



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 HD1
RELATING TO HEALTH.**

REPRESENTATIVE SYLVIA J. LUKE, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: February 21, 2020
1:30 PM

Room Number: 308

1 **Department of Health Position:** The Department of Health (DOH) offers the following
2 **COMMENTS AND SUGGESTED AMENDMENTS** to HB 2047 HD1.

3 **Department of Health Testimony:** The subject matter of this measure intersects with the scope
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,
6 private and community resources. Through the BHA, the DOH is committed to carrying out this
7 mandate by reducing silos, ensuring behavioral health care is readily accessible, and person
8 centered.

9 The BHA provides the following testimony on behalf of the Department of Health.

10 HB 2047 HD1 asks for the creation of a Fetal Alcohol Spectrum Disorders (FASD) Task Force
11 in the BHA to address specific tasks:

12 (a) Review best care practices including therapies and treatments for adults with FASD.

13 (b) Conduct a study/submit a report to include:

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

- 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.

4 DOH appreciates the intent of a FASD Task Force. The issues faced by individuals, families and
5 systems impacted by FASD are complex and often poorly understood. Finding solutions in
6 communities requires a range of answers and the participation of many stakeholders. The
7 approach to finding sustainable solutions is just 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
15 FASD Task Force invite representatives from the Department of Education, Child Welfare, the
16 Judiciary, and Department of Public Safety, as well as representatives from primary and
17 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.

24 HB 2047 HD1, as written, places emphasis on a specific array of Medicaid home and community
25 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

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

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

7 What may strengthen the charge of a task force is a charge to identify strategies to reduce the
8 incidence and impact of FASD in Hawaii to encompass screening and diagnosis, prevention,
9 health promotion, and interventions that take into consideration needs across the lifespan and
10 specific transition periods. The DOH supports this more comprehensive approach that looks at
11 the most effective strategies, supports and services needed by the population of individuals and
12 families affected by FASD.

13 The recommendation is to amend HB 2047 HD1 to include the suggested amendments below.

14 **Suggested Amendments:**

15 The Department of Health respectfully requests the following amendment to HB 2047 HD1:

16 INSERT in Section 2 (b) on page 5, starting on line 17, a new (3) to read:

17 (3) Strategies to reduce the incidence and impact of fetal alcohol spectrum
18 disorder in Hawaii that encompass the areas of screening and diagnosis,
19 prevention, health promotion, and interventions that take into
20 consideration needs across the lifespan through a community-wide,
21 coordinated effort;

22 INSERT in SECTION 2 on page 6, starting on line 4, a new (c) to read:

23 (c) Two or more members of the task force, but less than the number of
24 members that would constitute a quorum for the task force, may discuss

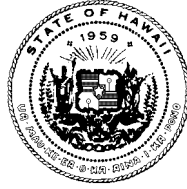
1 between themselves matters relating to official business of the task force
2 to enable members to faithfully perform their duties to the task force and
3 the organizations they represent, as long as no commitment to vote is
4 made or sought. Such discussions shall be a permitted interaction under
5 section 92-2.5, Hawaii Revised Statutes.

6

7 Thank you very much for the opportunity to testify.

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

DAVID Y. IGE
GOVERNOR



PANKAJ BHANOT
DIRECTOR

CATHY BETTS
DEPUTY DIRECTOR

STATE OF HAWAII
DEPARTMENT OF HUMAN SERVICES
P. O. Box 339
Honolulu, Hawaii 96809-0339

February 20, 2020

TO: The Honorable Representative Sylvia Luke, Chair
House Committee on Finance

FROM: Pankaj Bhanot, Director

SUBJECT: **HB 2047 HD1 – RELATING TO HEALTH**

Hearing: February 21, 2020, 1:30 p.m.
Conference Room 308, 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 Committee on Health that broadened the task force's charge to include recommendations for a comprehensive solution through community-wide initiatives and strategic planning.

PURPOSE: The bill establishes 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. The bill requires the task force to recommend any necessary policy changes, rule changes, or legislation to increase access to these therapies and services. The bill requires a report to the Legislature. It is effective 7/1/2050.

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 expand the charge 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.



