

STATE OF HAWAII DEPARTMENT OF HEALTH

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Testimony COMMENTING on S.B. 3122 RELATING TO HEALTH.

SENATOR RUSSELL E. RUDERMAN, CHAIR SENATE COMMITTEE ON HUMAN SERVICES

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

Hearing Date: February 5, 2020 Room Number: 016

- 1 **Department Position:** The Department of Health offers the following comments.
- 2 **Department Testimony:** The subject matter of this measure intersects with the scope of the
- 3 Department's Behavioral Health Administration (BHA) whose statutory mandate is to assure a
- 4 comprehensive statewide behavioral health care system by leveraging and coordinating public,
- 5 private and community resources. Through the BHA, the Department is committed to carrying
- 6 out this mandate by reducing silos, ensuring behavioral health care is readily accessible, and
- 7 person centered. The BHA's Developmental Disabilities Division (DDD) provides the following
- 8 testimony on behalf of the Department.
- 9 SB 3122 would establish a Medicaid Home and Community Based Services (HCBS) program
- 10 for individuals with an intellectual or developmental disability (I/DD) who do not meet
- 11 Medicaid's institutional level of care criteria for HCBS, but are at risk of institutionalization
- because they lack independent daily living skills or are unable to manage their own care or to
- access the supports necessary to maintain their independence. The terms I/DD encompass people
- with autism spectrum disorders.
- 15 Currently the DDD, through a memorandum of agreement with the Department of Human
- Services (DHS), is the operating agency for the Medicaid 1915(c) waiver for individuals with

- 1 I/DD who do meet the institutional level of care criteria, which is defined by the Centers for
- 2 Medicare and Medicaid Service for 1915(c) waivers as an Intermediate Care Facility for
- 3 Individuals with Intellectual Disabilities (ICF/IID) level of care.
- 4 It is believed that there may be from hundreds to thousands of people in the "at-risk group," in
- 5 Hawaii, which includes youth with autism and other I/DDs who may be transitioning from
- 6 school and need supports and services to transition to meaningful lives through work and/or the
- 7 community-life roles they want. DDD has met with stakeholders and DHS since last session to
- 8 look at ways to improve access, and define services and service approaches for meeting the
- 9 needs of this population. As such, DOH appreciates the intent of SB 3122 and its approach that
- 10 could allow DHS to further convene stakeholders to better define the population, the projected
- 11 number of people who need services, and the services they need.
- SB 3122 does clarify that an individual at-risk of institutionalization cannot meet an ICF-IID
- level of care, that eligibility for HCBS must be tied to an assessment of needs, and that
- individuals in institutional or group home care could not access HCBS through the "at-risk"
- program. SB 3122 further states that individuals in the "at-risk" group must have been found
- through a functional assessment to be at risk of deteriorating to the institutional level of care, and
- have been found ineligible to receive Medicaid long term services and supports (LTSS) or the
- 18 I/DD waiver. DOH is not aware of functional assessments normed specifically for the purpose of
- measuring whether an individual is at risk of deteriorating to an institutional level of care, so a
- 20 clear eligibility description based on level of need would need to be operationalized, which is a
- 21 requirement of Medicaid HCBS waivers. Further, if there is unclear eligibility criteria it could
- cause confusion and overlap of eligibility criteria of the population served through the current
- 23 1915(c) waiver for individuals with I/DD, which includes individuals with functional limitations
- in three or more life areas. As well, requiring people to first be found ineligible for Medicaid
- 25 LTSS or the I/DD waiver might be a barrier in accessing timely services.
- 26 DOH respectfully suggests working with DHS and stakeholders to clearly define the specific
- 27 population of Medicaid beneficiaries and eligibility criteria for the people that would benefit

1	from a program for at-risk individuals with intellectual and developmental disabilities. As well,
2	the service needs and numbers in the population would need to be defined in order to estimate
3	annual costs, which is best done through a comprehensive cost study.
4	Suggested Amendments: DOH respectfully suggests the following amendments to SB 3122.
5	• Delete " <u>functional</u> " in SECTION 3 (2) on page5, line 3
6	• Delete "[h]ave been found ineligible to receive medicaid long term services and supports
7	or the I/DD waiver" and substitute "[a]re ineligible for other Medicaid waiver programs
8	for individuals with intellectual or developmental disabilities" in SECTION 3 (3) on page
9	3, lines 6-7.
10	Fiscal Implications: A cost study for an "at risk" HCBS program is needed to inform an
11	appropriation. Factors are dependent on the definition of eligible population, the projection of
12	numbers, and the types of services needed by the population to live successfully in the
13	community. There would also need to have consideration of the costs for development of a
14	workforce and service delivery infrastructure.
15	Thank you for this opportunity to testify.
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PANKAJ BHANOT DIRECTOR

CATHY BETTS
DEPUTY DIRECTOR

STATE OF HAWAII DEPARTMENT OF HUMAN SERVICES

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

February 4, 2020

TO: The Honorable Senator Russell E. Ruderman, Chair

Senate Committee on Human Services

The Honorable Representative Senator Rosalyn H. Baker, Chair

Senate Committee on Commerce, Consumer Protection, and Health

FROM: Pankaj Bhanot, Director

SUBJECT: SB 3122 – RELATING TO HEALTH

Hearing: February 5, 2020, 2:45 p.m.

Conference Room 016, State Capitol

<u>DEPARTMENT'S POSITION</u>: The Department of Human Services (DHS) appreciates the intent of the bill and offers comments and suggestions.

<u>PURPOSE</u>: The purpose of this bill is to create a new program to provide Home- and Community-Based Services (HCBS) to individuals with intellectual disabilities or developmental disabilities who are at-risk of requiring institutionalization.

Since last legislative session, DHS has regularly met with stakeholders to discuss ways that the present system and continuum of care can be improved for individuals who are transitioning out of services provided by other state agencies like the Department of Education (DOE) and the Department of Health (DOH) Child & Adolescent Mental Health Division (CAMHD). These individuals are often at-risk of institutionalization. Expanding access to services would help these individuals engage in their communities and would provide support for their families, who must often struggle on their own to support their child. As a general principle, DHS supports expanding access to some HCBS to this population provided that it does not replace or adversely impact the budget priorities identified in the executive budget.

DHS believes the prudent and fiscally sound way forward is to conduct a rate study before passing this legislation. A rate study would have to be completed before DHS could submit a request to the Centers for Medicare and Medicaid Services (CMS) to cover HCBS for an at-risk population. A completed rate study would give DHS, stakeholders, and the legislature the best idea of what the appropriation would be for this program. A rate study would not be an additional, unneeded next step, and could support program sustainability with federal matching funds once approved by CMS.

DHS would collaborate with DOH and stakeholders on the rate study. The rate study process could be used to further refine a potential at-risk program in regard to the services offered and the individuals covered. The rate study would give the Legislature the best idea of what the cost of this program would be.

DHS understands that the Legislature may want to pass a bill this year to begin covering this population. If the Legislature moves forward with this bill without a rate study, then DHS will estimate the potential expenditures for the program to the best of its ability. DHS counsels that a large general fund appropriation may be necessary because of unknowns surrounding the potential population and their use of services.

DHS suggests the following recommendations in the event that the Legislature wishes to move forward without a rate study.

First, DHS would recommend that the Legislature make it clear that the population covered under this bill be determined by DHS to be eligible for federally-funded Medicaid assistance.

Second, DHS would recommend deleting "functional" on page 3, line 3. DHS would also recommend deleting "[h] ave been found ineligible to receive medicaid long term services and supports or the I/DD waiver" and substituting "[a]re ineligible for other Medicaid waiver programs for individuals with intellectual or developmental disabilities" on page 3, lines 6-7. These changes align better with the Medicaid programs.

DHS also notes it is unclear when individuals residing in a shelter would be eligible for services as the individual or entity that makes the determination on whether services are appropriate for an individual's living environment has been left blank in this version of the bill.

Thank you for the opportunity to testify on this bill.



STATE OF HAWAI'I

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

1010 RICHARDS STREET, Room 122 HONOLULU, HAWAI'I 96813 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543

February 5, 2020

The Honorable Senator Russell E. Ruderman, Chair Senate Committee on Human Services and The Honorable Senator Rosalyn H. Baker, Chair Senate Committee on Commerce, Consumer Protection, and Health Thirtieth Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Senator Ruderman, Senator Baker, and Members of the Committees:

SUBJECT: SB 3122 – Relating to Health

The State Council on Developmental Disabilities **STRONGLY SUPPORTS SB 3122**, requires the Department of Human Services, upon approval from the Centers for Medicare and Medicaid Services, to establish and implement a program for providing home-and community-based services to at-risk individuals having intellectual or developmental disabilities who meet certain criteria. Requires the department to utilize any vehicle available, including a state plan amendment or waiver to the QUEST integration section 1115 demonstration project to provide home-and community-based services for individuals having intellectual or developmental disabilities.

The Council appreciated the work done between legislative sessions with the Fetal Alcohol Spectrum Disorder and Autism Spectrum Disorder groups. Hilopaa family to family Inc, facilitated meetings with the groups, the Council, and representation of the Department of Human Services and the Department of Health. We worked together to build common ground and language that supports individuals that have been known to fall in between the cracks.

Thank you for the opportunity to submit testimony strongly supporting SB 3122.

Sincerely,

Daintry Bartoldus

Executive Administrator

Submitted on: 1/31/2020 5:38:35 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

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

Comments:

We definitely want to see more coverage for the entire population that is set forth in this bill. We have long advocated that there are many individuals who may not meet the strict criteria for either DD eligibility or for the Medicaid Level of Care requirements. Yet, they have real needs and may not have any services. For those reasons, we welcome this bill.

That said, we seem to recall that last session the Department of Human Services indicated that CMS requirements might preclude the provisions this bill seeks to advance and so we would like to hear their input on this proposal. In any event, this bill offers an excellent vehicle for discussion as to how we can serve this population in the most effective and efficient way.

Submitted on: 2/1/2020 9:12:58 AM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing	
Lisa	Testifying for WCCHC	Support	No	Ī

Comments:

February 1, 2020

To: Senator Russell E. Ruderman, Chair

And Members of the Senate Committee on Human Services

Senator Rosalyn H. Baker, Chair

And Members of the Senate Committee on Commerce, Consumer Protection, and Health

Date & Time of Hearing: February 5, 2020, 2:45 pm, Room 016

Testimony in Support of SB3122: Directs DHS to Establish & Implement Home and Community-Based Care for At-Risk Individuals having Intellectual or Developmental Disabilities

Numerous reports show that Fetal Alcohol Spectrum Disorder (FASD) is a public health issue with serious social, economic, and health impacts. While FASD is a permanent disability, it's behaviors and symptoms are treatable, but only if the resources are accessible. People with Fetal Alcohol Spectrum Disorder (FASD) are discriminated from receiving necessary services. Individuals suffering from FASD and their families are stigmatized due to the nature and cause of FASD. FASD is a developmental disorder resulting from neonatal exposure to alcohol. FASD causes behaviors and symptoms that affect normal functioning for successful and independent living such as hyperactivity, impulsiveness, inattention, and memory deficits, inability to complete tasks, poor social skills, cognitive impairment or decline, and emotional dysregulation. Much research shows that many individuals with FASD have average cognitive functioning but struggle with other symptoms that prevents the from attaining a higher quality of life. Studies demonstrate that ~60% of adults with FAS/FAE encountered the criminal justice system; ~60% had disrupted school experiences; and ~50% had Alcohol/Drug problems.

FASD has significant economic impacts that can be reduced by inclusion in prevention and treatment services. Some reports demonstrate the current cost per

person annually is about 1-2 million and about 8 billion annually as a whole. These reports includes costs such as police enforcement, encounters with justic system, and emergency health care costs. However, they do not include general mental and physical health services, substance abuse treatment, and loss of productivity (services which would be cheaper and prevent such high economic stress).

Without your support, Individuals with FASD will be further neglected and preventable costs will continue to rise. This measure provides much-needed Developmental Disabilities services which would reduce the econmic stress on the state and significantly and deservingly increase an individuals right to a better quality of life. I have included some links for further review of the issues, research, and benefits of developmental disabilities services.

https://www.eenet.ca/resource/economic-impact-fetal-alcohol-syndrome-fas-and-fetal-alcohol-spectrum-disorder-fasd

https://www.cdc.gov/ncbddd/fasd/index.html

Mahalo for your consideration.

Sincerely,

Lisa Garcia, PSYD

<u>SB-3122</u> Submitted on: 2/3/2020 8:09:35 AM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Julie Yurie Takishima- Lacasa	Testifying for Hawai'i Psychological Association	Support	No

Comments:

<u>SB-3122</u> Submitted on: 2/3/2020 8:23:10 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Alan Shinn	Testifying for FASD Action Group	Support	No

Comments:

Aloha. Please accept my testimony in support of SB 3122. Mahalo.

Submitted on: 2/4/2020 1:42:59 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Melodee Haole	Testifying for K.E.L.I.I. FOUNDATION	Support	Yes

Comments:

Hello My name is Melodee Haole I am the founder and President of the K.E.L.I.I. foundation. I am a mother of a severe Autistic young adult, my son already have DDD services so this Bill will not help him but this Bill should help about 5,000 of our "at RISK" children and young adults.

Last year our group walked the capital talking to Senators and Representatives with parents trying to figure out how we can help these "at Risk" groups. There is two groups that is "at risk" who don't have IDD waiver services (the Dual Diagnoses and Developmental Disablility "At RISK"). The past 3 months Ive been meeting with Mary Brogan from (DDD), Judy Peterson from (DHS) and DD Council Daintry to figure out how we can get this Bill pass. We found out last years BILL was talking about two separate groups and this was confusing people. So we took out the "Dual Diagnoses" that fall within the IDD waiver eligibility criteria but because they have the comorbid condition with some kind of mental illness "they get denied' this group usually are sent to the mainland and institutionalized. It was advised to us to do a Resolution for this group because IDD medicaid waiver will be working more with these families. The second group is "At Risk" don't fall within the IDD waiver and without any support or community base services, life skills training they maybe at risk, vulnerable to be taking advantage of, homeless, or even institutionalized. Example: I just helped an autistic young lady (23) years old she did not met the IDD criteria, had a child with autism, husband has developmental disability but he didnt have any services, she was working 25 hrs a week, sad to say she didn't have a supportive family they manipulated her took all her money, then kicked her and her family out and they where homeless and vulnerable now on the streets. One of her co workers found me through facebook and I helped her to get into a homeless shelter. I work with many families that get denied on a daily bases from medicaid waiver and its sad to see that some families leave the island because of the lack of services to help these children and young adults to be successful in their future and to be a productive citizen. I already met a few Autistic young adults that is homeless due to their parents past away or people taking advantage of them. Please HELP this "AT RISK" populations, this will save the STATE so much money in the future. I also want to thank Mary Brogran, Judy Peterson, Daintry, and Leolinda for all their support to help our community.

Submitted on: 2/4/2020 2:37:01 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
chanel	Testifying for Kelii Foundation	Support	Yes

Comments:

Aloha Representatives,

Being a single, working mother of a child with severe autism and another young, neurotypical child in Hawai'i has been a challenge. As a registered nurse I would never allow my son with Autism to be institutionalized at a place like the State Hospital, where, apparently, funds are going towards housing the patients/clients there costing the state/tax payers about \$250,000 per patient, while the state refuses to invest \$45k per year on our loved ones. How am I supposed to help my son become a productive member of society and keep him from being institutionalized, costing the state more money in the long run to house them in hospitals? Why do we as parents have to struggle so hard to get and maintain Medicaid services for our loved ones without going into poverty due to the ridiculous income limits set by Medicaid?

Thus, I depend on my son's Pab and respite workers who are funded by the DDD on a daily basis to for the precious reasons mentioned but also so that—

1-my son and my family can remain safe at home and in the community when my son has his behaviors,

2-my son can be escorted to all his medical appointments while I'm at work,

3-so that my son can have help getting ready for school and get on the school bus safely while I'm at work, and

4-so that I can keep my job and be able to support all my keiki.

Without these workers who are funded by the DDD, I would not be able to stay in Hawaii where my keiki, I, and generations of my Hawaiian lineage have been rooted. I've considered moving to the various states in mainland that could offer my son better health/in-home community services, but I can't take them away from their home, their schools, their Ohana, and their lives here in Hawai'i. Why does it have to be that way?

Just 1 week ago, I got an official letter from the DDD stating that my son's services would be denied. This means that we would no longer have workers to help me with my son or it means that I would have find affordable childcare so that I can keep my job as a nurse and have to cut my hours. I have to pay for a mortgage and child care for my younger son. I absolutely cannot afford to lose our current workers. With the advocacy of our legislators we finally got services for my son from the DDD after having waited 1 year, and, now, we need our legislators help again to keep his services by supporting SB3122.

As a working, middle-class mother I don't receive social security income, Food stamps, EBT, WIC, housing assistance, or child support. There is no way I can afford to pay out of pocket for all the services that my son, or any person with Autism, desperately needs simply because DDD decided to cut our services and because these services are not covered by insurance. Please help my son and all our loved ones with Autism by supporting Kelii's Bill SB3122.

so that I, as a single mother, can keep working to provide for both of my young children and prevent my child with Autism from ending up institutionalized at a place like the State Hospital, where, apparently, funds are going towards housing the patients/clients there costing the state/tax payers about \$250,000 per patient, while the state refuses to invest \$45k per year on our loved ones with Autism. How are we supposed to help our family members with Autism become productive members of society and keep them from being institutionalized, costing the state more money in the long run to house them in hospitals? Why do we as parents have to struggle so hard to get and maintain Medicaid services for our loved ones without going into poverty due to the ridiculous income limits set by Medicaid?

January 30, 2020

To: Representative Joy A. San Buenaventura, Chair

And Members of the Committee on Human Services and Homelessness

<u>Testimony in Support of HB2098 Relating to Home- and Community-based Services</u> <u>to At-Risk Individuals with Developmental Disabilities</u>

I am a retired biochemist and have researched some of the biochemical processes that contribute to fetal alcohol spectrum disorder (FASD). From what I have researched, in a culture and society where consumption of alcohol is a living issue, FASD is a permanent and life-long brain disorder that lead to compromised adaptive functioning behaviors. individuals born with FASD are "Born into an Impossible World". It is our responsibility to make the World "possible" for not only those afflicted with FASD, but all developmental/functional disabilities. Part of this responsibility and making the world "possible" for those with DDs (including FASD) is having access and qualifying for home and community-based services. Many with FASD fall into gaps that disqualify them for these much-needed services because of age limits and/or IQ score. We tend to forget the caregivers of those afflicted by DDs who must advocate for the aforementioned services. I strongly support passage of HB2098 to encourage Hawaii's Department of Human Services secure more Medicaid/Medicare funds for home and community based services to help those with FASD and all developmental disabilities have access to a productive life of "possibilities". Thank you for your consideration in passage of HB 2098.

Respectfully,

Kenichi K. Yabusaki, Ph.D.

January 31, 2020

To: Senator Russell E. Ruderman, Chair

And Members of the Senate Committee on Human Services

Senator Rosalyn H. Baker, Chair

And Members of the Senate Committee on Commerce, Consumer Protection, and Health

Date & Time of Hearing: February 5, 2020, 2:45 pm, Room 016

<u>Testimony in Support of SB3122: Directs DHS to Establish & Implement Home and Community-Based</u> <u>Care for At-Risk Individuals having Intellectual or Developmental Disabilities</u>

I am writing on behalf of myself and individuals, parents and families that I serve who seek services for their adult children with a Fetal Alcohol Spectrum Disorder (FASD) and other developmental disabilities. FASDs are permanent brain-based disorders that affect many individuals who were exposed to alcohol during pregnancy. Brain impairment of FASD varies from individual to individual and often goes undiagnosed and misdiagnosed. Families are faced with few, if any, services for their adult children. We know that individuals with FASD function best with supervision and structure and can lead productive and meaningful lives. But they and their families need help.

This measure provides much-needed services for people who are currently ineligible for Developmental Disabilities services. A comprehensive study in the U.S. (Streissguth, A., et al., 2004) noted that most (~75%) of adults with FAS/FAE had IQs within the normal range. In spite of this finding, ~60% of adults with FAS/FAE encountered the criminal justice system; ~60% had disrupted school experiences; and ~50% had Alcohol/Drug problems. With lifelong services, we can make a difference to those affected by FASD and other developmental disabilities, their families, and community.

Thank you for your consideration. Sincerely, Ann S. Yabusaki, Ph.D., MFT

<u>SB-3122</u> Submitted on: 2/1/2020 11:17:10 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Mr and Mrs John McComas	Individual	Support	No

Comments:

Submitted on: 2/2/2020 2:04:51 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing	
Linda Jones	Individual	Support	No	

Comments:

SB3122 is much needed in our special need community. It offers support to our often neglected members who don't have a voice.

My son is 4 years old and has autism. I don't know what the future will be like for him, but currently he is having lots of aggression. He has limited communication and gets aggressive when frustrated, for now I can manage his out bursts and hopefully with ABA therapy we can help him regulate and help him with self control. If he gets older and struggles, SB3122 will help our family and many more families. There is growing number of people being diagnosed with autism every year. We need SB3122.

Linda Jones

Submitted on: 2/3/2020 1:30:20 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing	
Adonis Buttel	Individual	Support	No	

Comments:

Aloha,

My name is Adonis Buttel and I am a father of a 9 year old son with autism. As of right now, autism disorder will be with my son for the rest of his life and bill SB3122 will help ensure that when he gets older, hell be able to get services that will help him succeed in life. I am very fortunate right now that my wife and I are able to cover his therapy treatments through our insurance but we realize that there are so many families out there that aren't as fortunate as we are. Also in the case that something should happen to my wife or myself, we then would have to rely on these types of services for the betterment of our son. I truly hope that this bill becomes law to help ease the burden on these families that are already dealing with a tough life caring for someone with a disability. Thank you so much for your time.

Submitted on: 2/3/2020 8:40:39 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

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

Comments:

I'm a single parent of a teenager with high functioning autism. I had to stop working and spend all my time being a caregiver of my child 100% of my time. I went to DDD when my child was 3 years old and got denied because my child has a high IQ. I got tired of trying to get services through DOE and had to homeschool. Now that my child is getting closer to transition I'm at lost. We desperately need some kind of guidance and help.

BILL SB3122 "Kelii's law"

TESTIMONY

February 3, 2020 KURT RHONEY 58-306 KAUNALA PLACE HALEIWA, HI 96712

To whom it may concern:

I have never ever taken the time to the time to write or support a bill or law of any kind in my life, but the proposed bill SB3122 is different. It's a law intended to help those who need it most in our community and our state. I have a handicapped son who might possibly need these services in the future and know of many families struggling to get needed services for children and young adults. The help this bill provides will likely help keep families together and possibly reduce the chance of family members becoming wards of the state when dependents become unmanageable for elderly parents or deteriorate mentally due to lack of outside/inside services available.

Please consider the long-term positive effects this Bill will have for your constituents around the state when you vote for Bill SB 3122.

Mahalo for your time	and consideration	to help those i	n need.
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Sincerely,

Kurt Rhoney

Submitted on: 2/4/2020 8:26:46 AM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Eri Rodrigues	Individual	Support	No

Comments:

February 4, 2020

To: Senator Russell E. Ruderman, Chair and the Members of the Senate Committee on Human Services

Senator Rosalyn H. Baker, Chair and the Members of the Senate Committee on Commerce, Consumer Protection, and Health

Date and Time of Hearing: February 5, 2020 at 2:45 p.m.

Testimony in Support of SB3122 Department of Human Services to Establish and Implement Home- and Community-based Services for At-Risk Individuals with Intellectual or Developmental Disabilities

I am writing to express my support for this measure for home- and community-based services to be created for at-risk individuals with intellectual or developmental disabilities, which includes individuals with Fetal Alcohol Spectrum Disorder (FASD) under Department of Human Services. As a social worker, I have had opportunities to work with individuals and families impacted by FASD in our community. Studies and services from other states as well as countries overseas present that individuals with FASD benefit from structure and supports that cater to their unique needs. Currently however in this state, individuals and families are under-identified and served due to limitations in accessibility and provision of services. And this measure, I believe will create services and supports to start to fill those gaps.

Thank you for your consideration and allowing me to express my support toward this measure.

Sincerely,

Eri N. Rodrigues, LSW

<u>SB-3122</u>

Submitted on: 2/4/2020 2:23:25 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

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

Comments:

Aloha Chairs Ruderman and Baker, Vice Chairs Rhoads and Chang, and members of the committees:

I am writing to show my support for SB3122. Families like ours with special needs children need support so our future adults will be out in the community successfully participating and contributing. Hawaii needs programs established so families don't have to move away to the mainland for services and care. We want what every other parent wants, the possibility of a happy and fulfilling future for our child.

Mahalo for your time,

Jeanette White

Submitted on: 2/4/2020 2:50:40 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Cynthia Bartlett	Individual	Support	Yes

Comments:

As a parent of a 26 year old and a Board Member of Hawaii Autism Fondation I meet many parents of children who have finished high school and have tested as higher functioning on state tests but have no support and want to become more independent. These young adults want to try to go to community collehe, they want to learn how to get a job, they want to learn better how to ride a bus and get to the rifght place.... some even need to keep up on their personal hygene and safety life skills.

I attended a meeting for families who had special needs adults now in thier 20s . When I asked who here was getting support services of any kind after they left the DOE about 25 out of the 40 raised thier hands. When asked what was their greatest need they answered their young adults needed help to go to community college and to become more independent.

They wanted their adult to achieve the highest level of independence and have a chance at a happy and fulfilled life. Their goals are community college, a job and to safely move into thier own apartment.

When these higher testing adults succeed at independent skills it saves the state money and creates more jobs and taxible income.

However without some home and community support hours each month this population becomes at risk. At risk for homelessness. At risk for becoming vulverable to getting lost on a bus or failing at maintaning a budget. At risk for extreme memtal frustration which can lead to expensive hospitalization. Similar to our seniors who receive at risk supports this population needs support. Even if it appears they can live in an apartmentr what if someone takes their money and gives them drugs? What if they don't shower for several weeks and develop boils? What if they mentally break down?

What if they could have taken courses at community college and never did. I know a a 30 year old young autistic man whose dream was to go to community college but there was no one to show him how. Now he only cuts branches at his family home. Please help support aid for this population. Thank you, Cynthia Bartlett. Hawaii Autism Foundation

Submitted on: 2/4/2020 10:36:53 PM

Testimony for HMS on 2/5/2020 2:45:00 PM

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

Comments:

Aloha,

I am writing in support of SB 3122 that would require the Department of Human Services, upon approval from the Centers for Medicare and Medicaid Services, to establish and implement a program for providing home- and community-based services to at-risk individuals having intellectual or developmental disabilities who meet certain criteria.

As you aware, there has been a significant increase in the number of children diagnosed with Autism Spectrum Disorder both locally and nationally. Despite this knowledge, our community lacks home and community based serviced for individuals with intellectual and developmental disabilities who fall into this gap group.

It's my understanding that the primary barrier to enacting this bill comes down to financial resources. Providing home and community based services is costly, however, it is far less costly than institutionalizing or incarcerating an individual.

Our jails and prisons are bursting at the seams. Yet, the Legislature continues to allocate funding to lock up a person annually at the price tag of \$60,000 or more, even though a substantial number of these individuals are pretrial detention status and are simply too poor to post bail. Instead of spending our money on overincarceration, let's divert some of that money towards home and community bases services for individuals with developmental and intellectual disabilities who need additional support.

Please pass SB3122.

Submitted on: 2/5/2020 6:59:40 AM

Testimony for HMS on 2/5/2020 2:45:00 PM

Submitted By	Organization	Testifier Position	Present at Hearing
Vania Simmons	Individual	Support	No

Comments:

I am a parent of two individuals on the autism spectrum disorder. One of whom has aged out of DOE while living in the state of Hawaii. Two years after his graduation and having applied and appealed with DOH-DD, my son was still sitting at home with no services, no support. It felt as if he had fallen off the planet. The system that is in place right now is disorganized and inhumane. The intake process took 9 months instead of 90 days (as promised) to realize that my son was not eligible. To add insult to injury, I had to miss work (I am a single parent) to be able to do take my son to MORE assessments that were needed for eligibility criteria (it took a few months for the assessment to be scheduled because I had NO TIME to attend in person). They don't offer to come to your house to do it. In addition, the intake worker never answered my calls (only mailbox) and there was no email or text communications. In other words, we were unable to communicate directly to them and there was so paper trail, except to let me know that my son was denied. Well, I had no choice but to LEAVE the state of Hawaii. Our family is now in Colorado and guess what? It took 5 months for my son to be eligible for Disability services here. Also, the intake workers were super professional and expedient. They communicated via e-mail, text, and send me detailed instructions on what was expected of me and the next steps to take. They came to OUR HOUSE at our own convenience to conduct all the assessments. I am so happy to finally have something for my 21-year-old son! I understand that not all parents can relocate as my family did. It was the best thing I could have done for them and there are no regrets. My only regret was to live in Hawaii and have my son graduate from DOE in one of the worst states in the union for people with disabilities. I beg of you HI Senator and Representatives to fix this ridiculously painful situation for parents like myself. I am speaking for thousands of others as well that are in the same predicament. Don't just dump our young adults into the system. WE ELECT YOU to work for us and support our families. We will be watching you! Thank you!