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 27, 2023

TO: The Honorable Senator Jarrett Keohokalole, Chair Senate Committee on Commerce & Consumer Protection

The Honorable Senator Donovan Dela Cruz, Chair Senate Committee on Ways & Means

FROM: Cathy Betts, Director

SUBJECT: SB 1473 SD1 – RELATING TO HEALTH.

Hearing: March 1, 2023, 9:30 a.m. Conference Room 225 & Videoconferencing, State Capitol

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

PURPOSE: 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. Appropriates funds. (SD1) 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.

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. 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 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.

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. 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.

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 SD1 RELATING TO HEALTH

SENATOR JARRETT KEOHOKALOLE, CHAIR SENATE COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

SENATOR DONOVAN M. DELA CRUZ, CHAIR SENATE COMMITTEE ON WAYS AND MEANS

Hearing Date: 3/1/23

Room Number: 211

1 Department Testimony:

2 SB1473 requires the Department of Health (DOH) and the Department of Human Services (DHS) to develop and adopt rules, policies, and plan amendments necessary to ensure 3 4 that the state Medicaid program covers medically necessary services, including applied behavior analysis (ABA) services, for individuals aged twenty-one and older with neurodevelopmental 5 disorders, including autism spectrum disorder (ASD). 6 7 SB1473 further requires the DOH and DHS to apply for any necessary approvals from the Centers for Medicare and Medicaid Services (CMS) to amend the state Medicaid plan to 8 provide reimbursements for medically needed services, including ABA services to Medicaid-9 10 eligible individuals over twenty-one diagnosed with ASD. The DOH appreciates the intent of providing medically necessary supports and services 11 12 to adults with autism, and offers the following comments: 13 The Developmental Disabilities Division (DDD) operates Hawaii's Medicaid §1915(c) 14 Home and Community-Based Services (HCBS) Waiver for Individuals with Intellectual and Developmental Disabilities (I/DD) on behalf of the DHS-MedQUEST Division (DHS-MQD), 15 16 the state Medicaid agency. DOH-DDD serves many adults with autism who meet §1915(c) 17 HCBS waiver eligibility providing an array of services in people's homes and in the community. Based on our review of the literature, there is a lack of evidence to provide strong practice 18

| 1 | recommendations that ABA services are effective in treating the population of adults with |
|----------|---|
| 2 | neurodevelopmental disorders. |
| 3 | We would point out that the Council of Autism Service Providers (CASP) published |
| 4 | ABA practice guidelines for ASD in 2014. The CASP guidelines were developed by the |
| 5 | Behavior Analyst Certification Board (BACB) and were intended to provide healthcare funders |
| 6 | and managers with information to guide decision-making about ABA treatment. The section on |
| 7 | Client Age reports: |
| 8 | |
| 9 | "Treatment should be based on the clinical needs of the individual and not constrained by |
| 10 | age. Consistent ABA treatment should be provided as soon as possible after diagnosis, |
| 11 | and in some cases services are warranted prior to diagnosis. There is evidence that the |
| 12 | earlier treatment begins, the greater the likelihood of positive long-term outcomes. |
| 13 | Additionally, ABA is effective across the life span. Research has not established an age |
| 14 | limit beyond which ABA is ineffective." |
| 15 | |
| 16 17 | The CASP guidelines were clarified in February 2019 by the BACB: |
| 18 | "Determinations as to whether ABA treatment should be focused or comprehensive and |
| 19 | the intensity of treatment should be based on the medical necessity of the treatment for |
| 20 | each individual client rather than the client's chronolocal age, duration or nature of |
| 21 | previous ABA services, or the like." |
| 22 | |
| 23 | The rationale that "research has not established an age limit beyond which ABA is |
| 24 | ineffective" is problematic in that it suggests widespread application of a treatment without a |
| 25 | requirement to demonstrate efficacy in the population(s) of interest. The CASP guidelines cite |
| 26 | three studies supporting the opinion that ABA may be effective for people of any age and |
| 27 | varying diagnoses. These publications state that "research into the effectiveness of such |
| 28 | treatment has been scarce" and "the relatively small numbers in our trial and the variance of the |
| 29 | cost data mean, however, that confirmation in larger studies of service provision is required". |
| 30 | The large peer reviewed studies that are necessary to meet scientific criteria for establishment of |
| 31 | strong treatment recommendations have not been conducted. Evidence-based, peer-reviewed |

