DAVID Y. IGE
GOVERNOR

PANKAJ BHANOT
DIRECTOR

CATHY BETTS
DEPUTY DIRECTOR

STATE OF HAWAII
DEPARTMENT OF HUMAN SERVICES
P. O. Box 339
Honolulu, Hawaii 96809-0339

February 7, 2019

TO: The Honorable Senator Russell E. Ruderman, Chair
Senate Committee on Human Services

The Honorable Senator Rosalyn H. Baker, Chair
Senate Committee on Commerce, Consumer Protection, and Health

FROM: Pankaj Bhanot, Director

SUBJECT: **SB 242 – RELATING TO HEALTH**

Hearing: Friday, February 8, 2019, 2:45 p.m.
Conference Room 016, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) offers comments and requests clarification regarding the intent of the bill to seek approval from the Centers for Medicare and Medicaid Services (CMS) to provide Home- and Community-Based Services (HCBS) to individuals diagnosed with autism.

PURPOSE: The purpose of this bill is beginning January 1, 2020, requires the State's Medicaid managed care and fee-for service programs to provide coverage for home and community-based services for individuals diagnosed as having autism. Requires the Department of Human Services to seek a section 1115 waiver to amend the state Medicaid plan to include this coverage.

DHS currently provides coverage of HCBS to individuals with autism in both the QUEST Integration (QI) program and in the Medicaid waiver for individuals with intellectual and developmental disabilities (I/DD waiver) administered by the Developmental Disabilities Division (DDD) in the Department of Health (DOH). However, of note, in both programs, all beneficiaries receiving HCBS must meet a Level of Care (LOC) criteria independent of their autism diagnosis. To meet the LOC criteria, an individual must be assessed to have some functional limitations that reflect the need for HCBS.

Thus, a beneficiary's functional needs and whether they meet LOC requirements qualify them for HCBS rather than their diagnosis. Some beneficiaries with autism may function at a high level and do not quality for HCBS because they do not have functional limitations that would meet LOC requirements, while other beneficiaries who function at a lower level qualify for a significant amount of HCBS. Beneficiaries with autism cover a wide spectrum of function and are not homogeneous in their need for HCBS.

The bill clarifies that applicable federal requirements related to utilization, coverage, and reimbursement for services provided to individuals who have been diagnosed with autism would still apply. Under federal rules, individuals must meet a state's LOC to access HCBS. Thus, the text of the bill seems to reiterate the current rules and requirements of DHS and the federal government: individuals with an autism diagnosis can access HCBS if they meet LOC requirements. If this is the intent, the bill as written is not needed. The policy to include individuals with autism is already a requirement in the I/DD waiver and the QI program.

If the bill were intended to provide access to HCBS for individuals with an autism diagnosis <u>without</u> meeting present LOC requirements, DHS would have to expend additional state dollars and require an additional appropriation. The reason for this is that CMS likely would likely have concerns and would not approve HCBS for beneficiaries who would not meet LOC. In this situation, all state dollars would have to be used to pay for services for anyone not meeting the LOC need. The average spend per person in the DDD waiver is approximately $45,000 a year. There were approximately 1,600 beneficiaries with an autism diagnosis covered by Hawaiʻi Medicaid program in 2017, and the number appears to be growing. If just 25 percent of these individuals were to access HCBS, then the cost could be $16.7 million. If DHS could not agree with CMS on a no/minimal LOC requirement for those beneficiaries, then the State would have to pay for all of those services. For these reasons, we have serious concerns if the intent were to provide HCBS for any individual with autism diagnosis regardless of their level of care functional need.

In addition to the comments above, DHS would recommend that the reference to the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services benefit in Section 3 (b)17 be deleted from the bill because it is already covered through the QI program. EPSDT encompasses a broad range of medically necessary preventive, dental, mental health, developmental, and specialty services for all children and adolescents up to 21 years-of-age. DHS is already providing these services such as comprehensive dental care and Applied Behavior Analysis (ABA) therapy during the day through the QI program. The reference to EPSDT is unnecessary because it must be covered already under federal Medicaid rules regardless of any particular diagnosis.

Thank you for the opportunity to testify on this bill.

DAVID Y. IGE
GOVERNOR OF HAWAII

BRUCE S. ANDERSON, PHD
DIRECTOR OF HEALTH

STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
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Testimony COMMENTING on SB 242
RELATING TO HEALTH

SENATOR RUSSELL RUDERMAN, CHAIR
SENATE COMMITTEE ON HUMAN SERVICES

SENATOR ROSALYN BAKER, CHAIR
SENATE COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH

Hearing Date: February 8, 2019 Room Number: 016
2:45 P.M.

Fiscal Implications: Potential cost of SB 242 needs to be studied, but is believed to be substantial. The Department of Health (DOH) defers to the Department of Human Services (DHS).

Department Testimony: The Department of Health respectfully offers comments and seeks clarification on the intent of SB 242.

This measure proposes coverage for individuals with an autism spectrum disorder diagnosis through Medicaid home and community-based services (HCBS) in both managed care and fee-for services programs. It proposes an array of services to be part of that coverage. This bill asks DHS to seek a waiver under the 1115 authority of the Social Security Act to provide these services under the QUEST Integration (QI) health plans.

DHS currently provides HCBS to individuals with autism through the QI health plans and through the 1915(c) Medicaid Waiver for People with Intelllectual and Developmental Disabilities (I/DD) operated by the DOH-Developmental Disabilities Division.

This measure states that all applicable federal requirements must be met for individuals to be in an HCBS program. In HCBS programs, eligibility is not based on a diagnosis, but on a Level of Care (LOC) assessment of the person's functional limitations. This is a Medicaid requirement.

In the I/DD waiver, for example, participants are required to have substantial functional limitations in three or more areas of major life activity such as self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. In addition, participants must meet the LOC requirement that they would otherwise need the LOC of an institution if not for HCBS services. There is a wide range of functioning within diagnoses such as autism, and many people with autism do not need the substantial levels of support that would be provided by HCBS programs.

If this meaure were to be approved, substantial funding would be needed as it asks for access to HCBS programs without meeting the Medicaid LOC requirement. Further, it is unclear if the Centers for Medicare and Medicaid Services (CMS) would approve this approach, which means the State would have to fully finance service for people that do not meet the HCBS LOC requirements.

Thank you for the opportunity to testify.

SB-242
Submitted on: 2/4/2019 3:30:47 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Comments	Yes

Comments:

No agency has been more involved with fighting for the rights of individuals diagnosed with Autism Spectrum Disorder than the Hawaii Disability Rights Center. For that reason, we welcome any initiatives that would provide more services to these individuals.What is not clear to us is what the actual impact of this bill would be compared to the array of services that are currently available. Children under EPSDT are now receiving services as a result of a lawsuit we filed against DHS a few years ago. The DD division provides home and community based sercices to eligible individuals and generally a diagnosis of autism should qualify. So, would this bill expand eligibility to children with ASD such that they would not currently have to qualify for DD services? Would it provide an additional source of funds? We would be interested in learning more about the mechanics of how this waiver would work. It appears that it would automatically qualify anyone with autism and that certainly is something that would be very welcome.

AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Hawaii

TESTIMONY COMMENTING ON S.B. 242
RELATING TO HEALTH

THE SENATE
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2019
COMMITTEE ON HUMAN SERVICES
COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH

Friday, February 8, 2019, 2:45 p.m., Conference Room 016

February 6, 2019

The Honorable Russell E. Ruderman, Chair
The Honorable Karl Rhoads, Vice Chair
Committee on Human Services

The Honorable Rosalyn H. Baker, Chair
The Honorable Stanley Chang, Vice Chair
Committee on Commerce, Consumer Protection, and Health

Dear Chairs, Vice Chairs, and Members of the Committees:

We offer the following comments on the subject bill that would make home and community-based services funded by Medicaid available to individuals with autism.

In 1999, the Supreme Court held that individuals with mental disabilities have a right to live in the community rather than in institutions if State officials determine that is appropriate and community placement can be reasonably accommodated. *Olmstead v. L.C.,* 527 U.S. 581 (1999). Consistent with that decision, Hawaii closed its only institution, Waimano Training School and Hospital, in June 1999.

Since the Waimano facility closed, individuals with autism who are unable to live independently but who are not in need of institutional Mainland care live with relatives and friends or in one of approximately 1,000 care homes licensed by the State of Hawaii. Most care homes operate "under the radar," meaning there is no significant oversight and, in many cases, few services. Individuals living at home rely increasingly on aging parents who are hard-pressed to find reasonable accommodations for autism.

In 2013, the Ninth Circuit held that the Hawaii Department of Education ("DOE") violated the rights of students with disabilities from age 20 to 22 by excluding them from high schools where they could receive vocational training and independent living skills. *E.R.K. v. DOE*, 728 F.3d 982 (9th Cir. 2013). The DOE deposited $8.75 million in federal court to pay for community-based services for the class of 500 disabled students, but at the end of the first of three years settlement funds will be available, only nine (9) of the 500 class members (less than 2%) had found services to meet their needs. *E.R.K. v. Dept. of Education,* Civ. No. 10-00436 (SOM/KSC), ECF Doc. 516-1 (D. Haw., Dec. 21, 2018). Funds expended totaled $60,563.69, barely 0.7% of the funds on deposit.

The lack of progress in the remedy phase of the *E.R.K.* litigation is graphic proof of the lack of community-based services for individuals with autism. It shows that the State of Hawaii has made little, if any, progress since 1999 to comply with the *Olmstead* mandate of the Supreme Court.

Thirty years ago, two children in 10,000 born in the United States were diagnosed with autism. Today, the Centers for Disease Control estimate 1 in 59 (1.7%) will be so diagnosed. The Hawaii Department of Health reports there were 7,843 births in Hawaii during the first half of 2018. That means there will be at least 266 children with autism born in our State each year. The cost of caring for that population will be prohibitive if they are not able to find employment and live with some degree of independence.

This bill would require the State to seek and make available Medicaid funds for individuals as *Olmstead* requires. It would provide help to individuals with autism who are capable of joining the workforce and living independently but who must now stay at home or attend custodial programs providing little benefit and virtually no opportunities for future advancement.

Thank you for the opportunity to testify.

Respectfully submitted,

Dennis C. Maher
President, Autism Society of Hawaii

John P. Dellera
Former Director (emeritus)

hmsa

An Independent Licensee of the Blue Cross and Blue Shield Association

February 6, 2019

The Honorable Russell E. Ruderman, Chair
The Honorable Karl Rhoads, Vice Chair
Senate Committee on Human Services

The Honorable Rosalyn H. Baker, Chair
The Honorable Stanley Chang, Vice Chair
Senate Committee on Commerce, Consumer Protection, and Health

Re: SB 242 – Relating to Health

Dear Chair Ruderman, Chair Baker, Vice Chair Rhoads, Vice Chair Chang, and Committee Members:

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 242, which requires the State's Medicaid managed care and fee-for service programs to provide coverage for home and community-based services for individuals diagnosed as having autism, beginning January 1, 2020. Additionally, SB 242 requires the Department of Human Services to seek a section 1115 waiver to amend the state Medicaid plan to include this coverage. We have concerns with this measure and respectfully offer the following comments:

1. The definition of "therapeutic care" included in the bill is different from the definition included in HRS §432:1-614, which mandates coverage for autism services.

2. Some of the services identified in this bill are already provided under the child health component (Early Periodic Screening, Diagnostic and Treatment) of Medicaid.

3. Home and community-based services (HCBS) are already available for Medicaid individuals diagnosed with autism, through the Department of Health's Developmental Disabilities Division (DDD), as long as they meet the level of care criteria.

4. Requiring coverage for HCBS for individuals diagnosed with autism, in the Medicaid managed care and fee-for service programs, will place a significant financial burden on these programs.

Thank you for allowing us to provide these comments on SB 242.

Sincerely,

Pono Chong
Vice President, Government Relations

Hawai‘i Psychological Association

For a Healthy Hawai‘i

P.O. Box 833
Honolulu, HI 96808
www.hawaiipsychology.org
Phone: (808) 521-8995

Testimony in SUPPORT of SB242
RELATING TO HEALTH

COMMITTEE ON HUMAN SERVICES
Senator Russell E. Ruderman, Chair
Senator Karl Rhoads, Vice Chair

COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH
Senator Rosalyn H. Baker, Chair
Senator Stanley Chang, Vice Chair

Friday, February 8, 2019, 2:45pm
Conference Room 016
State Capitol
415 South Beretania Street

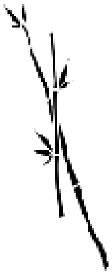
The Hawai’i Psychological Association (HPA) strongly supports SB242. This bill requires the State’s Medicaid managed care and fee-for-service programs to provide coverage for a comprehensive array of home and community-based services for individuals diagnosed as having autism and will help to ensure that they have access to the kinds of services that will allow them to participate in their communities.

We also support the amendment requested by other advocates that this bill incorporate all developmental disabilities, including fetal alcohol spectrum disorder.

Thank you for the opportunity to provide input into this important bill.

Sincerely,

Julie Takishima-Lacasa, Ph.D.
Chair, Legislative Action Committee
Hawai’i Psychological Association



Hawai‘i Psychological Association

For a Healthy Hawai‘i

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SB-242
Submitted on: 2/7/2019 2:38:01 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Melodie Aduja	Testifying for O`ahu County Committee on Legislative Priorities of the Democratic Party of Hawai`i	Support	No

Comments:

SB-242
Submitted on: 2/4/2019 2:38:18 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Kenichi Yabusaki	Individual	Support	No

Comments:

Aloha Senators Gabbard, Baker and Committee Members:

I strongly support the passage of SB242 better known as Kelii's Law. Individuals afflicted by autism and all developmental disabilities, including Fetal Alcohol Spectrum Disorders (FASD), should be waived under Section 1115 for services. The aforementioned individuals have permanent conditions that require life-long support to have a quality of life just like any "normal" individual. We have created a society of "exclusion" from the semantics of "disabilities". To this end, this waiver is about any developmental disability. I urge all legislators and those administrators who make the decision on who qualifies for DD services to put yourselves into the shoes of those with and/or those caregivers of those afflicted with to no fault of their own a developmental disability such as autism, cerebral palsy, spina bifida, Down Syndrome, and FASD. Mahalo nui,

K. Ken Yabusaki, Ph.D.

SB-242
Submitted on: 2/4/2019 2:46:00 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Freddie Cullen	Individual	Support	No

Comments:

I support Kelii's Law.

