

#### STATE OF HAWAI'I

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

March 22, 2023

The Honorable Representative Au Belatti, Chair House Committee on Health and Homelessness The Thirty-Second Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Representative Au Belatti and Committee Members:

SUBJECT: SB318 SD2 Related to Fetal Alcohol Spectrum Disorders

The Hawaii State Council on Developmental Disabilities **Supports SB318 SD2**, which requires the Department of Health to establish and administer a 5-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders. Appropriates funds.

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 one Developmental Disability that can be prevented. We would like to request an amendment to add an appropriation of \$35,000 to the State Council on Developmental Disabilities. This is similar to what our Council spends on annual outreach for awareness 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.

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 the opportunity to submit testimony in **support of SB318 SD2.** 

Sincerely,

Daintry Bartoldus

**Executive Administrator** 



# DISABILITY AND COMMUNICATION ACCESS BOARD

1010 Richards Street, Room 118 • Honolulu, Hawaii 96813 Ph. (808) 586-8121 (V) • Fax (808) 586-8129

March 22, 2023

#### TESTIMONY TO THE HOUSE COMMITTEE ON HEALTH & HOMELESSNESS

Senate Bill 318, SD2 – Relating to Fetal Alcohol Spectrum Disorders

The Disability and Communication Access Board (DCAB) supports Senate Bill 318, SD2 - Relating to Fetal Alcohol Spectrum Disorders. The bill would require the Department of Health to establish and administer a five-year pilot program to implement a comanagement system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders and appropriates funds.

Proper diagnosis and treatment of fetal alcohol spectrum disorders helps to mitigate its impacts. Understanding fetal alcohol spectrum disorders and service needs are essential to improve the quality of life for individuals with disabilities.

Thank you for the opportunity to provide testimony,

Respectfully submitted,

KIRBY L. SHAW Executive Director



#### SB318 SD1 FSAD Task Force and Funding

COMMITTEE ON HEALTH & HOMELESSNESS
Rep. Della Au Belatti, Chair
Rep. Jenna Takenouchi, Vice Chair

Rep. Jenna Takenouchi, Vice Chair

Wednesday, Mar 22, 2023: 11:20: Room 329 Videoconference

#### Hawaii Substance Abuse Coalition supports SB318 SD2

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.

Submitted on: 3/21/2023 9:40:55 AM

Testimony for HLT on 3/22/2023 11:20:00 AM

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

#### Comments:

Dear Representative Belatti, Chair, Representative Takenouchi, Vice Chair and members of the Committee on Health & Homelessness...and

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

On behalf of Hawai'i Fetal Alcohol Spectrum Disorders FASD Action Group a 501 c 3 in the State of Hawai'i, we strongly support SB 318, SD2 (SSCR670) relating to fetal alcohol spectrum disorders, requiring the Department of Health to establish and administer a 5-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders and appropriate funds accordingly.

FASD is a serious public health issue as acknowledged by the National Institutes of Health and Centers for Disease Control & Prevention.

- 1. FASDs are lifelong physical, developmental, behavioral, and intellectual disabilities.
- 2. As many as 1 in 20 in the US are affected by FASDs.
- 3. **The State of Hawai'i has no, none, zero diagnostic capabilities known to us**, the only 501 c 3 in the State of Hawai'i dedicated to the awareness, prevention and health of people with FASD.
- 4. Lack of supports and treatment increases the likelihood of individuals to experience adverse outcomes.
- 5. Investment in prevention and early intervention will improve schooling for individuals with FASDs, while improving the safety and welfare of all students and teachers in our schools.
- 6. Effective awareness of these issues requires coordination across the private and public sectors.
- 7. Based on the work we do at fasdhawaii.org, we are certain that a high percentage of Hawaii's youth offenders in the courts and prisons suffer from a FASD.
- 8. FASD is 100% preventable!

By acknowledging these realities, the State of Hawai'i Legislature is affirming what the FASD world already knows: adequate supports, treatments, and diagnostic capabilities can lead to positive change for individuals with FASDs, and that this reality has been ignored for too long.

State programs will provide public awareness and help us educate, advocate and train healthcare providers to prevent abuse of alcohol during pregnancy. By focusing on a 5-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders we can all push forward to shed light and make FASD - "Invisible No More"

We sincerely thank you for your support of this worthy cause and appreciate your efforts to pass SB318 SD2.

With regards,

Cleota Brown, President

fasdhawaii.org

Submitted on: 3/20/2023 2:43:39 PM

Testimony for HLT on 3/22/2023 11:20:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Jeremy Daniel	Individual	Support	Written Testimony Only

#### Comments:

I am a parent with a child with an FASD. There is no support, no money, and no structure in the state of Hawaii to support people who suffer with these challenges. Studies show that more than 5% of the population has some form of FASD. That is more than autism and down's syndrome COMBINED. Most people with an FASD are not diagnosed and without the propoer supports will struggle to live within societal norms. They CAN, but they need support. Ignoring this issue only continues to contribute to other social issues such as homelessness, poverty, and higher crime rates. We are doing these individuals a disservice by not providing them the help that they need to be successful in society.

Date: March 20, 2023

To: Representative Della Au Belatti, Chair

Representative Jenna Takenouchi, Vice Chair

Members of the Committee on Health and Homelessness

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

RE: Strong support of SB No. 318 (SD2)

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. Because FASD--a brain disorder due to drinking alcohol during pregnancy--is challenging to diagnose because it can encompass autism, learning disabilities, ADHD, trauma and other diagnoses. Many individuals are missed or misdiagnosed. In one study of adopted children and children in foster care, 85% were missed or misdiagnosed.
- 3. Because of their disabilities, many can enter into our criminal justice system, homeless population, substance abuse, mental health, medical, and other systems.
- 4. FASD is a life-long brain disorder that requires lifelong interventions.
- 5. Hawaii lacks a model of FASD-informed care to assess, diagnose, intervene, or prevent 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 (SD2) is a major first step in trying to address the complexities of FASD. Lifelong supports can help many affected by FASD to lead productive and live meaningful lives.

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.

Submitted on: 3/20/2023 4:35:52 PM

Testimony for HLT on 3/22/2023 11:20:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kenichi Yabusaki	Individual	Support	Written Testimony Only

#### Comments:

Aloha Chair Belatti, Vice Chair Takenouchi and Committee Members:

I strongly support SB318 with one modification, the need for a five-year pilot study to put together a taskforce to determine the prevalence of FASD in Hawaii. is ridiculous. At least 900 individuals are affected every year with FASD, based on a multi-region study that showed one in twenty first-grade children have FASD. Based on Hawaii's annual birth rate of 18,000, an unintended pregnancy rate near 50%, and increased binge drinking among childbearing-aged women, a study over five years extrapolates to nearly 4,500 individuals with FASD that need vital services now. Not to stigmatize those with FASD, we can prevent tragedies like the Parkland, FL, shooter Nicolas Cruz, who was diagnosed with FASD and killed 17 individuals. Early intervention with FASD-informed care is essential to an individual being a productive member of society. Those with FASD are gifted but need society to change to make the world possible. Hawaii needs an assessment center with FASD-informed professionals to properly diagnose and treat those affected by FASD. To this end, Hawaii needs to recruit professionals as part of the DOH, DHS, and DOE that fully understand FASD. Knowing about FASD is one thing, but Understanding FASD is a different world. Please make amendments to SB318 so we don't have to wait five years, but immediately form a taskforce to bring FASD informed professionals into our healthcare system. Thank you

Sincerley,

Kenichi Yabusaki, Ph.D.

Submitted on: 3/20/2023 8:05:47 PM

Testimony for HLT on 3/22/2023 11:20:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Eri Rodrigues	Individual	Support	Written Testimony Only

#### Comments:

I am in full support of this measure to improve systems of care for the individuals and families impacted by FASD in our community.

