

STATE OF HAWAI'I STATE COUNCIL ON DEVELOPMENTAL DISABILITIES 1010 RICHARDS STREET, Room 122 HONOLULU, HAWAI'I 96813 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543 March 21, 2023

The Honorable Representative John M. Mizuno, Chair House Committee on Human Services The Honorable Representative Della Au Belatti, Chair House Committee on Health & Homelessness The Thirty-Second Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Representative Mizuno, Representative Belatti, and Committee Members:

SUBJECT: SB1473 SD2 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS SB1473 SD2**, which requires the Department of Health and Department of Human Services to develop and adopt rules, policies, and plan amendments necessary to ensure that the state Medicaid program covers medically necessary services, including applied behavior analysis services, for individuals aged twenty—one and older with neurodevelopmental disorders, including autism spectrum disorder. Requires the Department of Health and Department of Human Services to apply for any necessary approvals from the Centers for Medicare and Medicaid Services to amend the state Medicaid plan to provide reimbursements for medically necessary services, including applied behavior analysis services to Medicaid-eligible individuals over the age of twenty-one diagnosed with autism spectrum disorder. Appropriates funds. Effective 7/1/2050. (SD2)

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 are unable to 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 the age of 21. For example, individuals with Down-Syndrome have benefitted from these services and this measure will ensure their needs are met.

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

Sincerely,

Daintry Bartoldus Executive Administrator



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 RELATING TO HEALTH

REPRESENTATIVE JOHN M. MIZUNO, CHAIR HOUSE COMMITTEE ON HUMAN SERVICES

REPRESENTATIVE DELLA AU BELATTI, CHAIR HOUSE COMMITTEE ON HEALTH AND HOMELESSNESS

Hearing Date: 3/21/23

Room Number: 329

1 Department Position:

- 2 The Department of Health (DOH) offers the following comments and defers to the
- 3 Department of Human Services (DHS) with respect to the State Medicaid program and fiscal
- 4 impact of SD2.

6

5 Department Testimony:

- SB1473 SD2 requires the DOH and the DHS:
- (1) To develop and adopt rules, policies, and plan amendments necessary to ensure 7 8 that the State Medicaid program covers medically necessary services, including applied behavior analysis (ABA) services, for individuals age 21 and older with 9 neurodevelopmental disorders, including autism spectrum disorder (ASD) (section 1 10 of the SD2); and 11 12 (2) To apply for any necessary approvals from the federal Centers for Medicare and Medicaid Services (CMS) to amend the State Medicaid plan to provide 13 14 reimbursements for medically necessary services, including ABA services, to
- 15 Medicaid-eligible persons over the age of 21 diagnosed with ASD (section 2 of the
- 16 SD2).

1	Section 3 of SD2 makes an unspecified general fund appropriation in FY24 and FY25 for
2	DOH and DHS to develop and adopt rules, policies, and plan amendments necessary to ensure
3	that the State Medicaid program covers medically necessary services for individuals age 21 and
4	older with neurodevelomental disorders, including ASD.
5	Sections 1 and 3 of SD2 refers to "neurodevelopmental disorders", the scope of which is
6	not defined, whereas Section 2 of the bill refers to those diagnosed with ASD.
7	The DHS, Med-QUEST Division (MQD), is the designated State Medicaid agency
8	responsible for administering the State's Medicaid plan and Hawaii's two Medicaid Waivers.
9	Medicaid beneficiaries receive coverage for physical and behavioral health benefits through
10	managed care organizations that contract with DHS-MQD.
11	The DOH-Developmental Disabilities Division (DOH-DDD) operates, on behalf of DHS-
12	MQD, the Medicaid §1915(c) Home and Community Based Waiver for Individuals with
13	Intellectual and Developmental Disabilities. The §1915(c) Waiver provides services and
14	supports that allow eligible individuals who have met the requirements for Medicaid and the
15	institutional level of care to live at home and in the community, rather than in an institution.
16	DOH-DDD does not develop and adopt rules, policies, and plan amendments necessary to ensure
17	that the State Medicaid program covers medically necessary services, nor does it have the
18	authority to apply for any necessary approvals from CMS to amend the State Medicaid plan.
19	Private health insurance plans offered by health insurers, mutual benefit societies (MBS),
20	and health maintenance organizations (HMO) are mandated to provide coverage for the
21	diagnosis and treatment of ASD for those under age 14, pursuant to HRS §§ 431:10A-133 ¹ ,
22	432:1-614 ² , and 432D-23. Coverage for ABA is limited to a maximum benefit of \$25,000 per

¹ Each individual or group accident and health or sickness insurance policy issued or renewed in this State after January 1, 2016, shall provide to the policyholder and individuals under fourteen years of age covered under the policy coverage for the diagnosis and treatment of autism. HRS §431:10A-133(a) (2019 Repl.).

² Each hospital and medical service plan contract issued or renewed in this State after January 1, 2016, shall provide to the member and individuals under fourteen years of age covered under the plan contract coverage for the diagnosis and treatment of autism. HRS §432:1-614(a) (2019 Repl.).

