

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 17, 2020

The Honorable Senator Donovan Dela Cruz, Chair Senate Committee on Ways and Means Thirtieth Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Senator Dela Cruz and Members of the Committee:

SUBJECT: HB 2047 HD1 SD1 - Relating to Health

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS HB 2047 HD1 SD1** to establish a task force to identify therapies and home- and community-based care services that may benefit persons having fetal alcohol spectrum disorders (FASD).

In 2004 the Hawaii State Legislature passed the following Resolutions, SCR76/SR36 and HR98/HCR141 "Requesting the Department Of Health to Establish a Coordinated Statewide Effort to Address Fetal Alcohol Spectrum Disorder (FASD)". Within the Resolutions contained the following "whereas statement", "WHEREAS, FASD is the most under-diagnosed developmental disability, both in Hawaii and across the United States; and".

Throughout the years the legislature continued to address FASD and the State Council on Developmental Disabilities continued to support the statement that Fetal Alcohol Spectrum Disorder is the most under-diagnosed developmental disability. However, even if we improved on diagnosing, the diagnosis alone, does not guarantee admission and supports through one agency. For example, given that the prevalence rate of 1.58 percent of the population has an intellectual and developmental disability (I/DD), less than 8% of the I/DD population in Hawaii, are eligible for services through the Department of Health, Developmental Disabilities Division. Of that 8% there is a very small percentage that have FASD. Children who are born with FASD typically have a mixure of problems, ranging from medical, intellectual, behavioral, educational, and social problems. The problems caused by FASD vary from child to child, but defects caused by FASD are not reversible.

The Council understands and respects the struggles the Department of Health, Department of Human Services, Department of Education, Department of Public Safety and the Legislature have gone through while trying to address which agency or department should address the different problems caused by FASD and the complexity to provide the supports needed for those affected by FASD. We need to find a way we can work together to braid services and funding to sustain supports for this population. The Council is hopeful that the creation of a Task Force will result in finding a sustainable solution to support individuals, their families, and circle of supports affected by FASD.

Thank you for this opportunity to submit testimony in **strong support of HB2047 HD1 SD1.** 

Sincerely,

Rainty Bartoldus Daintry Bartoldus Executive Administrator 2

DAVID Y. IGE GOVERNOR OF HAWAII



BRUCE S. ANDERSON, PHD DIRECTOR OF HEALTH

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

# Testimony COMMENTING on H.B. 2047 SD1 **RELATING TO HEALTH.**

SENATOR DONOVAN M. DELA CRUZ, CHAIR SENATE COMMITTEE ON WAYS AND MEANS

Hearing Date: March 17, 2020 2:16 P.M.

Room Number: 211

- Department of Health Position: The Department of Health (DOH) offers the following 1
- COMMENTS on HB 2047 SD1. 2
- **Department of Health Testimony:** The subject matter of this measure intersects with the scope 3
- 4 of the DOH's Behavioral Health Administration (BHA) whose statutory mandate is to assure a
- 5 comprehensive statewide behavioral health care system by leveraging and coordinating public,
- private and community resources. Through the BHA, the DOH is committed to carrying out this 6
- mandate by reducing silos, ensuring behavioral health care is readily accessible, and person 7
- 8 centered.
- The BHA provides the following testimony on behalf of the Department of Health. 9
- HB 2047 SD1 would create a Fetal Alcohol Spectrum Disorders (FASD) Task Force in the BHA 10
- to address specific tasks: 11
- (a) Review best care practices including therapies and treatments for adults with FASD; 12
- (b) Conduct a study/submit a report to include: 13
- 14

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16

- 1) Identification of all populations and sub-populations of people who have FASD in Hawaii that have difficulty navigating and accessing care services; 2) Identification of therapies and home and community based services (HCBS),
- including for adults, and to consider an array of HCBS; 17

1	3) Recommendations for changes to state policy and regulations that may
2	increase access to services; and

3

#### 4) Recommendations for any necessary legislation.

DOH appreciates the intent of a FASD Task Force. The issues faced by individuals, families and
systems impacted by FASD are complex and often poorly understood. Finding solutions in
communities requires a range of answers and the participation of many stakeholders. The

7 approach to finding sustainable solutions is as important as the solutions themselves.