Submitted on: 3/20/2023 9:10:26 PM

Testimony for HLT on 3/22/2023 11:20:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kendrick Farm	Individual	Support	Written Testimony Only

#### Comments:

Position: Support SB318 SD2

Hawaii will diagnose more than 800 new individuals each year with this FASD this does not include the estimated 71,000 residents that are coping with it now. The proposed legislation is that response by providing for a five-year study to establish and administer a program of care with the Hawaii Department of Health.

I strongly support this critical measure because it is our societal duty to provide care for those impacted and the pilot may assist with identifying best practices. Hawai`i will diagnose more than 800 new individuals each year with this Fetal Alcohol Spectrum Disorder(s) (FASD) this does not include the estimated 71,000 residents that are coping with it now. But there are currently no measures in place to support the diagnosis and treatment of individuals with FASD.

SB 318 when implemented will prove to be both cost-efficient and humane. Please pass this measure out of committee, thank you for the opportunity to testify on this measure.

Mahalo,

Ken Farm

Submitted on: 3/21/2023 2:11:34 AM

Testimony for HLT on 3/22/2023 11:20:00 AM

<b>Submitted By</b>	Organization	<b>Testifier Position</b>	Testify
mark matsushita	Individual	Support	Written Testimony Only

#### Comments:

I'm writing to ask your approval of SB318. Fetal Alcohol Syndrome affects everyone. Not only the families and their child but also our community as a whole. Please vote in favor of this bill

Submitted on: 3/21/2023 9:15:52 PM

Testimony for HLT on 3/22/2023 11:20:00 AM

<b>Submitted By</b>	Organization	<b>Testifier Position</b>	Testify
Louis Erteschik	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. 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 SD2 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".

Submitted on: 3/22/2023 7:32:09 AM

Testimony for HLT on 3/22/2023 11:20:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Richard Collins	Individual	Support	Written Testimony Only

#### Comments:

As a mental health professional who specialized in youth development, I saw first-hand the effects that FASD can have on both the child and the caregivers surrounding that child. We can do more to prevent and treat FASD and this measure will allow us the time to assessment, build capacity, and improve our prevention and treatment. It will improve the health and wellness of many youth and families on our islands. Please pass SB318. Mahalo.

Submitted on: 3/22/2023 8:54:43 AM

Testimony for HLT on 3/22/2023 11:20:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Robert M Armstrong	Individual	Support	Written Testimony Only

Comments:

Aloha,

I apologize for my late testimony but want to stand in strong **support** of SB 318 and the potential of it's positive passing this session.

It is an enormously important bill for it will (finally) put funding and parameters around defining the scope, seriousness, and solutions needed to address **Fetal Alcohol Spectrum Disorders** in our State. While perhaps some of you and certainly the public have not heard of this problem, I can assure the issue is *real* and like autism, affects almost everyone to some degree in Hawai'i. Along with HB 899, this legislation will make it possible for us to greatly elevate the issue and its correlated needs to a much clearer extent.

Please pass SB 318 and thank you for your kind consideration and appoval!

Robert M. Armstrong

FASD Group Board Member, Honolulu

Submitted on: 3/22/2023 9:00:39 AM

Testimony for HLT on 3/22/2023 11:20:00 AM

<b>Submitted By</b>	Organization	<b>Testifier Position</b>	Testify
Kaili Swan	Individual	Support	Remotely Via Zoom

#### Comments:

i am in strong support of this SB 316 SD2 please pass this bill thank you.

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.
DIRECTOR OF HEALTH
KA LUNA HO'OKELE

# 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 RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS.

#### REP. DELLA AU BELATTI, CHAIR HOUSE COMMITTEE ON HEALTH & HOMELESSNESS

Hearing Date: March 23, 2023 Room Number: 329

- 1 **Fiscal Implications:** An appropriation of \$150,000 for each of the five years, or \$750,000, 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
- 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-
- management system where the "Primary Care Provider (PCP), the Behavioral Health Provider
- 14 (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
- 16 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
- 2 information, including the FASD specialist(s) assessment and treatment plan, will be
- 3 sent;
- 3. The PCP and/or BHP will involve the patient's family and school as recommended in the
- 5 treatment plan;
- 4. The BHPs will provide the treatment (medication and other modalities); the BHP will
- 7 provide periodic reports to the PCP;
- 5. The PCP will monitor the patient's progress from patient contact and communication
- 9 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
- 11 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."
- DOH has established contact with a potential partner to develop the concept further. An
- approrpation of \$150,000 for each of the five years is recommended.
- 16 Thank you for the opportunity to testify.
- 17 **Offered Amendments:** DOH respectfully requests two amendments:
- 18 <u>Lapsing</u>
- 19 Since this measure proposes a five-year project window, DOH requests an amendment that
- 20 prevents lapsing of funds for the five-year period.
- 21 <u>Prevention</u>
- 22 Early discussions with potential partners reveals the importance of prevention, though DOH
- 23 wishes to respect the original intent of the advocates by continuing to focus on tertiary care.

- 1 SECTION 2. (a) The department of health shall establish
- 2 and administer a five-year pilot program with a primary and
- 3 secondary prevention component and a tertiary prevention
- 4 component that implements [to implement] a co-management system
- 5 of care for persons with a fetal alcohol spectrum disorder in
- 6 which the primary care provider; behavioral health provider; and
- 7 fetal alcohol spectrum disorders specialist with a
- 8 specialization in genetics, pediatric neurology, developmental-
- 9 behavioral, or other applicable field; each plays a role.

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

#### **COMMITTEE ON HEALTH & HOMELESSNESS**

Rep. Della Au Belatti, Chair Rep. Jenna Takenouchi, Vice Chair

Rep. Terez Amato Rep. John M. Mizuno
Rep. Greggor Ilagan Rep. Scott Y. Nishimoto
Rep. Bertrand Kobayashi Rep. Diamond Garcia

#### **NOTICE OF HEARING**

DATE: Wednesday, March 22, 2023

TIME: 11:20 AM

PLACE: VIA VIDEOCONFERENCE

Conference Room 329

State Capitol

415 South Beretania Street

#### POSITION: STRONG SUPPORT SB 318 SD2

Dearest Chair, Honorable Representative Della Au Belatti and Vice Chair, Honorable Representative

Jenna Takenouchi and members of the Health and Homelessness 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 SD2 -** requiring the Department of Health to establish and administer a 5-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders.

I am again pleading and humbly requesting for your VOTE, SUPPORT and to PASS SB 318 SD2 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 SD2.** 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

American Psychological Association. (n.d.). *A hidden epidemic of fetal alcohol syndrome*. Monitor on Psychology. Retrieved January 14, 2023, from <a href="https://www.apa.org/monitor/2022/07/news-fetal-alcohol-">https://www.apa.org/monitor/2022/07/news-fetal-alcohol-</a>

syndrome#:~:text=Experts%20estimate%20that%202%25%20to,growth%2C%20behavior%2C%20and%20learning.

Mela, M. (2023). Patients with prenatal alcohol exposure frequently misdiagnosed, face multiple challenges. *Psychiatric News*, *58*(01). <a href="https://doi.org/10.1176/appi.pn.2023.01.1.12">https://doi.org/10.1176/appi.pn.2023.01.1.12</a>

Moran, M. (2018). Fetal alcohol spectrum disorders may be more common than previously thought. *Psychiatric News*, *53*(5). https://doi.org/10.1176/appi.pn.2018.3a8

Zagorski, N. (2017). Study estimates 630K infants born with FASD globally each year. *Psychiatric News*, 52(19), 1–1. <a href="https://doi.org/10.1176/appi.pn.2017.9b19">https://doi.org/10.1176/appi.pn.2017.9b19</a>