HAWAI'I STATE ETHICS COMMISSION

State of Hawai'i · Bishop Square, 1001 Bishop Street, ASB Tower 970 · Honolulu, Hawai'i 96813

Committee: Committee on Finance
Bill Number: H.B. 2047, H.D.1
Hearing Date/Time: Friday, February 21, 2020, 1:30 p.m.
Re: Testimony of the Hawai'i State Ethics Commission
with **COMMENTS AND PROPOSED AMENDMENT** to
H.B. 2047, H.D.1, Relating to Health

Chair Luke, Vice Chair Cullen, and Committee Members:

The Hawai'i State Ethics Commission ("Commission") respectfully suggests the deletion of the second sentence of Section 2, subsection (c): "No member of the task force shall be made subject to section 84-17, Hawaii Revised Statutes, solely because of that member's participation on the task force."

Just last session, the Legislature enacted language in the Ethics Code that specifically applies to task force members and their potential conflicts of interests:

[E]very task force member or designee or representative of a task force member shall publicly disclose the nature and extent of any interest or transaction that the task force member or task force member's designee or representative believes may be affected by the task force member's official action.

HRS § 84-13(c).¹ As such, an outright exemption for task force members from HRS § 84-17 appears contrary to the Legislature's intent in enacting the above-quoted language just last year.

The Commission respectfully requests that the Committee delete this proposed language from H.B. 2047. The Commission is aware that bills proposing task forces often contain an

¹ The Legislature also directed the Commission to adopt rules to effectuate this section; on March 19, 2020, the Commission intends to hold a public hearing on a large package of administrative rules, including a proposed rule regarding task force members' disclosures of potential conflicts of interests. The proposed rule on this topic currently provides as follows:

This disclosure shall be made verbally at the first available meeting of the task force and shall be memorialized in any task force report. If no meeting is to occur before the task force member, designee, or representative takes official action affecting their interests, the disclosure shall be made in writing to all other task force members, and then subsequently in any task force report.

identical sentence purporting to exclude task force members from HRS § 84-17, and the Commission will be making the same request as to those measures as well.

Thank you for your continuing support of the Commission's work and for considering the Commission's testimony on H.B. 2047, H.D.1.

Very truly yours,

Daniel Gluck
Executive Director and General Counsel



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
February 21, 2020

The Honorable Representative Sylvia Luke, Chair
House Committee on Finance
Thirtieth Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Luke and Members of the Committees:

SUBJECT: HB 2047 HD1 – Relating to Health

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS HB 20472 HD1** 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 mixture 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.

The Council respectfully has one recommendation, that the Task Force also examine the past 16 years of Hawaii State Legislation relating to FASD and the reports submitted to the Legislature. It could provide the Task Force with the perspective for a sustainable solution.

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

Sincerely,

A handwritten signature in blue ink that reads "Daintry Bartoldus". The signature is written in a cursive style with a large initial "D".

Daintry Bartoldus
Executive Administrator

HB-2047-HD-1

Submitted on: 2/19/2020 5:40:09 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------------------|---------------------------|---------------------------|
| Louis Erteschik | Hawaii Disability Rights Center | Support | No |

Comments:

This is an excellent idea. We have been advocating for several years that there needs to be a program for children born with fetal alcohol syndrome. They truly fall into a gap group, and have often failed to qualify either for DD services or mental health services. The current approach in the state is focused mostly on educating women about the dangers of consuming alcohol while pregnant. While laudable, this is highly insufficient and ineffective. These people need services. There has been much discussion in the past few sessions about the provision of services but these discussions have been somewhat ad hoc. A Task Force would formalize this and lead to a Report with concrete proposals and that is exactly what we need.

**LIQUOR COMMISSION
CITY AND COUNTY OF HONOLULU**

711 KAPIOLANI BOULEVARD, SUITE 600, HONOLULU, HAWAII 96813-5249
PHONE (808) 768-7300 or (808) 768-7333 • FAX (808) 768-7311
INTERNET ADDRESS: www.honolulu.gov/liq • E-MAIL: liquor@honolulu.gov



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ASSISTANT ADMINISTRATOR

February 20, 2020

The Honorable Sylvia Luke, Chair
The Honorable Ty J.K. Cullen, Vice Chair
and Members of the Committee on Finance
House of Representatives
State Capitol, Room 308
415 South Beretania Street
Honolulu, Hawaii 96813

Dear Chair Luke, Vice Chair Cullen, and Members of the Committee:

SUBJECT: House Bill No. 2047 HD1
Relating to Health

In the City and County of Honolulu, the statutory mandate of the Liquor Commission (Commission) is to regulate the manufacture, importation, or sale of alcohol through the licensing and enforcement process. While the issue addressed by House Bill 2047 HD1 is not directly within the Commission's purview, it is an unfortunate by-product of alcohol that is manufactured, imported, or sold in our jurisdiction. Therefore, for matters involving misuse of alcohol – whether it be overconsumption, sales to minors, or fetal alcohol spectrum disorder – the Commission is supportive of programs meant to address these misuses and further education and awareness of responsible alcohol consumption.