8 The range of problems faced by people with FASD include many associated psychiatric 9 comorbidities in addition to intellectual disabilities across the lifespan including attention deficit 10 hyperactivity disorder, affect regulation, conduct disorders, post traumatic stress disorder, and 11 attachment disorders. These comorbidities require diagnostic and treatment services, and in most 12 states mental health interventions are the primary intervention modality. As well, people with 13 FASD encounter difficulties in multiple systems including human service, primary care, health 14 care, educational and courts/corrections.

If this measure should pass, it is suggested that the FASD Task Force invite representatives from
the Department of Education, Child Welfare, the Judiciary, and Department of Public Safety, as

17 well as representatives from primary and specialty health care, which is allowed in the bill.

18 A foundational step in ensuring access to services is stakeholder agreed-upon diagnostic

19 categories and public health strategies for identifying the population and subpopulation to be

20 served. Most successful national programs emphasize prevention of drinking alcohol during

21 pregnancy as the foremost strategy for preventing incidences of FASD. A trauma-informed

22 approach across systems is particularly important given that the symptoms of FASD may

23 predispose clients to higher rates of victimization and trauma than the general population.

HB 2047 SD1, as written, places emphasis on a specific array of Medicaid home and community

based services that may or may not be needed across the population of people with FASD.

26 People diagnosed with FASD who have more severe functional limitations and who meet

27 eligibility for the Developmental Disabilities Division are already served primarily through the

Medicaid Home and Community Based Services 1915(c) waiver for Individuals with Intellectual
 and Developmental Disabilities.

Because of the many families who encounter problems in the Department of Education, Child
Welfare, the Judiciary, and Department of Public Safety, as well as in primary and specialty
health care the recommendation is to include representatives from these systems which is
allowed in the bill as written once the task force commences.

HB 2047 SD1 charges the proposed task force to identify strategies to reduce the incidence and
impact of FASD in Hawaii to encompass screening and diagnosis, prevention, health promotion,
and interventions that take into consideration needs across the lifespan and at specific transition
periods. The DOH supports this more comprehensive approach that looks at the most effective
strategies, supports and services needed by the population of individuals and families affected by
FASD.

13 Thank you very much for the opportunity to testify.

Fiscal Implications: The cost impact for a state funding match for Medicaid services would be high if the Task Force recommendations include the array of treatment and Medicaid HCBS listed in the bill. A full cost analysis and rate study would be necessary. If the Task Force includes recommendations for implementing screening and diagnosis, health promotion and prevention activities, these would need to be considered in a cost analysis.



PANKAJ BHANOT DIRECTOR

CATHY BETTS DEPUTY DIRECTOR

# STATE OF HAWAII DEPARTMENT OF HUMAN SERVICES

P. O. Box 339 Honolulu, Hawaii 96809-0339

March 16, 2020

TO: The Honorable Senator Donovan M. Dela Cruz, Chair Senate Committee on Ways and Means

FROM: Pankaj Bhanot, Director

SUBJECT: HB 2047 HD1 SD1 – RELATING TO HEALTH

Hearing: March 17, 2020, 2:16 p.m. Conference Room 211, State Capitol

**DEPARTMENT'S POSITION**: The Department of Human Services (DHS) appreciates the intent of the bill and offers comments. DHS appreciates the amendments made by the House Committee on Health and the Senate Committee on Commerce, Consumer Protection, and Health that broadened the task force's charge and focus.

**PURPOSE**: The bill establishes a task force within the Department of Health to identify therapies and home- and community-based care services (HCBS) that may benefit persons having fetal alcohol spectrum disorders, including therapies and treatments that may benefit them as adults. Requires the task force to recommend any necessary policy changes, rule changes, or legislation to increase access to these therapies and services. Requires a report to the Legislature. Effective 7/1/2050. (SD1)

DHS appreciates the intent of this measure. Individuals with FASD and their families face significant and complex challenges that they often must shoulder alone. DHS believes a task force is an appropriate way to study and make recommendations on ways to improve the system and continuum of care for individuals with FASD and their families. DHS looks forward to participating in the task force.

The amendments reflected in HB 2047 HD1 SD1 expand the charge and focus of the task force. DHS believes this is a good step, as the FASD community would be best served by a broad evaluation of their needs rather than a singular focus on HCBS, which may already be provided to many individuals. Individuals with FASD and their families may benefit from other services and initiatives, such as needs assessment, prevention, health promotion, and other interventions, that could be studied and evaluated by the task force.