Writing in Support of SB242.

Dear Senator Baker and Members of the Senate Committee on Human Services and Committee on Commerce, Consumer Protection, and Health,

I am a psychologist and family therapist who works with children and families affected with disabilities. I am also a member of the Hawaii Fetal Alcohol Spectrum Disorders (FASD) Action Group who tries to find/create services for this invisible disability. This bill hopes to fill the gaps in service for all developmental disabilities, including FASD. All of these disabilities are lifelong and many are ineligible for services once they become adults.

I urge you to please pass this important bill with the amendment that it “includes all disabilities including fetal alcohol spectrum disorders.”

Thank you for your consideration,

Ann S. Yabusaki, Ph.D., MFT

SB-242
Submitted on: 2/5/2019 9:39:18 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Jeanette White	Individual	Support	No

Comments:

SB-242
Submitted on: 2/6/2019 8:50:38 AM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
chanel	Individual	Support	No

Comments:

My son had to wait 1 year before being approved for services from the Developmental Disabilities Division (DD). After appealing to state representatives twice, he finally started receiving services; however, I keep having to fight for these limited hours of service annually just so that I, as a single mother, can keep working to provide for both of my young children and prevent my child with Autism from ending up institutionalizationed at a place like the State Hospital, where, apparently, funds are going towards housing the patients/clients there costing the state/tax payers about $250,000 per patient, while the state refuses to invest $45k per year on our loved ones with Autism. How are we supposed to help our family members with Autism become productive members of society and keep them from being institutionalized, costing the state more money in the long run to house them in hospitals? Why do we as parents have to struggle so hard to get and maintain Medicaid services for our loved ones without going into poverty due to the ridiculous income limits set by Medicaid? There is no way I can afford to pay out of pocket for all the services that my son, or any person with Autism, desperately needs simply because these services are not covered by insurance. With the increasing numbers of Autism in Hawaii, I am confused and heart broken why members of our state and government refuses to help make the lives of parents and family members of our Autism community a little easier by approving SB 242. Perhaps, they never had to experience the struggles of being a caregiver for a citizen with Autism, but with the rapidly increasing numbers of Autism in Hawaii and lack of support for the Autism population, maybe they or their family members will one day soon. Is that what it will take to get support from our legislatures?

SB-242
Submitted on: 2/6/2019 8:36:04 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Kimberly McGee	Individual	Support	No

Comments:

My journey begins when I became a foster parent and a 4 year old was placed in my home. Unfortunately being a foster child he came with a lot of trauma, and was already diagnosed with ADHD and ODD. I was his 3rd foster placement since he was 2 years old. He was already medicated at the age of 4 in ritalin. He continued to be medicated. Hes been hospitalized three times in the psychiatric unit. Suspended multiple times for aggression and destruction of property and attacking adults and elopement. It took 5 years to actually adopt him die ro the immense amount of things we needed to work out for him. We moved to Hawaii in 2017. I immediately applied for DDD services and I was denied. Due to not having a diagnosis based on their criteria. I have gotten a full psychological testing and he has a more specific diagnosis. Since he came here he has been suspended at every daycare, summer program and at school. I had to.move him to a different school because his former school wasn't helping him.get services that he needs. Hes been at his school for 3 weeks and has had 8 incidents that resulted in me picking him up from school. Child psychiatrists are far and few everyone has a wait list. He desperately needs a PAB or CLS to teach him social skills, safety in the community, and among so many more issues he needs help with. Je has a one to one aid at school but that person is just a babysitter. They aren't working with him to help give him new skills or how to facilitate a friendship. All the aid does is take data. I am a former PAB and I know what the job entails, and it's so much more than that. It saddens me that he having so ma y problems in school and at home. We need more than just medal and therapy. We've been in therapy since 2012.his behavior has not changed. His disability is causing him to lose friends, kicked out of school, and making him.feel that he will.never be ok and he will never ha e a true friend. Please change the criteria for DDD services. A lot of families like mine need this. Our children will grow up going to jail. Joining gangs, not able to work because the services are not being provided for our children. We shouldn't have to jump.through hoops to get services for our children. Please we need DDD to protect our children. These services will either encourage our children that they can be in the community safely, the schools will start to understand our special needs kids. This is honestly a life of someone who gets the help he needs, and becomes a successful person or you will cause our children to be bullied, committing suicide from being picked on, geting beat up or killed, or spend the rest of their lives in prison. You have the chance to change our children's future. They are truly the future or the United States.

Thank you

Kimberly McGee

Cheryl Toyofuku
Mother, Grandmother, Registered Nurse, Health Advocate
1025 Noelani Street, Pearl City, HI 96782
January 30, 2019 at 8:30 am.

Representative John Mizuno, Chair House Health Committee
Members of House Health Committee
Hearing Date and Time: January 31, 2019 at 9:30 a.m.
Re: HB42 Relating to Health

Aloha Representive Mizuno and the Members of the House Health Committee,

I am in strong support of HB42 requiring the State's Medicaid managed care and fee-for service to provide coverage for home and community-based services for individuals diagnosed as having autism.

According to the **Centers for Disease Control and Prevention** (CDC) on **Autism Spectrum Disorder (ASD):**
https://www.cdc.gov/ncbddd/autism/data.html

"***About 1 in 59 children has been identified with autism spectrum disorder (ASD)*** *according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network*."
https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm

*"**About 1 in 6 children in the United States had a developmental disability** in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism."*
https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html

The above CDC report of 1 in 59 children identified with an ASD is an estimate which "***is a 14% increase from the 1 in 68 rate in 2016 and a 47% increase from the 1 in 88 rate in 2012. In the 1980s autism prevalence was reported as 1 in 10,000. In the nineties, prevalence was 1 in 2500 and later 1 in 1000."***
https://autismsciencefoundation.org/what-is-autism/how-common-is-autism/

According to Dr. Stephanie Seneff, research scientist from the Massachusetts Institute of Technology (MIT):
"***half the children, eighty percent of the boys born in 2032 will end up on the spectrum—diagnosed on the spectrum.":***
https://www.ageofautism.com/2017/06/mits-dr-stephanie-seneff-on-autism-explosion-vs-media-coverage.html

This autism epidemic has many shocked by the increase in diagnoses over the recent years. Distinctive symptoms of autism (a type of brain damage) include difficulty with social interaction, problems with verbal and nonverbal communication, and repetitive actions or obsessive interests. Testimonies range from mild to disabling and often some with violent behavior due to severe encephalitis.

As a health advocate, I have worked with family and friends that have been touched by autism. An eleven year old who was without speech and still in diapers, toddlers/children who are not able to focus and frequently stem (repetitive motions), teens that have self-destructive behavior and parents who are struggling financially to care for their autistic child, youth or young adult.

Our Hawaii keiki, youth and young adults on the autism spectrum require our understanding, compassion and proactive assistance for behavioral, developmental, medical, nutritional therapies and services. Please support and pass HB42 out of your Committee. Mahalo.

Thank you to the committee for allowing me this opportunity to voice my support for Senate Bill 242 also known as Keli'I's law. Upon reviewing testimony from the Department of Human Services on HB 42 the companion bill to SB 242 I noticed that the amount expended on each individual who is autistic and HCBS eligible is $45,000 per year. It also mentions that if they were to provide services for only 25% of the 1600 autistic individuals, the amount spent would be over 16 million dollars. This statement confirms my fears that the department does not look to qualifying people but to disqualifying people due to money constraints. I look at the $45,000 spent every year as an investment that will pay dividends by not having to institutionalize these people at the Hawaii state hospital which would cost this state $250,000 a year according to department of health statistics; in which a majority of the amount spent would be spent on staff. Failure to provide these much-needed services now could also result in unjustified incarceration of our individuals afflicted with autism; an option which according to representative Joy Buenaventura would cost the state prison system $151,000 a year. I strongly urged his committee to look past being penny-wise and pound-foolish and provide the services that are so needed by the individuals and the families so affected and by doing so enrich the community.

Thank you

John Bernard

SB-242
Submitted on: 2/7/2019 1:04:42 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Joelle Branch	Testifying for =individual, families, advocates of disabilities	Support	No

Comments:

Thank you to the committee for allowing me the opportunity to voice my support for SB 242 also known as Kelii's Law.

My name is Joelle Branch and I am writing testimony on support of Kelii's Law. I am the mom of a 19yo autistic son named Monroe who also has breast cancer. Monroe has the type of Autism that presents violent behaviors. He was not always this way. From a young age he was determined to be developmentally delayed but appeared to thrive. He was always a happy kid until the age of 14 when he had his first meltdown which resulted in him punching me in my face. We immediately sought help from a psychiatrist with his health plan and he was prescribed medication which appeared to help and we saw a happy and thriving kid once again.

