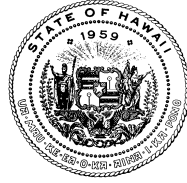


# SB1010

Measure Title:	RELATING TO HEALTH.
Report Title:	Department of Health; Developmental Disabilities; Fetal Alcohol Spectrum Disorder; Cerebral Palsy; Epilepsy; Autism Spectrum Disorder
Description:	Codifies certain developmental disabilities under the Department of Health.
Companion:	<a href="#">HB381</a>
Package:	Keiki Caucus
Current Referral:	CPH, WAM
Introducer(s):	BAKER, S. CHANG, HARIMOTO, KIDANI, K. RHOADS, Inouye, Kim, Shimabukuro, L. Thielen



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

**Testimony in OPPOSITION to SB 1010**  
**RELATING TO HEALTH**

SENATOR ROSALYN BAKER, CHAIR  
SENATE COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH  
Hearing Date: February 6, 2019 Room Number: 229  
9:30 A.M.

1 **Department Testimony:** The Department of Health respectfully opposes this measure to  
2 specify eligible conditions in the statutory definition of “developmental disabilities” in HRS §  
3 333F-1. Adding a list of eligible conditions could serve to exclude other conditions in the  
4 Diagnostic and Statistical Manual, Fifth Edition (DSM-5) that could make an individual eligible  
5 for DDD services.

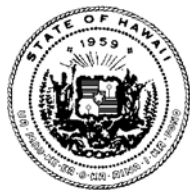
6 The current statutory definition is designed to adequately address **any** developmental disability  
7 where the individual experiences functional limitations as a result of their disability whereby  
8 they would benefit from DDD services. It is consistent with the federal definition found in the  
9 Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106–402 (DD  
10 Act), which does not list specific conditions and refers to the functional limitations of an  
11 individual.

12 Published by the American Psychiatric Association, DSM-5 serves as the principal authority for  
13 psychiatric diagnoses used by clinicians and researchers to diagnose and classify mental  
14 disorders. There are many disorders listed in DSM-5 that could potentially result in a finding of  
15 eligibility for DDD services. This was the precise reason Congress eliminated listing eligible  
16 conditions in the DD Act, and why they are not included in the State’s current statutory  
17 definition.

1 The term Fetal Alcohol Spectrum Disorders (FASD) is not meant for use as a clinical diagnosis.  
2 FASD is not listed in the DSM-5 for having clear evidence for which health care professionals  
3 can diagnose. There is a subset of FASD, called Neurobehavioral Disorder Associated with  
4 Prenatal Alcohol Exposure (ND-PAE) that is a recent addition to the DSM-5 but is not an official  
5 psychiatric disorder; it is included in Section III of the DSM-5 which lists conditions on which  
6 future research is encouraged in order to better understand them. ND-PAE is used in DSM-5 as  
7 an example for “Other Specified Neurodevelopmental Disorder,” code 315.8, which can trigger  
8 payment for services. Individuals who have prenatal alcohol exposure that affect their behavior  
9 are largely seen as having a behavioral disorder versus a developmental disability.

10 Under the current definition, an individual with FASDs may apply for DDD services, because  
11 FASDs are neurological disorders that occur during the developmental period (prior to age 22)  
12 and are likely to continue indefinitely. The individual would be assessed using the criteria set  
13 forth in HRS § 333F-1 that requires that the individual’s condition must result in substantial  
14 functional limitations in three or more areas of major life activity, such as self-care, receptive  
15 and expressive language, learning, mobility, self-direction, capacity for independent living, and  
16 economic self-sufficiency.

17 Thank you for the opportunity to testify.



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

February 4, 2019

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

FROM: Pankaj Bhanot, Director

SUBJECT: **SB 1010 – RELATING TO HEALTH**

Hearing: Wednesday, February 6, 2019, 9:30 a.m.  
Conference Room 229, State Capitol

**DEPARTMENT'S POSITION:** The Department of Human Services (DHS) appreciates the intent and provides comments. DHS has serious concerns regarding the bill to list specific eligible conditions in the definition of developmental disabilities in section 333F-1, Hawaii Revised Statutes (HRS) as the enumeration of eligible conditions could result in the exclusion of other conditions under the definition. Exclusion of other conditions may not align with eligibility requirements under the 1915(c) waiver program.

**PURPOSE:** The purpose of this bill is to describe the conditions eligible for inclusion under the definition of developmental disabilities.

DHS currently covers specialized services for individuals with developmental disabilities through the individuals with intellectual and developmental disabilities (I/DD) 1915(c) waiver operated in partnership with the Developmental Disabilities Division (DDD) at the Department of Health (DOH). Eligibility for waiver services is tied to the federal definition of developmental disabilities, which is based on the functional limitations rather than specific conditions.

The federal definition is a broad definition used for waiver eligibility. The enumeration of specific eligible conditions under this bill would not expand eligibility for waiver

services. Under federal rules, functionality is still a requirement and cannot be changed by state law.

If the 1915(c) waiver was changed to conform with the changes in this bill, then the result would be to restrict eligibility into the waiver program rather than expand it because only individuals with the conditions listed in the bill would be eligible.

The current statutory definition, however, does allow for any developmental disability where the individual has the functional limitations to benefit from waiver services, and it is consistent with federal rules.

Thank you for the opportunity to testify and offer concerns.



**STATE OF HAWAII**  
STATE COUNCIL  
ON DEVELOPMENTAL DISABILITIES  
PRINCESS VICTORIA KAMAMALU BUILDING  
1010 RICHARDS STREET, Room 122  
HONOLULU, HAWAII 96813  
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543  
February 6, 2019

**LATE**

The Honorable Senator Rosalyn Baker, Chair  
Senate Committee on Commerce, Consumer Protection and Health  
Thirtieth Legislature  
State Capitol  
State of Hawai'i  
Honolulu, Hawai'i 96813

Dear Senator Baker and Members of the Committee:

SUBJECT: SB 1010 - Relating to Health

The State Council on Developmental Disabilities appreciates the intent of SB 1010. The bill Codifies certain developmental disabilities under the Department of Health.

In order to prepare for this testimony, I met with Dr. Patricia Morrissey who wrote the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). She is also a current member of the State Council on Developmental Disabilities. We discussed the intent of the DD Act. It was written broadly to support young individuals with developmental disabilities to reach their highest level of independence in eight major areas of life activity. It was written to support an eighteen-year-old who went off to war, returned prior to the age of twenty-two, with a traumatic brain injury and needed lifelong supports to maintain their highest level of independence.

During recent testimony of HB381, we heard conditions being questioned if they are genuinely a qualifying Developmental Disability condition, which is needed in order to receive support through the Developmental Disabilities Division. Although the DD Act was written with the intent to be broad, so individuals with different developmental disabilities conditions would not be arbitrarily excluded, it appears this may be happening in Hawaii.

For this reason, we understand and support the role of the Legislature to bring awareness on specific eligible developmental disability conditions in order to create systems change. However, in order to avoid the perception of excluding a condition, we respectfully request you add to line 16; and all established criteria of the federal definition under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

Thank you for the opportunity to submit comments to SB1010.

Sincerely,

Daintry Bartoldus  
Executive Administrator

**SB-1010**

Submitted on: 2/4/2019 3:25:43 PM

Testimony for CPH on 2/6/2019 9:30:00 AM

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

Comments:

We have 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. While they do not receive services from programs designed to help those who are "mentally ill" or "intellectually disabled", they do exhibit symptoms that may overlap with some of these other diagnoses and they have real needs. 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 bill is a good beginning point for a discussion. That said, we must point out that classifying fetal alcohol syndrome as a developmental disability may not, in and of itself, accomplish that goal. We do believe that fetal alcohol syndrome is a developmental disability and should be classified as such. However, under the current DD rules there are adaptive functioning requirements and intellectual testing standards that must be met to establish eligibility. In our experience, many of these people may be deemed to be too high functioning to qualify for DD services. In that case, they will still not receive any assistance. In our view, it may be better to establish a separate program designed to serve this population.

We see this a work in progress and look forward to working with the Committee to refine this proposal as the session progresses.



# 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 with amendment of SB1010  
RELATING TO HEALTH

COMMITTEE ON COMMERCE, CONSUMER PROTECTION, AND HEALTH

Senator Rosalyn H. Baker, Chair  
Senator Stanley Chang, Vice Chair

Wednesday, February 6, 2019 9:30A  
Conference Room 229  
State Capitol  
415 South Beretania Street

The Hawai'i Psychological Association (HPA) supports this bill that codifies under the Department of Health *cerebral palsy or epilepsy, autism spectrum disorder, fetal alcohol spectrum disorder (FASD), or a disorder due to a neurological condition, central nervous system disorder, or chromosomal disorder that results in both substantial impairment of general intellectual functioning and adaptive behavior skill deficits similar to those of a person with an intellectual disability*. There is a lack of appropriate services available to our families and communities affected by developmental disabilities, and in particular a need to increase education, improve accurate diagnosis, and expand evidence-based services for FASD.

The State has expressed concern that this bill, as currently written, will result in restricting eligibility rather than expanding it because only individuals with the conditions listed in the bill would be eligible, and claim the current statutory definition is better because it does allow for any developmental disability where the individual has the functional limitations to benefit from waiver services, which is consistent with federal rules. We humbly suggest that this may be resolved by a minor amendment to the proposed new statutory language on page 2, line 10: "...conditions shall include, but shall not be limited to, cerebral palsy or epilepsy..."

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

Sincerely,

Julie Takishima-Lacasa, PhD  
Chair, HPA Legislative Action Committee



**SB-1010**

Submitted on: 2/5/2019 8:43:56 AM

Testimony for CPH on 2/6/2019 9:30:00 AM

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

Comments:

SB1010 FOR HEARING 2/6/19, 9:30 AM

Dear Chairperson, Senator Baker and members of the Commerce, Consumer Protection and Health Committee,

I am writing in support of SB1010 that codifies certain developmental disabilities such as fetal alcohol spectrum disorders (FASD) under the Department of Health. In a small study, as many as 85% of adoptees and children in foster care were misdiagnosed or undiagnosed with FASD. A national 2018 study found that as many as 1 in 20 first grade children were diagnosed with FASD. Clinicians privately admit that they have diagnosed their clients with FASD for autism to obtain services because there were no services for FASD. Indeed, people with FASD often receive services that do not account for their disabilities and thus may result in poor outcomes. At a recent hearing on the House companion bill, testimony noted that FASD is not a developmental disorder.

In the past 60 years, aggressive research describes a silent epidemic of people affected with an FASD, the need for FASD-informed services, and the difficulty of implementing promising practices. As a psychologist and family therapist, I find very few FASD-services for my families and clients affected by FASD.

By codifying FASD as a developmental disability, my colleagues and community may begin to recognize and diagnose FASD and create FASD-specific services. We have a long way to go.

Mahalo nui,

Ann S. Yabusaki, Ph.D., MFT

**SB-1010**

Submitted on: 2/2/2019 3:12:56 PM

Testimony for CPH on 2/6/2019 9:30:00 AM

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

Comments:

Dear Chairperson, Senator Baker and members of the Commerce, Consumer Protection and Health Committee,

I am writing in support of SB1010 that codifies certain developmental disabilities such as fetal alcohol spectrum disorders (FASD) under the Department of Health. In my experience as a clinician, who works with both children and adults, I have regularly seen intergenerational patterns of misdiagnosis followed by what is essentially mistreatment of persons with a disability within our human services sector. The way alcohol exposure effects the brain in utero is unique to each individual in accordance with the amount and stage and other developmental factors, however those who are diagnosed, with both confirmation of maternal history and physical and behavioral symptoms, will have this condition throughout the course of their lifetime. It is pervasive developmental disorder, there is no cure. They will likely require a lifetime of informed, individualized services to avoid other costly and often detrimental interventions, such as involvement in the criminal justice system.

In the past 60 years, aggressive research describes a silent epidemic of people affected with an FASD, the need for FASD-informed services, and the difficulty of implementing promising practices with legislative and policy support. In a small study, as many as 85% of adoptees and children in foster care were misdiagnosed or undiagnosed with FASD. A national 2018 study found that as many as 1 in 20 first grade children were diagnosed with FASD. I currently find very few FASD informed-services for my clients and families affected by FASD. By codifying FASD as a developmental disability, my colleagues and community may begin to recognize and diagnose FASD and create FASD-specific services. We have a long way to go, but this could be a big step in not only helping people with this disability get the services they need, but also contribute to breaking cycles in the way we treat persons affected.

Mahalo nui,

Amanda Luning, LMHC

**SB-1010**

Submitted on: 2/2/2019 3:23:55 PM

Testimony for CPH on 2/6/2019 9:30:00 AM

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

Comments:

Dear Senator Baker and Members of the Commerce, Consumer Protection and Health Committee:

I am writing in support of SB1010 which codifies developmental disabilities such as Fetal Alcohol Spectrum Disorders (FASD) with the Department of Health (DOH). It has been shown in one study that adoptee and foster children with FASD were misdiagnosed or undiagnosed 85% of the time. A recent national study found as many as one in twenty first grade children (conservative estimate) were diagnosed with FASD. I have personally witnessed children with confirmed diagnoses for FASD inappropriately referred for autism services because there were no informed FASD services for children in Hawaii. I have sat in on an Individual Educational Program (IEP) for a child with FASD where school officials attending the IEP clearly lacked in-depth knowledge of FASD and thus, no constructive interventions were made.

To a large degree, FASD is an invisible disability and many times seen only as a behavioral disorder. However, FASD is a permanent life-long brain condition and a developmental disability, one that began by prenatal exposure of the fetus to alcohol metabolites. Many parents with children afflicted with FASD are denied services because their child falls within a bureaucratic and/or political gap for services. Much of this is due to service providers lacking full-knowledge of FASD. To this end, many children with FASD have IQs within the normal range with low scores for executive functioning. However, because of a "normal" IQ score, these individuals are denied developmental disability services. The standards and guidelines for those with FASD must be lowered to make access to services equitable.

FASD is 100% preventable. And in a society where drinking alcohol is a cultural norm with unintended pregnancy rates near 50%, the government should take some responsibility to ensure that individuals afflicted by FASD are given the same access to developmental disability services as those afflicted with autism, cerebral palsy, Downs Syndrome, and spina bifida. I strongly urge you to consider codifying FASD because it is a developmental disability.

Mahalo nui,

K. Ken Yabusaki, Ph.D.

**SB-1010**

Submitted on: 2/4/2019 11:26:46 AM

Testimony for CPH on 2/6/2019 9:30:00 AM

<b>Submitted By</b>	<b>Organization</b>	<b>Testifier Position</b>	<b>Present at Hearing</b>
Krista Brown	Individual	Support	No

Comments:

SB1010 FOR HEARING 2/6/19, 9:30 AM

Dear Chairperson, Senator Baker and members of the Commerce, Consumer Protection and Health Committee,

I am writing in support of SB1010 that codifies certain developmental disabilities such as fetal alcohol spectrum disorders (FASD) under the Department of Health. In a small study, as many as 85% of adoptees and children in foster care who were impacted by prenatal exposure to alcohol/drugs and/or exhibiting symptoms consistent with FASD were diagnosed with another disorder (e.g., ADHD) or undiagnosed. A national study conducted in 2018 found that as many as 1 in 20 first grade children were diagnosed with FASD. People with FASD often receive services that are not appropriate for their disability, resulting in poor short- and long-term outcomes. At a recent hearing on the House companion bill, testimony noted that FASD was not a developmental disorder. Over the last ~60 years, research has described high rates of maternal alcohol use and FASD, a need for FASD-informed services and research, and the difficulty of implementing interventions with this population. Currently, there are very few services available for individuals and families affected by FASD in Hawaii.

By codifying FASD as a developmental disability, my colleagues and community may begin to recognize and diagnose FASD and create FASD-specific services.

Thank you for your consideration,

Krista Brown, Ph.D.