

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

February 18, 2020

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

FROM: Pankaj Bhanot, Director

SUBJECT: **HB 2098 HD2 – RELATING TO HEALTH**

Hearing: February 20, 2020, 1:00 p.m.
Conference Room 308, State Capitol

DEPARTMENT’S POSITION: The Department of Human Services (DHS) appreciates the intent of the bill, requests clarification, and offers comments and suggestions. DHS appreciates the amendments made by the House Committee on Consumer Protection & Commerce.

PURPOSE: The purpose of this bill requires DHS, upon approval from the Centers for Medicare and Medicaid Services, to establish and implement a program for providing home- and community-based services to at-risk individuals having intellectual or developmental disabilities who meet certain criteria. Seeks approval, no later than June 30, 2021, from the Centers for Medicare and Medicaid Services to provide coverage for services established under the program. Appropriates funds. Takes effect on December 31, 2059. (HD2)

Since last legislative session, DHS has regularly met with stakeholders to discuss ways that the present system and continuum of care can be improved for individuals who are transitioning out of services provided by other state agencies like the Department of Education (DOE) and the Department of Health (DOH) Child & Adolescent Mental Health Division (CAMHD). These individuals are often at-risk of institutionalization. Expanding access to services would help these individuals engage in their communities and would provide support for their families, who must often struggle on their own to support their child. As a general

principle, DHS supports expanding access to some HCBS to this population provided that it does not replace or adversely impact the budget priorities identified in the executive budget.

DHS believes the prudent and fiscally sound way forward is to conduct a rate study first, before passing this legislation. A rate study would have to be completed before DHS could submit a request to the Centers for Medicare and Medicaid Services (CMS) to cover HCBS for an at-risk population. A completed rate study would give DHS, stakeholders, and the legislature the best idea of what the appropriation would be for this program. A rate study would not be an unnecessary next step, and could support program sustainability with federal matching funds once approved by CMS.

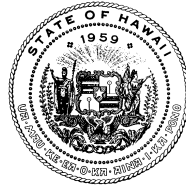
DHS would collaborate with DOH and stakeholders on the rate study. The rate study process could be used to further refine a potential at-risk program in regard to the services offered and the individuals covered. The rate study would give the Legislature the best idea of what the cost of this program would be.

DHS understands that the Legislature may want to pass a bill this year to begin covering this population. If the Legislature moves forward with this bill without a rate study, then DHS will estimate the potential expenditures for the program to the best of its ability. DHS counsels that a large general fund appropriation may be necessary because of unknowns surrounding the potential population and their use of services.

DHS also would recommend an amendment to delete “functional” on page 3, line 5 if the Legislature wishes to move forward without a rate study.

DHS notes it is unclear when beneficiaries residing in a shelter would be eligible for services as the provider or entity that makes the determination on whether services are appropriate has been left blank in this version of the bill on page 3, line 14. DHS requests clarification on which providers or entities are intended to make the determination on whether services are appropriate for a beneficiary’s living environment.

Thank you for the opportunity to testify on this bill.



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

Testimony COMMENTING on H.B. 2098 HD2
RELATING TO HEALTH

REPRESENTATIVE SYLVIA J. LUKE, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: February 20, 2020
1:00 p.m.

Room Number: 308

1 **Department Position:** The Department of Health (DOH/Department) offers the following
2 **COMMENTS.**

3 **Department Testimony:** The subject matter of this measure intersects with the scope of the
4 Department'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 Department is committed to carrying
7 out this mandate by reducing silos, ensuring behavioral health care is readily accessible and
8 person-centered.

9 The BHA provides the following testimony on behalf of the Department:

10 HB 2098 HD2 would establish a Medicaid Home and Community Based Services
11 (HCBS) program for individuals with an intellectual or developmental disability (I/DD) who do
12 not meet Medicaid's institutional level of care criteria for HCBS, but are at risk of being in that
13 level of care because they may lack independent daily living skills, are unable to manage their
14 own care or are unable to access the supports necessary to maintain their independence.

15 Since the last legislative session, DOH has met regularly with the Department of Human
16 Services (DHS) and other stakeholders to look at options for better serving this group of

1 individuals who are often at risk for adverse outcomes, and whose families often experience
2 extraordinary care burdens. Accessing services can be confusing, and the right types of services
3 are not always available. Often when young people with these disabilities exit school and/or
4 child-serving systems services can stop, and transitions to adult systems can be problematic or
5 unavailable.