1	year for services for children ages 13 and under, per HRS §§ 431:10A-133(d), 432:1-614(d), and
2	432D-23.
3	Coverage for the treatment of ASD by health insurers, MBS, and HMO is not limited to
4	ABA, per HRS §§ 431:10A-133(m), 432:1-614(m), and 432D-23.
5	"Treatment for autism" includes the following care prescribed or ordered for an
6	individual diagnosed with autism by a licensed physician, psychiatrist,
7	psychologist, licensed clinical social worker, or registered nurse practitioner if the
8	care is determined to be medically necessary:
9	(1) Behavioral health treatment;
10	(2) Pharmacy care;
11	(3) Psychiatric care;
12	(4) Psychological care; and
13	(5) Therapeutic care.
14	In terms of covering ABA services for adults, based on our review of the literature, there
15	is a lack of evidence to provide strong practice recommendations that ABA services are effective
16	in treating the population of adults with neurodevelopmental disorders, including ASD. For
17	example, the Council of Autism Service Providers (CASP) published ABA practice guidelines
18	based on limited data and scientific rigor. There has not been widespread adoption of CASP or
19	other clinical guidelines for ABA in adults. Therefore, any recommendation for ABA therapy in
20	adults has been considered on a case-by-case basis. Furthermore, there are a growing number of
21	peer-reviewed publications suggesting ABA may be harmful and have negative outcomes for
22	some individuals with ASD.
23	ABA and other medically necessary services have been established through the Early
24	Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit of Medicaid plans for
25	individuals under 21 years of age. This is based on a body of research that ABA is most
26	effective for younger children with ASD and has marginal effectiveness in improving health
27	outcomes. Until it is shown that ABA in adults meets the standard of medical necessity and
28	clinical practice guidelines are found to be safe and proven effective, we believe it is premature
29	to develop rules that ensure coverage of this service.

1 The DOH is aware of the challenges many adults with autism and their families have in 2 accessing the services and supports they need. Navigating insurance coverage and the best 3 treatments can be difficult and confusing. We are committed to continued work with our DHS 4 and community partners to look at solutions.

5 Fiscal Implications:

6 This measure requests a broad scope of coverage for all adults with any 7 neurodevelopmental disorder. The fiscal impact of this will likely be very large and require 8 extensive research on populations affected by such services. Without CMS approval, there 9 would be no federal cost-sharing and the State would be 100% responsible for the entire cost of 10 services. This would require a large general fund appropriation that would require analysis to 11 determine. The DOH defers to DHS with respect to the general fund appropriation necessary to 12 fund the services specified in SD2.

13 Thank you for the opportunity to testify.

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

March 19, 2023

TO: The Honorable Representative John M. Mizuno, Chair House Committee on Human Services

> The Honorable Representative Della Au Belatti, Chair House Committee on Health & Homelessness

FROM: Cathy Betts, Director

SUBJECT: SB 1473 SD2 – RELATING TO HEALTH.

Hearing: March 21, 2023, 9:00 a.m. Conference Room 329, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) offers comments and defers to the Department of Health (DOH). 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 and DHS to develop and adopt rules, policies, and state plan amendments necessary to ensure that the state Medicaid program covers medically necessary services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder. Requires the DOH and DHS to apply for any necessary approvals from the Centers for Medicare and Medicaid Services to amend the state Medicaid plan to provide reimbursements for medically necessary services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder.

Appropriates funds. (SD2)

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:

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

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. Applied Behavioral Analysis (ABA) and other medically necessary services for individuals under 21 are included in the Early Periodic Screening, Diagnostic, and Treatment (EPSDT) Medicaid benefit. However, ABA is most effective for younger ages with mild to moderate autism. However, the scientific evidence has shown marginal effectiveness in improving health outcomes, which is the medical necessity standard for most older individuals or individuals with severe autism. While ABA may be clinically effective for other neurodevelopmental disorders besides autism spectrum disorders, it is not clinically effective for all individuals with autism or other neurodevelopmental conditions. Therefore, although DHS can evaluate our policies, rules, and the State Plan regarding the coverage of any medically necessary services for an adult with any neurodevelopmental condition, given the broad parameters of both diagnoses and treatments the measure includes, it will take an extended time to research, analyze, adopt rules if and when necessary, and amend the Medicaid State Plan, if and when needed. Additionally, if the clinical evidence for ABA for adults is insufficient, it may not be feasible to adopt rules, policies, or changes to the state plan for general coverage beyond what is available currently, which is on a case-by-case basis.

The bill requires the development of state plan amendments to be able to reimburse for medically necessary services, including ABA, for those over 21 with "neurodevelopmental disorders." The broad nature of the coverage expansion will likely require a large

appropriation. However, as noted in our prior testimony, we have insufficient information to determine the fiscal impact. Thus, although the measure was amended to include an appropriation, which we appreciate, we are unable to provide any information on the fiscal impact without doing extensive research and analyses referenced above. We also note that an appropriation is necessary before any State Plan Amendment submission since those services will then have to be provided once approved. Without the appropriation, other existing services would have to be reduced or limited to pay for the added services.

