



STATE OF HAWAII
DEPARTMENT OF HUMAN SERVICES

P. O. Box 339
Honolulu, Hawaii 96809-0339

March 19, 2019

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

FROM: Pankaj Bhanot, Director

SUBJECT: **SB 242 SD 2 HD 1 – RELATING TO HEALTH**

Hearing: Wednesday, March 20, 2019 2:15 p.m.
Conference Room 329, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) offers comments on the bill to seek approval from the Centers for Medicare and Medicaid Services (CMS) to provide Home- and Community-Based Services (HCBS) to individuals diagnosed with autism or fetal alcohol spectrum disorder (FASD). DHS supports the intent to study and make recommendations on ways to improve HCBS coverage and suggests friendly amendments.

DHS currently provides coverage of HCBS to individuals with autism or FASD in both the QUEST Integration (QI) program and in the Medicaid waiver for individuals with intellectual and developmental disabilities (I/DD waiver) administered by Developmental Disabilities Division in the Department of Health (DOH-DDD). Notably, in both programs, all beneficiaries receiving HCBS must meet a Level of Care (LOC) criteria independent of their diagnosis. LOC criteria is a federal requirement and relates to a beneficiary's functional needs.

We have concerns about Sections 3 through 5 of the bill because a waiver request to CMS for HCBS based only upon diagnosis will be denied. As opposed to spending valuable time and resources on an unsuccessful effort that would not ultimately provide the services the families affected are advocating for, we would rather work with the legislature and stakeholders to improve access to HCBS for individuals with autism and FASD. For this reason,

we suggest amendments to use the task force proposed in Section 6 to review and make recommendations on Medicaid policies that could be approved by the federal government, if the legislature decides that a task force is necessary.

DHS also suggests a friendly amendment to Section 7 of the bill.

PURPOSE: The purpose of this bill is to assist persons who have been diagnosed with autism or FASD to participate in their communities by providing Medicaid coverage for HCBS in both managed care and fee-for-service. Under the bill, DHS shall seek a Section 1115 Demonstration waiver to expand HCBS coverage. The bill establishes a task force to address issues relating to access of essential services for the State's developmentally and intellectually disabled individuals. Finally, the bill would have the State revert to the prior system for evaluation of clients to determine services for I/DD waiver services until all providers and recipients have been educated on the new evaluation metrics or January 1, 2021, whichever occurs first.

DHS comments on the three initiatives under this bill below.

INITIATIVE 1 – Medicaid Coverage for HCBS for Individuals with Autism or FASD

Individuals with autism or FASD and their families face many difficult and profound challenges on a daily basis. DHS appreciates that the legislature and stakeholders have highlighted how the present system of care can be complicated to navigate. We have benefited from hearing from families and individuals directly affected by autism or FASD. The issues raised in stakeholder meetings, briefings, and testimonies for this bill and for similar bills have shown that these problems need thoughtful solutions.

We appreciate the intent of this bill but the approach specifically prescribed in Sections 3, 4, and 5 of the legislation will likely not result in a positive outcome because it could be read to leave out a federally-required Level of Care (LOC) and/or needs-based criteria requirement in the federal waiver request. Under federal rules, an individual's functional needs qualify them for HCBS rather than their diagnosis. An individual must be assessed to have some functional limitations that reflect the need for HCBS independent of their diagnosis. To reiterate, this is a federal requirement.

A HCBS program designed on diagnosis alone would not be approved under federal authorities because CMS would not waive the requirement that HCBS be tied to an individual's

functional needs. Through this legislative process, stakeholders have referenced the housing supports waiver that DHS received in 2018, as well as waiver programs in Minnesota and Virginia, as examples of what can be achieved through waivers. It is helpful to know that stakeholders are looking to those vehicles as ways to address gaps in coverage. However, it should be noted that the housing supports waiver does have a needs-based criteria requirement and took more than two years to develop and negotiate with CMS. Additionally, the DD waiver programs in Minnesota and Virginia have LOC requirements. Whenever CMS approves an HCBS waiver program, there must be a LOC or a needs-based criteria component. If that is missing, then a waiver will not be approved.

We strongly believe that the State and stakeholders need to come together, resolve our mutual misunderstandings, and develop a solution to this problem that will be successful. Part of that solution could be a waiver submission and we are ready to discuss working on waiver with stakeholders, if a waiver is necessary.

After each hearing, we have learned more about the experiences and needs of families with autism and FASD as well as the preference some families have for certain approaches to coverage. We believe that it would be better if we could continue this discussion and work towards implementing changes that would be approved by the federal government. However, the legislation as it is currently written may get in the way of that work rather than foster it because it may lock DHS into policies that cannot be approved by the federal government.

We are committed to work with our partners at DOH-DDD to comprehensively review access to HCBS and other wraparound services for individuals with autism or FASD in response to these pressing issues. DHS and DOH-DDD can begin working with stakeholders immediately to explore where coverage gaps exist and how they can be resolved under current state and federal authorities or waivers. We respectfully suggest that this collaborative approach to providing individuals with autism or FASD and their families with additional support would be a better course of action rather implementing the statutory change to 346, HRS in Section 3 as well as the actions required under Sections 4 and 5.

ISSUE 2 – Legislative Task Force Review

DHS believes the agency and DOH can work with stakeholders independent of a legislative task force. However, should the legislature choose to pursue a more formal

stakeholder process, we suggest adding a new Section 6(b)(5) to read “[p]roposed Medicaid policies to increase access to HCBS and other Medicaid services for individuals with developmental and intellectual disabilities” in order to facilitate stakeholder and State collaboration on the issues described in the testimony above. The intent of this language is to give the task force the charge to review current Medicaid policies and to propose potential changes or improvements to coverage that would better meet the needs identified for services and that would be acceptable to the federal government so that any necessary changes to Medicaid policy can be successfully approved.

We also suggest adding the proposed list of services in Section 3, (page 2, line 5 through page 3, line 5, proposed section 346- (b)(1)-(16)), to follow the proposed Section 6(b)(5) so that the task force has the charge to look at the services identified in that section.

We suggest amending Section 6(b)(1) to read “[g]aps in service and ways to improve coverage;”; amending Section 6(b)(2) to read “[a]ccessibility issues, including ways to better promote access-to-care;” and amending Section 6(b)(4) to read “[p]roposed legislation to improve existing services, improve coverage, and promote access-to-care to essential services; and”.

Since the charge to review Medicaid coverage would be given to the task force, any other pertinent language in Sections 1, 3, 4, 5, and 11 could be combined with Section 6 as activities that *may* be necessary as part of the recommendations made by the task force.

ISSUE 3 – Reverting to Previous Evaluation Method for Services

DHS also suggests an amendment to Section 7. We are sympathetic to the providers, case workers, and families regarding the major changes made between the prior and present systems. We strongly believe that the State should continue and increase its efforts to educate and train providers so that services can be provided most effectively and efficiently. However, the current criteria to determine need levels and supports budgets for the I/DD waiver program was approved by the federal government when the I/DD waiver was renewed. It is not an option under the current approval to go back to the previous process for even a short period of time.

The state would be in non-compliance with the federal government if it reverts to a previous evaluation method without federal approval of a waiver amendment. This would put

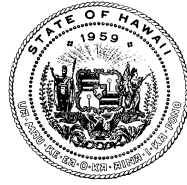
the state at risk of having to pay with general funds, for some, or perhaps all, I/DD waiver services with state-only funds if it changes the evaluation process before an amendment may be approved.

In the experience of DHS, waiver amendments and approvals can take more than a year to develop, draft, circulate with stakeholders, finalize, submit to the federal government, negotiate, and finally receive approval. We believe that a better course of action is to continue and intensify the State's educational efforts toward providers and beneficiaries to make sure the current system is working effectively.

For this reason, we respectfully suggest amending Section 7 by replacing the text with the following language:

“The department of health and department of human services shall work with stakeholders to ensure that service providers and recipients have been educated on the new evaluation metrics for eligibility for services provided by the Medicaid waiver program by January 1, 2021.”

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 SB 242 SD2, HD1
RELATING TO HEALTH**

REPRESENTATIVE ROY TAKUMI, CHAIR
HOUSE COMMITTEE ON CONSUMER PROTECTION & COMMERCE

Hearing Date: March 20, 2019
2:15 p.m.

Room Number: 329

1 **Fiscal Implications:** The Department of Health (DOH) defers to the Department of Human
2 Services (DHS) on the potential cost of SB 242 SD2 HD1, which needs to be studied and is
3 believed to be substantial.

4 **Department Testimony:** The DOH respectfully offers comments on SB 242 SD2 HD1.
5 Families and stakeholders have expressed their experiences regarding the difficulty of
6 understanding eligibility criteria for Medicaid Med-QUEST and waiver services and how to
7 access services. DOH is very willing to work with DHS, families, and stakeholders to enhance
8 communication and education about access to services for individuals with autism spectrum
9 disorder (ASD) and fetal alcohol spectrum disorders (FASD) through the QUEST Integration
10 (QI) health plans and through the 1915(c) Medicaid Waiver for People with Intellectual and
11 Developmental Disabilities (I/DD) operated by the DOH-Developmental Disabilities Division.
12 It is important to understand any gaps in coverage for individuals with ASD and FASD, what
13 treatments and supports are needed, and where families may need help in accessing services. The
14 more that we collectively understand federal benefits and requirements, the more we can ensure
15 necessary services are accessed for people with ASD and FASD. The task force requested in
16 SECTION 6 may serve as a means for researching and understanding policy options available to
17 the State. DOH believes the task force would be better established in the DHS-MedQUEST
18 Division, since it is the State Medicaid agency responsible for Medicaid and Medicaid waivers
19 pursuant to HRS § 346D-2.

1 SECTION 3 adds a new section to HRS chapter 346 requiring coverage beginning January 1,
2 2020, for any individual diagnosed with ASD and FASD through Medicaid home and
3 community-based services (HCBS) in both managed care and fee-for service programs, and
4 specifying a broad array of services. SECTION 7 requires the DOH-DDD to revert to prior
5 client evaluation metrics until all I/DD waiver service providers and recipients are educated on
6 the new evaluation metrics. These two provisions of the bill are particularly concerning.
7 The DOH believes that people with ASD and FASD who need services should have access to the
8 supports they need. However, the HD1, as currently drafted, may not be the best means to
9 address the concerns raised by interested individuals and to provide necessary services to those
10 with ASD and FASD. In Medicaid HCBS programs, eligibility is based on a Level of Care
11 (LOC) assessment of the person's functional limitations, and not on a diagnosis. In the I/DD
12 waiver, for example, participants are required to have an I/DD as well as substantial functional
13 limitations in three or more areas of major life activity such as self-care, receptive and expressive
14 language, learning, mobility, self-direction, capacity for independent living, and economic self-
15 sufficiency. There is a wide range of functioning within diagnoses such as autism and fetal
16 alcohol spectrum disorders. Without meeting the LOC required by HCBS programs, the Centers
17 for Medicare and Medicaid Services (CMS) may not approve funding, which means the State
18 would have to fully finance service for people that do not meet the HCBS LOC requirements.
19 There is no appropriation in the HD1 for this potential expenditure. DOH defers to DHS on any
20 recommended amendments to SECTIONS 3-5 of this measure.

21 SECTION 7 of this measure would require DOH to discontinue its current assessment system,
22 which uses the Supports Intensity Scale (SIS) as approved by CMS. The SIS is used to
23 determine support needs and Individual Support Budgets, and serves as the foundation of the rate
24 structure. Both the SIS and the rate methodologies are requirements of the HCBS I/DD Waiver.
25 They have undergone the requisite public comment process and have been approved by CMS.
26 The State is not allowed to change waiver provisions without obtaining federal approval from
27 CMS. Proceeding without CMS approval would likely result in non-compliance with federal
28 waiver requirements, and may jeopardize federal funding of Hawaii's HCBS I/DD Waiver.
29 Therefore, DOH respectfully requests an amendment to delete SECTION 7.

1 **Suggested Amendments:**

2 The DOH respectfully requests the following amendments:

- 3 • **SECTIONS 3-5.** DOH defers to DHS on amendments to these Sections.
- 4 • **Amend SECTION 6 on page 4, line 16.** DOH requests establishing the task force in
5 DHS, the State agency responsible for administering Medicaid waivers under HRS
6 § 346D-2. The task force would address broader Medicaid policy issues, which
7 involve the 1115 waiver as well as the I/DD waiver.
- 8 • **Delete SECTION 7 on page 7, lines 4-8.** Discontinuing the use of CMS-approved
9 waiver requirements without the prior approval of CMS will result in non-compliance
10 with the waiver and potential loss of the federal match for HCBS I/DD waiver
11 services.
- 12 Thank you for the opportunity to testify.

SB-242-HD-1

Submitted on: 3/15/2019 6:18:14 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

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

Comments:

No agency has been more involved with fighting for the rights of individuals diagnosed with Autism Spectrum Disorder than the Hawaii Disability Rights Center. For that reason, we welcome any initiatives that would provide more services to these individuals. This HD1 does address what previously had not been clear to us in terms of what the actual impact would be compared to the array of services that are currently available. While children under EPSDT are now receiving ABA services as a result of a lawsuit we filed against DHS a few years ago, this bill would provide a huge array of home and community based services to help them live successfully in the community.

We have also been advocating for several years that there needs to be a program for children born with fetal alcohol syndrome. They truly fall into a gap group, and have not been recognized to date by the DD Division as generally qualifying for services. The current approach in the state is focused mostly on educating women about the dangers of consuming alcohol while pregnant. While laudable, this is highly insufficient and ineffective. These people need services. This HD1 also addresses the concerns we expressed earlier in the session that merely classifying fetal alcohol syndrome as a developmental disability may not, in and of itself, accomplish that goal, based on their level of functioning. Since many of these people may be deemed to be too high functioning to qualify for DD services, the approach in this bill to establish a separate program designed to serve this population is much better.

We also think the Task Force is a very good idea. We have extensively discussed our concerns with the DD Division in our testimony on HB 1273 before the House Health Committee and we strongly support the contents of that measure. Our remarks in that regard are equally applicable here and we also support the Task Force proposed herein which appears to be broader in focus and will encompass a larger population.

We suggest further amendments to the bill. We believe that the directive to DD to cease using the current evaluation tool is a good provision. However, it qualifies its language by stating that the cessation shall last until providers and recipients have been educated on the new evaluation metrics. We believe this language is too open ended and allows the Division to claim that everyone has been trained and so in effect that can nullify the

provision. We believe the better course would be for legislature to have the Legislative Auditor conduct a financial and management and programmatic audit of the DD Division and direct the Department to refrain from any reductions in services until the Audit is completed and the Legislature has had an opportunity to receive a full briefing next session.



**TESTIMONY COMMENTING ON S.B. 242, SD 2, HD1
RELATING TO HEALTH**

**HOUSE OF REPRESENTATIVES
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2019
COMMITTEE ON CONSUMER PROTECTION & COMMERCE**

Wednesday, March 20, 2019, 2:15 p.m., Conference Room 329

March 17, 2019

The Honorable Roy M. Takumi, Chair
The Honorable Linda Ichiyama, Vice Chair

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

We offer the following comments on the subject bill that would make home and community-based services funded by Medicaid available to individuals with autism. The bill would also establish a task force consisting of state officials and “[a]t least one member of a developmental or intellectual disability advocacy group” to report to the legislature on proposed legislation “to improve existing services, close service gaps, and decrease barriers to essential services.” SB 242, SD2, HD1, Section 7.

In 1999, the Supreme Court held that individuals with mental disabilities have a right to live in the community rather than in institutions if State officials determine that is appropriate and community placement can be reasonably accommodated. *Olmstead v. L.C.*, 527 U.S. 581 (1999). Consistent with that decision, Hawaii closed its only institution, Waimano Training School and Hospital, in June 1999.

Since the Waimano facility closed, individuals with autism who are unable to live independently but who are not in need of institutional Mainland care live with relatives and friends or in one of approximately 1,000 care homes licensed by the State of Hawaii. Most care homes operate “under the radar,” meaning there is no significant oversight and, in many cases, few services. Individuals living at home rely increasingly on aging parents who are hard-pressed to find reasonable accommodations for autism.

In 2013, the Ninth Circuit held that the Hawaii Department of Education (“DOE”) violated the rights of students with disabilities from age 20 to 22 by excluding them from high schools

where they could receive vocational training and independent living skills. *E.R.K. v. DOE*, 728 F.3d 982 (9th Cir. 2013). The DOE deposited \$8.75 million in federal court to pay for community-based services for the class of 500 disabled students, but at the end of the first of three years settlement funds will be available, only nine (9) of the 500 class members (less than 2%) had found services to meet their needs. *E.R.K. v. Dept. of Education*, Civ. No. 10-00436 (SOM/KSC), Page 2, ECF Doc. 516-1 (D. Haw., Dec. 21, 2018). Funds expended totaled \$60,563.69, barely 0.7% of the funds on deposit.

The lack of progress in the remedy phase of the *E.R.K.* litigation is graphic proof of the lack of community-based services for individuals with autism. It shows that the State of Hawaii has made little, if any, progress since 1999 to comply with the *Olmstead* mandate of the Supreme Court.

Thirty years ago, two children in 10,000 born in the United States were diagnosed with autism. Today, the Centers for Disease Control estimate 1 in 59 (1.7%) will be so diagnosed. The Hawaii Department of Health reports there were 7,843 births in Hawaii during the first half of 2018. That means there will be at least 266 children with autism born in our State each year. The cost of caring for that population will be prohibitive if they are not able to find employment and live with some degree of independence.

This bill would require the State to seek and make available Medicaid funds for individuals as *Olmstead* requires. It would provide help to individuals with autism who are capable of joining the workforce and living independently but who must now stay at home or attend custodial programs providing little benefit and virtually no opportunities for future advancement.

The proposed Task Force is consistent with federal laws that mandate inclusion of parents in the development of special education and other programs affecting individuals with disabilities. It would bring those advocates together with government officials to design programs that meet the real needs of intended beneficiaries. The Autism Society would be honored to serve on such a task force.