research into the effectiveness of ABA treatment in adults has been scarce and lacks the 1 2 scientific rigor required for widespread acceptance as a standard of care practice across the 3 lifespan. As a result, adoption of clinical practice guidelines and authorization for ABA across all 4 ages and neurodevelopmental diagnoses has not been realized. Adults with autism and other neurodevelopmental disorders have received ABA on a case-by-case basis with varied results. 5 6 Clinical guidelines and policy should not accept a practice standard based on a few studies of 7 limited scope and size as they may not represent the population. Furthermore, there are a 8 growing number of peer reviewed publications suggesting ABA may be harmful and have negative outcomes for some individuals with ASD. Medical necessity and clinical practice 9 guidelines are developed for selected therapeutic or diagnostic services found to be safe and 10 proven effective in a limited, defined population of patients or clinical circumstances. Medical 11 necessity guidelines have not been established by Medicaid for the use of ABA treatment in 12 adults with autism or other neurodevelopmental disorders. 13

SB1473 requires the development of rules, policies, and state plans for individuals 14 diagnosed with all neurodevelopmental disorders, not just autism spectrum disorder. SB1473 15 does not clarify the scope of diagnoses that constitute a neurodevelopmental disorder. This 16 considerably broadens a review and adoption of coverage as there is insufficient evidence 17 18 suggesting effectiveness of ABA for people diagnosed with the wide array of neurodevelopmental disorders. For example, the efficacy of ABA for individuals diagnosed with 19 the most prevalent neurodevelopmental disorders such as attention-deficit/hyperactivity disorder 20 21 (ADHD), developmental language disorder, traumatic brain injury, dyslexia and other learning 22 disabilities, tic disorders, intellectual disability, neurogenetic disorders such as Down syndrome, 23 and movement disorders such as cerebral palsy has not been demonstrated. Given the lack of 24 scientific evidence showing benefit in each of these categories and conditions, it is premature to 25 determine ABA as a therapeutic necessity applicable to all neurodevelopmental disorders.

It should be noted that DOH does not have the federal authority to apply for state plan amendments from CMS as DHS-MQD is the state Medicaid agency, and DOH also defers to DHS regarding likelihood of CMS approving ABA services for adults. If DOH and DHS were to adopt rules and polices to cover services without CMS approval, the state would likely be responsible for the entirety of the cost of services.

| 1 | References |
|---|------------|
| 1 | References |

| 2 | 1. | MQD MEMO NOS QI-2301 and FFS-23-01: https://medquest.hawaii.gov/en/plans- |
|----|--------|---|
| 3 | | providers/provider-memo.html |
| 4 | 2. | Hyman SL, Levy SE, Myers SM, AAP COUNCIL ON CHILDREN WITH DISABILITIES, |
| 5 | | SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Identification, |
| 6 | | Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. |
| 7 | | 2020;145(1):e20193447 |
| 8 | 3. | chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://casproviders.org/wp- |
| 9 | | content/uploads/2020/03/ABA-ASD-Practice-Guidelines.pdf |
| 10 | | |
| 11 | Fiscal | Implications: |
| 12 | | DOH defers to DHS-MQD regarding analysis of funding needed to implement the |
| 13 | propos | ed legislation, but believes it would have considerable cost impact for the state given the |
| 14 | wide p | revalence of adults with neurodevelopmental disorders. |
| 15 | | |
| 16 | Thank | you for the opportunity to testify. |



Committee on Commerce and Consumer Protection Committee on Ways and Means

> Wednesday, March 1, 2023 9:00 a.m. VIA VIDEOCONFERENCE Conference Room 211 State Capitol 415 South Beretania Street

SUPPORT SB1473 SD1 RELATING TO HEALTH

Honorable Chairs, Vice Chairs, 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 **support** of SB1473 SD1, 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.

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).

In light of testimony submitted in the last hearing, 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 Insurance Coverage of

<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,

10BADT

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

<u>SB-1473-SD-1</u> Submitted on: 2/24/2023 7:05:45 PM Testimony for CPN on 3/1/2023 9:30:00 AM

| Submitted By | Organization | Testifier Position | Testify |
|-----------------|---|---------------------------|---------------------------|
| Louis Erteschik | Testifying for 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.



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 1, 2023

The Honorable Senator Jarrett Keohokalole, Chair Senate Committee on Commerce and Consumer Protection And The Honorable Senator Donovan M. Dela Cruz, Chair Senate Committee on Ways and Means The Thirty-Second Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Senator Keohokalole, Senator Dela Cruz, and Committee Members:

SUBJECT: SB1473 SD1 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS SB1473 SD1**, 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, for individuals aged twenty—one and older with neurodevelopmental disorders, including applied behavior analysis services, for individuals aged twenty—one and older with neurodevelopmental disorders, including autism spectrum disorder. Appropriates funds. (SD1)

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 SD1.

Sincerely,

Daintry Bartoldus Executive Administrator

DATE: February 26, 2023

TO:

Senator Jarrett Keohokalole, Chair Senator Carol Fukunaga, Vice Chair Members of the Commerce and Consumer Protection Committee

Senator Donovan M. Dela Cruz, Chair Senator Gilbert S.C. Keith-Agaran, Vice Chair Members of the Ways and Means Committee

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

RE: Support of SB1473 SD1 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.

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.

<u>SB-1473-SD-1</u> Submitted on: 2/26/2023 11:40:56 AM Testimony for CPN on 3/1/2023 9:30:00 AM

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

Comments:

Aloha Senator and Chair Keohokalole, Vice-chair Fukunaga and Members of the Commerce and Consumer Protection Committee and

Aloha Senator and Chair Dela Cruz, Vice-chair Keith-Agaran and Members of the Ways and Means Committee:

I fully support SB1473. However, please consider amending the Bill to include those individuals with Fetal Alcohol Spectrum Disorder (FASD), as those with FASD often do not qualify for medically related and necessary services due to the guidelines of what defines developmentally disabled.

FASD is an alcohol-related neurodevelopmental disorder caused when the human fetus is exposed to the metabolites of alcohol consumption during pregnancy. The numbers of those affected by FASD exceed those affected by Autism, Cerebral Palsy, Spina Bifida, and Down Syndrome combined. Thus, it's imperative that SB715 include those affected by FASD.

Thank you for this consideration as an addition to and supporting SB1473.

Sincerely,

Kenichi Yabusaki, Ph.D.

<u>SB-1473-SD-1</u> Submitted on: 2/27/2023 9:41:12 AM Testimony for CPN on 3/1/2023 9:30:00 AM

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

Comments:

Aloha Members of the Legislature,

I am writing to express my strong support for SB1473, which 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.

As the parent of two children with autism spectrum disorder, who are 12 and 10 years old, since they were 6 and 4, respectively, both have received applied behavior analysis services through their Medicaid plans. Even though they have developed a great deal of skills and the capacity for verbal communication, we are going through various stages of maturation that call for ongoing adjustments to their services. Many individuals with neurodevelopmental disorders require ongoing support and services as they transition into adulthood, and it is essential that the state Medicaid program provide coverage for these services.

Applied behavior analysis services have been shown to be an effective treatment for individuals with autism spectrum disorder, but access to these services can be limited, particularly for adults. By requiring the state Medicaid program to cover medically-necessary services, including ABA services, for individuals aged twenty-one and older with neurodevelopmental disorders, SB1473 would help to ensure that individuals with disabilities receive the care they need to lead full and fulfilling lives.

I strongly urge you to support SB1473 and to prioritize the needs of the disability community in your policymaking. By providing necessary funding and support for these services, we can ensure that all individuals with disabilities have the opportunity to reach their full potential.

Mahalo nui loa,

Naomi Tachera

SB-1473-SD-1

Submitted on: 2/27/2023 1:15:06 PM Testimony for CPN on 3/1/2023 9:30:00 AM

| Submitted By | Organization | Testifier Position | Testify |
|--------------|--------------|---------------------------|---------------------------|
| Vivian Aiona | Individual | Support | Written Testimony Only |

Comments:

As a Board Member of the **Hawaii Fetal Alcohol Spectrum Disorders Action Group**, I fully support **SB1473 SD1**, to include Hawaii FASD, along with Autism Spectrum Disorder and other neurodevelopmental disorders, as noted in the bill description.

The adults and keiki with such disorders, and their families, have fought tirelessly for recognition and support. Medicaid can be the *hand up* to serve this long neglected part of our ohana.

Respectfully,

Vivian Aiona

<u>SB-1473-SD-1</u> Submitted on: 2/27/2023 7:02:14 PM Testimony for CPN on 3/1/2023 9:30:00 AM

| Submitted By | Organization | Testifier Position | Testify |
|--------------|--------------|---------------------------|---------------------------|
| Sina Pili | Individual | Support | Written Testimony Only |

Comments:

Aloha Chair, Vice Chair, and Committee Members,

I support this bill.

Mahalo,

Sina P. Pili

<u>SB-1473-SD-1</u> Submitted on: 2/28/2023 6:41:15 AM Testimony for CPN on 3/1/2023 9:30:00 AM

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

Comments:

I support this bill to expand coverage for ABA to Medicaid eligible adults 21+ and provide parity with those on private insurance already able to access these services across the lifespan.

Thank you,

Kristen

Maui

<u>SB-1473-SD-1</u>

Submitted on: 2/28/2023 6:43:08 AM Testimony for CPN on 3/1/2023 9:30:00 AM

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

Comments:

As a previous service provider for adults in the DOH-DDD waiver system, I strongly support this bill to create access to medically necessary services for those 21+ through their Medicaid health coverage.

SB-1473-SD-1

Submitted on: 2/28/2023 9:27:15 AM Testimony for CPN on 3/1/2023 9:30:00 AM

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

Comments:

An individual's need for medically necessary services does not suddenly stop at a specified age. Once individuals with neurodevelopmental disabilities age out of school services, there are very few services available to support them and their families. Allowing continued access to medically necessary services through medicaid beyond the age of 21 could be life changing for many individuals and their families.

<u>SB-1473-SD-1</u> Submitted on: 2/28/2023 10:14:45 AM Testimony for CPN on 3/1/2023 9:30:00 AM

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

Comments:

Dear Senator Keohokalole, Chair, Senator Fukunaga, Vice Chair, and Members of the Commerce and Consumer Protection Committee:

Dear Senator Dela Cruz, Chair and Senator Keith-Agaran, Vice Chair, and Members of the Ways and Means Committee:

On behalf of the Board of Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group a 501 c 3 and its 200+ volunteers, we are writing to **express our strong support for SB1473 SD1.**

SB1473 SD1, 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, for individuals aged twenty—one and older with neurodevelopmental disorders, including autism spectrum disorder. Appropriates funds. (SD1)

We fully believe and support the need for the Department of Health and Department of Human Services to take the necessary action to obtain the necessary approvals and amend the state medicaid plan to provide reimbursements for medically - necessary services, including applied behavior analysis services, for all individuals, especially adults with neurodevelopmental disorders, including autism spectrum disorder **and fetal alcohol spectrum disorders** which is often misdiagnosed as autism spectrum disorders. People with disabilities should never be denied informed care and services in Hawai'i who holds the distinction of being the top state for health care in the USA. <u>PEW Trust The Commonwealth Fund</u>

We sincerely hope the Commerce and Consumer Protection Committee will pass SB1473 SD1 and the Ways and Means Committee will approve the funding for the long overdue error of omission for adequate diagnosis treatment and services for neurodevelopmental disorders.

We appreciate this opportunity to submit testimony on this impactful legislation.

Sincerely yours,

Cleota G. Brown, President

fasdhawaii.org

<u>SB-1473-SD-1</u> Submitted on: 2/28/2023 9:48:43 AM Testimony for CPN on 3/1/2023 9:30:00 AM

| Submitted By | Organization | Testifier Position | Testify |
|--------------|--------------|---------------------------|---------------------------|
| Linda Elento | Individual | Support | Written Testimony Only |

Comments:

Aloha Senator Keohokalole, Vice Chair, Senator Fukunaga, Vice Chair, and Members of the Senate Committee on Commerce and Consumer Protection,

Aloha Senator Dela Cruz, Chair, Senator Keith-Agaran, Vice Chair, and Members of the Senate Committee on Ways and Means,

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."

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

Medical treatments and therapies covered under Medicaid such as medication and counseling are not alternatives for ABA for my adult son born with developmental disabilities. For over a year, Medicaid and the Medicaid Waiver provision for a service that is not ABA, per se, are still not accessible for my son. (Ref. previous testimony by state for SR114; **SR114SD was adopted by the Senate in 2022** to request the state agencies to work towards providing medically-necessary ABA to individuals 21 or older hrough Medicaid.

A court in Indiana ruled that the arbitrary age cut-off on the 21st birthday is disability discrimination towards individuals with autism (autism doesn't stop on the 21st birthday), violating the Americans with Disabilities Act (ADA) (Ref. 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.

For individuals such as my son ABA is medically-necessary. My son had received ABA services provided by skilled and experienced licensed ABA professionals at school and through health insurance. He continues to need ABA to further develop communication and independent-living

skills. Yet medically-necessary ABA was no longer accessible through Medicaid when he turned 21.

Thank you for your consideration of this testimony in support of passing SB1473 SD1.



<u>SB-1473-SD-1</u> Submitted on: 2/28/2023 12:58:11 PM Testimony for CPN on 3/1/2023 9:30:00 AM

| Submitted By | Organization | Testifier Position | Testify |
|-----------------|--------------|---------------------------|---------------------------|
| Kathy Dougherty | Individual | Support | Written Testimony Only |

Comments:

I support

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, for individuals aged twenty—one and older with neurodevelopmental disorders, including autism spectrum disorder. Appropriates funds. (SD1)