Many adults with autism 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, impacted families, and community partners to find solutions.

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



DISABILITY AND COMMUNICATION ACCESS BOARD

1010 Richards Street, Room 118 • Honolulu, Hawaii 96813 Ph. (808) 586-8121 (V) • TTY (808) 586-8162 • Fax (808) 586-8129

March 21, 2023

TESTIMONY TO THE HOUSE COMMITTEES ON HUMAN SERVICES AND HEALTH & HOMELESSNESS

Senate Bill 1473 SD2 - Relating to Health

The Disability and Communication Access Board (DCAB) supports the intent of Senate Bill 1473 SD2 – Relating to Health. This bill would require the Department of Health and Department of Human Services to develop and adopt rules, policies, and plan amendments necessary to ensure that the state Medicaid program covers medically necessary services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder and require the Department of Health and Department of Human Services to apply for any necessary approvals from the Centers for Medicare and Medicaid Services to amend the state Medicaid plan to provide reimbursements for medically necessary services, including applied behavior analysis services to Medicaid-eligible individuals over the age of twenty-one diagnosed with autism spectrum disorder.

The State currently has a "gap group" of individuals with intellectual or developmental disabilities who do not qualify for services under the Developmental Disabilities Division and are above the age of twenty-one. If these individuals with intellectual or developmental disabilities only have Med-QUEST coverage they are unable to receive needed behavioral analysis services. This measure will ensure that individuals over the age of twenty-one will be able to access medically necessary services.

Thank you for the opportunity to provide testimony.

Respectfully submitted,

KIRBY L. SHAW Executive Director

<u>SB-1473-SD-2</u> Submitted on: 3/14/2023 10:14:00 PM Testimony for HUS on 3/21/2023 9:00:00 AM

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

Comments:

We support this bill. Currently, individuals under 21 are covered for these services under the Medicaid program known known as EPSDT. It is an excellent program designed to provide essential medical services to children that might not otherwise be covered under the Medicaid state plan. While it is true that generally applied behavior analysis is most effective when begun at an early age we understand that a growing body of research supports its continued value for people beyond that. So to the extent that these services could continue to be provided past the age of 21 to individuals with autism spectrum disorder it would be very valuable to them.

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 12:08:57 PM Testimony for HUS on 3/21/2023 9:00:00 AM

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

Comments:

To: Representative Belatti, Chair, Representative Takenouchi, Vice Chair and members of the Health and Homelessness Committee;

To: Representative Mizuno, Chair, Representative Amato, Vice Chair and members of the Human Services Committee

On behalf of the Hawai'i Fetal Alcohol Spectrum Disorders FASD Action Group we offer our strong support SB 1473, SD2.

"This legislation requires the Department of Health and Department of Human Services to develop and adopt rules, policies, and plan amendments necessary to ensure that the state Medicaid program covers medically necessary services, including applied behavior analysis services, for individuals aged twenty—one and older with neurodevelopmental disorders, including autism spectrum disorder."

We kindly request an amendment to add fetal alcohol spectrum disorders (FASD).

FASD results in birth defects and developmental disabities that are frequently misdiagnosed and often do not qualify for adequate FASD informed services. In fact, to my knowledge there is a lack of FASD informed services in Hawai'i. FASD is more prevalent than autism spectrum disorder which is named in this legislation.

We appreciate this opportunity to offer our support for SB1473 SD2.

Sincerely yours,

Cleota Brown, President

hawaiifasd.org

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

COMMITTEE ON HUMAN SERVICES

Rep. John M. Mizuno, Chair Rep. Terez Amato, Vice Chair

Rep. Della Au Belatti	Rep. Jenna Takenouchi
Rep. Greggor Ilagan	Rep. Scott Y. Nishimoto
Rep. Bertrand Kobayashi	Rep. Diamond Garcia

COMMITTEE ON HEALTH & HOMELESSNESS

Rep. Della Au Belatti, Chair Rep. Jenna Takenouchi, Vice Chair

Rep. Terez Amato	Rep. John M. Mizuno
Rep. Greggor Ilagan	Rep. Scott Y. Nishimoto
Rep. Bertrand Kobayashi	Rep. Diamond Garcia

NOTICE OF HEARING

DATE: Tuesday, March 21, 2023 TIME: 9:00am PLACE: VIA VIDEOCONFERENCE Conference Room 329 State Capitol 415 South Beretania Street

POSITION: STRONG SUPPORT SB 1473 SD2.

Dearest Chairs, Honorable Representative John M. Mizuno, Honorable Representative Della Au Belatti, Vice Chairs, Honorable Representative Terez, Honorable Representative Jenna Takenouchi, Human Services Committee, and Health and Homelessness Committee Members.

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 <u>STRONG SUPPORT of SB 1473 SD2 with a humble</u> request for an amendment to include FASD coverage under Medicaid.

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.

SB1473 SD2, which requires the Department of Health and Department of Human Services to develop and adopt rules, policies, and plan amendments necessary to ensure that the state Medicaid programs cover medically—needed services for individuals aged twenty-one and older with neurodevelopment disorders, including Fetal Alcohol Spectrum Disorder or FASD, a population who currently without any available services. I support creating access to medically necessary services across the lifespan. In our state, MedQUEST beneficiaries under the age of 21 with an autism diagnosis can access their medically necessary services through their health plan, while FASD has none. This bill would ensure that FASD individuals aged 21 and over could access medically necessary services. Further, this bill would create parity for QUEST beneficiaries.

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.** 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 <u>https://www.apa.org/monitor/2022/07/news-fetal-alcohol-</u>syndrome#:~:text=Experts%20estimate%20that%202%25%20to,growth%2C%20behavior%2C%20and

syndrome#:~:text=Experts%20estimate%20that%202%25%20to,growth%2C%20behavior%2C%20 %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). <u>https://doi.org/10.1176/appi.pn.2018.3a8</u>

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



Committee on Human Services Committee on Health and Homelessness

> Tuesday, March 21, 2023 9:00 am VIA VIDEOCONFERENCE Conference Room 329 State Capitol 415 South Beretania Street

SUPPORT SB1473 SD2 RELATING TO HEALTH

Honorable Chairs Mizuno and Belatti, Vice Chairs Amato and Takenouchi, and Members of the Committees:

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, which requires the Department of Health and Department of Human Services to develop and adopt rules, policies, and plan amendments necessary to ensure that the state Medicaid programs covers medically necessary services, including applied behavior analysis (ABA) services, for individuals aged twenty-one and older with neurodevelopment disorders, including autism spectrum disorder.

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.

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 coverage of ABA.

The Council of Autism Service Providers (CASP) is a nonprofit organization that publishes the generally accepted standards of care for medically necessary ABA—<u>Applied Behavior Analysis: Treatment of</u> <u>Autism Spectrum Disorder Practice Guidelines for Healthcare Funders and Managers</u> 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).

In light of testimony submitted in prior hearings, 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 metanalyses, 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 <u>Insurance Coverage of</u> <u>Applied Behavior Analysis for Adults with Autism: A Review of the Evidence</u>. 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 <u>National Standards Project</u>, <u>Phase 2: Addressing the</u> <u>need for evidence-based practice guidelines for autism spectrum disorder</u>. 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.

The ABA Coding Coalition's publication, <u>Model Coverage Policy for Adaptive Behavior</u> <u>Services</u> 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.

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,

1*08*000

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

Submitted on: 3/17/2023 12:38:54 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kelly McCloskey	НАВА	Support	Written Testimony Only

Comments:

I am writing to support the Medquest 21+ bill as a person who lives on an outer island where we have little resources available for adults with disabilies. ABA should be made accessable and financially available through isurace funding for all who need it.

Submitted on: 3/17/2023 2:51:18 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Pamela Wood	BAYADA Behavioral Analysis	Support	Written Testimony Only

Comments:

I support this bill related to coverage for individuals aged 21+ to receive ABA services through their QUEST health plan. Currently, adults in our state with QUEST are not able to access medically necessary services.



March 20, 2023

Re: SB1473 SD2

Medicaid; Coverage; Autism Spectrum Disorder; Applied Behavior Analysis; Department of Health; Department of Human Services

I write to you today on behalf of The Council of Autism Service Providers (CASP) in support of SB1473 SD2. CASP is a non-profit association of organizations committed to providing evidence-based care to individuals with autism. CASP represents the autism provider community to the nation at large, including government, payers, and the general public. We provide information and education and promote standards that enhance quality of care.

Of particular interest to our members is the coverage of evidence-based care in both private health insurance plans as well as through Medicaid.

The State of Hawaii took an important step in 2015, when it passed legislation requiring coverage of medically necessary care for ASD. Since then, individuals diagnosed with ASD have had access to meaningful interventions, reducing their need for special education services, improving their quality of life, and opening doors for further education and employment.

We appreciate your thoughtful consideration of the critical need for access to applied behavior analysis for Hawaiians of all ages. Coverage by not only private health insurance plans, but also Medicaid will ensure best practice availability across the lifespan. The Centers for Disease Control estimates that 1 in 44 people are diagnosed with autism spectrum disorder and that:

Fewer young people with ASD have the same opportunities as their peers without ASD.

High rates of unemployment or under-employment ^[1-7] Low participation in education beyond high school ^[4, 7, 8] Majority continue to live with family members or relatives [1.9]

Limited opportunity for community or social activities—nearly 40% spend little or no time with friends [6, 10-12]

In addition, individuals with ASD may experience changes in their ASD symptoms, behaviors, and co-occurring health conditions during adolescence and young adulthood. These changes can affect their ability to function and participate in the community.¹

Generally accepted standards² of care specific to medically necessary treatments for individuals diagnosed with an autism spectrum disorder indicate that although:

There is evidence that the earlier treatment begins, the greater the likelihood of positive longterm outcomes.

Treatment should be based on the clinical needs of the individual and not constrained by age. Consistent ABA treatment should be provided as soon as possible after diagnosis, and in some cases, services are warranted prior to diagnosis. There is evidence that the earlier treatment begins, the greater the likelihood of positive long-term outcomes. Additionally, ABA is effective across the life span. Research has not established an age limit beyond which ABA is ineffective.

We wholeheartedly support <u>SB1473 SD2</u> and ask for your favorable passage of it today. Should you need any additional information. Please do not hesitate to contact me.

Respectfully,

Judith Wroth

Judith Ursitti Vice President of Government Affairs

¹ <u>https://www.cdc.gov/ncbddd/autism/autism-spectrum-disorder-in-teenagers-adults.html</u>

² Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers (2nd ed.)

DATE: March 15, 2023

TO: Representative John Mizuno, Chair Representative Terez Amato, Vice-Chair Members of the Committee on Human Services

> Representative Della Au Belatti, Chair Representative Jenna Takenouchi, Vice-Chair Members oif the Committee on Health and Homelessness

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

RE: Hearing scheduled March 21, 2023

Writing in Support of SB1473 SD1, SD2 with amendment to include Fetal Alcohol Spectrum Disorders (FASD)

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.

My clients with or undiagnosed FASD and their families need support throughout the lifespan. With support, for 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. Prevention is far less costly than treatment. The cost of human suffering is immeasurable for those affected and their families.

Thank you for your support.

Submitted on: 3/15/2023 3:40:32 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Josliene Miller	Individual	Support	Written Testimony Only

Comments:

Providing access to medically necessary ABA for adults (21+) through their QUEST health plan is critical. Sadly, adults in our state currently can only access ABA through their health plan if they pay privately for their insurance and cannot access ABA through their QUEST health plan. I'm advocating to change this!

Submitted on: 3/15/2023 3:42:47 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Rachel Miller	Individual	Support	Written Testimony Only

Comments:

As an individual who has worked with individuals with autism and other developmental disabilities in Hawaii for the past 10+ years, I'm submitting testimony in support of this bill.

<u>SB-1473-SD-2</u>

Submitted on: 3/15/2023 3:58:36 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Tiffany Hankins	Individual	Support	Written Testimony Only

Comments:

I am in support of this bill as it will provide increased opurtunity for adult inviduals diagnosis with disabilites in our community to recive medically necessary ABA services. Individuals of all ages are impacted by disabilites (such as Autism Spectrum Disorder which is treated with ABA therapy) and those impacted deserve equal opputunity to obtain services. The neighboring islands of Hawaii are currenly experiencing a deficit in services of adults diagnosed with Austism Spectrum Disorder.

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 4:08:20 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Emily Henderson	Individual	Support	In Person

Comments:

I support SB1473

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 4:37:11 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Deborah Krekel	Individual	Support	Written Testimony Only

Comments:

Dear Legislative Committee Members,

I am in support of requiring the Department of Health and Department of Human Services to apply for any necessary approvals from the Centers for Medicare and Medicaid Services to amend the state Medicaid plan to provide reimbursements for medically necessary services, including applied behavior analysis services to Medicaid-eligible individuals over the age of twenty-one diagnosed with autism spectrum disorder.

As a parent of an autistic teenager I have seen first hand the positive results of having access to medically necessary applied behavior analysis services over the years. Because of his access to ABA my son will have a greater chance to become as an adult a contributing member of his community. I also know as a parent and a professional licensed behavior analyst there are many families who require services beyond the age of twenty-one to have equal opportunities to be as independent as possible and live and work in our community. This is why this bill is important! Please give ALL families and adults over the age of 21 a chance to have the meaningful lives they deserve by supporting extending the access to medically necessary applied behavior analysis for Medicare/Medicaid recipients.

Thank for the opportunity to testify on this bill!

Sincerely,

Deborah Krekel MSCP, BCBA, LBA

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 4:57:01 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Deborah Ho'ohuli	Individual	Support	Written Testimony Only

Comments:

I support SB1473 SD2

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 5:00:07 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Karen Baker	Individual	Support	Written Testimony Only

Comments:

Aloha. I am writing in support of SB1473. I am aware of many families in Hawaii who are currently receiving ABA treatment through QUEST. It is my belief that many of the individuals who are receiving this care will continue to benefit and make progress if their treatment extends beyond the age of 21. It is always my hope that children receive needed services and that some day they will graduate from those services and can live a more independent life. The reality is that there are some individuals who are over the age of 21 who still need and can benefit from services which helps not only the individual, but also their family members and the rest of the community.

Thank you for your consideration of this legislation that would provide access to medically necessary ABA treatment for adults (21+).

Submitted on: 3/15/2023 6:13:00 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Mr and Mrs John McComas	Individual	Support	Written Testimony Only

Comments:

Dear Chair Belatti,

We strongly support the passing of SB1473 to assure for medically necessary supports that includes Applied Behavior Analysis be covered under Medicaid, for adults with disabilities over the age of 21.

Respectfully Yours,

John and Maureen McComas

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 6:51:23 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Jenifer Olin	Individual	Support	Written Testimony Only

Comments:

I support the bill

Submitted on: 3/15/2023 8:13:37 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Joe Dalessandro	Individual	Support	Written Testimony Only

Comments:

As a parent of a disabled adult child with autism and a former member of the Maui county commission on persons with disabilities I know how difficult it is to get services for our developmentally disabled loved ones due to insufficient reimbursement rates. As parents like us age we can no longer support or take care of our disabled adult chuldren. The state needs to support the most vulnerable among us which is the Dias led community. Please feel free to contact me if you need any info on my family's experience with taking care of a disabled adult child. Mahalo.

<u>SB-1473-SD-2</u> Submitted on: 3/15/2023 8:33:44 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Michael Fredeluces	Individual	Support	Written Testimony Only

Comments:

I would like to support SB1473 SD2. In the behavior health community focusing on individuals under the age of 21, many receive much support for their medically diagnosed deficit of Autism Spectrum Disorder, however once these young adults turn the age of 21, to no fault of their own, they lose access to needed funding to continue with their treatments. By turning the age 21, that does not mean that they overcome their Autism, but they lose support needed to be integrated into our everyday lives. In my line of work as a case manager helping families through the insurance system, it breaks my heart when I would have to inform a family that I can no longer help them after they "age out" of the coverage. I am then met with the one question I can never answer, "what do we do now or when that time comes?" Affording access to ABA services to this population of adults, I believe is the right thing to do to properly care for them. Mahalo for your time.

<u>SB-1473-SD-2</u> Submitted on: 3/16/2023 7:58:46 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kristian Guynes	Individual	Support	Written Testimony Only

Comments:

ABA services for adults (21+) should be made available to all those that need services. Our state does a great job at supporting children that need ABA services, but neglect those same individuals when they become an adult. Currently, adults can only access these services through their health plan if they pay privately for their insurance and cannot access ABA through their Quest health plan. As you know, private pay medical is not financially reasonable and I don't feel that ABA services should only be accessible for those that can afford these services. I have first handedly seen the power of ABA. Children who were once aggressive or highly behavioral received the necessary ABA services and have drastically progressed for the better. Some individuals take longer than others to progress, so I don't feel it's right to strip them of these services as they get older. Individuals needing ABA are also a hardship on families if they don't get the necessary services. With necessary ABA, some individuals are able to live fulfilling lives without needing 24/7 care. This bill would be in the best interest of our state and community.

<u>SB-1473-SD-2</u> Submitted on: 3/16/2023 8:07:58 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Leslie Allison Schurtz	Individual	Support	Written Testimony Only

Comments:

In support of older learners and adults accessing services they need without the out of pocket cost they currently incure with their private insurance.

<u>SB-1473-SD-2</u> Submitted on: 3/16/2023 8:38:42 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kristina Brown	Individual	Support	Written Testimony Only

Comments:

I am in support of this bill, everyone should have access to ABA!

Submitted on: 3/16/2023 8:45:39 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Andrea	Individual	Support	Written Testimony Only

Comments:

As someone that's worked for the state, DOE, and a health care company, I've heard and seen many individuals struggle to get services for their children, parents, and even themselves. I know too many people that turn down services all together due to it not being affordable because it's not covered. QUEST allows many people to receive services they need without taking a hit to their bank account. Have these types of services to be covered by QUEST, even if just a portion of the cost, wil make the biggest impact. It's a step in the right direction of helping provide for our people. It's expensive enough to live here in Hawai`i, every bit of help will make a difference. If we can prevent financial hardships for services that can directly impact our livelihood, then what's stopping us.

<u>SB-1473-SD-2</u> Submitted on: 3/16/2023 9:18:12 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Jason J Stauffer	Individual	Support	Written Testimony Only

Comments:

I support this bill that would allow indviduals to continue to receive medically necessary support services to increase their quality of life.

Submitted on: 3/16/2023 10:52:36 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Alohalyn R Espejo	Individual	Support	Written Testimony Only

Comments:

It's sad that adults in our state currently can only access ABA through their health plan if they pay provately for their insurance and cannot access ABA through their QUEST health plan!

<u>SB-1473-SD-2</u> Submitted on: 3/16/2023 11:14:02 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kenichi Yabusaki	Individual	Support	Written Testimony Only

Comments:

Dear Chair Mizuno, Vice-chair Belatii, Members of the Human Services Committee, Chair Belatti, Vice-chair Takenouchi, and Members of the Health and Homelessness Committee:

I fully support the hearing/passage of SB1473 SD2 as it relates to providing Medicaid services to the Developmentally Disabled(DD), which comes from appropriate funding desperately needed for this population which is overlooked. Although Autism Spectrum Disorders are mentioned in the above Bill, I strongly urge the addition of Fetal Alcohol Spectrum Disorders (FASD) to SB1473 SD2 because those affected by FASD exceed the number of those affected by Autism, Spina Bifida, Cerebral Palsy, and Downs Syndrome combined. The State of Hawaii needs to ensure all those that fit the category of DD qualify for the specific services they need. Please amend SB1473 SD2 to include those affected by FASD as an estimated 900 individuals are affected by FASD yearly in Hawaii alone. To this end, I humbly ask for your to pass SB1473 SD2

Respectfully submitted

Kenichi Yabusaki, Ph.D.

Submitted on: 3/16/2023 3:30:35 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Andrew Torres	Individual	Support	Written Testimony Only

Comments:

Strongly support this bill, as this will help ABA providers serve large populations of adults in need of medically necessary services, ranging from vocational training, independence, daily living skills, and much more.

Submitted on: 3/16/2023 3:55:26 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Susan Oka	Individual	Comments	Written Testimony Only

Comments:

Dear Representative Della Au Belatti, Chair and Representative Jeanna Takenouchi, Vice Chair,

I ask you to please amend this bill to include FASD (Fetal Alcohol Spectrum Disorder).

Thank you,

Susan Oka

Submitted on: 3/17/2023 9:02:04 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Melissa Tamashiro	Individual	Support	Written Testimony Only

Comments:

I have worked with individuals diagnosed with autism since 2005. Thinking of my severely impacted clients not receiving support is heartbreaking. I have seen parents worry and struggle with the thought of their services ending services they desperately need. Behavior challenges do not disappear when the client turns 21. Let's provide these families with the compassion and care that they need.

Submitted on: 3/17/2023 9:40:20 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Anastasia Keller-Collins	Individual	Support	Written Testimony Only

Comments:

Thank you very much for understanding the grave need for ABA services that individuals with autism contine to require past the age of 21. Autism is a life-long disability and ABA has proven scientific results as a health care intervetion to give people skills needed to be more independent. In our efforts to support these individuals, assists all of us as community to pay "less" later.

Submitted on: 3/17/2023 10:02:55 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Jari S.K. Sugano	Individual	Support	Written Testimony Only

Comments:

Chairs Mizuno & Au Bellatti, Vice Chairs Amato & Takenouchi and members of the House Health and Homelessness and Human Services,

My name is Jari Sugano and I have two children with Autism and other special needs. Applied behavior analysis is a critical and proven data driven approach to assisting those with behavior issues. Extending the period of time for qualified services under Quest would help many local families. These services are hard to access in the public education setting for children with behavioral needs.

I strongly support SB1473.

Submitted on: 3/17/2023 11:20:21 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kristen Koba-Burdt	Individual	Support	Written Testimony Only

Comments:

Thank you for the opportunity to submit testimony in support of SB1473 SD2 focused on creating access to medically necessary applied behavior analysis (ABA) services for Med-QUEST beneficiaries age 21+. As a longtime service provider for adults with autism and other neurodevelopmental disorders, there is a significant need for access to these medically necessary services. Our state has historically struggled to meet the needs of this population through the DOE and was one of the last states to pass autism insurance reform. As a result, numerous children went without the needed behavioral supports when they were young, creating a bigger need for these services now for adults.

The DOH-DDD waiver program provides some needed services but does not address access to medically necessary ABA for those with the most significant needs, such as challenging behaviors of self-injury or other behaviors that jeopardize the safety and welfare of the individual and their caregivers. Too often families report not being able to access the level of care that they need for their adult dependents and feel at a loss when their child ages out of DOE with no resources to turn to.

Additionally, adults with private insurance coverage can already access these services through their health plan, creating a mental health parity issue for those with QUEST unable to access care.

Thank you,

Kristen Koba-Burdt, BCBA, LBA, CDP

Maui

Submitted on: 3/17/2023 11:26:55 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Naomi Tachera	Individual	Support	Written Testimony Only

Comments:

Aloha Legislators,

Please support SB1473 for coverage of individuals aged 21+ to receive ABA services through their QUEST health plan. The adults in Hawai'i with Intellectual and Developmental Disabilities with QUEST need access to medically necessary services.

Mahalo,

Naomi Tachera

Submitted on: 3/17/2023 11:28:28 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Brian Burdt	Individual	Support	Written Testimony Only

Comments:

As a former DOH-DDD waiver provider for adult services, I strongly support this bill which would provide access to medically-necessary services, including applied behavior analysis (ABA), for individuals aged 21+ with neurodevelopmental disorders, including autism under Med-QUEST.

<u>SB-1473-SD-2</u> Submitted on: 3/17/2023 11:49:26 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Marija Colic	Individual	Support	Written Testimony Only

Comments:

Please support the bill!! The individuals aged 21+ have rights to receive ABA services through their QUEST health plan!!

Submitted on: 3/17/2023 12:02:31 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Erin Walters	Individual	Support	Written Testimony Only

Comments:

SB1473 is incredibly important to me. Working as a behavior analyst since 2015, I have seen a significant need for services for adult clients. Currently providing services in school where students no longer qualify for special education services at the age of 22 and will no longer qualify for insurance funded ABA services before that, there is a need for adults with special needs to continue learning vital life skills to increase their independence and access meaningful community benefits. I support SB1473 because adults continue to require support and access to services that will help them lead more independent lives. Behavior reduction/replacement behaviors, vocational, self-help, adaptive and independent living skills, and social skills are skills that everyone should have access to learn to improve their and their families lives.

<u>SB-1473-SD-2</u> Submitted on: 3/17/2023 1:04:06 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Amanda Bolgren	Individual	Support	Written Testimony Only

Comments:

As a provider of ABA, the continued benefits the adult population would receive through accessing ABA outweighs current programs available.

<u>SB-1473-SD-2</u> Submitted on: 3/17/2023 9:07:11 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Siyuan Wang	Individual	Support	Written Testimony Only

Comments:

I support to have coverage for individuals aged 21+ to receive ABA services through their QUEST health plan.

Submitted on: 3/18/2023 7:30:13 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Shauna Paul	Individual	Support	Written Testimony Only

Comments:

As a practicing BCBA in the state of Hawaii I am in support of this bill as applied behaivor analysis is the only evidenced based treatment for individuals with autism. There are many programs available for individuals birth-20, however, so often families and individuals lose support when they age out. This bill would help with that.

Sincerely

Shauna Paul

<u>SB-1473-SD-2</u> Submitted on: 3/18/2023 1:44:40 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Mike Ching	Individual	Support	Written Testimony Only

Comments:

I support SB1473, SD2 with the following amendment: To add Fetal Alcohol Sepectrum Disorder (FASD) to be included with Autism in this measure.

The bill requires the Department of Health (DOH) and DHS to develop and adopt rules, policies, and state plan amendments necessary to ensure that the state Medicaid program covers medically necessary services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder. Requires the DOH and DHS to apply for any necessary approvals from the Centers for Medicare and Medicaid Services to amend the state Medicaid plan to provide reimbursements for medically necessary services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder.

By including FASD this will more fairly represent the disabilites which should be covered by this bill.

<u>SB-1473-SD-2</u> Submitted on: 3/19/2023 5:07:30 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kathleen Penland	Individual	Support	Written Testimony Only

Comments:

Aloha,

Our adults deserve quality care. We cannot continue to abandon this vulnerable and important part of our community. I support SB1473.

Best,

Kathleen Penland, M. Ed., BCBA

<u>SB-1473-SD-2</u> Submitted on: 3/19/2023 6:00:08 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Alison Kaneshiro	Individual	Support	Written Testimony Only

Comments:

Health disparities in certain racial and ethnic groups, those living in poverty, and those in rural settings are compounded for those with intellectual and developmental disabilities (I/DD) such as downs syndrome and autism. Mortality rates of adults with IDD are higher than the general population with many of these deaths being preventable with appropriate health care (Franklin, et al., 2022). With improved access to Medicaid insurance coverage, access to needed care can increase and lessen disparities in care here in Hawaii.

Reference

Franklin, M. S., Bush, C., Jones, K. A., Davis, N. O., French, A., Howard, J., Greiner, M. A., & Maslow, G. R. (2022). Inequities in receipt of the North Carolina Medicaid waiver among individuals with intellectual disability or autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, 43(7), 393–401. <u>https://doi.org/10.1097/DBP.000000000001075</u>

<u>SB-1473-SD-2</u> Submitted on: 3/20/2023 3:19:22 AM Testimony for HUS on 3/21/2023 9:00:00 AM

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

Comments:

Aloha Rep. John M. Mizuno, Chair, Rep. Terez Amato, Vice Chair, and Members of the Committee on Human Services,

Rep. Della Au Belatti, Chair, Rep. Jenna Takenouchi, Vice Chair, and Members of the Committee on Health & Human Services,

Testimony In Support

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).

Hawaii 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 SD2** and to request the Committees change the effective date to effective upon its approval.

Submitted on: 3/20/2023 8:18:34 AM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Melody Mann	Individual	Support	Written Testimony Only

Comments:

ABA services are essential and empericially proven to benefit student users. I support this bill for clients to recieve ABA services through their QUEST health plan.

Submitted on: 3/20/2023 7:18:22 PM Testimony for HUS on 3/21/2023 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Kaitlin Preciado	Individual	Support	Written Testimony Only

Comments:

Applied Behavior Analysis services extend far into one's lifespan, and a disability not simply end at the age of 21. Individuals within medicaid need guidelines and support to continue guidance for young adults with diabilities to continue to live a long and properous life per scientific backing.