Please respond as needed to Dennis.maher@autismsocietyofhawaii.org.

Thank you for the opportunity to testify.

Respectfully submitted,

Dennis C. Maher
President, Autism Society of Hawaii

John P. Dellera
Former Director (emeritus)



SB242 SD2 HD1 Autism and Fetal Alcohol Spectrum Disorder (FASD)

COMMITTEE ON CONSUMER PROTECTION & COMMERCE:

- Rep. Takumi, Chair; Rep. Ichiyama, Vice Chair
- Wednesday, Mar. 20, 2019: 2:15 pm
- Conference Room 329

Hawaii Substance Abuse Coalition Supports SB242 SD2 HD1:

GOOD MORNING CHAIR, VICE CHAIR AND DISTINGUISHED COMMITTEE MEMBERS. My name is Alan Johnson. I am the current chair of the Hawaii Substance Abuse Coalition (HSAC), a statewide organization of almost 40 non-profit alcohol and drug treatment and prevention agencies.

FASD is a preventable and treatable disability.

There are significant and increasingly improved interventions that are available for mental health issues such as Fetal Alcohol Spectrum Disorder and other disorders.

With home-based and community-based healthcare supported by Medicaid through a Section 1115 Waiver and a Task Force to improve access to essential services, we can make a difference.

FASD is a problem in Hawaii and efforts can be made to prevent this devastating condition as well as to treat children and adults that would increase their functioning:

- FASD is a range of neurodevelopmental (brain-based) disabilities that can affect any person exposed to alcohol before birth.
- FASD effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications that often co-occur with substance abuse and mental health issues.
- Proactive health care programs and interventions can help people develop new learning and coping skills to help them improve functioning. Modifications to existing treatment models can be very effective.
- FASD is very expensive to healthcare with estimates that the lifetime costs for each person is estimated to be over \$2M.
- Individuals with FASD are involved with the criminal justice system at an alarming rate. Youth and young adults with FASD have a form of brain damage that may make it difficult for them to stay out of trouble with the law. Without the aid of proper treatment, they do not know how to deal with police, attorneys, judges, social workers, psychiatrists, corrections and probation officers, and others they may encounter.

We can make a difference:

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

- Reduce the prevalence of FASD.
- Empower care givers to help FASD people reach their full potential.
- Address stigma by educating our communities to understand the complexities of this disability while promoting a more inclusive culture.
- Greatly improve upon outcomes through measurement brought about by Medicaid funding.
- Reduce childhood trauma by increasing supports for high-risk families, building resilience, and improving access to treatment.

Working together, we can join the growing number of states that claim to be a “FASD-Informed State.”

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

SB-242-HD-1

Submitted on: 3/18/2019 11:17:13 AM

Testimony for CPC on 3/20/2019 2:15:00 PM

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

Comments:

Dear Chairman Takumi and Members of the Consumer Protection & Commerce Committee:

I am writing in strong support of SB242. As a non-profit with a mission to create jobs for people with disabilities, PRIDE Industries see's firsthand the dire need for more access to services for adults with developmental disabilities. This is especially critical to people with brain disorders such as fetal alcohol spectrum disorders (FASD) with a desire to engage with the community in employment and contribute as a tax-payer rather than a tax recipient, dependent on public services.

Without adequate services, individuals are at high risk for mental health concerns, substance use, and other issues that can result in adverse experiences such as the criminal justice, homelessness, unemployment.

With supportive services to individuals affected by FASD, research and experience show that that they can be productive members of society and find deep meaning in life. We need to create resources for adult individuals affected with FASD and their families and by your elected role, you have the power to vote in favor of SB242 SD2 HD1.

I have worked with individuals with FASD and witnessed the positive results of supportive care and community support, but it often hard to come by due to misdiagnosis or lack of services.

People with FASD can be resilient and make a meaningful, purposeful life in spite of immense challenges, but it takes support from the community and professionals who can help them navigate and find assistance. This bill will give all people with developmental disabilities a chance at a full, meaningful LIFE.

Please vote YES for SB242 SD2 HD1.

Sincerely,

Sean Sullivan

Manager, Employment Services

PRIDE Industries 1003 Bishop Street

Pauahi Tower, Floor 27, Suite 2700

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SB-242-HD-1

Submitted on: 3/18/2019 10:13:57 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

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

Comments:

. My name is melodee Haole, I am the mother of Kelii who is 25 years old, he has severe autism with multiple diagnoses . Kelii been receiving DDD services from 8 years because he was diagnosed with a genetic disorder, kelii was high functioning played competitive soccer (Hysa), played basketball, karate, texted his friends, played video, had a mild learning disability. At 16 years old kelii behaviors started changing, he became very aggressive, had self injurious behaviors, hit his head, try to dig his eyeballs out, kelii then was placed in Queens Psych unit two times. At that time DDD was trying to release kelii because they said he was high functioning and had mental illness and he should be receiving services from CAMHD. OUR LIFE was in Chaos!, we had no help and didn't know what was happening to our son, later we found out through blood test that my son had a vaccine injury his antibodies could not fight of the vaccine because his genetic disorder Could have the potential to have low immune system. The Spect scan showed Kelii had brain damage due to neurotoxicity. slowly he started Deteriorating and ended up in a Catatonic stage we had to bath him, feed him and change his diapers. DDD was still trying to release my son, using kelii had mental illness. I got in touch with Senator Mike Gabbard, and because of senator Gabbard we received DDD and Camhd services together, but this took us over 6 months to get the appropriate services. In the mean time We had to bring home my middle son who was attending SMU to help us with his brother. Over time my son brain started healing but he had severe autistic violent behaviors, by 20 years old we started looking around to transition him to adulthood and that is when I realize there was nothing for young adults with severe autism and behaviors. The DDD worker gave me three choices, 1) to give Kelii up to the State, 2) put him in a mental institution, 3) quit work. I DECIDED TO QUIT WORK AND START A NON PROFIT CALLED KEIKI EDUCATION LIVING INDEPENDENT INSTITUTE (K.E.L.I.I.) FOR AUTISM AND OTHER SPECIAL NEEDS. in the past 6 years, I helped and Met many families from Oahu and the other islands, that been struggling to get services from DDD for their Autistic child and young adult with behaviors, multiple diagnosis with mental illness. Example of some families struggles,I have received permission to tell their stories.

First family live on oahu they have a 15 year son who is severe autistic with violent behaviors, due to lack of services from DOE and DDD DENIED services 3 times, this family been in crisis for over 1 year, their son has been placed in a psychic ward in Virginia because oahu dont have any placement or support shelter when our families are in crisis, he has been in Virginia for over 300 days.

Second family live on the Big Island they have a 8 years son who is severe autistic, the volcano burned down their house, 2 emergency shelter kicked this family out due to their Autistic son behaviors and melt downs because he could not handle change. They got DENIED by DDD services, and he had to be shipped off to the mainland pyshic ward due to no support on the Big island and Oahu.

Third family live on the Big Island they have a 22 year old young adult who has autism, ocd, anxiety, in aug of last year their son had a major meltdown, and became suicidal, the hilo and queens hospital did not have any beds, he got DENIED by DDD 3 times so he could not get help from the crisis hotline and center, he stayed 24 hrs in the waiting room before he got a hospital bed.

Recently I received a call from a parent that has a autistic son, he told me he met a young adult who is homeless, this young adult is 26 years old and autistic, the young adult told the man he is homeless because his parents died and no one can take care of him but his homeless friends help him. We are trying to find this young man so we can help him to get services. This is a FEAR of many of us parents.. "WHAT WILL HAPPEN TO OUR CHILD WHEN WE DIE ESPECIALLY IF THEY DONT HAVE DDD SERVICES OR ANY SUPPORT"

HOW ARE WE SUPPOSED TO HELP OUR FAMILY MEMBER WITH AUTISM TO BECOME A PRODUCTIVE MEMBERS OF SOCIETY AND TO KEEP THEM FROM BEING INSTITUTIONALIZED WITHOUT THE APPROPRIATE SERVICES. Ive learned a lot from the past few Senate Hearings and House Hearing about DDD waiver adding the 1115 waiver, and I have a few concerns. I also been part of the DD council task force for the past 6 months and I feel we got nothing resolved only had more unanswered questions about the GAP kids that is falling through the cracks.

I am also shock to know the 1915 DDD waiver is only servicing 1.58 percent of the population, when there is 23,000 individuals, in the DD division they are only servicing 2,700 individuals in their HCBS medicaid Waiver program, And other States has multiple 1915 waiver program.

I WOULD BE HONORED TO BE ON THE SB242 SD2 HD1 TASK Force.

thank you Melodee Haole

To: Committee Chair Representative Roy Takumi
Committee Vice Chair Representative Linda Ichiyama
Committee on Consumer Protection and Commerce

Date: March 18, 2019

RE: **Support for SB 242; Relating to health**

The Early Childhood Action Strategy (ECAS) is a statewide public-private collaborative designed to improve the system of care for Hawai'i's youngest children and their families. ECAS brings together government and non-governmental organizations to align priorities for children prenatal to age eight, streamline services, maximize resources, and improve programs to support our youngest keiki. The Early Childhood Action Strategy (ECAS) is a statewide public-private collaborative designed to improve the system of care for Hawai'i's youngest children and their families. ECAS partners are working to align priorities for children prenatal to age eight, streamline services, maximize resources, and improve programs to support our youngest keiki. ECAS supports SB 242, which would require the State's Medicaid managed care and fee-for-service programs to provide coverage for home and community-based services for individuals diagnosed as having autism or fetal alcohol spectrum disorder (FASD).

The need for services is critical for the success of individuals with FASD and autism. With support and coaching, they can be productive, empowered, and lead meaningful lives. Currently many services may end depending on the level of care needed and once these structured services are removed, individuals are at high risk for mental health concerns, substance use, and other issues that can result in adverse experiences such as incarceration, homelessness, and unemployment.

FASD is a completely preventable disorder. ECAS supports the task force established to study issues relating to the accessibility and utilization of essential services by the State's developmentally and intellectually disabled individuals, however, we encourage the task force to also focus on assessing and enhancing preventative interventions.

SB 242 would help individuals diagnosed with FASD and Autism receive beneficial life-long services allowing them the continued opportunity to improve the quality of their lives and we respectfully urge the Committee to support its passage. Thank you for the opportunity to provide this testimony.

SB-242-HD-1

Submitted on: 3/18/2019 1:50:17 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Brian I. Hauser	Aloha Independent Living Hawai'i	Support	No

Comments:

SB-242-HD-1

Submitted on: 3/16/2019 4:49:40 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Kimberly McGee	Individual	Support	No

Comments:

This bill will help my son receive the services he needs to better his life. His autism and behaviors that come along with Autism has caused him not to learn social skills in gaining friendships. I adopted him through foster care. He was severely abused and neglected at the age of 2. This alone is so challenging to deal with and it's in addition to him Javier g autism, adhd, dmddd. Please pass this bill so that he is given the services he needs to live a happy and full life.

Dear Chairman Takumi and Members of the Consumer Protection & Commerce Committee:

I strongly support of SB242. Access to service for adults with developmental disabilities is crucial for those with brain disorders such as fetal alcohol spectrum disorders (FASD). Many women unknowingly, but intentionally harm their babies when they drink during pregnancy and results with some born with an FASD. The effects of having an FASD range from severe to mild, but all require life-long supportive services. Without these services, individuals are at high risk for mental health concerns, substance use, and other issues that can result in adverse experiences such as the criminal justice, homelessness, unemployment. Yet, with life-long supportive services to individuals affected by FASD, research and experience show that that they can be productive members of society and find deep meaning in life. We need to create resources for adult individuals affected with FASD and their families.

As a retired biochemist, I have personally researched the devastating effects of the metabolites of alcohol consumption to the developing fetal brain. I have experienced individuals with FASD and witnessed the result of wraparound caring community support. I have seen people with FASD conduct research on their health conditions, raise families, teach others about resilience, and struggle courageously to make a life of purpose in spite of immense challenges. This bill will give all people with developmental disabilities a chance at LIFE. For myself, individuals with a permanent brain disorder and/or disability are alienated from an impossible world. It is our society's responsibility to make the world "possible" for them.

Mahalo nui loa for your consideration.

Kenichi K. Yabusaki, Ph.D.

SB-242-HD-1

Submitted on: 3/18/2019 8:05:28 AM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Donald Brown	Individual	Support	No

Comments:

We are the parents of an autistic son and we support HB242. These services and this support are very important for our families and our autistic children. Without this type of support - which is the case now - our children and our families are isolated from their communities and can't access basic services that would otherwise be available. This bill and the services it would make available are essential to the continued well being of the increasing number of families and children and adults with Autism in our community. Thank you.

SB-242-HD-1

Submitted on: 3/18/2019 8:01:56 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Joelle Branch	Individual	Support	No

Comments:

Thank you to the committee for allowing me the opportunity to voice my support for SB 242 SD2 also known as Kelii's Law.

My name is Joelle Branch and I am writing testimony on support of Kelii's Law. I am the mom of a 19yo autistic son named Monroe. Monroe has the type of Autism that presents violent behaviors. He was not always this way. He had some behaviors that we were able to contain however when Monroe turned 17 in October 25, 2017, he began hitting myself and his grandpa. This time it was different because he was no longer little; he was now a 5'10 250lb BIG kid and myself nor his grandpa could continue to restrain him when he would have meltdowns and turn violent towards us. He was admitted to Queen's Kekela 3 times with each stay no less than 2 months. Our family went through hell reaching out to every agency in Hawaii but no supports were available. We thought we would be able to obtain services from the Developmental Disabilities Division as my son was already in a locked facility, diagnosed as autistic, and developmentally delayed. To our shock my son was deemed in eligible for DD services. We did an informal appeal which my son was still denied services. We were in despair and reaching out to anyone as we knew the only way to bring him home, safely with us and in the community would be to have supports. When he was denied services again our hope just diminished.

I was in despair but was soon connected with the Kelii Foundation who helped me to continue to advocate for my son and thanks to them my son was finally eligible for DD services in March of 2018. Soon after, I was then diagnosed with breast cancer and spent the rest of 2018 battling breast cancer which I am still in treatments for. I am heartbroken writing this not because of my son or my situation with cancer, our story is only a vessel to be able to help others. My heartbreak comes from knowing that our story is not unique. Through these battles I've met so many families with autistic children who are suffering and trying their best to care for their child who needs supports.

This brings me to the common fear we all share as parents of what will happen to our children with autism once we pass on. While you are making your decision, I would like to plead with all of you, our leaders, to place yourself in our shoes and ask yourselves the following questions: What would you do if my son was your loved one and your time on this earth is near its end? How would you care for your loved one? Where would you

go to get services? Who's going to be there for your loved one when you are gone? Will your loved one be homeless or in prison? Will your loved one be scared? Will people take advantage of them? If you are like me and would be in fear of all of these questions if this was your loved one then I beg you to vote in support of Keli's Law which is a first step to ensuring our loved ones with autism have supports and continuity of care.

In testimony from DHS they cite the cost to provide services for autistic individuals would cost about 45,000 per year. During a hearing for another cause, the Hawaii State Hospital stated it cost 250,000 per year for one person. Its heartbreaking to know that services cannot be provided to our autistic loved ones at 45,000 per year but an obscene amount of money is expended for services at the State Hospital. The State Hospital is a much needed entity and I don't dispute what it takes to run a facility such as that however what concerns me is without services many of our autistic loved ones with violent behaviors have the potential to end up in the state hospital where a higher rate would be paid. 45,000 per year will help to keep individuals with autism with behaviors safe and supported with their families and in the community to allow them to thrive.

In my previous testimony I discussed the 1115 waiver because I was excited to see that DHS has the capability to complete one as evidence by the completed and approved 1115 waiver for the homeless and substance abuse which is a much needed effort for our community. Prior to this I was under the impression from DHS written and in person testimony that DHS has never done an 1115 waiver because DHS suggest that an 1115 waiver would not get approved or it will take up too much time. It might be there were different people who did that particular waiver for homeless and substance abuse are no longer with DHS so the current folks are not aware that this is doable so that's totally understandable. This is great news because in looking at this 1115 waiver for homeless and substance abuse it appears DHS could configure and write an 1115 waiver for individuals specified in this Bill. I believe if everyone works together and 1115 waiver for those indicated in this Bill and I plead with all of you to support Keli's Law and I am more than happy to assist DHS.

Mahalo and Appreciation for you time and consideration,

Joelle Branch

SB-242-HD-1

Submitted on: 3/18/2019 9:59:31 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Cynthia Bartlett	Individual	Support	Yes

Comments:

This bill is more than a social issue, **it is a public health issue** that affects our adult population of autism and Fetal Alcohol Syndrome. Without more sustained services when the school years end at age 22 there is not only regression which affects their ability to hold jobs and be part of the community, it also allows behavioral problems to escalate. This population can sadly one day fill the beds at the state mental hospital at the cost of \$250,000 per person per year. **This does not need to happen if we act now.** If we allot funds to help this adult population we can prevent this, save the state money and save families who now face an uncertain future.

Our family members with these disabilities who we love and have worked so hard to teach and support during the years they were under the Department of Education can face a different adult life. Without added services they can easily be mistaken as criminals when they have increased behaviors. We recently had a police officer draw his gun on an autistic boy and his aid on the public bus in Kailua. The youth was learning to ride a bus and was acting differently and his skills trainer was working with him, but someone on the bus called the police thinking there was a problem. Two officers rushed into the bus. The first drew his gun. The second officer who jumped on the bus on the bus recognized the boy and stood down the situation averting a possible tragedy.

This population will not be able to hold a job successfully or integrate with the community successfully without these adult lifespan services. They need to have services maintained and monitored.

The child and the adult are the **same person**. We cannot give one all the attention and forget the other. We budget for the child and marginalize the adults. The behavioral health agencies are advocating for the services during the school years, they are successful when they are awarded contracts. There are no contract awards for over age 22 so you at the capitol and in the court lawsuits will not hear from the agencies seeking to help this marginalized population..

As lawmakers and committee members you are presented with numbers and stats. I as a parent have experienced when I left the Department of Education an extreme sharp drop in services and in the quality of the workers who were paid much less for the same jobs. The skills aids for adults get far less than the skills trainers from

agencies. Why is this? There is a budget problem much like the military had with the cost of an "\$800 hammer" we all were astonished about. This is happening here in Hawaii. We are paying admin fees and costs to agencies when that money could be spent getting more direct services to these adults. Perhaps we need a full audit to find ways to use money more efficiently.

Our past Department Head of DD moved the money that came to the state around according to his discretion and was successful in taking Hawaii off the wait list states. Here in Hawaii we have no wait list for services. This was a huge accomplishment and proves that there is discretionary ways that a department can choose to use the money. I think if all the departments work together. Look at the Quest money as well we can allot funds to this terrible problem.

On a task force: **If** there needs to be a task force set up to study this, it is not fair to have anything less than two parents on the state side and two parents on the representative side. Parents are the practical ones who see the everyday problems and can present solutions. We work with this population day in and day out. I have witnessed professionals that are severely out of touch with this population. In fact at a ISP meeting where the Department of Health required a cognitive report, the psychologist asked questions and ignored the fact that my daughter cannot even talk. My daughter was so frustrated that she lifted up the conference table and turned it upside down and pulled a bookcase down. This is what happens where there is a mismatch and lack of services. She did not need a cognitive test, she needed behavioral therapy at the time. It was a waste and misdirection of state funds. Parents on a task force would be able to point out areas where money could be saved.

SB-242-HD-1

Submitted on: 3/19/2019 12:16:03 AM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Darlyn Chen Scovell	Individual	Support	Yes

Comments:

SB242, SD2, HD1 FOR HEARING March 20, 2019, 2:25 PM

Dear Chairperson, Representative Roy M. Takumi, Vice Chair, Linda Ichiyama, and members of the Committee Consumer Protection and Commerce,

In behalf of the Hawaii FASD Action Group, a group of volunteers appealing to you and being the voices of children, and individuals who have FASD whom for many years have been marginalized, unrecognized and without appropriate services. I am writing in support of SB242, SD2, HD1.

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 age 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 SB 242, SD 2, HD1 for the children and the families of Hawaii.

FASD is associated with secrecy and shame, quite possibly due to its preventable nature and the stigma attached to it. Alcohol is legal accessible therefore it is not surprising that the research stated that 1 in 20 first graders do have FASD. According to

a study questions, if this shame is 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 recognized. (Barker, Kulyk, Knorr, & Brenna, 2011).

Language and communication disorder are common neurodevelopmental symptoms associated with FASD as are the intellectual disability, memory impairment, motor impairment, and sensory which is side by side similar to Autism. The range and severity of impairments exhibited by individuals with ASD and FASD are both physical and neurodevelopmental each with a specific diagnosis. FASD has its cause specified, and Autism does not- both are Developmental Disabilities that equally need support and services.

FASD diagnosis is 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 in this cause. By codifying FASD as a developmental disability, my colleagues and community may begin to recognize and diagnose FASD and create FASD-specific services.

Mahalo Nui Loa,

Darlyn Chen Scovell RBT, MFT

Reference

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Diagnostic & Prevention Network. *Canadian Journal of Clinical Pharmacology*, 17(1), e132–e164.

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Cheryl Toyofuku
Mother, Grandmother, Registered Nurse, Health Advocate
1025 Noelani Street, Pearl City, HI 96782
March 19, 2019

Chair Representative Roy Takumi
Members of the House Consumer Protection and Commerce Committee
Hearing Date and Time: March 20, 2019 at 2:15 p.m.
Re: SB242 SD2 HD1 Relating to Health, Autism, Home and Community Based Services

Aloha Chair Representative Takumi and Members of the House CPC Committee,

I am in strong support of SB242 SD2 HD1 requiring the State's Medicaid managed care and fee-for service to provide coverage for home and community-based services for individuals diagnosed as having autism and fetal alcohol spectrum disorder.

According to the **Centers for Disease Control and Prevention (CDC)** :

“About 1 in 59 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network.”

<https://www.cdc.gov/ncbddd/autism/data.html>

“About 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.”

<https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html>

The above CDC report of 1 in 59 children identified with an ASD is an estimate which ***“is a 14% increase from the 1 in 68 rate in 2016 and a 47% increase from the 1 in 88 rate in 2012. In the 1980s autism prevalence was reported as 1 in 10,000. In the nineties, prevalence was 1 in 2500 and later 1 in 1000.”***

<https://autismsciencefoundation.org/what-is-autism/how-common-is-autism/>

According to Dr. Stephanie Seneff, research scientist from the Massachusetts Institute of Technology (MIT): ***“half the children, eighty percent of the boys born in 2032 will end up on the spectrum—diagnosed on the spectrum.”***:

<https://www.ageofautism.com/2017/06/mits-dr-stephanie-seneff-on-autism-explosion-vs-media-coverage.html>

This autism epidemic has many shocked by the increase in diagnoses over the recent years. Distinctive symptoms of autism (a type of brain damage) include difficulty with social interaction, problems with verbal and nonverbal communication, and repetitive actions or obsessive interests. Testimonies range from mild to disabling and often some with violent behavior due to severe encephalitis.

As a health advocate, I have worked with family and friends that have been touched by autism. An eleven year old who was without speech and still in diapers, toddlers/children who are not able to focus and frequently stem (repetitive motions), teens that have self-destructive behavior and parents who are struggling financially to care for their autistic child, youth or young adult.

Our Hawaii keiki, youth and young adults on the autism spectrum require our understanding, compassion and proactive assistance for behavioral, developmental, medical, nutritional therapies and services. Please support and pass SB242 SD1 out of your Committee. Mahalo.

SB-242-HD-1

Submitted on: 3/19/2019 10:04:20 AM

Testimony for CPC on 3/20/2019 2:15:00 PM

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

Comments:

From: Lisa Garcia

Submitted on: March 17, 2019

Testimony in support of SB242 Relating to coverage for home and community based services for autism and FASD.

Submitted to: House Consumer Protection and Commerce Committee (CPC) on Wednesday, 3/20, at 2:15 pm, Capitol room 329

Dear Chairman Takumi and Members of the Consumer Protection & Commerce Committee:

1. am writing in strong support of SB242. Access to service for adults with developmental disabilities is critical to people with brain disorders such as fetal alcohol spectrum disorders (FASD). Individuals born with an FASD experience effects ranging from severe to mild who require life-long supportive services. Without these services, individuals are at high risk for costly mental health concerns, substance use, and other issues that can result in adverse experiences such as the criminal justice, homelessness, unemployment. Yet, with life-long supportive services to individuals affected by FASD, research and experience show that that they can be productive members of society and find deep meaning in life. It makes economic, moral, and medical sense to create resources for adult individuals affected with FASD and their families.

I have worked with individuals with FASD and witnessed the result of wraparound caring community support. However I also witnessed the limitations in services and the negative effects and frustration of clients that seek to better themselves. This bill will give all people with developmental disabilities a chance at LIFE. It is not their fault they were created this way and they should not have to deal with it alone.

Other talking points:

- 94% of people with FASD have a mental health disorder
- 80% are unable to work full time
- 80% are unable to live independently

- 60% will have contact with the justice system
- 60% will have substance use disorders

Mahalo nui loa for your consideration.

A handwritten signature in black ink, appearing to read 'Lisa Garcia', with a stylized, cursive script.

Lisa Garcia PSYD

Clinical Psychologist.

House Committee on Consumer Protection & Commerce
Rep. Roy M. Takumi, Chair
Rep. Linda Ichiyama, Vice Chair

Wednesday, March 20, 2019, 2:15PM, Room 329
Hawai'i State Capitol

Testimony in **SUPPORT** of SB242 SD2 HD1
Relating to Health

Dear Chair Takumi and Members of the Committee:

Thank you for the opportunity to provide testimony on behalf of this important bill.

I wholeheartedly **support** the proposed legislation that requires the State's Medicaid managed care and fee-for-service programs to provide coverage for a comprehensive array of home and community-based services for individuals diagnosed as having a developmental disability, including fetal alcohol spectrum disorder, and will help ensure that they have access to the kinds of services that will allow them to participate in their communities. I also respectfully recommend reinstatement of licensed psychologists as eligible providers of care, as in the first draft of the bill.

Background

As a doctoral candidate in clinical psychology at the University of Hawai'i at Manoa, I have gained clinical and research experience related to issues of behavioral treatment and their outcomes. Individuals with ASD and FASD continue to have difficulties in various life domains well into adulthood; therefore, preparation and delivery of treatment and supports for these individuals and their families are imperative throughout their lifetime (Kamio *et al.*, 2013).

Studies have shown that individuals with ASD and FASD continue to experience behavioral (e.g., self-injury, aggression), emotional (e.g., depression, anxiety), psychosocial (e.g., legal issues, poor social skills), and/or cognitive difficulties (e.g., memory loss, language problems) as adults (Grant *et al.*, 2004; Malbin, 2004; Farley *et al.*, 2018). The severity of these difficulties appears to be predicted by childhood cognitive ability, severity of symptoms in childhood, early language abilities, and comorbidity with other mental health or developmental disabilities; such that individuals who had less severe symptoms, better language skills, and fewer issues of comorbidity in childhood, had better outcomes in adulthood (Magiati, Tay, & Howlin, 2013). Additionally, though symptoms related to autism appear to decrease in frequency with age, such as behavioral problems, these behaviors (e.g., unacceptable sexual behavior, tantrums, aggression, and self-injury) are more distressing and dangerous in adults than in children (Levy & Perry, 2011; Shea & Mesibov, 2005). Within the context of independent living and physical and mental health, adults who are able to live independently still require supports that address mental health and occupational functioning (Bishop-Fitzpatrick *et al.*, 2016).

Considering these concerns, treatment interventions for adults with ASD and FASD have been explored, including residential programs. However, studies have shown that currently available resources are not enough to address the employment, day, community, and residential needs of these adults, resulting in programmatic, financial, and personal consequences (Gerhardt & Lainer, 2011). This especially raises concerns for individuals in Hawai'i who may be receiving inadequate care as adults due to deficits in resources and then become institutionalized at the State Hospital. Therefore, it becomes even more imperative that access to care and services for these adults and their families be broadened. Moreover, family, social, and community supports are important in improving quality of life for these adults (Tobin, Drager, and Richardson, 2014).

Given the needs of adults with ASD and FASD, it is important that they continue to be able to receive the home and community-based supports that allow them to engage with their communities. Thus, I STRONGLY urge the

committee to pass SB242 SD2 HD1. I also recommend reinstatement of licensed psychologists as eligible providers of care, as in the first draft of the bill. Thank you again for the opportunity to testify.

Sincerely,

Katrina Obleada, M.A.
Ph.D. Candidate
Clinical Studies Program
Department of Psychology
University of Hawai'i at Mānoa

SB-242-HD-1

Submitted on: 3/19/2019 2:52:59 PM

Testimony for CPC on 3/20/2019 2:15:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Lisa Kimura	Healthy Mothers Healthy Babies	Support	No

Comments:

Dear Chair Takumi and Members of the Consumer Protection & Commerce Committee:

I am writing in strong support of SB242, SD2 HD1. Access to service for people with developmental disabilities is critical to helping those with brain disorders such as fetal alcohol spectrum disorders (FASD). Many women unknowingly harm their babies when they drink during pregnancy; individuals born with an FASD may have effects ranging from severe to mild, and may require life-long supportive services.

Without these services, individuals are at high risk for mental health concerns, substance use disorder, and other issues that can result in adverse experiences such as interactions with the criminal justice system, homelessness, unemployment. Yet, research and experience shows that supportive services can help people become productive, contributing members of society. We need to create trauma-informed resources for adult individuals affected with FASD and their families because evidence shows:

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

We have worked with individuals with FASD and witnessed the result of wraparound caring community support. This bill will give people with developmental disabilities a better chance at a higher quality of life.

Mahalo nui loa for the opportunity to testify.