DAVID Y. IGE GOVERNOR



CATHY BETTS DIRECTOR

JOSEPH CAMPOS II DEPUTY DIRECTOR

STATE OF HAWAII DEPARTMENT OF HUMAN SERVICES

P. O. Box 339 Honolulu, Hawaii 96809-0339

April 12, 2022

- TO: The Honorable Representative Ryan I. Yamane, Chair Committee on Health, Human Services and Homelessness
- FROM: Cathy Betts, Director
- SUBJECT: SCR130 REQUESTING THE DEPARTMENT OF HEALTH AND DEPARTMENT OF HUMAN SERVICES TO JOINTLY REVIEW ANY RESEARCH REGARDING APPLIED BEHAVIORAL ANALYSIS FOR ADULTS; AND TO DEVELOP AND ADOPT ALL RULES, POLICIES, AND PLAN AMENDMENTS NECESSARY FOR THE STATE MEDICAID PROGRAM TO COVER MEDICALLY-NEEDED SERVICES, INCLUDING APPLIED BEHAVIOR ANALYSIS SERVICES, FOR INDIVIDUALS AGED TWENTY-ONE AND OLDER WITH NEURODEVELOPMENTAL DISORDERS, INCLUDING AUTISM SPECTRUM DISORDER.

HEARING:April 14, 2022, 9:00 a.m.Via Videoconference, State Capitol Conference Room 329

DEPARTMENT'S POSITION: The Department of Human Services (DHS) offers comments with concerns.

PURPOSE: SCR 130 asks the Department of Health and the Department of Human Services to jointly review any research regarding Applied Behavioral Analysis (ABA) for adults and to develop rules, policies, and Medicaid state plan amendments necessary to cover medically needed services, including ABA for people aged twenty-one and older who have neurodevelopmental disorders including autism spectrum disorders.

ABA is provided for individuals under 21 through the Early Periodic Screening and Diagnostic and Treatment benefit for 0-21 aged beneficiaries served by the DHS Med-QUEST Division (MQD). ABA does have evidence of clinical effectiveness, especially for younger children. However, there are no clinical guidelines for its use in older individuals in the United States. While some clinical guidelines exist in the United Kingdom with similar behavioral supports and components to ABA, they are not defined as ABA or widely used in the United States.

For families struggling to find appropriate therapies and services for their children transitioning to adulthood, who have neurodevelopmental disorders, especially those that are severe, it can be extremely difficult and challenging as it is unclear what options are available for their children. While ABA services specifically are not provided for adults, various behavioral supports or intensive behavioral health services may be provided by their Medicaid QUEST Integration Health Plan or be covered by the waivered services for individuals with Intellectual/Developmental Disabilities who are served by the Department of Health's Developmental Disabilities Division.

Finally, as the committee likely is aware, not all medically needed care is available for Medicaid enrollees 21 and over. For example, oral health services are considered essential for health and well-being but are currently not covered by Medicaid except for emergency care. If the research conducted were to find evidence-based services for individuals with neurodevelopmental disorders, including autism, that are not currently a covered service, MQD would need to seek federal approvals to cover the services and request a general fund appropriation to cover the services. Federal approval and the general fund appropriation must occur before developing any rules or policies. More analysis would be needed to develop the fiscal impact.

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

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DAVID Y. IGE GOVERNOR OF HAWAII



Elizabeth A. Char, MD DIRECTOR OF HEALTH

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

Testimony in OPPOSITION to SCR130 SD1

REPRESENTATIVE RYAN I. YAMANE, CHAIR HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES, & HOMELESSNESS

Hearing Date/Time: April 14, 2022 9:00AM Room Number: 329

Department Position: The Department of Health (Department) requests that SCR130 SD1 be deferred.

3 Department Testimony:

SCR 130 asks the Department of Health and the Department of Human Services (DHS) to jointly
review the research regarding Applied Behavior Analysis (ABA) for adults, and develop rules,
policies, and Medicaid state plan amendments to cover medically necessary services, including
ABA for people aged twenty-one and older who have neurodevelopmental disorders including
autism spectrum disorders.

9 The Department acknowledges the struggles of families of adults with neurodevelopmental

10 disorders in finding the right therapies. Autism spectrum disorders, especially those that are

severe in nature, can be extremely difficult for families and individuals, and families with

12 children are often unclear about what services are available once their children become adults.

The Department opposes SCR130 SD1 for several reasons that relate to lack of a research base supporting efficacy of ABA for adults, and the process and requirements for providing services through a Medicaid program.

We were glad to see the Senate added our suggested amendment in SD1 to review the research
regarding ABA for adults. We note that currently, no evidence-based guidelines exist for specific

use of ABA to treat adults with autism. Evidence and clinical guidelines are a requisite when 1 adding a service to be covered under a Medicaid State Plan. While we have found Clinical 2 Guidelines out of the United Kingdom for supporting adults with autism with psychosocial 3 interventions based on behavioral principles and informed by a functional analysis of behavior, 4 they do not name ABA specifically, and have not been adopted in the United States. We believe 5 that at this time there is insufficient evidence that would support medical necessity for ABA for 6 adults, and we are unclear how medical necessity for adults across the lifespan would be 7 determined in absence of published guidelines. 8

9 The Centers for Medicare and Medicaid (CMS) must approve any additions to covered services
10 in State Plans. Based on the lack of clinical evidence and published guidelines, and that no other
11 state that we know of currently covers ABA services for adults, it is questionable that CMS
12 would approve coverage for this service.

SCR130 SD1 also asks the Departments to begin to develop rules and policies to cover medically necessary services, including ABA for people aged twenty-one and older. We believe these are premature activities. The Department of Human Services has explained in previous testimony that not all medically necessary care is available for Medicaid enrollees 21 and over. In addition to seeking federal approval, the Departments would need to request general fund appropriations to cover the state's share of cost of services.

19 The Department of Health- Developmental Disabilities Division (DOH-DDD) operates the 20 Medicaid 1915(c) waiver for individuals with intellectual and developmental disabilities on 21 behalf of DHS, MedQUEST Division. In the 1915(c) waiver, DOH-DDD provides Training and 22 Consultation Behavior services when needed by adults in the program aged twenty-one and 23 older. These services are for the purposes of completing a functional behavior analysis, 24 developing a behavior support plan (BSP), and training others in implementation of the BSP. 25 These services are not ABA per se but allow for a range of behavior support approaches provided by different types of providers. Per Medicaid regulations, children in the 1915(c) 26

27 waiver under the age of twenty-one who need intensive behavioral services such as ABA

- 1 services, can receive those services through the Early and Periodic Screening, Diagnostic, and
- 2 Treatment benefit under their Medicaid QUEST Integration Health Plan.
- 3 In summary, we believe that it would be premature for the Departments to develop rules,
- 4 policies, and Medicaid state plan amendments to cover services, including ABA for adults aged
- 5 twenty-one and older who have neurodevelopmental disorders including autism spectrum
- 6 disorders in the absence of Federal approval, published evidence-based guidelines, and a full cost
- 7 analysis that would allow the state to make informed decisions about such a policy direction.
- 8 Fiscal Implications: The Department believes there would likely be a large fiscal impact for the
- 9 state for enacting SCR130 SD1. A full fiscal, clinical, and policy analysis is needed to evaluate
- 10 the impact of mandating coverage of these services.



Thank you for the opportunity to submit testimony in strong support of SCR 130.

As proposed, this resolution would request that the Department of Health and Department of Human Services jointly develop and adopt all rules, policies, and plan amendments necessary to ensure that the State Medicaid program covers medicallynecessary services, including Applied Behavior Analysis services (ABA), for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder.

To date, ABA is the most scientifically proven and effective treatment for autism across the lifespan, including the carryover from childhood/adolescence to adulthood. Currently, Medicaid eligible adults in need of medically-necessary ABA services are unable to access this essential service because they are over the age of 21. Treatment should be based on the clinical needs of the individual and not constrained by age. Research has not established an age limit beyond which ABA is ineffective.

Treatment duration is effectively managed by evaluating the individual's response to treatment. Some individuals will continue to demonstrate medical necessity and require treatment for a substantial duration (e.g., over a period of years).

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.

Thank you for your time.

Mey Elah

Stacey Kuhn, MS, BCBA, LBA Hawaii Licensed Behavior Analyst #16 Oahu



COMMITTEE ON HEALTH, HUMAN SERVICES, & HOMELESSNESS Representative Ryan Yamane, Chair Representative Adrian Tam, Vice Chair

> Thursday, April 14, 2022 9:00am Conference Room 329 and Video conference

> > Support of S.C.R No. 130 SD1 With Comments

Honorable Chair Yamane, Vice Chair Tam, and members of the committee:

The Hawai'i Association for Behavior Analysis (HABA) supports Senate Concurrent Resolution 130 SD1 with comments. We respectfully request that the Department of Health (DOH) and Department of Human Services (DHS) work together to develop and adopt all rules, policies and plan amendments necessary for the state Medicaid program to cover medically-needed services, including applied behavior analysis (ABA) services, for adult individuals aged twenty-one and older with neurodevelopmental disabilities, including autism spectrum disorder (ASD). HABA further supports that any rules, policies and planned amendments adopted do not impair or limit any existing coverages.

Since SCR 130 SD1 has been amended requesting DOH and DHS jointly review research that shows ABA is an effective evidence-based intervention, we would like to offer the following comments and information. For many persons with ASD, medically-needed services will be required well past the age of twenty-one. Additionally, ABA has proven to be the most effective behavioral health treatment to address the medical needs of many individuals with ASD including individuals over age twenty-one.

The ABA Coding Coalition Model Coverage Policy for Adaptive Behavior Services and the Council of Autism Service Providers ASD Practice Guidelines, outline how medically necessary services should be covered and have specific sections on age. According to the ABA Coding Coalition (2022) Model Coverage Policy for Adaptive Behavior Services, there is abundant evidence that a wide array of ABA treatment procedures is effective for the reduction of maladaptive behaviors and building adaptive skills across the lifespan (p. 7). Additionally, the Council of Autism Service Providers (CASP) ASD Practice Guidelines states the following: "*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" (p.18).

The effectiveness of ABA for adults is further supported by additional research. For example, the National Autism Center also addressed the need for evidence-based practice guidelines for ASD and published Findings and Conclusions National Standards Project Phase 2 (NSP2), which reviewed research on effective treatments across the lifespan including adults. Established interventions for individuals ages 22 years and older fall into the Behavioral Intervention category, which consists of applied behavior analytic interventions to increase adaptive behaviors and decrease challenging behaviors. Results revealed that ABA interventions were established to be effective at decreasing problem behaviors and increasing communication, personal responsibility and self-regulation. Examples of specific strategies identified in the 17 articles supporting Behavioral Interventions include interventions commonly

utilized in ABA treatment such as prompting, extinction, differential reinforcement of incompatible behavior, and Functional Communication Training (p. 73-75). Given all of the research pointing to ABA as a well-established, effective evidence-based treatment, HABA respectfully requests that the Committee amend the language to the previous SCR130. ABA services should not be exclusive to children or limited across the life span. This vulnerable population needs continuity of care, which for many includes access to ongoing ABA services.

Thank you for the opportunity to testify regarding S.C.R No. 130 SD1 and for all that you do to support the health and consumer protection of individuals with autism and neurodevelopmental disorders. We truly appreciate your efforts to ensure these vulnerable populations receive equitable access to **all** medically necessary services including applied behavior analysis.

Mahalo,

Ashley Hogan

Ashley Hegan, LBĂ #77 President, Hawai'i Association for Behavior Analysis

References:

ABA Coding Coalition. (2022). Model Coverage Policy for Adaptive Behavior Services (2nd Edition): Author.

Council of Autism Service Providers. (2020). Applied Behavior Analysis: Treatment of Autism Spectrum Disorder Practice Guidelines for Healthcare Funders and Managers and the Model Coverage Policy (2nd Edition.). Wakefield, MA: Author.

National Autism Center. (2015). Findings and conclusions: National standards project, phase 2. Randolph, MA: Author



April 12, 2022

House Committee on Health, Human Services & Homelessness Hawaii State Legislature

Chair Yamane, Vice Chair Tam and Members of the Committee:

Autism Speaks is a nonprofit organization dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of people with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

We are in strong support of the intent of SCR130 SD1 and respectfully request this Committee return to the original SCR130 language focused on providing coverage (as opposed to jointly reviewing researching). Applied behavior analysis (ABA) is a therapy based on the science of learning and behavior. It is typically used to help people with autism and other developmental disorders learn behaviors that help them live safer and more fulfilling lives.

