

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 February 15, 2023

The Honorable Senator Joy A. San Buenaventura, Chair Senate Committee on Health and Human Services The Thirty-Second Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Senator San Buenaventura and Committee Members:

SUBJECT: SB1473 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS SB1473**, 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—needed 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, including applied behavior analysis services, for individuals state medicaid plan to provide reimbursements for medically—needed services, including applied behavior analysis services, for individuals aged twenty—one and older with neurodevelopmental disorder.

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.

Sincerely,

Daintry Bartoldus Executive Administrator

<u>SB-1473</u> Submitted on: 2/11/2023 4:03:09 PM Testimony for HHS on 2/15/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Support	In Person

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.



Committee on Health and Human Services

Wednesday, February 15, 2023 1:00 p.m. VIA VIDEOCONFERENCE Conference Room 225 State Capitol 415 South Beretania Street

SUPPORT SB1473 RELATING TO HEALTH

Chair San Buenaventura, Vice Chair Aquino, 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 **support** of SB1473, 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—needed 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 standards for coverage of ABA.

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 Council of Autism Service Providers (CASP) publication, <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).

Additionally, the ABA Coding Coalition's publication, <u>Model Coverage Policy for Adaptive Behavior</u> <u>Services</u> originally published in 2020 and revised in 20202, includes model health insurance coverage policy and a bibliography of research examples including adults.

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,

[JBADT

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



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 RELATING TO HEALTH

SENATOR JOY A. SAN BUENAVENTURA, CHAIR SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Hearing Date: 2/15/23

Room Number: 225

1 Department Testimony:

- 3 The Department of Health- Developmental Disabilities Division (DOH-DDD) operates Hawaii's
- 4 §1915(c) Medicaid Home and Community-Based Services Waiver for Individuals with
- 5 Intellectual and Developmental Disabilities (I/DD) on behalf of the Department of Human
- 6 Services-MedQUEST Division (DHS-MQD), which is the state Medicaid agency. DOH-DDD is
- 7 committed to quality medically necessary behavioral interventions.
- 8

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- 9 SB1473 requires the DOH and the DHS to develop and adopt rules, policies, and plan
- 10 amendments necessary to ensure that the state Medicaid program covers medically-needed
- 11 services, including applied behavior analysis (ABA) services, for individuals aged twenty-one
- 12 and older with neurodevelopmental disorders, including autism spectrum disorder (ASD).
- 13
- 14 SB1473 further requires the DOH and DHS to apply for any necessary approvals from the
- 15 Centers for Medicare and Medicaid Services (CMS) to amend the state Medicaid plan to provide
- 16 reimbursements for medically needed services, including ABA services, for individuals aged
- 17 twenty-one and older with neurodevelopmental disorders, including ASD.
- 18
- 19 The Council of Autism Service Providers (CASP) published ABA practice guidelines for ASD in
- 20 2014. The CASP guidelines were developed by the Behavior Analyst Certification Board

1	(BACB) and were intended to provide healthcare funders and managers with information to
2	guide decision-making about ABA treatment. The section on Client Age reports:
3	
4	"Treatment should be based on the clinical needs of the individual and not constrained by
5	age. Consistent ABA treatement should be provided as soon as possible after diagnosis,
6	and in some cases services are warranted prior to diagnosis. There is evidence that the
7	earlier treatment begins, the greater the likelihood of positive long-term outcomes.
8	Additionally, ABA is effective across the life span. Research has not established an age
9	limit beyond which ABA is ineffective."
10	
11	The CASP guidelines were clarified in February 2019 by the BACB:
12	
13	"Determinations as to whether ABA treatment should be focused or comprehensive and
14	the intensity of treatment should be based on the medical necessity of the treatment for
15	each individual client rather than the client's chronolocal age, duration or nature of
16	previous ABA services, or the like."
17	
18	The rationale that "research has not established an age limit beyond which ABA is ineffective" is
19	problematic in that it suggests widespread application of a treatment without a requirement to
20	demonstrate efficacy in the population(s) of interest. The CASP guidelines cite three studies
21	supporting the opinion that ABA may be effective for people of any age and varying diagnoses.
22	These publications state that "research into the effectiveness of such treatment has been scarce"
23	and "the relatively small numbers in our trial and the variance of the cost data mean, however,
24	that confirmation in larger studies of service provision is required". These larger peer reviewed
25	studies that meet scientific criteria for establishment of treatment recommendations have not
26	been conducted. Evidence-based, peer-reviewed research into the effectiveness of ABA
27	treatment in adults has been scarce and lacks the scientific rigor required for widespread
28	acceptance as a standard of care practice across the lifespan. As a result, adoption of clinical
29	practice guidelines and authorization for ABA across all ages and neurodevelopmental diagnoses

has not been realized. Adults with autism and other neurodevelopmental disorders have received 1 2 ABA on a case-by-case basis with varied results. Clinical guidelines and policy should not accept a practice standard based on a few studies of limited scope and size as they may not 3 represent the population. Furthermore, there are a growing number of peer reviewed publications 4 suggesting ABA may be harmful and have negative outcomes for some individuals with ASD. 5 6 Medical necessity and clinical practice guidelines are developed for selected therapeutic or diagnostic services found to be safe and proven effective in a limited, defined population of 7 patients or clinical circumstances. Medical necessity guidelines have not been established by 8 Medicaid for the use of ABA treatment in adults with autism or other neurodevelopmental 9 10 disorders.

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Peer reviewed, evidence-based, clinical practice guidelines have been established for the application of ABA for children (Hyman et al, 2020). On January 13, 2023, MQD released a memo updating coverage for ABA in children. The memo discusses CMS guidance clarifying Medicaid coverage for children with ASD pursuant to section 1905(a) of the Social Security Act (the Act) for the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. Under this section of the Act, state Medicaid programs must cover medically necessary services for members under 21 years of age, including those with ASD.

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SB1473 requires the development of rules, policies, and state plans for individuals diagnosed 20 21 with all neurodevelopmental disorders, not just autism spectrum disorder. SB1473 does not clarify the scope of diagnoses that constitute a neurodevelopmental disorder. This considerably 22 23 broadens a review and adoption of coverage as there is insufficient evidence suggesting effectiveness of ABA for people diagnosed with the wide array of neurodevelopmental disorders. 24 25 For example, the efficacy of ABA for individuals diagnosed with the most prevalent neurodevelopmental disorders such as attention-deficit/hyperactivity disorder (ADHD), 26 27 developmental language disorder, traumatic brain injury, dyslexia and other learning disabilities, tic disorders, intellectual disability, neurogenetic disorders such as Down syndrome, and 28 29 movement disorders such as cerebral palsy has not been demonstrated. Given the lack of

1	scientific evidence showing benefit in each of these categories and conditions, it is premature to
2	determine ABA as a therapeutic necessity applicable to all neurodevelopmental disorders.
3	
4	DOH defers to DHS regarding any precedence of CMS approving ABA services for adults.
5	
6	References:
7	1. MQD MEMO NOS QI-2301 and FFS-23-01: <u>https://medquest.hawaii.gov/en/plans-</u>
8	providers/provider-memo.html
9 10	2. Hyman SL, Levy SE, Myers SM, AAP COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Identification,
11	Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics.
12	2020;145(1):e20193447
13	3. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://casproviders.org/wp-
14	content/uploads/2020/03/ABA-ASD-Practice-Guidelines.pdf
15	content aproads/2020/05/ADA-ASD-1 factice-Outdennes.pdf
16	Fiscal Implications:
17	DOH defers to DHS-MQD regarding analysis of the funding required to implement the proposed
18	legislation, but believes it would have considerable cost impact for the state.
19	
20	Offered Amendments: None.
21	
22	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

February 14, 2023

TO: The Honorable Senator Joy A. San Buenaventura, Chair Senate Committee on Health & Human Services

FROM: Cathy Betts, Director

SUBJECT: <u>SB 1473</u> – RELATING TO HEALTH.

Hearing: February 15, 2023, 1:00 p.m. Conference Room 225 & Videoconferencing, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) offers comments and requests an amendment. DHS also defers to the Department of Health.

PURPOSE: The bill's purpose 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—needed 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—needed services, including applied behavior analysis services, for individuals aged twenty—one and older with neurodevelopmental disorders, including autism spectrum disorder.

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

Page 2

conditions, such as autism. Applied Behavioral Analysis (ABA) and other medically necessary services for individuals under 21 are included as part of the Early Periodic Screening, Diagnostic, and Treatment (EPSDT) Medicaid benefit. ABA is most effective for younger ages with mild to moderate autism, with marginal effectiveness in improving health outcomes – the medical necessity standard – for most older individuals or individuals with severe autism. ABA may be clinically effective for other neurodevelopmental disorders besides autism spectrum disorders; however, it is not clinically effective for all individuals with autism or other neurodevelopmental conditions. Therefore, 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. However, given the broad parameters of both diagnoses and treatments, it will take an extended time to research, analyze, adopt rules if and when necessary, and amend the Medicaid State Plan, if needed.

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." Similar to the prior rules and policies, the broad nature of the expansion will likely require a large appropriation. For this reason, we request that the fiscal impact be determined, and that any appropriation is allocated before implementing changes to rules or the Medicaid State Plan. For the Committee's information, if there is no general fund appropriation and DHS prepares a State Plan Amendment and the Centers for Medicare & Medicaid Services approves it, those services will have to be provided, and other existing services will have to be reduced or limited to pay for the added services.

We would note that for the purposes of our testimony, we are interpreting the term "medically-needed" to be synonymous with "medically necessary" or "medical necessity," the latter two being the terminology used for the Medicaid standard. For clarity, we would request that the bill be amended to use the standard "medically necessary" terminology.

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

<u>SB-1473</u> Submitted on: 2/14/2023 1:33:14 PM Testimony for HHS on 2/15/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Linda Elento	Individual	Support	In Person

Comments:

Aloha Chair San Buenaventura, Vice Chair Aquino, and Members of the Senate Committee on Health and Human Services,

To continue the Senate's efforts in adopting SR114SD1 (2022), I support SB1473 for Medicaid to provide continued medically-needed Applied Behavior Analysis (ABA) services to individuals who turn 21, with providers such as state licensed behavior analysts and state registered behavior technicians.

Individuals and their families, teachers and employers struggle if a 21-year-old cannot access medically-necessary ABA services, as well as disabled special education students who remain in the DOE system until age 22 (Medicaid could then still be billed by the DOE).

Unfortunately HCBS Waiver put together an unequal ABA type of service and providers have not been available, refer to the DHS March 21, 2022 testimony and comments for SR114:

"The waiver services for individuals with Intellectual/Developmental Disabilities are delivered by the Department of Health's Developmental Disabilities Division. While they do not provide Applied Behavioral Analysis (ABA) per se, similar services are provided to individuals who are 21 and older."

https://www.capitol.hawaii.gov/session/archives/measure_indiv_Archives.aspx?billtype=SR&bil lnumber=114&year=2022

In December 2022, DDD case management reported that contracted providers report they do not have Registered Behavior Technicians (RBT) for Medicaid DD Waiver Program (not quite the same ABA service) yet they have staffing for ABA through private insurance and DOE clients. For example, no RBTs have been available on Oahu for an individual for over a year, hindering progress previously made and school, volunteer, work and social opportunities.

I do not believe we need a task force or lengthy study proposed in other bills for Medicaid funding, but a decision to move forward with ABA included in the Medicaid funding bills and to

provide ABA services as my 22-year-old had before he turned 21, which are medicallynecessary and allowed under the federal Medicaid laws.

Judge Rules Medicaid Age Limit for People with Autism Is Discriminatory (Taken from https://www.mjcattorneys.com/media/2021/july/judge-rules-medicaid-age-limit-for-people-with-a/)

By Massillamany, Jeter & Carson LLP | July 01, 2021 (Indiana)

State Residents Age 21+ with Autism Can Receive Medicaid Benefits for ABA Therapy

"The court concluded that the age restriction unlawfully denies access to medically necessary services for individuals age 21+ who have autism, in violation of the Americans with Disabilities Act."

Thank you for your Committee's consideration of SB1473 and of the needs of our family and this population in our communities across the islands.

Linda Elento, Hawaii citizen.

<u>SB-1473</u> Submitted on: 2/10/2023 2:02:49 PM Testimony for HHS on 2/15/2023 1:00:00 PM

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

Comments:

Dear Members of the Senate Health and Human Services Committee:

I fully support SB1473 to provide Medicaid services to those individuals affected by a neurodevelopmental disability. Services to individuals affected by not only Fetal Alcohol Spectrum Disorder (FASD), autism, etc. should not terminate at age 22, but the above conditions are permanent Brain conditions and life-long. By providing the services as related to SB1473, beyond the age of 22 will allow these individuals to have a fighting chance to become productive members of our society. Please pass SB 1473 and make the world possible for those born into an impossible world.

Sincerely,

Kenichi Yabusaki, Ph.D.

Dear Senator San Buenaventura, Chair, Senator Aquino, Vice Chair, and members of the Health and Human Services Committee:

I am writing in full support of SB1473 and urge that it be amended 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.

I am a psychologist with clients and families affected by the effects of prenatal alcohol exposure. 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.

Thank you for your consideration.

Ann S. Yabusaki, PhD

<u>SB-1473</u> Submitted on: 2/14/2023 8:52:55 AM Testimony for HHS on 2/15/2023 1:00:00 PM

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

Comments:

I support SB1473 for Med-QUEST coverage of medically necessary applied behavior analysis (ABA) services for adults. As a longtime provider for adult services on Maui, I can personally attest that this is a needed service and the significant behavioral needs for this population too often go unmet, or when addressed by the DOH-DDD waiver come with a significant cost to the state. Adults with autism and significant behavioral needs need to be able to access medically necessary services through their health plan, in coordination with other home and community-based supports offered through the waiver. Currenlty in our state, those with private insurance are able to access their medically necessary ABA services, while QUEST beneficiaries are left behind, creating a mental health parity issue for QUEST members.

I respectfully request this committee pass this bill.