



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

Testimony in OPPOSITION to HB42
RELATING TO HEALTH

REPRESENTATIVE JOHN M. MIZUNO, CHAIR
HOUSE COMMITTEE ON HEALTH

Hearing Date: January 31, 2019 Room Number: 329
9:30 A.M.

- 1 **Fiscal Implications:** Potential cost of HB 42 need to be studied. The Department of Health
- 2 (DOH) defers to the Department of Human Services (DHS).

- 3 **Department Testimony:** HB 42 proposes coverage for individuals with an autism spectrum
- 4 disorder diagnosis with Medicaid home and community based services (HCBS) through both
- 5 managed care and fee-for services programs. It proposes an array of services to be part of that
- 6 coverage. The bill asks DHS to seek a waiver under the 1115 authority of the Social Security Act
- 7 to provide these services under the QI health plans.

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

- 11 HB 42 states that all applicable federal requirements must be met for individuals to be in an
- 12 HCBS program. In these HCBS programs, eligibility is not based on a diagnosis, but on a Level
- 13 of Care (LOC) assessment of the person's functional limitations. This is a Medicaid requirement.
- 14 In the I/DD waiver, participants are required to have substantial functional limitations in three or
- 15 more areas of major life activity such as self-care, receptive and expressive language, learning,
- 16 mobility, self-direction, capacity for independent living, and economic self-sufficiency. There is
- 17 a wide range of functioning within diagnoses such as autism, and many people with autism do
- 18 not need the substantial levels of support that would be provided by HCBS programs.

- 1 If HB 42 were to be approved, substantial funding would be needed as it asks for access to
- 2 HCBS programs without meeting the LOC requirement. Further, it is unclear if the Centers for
- 3 Medicare and Medicaid Services would approve this approach, which means the State would
- 4 have to fully finance service for people that do not meet the HCBS LOC requirements.
- 5 Thank you for the opportunity to testify.



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

January 30, 2019

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

FROM: Pankaj Bhanot, Director

SUBJECT: **HB 42 – RELATING TO HEALTH**

Hearing: Thursday, January 31, 9:30 a.m.
Conference Room 329, 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 to assist persons who have been diagnosed with autism to participate in their communities by providing Medicaid coverage for HCBS in both managed care and fee-for-service.

DHS currently provides coverage of HCBS to individuals with autism in both the QUEST Integration (QI) program and in the Medicaid 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 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. 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 would not be needed.

If the bill were intended to provide access to HCBS for individuals with an autism diagnosis without meeting present LOC requirements, DHS would likely have to expend additional dollars. First, CMS would likely have concerns and may not approve HCBS for beneficiaries who would not meet LOC. In this situation, all state dollars would have to be used to finance HCBS for the non-LOC meeting population.

Second, 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. If DHS could not agree with CMS on a no- or 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 (LOC) 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 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.

Dear Representative Mizuno, Chair, and Members of the House Health Committee:

I am writing in full support of HB42. The need for lifetime services is critical for people and families affected by autism.

I suggest we amend the bill to include all developmental disabilities including fetal alcohol spectrum disorders (FASD). A recent study in the U.S. conservatively estimates that 1 in 20 first grade children will 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

Thank you for your consideration.

Respectfully,

S. Joy Quick, MA, LMFT, CSAC
Program Director/Director of Training
Marriage and Family Therapy Program
Argosy University Hawaii
Legislative Chairperson for Hawaiian Islands Association for Marriage and Family Therapy

HB-42

Submitted on: 1/29/2019 5:49:18 PM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------------------|---------------------------|---------------------------|
| Louis Erteschik | 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 services 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.



Hawai'i Psychological Association

For a Healthy Hawai'i

P.O. Box
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Honolulu,
HI 96808

www.hawaiipsychology.org

Email:
hpaexec@gmail.com
Phone: (808)
521-8995

Testimony in SUPPORT of HB42
RELATING TO HEALTH

COMMITTEE ON HEALTH

Representative John M. Mizuno, Chair
Representative Kobayashi, Vice Chair

Thursday, January 31, 2019, 9:30am
Conference Room 329
State Capitol
415 South Beretania Street

The Hawai'i Psychological Association (HPA) strongly supports HB42. 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.

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



January 29, 2019

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

Re: HB 42 – Relating to Health

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

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on HB 42, 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, HB 42 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 require additional financial resources.

