



STATE OF HAWAII
DEPARTMENT OF HEALTH
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Testimony COMMENTING on SB 242 SD1
RELATING TO HEALTH

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

Hearing Date: February 25, 2019
10:30 a.m.

Room Number: 211

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

4 **Department Testimony:** The Department of Health respectfully offers comments on SB242
5 SD1.

6 DOH commits to working with DHS and other stakeholders to examine access to services for
7 individuals with autism through the QI health plans and through the 1915(c) Medicaid Waiver
8 for People with Intellectual and Developmental Disabilities (I/DD) operated by the DOH-
9 Developmental Disabilities Division. It is important for the Departments to understand if there
10 are gaps in coverage for individuals for autism and fetal alcohol syndrome, what treatments and
11 supports they need, and where families may need help in accessing services. We believe the
12 more we collectively understand federal benefits and requirements, the more we can ensure
13 necessary services are accessed for people with autism and fetal alcohol syndrome.

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

1

2 For example, SB242 SD1 states that all applicable federal requirements must be met for
3 individuals to be in an HCBS program. In HCBS programs, eligibility is not based on a
4 diagnosis, but on a Level of Care (LOC) assessment of the person's functional limitations. This
5 is a Medicaid requirement. In the I/DD waiver, for example, participants are required to have
6 substantial functional limitations in three or more areas of major life activity such as self-care,
7 receptive and expressive language, learning, mobility, self-direction, capacity for independent
8 living, and economic self-sufficiency. In addition, participants must meet the LOC requirement
9 that they would otherwise need the LOC of an institution if not for HCBS services. There is a
10 wide range of functioning within diagnoses such as autism and fetal alcohol syndrome, and many
11 people with autism do not need the substantial levels of support that would be provided by
12 HCBS programs.

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

18 We suggest that SB 242 SD1 be amended to convene stakeholders to discuss these issues. The
19 DOH looks forward to working with stakeholders, and thanks you for the opportunity to testify.

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 24, 2019

TO: The Honorable Senator Donovan M. Dela Cruz, Chair
Senate Committee on Ways and Means

FROM: Pankaj Bhanot, Director

SUBJECT: **SB 242 SD1 – RELATING TO HEALTH**

Hearing: Monday, February 25, 2019 10:30 a.m.
Conference Room 211, State Capitol

DEPARTMENT'S POSITION: The Department of Human Services (DHS) offers comments on 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 or fetal alcohol spectrum disorder (FASD).

DHS currently provides coverage of HCBS to individuals with autism or FASD in both the QUEST Integration (QI) program and in the Medicaid waiver for individuals with intellectual and developmental disabilities (I/DD waiver) administered by DOH-DDD. Notably, in both programs, all beneficiaries receiving HCBS must meet a Level of Care (LOC) criteria independent of their diagnosis. LOC criteria is a federal requirement and relates to a beneficiary's functional needs.

As LOC criteria is federally required, a waiver request to CMS for services based only upon diagnosis will likely be denied. Consequently, the program would need to be completely state funded and would require an additional general fund appropriation.

DHS intends to work with DOH and stakeholders to address issues and challenges raised in stakeholder meetings, briefings, and testimony to improve access to services for those

currently eligible and to examine processes and additional supports to provide families who do not currently meet LOC criteria with some relief.

PURPOSE: The purpose of this bill is to assist persons who have been diagnosed with autism or FASD to participate in their communities by providing Medicaid coverage for HCBS in both managed care and fee-for-service. Under the bill, DHS shall seek a Section 1115 Demonstration waiver to expand HCBS coverage.

Individuals with autism or FASD and their families face many difficult and profound challenges on a daily basis. DHS appreciates that the legislature and stakeholders have highlighted how the present system of care can be complicated to navigate. DHS has benefited from hearing from families and individuals directly affected by autism or FASD. The issues raised in stakeholder meetings, briefings, and testimonies for this bill and for similar bills have shown that these problems need thoughtful solutions.

DHS has committed to work with its partners at Developmental Disabilities Division in the Department of Health (DOH-DDD) to comprehensively review access to HCBS and other support services for individuals with autism or FASD in response to these pressing issues. DHS and DOH-DDD can begin working with stakeholders immediately to explore where coverage gaps exist and how they can be resolved under current state and federal authorities or waivers. DHS respectfully suggests that this may be a better approach to providing individuals with autism or FASD and their families with additional support for the following reasons.

DHS believes that the issues that families and stakeholders have brought up regarding the state's HCBS programs relates to federally-required Level of Care (LOC) requirements. While DHS currently provides coverage of HCBS to individuals with autism or FASD in both the QUEST Integration (QI) program and in the Medicaid waiver for individuals with intellectual and developmental disabilities (I/DD waiver) administered by DOH-DDD, notably, in both programs, all beneficiaries receiving HCBS must meet a LOC criteria independent of their diagnosis.

LOC criteria relates to a beneficiary's functional needs. Under federal rules, an individual's functional needs qualify them for HCBS rather than their diagnosis. An individual must be assessed to have some functional limitations that reflect the need for HCBS. For autism or FASD, an individual eligible for HCBS must be an individual who would otherwise require the LOC furnished in Intermediate Care Facilities for Individuals with Intellectual

Disability (ICD/IID) or some other type of institution. In other words, they must meet an institutional level of care. To reiterate, this is a federal requirement.

Currently, the LOC requirement is what qualifies individuals with autism or FASD for HCBS rather than their diagnosis in both the QI program and the I/DD waiver. Some beneficiaries with autism may function at a high level and do not qualify 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.

DHS and DOH-DDD are willing and intend to work with stakeholders to help find ways of making sure that individuals with autism or FASD that do meet LOC are appropriately determined and given access to HCBS. If there is confusion for individuals who should be receiving HCBS under current rules then DHS would like to resolve that confusion and make sure eligible individuals are receiving HCBS.

For individuals who do not meet federally-required LOC for HCBS, DHS intends to work with stakeholders to review and study what processes or additional supports and services can be put into place that would give individuals and families some additional relief. DHS intends for that review to be finished before the next legislative session.

DHS appreciates the intent of this bill but does not think the approach prescribed by the legislation will result in a positive outcome using federal matching funds because it explicitly leaves out a LOC requirement. In SSCR298, the Committees on Human Services and Commerce, Consumer Protection, and Health found that this legislation “ensures that home and community services are provided to all individuals diagnosed with autism, regardless of the level of care needed.” A HCBS program designed under this bill’s language would not be approved under federal authorities because CMS would not waive the LOC requirement. A waiver request would be denied and Section 5 of the legislation would never take effect as outlined in Section 9.

If DHS were to provide coverage for HCBS for individuals with autism or FASD without LOC requirements, then the State would have to appropriate additional state dollars and devise a new program. 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 Hawai’i Medicaid 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. A cost study would have to be undertaken to get a better estimate of the costs for expanding coverage to individuals with autism or FASD. The State would have to pay for all of those services for individuals not meeting LOC requirements using state funds only as there would not be any federal Medicaid matching dollars available.

Thank you for the opportunity to testify on this bill.

SB-242-SD-1

Submitted on: 2/22/2019 1:53:37 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---|---------------------------|---------------------------|
| Kenichi Yabusaki | Testifying for Hawaii Fetal Alcohol Spectrum Disorders Action Group | Support | Yes |

Comments:

Aloha Senator Dela Cruz and WAM Committee Members:

I strongly support and humbly ask for you to pass SB242SD1 which will provide home and community-based services to those afflicted with Autism and Fetal Alcohol Spectrum Disorders (FASD). Both Autism and FASD are life-long, permanent, brain-based disorders and those afflicted with these conditions should have the necessary Medicaid home and community-based services. In a society that has made alcohol consumption as part of its culture, it is the responsibility of our government to ensure those afflicted with FASD by prenatal exposure to alcohol are given the necessary services to lead a productive life. There are no conclusive causes of Autism; to this end, those with Autism should be given both home and community-based Medicaid services as well so they can have a productive life. I humbly ask for you to pass SB242 SD1 for these special need individuals. Mahalo nui,

Kenichi K. Yabusaki, Ph.D.

SB-242-SD-1

Submitted on: 2/22/2019 2:25:33 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

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

Comments:

I support Keli's Law.

Dear Members of the Ways and Means Committee,

I am writing in strong support of SB242. I see this bill as an access to service issue that is critical to the health of people with brain-disorders such as fetal alcohol spectrum disorders (FASD). I am a psychologist and family therapist who treats individuals and families affected by FASD. My clients range from severe to mildly impaired. In spite of the range of disabilities, FASD is a brain-based disorder that requires life-long supportive services. Without these services, the individual can become increasingly impaired with mental health problems and other issues that can result with their entering into the criminal justice, homeless, unemployed systems. Too many are lost because of the lack of access to services once they have "aged out of services for youth."

I lost a young client to mental health and brain damage issues recently because the mother used alcohol while pregnant. I was informed that he was facing assault charges; yet I knew he did not know how to control his impulses and could not understand why he was being charged. The lack of understanding and remorse that follows breaks my heart. A good, gentle, kind young man was to be incarcerated because he did not have the strong guidance needed for brain-injured individuals from our community. Again, the lack of services astounds me.

Mahalo nui loa for your consideration.

Ann S. Yabusaki, Ph.D, MFT

SB-242-SD-1

Submitted on: 2/22/2019 3:08:43 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|--------------------------------|---------------------------|---------------------------|
| Ernell Bernard | Testifying for Keli foundation | Support | No |

Comments:

Support keli foundation



SB242 Home and Community-Based Services for Autism and Fetal Alcohol Spectrum Disorder

COMMITTEE ON WAYS AND MEANS:

- Sen. Dela Cruz, Chair; Sen. Keith-Agaran, Vice Chair
- Monday, Feb. 25, 2019: 10:30 am
- Conference Room 211

Hawaii Substance Abuse Coalition Supports SB242:

GOOD MORNING CHAIR, VICE CHAIR AND DISTINGUISHED COMMITTEE MEMBERS. My name is Alan Johnson. I am the current chair of the Hawaii Substance Abuse Coalition (HSAC), a statewide organization of almost 40 non-profit alcohol and drug treatment and prevention agencies.

FASD is a preventable and treatable disability.

There are significant and increasingly improved interventions that are available for mental health issues such as Fetal Alcohol Spectrum Disorder and other disorders.

FASD is a problem in Hawaii and efforts can be made to prevent this devastating condition as well as treat children and adults to increase functioning:

- FASD is a range of neurodevelopmental (brain-based) disabilities that can affect any person exposed to alcohol before birth.
- FASD effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications that often co-occur with substance abuse and mental health issues.
- Proactive health care programs and interventions can help people develop new learning and coping skills to help them improve functioning. Modifications to existing treatment models can be very effective.
- FASD is very expensive to healthcare with estimates that the lifetime costs for each person is estimated to be over \$2M.
- Individuals with FASD are involved with the criminal justice system at an alarming rate. Youth and young adults with FASD have a form of brain damage that may make it difficult for them to stay out of trouble with the law. Without the aid of proper treatment, they do not know how to deal with police, attorneys, judges, social workers, psychiatrists, corrections and probation officers, and others they may encounter.

With home-based and community-based healthcare supported by Medicaid, we can make a difference:

- Understand the disorder and reshape some of our interventions to change a child's behavior and improve functionality.
- Reduce the prevalence of FASD.
- Empower care givers to help FASD people reach their full potential.

- Address stigma by educating our communities to understand the complexities of this disability while promoting a more inclusive culture.
- Greatly improve upon outcomes through measurement brought about by Medicaid funding.
- Reduce childhood trauma by increasing supports for high-risk families, building resilience, and improving access to treatment.