6 The precise numbers of people who fall into this population in Hawaii is unknown. There may be
7 thousands of people who are in an “at-risk group” and need supports and services to lead
8 meaningful lives in the community. The Department remains committed to working with the
9 DHS and all stakeholders to develop and implement viable solutions to link this population to
10 services based on their individual needs. As such, DOH appreciates the intent of HB 2098 HD2
11 and its approach that could allow DHS to further convene stakeholders to better define the
12 population and their service needs, as well as the projected number of people who need services.

13 Currently the DOH’s Developmental Disabilities Division (DDD), through a memorandum of
14 agreement with the DHS, is the operating agency for the Medicaid 1915(c) waiver for
15 individuals with I/DD who meet the institutional level of care criteria, which is defined by the
16 Centers for Medicare and Medicaid Services (CMS) for 1915(c) waivers as an Intermediate Care
17 Facility for Individuals with Intellectual Disabilities (ICF/IID) level of care.

18 The group of people that would be affected by HB 2098 HD2 are individuals at risk of reaching
19 the institutional level of care, but do not meet an ICF/IID level of need. The bill states that
20 eligibility for the “at-risk program” must be tied to an assessment of need, and that individuals in
21 institutional or group home care could not access HCBS through the “at-risk” program. The
22 measure further states that individuals in the “at-risk” group must have been found through a
23 functional assessment to be at risk of deteriorating to the institutional level of care. The bill
24 would allow DHS to work with stakeholders to define and operationalize the eligibility criteria
25 based on functional assessments to identify individuals who are at risk of deteriorating to an
26 institutional level of care. Unclear eligibility criteria could cause confusion and overlap of
27 eligibility criteria of the population served through the current 1915(c) waiver for individuals

1 with I/DD, which includes individuals with functional limitations in three or more life areas as
2 defined in Section 333F-1 Hawaii Revised Statutes.

3 The process for applying for an HCBS waiver includes defining eligibility criteria, services
4 needed and estimate of numbers in the population in order to calculate annual costs. In waiver
5 applications, CMS requires costs to be estimated for each proposed service through an approved
6 rate study. A definition of the population might reflect the description in the HB 2098 HD2
7 preamble: individuals at risk of being in the ICF/IID level of care because they lack independent
8 daily living skills, are unable to manage their own care or are unable to access the supports
9 necessary to maintain their independence. DOH suggests a rate study be conducted to estimate
10 costs associated with the proposed program

11 **Suggested Amendments:** None.

12 **Fiscal Implications:** A full cost study based on definition of the eligible population, prevalence
13 in Hawaii, and specific services to be funded, is needed to estimate cost.

14 Thank you very much for the opportunity to testify.

HB-2098-HD-2

Submitted on: 2/18/2020 1:55:23 PM

Testimony for FIN on 2/20/2020 1:00:00 PM

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

Comments:



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 20, 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 2098 HD2 – Relating to Health

The State Council on Developmental Disabilities **STRONGLY SUPPORTS HB2098 HD2**, requires DHS, upon approval from the Centers for Medicare and Medicaid Services, to establish and implement a program for providing home- and community-based services to at-risk individuals having intellectual or developmental disabilities who meet certain criteria. Seeks approval, no later than June 30, 2021, from the Centers for Medicare and Medicaid Services to provide coverage for services established under the program.

The Council appreciated the work of Representative Mizuno to bring together the groups supporting individuals with Fetal Alcohol Spectrum Disorder and Autism Spectrum Disorder. Hilopaa Family to Family Inc, facilitated meetings with the groups, and included the Council, Department of Human Services and Department of Health. We worked together to build common ground and language that supports individuals that have been known to fall in between the cracks. These individuals are adults, that did or would not qualify for Department of Health Developmental Disability Division services. For this reason, we advocate for supports through the Department of Human Services. The language of HB 2098 comes from the group of individuals with developmental disabilities, their families, friends and stakeholders. Who requested not to separate the group by diagnosis, but to identify the individuals as adults with intellectual or developmental disabilities, who are "at risk". At risk of; going to the emergency room for mental health support, losing their community placement, being homeless, being admitted into the State Hospital, or being arrested. The Council strongly supports this type of advocacy.

Thank you for the opportunity to submit testimony **strongly supporting HB2098 HD2.**

Sincerely,

Daintry Bartoldus,
Executive Administrator

HB-2098-HD-2

Submitted on: 2/18/2020 8:11:19 PM

Testimony for FIN on 2/20/2020 1:00:00 PM

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

Comments:

HB-2098-HD-2

Submitted on: 2/19/2020 2:34:54 PM

Testimony for FIN on 2/20/2020 1:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
chanel	KELII Foundation	Support	No

Comments:

Aloha Representatives,

Being a single, working mother of a child with severe autism and another young, neurotypical child in Hawai'i has been a challenge. As a registered nurse I would never allow my son with Autism to be institutionalized at a place like the State Hospital, where, apparently, funds are going towards housing the patients/clients there costing the state/tax payers about \$250,000 per patient, while the state refuses to invest \$45k per year on our loved ones. How am I supposed to help my son become a productive member of society and keep him from being institutionalized, costing the state more money in the long run to house them in hospitals? Why do we as parents have to struggle so hard to get and maintain Medicaid services for our loved ones without going into poverty due to the ridiculous income limits set by Medicaid?

Thus, I depend on my son's Pab and respite workers who are funded by the DDD on a daily basis to for the precious reasons mentioned but also so that—

1-my son and my family can remain safe at home and in the community when my son has his behaviors,

2-my son can be escorted to all his medical appointments while I'm at work,

3-so that my son can have help getting ready for school and get on the school bus safely while I'm at work, and

4-so that I can keep my job and be able to support all my keiki.

Without these workers who are funded by the DDD, I would not be able to stay in Hawaii where my keiki, I, and generations of my Hawaiian lineage have been rooted. I've considered moving to the various states in mainland that could offer my son better health/in-home community services, but I can't take them away from their home, their schools, their Ohana, and their lives here in Hawai'i. Why does it have to be that way?

Just 1 week ago, I got an official letter from the DDD stating that my son's services would be denied. This means that we would no longer have workers to help me with my son or it means that I would have find affordable childcare so that I can keep my job as a nurse and have to cut my hours. I have to pay for a mortgage and child care for my younger son. I absolutely cannot afford to lose our current workers. With the advocacy of our legislators we finally got services for my son from the DDD after having waited 1 year, and, now, we need our legislators help again to keep his services by supporting SB3122.

As a working, middle-class mother I don't receive social security income, Food stamps, EBT, WIC, housing assistance, or child support. There is no way I can afford to pay out of pocket for all the services that my son, or any person with Autism, desperately needs simply because DDD decided to cut our services and because these services are not covered by insurance. Please help my son and all our loved ones with Autism by supporting Kelii's Bill SB3122.

HB-2098-HD-2

Submitted on: 2/19/2020 10:30:39 AM

Testimony for FIN on 2/20/2020 1:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Melodee Haole	K.E.L.I.I. FOUNDATION	Support	Yes

Comments:

Hello My name is Melodee Haole I am the founder and President of the K.E.L.I.I. foundation. I am a mother of a severe Autistic young adult, my son already have DDD services so this Bill will not help him but this Bill should help about 5,000 of our "at RISK" children and young adults.

Last year our group walked the capital talking to Senators and Representatives with parents trying to figure out how we can help these "at Risk" groups. There is two groups that is "at risk" who don't have IDD waiver services (the Dual Diagnoses and Developmental Disability "At RISK"). The past 3 months Ive been meeting with Mary Brogan from (DDD), Judy Peterson from (DHS) and DD Council Daintry to figure out how we can get this Bill pass. We found out last years BILL was talking about two separate groups and this was confusing people. So we took out the "Dual Diagnoses" that fall within the IDD waiver eligibility criteria but because they have the comorbid condition with some kind of mental illness "they get denied" this group usually are sent to the mainland and institutionalized. It was advised to us to do a Resolution for this group because IDD medicaid waiver will be working more with these families. The second group is "At Risk" don't fall within the IDD waiver and without any support or community base services, life skills training they maybe at risk, vulnerable to be taking advantage of, homeless, or even institutionalized. Example: I just helped an autistic young lady (23) years old she did not met the IDD criteria, had a child with autism, husband has developmental disability but he didnt have any services, she was working 25 hrs a week , sad to say she didn't have a supportive family they manipulated her took all her money, then kicked her and her family out and they where homeless and vulnerable now on the streets. One of her co workers found me through facebook and I helped her to get into a homeless shelter. I work with many families that get denied on a daily bases from medicaid waiver and its sad to see that some families leave the island because of the lack of services to help these children and young adults to be successful in their future and to be a productive citizen. I already met a few Autistic young adults that is homeless due to their parents past away or people taking advantage of them. Please HELP this "AT RISK" populations, this will save the STATE so much money in the future. I also want to thank Mary Brogran, Judy Peterson, Daintry, and Leolinda for all their support to help our community.

Testimony in Support of HB 2098, HB2 – Relating to Health
Hearing on February 20, 2020, 1:00 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

Please accept my testimony in support of HB 2098, HD2- Relating to Health, that requires the DHS, upon approval of the Center for Medicare and Medicaid Services, to establish and implement a program for providing additional home and community-based services to at-risk individuals with intellectual disabilities or developmental disabilities. Individuals must meet certain criteria and DHS to seek a section 1115 waiver to amend the state Medicaid plan for specific disabilities. This bill includes an appropriation of funds.

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.

Intellectual and developmental disabilities are 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. This puts a tremendous emotional and financial burden on the families with disabled members who lack resources.

Thank you for the opportunity to submit testimony in support of HB 2098.

HB-2098-HD-2

Submitted on: 2/18/2020 8:54:13 PM

Testimony for FIN on 2/20/2020 1:00:00 PM

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

Comments:

February 18, 2020

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

Date and Time of Hearing: February 20, 2020 at 1:00 p.m.

Testimony in Support of HB2098 HD2 Relating to Home- and Community-based Services**to At-Risk Individuals with Developmental Disabilities**

I am writing to express my support for this measure for additional home- and community-based services to be created for at-risk individuals with developmental disabilities, including individuals with Fetal Alcohol Spectrum Disorder (FASD). As a social worker, I have had opportunities to work with individuals as well as families impacted by FASD in our community. Studies and services from other states and countries overseas present that individuals with FASD benefit from structure and supports that cater to their unique needs. Currently however in this state, individuals as well as families are under-identified and served due to limitations in accessibility and provision of services. And this measure, I believe will create means for services and supports to be developed 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-2098-HD-2

Submitted on: 2/19/2020 10:13:45 AM

Testimony for FIN on 2/20/2020 1:00:00 PM

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

Comments:

February 19, 2020**To: Representative Sylvia Luke, Chair****And Members of the Committee on Finance****Testimony in Support of HB2098, HD2 Relating to Home- and Community-based Services****to At-Risk Individuals with Developmental Disabilities****I strongly support this bill.**

I am a licensed marriage and family therapist who has worked approximately 15 years in the field of mental health. I have worked with individuals with Fetal Alcohol Spectrum Disorders (FASD) and their families throughout this time frame. Many may not be aware that FASD is a developmental disability. Many individuals with FASD have an IQ in the average range which disqualifies them for home and community-based services. However, their adaptive functioning is quite low. They miss the ability to acquire daily living skills that can help them with basic needs. They are at high-risk for unemployment, homelessness, substance abuse, victimization, and other adverse life situations. In fact, I personally know of individuals with FASD who struggle with all of the above! I have watched them age out of a youth system of services and want to try independent living as most 18 years olds would. However, due to their developmental disability, low mental age, and other challenges, they struggle and safety becomes a huge concern.

This bill will provide some support in the way of services for individuals with functional disabilities who are currently ineligible. Services across the lifespan is an essential part of creating healthy opportunities for those with FASD to grow, healthy ways for their family to cope as caregivers, and healthy ways our community as whole will get stronger.

Thank you for your consideration.

Sincerely,

Jana Moya.MS, LMFT

February 18, 2020

To: Representative Sylvia Luke, Chair

And Members of the Committee on Finance

**Testimony in Support of HB2098, HD2 Relating to Home- and Community-based Services
to At-Risk Individuals with Developmental Disabilities**

I write in strong support of this bill.

I am a retired biochemist who understands the biochemical basis for Fetal Alcohol Spectrum Disorders (FASD) and other developmental disabilities. These developmental disabilities also affect those who care for those with FASDs. FASDs are permanent developmental disabilities. Many individuals with FASD function at a high enough level that disqualifies them for home and community-based services. Yet, without support, they have difficulty functioning independently and can be at high-risk for unemployment, homelessness, substance abuse, victimization, and other adverse life situations.

For example, many families provide the structure necessary for their children with FASD to succeed in the home and at school. Once they “age out” of school-based services, parents, grandparents, and other relatives find few support services for adults. Without ongoing support, the families, I, and other providers are concerned about the safety and future of the children.

This bill will fill some of the gaps in service for individuals with functional disabilities who are currently ineligible for services. As a community service provider, I know that supportive services across the lifespan will help keep individuals with FASD safe and productive giving them a chance at purposeful and meaningful lives.

Thank you for your consideration.

Sincerely,

Kenichi K. Yabusaki, Ph.D.

February 18, 2020

To: Representative Sylvia Luke, Chair

And Members of the Committee on Finance

Testimony in Support of HB2098, HD2 Relating to Home-and Community-based Services

to At-Risk individuals with Developmental Disabilities

I am a public health professional who works with individuals recovering from alcohol and drug abuse disorders. FASDs are developmental disabilities. Many individuals with FASD function with what are considered within the range of normal academic effectiveness. Because of this mutually conflicting condition, this population is disqualified from community-based services. With the support of this bill, they could function independently significantly reducing their probability of unemployment, homelessness, substance abuse, victimization, and other adverse life situations.

My experience with the FASD community has taught me that families and loved ones are providing the structure necessary for them to achieve degrees of success in the home and school. However, once they become adults and want to experience independence, parents and grandparents, discover there are few support services. We are all concerned about the safety and future of this population and want to provide the best opportunities for Hawaiian all families.

This bill will fill some of the gaps in service for individuals with functional disabilities. As a community service practitioner, I experience daily, that supportive services for individuals with FASD can provide a safe, productive, and a higher probability for this population to experience meaningful lives.

With Gratitude,

Rick

Richard D. Le Burkien, MPH

www.rleburkien.com

rickleburkien@gmail.com

916-316-0014

"Here's to the ones who see things differently"

February 18, 2020

To: Representative Sylvia Luke, Chair

And Members of the Committee on Finance

**Testimony in Support of HB2098, HD2 Relating to Home- and Community-based Services
to At-Risk Individuals with Developmental Disabilities**

I write in strong support of this bill.

I am a psychologist and marriage and family therapist who treats/assists individuals with Fetal Alcohol Spectrum Disorders (FASD) and their families. FASDs are developmental disabilities. Many individuals with FASD function at a high enough level that disqualifies them for home and community-based services. Yet, without support, they have difficulty functioning independently and can be at high-risk for unemployment, homelessness, substance abuse, victimization, and other adverse life situations.

For example, many families provide the structure necessary for their children with FASD to succeed in the home and at school. Once they “age out” of school-based services, parents, grandparents, and other relatives find few support services for adults. Without ongoing support, the families, I, and other providers are concerned about the safety and future of the children.

This bill will fill some of the gaps in service for individuals with functional disabilities who are currently ineligible for services. As a community service provider, I know that supportive services across the lifespan will help keep individuals with FASD safe and productive giving them a chance at purposeful and meaningful lives.

Thank you for your consideration.

Sincerely,

Ann S. Yabusaki, Ph.D., MFT

HB-2098-HD-2

Submitted on: 2/18/2020 4:07:41 PM

Testimony for FIN on 2/20/2020 1:00:00 PM

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

Comments:

I am submitting testimony in strong support of this bill.

My name is Jeremy Daniel, and my wife, Terra, and I have an adopted daughter with an FASD (Fetal Alcohol Spectrum Disorder). If you have heard of FASD and could define it before being introduced to this bill, I would be very impressed. Most people and established institutions don't really know what it is. It is organic brain damage caused by exposure to alcohol in the womb.

It is 3 times more prevalent than autism, yet it receives relatively no support by comparison. There is no funding. There are no supports. There is no plan. So, we need to do something about that.

When our daughter's school psychologists, teachers, and IEP team have no idea what they're dealing with, we provide training and education. When her physicians have no idea what they're dealing with, we explain. We advocate for her to receive the services that she needs, we attend conferences, we speak to experts, and we are trying to create awareness.

If she had autism, the support structure she would need is there. But she doesn't have autism and you can't treat an FASD the same way.

That said, I am beyond thankful that the State of Hawaii is willing to consider what they can do to support a community of individuals who make up approximately 5% of our population (an estimated 1 in 20 Kindergarteners have an FASD).

A very high percentage (compared to the non-FASD community) of individuals with an FASD end up homeless. They end up in the correction system. They end up with substance abuse issues. These problems impact our entire society and our overall economy. Once they are homeless, it's too late. Once they are in the correction system, it is too late.

We need to be proactive and not reactive. I hope the great State of Hawaii can help lead this charge for a population with no support!

Mahalo for listening,

Jeremy Daniel
Concerned Citizen
Parent to a child with an FASD

HOUSE OF REPRESENTATIVES
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2020

LATE

COMMITTEE ON FINANCE

Rep. Sylvia Luke, Chair

Rep. Ty J.K. Cullen, Vice Chair

Rep. Stacelynn K.M. Eli	Rep. Nadine K. Nakamura
Rep. Cedric Asuega Gates	Rep. Scott Y. Nishimoto
Rep. Troy N. Hashimoto	Rep. Chris Todd
Rep. Daniel Holt	Rep. Tina Wildberger
Rep. Lisa Kitagawa	Rep. Kyle T. Yamashita
Rep. Bertrand Kobayashi	Rep. Bob McDermott
Rep. Scot Z. Matayoshi	

NOTICE OF HEARING

DATE: Thursday, February 20, 2020

TIME: 1:00 P.M.

PLACE: Conference Room 308

State Capitol

415 South Beretania Street

POSITION: **STRONG SUPPORT HB2098 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 HB2098**

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)