



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
April 3, 2023

The Honorable Representative Kyle T. Yamashita, Chair
House Committee on Finance
The Thirty-Second Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Yamashita and Committee Members:

SUBJECT: SB1473 SD2 HD1 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS SB1473 SD2 HD1**, which requires DOH, DHS, and DOE to research rules, policies, and plan amendments necessary to ensure that medically necessary services, including applied behavior analysis services, for individuals twenty-six years of age or younger with neurodevelopmental disorders, including autism spectrum disorder and fetal alcohol spectrum disorders, are covered under the early and periodic screening, diagnostic, and treatment benefit; state special education services and programs; and the medicaid section 1915(c) home and community based waiver for individuals with intellectual and developmental disabilities.

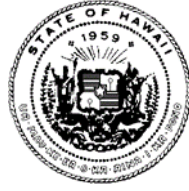
Our state currently has a "gap group" of individuals with Intellectual/Developmental Disabilities (I/DD) who do not qualify for services under the Developmental Disabilities Division and are above the age of 21. If these individuals with I/DD only have Med-Quest coverage, they cannot receive needed behavioral analysis services. Other individuals with neurodevelopment disabilities other than autism have also been shown to have positive results from receiving applied behavioral analysis services after age 21. For example, individuals with Down-Syndrome have benefitted from these services, and this measure will help us get closer to ensuring their needs are met.

Thank you for the opportunity to submit testimony in **support of SB1473 SD2 HD1**.

Sincerely,

Daintry Bartoldus
Executive Administrator

JOSH GREEN, M.D.
GOVERNOR
KE KIA'ĀINA



CATHY BETTS
DIRECTOR
KA LUNA HO'OKELE

JOSEPH CAMPOS II
DEPUTY DIRECTOR
KA HOPE LUNA HO'OKELE

STATE OF HAWAII
KA MOKU'ĀINA O HAWAI'I
DEPARTMENT OF HUMAN SERVICES
KA 'OIHANA MĀLAMA LAWELAWE KANAKA
Office of the Director
P. O. Box 339
Honolulu, Hawaii 96809-0339

April 2, 2023

TO: The Honorable Representative Kyle T. Yamashita, Chair
House Committee on Finance

FROM: Cathy Betts, Director

SUBJECT: [SB 1473 SD2 HD1](#) – RELATING TO HEALTH.

Hearing: April 3, 2023, 2:30 p.m.
Conference Room 308, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) appreciates the intent, offers comments, and defers to the Department of Health (DOH) and Department of Education (DOE). DHS respectfully requests that any appropriation not replace or reduce priorities identified in the executive budget and Governor's Messages.

PURPOSE: The bill requires DOH, DHS, and DOE to research rules, policies, and plan amendments necessary to ensure that medically necessary services, including applied behavior analysis services, for individuals twenty-six years of age or younger with neurodevelopmental disorders, including autism spectrum disorder and fetal alcohol spectrum disorders, are covered under the early and periodic screening, diagnostic, and treatment benefit; state special education services and programs; and the Medicaid section 1915(c) home and community based waiver for individuals with intellectual and developmental disabilities. Effective 7/1/3000. (HD1)

The SD1 amended the measure by:

(1) Replacing the term "medically-needed" to "medically necessary" throughout; and

- (2) Inserting language appropriating an unspecified amount of funds to the Department of Human Services to implement this measure.

The SD 2 amended the measure by:

- (1) Inserting an effective date of July 1, 2050, to encourage further discussion; and
- (2) Making a technical, nonsubstantive amendment for the purposes of clarity and consistency.

The HD1 amended the measure by:

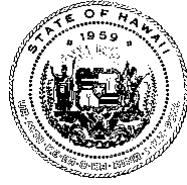
- (1) Deleting language requiring the Department of Health and Department of Human Services to develop and adopt rules, policies, and plan amendments regarding Medicaid coverage of certain services for persons twenty-one years of age or older with neurodevelopmental disorders and seek associated approvals from the Centers for Medicare and Medicaid Services;
- (2) Inserting language requiring the Departments of Health, Human Services, and Education to research what rules, policies, and plan amendments are necessary to ensure medically necessary services, including applied behavior analysis services, for individuals twenty-six years of age or younger with neurodevelopmental disorders, including autism spectrum disorder and fetal alcohol spectrum disorders are covered under the following:
 - (A) The Early and Periodic Screening, Diagnostic, and Treatment benefit under the State's Medicaid program;
 - (B) Any applicable state special education services and programs; and
 - (C) The Medicaid Section 1915(c) Home and Community Based Waiver for Individuals with Intellectual and Developmental Disabilities;
- (3) Changing the appropriation to be for Fiscal Year 2023- 2024 only, rather than the Fiscal Biennium 2023-2025, and amending its purpose;
- (4) Changing the effective date to July 1, 3000, to encourage further discussion; and
- (5) Making technical, nonsubstantive amendments for the purposes of clarity, consistency, and style.

DHS recognizes that it can be very difficult and challenging for families struggling to find appropriate services for their children transitioning to adulthood with neurodevelopmental conditions, such as autism or fetal alcohol spectrum disorders. DHS also appreciates the House Committees on Health and Homelessness' and Human Services' recognition of these challenges. As noted in the Standing Committee Report No. [1488](#), there is a gap group of individuals with intellectual or developmental disabilities (I/DD) who have been receiving Applied Behavioral Analysis (ABA) and other medically necessary services for individuals under 21 as part of the Early Periodic Screening, Diagnostic, and Treatment (EPSDT) Medicaid benefit, who when they

age out of the program may not have access to ABA under the Medicaid section 1915(c) Home and Community Based waiver for individuals with I/DD operated by DOH. DOE may also provide services for some of these individuals.

Many adults with autism or fetal alcohol spectrum disorders and their families face challenges accessing the necessary services and support. Navigating the best services and treatments can be difficult and confusing. We are committed to working with DOH, DOE, impacted families, and community partners to research best practices for Hawaii to improve services and supports for these individuals and identify possible rules, policies, and Medicaid state plan amendments that may be needed. We concur with DOH's testimony noting that it may take time to do the comprehensive analysis of the broad range of neurodevelopmental disorders. However, if autism and fetal alcohol spectrum disorders were prioritized, it may be possible to research rules, policies, and possible state plan amendments in the specified time.

Thank you for the opportunity to provide comments on this measure.



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

**Testimony COMMENTING on SB1473 SD2 HD1
RELATING TO HEALTH**

REPRESENTATIVE KYLE T. YAMASHITA, CHAIR
HOUSE COMMITTEE ON FINANCE

Hearing Date: April 3, 2023

Room Number: 308

1 **Department Position:**

2 The Department of Health (DOH) offers the following comments on SB1473 SD2 HD1.

3 **Department Testimony:**

4 SB1473 SD2 HD1 requires the DOH, the Department of Human Services (DHS) and the
5 Department of Education (DOE) to research what rules, policies, and plan amendments are
6 necessary to ensure that medically necessary services, including applied behavior analysis
7 services, for individuals twenty-six years of age or younger with neurodevelopmental disorders,
8 including autism spectrum disorder and fetal alcohol spectrum disorders, are covered under:

- 9 (1) The Early And Periodic Screening, Diagnostic, and Treatment benefit under the
10 State's Medicaid program;
11 (2) Any applicable state Special Education services and programs; and
12 (3) The Medicaid §1915(c) Home and Community Based Services (HCBS) Waiver for
13 Individuals with Intellectual and Developmental Disabilities (IDD).

14 The DOH-Developmental Disabilities Division (DOH-DDD) operates, on behalf of DHS-
15 Med-QUEST Division the Medicaid §1915(c) HCBS Waiver for Individuals with IDD. The
16 §1915(c) Waiver provides services and supports that allow eligible individuals who have met the
17 requirements for Medicaid and the institutional level of care to live at home and in the
18 community, rather than in an institution.

19 This measure requests the DOH, the DHS, and the DOE conduct research on service
20 coverage for individuals twenty-six years of age and younger with any neurodevelopmental

1 disorder. The bill does not clarify the scope of diagnoses that constitutes a neurodevelopmental
2 disorder (NDD). The diagnostic class of NDDs in the current Diagnostic and Statistical Manual
3 of Mental Disorders (DSM) is broad and defines NDDs as a group of conditions with onset in the
4 developmental period, inducing deficits that produce impairments of functioning. NDDs
5 comprise intellectual disability (ID); Communication disorders; Autism Spectrum Disorder
6 (ASD); Attention-Deficit/Hyperactivity Disorder (ADHD); Neurodevelopmental motor
7 disorders, including Tic disorders; and Specific learning disorders.

8 Research that would conclude what rules, policies and Medicaid state plan amendments
9 are necessary to cover this population is a worthy endeavor, and would be rooted in looking at
10 the needs of the population both from a treatment and support services perspective, coupled with
11 the best evidence in these areas. Such a study requires specialized knowledge across the medical,
12 individual supports, and policy domains both in the Medicaid and educational spheres. We
13 would suggest that such a study would need to be adequately resourced and could offer
14 recommendations for policy directions for the state including cost projection information.

15 The DOH is aware of the challenges faced by individuals with disabilities and their
16 families in accessing services and supports that help them achieve the lives they choose, and is
17 willing to work with others to design solutions.

18 **Fiscal Implications:**

19 The DOH defers to DHS with respect to the general fund appropriation necessary to fund
20 the research requested in SB1473 SD1 HD1.

21 **Offered Amendments:**

22 The DOH believes it would take more than one year to secure the expertise needed to
23 adequately conduct this research, and suggests the following amendment:

24 SECTION 2, Page 1, starting with line 16 be amended to read:

25 “There is appropriated out of the general revenues of the State of Hawaii the sum of \$
26 or so much thereof as may be necessary for ~~fiscal year 2023-2024~~ fiscal years 2023-24
27 and 2024-25 for the department of health, department of human services, and department

1 of education to carry out the research of rules, policies, and plan amendments as required
2 under section 1 of this Act.”

3

4 Thank you for the opportunity to testify.

SB-1473-HD-1

Submitted on: 4/1/2023 10:24:25 AM

Testimony for FIN on 4/3/2023 2:30:00 PM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Hawaii Disability Rights Center	Support	Written Testimony Only

Comments:

This an excellent idea and we are in strong support.

SB-1473-HD-1

Submitted on: 4/1/2023 2:21:59 PM

Testimony for FIN on 4/3/2023 2:30:00 PM

Submitted By	Organization	Testifier Position	Testify
Cleota Brown	Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group	Support	Written Testimony Only

Comments:

Dear Rep. Yamashita, Chair, Rep. Kitagawa, Vice Chair and members of the Committee on Finance:

On behalf of Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group a 501 c 3 with a **Mission** to raise awareness through education, advocacy, and research on the impact of Fetal Alcohol Spectrum Disorder (FASD) on individuals, their families, and the communities of Hawai'i, **we strongly support SB1473 SD2 HD1**. We also appreciate the inclusion of fetal alcohol spectrum disorder in this legislation.

This legislation if enacted, will provide a lifeline of hope for people with a FASD and their families and caregivers. For many years FASD has been an invisible disability in the State of Hawai'i, lacking funding, informed services and support.

We encourage you to pass SB1473 and help us make FASD invisible no more.

Sincerely yours,

Cleota Brown, President

fasdhawaii.org



HB900 FSAD Task Force and Funding

COMMITTEE ON FINANCE

Rep. Kyle T. Yamashita, Chair

Rep. Lisa Kitagawa, Vice Chair

Monday, Apr. 3, 2023: 2:30 : Room 308 Videoconference

Hawaii Substance Abuse Coalition supports SB1473 SD2 HD1

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 for substance use disorder and co-occurring mental health disorder treatment and prevention agencies and recovery services.

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 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.



Committee on Finance

Monday, April 3, 2023
2:30 p.m.

VIA VIDEOCONFERENCE
Conference Room 308
State Capitol
415 South Beretania Street

SUPPORT SB1473 SD2 HD1 RELATING TO THE DEPARTMENT OF HUMAN SERVICES

Chair Yamashita, Vice Chair Kitagawa, and members of the Committee:

On behalf of the Hawai'i Association for Behavior Analysis (HABA) we thank you for the opportunity to submit testimony in strong support of SB1473 SD2 HD1, which requires the Department of Health, Department of Human Services, and Department of Education research rules, policies, and plan amendments necessary to ensure that the state Medicaid program covers medically necessary services, including applied behavior analysis for individuals twenty-six years of age or younger.

for applied behavior analysis (ABA) services for adults, and develop and adopt

HABA would greatly appreciate any opportunity to work with DOH, DHS, and other stakeholders in support of this effort.

Hawaii can look to the state of New Mexico, which adopted a bill to remove age caps on Medicaid covered ABA services related to autism and has a state plan amendment approved by CMS (see [New Mexico SPA NM-22-0022 approved on January 25, 2023](#).) Additionally, the [State of New Mexico Medical Assistance Program Manual Supplement for ABA Guidance](#) includes specifics for adult recipients of ABA services.

HABA supports creating access to medically necessary services across the lifespan. In our state, Med-QUEST beneficiaries under the age of 21 with an autism diagnosis can access their medically necessary services through their health plan; however, when they turn 21, as a QUEST beneficiary they lose access to therapy. This bill would ensure that individuals aged 21 and over would be able to access medically necessary services. Further, this bill would create parity for QUEST beneficiaries, as those with private insurance are already covered across the lifespan. (Although the Hawaii autism insurance reform law HRS §§ 431:10A-133, Luke's Law, passed in 2015 does include age and dollar caps, these do not align with the [federal mental health parity act \(MHPAEA\)](#) and therefore private insurers in the state do not limit access to ABA based on age.)

There is a robust body of literature available supporting ABA which includes both clinical research applications for evidence-based treatment with adults as well as published generally accepted standards of care for ABA.

The ABA Coding Coalition's publication, [Model Coverage Policy for Adaptive Behavior Services](#) originally published in 2020 and revised in 2022, **includes model health insurance coverage**

policy and a bibliography of research examples including adults and other neurodevelopmental conditions.

The Council of Autism Service Providers (CASP) is a nonprofit organization that publishes the generally accepted standards of care for medically necessary ABA—[Applied Behavior Analysis: Treatment of Autism Spectrum Disorder Practice Guidelines for Healthcare Funders and Managers](#) in its second edition published in 2020 notes “Treatment should be based on the clinical needs of the individual and not constrained by age [...] ABA is effective across the life span. Research has not established an age limit beyond which ABA is ineffective” (p. 18). It is worth noting that the CASP practice guidelines include a *selected bibliography*, not a comprehensive list of available research and the bibliography has not been updated since its original publication in 2014 (the selected bibliography includes 15 studies, three of which focus on adults). Research, including randomized control trials and meta-analyses, have demonstrated the effectiveness of behavioral intervention for adults and many of these studies are housed by the National Library of Medicine.

In 2014, the nonprofit organization, Autism New Jersey, published a report titled [Insurance Coverage of Applied Behavior Analysis for Adults with Autism: A Review of the Evidence](#). In this report, the authors concluded “The robust empirical support for ABA-based interventions for children with autism combined with the effectiveness of focused ABA-based interventions for adults with autism make a compelling argument to require insurance coverage of ABA-based interventions for adults with autism” (p.7).

In 2015, the National Autism Center published the [National Standards Project, Phase 2: Addressing the need for evidence-based practice guidelines for autism spectrum disorder](#). This report reviewed research findings for adults age 22+ and found that there was a body of research available for behavioral intervention (ABA) with adults to conclude that ABA is the only established intervention meeting the criteria for evidence-based intervention.

Extending coverage of ABA services to Medicaid eligible adults would greatly benefit our community by creating access to needed behavioral health services and addressing this health equity issue for a vulnerable population.

Mahalo,



Kristen Koba-Burd, BCBA, LBA, CDP
Legislative Chair
Hawai'i Association for Behavior Analysis

DATE: April 1, 2023

TO: Representative Kyle Yamashita, Chair
Representative Lisa Kitagawa, Vice-Chair
Members of the Committee on Finance

FROM: Ann S. Yabusaki, Ph.D., psychologist

RE: **Writing in Support of SB1473 SD1, SD2**

Much like individuals affected by autism, individuals affected by fetal alcohol spectrum disorders (FASD) are often unseen and unheard and often do not qualify for medically necessary services under the current guidelines of the developmentally disabled. Although FASD is considered a neurodevelopmental disorder associated with significant functional disabilities such as memory, learning, language, executive functioning, behavioral challenges, and other brain-related (hidden) disabilities, people with FASD often have normal IQs excluding them from receiving services for the developmentally disabled. Indeed, there are few to no services for people affected by FASD.

By adopting FASD as a neurodevelopmental disorder on FUNCTIONAL needs and not IQ, we create an important doorway for people to receive services.

My clients with or undiagnosed FASD and their families need support throughout the lifespan. Individuals who appear functional but unable to care for themselves often impact our homeless population, criminal justice system, mental health and substance abuse programs, medical systems, and other programs. With proper FASD-informed support many can achieve successful, happy, and productive lives. Expanded Medicaid and Medicare services to include medically-necessary reimbursement would benefit this group of individuals tremendously. The cost of human suffering is immeasurable for those affected and their families.

We continue to work towards prevention, which is far less costly than treatment, but the need is now—for those who are affected by FASD.

Thank you for your support.

DATE: April 1, 2023

TO: Representative Kyle Yamashita, Chair
Representative Lisa Kitagawa, Vice-Chair
Members of the Committee on Finance

FROM: Kenichi Yabusaki, Ph.D., retired biochemist

RE: **Writing in Support of SB1473 SD1, SD2**

Like individuals affected by autism, individuals affected by fetal alcohol spectrum disorders (FASD) are often misdiagnosed and treated for autism. However, treatment for autism does not work for those affected by FASD. Autism does not cause FASD. Thus, those with FASD often do not qualify for medically necessary services under the current guidelines for the developmentally disabled under which those with autism qualify. FASD is an alcohol-related neurodevelopmental disorder associated with significant functional disabilities such as memory, learning, language, executive functioning, behavioral challenges, and other brain-related (hidden) disabilities. People with FASD often have normal IQs excluding them from receiving services for the developmentally disabled. Indeed, there are few to no services for people affected by FASD. Qualifying for services for those affected by FASD should be based on “Functionality” and not IQ.

Adopting FASD as a neurodevelopmental disorder on FUNCTIONAL needs and not IQ creates an important doorway for people to receive services. Such action makes the world “possible” for them. Society must change because those affected by FASD cannot change due to permanent impairment of parts of the brain.

Many individuals affected by FASD cannot care for themselves, and they often impact our homeless population, the criminal justice system, mental health and substance abuse programs, medical systems, and other programs. With proper FASD-informed support, many can achieve successful, happy, and productive lives. Expanded Medicaid and Medicare services to include medically-necessary reimbursement would benefit this group of individuals tremendously. The cost of human suffering is immeasurable for those affected and their families.

We continue to work towards prevention, which is far less costly than treatment, but the need is now—for those affected by FASD.

Thank you for your support.

HOUSE OF REPRESENTATIVES
THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON FINANCE

Rep. Kyle T. Yamashita, Chair
Rep. Lisa Kitagawa, Vice Chair

Rep. Micah P.K. Aiu	Rep. Rachele F. Lamosao
Rep. Cory M. Chun	Rep. Dee Morikawa
Rep. Elle Cochran	Rep. Scott Y. Nishimoto
Rep. Andrew Takuya Garrett	Rep. Mahina Poepoe
Rep. Kirstin Kahaloa	Rep. Jenna Takenouchi
Rep. Darius K. Kila	Rep. David Alcos III
Rep. Bertrand Kobayashi	Rep. Gene Ward

NOTICE OF HEARING

DATE: Monday, April 3, 2023
TIME: 2:30 p.m.
PLACE: VIA VIDEOCONFERENCE
Conference Room 308
State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT SB 1473 SD2 HD1.**

Dearest Chair, Honorable Representative Kyle T. Yamashita and Vice Chair, Honorable Representative Lisa Kitagawa and members of the Committee on Finance,

I am Darlyn Chen Scovell, a volunteer advocate for families and children with FASD (Fetal Alcohol Spectrum Disorder) and the Hawaii FASD Action Group. Being the voice of children who have none and individuals with FASD who have been marginalized, unrecognized, and without help, attention, and services for many, many years. I am writing in **STRONG SUPPORT of SB 1473 SD2 HD1.**

SB1473 SD2 HD1, Requires DOH, DHS, and DOE to research rules, policies, and plan amendments necessary to ensure that medically necessary services, including applied behavior analysis services, for individuals twenty-six years of age or younger with neurodevelopmental disorders, including autism spectrum disorder and fetal alcohol spectrum disorders, are covered under the early and periodic screening, diagnostic, and treatment benefit; state special education services and programs; and the Medicaid section 1915(c) home and community-based waiver for individuals with intellectual and developmental disabilities. Undiagnosed FASDs and their families need support throughout their lifespans. Support for individuals who appear functional but unable to care for themselves often impacts our homeless population, the criminal justice system, mental health and substance abuse programs, medical systems, and other programs.

Fetal Alcohol Spectrum Disorders (FASD) are often unseen and unheard of and do not qualify for medically necessary services under the current guidelines for the developmentally disabled. Although FASD is considered a neurodevelopmental disorder associated with significant functional disabilities such

as memory, learning, language, executive functioning, behavioral challenges, and other brain-related invisible disabilities, people with FASD often have normal IQs excluding them from receiving services for the developmentally disabled. Indeed, there are few to no services for people affected by FASD.

FASD diagnosis is a processing disorder, learning disability, and attention-deficit/ hyperactivity disorder, similar to Autism Spectrum Disorders, however distinctly VERY DIFFERENT. The NEURODEVELOPMENTAL IMPAIRMENTS associated with FASD came WITH SIGNIFICANT SOCIAL COST ACROSS THE LIFESPAN in increased medical, educational, and vocational support and lost productivity. I have worked with children with Autism as a Registered Behavioral Therapist under ABA Guidelines. In my observations, FASD is a Developmental Disability that is equally as severe as Autism, with the significant challenge that **FASD disability is NOT VISIBLE**; they look like you and me, and their IQ may pass as normal initially, but the damage is in the brain, neurological damage caused by ALCOHOL consumption during pregnancy. This is a CAUSE SPECIFIC AND PREVENTABLE.

According to the *DSM-5*, the diagnostic terms fetal alcohol spectrum disorder (FASD) or neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE) describes the combined challenges and strengths common in people whose mothers consumed sufficient alcohol at the threshold known to be associated with adverse neurobehavioral effects. Individuals diagnosed with Neuro Developmental-Prenatal Alcohol Exposure suffer primarily from cognitive and intellectual deficits, including the areas of learning and memory, language, attention, executive functioning, and adaptive and social functioning (Mela, 2023). Experts estimated that 2% to 5% of U.S. schoolchildren—as many as 1 in 20—are affected by prenatal alcohol exposure, which can cause complications with growth, behavior, and learning (APA, 2022). The prevalence of fetal alcohol spectrum disorder (FASD) in the United States may be much higher than previous estimates have indicated. Researchers reported in the February 6 JAMA that in four communities they studied, as much as 1.1 percent to 5 percent of first-grade children were affected, and those were conservative estimates (Moran, 2018).

Please help me help these children and families impacted with FASD. Please **VOTE to PASS SB 1473 SD2 HD1**. Thank you so much. Please do let me know if there is anything else I can do to help this population who they say have fallen into the crack of our society and in my opinion, they fallen on the cliff and have been forgotten. FASD children who have an invisible disability – INVISIBLE NO MORE!

These children are born in an impossible world ~ Please let us make this world possible for them.

Thank you so much for your kind consideration, for the opportunity to advocate and testify.
Always with Gratitude.
Respectfully yours,
Darlyn Chen Scovell

Reference

American Psychological Association. (n.d.). *A hidden epidemic of fetal alcohol syndrome*. Monitor on Psychology. Retrieved January 14, 2023, from <https://www.apa.org/monitor/2022/07/news-fetal-alcohol-syndrome#:~:text=Experts%20estimate%20that%20%25%20to,growth%2C%20behavior%2C%20and%20learning>.

Mela, M. (2023). Patients with prenatal alcohol exposure frequently misdiagnosed, face multiple challenges. *Psychiatric News*, 58(01). <https://doi.org/10.1176/appi.pn.2023.01.1.12>

Moran, M. (2018). Fetal alcohol spectrum disorders may be more common than previously thought. *Psychiatric News*, 53(5). <https://doi.org/10.1176/appi.pn.2018.3a8>

Zagorski, N. (2017). Study estimates 630K infants born with FASD globally each year. *Psychiatric News*, 52(19), 1–1. <https://doi.org/10.1176/appi.pn.2017.9b19>

SB-1473-HD-1

Submitted on: 4/2/2023 3:30:47 AM

Testimony for FIN on 4/3/2023 2:30:00 PM

Submitted By	Organization	Testifier Position	Testify
mark matsushita	Individual	Support	Written Testimony Only

Comments:

FASD diagnosis is a processing disorder, learning disability, and attention-deficit/ hyperactivity disorder, similar to Autism Spectrum Disorders, however distinctly VERY DIFFERENT. The NEURODEVELOPMENTAL IMPAIRMENTS associated with FASD came WITH SIGNIFICANT SOCIAL COST ACROSS THE LIFESPAN in increased medical, educational, and vocational support and lost productivity. I have worked with children with Autism as a Registered Behavioral Therapist

under ABA Guidelines. In my observations, FASD is a Developmental Disability that is equally as severe as Autism, with the significant challenge that FASD disability is NOT VISIBLE; they look like you and me, and their IQ may pass as normal initially, but the damage is in the brain, neurological damage caused by ALCOHOL consumption during pregnancy. This is a CAUSE SPECIFIC AND PREVENTABLE.

According to the DSM-5, the diagnostic terms fetal alcohol spectrum disorder (FASD) or neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE) describes the combined challenges and strengths common in people whose mothers consumed sufficient alcohol at the threshold known to be associated with adverse neurobehavioral effects. Individuals diagnosed with Neuro Developmental-Prenatal Alcohol Exposure suffer primarily from cognitive and intellectual deficits, including the areas of learning and memory, language, attention, executive functioning, and adaptive and social functioning (Mela, 2023). Experts estimated that 2% to 5% of U.S. schoolchildren—as many as 1 in 20—are affected by prenatal alcohol exposure, which can cause complications with growth, behavior, and learning (APA, 2022). The prevalence of fetal alcohol spectrum disorder (FASD) in the United States may be much higher than previous estimates have indicated. Researchers reported in the

February 6

JAMA that in four communities they studied, as much as 1.1 percent to 5 percent of first-grade children

were affected, and those were conservative estimates (Moran, 2018).

Please help me help these children and families impacted with FASD. Please VOTE to PASS SB 1473 SD2 HD1. Thank you so much. Please do let me know if there is anything else I can do to help this

population who they say have fallen into the crack of our society and in my opinion, they fallen on the

cliff and have been forgotten. FASD children who have an invisible disability – INVISIBLE NO MORE!

These children are born in an impossible world ~ Please let us make this world possible for them.

Mark Matsushita LMFT, CSAC

Licensed Marriage and Family Therapist

Certified Substance Abuse Counselor

SB-1473-HD-1

Submitted on: 4/2/2023 2:28:06 PM

Testimony for FIN on 4/3/2023 2:30:00 PM

Submitted By	Organization	Testifier Position	Testify
Linda Elento	Individual	Support	Remotely Via Zoom

Comments:

Aloha,

Testimony In Support

Simply put my adult child would have had the opportunity to continue ABA services under Medicaid, medically-necessary outside of school goals and needs on his 21st birthday had our state's Medicaid plan included ABA to continue on his 21st birthday. ABA is based on a medically qualified professional's evaluations and periodic progress is measured, reviewed and submitted for prior authorizations, not and endless service with unpredictable costs.

My understanding is that parents like myself can choose or decline allowing the DOE to bill Medicaid. We don't want that to limit any services that the student needs outside of school.

I do ask the Legislature to consider ABA as necessary for a student to not be discriminated on the basis of disability per Sec. 504 at school and on fieldtrips if ABA is required.

Some disabled individuals who are still in school until age 22 need to continue medically-necessary ABA; yet if they are needing health care through Medicaid, ABA arbitrarily ends on the 21st birthdate.

Instead a myriad of evaluation, incomplete, have been paid for by the state and enormous amount of time spent qualifying for DDD services and yet none have been successful in continuing ABA outside of school. The Medicaid waiver service is not ABA anyway.

Previous testimony to the Legislature stated "...individuals with disabilities who need assistance with activities of daily living such as getting dressed and bathing, preparing and eating meals, and tending to chores in the home. Recipients of Medicaid Home- and Community-Based Services are able to remain in their home and community." In another testimony a state agency reported that the Medicaid DD waiver service is not ABA, per se, which my son has tried to access for over a year; however a provider has not been available for him anyway on Oahu.

Applied Behavior Analysis (ABA) is not providing assistance in an activity but rather providing a medical treatment/service plan for an individual to work towards independence, and to develop communication skills, for example.

SB1473 is needed to continue the purpose of **SR114 SD1 adopted by the Senate in 2022** to request the state agencies to work towards providing medically-necessary ABA to individuals 21 or older through Medicaid.

A court in Indiana ruled that the arbitrary age cut-off on the 21st birthday is disability discrimination towards individuals with autism (because autism doesn't stop on the 21st birthday), violating the Americans with Disabilities Act (ADA) (Reference: Tom Blessing, Attorney, plaintiff). There are new cases becoming evident that decided the same, **ending ABA in an individual's 21st birthday under Medicaid (at least for an autism diagnosis) is a violation of the ADA.**

Hawai'i has an urgent need for Medicaid coverage of Applied Behavior Analysis (ABA) for individuals age 21 and older; **based on medical-necessity, not a diagnosis.**

Thank you for the opportunity to provide testimony **in support of SB1473** and to request the Committees change the effective date to effective upon its approval.