Thank you for allowing us to provide these comments on HB 42.

Sincerely,

Pono Chong
Vice President, Government Relations

HB-42

Submitted on: 1/30/2019 11:13:34 AM

Testimony for HLT on 1/31/2019 9:30:00 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:

HB-42

Submitted on: 1/30/2019 1:43:58 PM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|--|---------------------------|---------------------------|
| kristine altwies | hawaii international child placement and family se | Support | Yes |

Comments:

Aloha!

I am here to support HB42 and HB 379.

Thank you for considering these important bills.

I have worked with orphaned, post-institutionalized, fostered, and adopted children for the past 28 years as the Executive Director of Hawaii International Child. I have seen hundreds of children afflicted with Fetal Alcohol Syndrome, (FAS) and Fetal Alcohol Effect disorder. Far too many of these children were never properly diagnosed, were misdiagnosed, were put on ADHD or other, often harmful medications. Many of these children were forced to exist within systems wherein those charged with caring for, or supporting them, had no idea what FASD is, or how it manifests in children, how it affects behavior. Many of these children were inappropriately held accountable for behaviors which were simply outside of their control. Many of these children were vilified and sent on quickly downward spiraling trajectories, eventually leading to juvenile delinquency, drug addiction, homelessness, etc. Many of these children exhibited extremely challenging behaviors, many were unable to mainstream into schools. Many of these children bounced from one resource to another, never landing with anyone who actually understood the neurological and permanent condition of FASD. Those working with FASD children and youth need to understand that the neurological issues around FASD result in limited, impaired, or even nonfunctioning brain areas. Expecting a child with FASD to understand cause and effect, to employ executive thinking, to feel remorse or empathy, is simply impossible in many cases. Children and youth with FASD deserve to live in a world where those responsible for their care, understand their condition. I support any efforts to create and provide ample training to any and all who would come in contact with FASD children and youth. A child born with FASD has done nothing wrong. FASD children are over-represented in the juvenile justice system. They deserve all the love and support we can find to help them. Thank you.

Kristine Altwies, MA

Executive Director/CEO

Hawaii International Child

200 N. Vineyard Blvd. Ste. 420

Honolulu, HI 96817

808 380 1137

email: kristine@hawaiiinternationalchild.org

Dear Representative Mizuno, Chair, and Members of the House Health Committee:

I am writing in full support of HB42. The need for life services is critical for people and families affected by autism.

I suggest we amend the bill to include all developmental disabilities including fetal alcohol spectrum disorders (FASD). A recent study in the U.S. conservatively estimates that 1 in 20 first grade children will 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

Thank you for your consideration.

Respectfully,

Ann S. Yabusaki, Ph.D., MFT

HB-42

Submitted on: 1/29/2019 2:45:28 PM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Kenichi Yabusaki | Individual | Support | Yes |

Comments:

Aloha Representative Mizuno and Members of the Health Committee:

I am a retired biochemist and have researched the biochemical effects of prenatal exposure to alcohol which can lead to fetal alcohol spectrum disorders and in some instances lead to autism as well. This leads to long and/or life-time disabilities. I strongly urge you to consider including Fetal Alcohol Spectrum Disorders (FASD) as part of HB42. From a developmental and/or neurodevelopmental disability standpoint, autism and FASD are about "disabilities". Also, the number of individuals with FASD out numbers those with autism, cerebral palsy, spina bifida, Down Syndrome combined. To this end, the proposed waiver in HB42 is vital for these individuals to receive the proper developmental disability services. Thank you for your consideration.

K. Ken Yabusaki, Ph.D.

HB-42

Submitted on: 1/29/2019 3:13:04 PM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| terra daniel | Individual | Support | Yes |

Comments:

Aloha -

I am writing in support of HB42 with an amendment to include individuals with an FASD and not only for those with autism. The need for life long services is critical for people and families affected by developmental disabilities.

As the mother to an individual who lives with an FASD, 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 every 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.

I strongly suggest we amend the bill to include ALL developmental disabilities including Fetal Alcohol Spectrum Disorders (FASD). A recent study in the U.S. conservatively estimates that 1 in 20 first grade children will 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.

Mahalo,

Terra Daniel

HB-42

Submitted on: 1/29/2019 4:47:16 PM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| Amanda Luning | Individual | Support | No |

Comments:

(I'm sorry if this is submitted twice, I'm not sure I'm using this system correctly!)

Dear Representative Mizuno, Chair, and Members of the House Health Committee:

I am writing in full support of HB42, as both a private citizen and a clinical provider.

I would like to suggest that we amend this bill to include ALL developmental disabilities including, but not limited to, Fetal Alcohol Spectrum Disorders (FASD). A recent study by the American Medical Association conservatively estimates that 1 in 20 first grade children are affected by FASD (this is likely higher, as we know that more than 40% of pregnancies are unplanned). This is a complex, life-long issue and without appropriate, informed services, many people with fetal alcohol spectrum disorders will be misdiagnosed, mistreated and, more often than not, 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

This is not a niche issue. It is likely touching more than half of the people in our entire society in some way, shape or form. The resources are already being utilized, just not appropriately. **Disabilities should never be treated with punitive processes.** I respectfully, compassionately, on behalf of the children and families that I work with daily, request that you consider supporting this bill and the other measures (on FASD in this year's Keiki Caucus package) surrounding increased awareness, training and

informed services for persons touched by this complex and often extremely misunderstood issue.

Sincerely,

Amanda Luning

Licensed Mental Health Counselor

Child/Parent Psychotherapist

Infant/Family Specialist

Parent and Voter

HB-42

Submitted on: 1/29/2019 4:48:43 PM

Testimony for HLT on 1/31/2019 9:30:00 AM

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

Comments:

I support Kelii law.

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 Representative 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.

HB-42

Submitted on: 1/30/2019 9:00:51 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

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

Comments:

To Whom It May Concern:

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 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 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 Keli'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 Keli'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. Joelle Branch

HB-42

Submitted on: 1/30/2019 9:09:25 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Maly Nakoa | Individual | Support | No |

Comments:

With the astronomical growth of children and now adults with autism 'tis imperative that adequate resources for their care be appropriated.

HB-42

Submitted on: 1/30/2019 9:14:56 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|-----------------------------|---------------------------|---------------------------|
| Kim Haine | Hawaii for Informed Consent | Support | No |

Comments:

Dear Chair Mizuno and House Health Committee,

Thank You for supporting this very important bill. Currently according to CDC statistics we have 1 in 6 children with Neurodevelopmental Disabilities in the US. Autism is at 1 in 36 in some states. This is an epidemic that requires immediate attention on all levels; not only services, but exploration of cause and prevention. As you consider supporting this bill, please do your due diligence and keep an open mind on all fronts. The future of our children and our country are depending on it.

Mahalo,

Kim Haine

HB-42

Submitted on: 1/30/2019 9:29:52 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| T O | Individual | Support | No |

Comments:

HB-42

Submitted on: 1/30/2019 9:32:17 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| natasha sky | Individual | Support | No |

Comments:

Laurie West

1530 Ulupuni Street
Kailua, HI 96734

January 30, 2019

Representative John Mizuno, Chair House Health Committee
Members of House Health Committee
Hearing Date and Time: January 31, 2019, 9:30am

Re: **STRONG SUPPORT FOR KELI'I'S LAW, HB42**

Aloha Representative Mizuno and Members of House Health Committee:

As a mother of two children who participated in Hawai'i's Zero-to-Three early intervention program, one of whom was diagnosed with autism, now recovered, I write to you now urging you to support Keli'i's Law, HB42.

We must care for the ever-growing population of individuals afflicted with autism, and assist their families and other caregivers. This law would be a step forward in that effort.

Furthermore, we must recognize that the skyrocketing incidence of autism cannot possibly be due solely to genetic anomalies - there is no such thing as a "genetic disorder epidemic." There must be some environmental factor or factors, perhaps intermingling with the genetics of some people. That pursuit is for other legislation.

For now, please help families and society by offering resources to treat people with autism.

Sincerely,

Laurie West

Mother of a child formerly on the autistic spectrum, now recovered

| Vaccine | Contains |
|---|---|
| Td (Tenivac) | aluminum phosphate, formaldehyde, modified Mueller-Miller casamino acid medium without beef heart infusion, ammonium sulfate, sodium chloride, water |
| Td (Mass Biologics) | aluminum phosphate, formaldehyde, thimerosal, modified Mueller's media which contains bovine extracts, ammonium sulfate |
| Tdap (Adacel) | aluminum phosphate, formaldehyde, 2-phenoxyethanol, Stainer-Scholte medium, casamino acids, dimethyl-beta-cyclodextrin, glutaraldehyde, modified Mueller-Miller casamino acid medium without beef heart infusion, ammonium sulfate, modified Mueller's growth medium |
| Tdap (Boostrix) | modified Latham medium derived from bovine casein, Fenton medium containing a bovine extract, formaldehyde, modified Stainer-Scholte liquid medium, glutaraldehyde, aluminum hydroxide, sodium chloride, polysorbate 80 |
| Typhoid (Typhim Vi) | hexadecyltrimethylammonium bromide, formaldehyde, phenol, polydimethylsiloxane, disodium phosphate, monosodium phosphate, semi-synthetic medium, sodium chloride |
| Typhoid (Vivotif Ty21a) | yeast extract, casein, dextrose, galactose, sucrose, ascorbic acid, amino acids, lactose, magnesium stearate, gelatin |
| Varicella (Varivax) <i>Frozen</i> | MRC-5 human diploid cells, including DNA & protein, sucrose, hydrolyzed gelatin, sodium chloride, monosodium L-glutamate, sodium phosphate dibasic, sodium phosphate monobasic, potassium phosphate monobasic, potassium chloride, EDTA, neomycin, fetal bovine serum |
| Varicella (Varivax) <i>Refrigerator Stable</i> | MRC-5 human diploid cells, including DNA & protein, sucrose, hydrolyzed gelatin, sodium chloride, monosodium L-glutamate, urea, sodium phosphate dibasic, potassium phosphate monobasic, potassium chloride, neomycin, bovine calf serum |
| Yellow Fever (YF-Vax) | sorbitol, gelatin, sodium chloride, egg protein |
| Zoster (Shingles) (Zostavax) <i>Frozen</i> | MRC-5 human diploid cells, including DNA & protein, sucrose, hydrolyzed porcine gelatin, sodium chloride, monosodium L-glutamate, sodium phosphate dibasic, potassium phosphate monobasic, potassium chloride; neomycin, bovine calf serum |
| Zoster (Shingles) (Zostavax) <i>Refrigerator Stable</i> | MRC-5 human diploid cells, including DNA & protein, sucrose, hydrolyzed porcine gelatin, urea, sodium chloride, monosodium L-glutamate, sodium phosphate dibasic, potassium phosphate monobasic, potassium chloride, neomycin, bovine calf serum |
| Zoster (Shingles) (Shingrix) | sucrose, sodium chloride, dioleoyl phosphatidylcholine (DOPC), potassium dihydrogen phosphate, cholesterol, sodium dihydrogen phosphate dihydrate, disodium phosphate anhydrous, dipotassium phosphate, polysorbate 80 |

A table listing vaccine excipients and media by *excipient* can be found in:

Grabenstein JD. *ImmunoFacts: Vaccines and Immunologic Drugs* – 2013 (38th revision). St Louis, MO: Wolters Kluwer Health, 2012.

LATE

HB-42

Submitted on: 1/31/2019 9:02:27 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|---------------------|---------------------------|---------------------------|
| Jeremy Daniel | Individual | Support | Yes |

Comments:

I am in full support of this bill; however, I am requesting that the bill be amended to include ALL developmental disabilities including fetal alcohol spectrum disorders (FASD). To allow the bill to proceed as presently written clearly discriminates against individuals with developmental disabilities other than autism. I believe the intent of this bill to be excellent, but let's remember that people like my daughter would automatically be excluded because she does not have an autism diagnosis. We adopted her at birth and she had experienced pre-natal exposure to alcohol which caused permanent and irreversible brain damage. She scores in the 1st percentile (or below) for cognitive and physical abilities. Even though she is not diagnosed with autism, she, and others like her need and deserve the support that this bill would provide.

LATE

HB-42

Submitted on: 1/31/2019 9:39:21 AM

Testimony for HLT on 1/31/2019 9:30:00 AM

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

Comments:

Dear Representative Mizuno, Chair, and Members of the House Health Committee:

I am writing in full support of HB42. The need for life services is critical for people and families affected by autism.

I suggest we amend the bill to include all developmental disabilities including fetal alcohol spectrum disorders (FASD). A recent study in the U.S. conservatively estimates that 1 in 20 first grade children will 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

Thank you for your consideration.

Respectfully,

Sheyanne Petrovich