Thank you for the opportunity to provide comments on House Bill 2047 HD1.

Sincerely,


Franklin Don Pacarro, Jr.
Administrator

FDPjr:ACH

HB-2047-HD-1

Submitted on: 2/19/2020 8:16:18 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|----------------------------------|---------------------------|---------------------------|
| Katrina Obleada | Hawaii Psychological Association | Support | No |

Comments:



HB2047 HD1 FASD Task Force

COMMITTEE ON FINANCE :

- Rep. Sylvia Luke, Chair; Rep. Ty Cullen, Vice Chair
- Tuesday, Feb. 21st, 2020: 1:30 pm
- Conference Room 308

Hawaii Substance Abuse Coalition Recommends and Supports HB2047 HD1:

GOOD MORNING 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 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.



DOING THE MOST GOOD

Founded in 1865

William Booth
Founder

Brian Peddle
General

Kenneth Hodder
Territorial Commander

Jeff Martin
Eloisa Martin
Divisional Leaders

Melanie Boehm
Executive Director

The Salvation Army

Addiction Treatment Services and Family Treatment Services

2-19-20

HB2047 HD1 FASD Task Force

COMMITTEE ON FINANCE

- Rep. Sylvia Luke, Chair; Rep. Ty Cullen, Vice Chair
- Tuesday, Feb. 21st, 2020: 1:30 pm
- Conference Room 308

The Salvation Army Addiction Treatment Services and Family Treatment Services Recommends and Supports HB2047 HD1:

Fetal Alcohol Spectrum Disorder [FASD] is a preventable and treatable disability.

There are significant and increasingly improved interventions that are available for mental health issues such as FASD 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 treat in the healthcare system 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 by:

- Understanding the disorder and reshape some of our interventions to change a child's behavior and improve functionality.

Addiction Treatment Services

3624 Waokanaka Street ♦ Honolulu, Hawai'i 96817 ♦Tel: (808) 595-6371 ♦Fax: (808) 595-8250

Family Treatment Services

845 22nd Avenue ♦ Honolulu, Hawai'i 96816 ♦Tel: (808) 732-2802 ♦Fax: (808) 734-7470

Visit us at: www.SalvationArmyHawaii.org

Participating Agency



Aloha United Way



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William Booth
Founder

Brian Peddle
General

Kenneth Hodder
Territorial Commander

Jeff Martin
Eloisa Martin
Divisional Leaders

Melanie Boehm
Executive Director

The Salvation Army

Addiction Treatment Services and Family Treatment Services

- Reducing the prevalence of FASD.
- Empowering caregivers to help FASD people reach their full potential.
- Addressing stigma by educating our communities to understand the complexities of this disability while promoting a more inclusive culture.
- Greatly improving outcomes through measurement brought about by Medicaid funding.
- Reducing 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.

Sincerely,

Melanie T. Boehm MA, LMHC, CSAC
Executive Director ATS-FTS

Participating Agency



Addiction Treatment Services

3624 Waokanaka Street ♦ Honolulu, Hawai'i 96817 ♦ Tel: (808) 595-6371 ♦ Fax: (808) 595-8250

Family Treatment Services

845 22nd Avenue ♦ Honolulu, Hawai'i 96816 ♦ Tel: (808) 732-2802 ♦ Fax: (808) 734-7470

Visit us at: www.SalvationArmyHawaii.org

Testimony in Support of HB 2047, HD1 – Relating to Health
Hearing on February 21, 2020, 1:30 PM
Conference Room 308 of the State Capitol

TO: Committee on Finance
Rep Sylvia Luke, Chair
Rep Ty Cullen, Vice Chair

FR: Alan Shinn
2869 Park Street
Honolulu, HI 96817
(808) 261-9612

I am providing testimony in support HB 2047, HD1 – 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.

