



STATE OF HAWAII
DEPARTMENT OF HEALTH
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**Testimony COMMENTING on SB 242 SD2 HD2
RELATING TO HEALTH**

REPRESENTATIVE SYLVIA LUKE, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: March 28, 2019
2:00 p.m.

Room Number: 308

1 **Department Testimony:** The Department of Health (DOH) respectfully offers comments on SB
2 242 SD2 HD2. DOH is willing to work with DHS, families, and stakeholders to enhance
3 communication and education about access to services for individuals QUEST Integration (QI)
4 health plans and through the 1915(c) Medicaid Waiver for People with Intellectual and
5 Developmental Disabilities (I/DD) operated by the DOH-Developmental Disabilities Division.
6 It is important to understand any gaps in coverage for individuals with various disabilities, what
7 treatments and supports are needed, and where families may need help in accessing services. The
8 more that we collectively understand federal benefits and requirements, the more we can ensure
9 necessary services are accessed.

10 DOH believes a task force would be better established in the DHS-MedQUEST Division, since it
11 is the State Medicaid agency responsible for Medicaid and Medicaid waivers pursuant to HRS §
12 346D-2.

13 **Suggested Amendment:**

14 The DOH respectfully requests the following amendment:

- 15 • **Amend SECTION 1 on page, lines 1-2.** DOH requests establishing the task force in DHS,
16 the State agency responsible for administering Medicaid waivers under HRS § 346D-2. The
17 task force would address broader Medicaid policy issues, which involve the 1115 waiver as
18 well as the I/DD waiver.

19 Thank you 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 27, 2019

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

FROM: Pankaj Bhanot, Director

SUBJECT: **SB 242 SD2 HD2 – RELATING TO HEALTH**

Hearing: Thursday, March 28, 2019 2:00 p.m.
Conference Room 308, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) supports the intent of the bill and offers comments.

PURPOSE: The purpose of this bill is to establish a task force to address issues relating to access of essential services for the State's intellectual and developmental disabilities (I/DD) population (SB242 HD2).

DHS believes that robust stakeholder engagement plays a crucial role in the successful implementation of government programs. Throughout the legislative process this year, we benefitted from learning more about the experiences and needs of families with autism and fetal alcohol syndrome disorder (FASD). Individuals with autism or FASD and their families face many difficult and profound challenges on a daily basis. We appreciate that the legislature and stakeholders have highlighted how the present system of care can be complicated to navigate.

We are committed to work with our partners at the Department of Health (DOH) to comprehensively review access to Medicaid Home and Community-Based Services (HCBS) and other Medicaid services for individuals with autism or FASD in response to these pressing issues. DHS and DOH 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. While we believe that the departments can work with stakeholders independent of a legislative task force, we respect and understand the wishes of legislators and stakeholders to establish a more formal process.

We would like to thank the House Committee on Consumer Protection and Commerce for their amendments. Earlier drafts of the bill contained language surrounding Medicaid coverage that would have been impossible to implement unless state-only dollars were used. SB242 SD2 HD2 draft gives DHS, DOH, and stakeholders the opportunity to collaborate on a review of Medicaid policies that can result in positive policy developments that could be approved by the federal government. SB242 SD2 HD2 draft puts the State on a better course to make sure individuals with autism and FASD have the supports and services they need.

Thank you for the opportunity to testify on this bill.



Hawai'i Psychological Association

For a Healthy Hawai'i

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Testimony in SUPPORT of SB242 SD2 HD2
RELATING TO HEALTH

COMMITTEE ON FINANCE
Rep. Sylvia Luke, Chair
Rep. Ty J. K. Cullen, Vice Chair

Tuesday, March 28, 2019, 2:00pm
Conference Room 308
State Capitol
415 South Beretania Street

SB242 SD2 HD2 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 to ensure that they have access to the kinds of services that will allow them to participate in their communities.

The Hawai'i Psychological Association (HPA) conditionally supports SB242 SD2 HD2, with the provision that licensed psychologists are specified as eligible providers of care, as in the original version of this bill.

Thank you for the opportunity to provide input into this important bill.

Sincerely,

Julie Takishima-Lacasa, Ph.D.
Chair, HPA Legislative Action Committee



SB242 SD2 HD2 Autism and Fetal Alcohol Spectrum Disorder (FASD)

COMMITTEE ON FINANCE:

- Rep. Luke, Chair; Rep. Cullen, Vice Chair
- Thursday, Mar. 28, 2019: 2:00 pm
- Conference Room 308

Hawaii Substance Abuse Coalition Supports SB242 SD2 HD2:

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.

SB242, SD2, HD1 FOR HEARING March 28, 2019, 2:00 PM

Dear Chairperson, Representative Sylvia Luke, Vice Chair, Ty J.K. Cullen and members of the Committee on Finance,

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.

Hindsight, we will be able to save our children, women and families of Hawaii, and also our tax dollars when your support and the services are appropriated to this bill. Often, these children with FASD are seen with as children only with behavioral issues in our school system, get kicked out and eventually these children without no support will join into crime committing and delinquent groups who end up in our prison systems as juveniles and eventually as adults. This cost our State \$55,000.00 a year, not to mention that our prison system is over populated and we ship our State Inmates to other States which cost us \$35,000.00 a year per inmate. This cost doesn't include property damages, medical and other cost to tax dollars. With this bill services will be provided and these individuals can be a productive member of our society and somehow contribute not only for their own growth and needs but also to our community.

Mental Health Problems - 60% of children with FASD have ADDH and most individuals have clinical depression as adults; 23% of the adults had attempted suicide, and 43% had threatened to commit suicide. • Disrupted School Experience - 43% experienced suspension or expulsion or drop out; • Trouble with the Law - 42% had involvement with police, charged or convicted of crime; • Confinement – 60% of these children age 12 and over experienced inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime. • Inappropriate Sexual Behavior – Reported in 45% of those 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 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

- Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Canadian Journal of Clinical Pharmacology*, 17(1), e132–e164.
- Barker, C., Kulyk, J., Knorr, L., & Brenna, B. (2011). Open Inclusion or Shameful Secret: A Comparison of Characters with Fetal Alcohol Spectrum Disorders (FASD) and Characters with Autism Spectrum Disorders (ASD) in a North American Sample of Books for Children and Young Adults. *International Journal of Special Education*, 26(3), 171–180. Retrieved from <http://search.ebscohost.com.libproxy.edmc.edu/login.aspx?direct=true&db=eric&AN=EJ959010&site=eds-live>
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Testimony in Support of SB242 SD2 HD1

March 26, 2019

Dear Chairperson Luke and Members of the Finance Committee:

I was asked to represent the Hawaii Fetal Alcohol Spectrum Disorders (FASD) Action Group in support of this bill. FASD is a neurodevelopmental disorder that affects the lifespan of individuals and their families. The child is born with brain damage from a mother's use of alcohol during pregnancy, and this child will require help throughout its life. Brain damage ranges from severe to mild; nevertheless, impairment in judgment, insight, difficulty recognizing and responding to social cues, and other brain-related difficulties make people with FASD at high risk for homelessness, substance use and mental disorders, unemployment, victims of crime and violence, and adverse life situations.

This bill recognizes life-long brain injuries. The Bill gives life-long support to children and adults with incurable brain injuries and may help to prevention and/or mitigate the risk factors associated with neurodevelopmental disabilities. Prevention through support costs less in dollars and in human suffering. The bill addresses our concerns to find help for our children and adults affected by FASD and any other neurodevelopmental disorder.

Thank you.

Ann S. Yabusaki, Ph.D., MFT

For: Hawaii FASD Action Group

House Committee on Finance
Rep. Sylvia Luke, Chair
Rep. Ty J. K. Cullen, Vice Chair

Thursday, March 28, 2019, 2:00PM, Room 308
Hawai'i State Capitol

Testimony in **SUPPORT** of SB242 SD2 HD2
Relating to Health

Dear Chair Luke 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. This legislation 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 original version of this 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 behavioral treatment and their outcomes. Individuals with ASD and FASD continue to have difficulties in multiple 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, such as behavioral problems, appear to decrease in frequency with age, 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 insufficient 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 is 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 HD2. I also recommend reinstatement of licensed psychologists as eligible providers of care, as in the original version of this 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-2

Submitted on: 3/26/2019 1:24:09 PM

Testimony for FIN on 3/28/2019 2:00:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
adriane nishimura	Individual	Support	No

Comments:

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

I 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). Many women unknowingly harm their babies when they drink during pregnancy. The potential result is Individuals born with an FASD whose effects range from severe to mild who 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 adults affected with FASD and their families.

This bill will give all people with developmental disabilities a chance at LIFE.

Please consider that for individuals who fall within the spectrum of FASD:

- 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

Adriane Nishimura