Thank you for the opportunity to testify on this bill.



MERTON CHINEN EXECUTIVE DIRECTOR

Phone: (808) 587-5710 Fax: (808) 587-5734

STATE OF HAWAII DEPARTMENT OF HUMAN SERVICES

OFFICE OF YOUTH SERVICES 1010 Richards Street, Suite 314 Honolulu, Hawaii 96813

March 16, 2020

TO: The Honorable Senator Donovan M. Dela Cruz, Chair Senate Committee on Ways and Means

FROM: Merton Chinen, Executive Director

SUBJECT: HB 2047, HD1, SD1 - RELATING TO HEALTH

Hearing: Tuesday, March 17, 2020 2:16 p.m. State Capitol, Conference Room 211

**OFFICE'S POSITION:** The Office of Youth Services (OYS) supports the measure.

It is difficult to ascertain the true prevalence of youth affected by fetal alcohol syndrome disorder (FASD) who are involved with the juvenile justice system, however, data from other countries such as Australia and Canada indicate a range as high as 80%. Youth with FASD diagnosis often display impulsive behaviors, have trouble linking the consequences of their actions, have a poor sense of personal boundaries, and are susceptible to peer pressure that may lead to criminal behaviors. The establishment of a task force would help to bring focus on the needs of FASD youth, and document effective practices and resources that could assist the juvenile justice system to be more responsive with better outcomes.

**PURPOSE**: The purpose of the measure is to establish a task force within the Department of Health to identify therapies and home- and community -based care services that may benefit person having fetal alcohol spectrum disorders.

Thank you for the opportunity to present this testimony.



# HB2047 HD1 SD1 Stabilization Beds

COMMITTEE ON WAYS AND MEANS

- Sen. Donovan Dela Cruz, Chair; Sen. Gilbert Keith-Agaran, Vice Chair
- Tuesday, March 17, 2020: 2:16 pm
- Conference Room 211

# Hawaii Substance Abuse Coalition Supports HB2047 HD1 SD1:

ALOHA CHAIR, VICE CHAIR AND DISTINGUISHED COMMITTEE MEMBERS. My name is Alan Johnson. I am the current chair of the Hawaii Substance Abuse Coalition (HSAC), a statewide organization of over 30 non-profit alcohol and drug treatment and prevention agencies.

# 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 a Task Force to support a home-based and community-based healthcare 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.

HB-2047-SD-1 Submitted on: 3/15/2020 10:11:13 AM Testimony for WAM on 3/17/2020 2:16:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Katrina Obleada	Testifying for Hawaii Psychological Association	Support	No

Comments:

Testimony in Support of HB 2047, HD1, SD1 – Relating to Health Hearing on March 17, 2020, 2:15 PM Conference Room 211 of the State Capitol

- TO: Committee on Ways and Means Sen Donovan Dela Cruz, Chair Sen Gilbert Keith-Agaran, Vice Chair
- FR: Alan Shinn 2869 Park Street Honolulu, HI 96817

I am providing testimony in support HB 2047, HD1, SD1 – Relating to Health, which establishes a task force within the DOH to identify therapies and home and community-based care service that may benefit person with FASD, including adults. Requires the task force to recommend policy and rule changes, or legislation to increase access to these services. Finally, it requires a report to the Legislature.

I am a volunteer member of the Fetal Alcohol Spectrum Disorder (FASD) Action Group with a mission to raise awareness on the impact of FASD on individuals, their families, and the community through education, advocacy, and research in Hawaii.

FASD represents life-long disabilities and require on-going supportive services in the home and community for these individuals to live as normalized a lifestyle possible in the community. Currently they are not afforded continuum-of-care support as children and adolescents mature and become adults. This puts a tremendous emotional and financial burden on the families with disabled members who lack resources and must struggle to provide support to their disabled family members. It also places a strain on educational, law enforcement, judicial, health care, and other community resources that try but do not successfully deal with the unique challenges of FASD individuals.

A FASD task force is a good first step in allowing professionals, parents, advocates, and decision makers a chance to discuss and bring forth state-of-the-art science on FASD that might help determine what early interventions and techniques might mitigate intellectual, behavioral, and psychological impairments in children and adolescents in the home, school and community. Also, discussion of change in policy, projected costs and potential funding sources for these specialized therapies and services could be determined.

