

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 HD1
RELATING TO HEALTH.

REPRESENTATIVE ROY M. TAKUMI, CHAIR
HOUSE COMMITTEE ON CONSUMER PROTECTION AND COMMERCE

Hearing Date: February 10, 2020
2:00 p.m.

Room Number: 329

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

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 HD1 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 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 and other stakeholders to look at the current continuum of care and options for better
17 serving this group of individuals who are often at-risk for adverse outcomes. There is often

1 extraordinary burden on the families of these individuals. Accessing services can be confusing,
2 and the right types of services are not always there. Often when young people with these
3 disabilities exit school and/or child-serving systems, services can stop and transitioning to adult
4 systems can be problematic or inaccessible.

5 It is believed that there may be thousands of people in Hawaii who are in an “at-risk group” and
6 need supports and services to lead meaningful lives in the community. The Department remains
7 committed to working with the DHS and all stakeholders to develop and implement viable
8 solutions to link this population to services based on their individual needs. As such, DOH
9 appreciates the intent of HB 2098 HD1 and its approach that could allow DHS to further convene
10 stakeholders to better define the population, the projected number of people who need services,
11 and the services they need.

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

18 The group of people that would be affected by HB 2098 HD1 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

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

The process for applying for an HCBS waiver includes defining eligibility criteria, services needed and estimate of numbers in the population in order to calculate annual costs. In waiver applications, CMS requires costs to be estimated for each proposed service through an approved rate study. A definition of the population might reflect the description in the HB 2098 HD1 preamble: individuals at risk of being in the ICF/IID level of care because they lack independent daily living skills, are unable to manage their own care or are unable to access the supports necessary to maintain their independence.

HB 2098 HD1 would require people, in order to qualify to the “at-risk” program, to have been found ineligible to receive Medicaid long term services and supports (LTSS) or the I/DD waiver. Requiring people to first be found ineligible for Medicaid LTSS or the current 1915(c) I/DD waiver before they access the “at-risk” program might be a barrier to accessing timely services and cause undue stress on individuals and families.

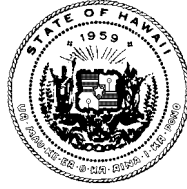
Suggested Amendments:

DOH respectfully recommends the following amendments to HB 2098 HD1:

- In SECTION 3, in § 346-C:
 - (a) (3) Delete “[h]ave been found ineligible under Medicaid for treatment at an intermediate care facility” and substituting “[a]re ineligible for other Medicaid waiver programs for individuals with intellectual or developmental disabilities” on page 3, lines 8-9.

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

Thank you very much for the opportunity to testify.



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

February 9, 2020

TO: The Honorable Representative Roy M. Takumi, Chair
House Committee on Consumer Protection and Commerce

FROM: Pankaj Bhanot, Director

SUBJECT: **HB 2098 HD1 – RELATING TO HEALTH**

Hearing: February 10, 2020, 2:00 p.m.
Conference Room 329, 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 amendment of the House Committee on Human Services & Homelessness to require establishment upon the approval by Centers of Medicare and Medicaid Services.

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. (HD1)

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 additional, unneeded 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 suggests the following recommendations if the Legislature wishes to move forward without a rate study.

First, DHS would recommend that the Legislature make it clear that the population covered under this bill be determined by DHS to be eligible for federally-funded Medicaid assistance.

Second, DHS would recommend deleting “functional” on page 3, line 5. DHS would also recommend deleting “[h]ave been found ineligible to receive medicaid long term services and supports or the I/DD waiver” and substituting “[a]re ineligible for other Medicaid waiver programs for individuals with intellectual or developmental disabilities” on page 3, lines 8-9. These changes align better with the Medicaid programs.

DHS also notes it is unclear when individuals residing in a shelter would be eligible for services as the individual 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 13.

Thank you for the opportunity to testify on this bill.

HB-2098-HD-1

Submitted on: 2/8/2020 2:51:56 PM

Testimony for CPC on 2/10/2020 2:00:00 PM

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

Comments:

HB-2098-HD-1

Submitted on: 2/9/2020 8:46:44 AM

Testimony for CPC on 2/10/2020 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Katrina Obleada	Hawaii Psychological Association	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 10, 2020

The Honorable Representative Roy M. Takumi, Chair
House Committee on Protection & Commerce
Thirtieth Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Takumi and Members of the Committees:

SUBJECT: HB 2098 HD1 – Relating to Health

The State Council on Developmental Disabilities **STRONGLY SUPPORTS HB2098 HD1**, 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 advocating for supports through the Department of Human Services. The language of HB 2098 HD1 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 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. We respectfully request that the diagnosis of an individual is not included within this measure and keep it as, "individuals having intellectual or developmental disabilities who meet certain criteria". The Council continues to advocate for individuals within the Fetal Alcohol Spectrum Disorder to be recognized as individuals with a Developmental Disability, along with individuals within the Autism Spectrum Disorder (ASD) who were once seen as individuals with a mental illness. We support this position through literature from the National Association of State Directors of Developmental Disabilities Services, National Association of Councils on Developmental Disabilities, Administration for Community Living, and Centers for Disease Control and Prevention.

Thank you for the opportunity to submit testimony **strongly supporting HB2098 HD1**.

Sincerely,

Daintry Bartoldus,
Executive Administrator

February 7, 2020

To: Representative Roy M. Takumi, Chair
And Members of the Committee on Consumer Protection & Commerce

**Testimony in Support of HB2098, HD1. Relating to Home- and Community-based Services
to At-Risk Individuals with Developmental Disabilities**

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. Individuals present with functional disabilities ranging from very serious to somewhat mild. 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, families are concerned about the safety and future of their children.

This bill will fill some of the gaps in service for individuals with functional disabilities who are currently ineligible for services. Supportive services across the lifespan will help keep them safe and productive and give them a chance at a purposeful and meaningful life.

Thank you for your consideration.

Sincerely,

Ann S. Yabusaki, Ph.D., MFT

February 7, 2020

To: Representative Roy Takumi, Chair

And Members of the Committee on Consumer Protection and Commerce

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

I am a retired biochemist and have researched some of the biochemical processes that contribute to fetal alcohol spectrum disorder (FASD). From what I have researched, in a culture and society where consumption of alcohol is a living issue, FASD is a permanent and life-long brain disorder that lead to compromised adaptive functioning behaviors. individuals born with FASD are "Born into an Impossible World". It is our responsibility to make the World "possible" for not only those afflicted with FASD, but all developmental/functional disabilities. Part of this responsibility and making the world "possible" for those with DDs (including FASD) is having access and qualifying for home and community-based services. Many with FASD fall into gaps that disqualify them for these much-needed services because of age limits and/or IQ score. We tend to forget the caregivers of those afflicted by DDs who must advocate for the aforementioned services. I strongly support passage of HB2098 as it will help those with FASD and all developmental disabilities have access to a productive life of "possibilities". Thank you for your consideration in passage of HB 2098.

Respectfully,

Kenichi K. Yabusaki, Ph.D.

HB-2098-HD-1

Submitted on: 2/9/2020 4:27:39 PM

Testimony for CPC on 2/10/2020 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Cynthia Bartlett	Hawaii Autism Foundation	Support	Yes

Comments:

Thank you so much for replacing the wording of HB2098 in this draft using instead the wording of SB-3122. I appreciate your understanding that we are not talking about children in this bill, we are talking about a category of at risk adults who currently have no services.

Thank you.

Cynthia Bartlett

Hawaii Autism Foundation

Following is my testimony reasons why I support for SB-3122 (contains an interesting story about what parents of these adults say they most need)

SB-3122 Submitted on: 2/4/2020 2:50:40 PM Testimony for HMS on 2/5/2020 2:45:00 PM Submitted By Organization Testifier Position Present at Hearing Cynthia Bartlett Individual Support Yes Comments: As a parent of a 26 year old and a Board Member of Hawaii Autism Foundation I meet many parents of children who have finished high school and have tested as higher functioning on state tests but have no support and want to become more independent. These young adults want to try to go to community college, they want to learn how to get a job, they want to learn better how to ride a bus and get to the right place.... some even need to keep up on their personal hygiene and safety life skills. I attended a meeting for families who had special needs adults now in their 20s. When I asked who here was getting support services of any kind after they left the DOE about 25 out of the 40 raised their hands. When asked what was their greatest need they answered their young adults needed help to go to community college and to become more independent. They wanted their adult to achieve the highest level of independence and have a chance at a happy and fulfilled life. Their goals are community college, a job and to safely move into their own apartment. When these higher testing adults succeed at independent skills it saves the state money and creates more jobs and taxable income. However, without some home and community support hours each month this population becomes at risk. At risk for homelessness. At risk for becoming vulnerable to getting lost on a bus or failing at maintaining a budget. At risk

for extreme mental frustration which can lead to expensive hospitalization. Similar to our seniors who receive at risk supports this population needs support. Even if it appears they can live in an apartment what if someone takes their money and gives them drugs? What if they don't shower for several weeks and develop boils? What if they mentally break down? What if they could have taken courses at community college and never did. I know a 30-year-old young autistic man whose dream was to go to community college but there was no one to show him how. Now he only cuts branches at his family home. Please help support aid for this population. Thank you, Cynthia Bartlett. Hawaii Autism Foundation

HB-2098-HD-1

Submitted on: 2/9/2020 4:58:27 PM

Testimony for CPC on 2/10/2020 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Melodee Haole	K.E.L.I.I. FOUNDATION	Support	No

Comments:

We support the new version of HB2098 HD1. Thank you for you dedication in helping and support our special

Needs families.

HB-2098-HD-1

Submitted on: 2/9/2020 4:54:11 PM

Testimony for CPC on 2/10/2020 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Teresa Ocampo	Individual	Support	No

Comments:

I completely SUPPORT HB2098 HD1. Hawaii has failed our disabled children for decades by ignoring their needs for home and community based services by putting money over individual lives. We need this bill sooner rather than later. Please have compassion and help these children. Do the right thing.

HOUSE OF REPRESENTATIVES
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2020

COMMITTEE ON CONSUMER PROTECTION & COMMERCE

Rep. Roy M. Takumi, Chair
Rep. Linda Ichiyama, Vice Chair

Rep. Henry J.C. Aquino	Rep. Sam Satoru Kong
Rep. Della Au Belatti	Rep. John M. Mizuno
Rep. Rida Cabanilla Arakawa	Rep. Richard H.K. Onishi
Rep. Romy M. Cachola	Rep. Lauren Matsumoto
Rep. Sharon E. Har	

AMENDED NOTICE OF HEARING

DATE: Monday, February 10, 2020
TIME: 2:00 pm
PLACE: Conference Room 329
State Capitol
415 South Beretania Street

HEARING HB2098 HD1

POSITION: **STRONG SUPPORT HB2098 HD1**

Dear Representative Takumi and Members of the Committees:

SUBJECT: HB 2098 HD1 – Relating to Health

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 the individuals who have FASD whom for many years have been marginalized, unrecognized and without appropriate services. I am writing in strong support of HB2098 HD1.

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 from the Centers for Medicare and Medicaid Services to provide coverage for services established under the program

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?

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 advocating for supports through the Department of Human Services.

Hindsight, we will be able to save our children, women and families of Hawaii, and also our tax dollars when your 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 adults. This cost our State \$55,000.00 a year, not to mention that our prison system is over populated 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 other cost to our tax dollars. With this bill services will be provided and these individuals can be a productive member of our society and somehow contribute not only for 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 crime; • Confinement – 60% of these children age 12 and over experienced inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime. • Inappropriate Sexual Behavior – Reported in 45% of those ages 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 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 HB2098 HD1 for the children and the families of Hawaii.

Thank you for your kind consideration.

Respectfully yours,

Darlyn Chen Scovell MA., RBT

HB-2098-HD-1

Submitted on: 2/9/2020 9:30:53 PM

Testimony for CPC on 2/10/2020 2:00:00 PM

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

Comments:

February 9, 2020

To: Representative Roy M. Takumi, Chair and the Members of the Committee on Consumer Protection and Commerce

Date and Time of Hearing: February 10, 2020 at 2:00 p.m.

Testimony in Support of HB2098 HD1 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-1

Submitted on: 2/10/2020 1:53:03 AM

Testimony for CPC on 2/10/2020 2:00:00 PM

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

Comments:

February 9, 2020**To: Representative Roy M. Takumi, Chair****And Members of the Committee on Consumer Protection & Commerce****Testimony in Support of HB2098, HD1. Relating to Home- and Community-based Services****to At-Risk Individuals with Developmental Disabilities**

I am a licensed marriage and family therapist who has been in the field for approximately 15 years. I have worked with many individuals with Fetal Alcohol Spectrum Disorder (FASD) and their families. FASD is a developmental disability where the individual has difficulty with functional abilities like living independently, maintaining employment, staying away from substances and the criminal justice system and other barriers to a healthy happy life.

I am in strong support of this bill as it could, if found eligible, can help to provide much needed services to at-risk individuals. I am currently working with a 19 year old who could benefit from these services this bill could provide. She needs assistance from others with daily living skills. . I am also working with a 16 year old and a 17 year old who are struggling with the same barriers. They will be adults soon, and will need just as much supports, but the resources are far fewer after they turn 18 Please approve bill HB2098. Those with developmental disabilities need the help and support of disability services to help them in the home and community. It would be more reassuring for those working with young adults or soon to be young adults to know that this service may be eligible for them.

Thank you for your consideration.

Sincerely,

Jana-Macy Moya, MS, LMFT