However, when Monroe turned 17 in October 25, 2017, he began hitting myself and his grandpa. This time it was different because he was no longer little; he was now a 5'10 250lb BIG kid and myself nor his grandpa could continue to restrain him when he would have meltdowns and turn violent towards us. He was admitted to Queen's Kekela 3 times with each stay no less than 2 months. Our family went through hell reaching out to every agency in Hawaii but no supports were available. We thought we would be able to obtain services from the Developmental Disabilities Division as my son was already in a locked facility, diagnosed as autistic, and developmentally delayed. To our shock my son was deemed in eligible for DD services. We did an informal appeal which my son was still denied services. We were in despair and reaching out to anyone as we knew the only way to bring him home, safely with us and in the community would be to have supports. When he was denied services again our hope just diminished.

During all these battles I still had to work 2 jobs, make calls all day to try and get help on top of trying to maintain support to my son. Everyday my son was in the psych ward a piece of me just died. Aside from that time he was never away from home and I just wondered what was happening to him while in the psych ward because it's not like he could tell me what goes on due to his disability. I just had to pray and hope he was being cared for and not being hurt because I'm not there to protect him. Then I would question whether I could withstand him hitting me just so I could have him home where at least I know he's safe. I was in despair but was soon connected with the Kelii

Foundation who helped me to continue to advocate for my son and thanks to them my son was finally eligible for DD services in March of 2018. Soon after, I was then diagnosed with breast cancer and spent the rest of 2018 battling breast cancer which I am still in treatments for.

I am heartbroken writing this not because of my son or my situation with cancer, our story is only a vessel to be able to help others. My heartbreak comes from knowing that our story is not unique. Through these battles I've met so many families with autistic children who are suffering and trying their best to care for their child who needs supports. Obtaining services from DD could make a difference with helping these families to thrive. It appears resources are expended putting our kids in institutions, in jails or the Hawaii State Hospital just because they were born with a disability. By supporting Kelii's law you could change that outcome and help our loved ones thrive in this community. My son now has DD services and I can attest for our family, he is now out thriving in the community with supports. If someone told me in 2017 my son would be able to do a hike and not have a meltdown I would not believe it.

I went through so many battles with DOE, CAMHD, DD, every agency to get supports for my son. Its battles I wish on no one. Through all of this I don't hold on to fault or blame to any agency or individual. I hold on to all of us parents, families, advocates, providers, DD, and all agencies coming together to improve a system that appears broken and I truly believe we can do it. I want to believe none of these folks in any of these agencies took their jobs to deny help to families, I want to believe they want to help families, and are instead stuck in a broken system. I plead with you, our leaders, to help support this law that will provide supports and bring folks together for our autistic loved ones.

There's also a common fear we all share as parents of what will happen to our children with autism once we pass on. Two weeks ago, I was told by my oncologist that my cancer had spread to my bones and me living a "few" years would be ambitious. Thankfully I got a second opinion and was advised just this past week the tumor in my back was not cancer. The fear of what will happen to my son when I'm gone was even more prevalent than the day I discovered I had breast cancer. While you are making your decision, I would like to ask one final plea of you, our leaders, place yourself in my shoes during these last 2 weeks and ask yourself the following questions: What would you do if my son was your loved one and the second opinion confirmed the first for you where your time on this earth was now limited to a few years? How would you care for your loved one? Where would you go to get services? Who's going to be there for your loved one when you are gone? Will your loved one be homeless or in prison? Will your loved one be scared? Will people take advantage of them? If you are like me and would be in fear of all of these questions if this was your loved one then I beg you to vote in support of Kelii's Law which is a first step to ensuring our loved ones with autism have supports and continuity of care. Mahalo to all of you.

I wrote this testimony above also in support for HB 42. I also had the opportunity to read some very strong testimony from DHS which appears to be in opposition stating the cost to provide services to those with autism would cost $45,000 per year and with approximately 1600 individuals in the state diagnosed with Autism. This confirmed my fears that our autism families are intentionally being denied services because DHS is stating cost and there is no intent to provide services. I'm an emotional wreck having to discuss my son and others in monetary value however it appears this is what everything comes down too so I will do my best. Simple math tells me if all individuals received services it could cost $72,000,000 per year. Which yes I know that number is huge, however, in the hearing for HB 42, us parents were able to listen too other hearings one of which was the Hawaii State Hospital where they indicated to house one individual at the Hawaii State Hospital for a year costs $250,000 which comes up to a little over $55,000,000 per year. I am presenting this to you because we are families who have autistic loved ones that have the scary potential to get sent to the Hawaii State Hospital if services are not provided as evidence of my son above. My sons story is not unique, there are many families suffering in similar situations. I plead with you to please consider the funding for positive impacts on 1600 families of autistics through prevention and keeping our loved ones secure, safe, and productive in the community where many of them have the ability become productive citizens and contributing tax payers. Please don't have our loved ones suffer without supports which could lead to them going to the Hawaii State Hospital at which time our state will then spend $250,000 per year. Another thing to consider is DHS did state it would cost $45,000 per year to provide services for an autistic individual however that does not mean every autistic person will utilize all $45,000 as there are many different needs for autism as an individual. In addition, I watched a PBS show where Representative Joy Buenaventura stated that it costs the state $151.00 per day to house someone in jail which is another place our loved ones could end up going too without help. I plead with you to provide supports to keep families together versus having them ripped apart and spending more money in the long run when it could've been prevented.