Thank you for the opportunity to provide testimony in support of HB 2047, HD1, SD1.



March 16, 2020

To: The Senate Committee on Ways and Means The Honorable Donovan M. Dela Cruz, Chair The Honorable Gilbert S.C. Keith-Agaran, Vice Chair

Re: Strong Support of HB2047 HD1, SD1 Relating to Health

Hrg: March 17, 2020 at 2:16 PM at Capitol Room 211

Please excuse the lateness of this testimony. The Hawaii Public Health Association (HPHA) is a group of over 600 community members, public health professionals and organizations statewide dedicated to improving public health. HPHA also serves as a voice for public health professionals and as a repository for information about public health in the Pacific.

HPHA strongly **supports** HB2047 HD1, SD1 which would establish a task force within the Department of Health to identify therapies and home- and community-based care services that may benefit persons having fetal alcohol spectrum disorders (FASD), including therapies and treatments that may benefit them as adults. This measure also requires the task to recommend in the form of a report to the Legislature that includes necessary policy or rule changes, or legislation to increase access to these therapies and services.

Studies on the prevalence and characteristics of FASD found the prevalence to be 6 and 9 per 1,000 children.<sup>1</sup> Based on physical assessments, FASD prevalence could range as high as 1 to 5 per 100 school children.<sup>2</sup> With an existing need clear, HPHA urges successful passage of this measure, as any findings and recommendations coming from this task force would help the people of Hawaii not only better understand exactly the impacts of FASD on human development but also how to care for those currently with FASD and those in the future who will have it.

Thank you for the opportunity to provide testimony on important health issues affecting people in Hawaii.

Respectfully submitted,

Claire Townsend Ing, DrPH Legislative Committee Chair Hawaii Public Health Association

Sources Cited:

- CDC. Fetal Alcohol Syndrome Among Children Aged 7-9 Years Arizona, Colorado, New York, 2010. MMWR Morb Mortal Wkly Rep. 2015;64(3):54-57
- 2. May PA, Baete A, Russo J, Elliott AJ, Blankenship J, Kalberg WO, Buckley D, Brooks M, Hansken J, Abdul-Rahman O, Adam MP, Robinson LK, Manning M, Hoyme HE. Prevalence and characteristics of fetal alcohol spectrum disorders. Pediatrics. 2014; 134:855-66.



March 14w, 2020

 To: Senator Donovan Dela Cruz, Chair And Members of the Senate Committee on Ways and Means
 Date & Time of Decision Making: Tuesday, March 17, 2020, 2:15 pm, Conference room 211

#### <u>Testimony in Support of HB2047 HD1: Establishes a task Force for Home and Community-Based Care</u> to Benefit Persons with Fetal Alcohol Spectrum Disorders

I am writing on behalf of myself and individuals, parents, families, and communities that I serve who seek services for their children and adults with a Fetal Alcohol Spectrum Disorders (FASD). Brain impairment from exposure to alcohol *in utero* varies from individual to individual and often goes undiagnosed and misdiagnosed.

Many families are faced with few, if any, community resources for their children and adults with FASD. In fact, many do not qualify for public assistance. Parents are under tremendous stress caring for their children and often encounter stress-related health problems. We know that individuals with FASD function best with vigilant supervision, structure, and encouragement. As adults, they want to be "on their own" but without help, they have difficulty living independently.

A comprehensive study in the U.S. (Streissguth, A., et al., 2004) noted that most (~75%) of adults with FAS/FAE had IQs within the normal range but with severe to mild functional disabilities. The finding suggests that functional disabilities might contribute to the following statistics: ~60% of adults encounter the criminal justice system, ~60% had disrupted school experience, and ~50% experienced alcohol/drug problems. Many (~80%) cannot live independently.

A task force to develop a system that (1) identifies the number of people with FASD, (2) defines the needs and current gaps in service, and (3) creates needed services, would be a tremendous boost to creating solutions for this under-recognized and underserved population. With community help, individuals with FASD can lead productive and meaningful lives.