ABA focuses on teaching necessary skills and stopping dangerous behaviors rather than preventing harmless ones such as self-stimulatory behavior (stims). Therapists work with autistic people to improve skills like:

- Communication and language abilities
- Social skills
- Self-care and hygiene routines
- Play and leisure skills
- Motor abilities

While therapy looks different in young children versus adolescents and adults, the principles remain the same and ABA is effective for people of all ages. Applied Behavior Analysis is a well-developed discipline among the helping professions, with a mature body of scientific knowledge, established standards for evidence-based practice, distinct methods of service delivery, recognized experience and educational requirements for practice, and identified sources of requisite education

in universities. There is an existing body of literature readily available for application of ABA with adults, and additional information available for structuring coverage for adults as outlined in the *Council of Autism Service Providers Applied Behavior Analysis: Treatment of Autism Spectrum Disorder Practice Guidelines for Healthcare Funders and Managers and the Model Coverage Policy* (2020) and the *Model Coverage Policy for Adaptive Behavior Services (2022)*.

The Home and Community-Based Service (HCBS) waiver program for individuals with intellectual/developmental disabilities, delivered by the Department of Health's Developmental Disabilities Division, is designed to keep recipients from having to be institutionalized. Not everyone with autism and related conditions is at risk of potential institutionalization, nor qualifies for waiver services, and in many cases individuals have significant waits to be approved when they are eligible.

There is a group of non-insured autistic adults who would greatly benefit from ABA therapy to improve their quality of life, ability to work and live independently and even reduce their health care costs through better ability to communicate and comply with medical guidance. We encourage you to view the potential for adult ABA coverage under Medicaid as more like EPSDT coverage for children than like waiver services that help the highest need individuals avoid institutionalization.

Thank you for your thoughtful consideration of SCR130 SD1, and we urge passage.

Kelly Headrick

Kelly Headrick Senior Director, State Government Affairs kelly.headrick@autismspeaks.org 720.207.8102

<u>SCR-130-SD-1</u> Submitted on: 4/12/2022 4:12:00 PM Testimony for HHH on 4/14/2022 9:00:00 AM

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

Comments:

Support.

COMMITTEE ON HEALTH, HUMAN SERVICES, & HOMELESSNESS Rep. Ryan I. Yamane, Chair Rep. Adrian K. Tam, Vice Chair

> Thursday, April 14, 2022 9:00 am Conference Room 329 and Video conference

Support with Amendments for SCR 130 SD1

Honorable Chair Yamane, Vice Chair Tam, and members of the committee:

Thank you for the opportunity to submit testimony in **support of SCR 130 SD1 with amendments**. My name is Kristen Koba-Burdt and I am a licensed behavior analyst with significant experience in providing ABA treatment for adults with autism or other neurodevelopmental disorders.

In the previous hearing, the SD1 language was amended to focus on "jointly reviewing researching" based on the testimony submitted by the DOH and DHS indicating "an absence of published evidencebased guidelines." However, these is a robust body of literature available supporting applied behavior analysis (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 *Insurance Coverage of Applied Behavior Analysis for Adults with Autism: A Review of the Evidence*. In this report, the authors concluded "The robust empirical support for ABA-based interventions for children with autism combined with the effectiveness of focused ABA-based interventions for adults with autism make a compelling argument to require insurance coverage of ABA-based interventions for adults with autism" (p.7).

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

The Council of Autism Service Providers (CASP) publication, *Applied Behavior Analysis: Treatment of Autism Spectrum Disorder Practice Guidelines for Healthcare Funders and Managers and the Model Coverage Policy*, in it's 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, *Model Coverage Policy for Adaptive Behavior Services* originally published in 2020 and revised in 20202, includes model health insurance coverage policy and a bibliography of research examples including adults. Based on the above, as well as additional research available demonstrating the evidence-base for ABA, I respectfully request that the Committee amend the language to the previous SCR130. Currently, Medicaid eligible adults in need of medically-necessary ABA services are unable to access this essential service because they are over the age of 21. Additionally, there are teens/young adults who have been making progress in their ABA treatment, only to lose access to their medically-necessary ABA when they reach age 21. While some of these individuals are able to access 1915(c) waiver services, those services are not structured to provide medically necessary treatment, making this resolution and the continuity of care for adults 21+ so vital.

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.

Thank you,

10BADT

Kristen Koba-Burdt, BCBA, LBA, CDP Maui

References

ABA Coding Coalition. (2022). Model Coverage Policy for Adaptive Behavior Services (2nd Edition).: Author.

Autism New Jersey. (2014). Insurance Coverage of Applied Behavior Analysis for Adults with Autism: A Review of the Evidence. Robbinsville, NJ: Author.

Council of Autism Service Providers. (2020). Applied Behavior Analysis: Treatment of Autism Spectrum Disorder Practice Guidelines for Healthcare Funders and Managers and the Model Coverage Policy (2nd Edition.). Wakefield, MA: Author.

National Autism Center. (2015). Findings and conclusions: National standards project, phase 2. Randolph, MA: Author

COMMITTEE ON HEALTH, HUMAN SERVICES, & HOMELESSNESS

Rep. Ryan I. Yamane, Chair

Rep. Adrian K. Tam, Vice Chair

Thursday, April 14, 2022, 9am

Conference Room 329 and Video conference

Support with Amendments for SCR 130 SD1

Honorable Chair Yamane, Vice Chair Tam, and members of the committee:

Thank you for the opportunity to submit testimony in support of SCR 130 SD1 with amendments. My name is Deborah Krekel and I am a parent of a teenager with autism. Our son has been fortunate to receive the medically necessary treatment including access to applied behavior analysis since he was a young child, and has made meaningful gains as a recipient of these services. However, for many individuals with ASD, medically-needed services such as ABA will be required well past the age of twenty-one to allow for them to become contributing members of their communities and live fulfilling lives that could include equal access to employment and post-secondary educational opportunities. Therefore, ABA services should not be exclusive to children or teens. For many adults, this continuity of care is necessary for them to increase their quality of life.

I respectfully request that the Department of Health and Department of Human Services work jointly to develop and adopt all rules, policies and plan amendments necessary for the state Medicaid program to cover medically-needed services, including applied behavior analysis (ABA) services, for individuals aged twenty-one and older with neurodevelopmental disabilities, including autism spectrum disorder (ASD).

Additionally, ABA treatment has proven to be the most effective behavioral health treatment to address the medical needs of many individuals with ASD across the life span. There is a plethora of established evidence-based research to support this. Hence, I further support that any rules, policies and planned amendments adopted do not impair or limit any existing coverages. Furthermore, given the research that supports ABA services for adults with developmental disabilities including those with autism spectrum disorders, I respectfully request that the Committee amend the language to the previous SCR130.

I have gratitude for all that you do as legislators to support and ensure that individuals with autism and neurodevelopmental disorders receive equitable access to all medically necessary services including applied behavior analysis. Thank you for considering my testimony.

Sincerely,

Deborah Krekel

<u>SCR-130-SD-1</u> Submitted on: 4/13/2022 8:59:24 AM Testimony for HHH on 4/14/2022 9:00:00 AM

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

Comments:

Thank you. In Support.

LATE *Testimony submitted late may not be considered by the Committee for decision making purposes.

DAVID Y. IGE GOVERNOR OF HAWAII



ELIZABETH A. CHAR, M.D. DIRECTOR OF HEALTH

STATE OF HAWAI'I STATE COUNCIL ON DEVELOPMENTAL DISABILITIES PRINCESS VICTORIA KAMĀMALU BUILDING 1010 RICHARDS STREET, Room 122 HONOLULU, HAWAI'I 96813 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543 April 14, 2022

The Honorable Representative Ryan I. Yamane, Chair House Committee on Health, Human Services, and Homelessness The Thirty-First Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Representative Yamane and Committee Members:

SUBJECT: SCR130 SD1

The Hawaii State Council on Developmental Disabilities **SUPPORTS SCR130 SD1** requesting the Department of Health and Department of Human Services to jointly review any research regarding applied behavioral analysis for adults; and to develop and adopt all rules, policies, and plan amendments necessary for the State Medicaid program to cover medically-needed services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including Autism Spectrum Disorder.

Our state currently has a "gap group" of individuals with developmental disabilities who do not qualify for services under the Developmental Disability Division and are above the age of 21. If these individuals with developmental disabilities only have Med-Quest coverage they are unable to receive needed behavioral analysis services. As well other individuals with neurodevelopmental disabilities other than autism have been shown to have positive results from receiving applied behavioral services after the age of 21. For example, individuals with Down-Syndrome have benefited from these services.

The Council supports this resolution as it is a good conversation for our state to have regarding how to better support our gap groups.

Thank you for the opportunity to submit testimony in support of SCR130 SD1.

Sincerely,

Daintry Bartoldus Executive Administrator

SCR-130-SD-1

Submitted on: 4/13/2022 9:00:10 AM Testimony for HHH on 4/14/2022 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Judith Ursitti	Council of Autism Service Providers	Support	Remotely Via Zoom

Comments:

Regarding Senate Concurrent Resolution 130 S.D. 1

Requesting the Department of Health and Department of Human Services to jointly review any research regarding applied behavioral analysis for adults; and to develop and adopt all rules, policies, and plan amendments necessary for the state Medicaid program to cover medically-needed services, including applied behavior analysis services, for individuals aged twenty-one and older with neurodevelopmental disorders, including autism spectrum disorder

Dear Chair Yamane, Vice-Chair Tam, and Members of the Health, Human Services, and Homelessness Committee:

I write to you today on behalf of The Council of Autism Service Providers (CASP) and our member organizations in Hawaii which are serving children and adults diagnosed with autism spectrum disorder. 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 for autistic individuals of all ages in both private health insurance plans as well as through Medicaid.

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[1] estimate 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.[2]

Generally accepted standards^[3] 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 long-term 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 Senate Concurrent Resolution 130 S.D. 1 and ask for your favorable passage of it today. Should you need any adiditonal information. Please do not hesitate to contact me.

Judith Ursitti

Vice President Government Affairs

[1] https://www.cdc.gov/ncbddd/autism/new-data.html

[2] https://www.cdc.gov/ncbddd/autism/autism-spectrum-disorder-in-teenagers-adults.html

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

SCR-130-SD-1

Submitted on: 4/13/2022 11:04:37 AM Testimony for HHH on 4/14/2022 9:00:00 AM

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

Comments:

I support SCR130 for expanding access to applied behavior analysis (ABA) for Medicaid eligible adults. As a former waiver provider for adults with autism and other disabilities working under the DOH-DDD system, I have personally experienced the significant need for access to medically-necessary ABA for this population to meet their behavioral needs, separate from what is provided by DOH-DDD for 1915(c) waiver.

SCR-130-SD-1

Submitted on: 4/14/2022 8:54:04 AM Testimony for HHH on 4/14/2022 9:00:00 AM

Submitted By	Organization	Testifier Position	Testify
Zhizi Xiong	Individual	Support	In Person

Comments:

Dear Chair, Vice Chair & Members of the Committee,

My name is Zhizi Xiong and I'm testifying in strong support of this measure as a concerned citizen. My friends daughter is in high school and she was diagnosed with autism. She is very bright but has problems interacting socially. That is the condition of the developmental disability, it hinders significant social interactions & communication for the person who is suffering from autism.

She has a hard time getting mental health services because her parents & teachers are not trained to recognize the condition. As a disabled person and as someone who has navigated the health system, I recognized her condition and know what she needs. She needs to go to Assets and she needs mental health services. Assets is a special ed school that helps students with dyslexia, dysgraphia, and other disabilities.Public schools without an existing special ed program are not appropriate for students with disabilities.

I support the resolution and its intent to request DHS & DOH to review, research, develop & adopt policies pertaining to autism treatment. However, I'd like to ask the legislature to consider providing services to children & youth also. There are a lot of different initiatives the legislature could try in regards to assisting those with neurodevelopment disorders & disabilities. The legislature could consider providing basic medical training for staff at schools or at work to be able to recognize such health conditions & disabilities so that the most vulnerable of our society can access equitable health benefits.

Thank you for the chance to testify.

Blessings,

Zhizi Xiong