Mahalo,

Joelle Branch

SB-242
Submitted on: 2/7/2019 1:30:37 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Desi McKenzie	Individual	Support	No

Comments:

Desiree A. F. McKenzie

Aubrey L. McKenzie

95-510 Wikao St. G106

Mililani, Hawaii 96789

Hawaii Ambassadors

National Down Syndrome Society

February 7, 2019

Aloha!

RE: SB242

Aubrey and I support SB242.

Aubrey, 20, was born with Down syndrome. Aubrey was diagnosed with Autism as well--by psychologists and psychiatrists provided by the Hawaii Department of Education when Aubrey first showed the signs of Autism at age 9. She is also mildly hearing impaired.

The Hawaii DOE has refused to provide Aubrey the communication and mental health supports she has needed since she alleged assault in her high school five years ago.

In addition, the Hawaii DOE has refused to provide the *urgent medically necessary* ABA therapy in school that Aubrey so desperately needs for **ELEVEN LONG YEARS**.

Despite relentless advocacy over the past four years citing Hawaii Law Chapter 465D and multiple recommendations for 40 hours of ABA in school and community settings by multiple experts--the Hawaii DOE has failed to provide Aubrey with ABA Therapy under the supervision of a BCBA to date.

As of today, Aubrey's IEP is almost a year overdue for completion as Pearl City High School IEP team continues to delay the IEP process intentionally to delay her access to medically necessary mental health and ABA services.

Pearl City High School also refuses to amend Aubrey's IEP after multiple requests by our family to enable Aubrey access to medically necessary ABA services.

It should also be noted that the Department of Education finally brought on a BCBA last school year to evaluate Aubrey who refused to recommend ABA Services in his ABA Report. Our family rejected his report because he refused to recommend ABA therapy and thus we replaced his report at the IEP table--with an appropriate report **recommending 40 hours of ABA Therapy from BCBA Holsambeck Behavioral Health Services funded by HMSA Medicaid.**

Holdsambeck BCBA has evaluated Aubrey twice in the past 12 months and has continued to recommend 40 Hours of ABA Therapy provided in the school setting and in the community at Aubrey's IEP table. **Even with Medicaid funding the DOE still refuses to provide Aubrey with ABA services.** Aubrey has been approved for THREE CYCLES of ABA Therapy already by HMSA Medicaid and has not been able to access one minute of ABA as of yet--as school refuses to allow HMSA Funded Medicaid in her school setting.

In four months when Aubrey turns 21 her access to ABA funded by Medicaid is supposed to end?

It should also be noted that the Department of Health Developmental Disabilities Division could also be enabling Aubrey access to ABA but are not. **Aubrey's case manager has not contacted our single parent family for months. Aubrey's ISP is also months overdue for completion. Thus the Department of Human Services has also successfully delayed Aubrey's medically necessary ABA services.**

As a result of the absence of ABA Therapy at all by any qualified personnel anywhere, Aubrey has severely regressed in all areas to include behavior, communication, academics, etc. In addition, she is suffering from anxiety often refusing to go to school, and the self-calming repetitive behaviors like scratching herself and picking her thumbs until they bleed, engaging in unending self-talk that is harder and harder to redirect, etc. that makes it difficult for her to function socially—but moreover LEARN in school and be accepted when she navigates society. She is increasingly afraid to go to movies, concerts, fly an airplane, sometimes to just go out of the house and out into the community where she once thrived!

We are crippling her without appropriate mental health supports and ABA therapy!

Her anger grows as she is acutely aware of how underestimated and undervalued she is in this world.

Her confidence disappears more and more every day.

With our inaction we are destroying her.

Every human being has the right to access appropriate medical treatment and to access the supports they need to thrive in their community and become independent.

The passage of SB242 and the right language could make all the difference for Aubrey when the Hawaii DOE, Hawaii Department of Human Services/DOH have successfully--but moreover--recklessly delayed her medically necessary treatment when she soon will age out.

Thank you for valuing Aubrey as a human being and enabling her to become her best self.

To become less reliant on a system that encourages her to be reliant.

To become a contributing member of her community once agai

Her online resume alone proves that she can work and contribute to our community.

Every human is worth our sincere and collective efforts to empower them.

Mahalo for your help.

Desi and Aubrey McKenzie

SB-242

Submitted on: 2/7/2019 1:56:28 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Melodee Haole	Individual	Support	Yes

Comments:

I WOULD LIKE TO THANK ALL THE SENATORS THAT SIGNED TO INTRODUCE SB 242 AND TO ALLOW US PARENTS TO HAVE A VOICE. My name is melodee Haole, I am the mother of Kelii who is 25 years old, he has severe autism with multiple diagnoses . Kelii been receiving DDD services from 8 years because he was diagnosed with a genetic disorder, kelii was high functioning played competitive soccer (Hysa), played basketball, karate, texted his friends, played video, had a mild learning disability. At 16 years old kelii behaviors started changing, he became very aggressive, had self injurious behaviors, hit his head, try to dig his eyeballs out, kelii then was placed in Queens Psych unit two times. At that time DDD was trying to release kelii because they said he was high functioning and had mental illness and he should be receiving services from CAMHD. OUR LIFE was in Chaos!, we had no help and didn't know what was happening to our son, later we found out through blood test that my son had a vaccine injury his antibodies could not fight of the vaccine because his genetic disorder Could have the potential to have low immune system. The Spect scan showed Kelii had brain damage due to neurotoxicity. slowly he started Deteriorating and ended up in a Catatonic stage we had to bath him, feed him and change his diapers. DDD was still trying to release my son, using kelii had mental illness. I got in touch with Senator Mike Gabbard, and because of senator Gabbard we received DDD and Camhd services together, but this took us over 6 months to get the appropriate services. In the mean time We had to bring home my middle son who was attending SMU to help us with his brother. Over time my son brain started healing but he had severe autistic violent behaviors, by 20 years old we started looking around to transition him to adulthood and that is when I realize there was nothing for young adults with severe autism and behaviors. The DDD worker gave me three choices, 1) to give Kelii up to the State, 2) put him in a mental institution, 3) quit work. I DECIDED TO QUIT WORK AND START A NON PROFIT FOR AUTISM AND OTHER SPECIAL NEEDS. In the Past 6 years of doing this non profit, I helped and Met many families from all the islands that been struggling to get services From DDD for their Autistic child and young adult with behaviors, multiple diagnosis with mental illness. I am heart broken to know, The State Hospital, where, apparently funds are going towards housing patients/clients this is costing the State and tax payers about $250,000 per patients, while the State, while DHS states in their testimony DDD WAIVER IS APPROXIMATELY SPENDB$45,000 A YEAR AND THEY ARE SERVICES APPROXIMATELY 1,600 BENEFICIARIES WITH AN AUTISM DIAGNOSES in 2017. HOW ARE WE SUPPOSED TO HELP OUR FAMILY MEMEBER WITH AUTISM TO BECOME A PRODUCTIVE MEMBERS OF

SOCIETY AND TO KEEP THEM FROM BEING INSTITUTIONALIZED WITHOUT THE APPROPRIATE SERVICES. THANK YOU MELODEE Haole

SB-242
Submitted on: 2/7/2019 1:57:25 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Kathryn Taketa-Wong	Individual	Support	Yes

Comments:

My brother is an adult with autism and this law would help provide services for vocational training and supportive housing which is what he needs. I grew up looking for ways to help him so I became a naturopathic physician who primarily works with individuals with autism and special needs. I see many children and adults everyday who are in need of services, especially after they age out of the DOE. This bill would provide those much needed services for these children and adults. Particularly if services are provided to younger children, this would help to improve their functional level and greatly reduce the cost of their medical and therapeutic care when they are older.

Thank you,

Dr. Kathryn Taketa-Wong

SB-242
Submitted on: 2/7/2019 1:58:13 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Jesica La Rue	Individual	Support	No

Comments:

Aloha. We are parents of a 9 ur old son and are commuted to his growth . yes to this bill please. Mahalo

SB-242
Submitted on: 2/7/2019 2:21:23 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Kristine Uramoto, MD	Individual	Support	No

Comments:

As a physician and parent of a young adult with autism, I can attest to the need for home and community-based treatment. My son and most other people with autism cannot learn the necessary skills needed for activities of daily living only in a school setting (autistic children have difficulty generalizing skills from one setting to another). Most parents/students cannot get home or community-based services authorized through the DOE - therefore, Medicaid coverage for these services can be critical for these autistic students. Therefore, I support SB 242.

SB-242
Submitted on: 2/7/2019 2:30:58 PM
Testimony for HMS on 2/8/2019 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Nellie Rios	Individual	Support	No

Comments:

As the parent of an autistic child, I fully support this bill. There are environmental stimuli that a child needs help in overcoming that cannot be replicated in a clinical setting. Having help in the community setting will aid the child to better navigate in their world. As a parent it has been at times very difficult to have your child have an outburst out in public and not have any assistance in calming or deescalating the situation. We would greatly appreciate the passage of this bill.

Thank