Thank you for your consideration. Sincerely, Ann S. Yabusaki, Ph.D., MFT

#### March 14, 2020

 To: Senator Donovan Dela Cruz, Chair And Members of the Senate Committee on Ways and Means
 Date & Time of Decision Making: Tuesday, March 17, 2020, 2:15 pm, Conference room 211

#### <u>Testimony in Support of HB2047 HD1: Establishes a task Force for Home and Community-Based Care</u> to Benefit Persons with Fetal Alcohol Spectrum Disorders

As a retired biochemist, I'm testifying on behalf of myself and individuals, parents, families, and communities who seek services for their children and adults with a Fetal Alcohol Spectrum Disorders (FASD). I can attest that FASD is a permanent brain impairment from exposure to alcohol *in utero* varies from individual to individual and often goes undiagnosed and misdiagnosed.

Many families are faced with few, if any, community resources for their children and adults with FASD. In fact, many do not qualify for public assistance. Parents are under tremendous stress caring for their children and often encounter stress-related health problems. We know that individuals with FASD function best with vigilant supervision, structure, and encouragement. As adults, they want to be "on their own" but without help, they have difficulty living independently.

A comprehensive study in the U.S. (Streissguth, A., et al., 2004) noted that most (~75%) of adults with FAS/FAE had IQs within the normal range but with severe to mild functional disabilities. The finding suggests that functional disabilities might contribute to the following statistics: ~60% of adults encounter the criminal justice system, ~60% had disrupted school experience, and ~50% experienced alcohol/drug problems. Many (~80%) cannot live independently.

A task force to develop a system that (1) identifies the number of people with FASD, (2) defines the needs and current gaps in service, and (3) creates needed services, would be a tremendous boost to creating solutions for this under-recognized and underserved population. With community help, individuals with FASD can lead productive and meaningful lives.

Thank you for your consideration. Sincerely, Kenichi K. Yabusaki, Ph.D.

## HB-2047-SD-1

Submitted on: 3/15/2020 8:34:35 AM Testimony for WAM on 3/17/2020 2:16:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Melanie Van der Tuin	Individual	Support	No

## Comments:

To: Senator Donovan Dela Cruz, Chair

And Members of the Senate Committee on Ways and Means

Date & Time of Decision Making: Tuesday, March 17, 2020, 2:15 pm, Conference room 211

# Testimony in Support of HB2047 HD1: Establishes a task Force for Home and Community-Based Care

# to Benefit Persons with Fetal Alcohol Spectrum Disorders

Aloha.

I am writing on behalf of myself and individuals, parents, families, and communities that I serve who seek services for their children and adults with a Fetal Alcohol Spectrum Disorders (FASD). Brain impairment from exposure to alcohol *in utero* varies from individual to individual and often goes undiagnosed and misdiagnosed.

Many families are faced with few, if any, community resources for their children and adults with FASD. In fact, many do not qualify for public assistance. Parents are under tremendous stress caring for their children and often encounter stress-related health problems.

We know that individuals with FASD function best with vigilant supervision, structure, and encouragement. As adults, they want to be "on their own" but without help, they have difficulty living independently. A comprehensive study in the U.S. (Streissguth, A., et al., 2004) noted that most (~75%) of adults with FAS/FAE had IQs within the normal range but with severe to mild functional disabilities. The finding suggests that functional disabilities might contribute to the following statistics: ~60% of adults encounter the criminal justice system, ~60% had disrupted school experience, and ~50% experienced alcohol/drug problems. Many (~80%) cannot live independently.

A task force to develop a system that (1) identifies the number of people with FASD, (2) defines the needs and current gaps in service, and (3) creates needed services, would

be a tremendous boost to creating solutions for this under-recognized and underserved population. With community help, individuals with FASD can lead productive and meaningful lives.

Thank you for your consideration.

Sincerely,

Melanie Van der Tuin, MSCP

#### March 14, 2020

 To: Senator Donovan Dela Cruz, Chair And Members of the Senate Committee on Ways and Means
 Date & Time of Decision Making: Tuesday, March 17, 2020, 2:15 pm, Conference room 211

#### <u>Testimony in Support of HB2047 HD1: Establishes a task Force for Home and Community-Based Care</u> to Benefit Persons with Fetal Alcohol Spectrum Disorders

I am writing on behalf of myself and individuals, parents, families, and communities that I serve who seek services for their children and adults with a Fetal Alcohol Spectrum Disorders (FASD)impairment from exposure to alcohol *in utero* varies from individual to individual and often goes undiagnosed and misdiagnosed.

Many families are faced with few, if any, community resources for their children and adults with FASD. In fact, many do not qualify for public assistance. Parents are under tremendous stress caring for their children and often encounter stress-related health problems. We know that individuals with FASD function best with vigilant supervision, structure, and encouragement. As adults, they want to be "on their own" but without help, they have difficulty living independently.

A comprehensive study in the U.S. (Streissguth, A., et al., 2004) noted that most (~75%) of adults with FAS/FAE had IQs within the normal range but with severe to mild functional disabilities. The finding suggests that functional disabilities might contribute to the following statistics: ~60% of adults encounter the criminal justice system, ~60% had disrupted school experience, and ~50% experienced alcohol/drug problems. Many (~80%) cannot live independently.

A task force to develop a system that (1) identifies the number of people with FASD, (2) defines the needs and current gaps in service, and (3) creates needed services, would be a tremendous boost to creating solutions for this under-recognized and underserved population. With community help, individuals with FASD can lead productive and meaningful lives.

Thank you for your consideration. Sincerely, Micah Inoue MFT

HB-2047-SD-1 Submitted on: 3/15/2020 4:15:49 PM Testimony for WAM on 3/17/2020 2:16:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Kelsi Yonting	Individual	Support	No

Comments:

### THE SENATE THE THIRTIETH LEGISLATURE

#### **REGULAR SESSION OF 2020**

### COMMITTEE ON WAYS AND MEANS

Senator Donovan M. Dela Cruz, Chair

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

### NOTICE OF DECISION MAKING

DATE: Tuesday, March 17, 2020

TIME: 2:16 P.M.

PLACE: Conference Room 211

### Hawaii State Capitol 415 South Beretania Street

## POSITION: STRONG SUPPORT HB2047 HD1 SD1

In behalf of myself and the Hawaii FASD Action Group; a group of volunteers appealing to you, being the voices of children who have none, and individuals who have FASD whom for many years have been marginalized, unrecognized and without appropriate services. I am writing in **STRONG SUPPORT of HB2047 HD1 SD1** 

FASD is associated with secrecy and shame, quite possibly due to its preventable nature and the stigma attached to it. Alcohol is legally accessible, available in the community stores often left in unlocked cabinets in many homes, therefore, it is not surprising that the research stated that 1 in 20 first graders do have FASD. According to a research study questions, "Is this shame the reason for its marginalization of the children and families with FASD in general? While Autism Spectrum Disorders has increased public awareness, availability of therapeutic services and much recognition. (Barker, Kulyk, Knorr, & Brenna, 2011).

FASD diagnosis is a processing disorder, learning disability, and attention-deficit/ hyperactivity disorders almost the same with Autism Spectrum Disorders (Astley, 2010; Kodituwakku & Kodituwakku, 2014). Somewhere between 1% and 4% of all children worldwide are reported to have an FASD. The neurodevelopmental impairments associated with FASD came with significant social costs across the lifespan in the form of increased medical, educational, and vocational support and lost productivity (Lupton, Burd, & Harwood, 2004; Popova, Lange, Burd, & Rehm, 2015). I have worked with children with Autism as a Registered Behavioral Therapist under ABA Guidelines, and in my observations, FASD is a Developmental Disability is equally as severe as Autism. I find very few FASD services for many families and clients affected by FASD, which is why I support and believe that creating a task force is critical in establishing our own data in Hawaii to provide appropriate and necessary pieces of information for services in our own current demographics impacted by FASD. Through a task force, my colleagues and our community may begin to recognize and diagnose FASD and create FASD-specific services.

If the national data states that 1 in 20 first graders have FASD, we can make it 1 in 1,000 - 1 in 10,000, 100,000 even in 1 in a million because FASD is completely preventable. If we approach this to prevent, educate and rehabilitate with appropriate services, we together will be able to save children, youths and the current and future drinkers' children the less money we have to spend in the future. Now, the more I go on with my advocacy, we know we can do this but not without your support and the support of our community. I was able to meet with the Liquor Commission, many other agencies and they do support and believe we can do this together. I am tirelessly reaching out to everyone and anyone who will give me the time and will listen. I know we can make a difference taking care of tomorrow today. WE ARE GOING TO BE A RESPONSIBLE FASD INFORMED STATE. Please let us work for our Tomorrow Today. Let us help these innocent children born in an impossible world impacted by alcohol. We have the obligations to make their life and world possible for them as we made alcohol legal for public consumption.

Hindsight, we will be able to save our children, women, and families of Hawaii, and also our tax dollars when you support and the services are appropriated to this bill. Often, these children with FASD are seen with as children only with behavioral issues in our school system, get kicked out and eventually these children without no support will join into crime committing and delinquent groups who end up in our prison systems as juveniles and eventually as adult offenders. This cost our State \$55,000.00 a year per inmate, not to mention that our prison system is overpopulated and we ship our State Inmates to other States which cost us \$35,000.00 a year per inmate. This cost doesn't include property damages, medical and another cost to our tax dollars. With this bill, services will be provided and these individuals can be productive members of our society and somehow contribute not only to their own growth and needs but also to our community.

Mental Health Problems - 60% of children with FASD have ADDH and most individuals have clinical depression as adults; 23% of the adults had attempted suicide, and 43% had threatened to commit suicide. • Disrupted School Experience - 43% experienced suspension or expulsion or drop out; • Trouble with the Law - 42% had involvement with police, charged or convicted of a crime; • Confinement – 60% of these children age 12 and over experienced inpatient treatment for mental health, alcohol/drug problems, or incarceration for a crime. • Inappropriate Sexual Behavior – Reported in 45% of those aged 12 and over, and 65% of adult males with FAE. • Alcohol/Drug Problems – Of the adults with FAS, 53% of males and 70% of females experienced substance abuse problems. These children who have the potentials to become adult offenders can cost Hawaii \$55,000.00 a year in incarceration cost, and more economic challenges in societal, property damages and tax dollars. **I do beg of you to support and consider passing HB2047 HD1 SD1 for the children and the families of Hawaii**.

We are in dire need of a task force to define the needs, gaps in service and address this invisible disability because of the stigma surrounding its preventable cause. A task force will create FASD Informed care for the children who are born into an impossible world; together can make the world possible for them.

Thank you for your kind consideration.

Respectfully yours,

Darlyn Chen Scovell

#### Reference

Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. Canadian Journal of Clinical Pharmacology, 17(1), e132–e164.

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# <u>HB-2047-SD-1</u>

Submitted on: 3/15/2020 9:40:32 PM Testimony for WAM on 3/17/2020 2:16:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Annie Ahsing	Individual	Support	No

Comments:

I am for this bill, in behalf of my Ohana to take of our peoples future.

Aloha

Annie Ahsing

#### TO THE SENATE THE THIRTIETH LEGISLATURE REGULAR SESSION OF 2020

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

> DATE: Tuesday, March 17, 2020 TIME: 2:16 P.M. PLACE: Conference Room 211 State Capitol 415 South Beretania Street **HB2047 SD1**

#### POSITION: STRONG SUPPORT HB2047 SD1

The language in this bill creates the framework for addressing the needs of the (Fetal Alcohol Syndrome) community through the implementation of a task force. Furthermore, it will not only look at the what is needed and already there but where there could be gaps in services. All areas are important for a robust program toward addressing FAS issues.

A peer-reviewed 2004 study According to Streissguth, A., et al., that data suggest that 60% of persons with FAS had disrupted school experiences, and 50% had substance use problem and 60% of adults with FAS encountered the criminal justice system. These number are staggering, and also with important to note that the data of the study also suggest that, the 75% percent of the adults with FAS have IQ's that are within the median range of the typical population.

With regard to the criminal justice system, this it is important to identify the areas which create a possible pipeline toward encounters with the criminal justice system and incarceration and develop policies that prevent that those unnecessary occurrences. I support of amends with that will enhance the performance of the intent of this bill. Passage of this bill provides a special opportunity to remind and educate providers of care, systems of care, families, and communities in Hawaii about Fetal Alcohol Spectrum Disorders and the special needs of those affected and their families and the impact on communities. This measure will help to dispel FASDs as invisible disorders. Thank you for reading this testimony.

Mahalo,

Ken Farm

HB-2047-SD-1 Submitted on: 3/16/2020 8:48:04 AM Testimony for WAM on 3/17/2020 2:16:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
MaryGomes	Individual	Support	No

Comments: