts%20estimate%20that%202%25%20to,growth%2C%20behavior%2C%20and%20learning>.

Hunt, K. (2022, February 8). *From 2020 to 2021 Hawaii residents increased their alcohol consumption by 23 percent: Study*. KHON2. Retrieved March 28, 2023, from <https://www.khon2.com/local-news/from-2020-to-2021-hawaii-residents-increased-their-alcohol-consumption-by-23-percent>



March 29, 2023

Re: SB318 SD2 HD1 FSAD Task Force and Funding

COMMITTEE ON FINANCE
Rep. Kyle T. Yamashita, Chair
Rep. Lisa Kitagawa, Vice Chair
Thursday, Mar 30 2022: 3:00 : Room 308

The Coalition for a Drug-Free Hawaii strongly supports SB318 SD2 HD1

Aloha Chair, Vice Chair and distinguished committee members my name is Greg Tjapkes, and I am the Executive Director of the Coalition for a Drug-Free Hawaii (CDFH), and we strongly support **SB318 SD2 HD1** for the creation and funding of a FASD task force.

Our experience with Fetal Alcohol Spectrum Disorders (FASD) stems from Dr. Ann Yabusaki, formerly an employee of CDFH, and her work with adolescents in Juvenile Drug Court. 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.

CDFH has hosted, helped and encouraged the Hawaii FASD Action Group, and their efforts to prevent this spectrum of disorders, and to provide diagnosis and appropriate interventions to help those impacted. We are in full support of this measure, and encourage you to pass **SB318 SD2 HD1**.

Thank you for the opportunity to provide this testimony.

Sincerely,

Greg Tjapkes
Executive Director
Coalition for a Drug-Free Hawaii

SB-318-HD-1

Submitted on: 3/28/2023 10:54:17 PM

Testimony for FIN on 3/30/2023 3:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Jennifer Asperilla	Individual	Support	Written Testimony Only

Comments:

As a strong advocate for children, I am wholeheartedly in support of SB318 SD2 HD1 on Fetal Alcohol Spectrum Disorder (FASD).

SB-318-HD-1

Submitted on: 3/29/2023 3:20:50 AM

Testimony for FIN on 3/30/2023 3:00:00 PM

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

Comments:

I am writing in STRONG SUPPORT of SB 318 SD2 HD1 - requiring the Department of Health to establish and administer a 3-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders with amendment for this Bill to be effective upon approval.

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State are diagnosed with fetal alcohol spectrum disorders, or are misdiagnosed with other developmental disorders, resulting in absence in appropriate treatment. This measure is intended to

improve outcomes for individuals with fetal alcohol spectrum disorders and promote health equity by

establishing a pilot program for a multidisciplinary co-management system of care for individuals with fetal alcohol spectrum disorders.

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between 10–20%. However, Hawaii saw the opposite. According to the study, from 2020 to 2021, Hawaii

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estimated to have from 2020 to 2021. In Hawaii, they said the average drinker had 520 drinks in 2020 and

639 in 2021 (Hunt, 2022). The data also show that drinking in isolation found birthrates in 2021 to create

a net increase of 46,000 births above the pre-pandemic trend across the two years combined.

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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.

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jails, mental health programs, psychiatric hospitals, and homeless shelters. Do you know 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

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up amounts to \$51,100 per year per prisoner locked up in Hawaii. This data was dated in 2016, and I am

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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 - 117th 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 SD2 HD1. 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 for many many years. 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.

Mark Matsushita LMFT, CSAC

Licensed Marriage and Family Therapist

Certified Substance Abuse Counselor

To: Representative Kyle T. Yamashita, Chair
Representative Lisa Kitagawa, Vice Chair
Members of the Finance Committee

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

RE: **Full support of SB318.**

Individuals and families affected by fetal alcohol spectrum disorders (FASD), brain-induced behaviors due to prenatal alcohol exposure. Studies on FASD indicate that

- <5% are ever diagnosed¹
- ~85% missed or misdiagnosed in a sample of foster and adopted children²
- On average, a child with an FASD is 17 to 19 times more likely to be in the child welfare system than someone without an FASD.³
- Individuals affected by FASD and often do not qualify for services under the current guidelines of the developmentally disabled because their IQs fall within the “normal” range.
- A significant national research project conservatively estimated that one in twenty first graders may be affected by an FASD (May, et. al, 2018),⁴ suggesting that more individuals may be affected by an FASD than currently identified.

I have been trying to educate the public about FASD since 2002. In my practice as a psychologist, I have met many young adults with FASD and their families. Many have difficulties with memory, learning, understanding language, executive functioning, behavioral challenges, and other brain-related (hidden) disabilities. Some of my clients had been expelled from multiple schools, and are now homeless, in the criminal justice system, and have mental health and substance abuse issues. Yet, with proper support from families, service providers, and communities, people affected FASD can be successful, happy, and productive individuals.

There are no comprehensive screenings, assessments, or data on people with FASD in Hawaii. We must begin to address the issues as too many people are falling in the gaps of our society. A pilot project to create a comprehensive assessment center, adapt screening tools, and train service providers aggressively on FASD-informed intervention is sorely needed in our state. Thank you for your consideration.

¹ Onoye, J. (2018) addressing FASD in Hawaii. Powerpoint presentation 6/6/2018.

*Quality Improvement Center for Research-Based Infant-Toddler Court Teams. www.qicct.org

² Chasnoff, I., Wells, A.M., & King L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, **135**(2), DOI: 10.1542/peds.2014-2171.

<http://pediatrics.appublications.org/content/early/2015/01/07/peds.2014-2171>

³ Petrenko, CLM, Alto, ME, Hart, Arm, Freeze, SM, & Cole, LL. (2019). I'm doing my part, I just need help from the community: Intervention implications of foster and adoptive parents' experiences raising children and young adults with FASD. *J Fam Furs.* 25(2):314-347. doi: 10.1177/1074840719847/185. Epub 2019 zmay 13. PMID:PM6896784; PMID: 31079560.

⁴ 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

To: Representative Kyle T. Yamashita, Chair
Representative Lisa Kitagawa, Vice Chair
Members of the Finance Committee

From: Kenichi Yabusaki, Ph.D.

RE: **Full support of SB318.**

Individuals and families affected by fetal alcohol spectrum disorders (FASD), brain-induced behaviors due to prenatal alcohol exposure. Studies on FASD indicate that

- <5% are ever diagnosed¹
- ~85% missed or misdiagnosed in a sample of foster and adopted children²
- On average, a child with an FASD is 17 to 19 times more likely to be in the child welfare system than someone without an FASD.³
- Individuals affected by FASD and often do not qualify for services under the current guidelines of the developmentally disabled because their IQs fall within the “normal” range.
- A significant national research project conservatively estimated that one in twenty first graders may be affected by an FASD (May, et. al, 2018),⁴ suggesting that more individuals may be affected by an FASD than currently identified.

As a retired biochemist, I have researched the biochemical basis for how prenatal exposure to the metabolites of alcohol consumption causes permanent brain impairment with respect to mis-wired neurons during brain development. Thus, those affected by FASD may have difficulties with memory, learning, understanding language, executive functioning, behavioral challenges, and other brain-related (hidden) disabilities. Our society in its many roles not understanding FASD leads to homelessness, criminal justice system, and mental health and substance abuse issues. Yet, with proper support from families, service providers, and communities, people affected FASD can be successful, happy, and productive individuals.

There are no comprehensive screenings, assessments, or data on people with FASD in Hawaii. We must begin to address the issues as too many people are falling in the gaps of our society. A pilot project to create a comprehensive assessment center, adapt screening tools, and train service providers

¹ Onoye, J. (2018) addressing FASD in Hawaii. Powerpoint presentation 6/6/2018.

*Quality Improvement Center for Research-Based Infant-Toddler Court Teams. www.qicct.org

² Chasnoff, I., Wells, A.M., & King L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, **135**(2), DOI: 10.1542/peds.2014-2171.

<http://pediatrics.appublications.org/content/early/2015/01/07/peds.2014-2171>

³ Petrenko, CLM, Alto, ME, Hart, Arm, Freeze, SM, & Cole, LL. (2019). I’m doing my part, I just need help from the community: Intervention implications of foster and adoptive parents’ experiences raising children and young adults with FASD. *J Fam Furs.* 25(2):314-347. doi: 10.1177/1074840719847/185. Epub 2019 zmay 13.

PMCID:PMC6896784; PMID: 31079560.

⁴ 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

aggressively on FASD-informed intervention is sorely needed in our state. Thank you for your consideration.

SB-318-HD-1

Submitted on: 3/29/2023 9:55:06 AM

Testimony for FIN on 3/30/2023 3:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Sina Pili	Individual	Support	Written Testimony Only

Comments:

I support SB 318.

SB-318-HD-1

Submitted on: 3/29/2023 10:42:34 AM

Testimony for FIN on 3/30/2023 3:00:00 PM

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

Comments:

Dear Representative Yamashita, Chair, Representative Kitagawa, Vice Chair and members of the Committee on Finance:

On behalf of Hawai'i Fetal Alcohol Spectrum Disorders FASD Action Group a 501 c 3 with a **Mission** to raise awareness through education, advocacy, and research on the impact of Fetal Alcohol Spectrum Disorder (FASD) on individuals, their families, and the communities of Hawai'i and a **Vision** – to see Fetal Alcohol Spectrum Disorder (FASD) Invisible no more, **we strongly support SB 318 SD2 HD1.**

We need your support to raise awareness across the State of Hawai'i on the impact of alcohol causing lifelong physical, behavioral, and intellectual disabilities through fetal alcohol exposure. Of the 17,000 babies born annually in Hawai'i, as many as 840 are estimated to have a FASD.

FASD is 100% preventable. Let that sit in your mind. This is a debilitating disability that we can and should reduce the numbers through education and awareness.

SB 318, SD2, HD1 requires the Department of Health to establish and administer a three-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders.

Through this pilot program, we can and must focus on those children and adults in our community who are afflicted with FASD. We also must focus on awareness, prevention, education and diagnosis.

Please help us do more in Hawai'i to support people with fetal alcohol spectrum disorders FASD.

Sincerely yours,

Cleota Brown, President

fasdhawaii.org

IVAN M. LUI-KWAN

Pacific Guardian Center, Makai Tower
733 Bishop Street, Suite 1900
Honolulu, Hawaii 96813

HOUSE OF REPRESENTATIVES
THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON FINANCE

Rep. Kyle T. Yamashita, Chair
Rep. Lisa Kitagawa, Vice Chair

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Rep. Darius K. Kila	Rep. David Alcos III
Rep. Bertrand Kobayashi	Rep. Gene Ward

NOTICE OF HEARING

DATE: Thursday, March 30, 2023
TIME: 3:00 p.m.
PLACE: VIA VIDEOCONFERENCE
Conference Room 308
State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT SB 318 SD2 HD1**

Aloha Chair Kyle Yamashita and Vice Chair Lisa Kitagawa and members of the Committee on Finance,

I am writing in **STRONG SUPPORT** of **SB 318 SD2 HD1** - requiring the Department of Health to establish and administer a 3-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders.

For many years I served as chair and member of board of directors of the March of Dimes. The mission of the March of Dimes has been prevention of birth defects. Although the cause of birth defects is not precise, what has been clearly established is that major contributing causes of birth defects are the pregnant mothers' consumption of alcohol and smoking.

KHON recently reported on a study by the American Addiction Centers which indicated that in Hawaii, contrary to the national trend, from 2020 to 2021 alcohol consumption increased by 23%. It is my hope that adoption of SB 318 SD2 HD1 will advance not just diagnosis and treatment of persons with fetal alcohol spectrum disorders, but in the process provide awareness and education to pregnant mothers to avoid alcohol consumption to give their babies the best opportunity to live a healthy, productive and fulfilled life.

Mahalo nui for allowing me to provide this testimony in support of this bill.

Aloha ke Akua,

A handwritten signature in black ink, appearing to read "Ivan M. Lui-Kwan". The signature is stylized with a large "I" and "K".

Ivan M. Lui-Kwan

SB-318-HD-1

Submitted on: 3/29/2023 12:59:04 PM

Testimony for FIN on 3/30/2023 3:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Robert M Armstrong	Individual	Support	Remotely Via Zoom

Comments:

Aloha Finance Committee Members,

I strongly support **SB 318** for the initiation of a three-year pilot study to implement a care management system for those diagnosed and treated with Fetal Alcohol Spectrum Disorder.

This is a fiscally sound proposal as FASD affects more and more residents of Hawai`i than what was earlier suggested. Like autism, the impact of this misdiagnosed or undiagnosed condition costs the State (and by implication, all of us) much more in the long run by doing nothing because of lost revenue, workplace accidents, homelessness, and unreported or unattributed personal trauma (especially for elementary and middle school children, where the impact of FASD is particularly noted and profound).

I have worked with families and children for years as a non-profit administrative leader here. My last two positions as Executive Director, with the Hawai`i Lions Foundation and Junior Achievement of Hawai`i, saw my involvement with our youngest citizens increase dramatically. As a result, I firmly believe FASD could be a underlying and fundamental unrecognized cause for many of the problems we currently experience in our society. Whether it is the lack of advancement and retention in schools, to petty criminal activities like graffiti and shoplifting, to more serious issues like suicide, unemployment and homelessness, FASD permeates every corner of our Society and nearly every family in one way or another.

SB 318 will begin to break this senseless and heartbreaking cycle and help repair those directly and indirectly affected. I hope you can see this effort is just the 'tip of an iceberg' in the healing process and that your support is greatly needed now...and appreciated.

SB-318-HD-1

Submitted on: 3/29/2023 3:25:47 PM

Testimony for FIN on 3/30/2023 3:00:00 PM

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

Comments:

I strongly support this bill.

SB-318-HD-1

Submitted on: 3/30/2023 10:13:54 AM

Testimony for FIN on 3/30/2023 3:00:00 PM

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

Comments:

Please allow this bill to take full force and effect of law