HB-2047-HD-1

Submitted on: 2/19/2020 6:04:57 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Jud Cunningham | Aloha House, Inc. | Support | No |

Comments:

February 19, 2020

To: Representative Sylvia Luke, Chair
And Members of the House Committee on Finance

Date & Time of Hearing: Friday, February 21, 2020, 1:30 pm, Room 308

Testimony in Support of HB2047 HD1: Establishes a task Force for Home and Community-Based Care to Benefit Persons with FASD

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 Disorder (FASD). FASDs are permanent brain-based disorders that affect many individuals who were exposed to alcohol during pregnancy. Brain impairment from FASD varies from individual to individual and often goes undiagnosed and misdiagnosed leading to inappropriate interventions.

Many families are faced with few, if any, community resources for their children and adults. 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 better system that (1) identifies the number of people with FASD, (2) defines the needs and current gaps in service, and (3) suggests ways of creating 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

February 19, 2020

To: Representative Sylvia Luke, Chair
And Members of the House Committee on Finance
Date & Time of Hearing: February 21, 2020, 1:30 am, Room 308

Testimony in Support of HB2047: Establishes a task Force for Home and Community-Based Care to Benefit Persons with FASD

I am a retired biochemist and have researched some of the biochemistry relating to fetal alcohol spectrum disorders (FASD), a permanent, life-long, and 100% preventable condition caused by prenatal exposure to the metabolites of alcohol consumption. The use of Intelligent Quota (IQ) is one of the biggest injustices the U.S. uses as an index to qualify for human services. There is no correlation between a person's IQ and adaptive functioning by the standards set forth in our society. Many individuals afflicted with FASD do not qualify for developmental disability (DD, Medicaid) services because of IQ scores and/or their condition was not diagnosed until after well into adulthood. Those with life-long DD conditions (at no fault of their own) being denied services which include therapies (interventions) in both the home and in the community is a "Civil Right". It is the "Right" of those born with FASD in a society where alcohol consumption is a living issue to have access to the above services. Thus, to achieve this goal, it should be the State of Hawaii's Department of Health's responsibility to establish a Task force to implement a program(s) to obtain the need (FASD numbers), and seriously consider waivers via policy/rule changes that currently disqualify access to therapies and both home and community based services for those afflicted by FASD. It "...takes a village.." to support individuals with FASD and I strongly support HB 2047. Thank you for your consideration.

Respectfully,

Kenichi K. Yabusaki, Ph.D.

To: House Finance committee

Date & Time of Hearing: Friday, February 21, 2020, 1:30 pm, Room 308

Testimony in Support of HB2047: Establishes 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, 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.

I am a parent of an adoptive son (now 31 years old) with fetal alcohol spectrum disorder (FASD) This is an invisible brain and whole body based lifelong permanent disability. I have been involved on all previous Hi task forces and have started my own nonprofit organization FASD Communities to help develop communities for young adults with FASD.

There is a significant unawareness of this disability amongst all constituents of our community and thus little to no help available to these innocent victims and their families in Hawaii. They need and deserve help as society helps others with disabilities. Parents of people with disabilities go way above and beyond the realm of "normal Parenting" and do not receive adequate support in our community.

Although this is not a curable disability as many others are not, outcomes can be improved with ongoing interventions and supports.

Those affected are costing our community in many ways including incarceration, addiction programs, chronic unemployment and homelessness. It is my belief that money would be better spend on providing supports to this population and the outcomes would be more successful.

My son was recently hospitalized with a serious septic strep infection and I have to try and educate every nurse and doctor about this disorder to help them understand his lack of executive function despite him presenting as if he has it together. On top of this he is morbidly obese which will create more problems in his future. Research indicates that 45% of young FASD young adults struggle with obesity due to the effects of alcohol in utero on the metabolic and endocrine systems. Try and deal with this on your own with a child exhibiting adolescent behaviors towards a single mother. This is another battle to be fought with a different segment of the medical community as the expectations will be that he will need to be self-motivated and have the capacity to follow through, neither of which he can do.

Although he seems to be able to maintain employment it never last more than three or four months this is success for one of these kids. Somewhere along the way he got kicked off SSI as he made a little too much money. Another battle for me to fight again getting him requalified.

Long term housing supports are also needed with the appropriate supervision and structure which is why I created my nonprofit organization. Many years ago I decided that it would take the state way to long to make progress and this this organization was created and it although our first " FASD group home is in WI, for economic reasons it is working and the residents are thriving and their parents are happy as they know firsthand what is needed and they know their young adults are safe, happy, not being exploited by others and well cared for. If there were financial resources available in Hawaii I would be happy to open a home here specifically for FASD adults. If one individual can make this happen the State should be able to do better with its vast resources.

This is only a small snippet of my ongoing care of my son which will need to be ongoing.

You wonder why more parents do not submit more testimony it is because they don't have the time, knowledge or expertise and they are barely able to keep afloat.

I strongly encourage you to support SB 2350 and do not have the time to come and testify in person

Thanks for your time in reviewing this testimony

Sincerely

A handwritten signature in black ink that reads "Gigi Davidson". The signature is written in a cursive, flowing style.

Gigi Davidson

HB-2047-HD-1

Submitted on: 2/19/2020 12:58:54 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Lisa | Individual | Support | No |

Comments:

I am writing in strong support of HB2047 HD1. Access to service for adults with developmental disabilities is critical to people with brain disorders such as fetal alcohol spectrum disorders (FASD). Individuals born with an FASD experience effects ranging from severe to mild who require life-long supportive services. Without these services, individuals are at high risk for costly mental health concerns, substance use, and other issues that can result in adverse experiences such as the criminal justice, homelessness, unemployment. Yet, with life-long supportive services to individuals affected by FASD, research and experience show that that they can be productive members of society and find deep meaning in life. It makes economic, moral, and medical sense to create resources for adult individuals affected with FASD and their families.

A task force is necessary in defining services and resources needed and establishing those services.

Other talking points:

- 94% of people with FASD have a mental health disorder
- 80% are unable to work full time
- 80% are unable to live independently
- 60% will have contact with the justice system
- 60% will have substance use disorders

Mahalo nui loa for your consideration.

Lisa Garcia, PSYD

HB-2047-HD-1

Submitted on: 2/19/2020 12:55:13 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Colleen Fox | Individual | Support | No |

Comments:

HB-2047-HD-1

Submitted on: 2/19/2020 1:33:09 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Dannah Yamamoto | Individual | Support | No |

Comments:

I **strongly support HB 2047**. Those diagnosed with FASD often do not receive appropriate care due to a lack of specialized care. By having the DOH establish a task force to conduct necessary research on effective treatment options and recommend policy changes, we can see this minority population finally receiving the services they need. Thank you,

Dannah Yamamoto

HB-2047-HD-1

Submitted on: 2/19/2020 8:25:56 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Andrea Quinn | Individual | Support | No |

Comments:

HB-2047-HD-1

Submitted on: 2/19/2020 8:36:30 PM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Eri Rodrigues | Individual | Support | No |

Comments:

February 19, 2020

To: Representative Sylvia Luke, Chair and the Members of the Committee on Finance

Date and Time of Hearing: February 21, 2020 at 1:30 p.m.

Testimony in Support of HB2047 HD1 Establishing a Task Force for Home and Community-Based Care to Benefit Persons with Fetal Alcohol Spectrum Disorder

I would like to take this opportunity to express my support for the existing needs of individuals impacted by Fetal Alcohol Spectrum Disorder to be further assessed through this measure. Statistics in the United States indicate higher prevalence of Fetal Alcohol Spectrum Disorder compared to individuals with other diagnoses such as Autism Spectrum Disorder. Studies and services from other states as well as overseas present that individuals with Fetal Alcohol Spectrum Disorder benefit from structure and supports that cater to their unique needs, however these individuals as well as families are currently under identified and served in our state of Hawaii. This measure will create an opportunity for the gaps in services to be identified for those impacted by Fetal Alcohol Spectrum Disorder, for conversation to begin on how to fill those gaps.

Thank you for your consideration and allowing me to express my support toward this measure.

Sincerely,

Eri N. Rodrigues, LSW

HOUSE OF REPRESENTATIVES
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2020

COMMITTEE ON FINANCE

Rep. Sylvia Luke, Chair

Rep. Ty J.K. Cullen, Vice Chair

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| Rep. Scot Z. Matayoshi | |

NOTICE OF HEARING

DATE: Friday, February 21, 2020

TIME: 1:30 P.M.

PLACE: Conference Room 308
State Capitol
415 South Beretania Street

POSITION: STRONG SUPPORT HB2047 HD1

In behalf of myself, 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**

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 disorder 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 community may begin to recognize and diagnose FASD and create FASD-specific services.

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 SB2350 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.

Barker, C., Kulyk, J., Knorr, L., & Brenna, B. (2011). Open Inclusion or Shameful Secret: A Comparison of Characters with Fetal Alcohol Spectrum Disorders (FASD) and Characters with Autism Spectrum Disorders (ASD) in a North American Sample of Books for Children and Young Adults. *International Journal of Special Education*, 26(3), 171–180. Retrieved from <http://search.ebscohost.com.libproxy.edmc.edu/login.aspx?direct=true&db=eric&AN=EJ959010&site=eds-live>

Kodituwakku, P., & Kodituwakku, E. (2014). Cognitive and behavioral profiles of

children with fetal alcohol spectrum disorders. *Current Developmental Disorders Reports*, 1(3), 149–160. <https://doi.org/10.1007/s40474-014-0022-6>

Thorne, J. C. 1. jct6@uw. ed. (2017). Accentuate the Negative: Grammatical Errors During Narrative Production as a Clinical Marker of Central Nervous System Abnormality in School-Aged Children With Fetal Alcohol Spectrum Disorders. *Journal of Speech, Language & Hearing Research*, 60(12), 3523–3537. [https://doi-org.libproxy.edmc.edu/10.1044/2017pass:\[\]JSLHR-L-17-0128](https://doi-org.libproxy.edmc.edu/10.1044/2017pass:[]JSLHR-L-17-0128)

TO THE HOUSE OF REPRESENTATIVES
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2020

COMMITTEE ON FINANCE
Rep. Sylvia Luke, Chair
Rep. Ty J.K. Cullen, Vice Chair

DATE: Friday, February 21, 2020

TIME: 1:30 P.M.

PLACE: Conference Room 308
State Capitol

415 South Beretania Street
HEARING HB2047 HD1

POSITION: **STRONG SUPPORT HB2047, HD1**

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 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 suggests that 60% of persons with FAS had disrupted school experiences, and 50% had substance use problems and 60% of adults with FAS encountered the criminal justice system. These numbers are staggering, and important to note that the data of the study also suggest that, 75% percent of the adults with FAS have IQ's that are within the median range of the typical population.

Regarding the criminal justice system, 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 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-HD-1

Submitted on: 2/20/2020 11:59:35 AM

Testimony for FIN on 2/21/2020 1:30:00 PM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Jana-Macy Moya | Individual | Support | No |

Comments:

February 20, 2020

Dear Members of the House Finance Committee

Testimony in Support of HB2047: Establishes a task Force within Department of Health to Benefit Persons with FASD

Date & Time of Hearing: Friday, February 21, 2020, 1:30 am, Room 308

I am in strong support of HB2047 as it establishes a task force related to services that benefit individuals with Fetal Alcohol Spectrum Disorder (FASD). I have been in the mental health field for 15 years and throughout this time, I have seen the lack of adequate support services for those with FASD.

Many people may not be aware of how important services for an individual with FASD is. FASD is a brain-based developmental disorder that can affect those exposed to alcohol in utero. Part of why people may not be aware is because it is often undiagnosed or misdiagnosed in our communities. Some concerns of significance are difficulty in relationships, school, employment, independent living, and getting involved with the criminal justice system. Unfortunately, support services are largely not available or not optimal to meet the needs of this population and those who care for them.

A task force is needed to define the needs, identify the gaps in service, and find ways of addressing barriers and maximizing strengths. Our clients, our communities, and our families need the policy makers and service providers to support them in creating solutions that will help them live productive and meaningful lives.

Thank you for your consideration.

Sincerely,

Jana-Macy Moya, MS, LMFT



February 21, 2020

To: The House Committee Members on Finance
The Honorable Sylvia Luke, Chair
The Honorable Ty J.K. Cullen, Vice Chair

LATE

Re: Strong Support of HB2047 HD1, Relating to Health

Hrg: February 21, 2020 at 1:30 PM at Capitol Room 308

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, 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.¹ Based on physical assessments, FASD prevalence could range as high as 1 to 5 per 100 school children.² 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,

A handwritten signature in blue ink, appearing to read 'Claire Townsend', is written over a faint, light blue circular stamp.

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

Sources Cited:

1. 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.