Working together, we can join the growing number of states that claim to be a “FASD-Informed State.”

We appreciate the opportunity to provide testimony and are available for questions.



**TESTIMONY COMMENTING ON S.B. 242
RELATING TO HEALTH**

**THE SENATE
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2019
COMMITTEE ON WAYS AND MEANS**

Monday, February 25, 2019, 10:30 a.m., Conference Room 211

February 22, 2019

The Honorable Donovan M. Dela Cruz, Chair
The Honorable Gilbert S.C. Keith-Agaran, Vice Chair

Dear Chair, Vice Chair, 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),

Page 2

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. Delleria
Former Director (emeritus)

SB-242-SD-1

Submitted on: 2/22/2019 4:59:47 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| 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

SB-242-SD-1

Submitted on: 2/23/2019 12:39:26 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|--|---------------------------|---------------------------|
| Louis Erteschik | Testifying for Hawaii Disability Rights Center | Support | No |

Comments:



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_SD1
RELATING TO HEALTH

COMMITTEE ON WAYS AND MEANS
Senator Donovan M. Dela Cruz, Chair
Senator Gilbert S.C. Keith-Agaran, Vice Chair

Monday, February 25, 2019, 10:30am
Conference Room 211
State Capitol
415 South Beretania Street

The Hawai'i Psychological Association (HPA) strongly supports SB242 SD1. 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 a developmental disability, including fetal alcohol spectrum disorder, and will help to ensure that they have access to the kinds of services that will allow them to participate in their communities.

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

Sincerely,

Julie Takishima-Lacasa, Ph.D.
Chair, HPA Legislative Action Committee

SB-242-SD-1

Submitted on: 2/22/2019 8:33:59 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| 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-SD-1

Submitted on: 2/23/2019 5:17:21 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| ALYSON MATSUBARA | Individual | Support | No |

Comments:

I am in total support of this bill, as I have a daughter who is autistic, and I would feel at ease knowing that she would have the support from the State for home or community based services. Please have a heart for our children and our families of those affected by autism. It is real and they so need your kokua. There are are varying degrees of autism, but it does not make one less significant than the other. I would hope that you would help all children affected by autism. I would hope that the State of Hawaii would have our backs to help our children and families. We want a quality life for those affected by autism. Please consider passing SB242 SD1. Mahalo! Alyson & Wayne Matsubara

SB-242-SD-1

Submitted on: 2/23/2019 5:52:51 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Kim Haine | Individual | Support | No |

Comments:

The Government must be responsible for not only providing services for these children, but for putting an end to this epidemic. Current autism statistics are 1 in 36 children, with a continued trajectory of 1 in 2 by 2032. Hawaii and ALL communities will not be sustainable at this rate. We need solutions. Our Legislators and the media cannot continue ignoring this issue. Autism is an environmental, not genetic, disorder. The GMO foods, pesticides, and excessive vaccines during infancy must be stopped.

SB-242-SD-1

Submitted on: 2/23/2019 9:58:08 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Steven Cummings | Individual | Support | No |

Comments:

I sincerely thank all those who introduced and support this measure, I am a parent of twins who are on the Autism Spectrum and strongly support any measure that will provide additional support to Hawaii's Autistic individuals. It is nearly impossible for the average parent to financially provide the necessary medical and developmental support to their autistic kids that will give them a fighting chance to someday become productive citizens within our community. We as a community must provide all the support possible as many individuals on the spectrum may become a burden to our community. Autism is at epidemic proportions and this will not simply go away.

SB-242-SD-1

Submitted on: 2/23/2019 11:03:04 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Masako Cummings | Individual | Support | No |

Comments:

My 10 year old son is severe autism, non-verbal, not toilet trained, sensory issue and behavior problem due to the frustration of communication, overwhelming the environment and confusions. At school, he has 1:1. At home, I have to literally be with him since he doesn't aware danger and has behavior problems.

I stop taking him out in the community because of his behavior. He screams, yells, insuring himself, agressions and running around enough to scare small children and adults. When he was small, it was still acceptable to adults, but as he get older, we don't have any place that we can take him too. Last year, we had to move the place because the neighbor complained my son's screaming at night. There is no place in the state of Hawaii for us to feel safe and peaceful with my son.

We don't have any family members to help us. We are very poor family since I cannot work full time . I am full time mom to take care of severe autims child. Everyday, I am talking to myself that I am not sure how long I can continue to take care of my son. I am exhausted and overwhemed eveyday. My son's life depends on support he will receive.

We need your understanding and lots of supports for severe autism children and adults.

SB-242-SD-1

Submitted on: 2/23/2019 11:34:56 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| Teresa Ocampo | Individual | Support | Yes |

Comments:

I strongly support SB 242 SD1, providing Home and Community Based Services (HCBS) for children with autism and fetal alcohol spectrum disorder. Although DHS seems reluctant in seeking a section 1115 waiver to amend the state Medicaid plan to include HCBS, I hope DHS will recognize that these services are long overdue for these children.

Children in the DOE can receive an array of support services. Typically developing children can freely participate in many learning and educational programs to fortify their education. However, most special education students must go through a more formal process to get educational services through an Individualized Educational Program such as speech, occupational therapy, skills support, and Applied Behavioral Analysis and therapies. These services are necessary to teach children diagnosed with autism and other qualifying disabilities various skills and behaviors in order to receive a free appropriate public education. These skills are supposed to help children learn skills that will help them become independent in the community as young adults. Furthermore, children who have state Medicaid or private medical insurance can also get some of these services through their plans outside of school.

However, once special education children leave the DOE at 23 years old, there is nothing for them in the community. Many do not have a transitional IEP as required by IDEA and now these young adults have no plan in place, no place to go, no services or support, and minimal to no purposeful or useful programs to help them learn basic life skills such as going to the store, or buying food. The DOH and DHS currently have minimal programs and services for this group of young adults. Their families are their only lifeline for survival but what happens to these children when their parents die? SB 242 SD1 is desperately needed to give these individuals a chance to survive. Their lives have value and must be given a purpose. SB 242 SD1 gives them a chance to be independent.

Lastly, according to a 2013 report by the Cato Institute,[\[1\]](#) Hawaii provides over \$49,175 worth of entitlements to residents who do not work, the equivalent of \$60,590 in pre-tax income annually, the highest in the nation. Many people who receive free bus passes, EBT cards, and even prescription opioids have been known to sell these freebies for cash month after month.

While the DOH and the DHS claim that the Home, Community Based Services (HCBS) proposed in SB 242 SD1 will cost too much to serve the neediest children in this state, I refuse to believe that our taxpayer dollars are better spent by giving away the equivalent of \$60,590 annually to those people who abuse the generosity of the State, while autistic children cannot even qualify for services and respite that they desperately deserve and need for survival. I am sure DHS and DOH can successfully implement HBCS for these children if they really wanted to.

Again, I strongly support SB 242 SD1.

Sincerely,

Teresa Ocampo

[1] <https://dailycaller.com/2013/08/20/study-welfare-pays-more-than-work-in-most-states/>

SB-242-SD-1

Submitted on: 2/24/2019 12:10:25 AM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Lois J Young | Individual | Support | No |

Comments:

I strongly support this bill which will help our families with autistic children with financial aid and services.

Please vote Yes in SUPPORT of this bill.

Mahalo,

Lois Young

Cheryl Toyofuku
Mother, Grandmother, Registered Nurse, Health Advocate
1025 Noelani Street, Pearl City, HI 96782
February 24, 2019 at 6:50 a.m.

Chair Senator Donovan Dela Cruz of Senate Ways and Means Committee
Members of the Senate Ways and Means Committee
Hearing Date and Time: February 25, 2019 at 10:30 am.
Re: SB242 SD1 Relating to Health, Autism, Home and Community Based Services

Aloha Chair Dela Cruz and Members of the Senate HMS and CPH Committees

I am in strong support of SB242 SD1 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 and fetal alcohol spectrum disorder.

