



STATE OF HAWAII
DEPARTMENT OF HEALTH
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Honolulu, HI 96801-3378
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**Testimony COMMENTING on SB 242 SD2
Proposed HD1 - RELATING TO HEALTH**

REPRESENTATIVE JOHN M. MIZUNO, CHAIR
HOUSE COMMITTEE ON HEALTH

Hearing Date: March 12, 2019
9:00 a.m.

Room Number: 329

1 **Fiscal Implications:** Potential cost of SB 242 SD2 Proposed HD1 would need to be studied, but
2 is believed to be substantial. The Department of Health (DOH) defers to the Department of
3 Human Services (DHS).

4 **Department Testimony:** The DOH respectfully offers comments on SB242 SD2, as well as on
5 SB242 SD2 Proposed HD1.

6 DOH commits to working with DHS and other stakeholders to examine access to services for
7 individuals with autism through the QUEST Integration (QI) health plans and through the
8 1915(c) Medicaid Waiver for People with Intellectual and Developmental Disabilities (I/DD)
9 operated by the DOH-Developmental Disabilities Division. It is important 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 The Proposed HD1 proposes coverage for individuals with an autism spectrum disorder
15 diagnosis through Medicaid home and community-based services (HCBS) in both managed care
16 and fee-for services programs. It proposes an array of services to be part of that coverage. This
17 bill asks DHS to seek a waiver under the 1115 authority of the Social Security Act to provide
18 these services under the QI health plans.

1 The Proposed HD1 states that all applicable federal requirements must be met for individuals to
2 be in an HCBS program. In HCBS programs, eligibility is not based on a diagnosis, but on a
3 Level of Care (LOC) assessment of the person's functional limitations, which is a Medicaid
4 requirement. In the I/DD waiver, for example, participants are required to have substantial
5 functional limitations in three or more areas of major life activity such as self-care, receptive and
6 expressive language, learning, mobility, self-direction, capacity for independent living, and
7 economic self-sufficiency. In addition, participants must meet the LOC requirement that they
8 would otherwise need the LOC of an institution if not for HCBS services. There is a wide range
9 of functioning within diagnoses such as autism and fetal alcohol syndrome, and many people
10 with autism and FASD do not need the substantial levels of support that would be provided by
11 HCBS programs.

12 It is important to note, if the Proposed HD1 were to pass as currently drafted, substantial funding
13 would be needed as it asks for access to HCBS programs without meeting the Medicaid LOC
14 requirement. It is unclear if the Centers for Medicare and Medicaid Services (CMS) would
15 approve this approach, which means the State would have to fully finance service for people that
16 do not meet the HCBS LOC requirements.

17 **Suggested Amendment to the SB242 SD2 Proposed HD1:**

18 The DOH suggests deleting SECTIONS 3-5 of the Proposed HD1. The DOH further suggests
19 that the task force in SECTION 7 be established in DHS as discussions regarding access to
20 services for people with ASD and FASD are broader Medicaid policy issues, and would involve
21 the 1115 waiver as well as the I/DD waiver.

22 Thank 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

March 11, 2019

TO: The Honorable Representative John M. Mizuno, Chair
House Committee on Health

FROM: Pankaj Bhanot, Director

SUBJECT: SB 242 SD2 Proposed HD 1 – RELATING TO HEALTH

Hearing: Tuesday, March 12, 2019 9:00 a.m.
Conference Room 329, State Capitol

DEPARTMENT’S POSITION: The Department of Human Services (DHS) offers comments on the proposed HD1 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 supports the intent to study and make recommendations on ways to improve HCBS coverage and suggests friendly amendments.

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 Developmental Disabilities Division in the Department of Health (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.

DHS has concerns about sections 3 through 5 of the proposed HD1 because a waiver request to CMS for HCBS based only upon diagnosis will be denied. Valuable time and resources that could have been spent working with the legislature and stakeholders to improve access to HCBS for individuals with autism and FASD, will instead be spent on an unsuccessful effort. Thus,

DHS suggests amendments to use the task force proposed in Section 7 to review and make recommendations on Medicaid policies that could be approved by the federal government.

PURPOSE: The purpose of the proposed HD 1 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. The bill also establishes a task force to address issues relating to access of essential services for the State's developmentally and intellectually disabled individuals.

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. We have 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.

We believe that the issues that families and stakeholders have brought up regarding the state's HCBS programs relates to federally-required Level of Care (LOC) and/or needs-based criteria 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 and needs-based 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. To reiterate, this is a federal requirement.

DHS appreciates the intent of this bill but does not think the approach prescribed by the legislation will result in a positive outcome because it explicitly leaves out a LOC requirement. A HCBS program designed under this bill's language would not be approved under federal authorities because CMS would not waive the requirement that HCBS be tied to an individual's functional needs.

Section 11 makes the new HCBS coverage requirements for individuals with autism and FASD in Section 5 conditional upon federal approval of a waiver. DHS is concerned that no improvement in HCBS coverage for individuals with autism and FASD would be able to happen with the current bill since the federal government will not approve a waiver submission as mandated in the legislation.

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 collaborative approach to providing individuals with autism or FASD and their families with additional support would be a better course of action.

Should the legislature choose to pursue a more formal stakeholder process, DHS suggests adding a new Section 7(b)(5) to read “[p]roposed Medicaid policies to increase access to HCBS and other Medicaid services for individuals with developmental and intellectual disabilities.” The intent of this language is to give the task force the charge to review current Medicaid policies and to propose potential changes or improvements to coverage that would be acceptable to the federal government so that the State can get a federal match to pay for the services.

DHS suggests amending Section 7(b)(1) to read “[g]aps in service and ways to improve coverage[.]” DHS suggests amending Section 7(b)(2) to read “[a]ccessibility issues, including ways better promote access-to-care[.]” DHS also suggests amending Section 7(b)(4) to read “[p]roposed legislation to improve existing services, improve coverage, and promote access-to-care to essential services; and[.]”

Since the charge to review Medicaid coverage would be given to the task force, Sections 1, 3, 4, and 5 would no longer be needed. DHS suggests that Sections 1, 3, 4, and 5 be deleted from the bill. Additionally, the language in Section 11 that reads “provided that section 5 shall take effect upon approval of the 1115 waiver by the Centers for Medicare and Medicaid Services submitted pursuant to section 4 of this Act” should be deleted to conform with the other proposed amendments.

Thank you for the opportunity to testify on this bill.



SB242 SD2 Home and Community-Based Services for Autism and Fetal Alcohol Spectrum Disorder

COMMITTEE ON HEALTH :

- Rep. Mizuno, Chair; Rep. Kobayashi, Vice Chair
- Tuesday, Mar. 12, 2019: 9:00 am
- Conference Room 329

Hawaii Substance Abuse Coalition Supports SB242 SD2:

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.

With home-based and community-based healthcare supported by Medicaid through a Section 115 Waiver and Task Force to improve access to essential services, we can make a difference.

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.

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.

SB-242-SD-2

Submitted on: 3/9/2019 12:39:44 PM

Testimony for HLT on 3/12/2019 9:00:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Louis Erteschik	Hawaii Disability Rights Center	Support	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. This Proposed HD1 does address what previously had not been clear to us in terms of what the actual impact would be compared to the array of services that are currently available. While children under EPSDT are now receiving ABA services as a result of a lawsuit we filed against DHS a few years ago, this bill would provide a huge array of home and community based services to help them live successfully in the community.

We have also been advocating for several years that there needs to be a program for children born with fetal alcohol syndrome. They truly fall into a gap group, and have not been recognized to date by the DD Division as generally qualifying for services. The current approach in the state is focused mostly on educating women about the dangers of consuming alcohol while pregnant. While laudable, this is highly insufficient and ineffective. These people need services. This Proposed HD1 also addresses the concerns we expressed earlier in the session that merely classifying fetal alcohol syndrome as a developmental disability may not, in and of itself, accomplish that goal, based on their level of functioning. Since many of these people may be deemed to be too high functioning to qualify for DD services, the approach in this bill to establish a separate program designed to serve this population is much better.

We also think the Task Force is a very good idea. We have extensively discussed our concerns with the DD Division in our testimony on HB 1273 before this Committee and we strongly support the contents of that measure. Our remarks in that regard are equally applicable here and we also support the Task Force proposed herein which appears to be broader in focus and will encompass a larger population.



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_SD2
RELATING TO HEALTH

COMMITTEE ON HEALTH

Rep. John M. Mizuno, Chair
Rep. Bertrand Kobayashi, Vice Chair

Tuesday, March 12, 2019, 9:00am
Conference Room 329
State Capitol
415 South Beretania Street

The Hawai'i Psychological Association (HPA) strongly supports SB242 SD2. 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



**TESTIMONY COMMENTING ON S.B. 242, SD 2, HD1 (PROPOSED)
RELATING TO HEALTH**

**HOUSE OF REPRESENTATIVES
THE THIRTIETH LEGISLATURE
REGULAR SESSION OF 2019
COMMITTEE ON HEALTH**

Tuesday, March 12, 2019, 9:00 a.m., Conference Room 329

March 10, 2019

The Honorable John M. Mizuno, Chair
The Honorable Bertrand Kobayashi, Vice Chair

Dear Chair, Vice Chair, and Members of the Committee:

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. Proposed Draft HD1 would also establish a task force consisting of state officials and “[a]t least one member of a developmental or intellectual disability advocacy group” to report to the legislature on proposed legislation “to improve existing services, close service gaps, and decrease barriers to essential services.” SB 242, SD2, HD1, Section 7.

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.

The proposed Task Force is consistent with federal laws that mandate inclusion of parents in the development of special education and other programs affecting individuals with disabilities. It would bring those advocates together with government officials to design programs that meet the real needs of intended beneficiaries. The Autism Society would be honored to serve on such a task force.

Please respond as needed to Dennis.maher@autismsocietyofhawaii.org.

Thank you for the opportunity to testify.

Respectfully submitted,

Dennis C. Maher
President, Autism Society of Hawaii

John P. Deller
Former Director (emeritus)

SB-242-SD-2

Submitted on: 3/9/2019 9:36:24 AM

Testimony for HLT on 3/12/2019 9:00:00 AM

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

Comments:

Testimony for SB242 SD2 Proposed HD1

Dear Chairman Representative Mizuno and Committee,

I am writing in support of the above measure and ask that you please consider its implication for those with lifelong developmental disabilities such as fetal alcohol spectrum disorders. The need for services is critical for the success of these individuals. With support and much coaching, they can be productive, empowered, and lead meaningful lives. Currently these services stop after age of majority. Once these structured services are removed, individuals with FASD often are left bereft and end up in our systems of care: substance abuse facilities, jail, homeless, with challenging mental health problems.

My experience as a psychologist and marriage and family therapist shows how little I can be of help without other structures in place: community based services that help find financial support, living situations, employment appropriate for this population. A teen I treated with FASD is now entering the adult criminal justice system because the teen never learned to regulate their emotions. The brain has difficulty regulating itself, so other people are needed to help. People with FASD are teachable but they forget and need constant reminding.

I do hope support services for a brain damaged in utero will be offered to individuals with FASD.

Mahalo nui for your consideration.

Kenichi K. Yabusaki, Ph.D.

Testimony for SB242 SD2 Proposed HD1

Dear Chairman Representative Mizuno and Committee,

I am writing in support of the above measure and ask that you please consider its implication for those with lifelong developmental disabilities such as fetal alcohol spectrum disorders. The need for services is critical for the success of these individuals. With support and much coaching, they can be productive, empowered, and lead meaningful lives. Currently these services stop after age of majority. Once these structured services are removed, individuals with FASD often are left bereft and end up in our systems of care: substance abuse facilities, jail, homeless, with challenging mental health problems.

My experience as a psychologist and marriage and family therapist shows how little I can be of help without other structures in place: community based services that help find financial support, living situations, employment appropriate for this population. A teen I treated with FASD is now entering the adult criminal justice system because the teen never learned to regulate their emotions. The brain has difficulty regulating itself, so other people are needed to help. People with FASD are teachable but they forget and need constant reminding.

I do hope support services for a brain damaged in utero will be offered to individuals with FASD.

Mahalo nui for your consideration.

Ann S. Yabusaki, Ph.D., MFT

SB-242-SD-2

Submitted on: 3/11/2019 8:37:08 AM

Testimony for HLT on 3/12/2019 9:00:00 AM

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

Comments:

I support this and believe Joelle Branch deserves a metal.

SB-242-SD-2

Submitted on: 3/11/2019 9:12:14 AM

Testimony for HLT on 3/12/2019 9:00:00 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 SD2 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. Monroe has the type of Autism that presents violent behaviors. He was not always this way. He had some behaviors that we were able to contain 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.

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.

This brings me to the common fear we all share as parents of what will happen to our children with autism once we pass on. While you are making your decision, I would like to plead with all of you, our leaders, to place yourself in our shoes and ask yourselves the following questions: What would you do if my son was your loved one and your time on this earth is near its end? 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.

In testimony from DHS they cite the cost to provide services for autistic individuals would cost about 45,000 per year. During a hearing for another cause, the Hawaii State Hospital stated it cost 250,000 per year for one person. Its heartbreaking to know that services cannot be provided to our autistic loved ones at 45,000 per year but an obscene amount of money is expended for services at the State Hospital. The State Hospital is a much needed entity and I don't dispute what it takes to run a facility such as that however what concerns me is without services many of our autistic loved ones with violent behaviors have the potential to end up in the state hospital where a higher rate would be paid. 45,000 per year will help to keep individuals with autism with behaviors safe and supported with their families and in the community to allow them to thrive.

On a positive note, I was so happy and excited to see that DHS has done an 1115 waiver for the homeless and substance abuse. Prior to this I was under the impression from DHS testimony that DHS has never done an 1115 waiver because DHS suggest that an 1115 waiver would not get approved or it will take up too much time. It might be there were different people who did that particular waiver for homeless and substance abuse are no longer with DHS so the current folks are not aware that this is doable so that's totally understandable. I was also going to provide my assistance to DHS with youtube videos from other states who have been successful with obtaining 1115 waivers however I was happy to find out this may not be needed because DHS already has a 1115 waiver to assist with housing for homeless and substance abuse. This is great news because in looking at this 1115 waiver for homeless and substance abuse it appears DHS could configure and write an 1115 waiver for individuals specified in this Bill. I believe if everyone works together and 1115 waiver for those indicated in this Bill and I plead with all of you to support Kelii's Law and I am more than happy to assist DHS.

Mahalo and Appreciation for you time and consideration,

Joelle Branch

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-2

Submitted on: 3/10/2019 11:58:27 PM

Testimony for HLT on 3/12/2019 9:00:00 AM

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

Comments:

i am resubmitting my testimony from the Senate Bill and some concerns. 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 SPEND \$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. Ive learned a lot from the past few Senate Hearings and House Hearing about DDDwaiver adding the 1115 waiver, and I have a few concerns. I also been part of the DD council task force for the past 6 months and I feel we got nothing resolved only had more unanswered questions about the GAP kids that is falling through the cracks.

1. I am in shock to know DDD waiver is is only servicing 1.58 percent of the population, when there is 23,000 individuals, in the DD division they are only servicing 2,700 individuals in their HCBS medicaid Waiver program.

2. I received a email from DHS stating they have reservations to do the 1115 waiver for our Autism and FASD, but it looks like Hawaii already has a 1115 waiver for the homeless and behavioral health and substances abuse diagnoses (qualified beneficiaries who meet definition of being chronically homeless, who have a behavioral or physical illeness or substance abuse diagnoses).

3. Other States like Virginia and minnesota have mulitple DD waiver programs, so why cant we mimic these States.

THANK YOU MELODEE Haole

SB-242-SD-2

Submitted on: 3/11/2019 1:56:28 PM

Testimony for HLT on 3/12/2019 9:00:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
terra daniel	Individual	Support	No

Comments:

I am writing in SUPPORT of this bill. The need for life long services is critical for people and families affected by developmental disabilities.

As the mother to an individual who lives an FASD (Fetal Alcohol Spectrum Disorder), I know first hand of the impact this disability takes on a family and a community. Our daughter is 13 and was diagnosed at 16 months. For 12 years we have had to fight for supports in school, in the home and in the community. Services are hard to receive, if even possible. Our daughter will live with brain damage for her entire life. My husband and our children will always have to act as her external brain since understanding cause and effect and any form of executive functioning is not something she is capable of doing on her own.

While our daughter will always struggle, she IS capable of success and able to give back to the community that she lives in. Raising a child with a developmental disability is exhausting. It is hard and it can feel very lonely, frustrating and overwhelming. It is also filled with happiness and gives insight into what it means to get up very day and try again. Our daughter has taught us far more than we will ever teach her. She has taught us compassion and the magic in celebrating the simple things.

Please support us, and families like ours, who are doing all we can to help our children succeed in a world that will only be better off with their involvement.

A recent study in the U.S. conservatively estimates that 1 in 20 first grade children have an FASD. Developmental disabilities are life-long, and without services, many people with Fetal Alcohol Spectrum Disorders will impact many other systems of care:

- 60% are charged with a crime
- 95% are diagnosed with a mental illness
- 50% have a substance use problems
- 70% of children in foster care have an FASD
- 80% have trouble with independent living

- 80% have trouble with employment

- 70% have problems in school

Please help us to be the change we wish to see in the world. We NEED this bill to be passed. Please do NOT turn this into a Task Force or combine it with the bill 42, heard by the House. There is not a need to create a group of people to determine where and who this gap group effects and/or if they need services. The needs many individuals are NOT being met and we need to correct this.

Mahalo,

Terra Daniel

LATE

SB-242-SD-2

Submitted on: 3/12/2019 12:01:02 AM

Testimony for HLT on 3/12/2019 9:00:00 AM

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

Comments: