



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 ROSALYN H. BAKER, CHAIR
HOUSE COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH

Hearing Date: March 10, 2020
9:30 a.m.

Room Number: 229

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 would create a Fetal Alcohol Spectrum Disorders (FASD) Task Force in the BHA
11 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 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 at
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 Which would replace (DELETE) Section 2 (b) (4) on page 6:

23 (4) Recommendations for a comprehensive solution through community wide
24 initiatives and strategic planning

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

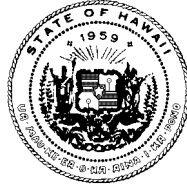
2 (c) Two or more members of the task force, but less than the number of
3 members that would constitute a quorum for the task force, may discuss
4 between themselves matters relating to official business of the task force
5 to enable members to faithfully perform their duties to the task force and
6 the organizations they represent, as long as no commitment to vote is
7 made or sought. Such discussions shall be a permitted interaction under
8 section 92-2.5, Hawaii Revised Statutes.

9

10 Thank you very much for the opportunity to testify.

11 **Fiscal Implications:** The cost impact for a state funding match depends on Task Force
12 recommendations and if they include the array of treatment and Medicaid HCBS listed in the
13 bill. A full cost analysis and rate study would be necessary. If the Task Force includes
14 recommendations for implementing screening and diagnosis, health promotion and prevention
15 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

March 9, 2020

TO: The Honorable Senator Rosalyn H. Baker, Chair
Senate Committee on Commerce, Consumer Protection, and Health

FROM: Pankaj Bhanot, Director

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

Hearing: March 10, 2020, 9:30 a.m.
Conference Room 229, 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 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 (HCBS) 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.

HB-2047-HD-1

Submitted on: 3/6/2020 6:30:25 PM

Testimony for CPH on 3/10/2020 9:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Support	Yes

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.



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
March 10, 2020

The Honorable Senator Rosalyn Baker, Chair
Senate Committee on Commerce, Consumer Protection, and Health
Thirtieth Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Senator Baker and Members of the Committee:

SUBJECT: HB 2047 HD1 – Relating to Health

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS HB 2047 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



HAWAII SUBSTANCE ABUSE COALITION

HB2047 HD1 (S) Stabilization Beds

COMMITTEE ON CONSUMER PROTECTION AND HEALTH:

- Sen. Rosalyn Baker, Chair; Sen. Stanley Chang, Vice Chair
- Tuesday, March 10, 2020: 9:30 am
- Conference Room 229

Hawaii Substance Abuse Coalition Supports HB2047 HD1 (S):

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 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.

HB-2047-HD-1

Submitted on: 3/8/2020 5:26:58 PM

Testimony for CPH on 3/10/2020 9:30:00 AM

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

Comments:

LATE

Testimony in Support of HB 2047, HD1 – Relating to Health
Hearing on March 10, 2020, 9:30 AM
Conference Room 229 of the State Capitol

TO: Committee on Commerce, Consumer Protection, and Health
Sen Rosalyn Baker, Chair
Sen Stanley Chang, 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.

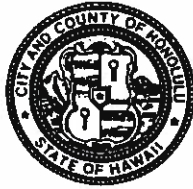
FASD represents life-long disabilities and require on-going supportive services in the home and community for these individuals to live as normalized a lifestyle possible in the community. Currently they are not afforded continuum-of-care support as children and adolescents mature and become adults. 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.

**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



KIRK CALDWELL
MAYOR

JOSEPH V. O'DONNELL
CHAIRMAN

NARSI A. GANABAN
CO-VICE CHAIR

MALAMA MINN
CO-VICE CHAIR

DARREN Y. T. LEE
COMMISSIONER

DUANE R. MIYASHIRO
COMMISSIONER

FRANKLIN DON PACARRO, JR.
ADMINISTRATOR

ANNA C. HIRAI
ASSISTANT ADMINISTRATOR

March 9, 2020

The Honorable Rosalyn H. Baker, Chair
The Honorable Stanley Chang, Vice Chair
and Members of the Committee on Commerce,
Consumer Protection, and Health
State Senate
State Capitol, Room 229
415 South Beretania Street
Honolulu, Hawaii 96813

Dear Chair Baker, Vice Chair Chang, 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,

Anna Hira
for Franklin Don Pacarro, Jr.
Administrator

FDPjr:ACH

LATE

March 7, 2020

To: Senator Roslyn Baker, Chair
And Members of the Senate Committee on Commerce, Consumer Protection and Health

From: Kristine Altwies, MA - ED/CEO Hawaii International Child, Inc.

Date & Time of Hearing: Tuesday, March 10, 2020, 9:30 am, Conference room 229

Testimony in Support of HB2047 HD1: Establishes a task Force for Home and Community-Based Care 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. People who have FASD suffer from permanent brain damage.

Working in adoption and foster care, we see too many families each year, struggling to figure out how to help their children, most of whom manifest with many or all of the classic FASD challenges yet who are unable to achieve diagnosis or if they have that, cannot find services, supportive school staff, or other needed resources in the community.

FASD is the largest, unidentified health crisis in our nation. According to the National Institutes of Health, "Prenatal alcohol exposure is a leading preventable cause of developmental disabilities worldwide," says NIAAA Director Dr. George F. Koob. "Estimating the prevalence of FASD in the United States has been complex due to the challenges in identifying prenatally exposed children. The findings of this study confirm that FASD is a significant public health problem, and strategies to expand screening, diagnosis, prevention, and treatment are needed to address it."

Thank you for your consideration.

With respect,

Kristine Altwies, MA
ED/CEO
Hawaii International Child

LATE

TO THE SENATE
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2020

COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH

Senator Rosalyn H. Baker, Chair
Senator Stanley Chang, Vice Chair

DATE: Tuesday, March 10, 2020

TIME: 9:30 AM

PLACE: Conference Room 229

State Capitol

415 South Beretania Street

HEARING HB2047

POSITION: **STRONG SUPPORT HB2047**

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

LATE

HB-2047-HD-1

Submitted on: 3/9/2020 10:01:13 AM

Testimony for CPH on 3/10/2020 9:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Jeremy Daniel	Individual	Support	No

Comments:

I am a parent of an adopted child with a FASD. This "invisible" disability often times results in children like ours not being able to receive the supports they need to be successful in life or contribute to society.

The MAJORITY of these individuals will end up incarcerated, with drug and/or alcohol issues, and/or homeless.

We need to be able to provide support in a preventative manner so that we can reverse these trends. I see it and LIVE it everyday. 1 in 20 of our Kindergarteners is affected. It is more prevalent than autism, cerebral palsy, and downs syndrome COMBINED, yet only a mere fraction of the resources are available. This is a civil rights issue, and these individuals need our support.

Mahalo for your support!

March 7, 2020

To: Senator Roslyn Baker, Chair
And Members of the Senate Committee on Commerce, Consumer Protection and Health
Date & Time of Hearing: Tuesday, March 10, 2020, 9:30 am, Conference room 229

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

HB-2047-HD-1

Submitted on: 3/9/2020 12:49:06 AM

Testimony for CPH on 3/10/2020 9:30:00 AM

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

Comments:

March 9, 2020

Members of the Senate Committee on Commerce, Consumer Protection, and Health

Testimony in Support of HB047: Establishes a task Force for Home and Community-Based Care

to Benefit Persons with FASD

Date & Time of Hearing: Tuesday, March 12, 2020, 9:00 am, Room 229

I am in strong support of HB2-47 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

COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH

Senator Rosalyn H. Baker, Chair
Senator Stanley Chang, Vice Chair

NOTICE OF HEARING

DATE: Tuesday, March 10, 2020

TIME: 9:30 AM

PLACE: Conference Room 229

State Capitol

415 South Beretania Street

POSITION: STRONG SUPPORT HB2047 HD1

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**

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.

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,


Darryn 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>
- Thome, 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)

March 7, 2020

To: Senator Roslyn Baker, Chair
And Members of the Senate Committee on Commerce, Consumer Protection and Health
Date & Time of Hearing: Tuesday, March 10, 2020, 9:30 am, Conference room 229

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

I am writing on behalf of myself and individuals, parents, families, and communities that 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. As a retired biochemist, I have educated myself about FASD and I can attest that this condition is a permanent (life-long) brain disorder with no correlation to IQ. The main emphasis should be on “functionality” in its many forms such as executive functioning as an example.

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-HD-1

Submitted on: 3/8/2020 9:27:27 PM

Testimony for CPH on 3/10/2020 9:30:00 AM

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

Comments:

March 8, 2020

To: Senator Rosalyn H. Baker, Chair and the Members of the Committee on Commerce, Consumer Protection, and Health

Date and Time of Hearing: March 10, 2020 at 9:30 a.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 toward this measure for the needs of individuals impacted by Fetal Alcohol Spectrum Disorder (FASD) to be further assessed in our community. National statistics in the United States indicate that one in twenty first graders are impacted by this disorder. Prevalence based on this number is higher than individuals with other diagnoses such as Autism Spectrum Disorder, however no data is currently available in our state of Hawaii. Due to limited resources and services available in the state at this time, individuals as well as families impacted by FASD are under-identified and under-served and this task force will identify ways to fill those gaps.

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

Sincerely,

Eri N. Rodrigues, LSW

HB-2047-HD-1

Submitted on: 3/8/2020 10:02:03 PM

Testimony for CPH on 3/10/2020 9:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Elizabeth zkong	Individual	Support	No

Comments:

Dear Legislators,

I am support of HB2047 for individuals, families amd members of the community who may be affected by Fetal Alcohol Syndrome and need mental health services and educational resources. As a School Counselor and having worked with persons Development Disabilities there is a desperate need for services specialized to deal with learning differences due to children with Fetal Alcohol Syndrome as well as emotional support for the families. A taskforce would support and research the needs for the peole of Hawaii. At my current school I persinally know of a student whose parent is too embarrassed to seek services as an alcoholic mother due to the stigma and shame. It would be advantageous to provide education and resources so parents can obtain the help they need without feeling embarrassed to say they drank alcohol during the pregnancy which in turn affected thier children which is in itslef a tragedy. Many women were unaware and some continue today as social drinking unknowly being pregnant. Please supoort the funding needed for services for FASD!

HB-2047-HD-1

Submitted on: 3/9/2020 8:30:09 AM

Testimony for CPH on 3/10/2020 9:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Gigi V Davidson	Individual	Support	No

Comments:

I strongly urge you to support HB2047. As a parent of an adult child with Fetal Alcohol Spectrum disorder there is a long way to go in bringing awareness of this disability to Hawaii. It is mostly misunderstood and there is basically not help available for those afflicted with this lifelong disability and their families. They need and deserve support and understanding throughout our community.

I have lived and supported an adoptive child for the last 27 years and I can assure you that nobody gets this disability and I feel that the medical community, educational community have been no help whatsoever and it has been a lonely frustration road. Please help us by supporting this bill

Respectfully

Gigi Davidson

HB-2047-HD-1

Submitted on: 3/10/2020 9:04:28 AM

Testimony for CPH on 3/10/2020 9:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Andrea Hiura	Individual	Support	No

Comments: