

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

SENATOR RUSSELL E. RUDERMAN, CHAIR
SENATE COMMITTEE ON HUMAN SERVICES

Hearing Date: March 6, 2020
2:45 p.m.

Room Number: 016

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 (HCBS)
11 program for individuals with an intellectual or developmental disability (I/DD) who do not
12 meet Medicaid's institutional level of care criteria for HCBS, but are at risk of being in that level
13 of care. This population may lack independent daily living skills, are unable to manage their own
14 care or have difficulty accessing the supports necessary to maintain their independence.
15 Navigating services can be confusing, and the right types of services are not always available
16 especially for young people exiting the school system.

1 DOH has met regularly with the Department of Human Services (DHS) and other stakeholders to
2 look at options for better serving this group of individuals who are often at risk for adverse
3 outcomes, and whose families often experience extraordinary care burdens.

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

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

16 The group of people that would be affected by HB 2098 HD2 are individuals at risk of reaching
17 the institutional level of care, but do not meet an ICF/IID level of need. The bill would allow
18 DHS to work with stakeholders to define and operationalize the eligibility criteria based on
19 functional assessments to identify the at risk individuals. Unclear eligibility criteria could cause
20 confusion and overlap of eligibility criteria of the population served through the current 1915(c)
21 waiver for individuals with I/DD, which includes individuals with functional limitations in three
22 or more life areas as defined in Section 333F-1 Hawaii Revised Statutes.

23 When applying for HCBS waivers, states need to define eligibility criteria for the population to
24 be covered, identify the specific services to be provided, and provide an estimate of numbers to
25 be served. This information is also needed to calculate annual costs and budget for the state share
26 of service payment. CMS requires costs to be estimated for each proposed service through an
27 approved rate study. As well, infrastructure for delivering the services needs to be defined such

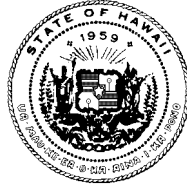
1 as provision of case management and other administrative functions. DOH suggests that each of
2 these factors needs to be defined through a comprehensive cost and rate study in order to
3 estimate costs associated with delivering the proposed program.

4 **Suggested Amendments:** None.

5 **Fiscal Implications:** A full cost study based on definition of the eligible population, numbers to
6 be served, and specific services to be funded, is needed to estimate costs.

7 Thank you very much for the opportunity to testify.

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 5, 2020

TO: The Honorable Senator Russell E. Ruderman, Chair
Senate Committee on Human Services

FROM: Pankaj Bhanot, Director

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

Hearing: March 6, 2020, 2:45 p.m.
Conference Room 016, 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 (HCBS) 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 study first, before passing this legislation. A 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 study would give DHS, stakeholders, and the legislature the best idea of what the appropriation would be for this program. A 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 study. The study process could be used to further refine a potential at-risk program in regard to the services offered and the individuals covered. The 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 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 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
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543

March 06, 2020

The Honorable Senator Russell Ruderman, Chair
Senate Committee on Human Services
Thirtieth Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Senator Ruderman 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: 3/3/2020 7:14:24 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

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

Comments:

HB-2098-HD-2

Submitted on: 3/4/2020 8:58:54 AM

Testimony for HMS on 3/6/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
James Kilgore	Testifying for Full Life	Support	No

Comments:

We estimate that there are approximately 25,000 people with intellectual/developmental disabilities (I/DD) living in Hawai'i. Developmental Disabilities Division serves only a fraction of the population with developmental disabilities due to a variety of factors (they may not need services, not eligible, not aware, etc.). HB 2098 will ensure that some of those people who need services but are not eligible can access services.

We strongly support providing services to people with I/DD who are at risk of using emergency services, at risk of institutionalization, loss of community placement, at risk of homelessness, or at risk of involvement with the criminal justice system.

Mahalo for your support!



HB2098 HD2 Home/Community Care for Developmental/Intellectual Disabilities

COMMITTEE ON HUMAN SERVICES:

- Sen. Russel Ruderman, Chair; Sen. Karl Rhoads, Vice Chair
- Friday, Mar. 6th, 2020: 2:45 pm
- Conference Room 016

Hawaii Substance Abuse Coalition Supports HB2098 HD2:

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.

HSAC supports the need for Medicaid Funding for Home and Community Based Services (HCBS) for Developmental/Intellectual Disabilities

Currently states opt for Intermediate Care Facilities for Intellectual Disability (ICF/ID) as an optional Medicaid benefit to provide health care and rehabilitation services to promote functional status and independence. Generally this optional benefit is an alternative to home and community-based services waivers for individuals at the ICF/ID level of care.¹

ICF/ID fills the need where individuals need immediate services and long term care is not readily available. However Medicaid coverage of ICF/ID services is available only in a residential facility licensed and certified by the state survey agency as an ICF/ID. Medicaid ICF/ID services are available only when other payment options are unavailable and the individual is eligible for Medicaid. There are few resources like an ICF/ID under any payment source.

States have been moving towards more HCBS because of the cost of alternatives.

In 2014, 53% of all Medicaid long term care spending was on home & community based services. Home and community based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs serve a variety of targeted populations groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.²

¹ Medicaid Intermediate Care Facilities For Individuals with Intellectual Disability. Medicaid.gov: Keeping America Healthy: <https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/intermediate-care-facilities-individuals-intellectual-disability/index.html>

² Medicaid Home and Community Based Services. Medicaid.gov: Keeping America Healthy: <https://www.medicaid.gov/medicaid/home-community-based-services/index.html>

Nearly all states offer services through HCBS Waivers. States can operate as many HCBS Waivers as they want. States can waive certain Medicaid program requirements under HCBS Waivers, including:

- *Can target waivers to areas of the state* where the need is greatest, or where certain types of providers are available;
- *Can make waiver services available only to certain groups of people who are at risk of institutionalization* such as
- *States can stipulate that Medicaid is only available to people who would otherwise be eligible in an institutional setting*, often due to the income and resources of a spouse or parent;
- *States choose the maximum number of people that will be served* under a HCBS Waiver program;
- *States can offer a variety of services* including case management, homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care as well as “other” types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.

TARGETED SERVICES

fetal alcohol spectrum disorder, autism, epilepsy, cerebral palsy, traumatic brain injury, HIV/AIDS, technology-dependent children, people with behavioral conditions, or people with intellectual disabilities;

Hawaii has great flexibility to add new groups of diagnosis as well as control services and financial costs to help reduce institutional care and costs – that’s why HCBS are active nationwide for an increasing variety of services.

We appreciate the opportunity to provide testimony and are available for questions.

HB-2098-HD-2

Submitted on: 3/4/2020 4:08:06 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

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

Comments:

HB-2098-HD-2

Submitted on: 3/4/2020 5:07:18 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Sean Sullivan	Testifying for PRIDE Industries	Support	No

Comments:

March 4, 2020

To: Senator Russell E. Ruderman, Chair

And Members of the Committee on Human Services

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.

As a non-profit provider of Employment Services for people with disabilities, PRIDE Industries assists individuals with Fetal Alcohol Spectrum Disorders (FASD) and other disabilities find and maintain employment on Oahu.

While many individuals with FASD function at a high enough level that disqualifies them for home and community-based services, they often have difficulty functioning independently and can be at high-risk for unemployment, homelessness, substance abuse, victimization, and other adverse life situations without on-going services and support.

Once these individuals "age out" of the the school-based services they strive to live independently as they lose supportive family memebbers, they have fewer support services as an adult and may expeirence a high-degree of homelessness and unemployment without ongoing support services.

This bill plans to fill some of the gaps in service for individuals with functional disabilities who are currently ineligible for services. As a community employment service provider on Oahu, I know from experience that supportive services across the lifespan will help individuals with a disability like FASD remain safe and assist them with the life skills needed to become more independent productive and contributing members of the community and for some, eventually transition from tax recipients to tax payers.

Thank you for your consideration of HB2098 HD2.

Sincerely,

Sean Sullivan

PRIDE Industries Employment Services Hawaii

HB-2098-HD-2

Submitted on: 3/4/2020 10:30:36 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

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

Comments:

By supporting this bill, you are supporting us--

parents and caregivers who need help on a daily, no, hourly basis

keeping our child or loved one out of the institutions and

giving hope to our loved one in becoming a productive member of society.

Of course, I support this bill. You would too if you were in our shoes.

HB-2098-HD-2

Submitted on: 3/5/2020 3:29:49 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

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

Comments:

This bill is about adults not children. It gives support to a group of higher functioning individuals with intellectual disabilities but right now receive NO services. They need some support like our seniors already get, Could be 10 or so hours a month so they have someone to support them through thier month. A lady in an ARC apartment had a job which moved and her anxiety did not allow her to track the changes so she went back home and lost her job. What if someone takes her check, tries to hand him or her drugs or they get evicted? They would probably walk to a park or homeless encampment.

We need to support these autistic and intellectually disabled adults. Without it they are at risk for homelessness and mental breakdowns.

HB-2098-HD-2

Submitted on: 3/5/2020 3:37:16 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

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

Comments:

Support this Bill

Testimony in Support of HB2098, HD2 – Relating to Health
Hearing on Friday, March 6, 2020, 2:45 pm
State Capitol, Conference Room 016

TO: COMMITTEE ON HUMAN SERVICES
Sen. Russel Ruderman, Chair
Sen. Karl Rhoads, 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, HD2.

THE SENATE
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2020
COMMITTEE ON HUMAN SERVICES

Senator Russell E. Ruderman, Chair

Senator Karl Rhoads, Vice Chair

NOTICE OF HEARING

DATE: Friday, March 6, 2020

TIME: 2:45pm

PLACE: Conference Room 016

State Capitol

415 South Beretania Street

NOTICE OF HEARING

POSITION: **STRONG SUPPORT HB2098 HD2**

Testimony Relating to Home- and Community-based Services to At-Risk Individuals with Developmental Disabilities.

Dearest Chair, Senator Russell E, Ruderman and Dearest Vice Chair, Senator Karl Rhoads,


On behalf of myself, the Hawaii FASD Action Group, a group of volunteers appealing to you, being the voices of children who have none, individuals and families who have FASD whom for many years have been marginalized, unrecognized and without appropriate services. I am writing in **STRONG SUPPORT of HB2098 HD2**

I am an active, passionate volunteer and advocate for Hawaii's families and children with FASD. 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). 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

80-90% of children and adults with FASD do not have facial nor physical features who are often undiagnosed. In the school system, they are often ones who are kicked out for their misunderstood behaviors and functions, they join in groups then becomes juvenile offenders, then adult offenders because of they do not have the capacity to think cohesively and trail of thoughts are unreliable and broken so they keep reoffending without any understanding of why they do the things they do. For every inmate, it cost us \$55,000.00 per adult inmate a year.

This bill plans to fill some of the gaps in service for individuals with functional disabilities who are currently ineligible for services. As an early childhood educator, clinician, and advocate, 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. If we are to provide the services we can save so much and on top of that, we are helping these individuals have a better life than being homeless, crime offenders, unemployed and illicit substance abusers on our streets. Many individuals with FASD function at a high enough level that disqualifies them for home and community-based services. Without ongoing support, the families, I, and other advocates are concerned about the safety and future of these individuals. WE need to provide the structure necessary for these 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.

Respectfully yours,


Darlyn Chen Scovell

Reference

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>

HB-2098-HD-2

Submitted on: 3/3/2020 4:40:54 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

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

Comments:

March 4, 2020

To: Senator Russell E. Ruderman, Chair

And Members of the Committee on Human Services

**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 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 these individuals.

This bill plans to 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

March 3, 2020

To: Senators Ruderman, Chair and Rhoades, Vice Chair

And Members of the Committee on Health & Human Services

**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 and understand what individuals with Fetal Alcohol Spectrum Disorders (FASD) and their families endure. FASDs are permanent brain-based 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 these individuals.

This bill plans to 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.

HB-2098-HD-2

Submitted on: 3/3/2020 10:48:34 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Liza Yogi	Individual	Support	No

Comments:

Dear Senator Russell Ruderman and his fellow Senators:

My name is Liza TH Yogi, Mother and Legal Guardian to a 36 year old Son who was Diagnosed with Developmental Disability at 2 and later found to be Intellectually disabled at 4. At age 21, he showed signs of depression. His desire to want a female partner became intense and the aggressive behavior began. At the age of 25, he was addicted to video games and wrestling. When he was told to stop, he became defiant. He also became obsessive of having a relationship with the opposite sex. After having a failed relationship, his anger grew and became combative and physically aggressive. I became his target because I cannot help him with his problem. Later on, everyone whom he felt that were against him in any way became his target.

He started to kick, spit, hit, swear, and yell very loud day and night. He had to be taken to Hilo Medical Psychiatric ward. They don't want to keep him there once he calmed down. Intermittently, he was aggressive. Acute is the word they always use so that my son can be discharged. In the meantime, my husband and I were scared of the waves of anger that he displayed.

I tried care homes but eventually failed. I tried the crisis shelter hoping he will learn to behave with less hostility. If he did , he has trained people to deal with it.

That wasn't the case. he was not treated as person with Developmental and Intellectual disability. It broke my heart to see him not cleaned and groomed. He looked like a hermit and his infection in the groin area was bad! My daughter and I will go there to treat his Peri Area, Shave him, and treat his eczema on his face and head due to the food allergies he had. All those factors were noted but somehow the lack of training of the staff led to those conditions. This happened even in the hospitals. In the hospitals, the quiet room was deemed illegal to have but instead, my son was strapped to a chair for 2.5 hours in Castle hospital with the help of the policemen as reported by a nurse to my daughter, Kristian Lei, who resides in hawaii and is his co-guardian. I they forced the discharged by giving me notice that I will lose my guardianship through the Attorney General's office if I didn't pick him up. The reason is, there is no budget for longer stay. They didn't inform me until later that on the day I picked him up, he injured 2 of their staff. Fortunately, he was just very happy to get out of there so he did not pose a threat to me when he was brought home to Hilo.

There were cases filed against him for his assault and Physical injury but later on dismissed due to his condition.

it is my sincere hope that there will be programs that are created to serve these individuals' reform and rehabilitation needs. If not given proper treatment and the care of by trained staff for their condition, they are candidates for institutionalization. There should be respite homes for their families and caregivers that will avail them of proper care and with security measures. Like it or not, they can be extremely dangerous. Parents, families, and caregivers will do their best to keep them continually but with the support of programs that will develop a healing and positive adaptation. Even if it is only temporary. My husband and I are senior citizens. We love our son dearly but we want programs in place so he can survive in the free environment even after we reach the end of our journey.

I implore that Medicare and Medicaid find a way to create programs, with the support of our honorable legislators to serve the needs of these individuals and their support system in order to keep them from being institutionalized. It is necessary for us to have respite homes and Crisis shelters with trained personnel to be available and funded continuously. They can have a combined community home based facility for the behavioral and non behavioral accommodations in order to sustain the operators with full occupancy. As an after thought, most of these behaviorally challenged individuals yell a lot and can make a lot of disturbance in the community. The Community based respite or crisis home should be funded to retrofit rooms with a sound proof feature.

It will be great to have them Statewide based on the statistical occurrence of need.

Sincerely,

Liza

HB-2098-HD-2

Submitted on: 3/4/2020 11:53:36 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Jana-Macy Moya	Testifying for Self-Employed	Support	No

Comments:

3/4/20

I strongly support HB 2098.

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

HB-2098-HD-2

Submitted on: 3/5/2020 2:28:58 PM

Testimony for HMS on 3/6/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Richard Le Burkien	Individual	Support	No

Comments:

To: Senator Russell E. Ruderman

And Members of the Committee on Human Services

Testimony in Support of HB2098, HD1 Relating to Health

I write in strong support of this bill.

I am a public health professional who works with individuals with individuals recovering from alcohol and drug abuse disorders. FASDs are developmental disabilities. Many individuals with FASD function with what is considered within the range of normal academic effectiveness. Because of this Catch-22 this population is disqualified from community-based services. With the support of this bill, they could function independently and can be a far lower-risk to employers, unemployment, homelessness, substance abuse, victimization, and other adverse life situations.

My experience with the FASD community has taught me that families provide 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.

This bill will fill some of the gaps in service for individuals with functional disabilities. As a community service practitioner, I know personally that supportive services for individuals with FASD can experience a safe and productive chance at purposeful and meaningful lives.

With Gratitude,

Rick

Richard D. Le Burkien, MPH

www.rdleburkien.com

916.316.0014