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 SB242 SD1 out of your Committee. Mahalo.

Feb. 24, 2019 8:30 a.m.

Chairman Donovan Delacruz, Members of the Senate Ways and Means Committee

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 urge this 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-SD-1

Submitted on: 2/24/2019 9:14:59 AM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| LAURIE A ADAMS | Individual | Support | No |

Comments:

Caregiving is very rewarding yet very

demanding for autistic adults. The

families need State Svcs to assist as

families work financially to survive to

provide for food & shelter alone not to mention

medical costs for the autistic adult.

Sometimes caregivers without any support

Develop their own mental & physical health deterioration

from so much emotional & physical stress put on ones body and the

one they caregiver for outlives them. I am in full support

of this bill. As I'm a single parent of an adult autistic son

along with other diagnoses & would definitely

appreciate State Services for support in our quality of life.

Thank you,

laurie

LATE

SB-242-SD-1

Submitted on: 2/24/2019 10:26:52 AM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Joelle Branch | Individual | Support | No |

Comments:

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

My name is Joelle Branch and I am writing testimony on support of Keli's Law to provide services to those with Autism. I am the mom of a 19yo autistic son named Monroe who is diagnosed with 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. At the age of 14 we experienced our first dose of violent behaviors and received support from our health plan which appeared to alleviate these symptoms.

However, when at age 17 on October 25, 2017, Monroe began hitting myself and his grandpa. This incident and the consecutive violent meltdowns attributed to the autism would be different because Monroe was no longer little. He had grown into a 5'10 250lb man that myself nor his grandpa could continue to restrain and the violent meltdowns would become progressively worse. As a result, 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 at minimum 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 ineligible 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 psychiatric ward a piece of me just died and I am not certain where I found the strength during this time to keep fighting. Aside from that time Monroe 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 Keli

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.

The only purpose for me sharing my situation with cancer is to illustrate the common fear many families have as to what will happen to our children with autism once we pass on and/or are no longer able to advocate for them because unfortunately the challenges of life does not stop for us just because our kids experience these afflictions. I would like to plead with all of you, our leaders, to place yourselves in my shoes and those of other families and ask yourselves the following questions: How would you care for your loved one who has autism? 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 were your loved one then I beg you to vote in support of Keli's Law.

I 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 1600 autistic 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 the same testimony, I could be wrong but it is my understanding that DHS has the capability of asking for a different type of waiver to allow access for services so that tells me they do have the ability to make positive changes. In addition, I watched a PBS show where Representative Joy Buena Ventura 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.

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.

Mahalo,

Joelle Branch

LATE

SB-242-SD-1

Submitted on: 2/24/2019 3:55:21 PM

Testimony for WAM on 2/25/2019 10:30:00 AM

| 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:

February 24, 2019

The Honorable Donovan M. Dela Cruz, Chair
The Honorable Gilbert S.C. Keith-Agaran, Vice Chair
Senate Committee on Ways and Means

Re: SB 242, SD1 – Relating to Health

Dear Chair Dela Cruz, Vice Chair Keith-Agaran, and Committee Members:

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 242, SD1, which 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 or fetal alcohol spectrum disorder. Additionally, SB 242, SD1 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. Some of the services identified in this bill are already provided under the child health component (Early Periodic Screening, Diagnostic and Treatment) of Medicaid.
2. Home and community-based services (HCBS) are already available for Medicaid individuals diagnosed with autism or fetal alcohol spectrum disorder, through the Department of Health's Developmental Disabilities Division (DDD), as long as they meet the level of care criteria.
3. Requiring coverage for HCBS for individuals diagnosed with autism or fetal alcohol spectrum disorder, 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, SD1.

Sincerely,



Pono Chong
Vice President, Government Relations

LATE

SB-242-SD-1

Submitted on: 2/25/2019 10:58:52 AM

Testimony for WAM on 2/25/2019 10:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Gabriel | Individual | Oppose | No |

Comments: