

JAN 16 2014

A BILL FOR AN ACT

RELATING TO HEALTH.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1 SECTION 1. The legislature finds that fetal alcohol
2 spectrum disorder is one of the most underdiagnosed
3 developmental disabilities in Hawaii and across the United
4 States. The effects of prenatal alcohol exposure are lifelong,
5 yet fetal alcohol spectrum disorder is completely preventable.
6 The devastating effects of fetal alcohol exposure can be
7 ameliorated through early intervention and effective systems of
8 care and services.

9 Fetal alcohol exposure is a leading cause of intellectual
10 disabilities in the United States, and the majority of those
11 exposed do not actually exhibit intellectual delays.
12 Individuals with diagnosed or undiagnosed fetal alcohol exposure
13 often suffer from secondary disabilities and other areas of
14 concern including child abuse and neglect, family separation or
15 disjointment, multiple foster placements, school related
16 failure, juvenile delinquency, job instability, depression,
17 aggression, and other serious mental health disorders. These
18 secondary concerns and intellectual disabilities come at a high



1 cost to the individual, their families, and society. These
2 problems can be substantially reduced, however, by early
3 diagnosis and appropriate, effective intervention.

4 Fetal alcohol spectrum disorder is an umbrella term
5 describing the range of effects that can occur as a result of an
6 individual's mother consuming alcohol during pregnancy. These
7 effects include physical, mental, behavioral, and learning
8 disabilities with lifelong implications.

9 Nationwide, the occurrence of fetal alcohol spectrum
10 disorder is estimated to be one per cent of live births. That
11 means forty thousand newborns per year are affected by fetal
12 alcohol spectrum disorder. There are more cases of fetal
13 alcohol spectrum disorder than down syndrome, cerebral palsy,
14 sudden infant death syndrome, cystic fibrosis, and spina bifida
15 combined. Human costs of prenatal alcohol exposure are great,
16 as are the economic costs. Caring for someone with fetal
17 alcohol spectrum disorder costs between \$1,400,000 and
18 \$1,500,000 over a lifetime, whereas implementing effective
19 systems of care and services will cost a fraction of that
20 amount.

21 There are currently very few fetal alcohol spectrum
22 disorder-specific services in Hawaii, yet thousands of women in



1 the State put their infants at risk for fetal alcohol spectrum
2 disorder. Based on the Hawaii pregnancy risk assessment
3 monitoring system data, approximately one thousand three hundred
4 women who gave birth in Hawaii during the years 2009 to 2011
5 reported that they drank alcohol in the last trimester of their
6 most recent pregnancy. In that same time period, approximately
7 two hundred women per year reported binge drinking in the last
8 trimester of their most recent pregnancy. Binge drinking for
9 women is defined as drinking four or more alcoholic drinks in
10 one sitting.

11 Hawaii pregnancy risk assessment monitoring system data
12 also states that of those surveyed, three thousand four hundred
13 females engaged in drinking prior to pregnancy. Pregnancy risk
14 assessment monitoring system data finds binge drinking is
15 estimated to increase over time, including during pregnancy. In
16 Hawaii, women under the age of twenty-five have the highest
17 estimates of binge drinking three months prior to pregnancy. It
18 should be noted that pregnancy risk assessment monitoring system
19 data does not include every woman who gives birth in Hawaii, so
20 the prevalence of drinking during pregnancy may well be higher
21 than reported. Because fetal alcohol spectrum disorder can
22 occur in any community where women consume alcohol during



1 pregnancy, it is a statewide public health concern that has
2 service, policy, and economic implications for virtually all
3 state departments.

4 Because fetal alcohol spectrum disorder is frequently
5 underdiagnosed, and families as well as providers have
6 significant problems in addressing the multiple and challenging
7 needs of persons with this disorder, fourteen states already
8 have permanent fetal alcohol spectrum disorder coordinators.
9 These fetal alcohol spectrum disorder coordinators serve as a
10 key educational, informational, and coordinative link between
11 departments and agencies dealing with persons with fetal alcohol
12 spectrum disorder.

13 Poor coordination hampers prevention, diagnosis, and
14 service delivery. A fetal alcohol spectrum disorder interagency
15 coordinating council with a fetal alcohol spectrum disorder
16 coordinator would organize all fetal alcohol spectrum disorder
17 related activities, and would ensure that a comprehensive state
18 strategic plan to address fetal alcohol spectrum disorder is
19 drafted and implemented.

20 The purpose of this Act is to coordinate and develop fetal
21 alcohol spectrum disorder information, education, policies, and
22 support services statewide by establishing a fetal alcohol



1 spectrum disorder interagency coordinating council with a fetal
2 alcohol spectrum disorder coordinator within the department of
3 health's family health services division.

4 SECTION 2. (a) There is established within the family
5 health services division of the department of health a fetal
6 alcohol spectrum disorder interagency coordinating council and a
7 fetal alcohol spectrum disorder coordinator. Members of the
8 council shall be appointed for three-year terms by the governor
9 and shall not be subject to section 26-34. The council shall
10 comprise no less than fifteen members and no more than seventeen
11 members as follows:

12 (1) At least three members shall be individuals with fetal
13 alcohol spectrum disorder or immediate relatives or
14 guardians of an individual with fetal alcohol spectrum
15 disorder, with at least one member from a neighbor
16 island;

17 (2) At least one member shall be a representative of the
18 maternal and child health branch of the department of
19 health;

20 (3) At least one member shall be a representative of the
21 children with special health needs branch of the
22 department of health;



1 (4) At least one member shall be a representative of the
2 developmental disabilities division of the department
3 of health;

4 (5) At least one member shall be a representative of the
5 alcohol and drug abuse division of the department of
6 health;

7 (6) At least one member shall be a representative of the
8 adult mental health division of the department of
9 health;

10 (7) At least one member shall be a representative of the
11 special education section of the department of
12 education;

13 (8) At least one member shall be a representative of the
14 comprehensive student support services section of the
15 department of education;

16 (9) At least one member shall be a representative of the
17 judiciary;

18 (10) At least one member shall be a representative of the
19 office of youth services of the department of human
20 services;

21 (11) At least one member shall be a representative of the
22 social services division of the department of human



1 services involved in providing services for foster and
2 adoptive families;

3 (12) At least one member shall be a representative of an
4 agency responsible for the recruitment, training, or
5 support of foster and adoptive families;

6 (13) At least one member shall be a representative of a
7 private nonprofit group concerned with services for
8 individuals with fetal alcohol spectrum disorder in
9 this State; and

10 (14) At least one member shall be from the native hawaiian
11 health care system;

12 provided that each member representing a state agency shall have
13 the authority to influence policy in the member's respective
14 agency.

15 Any vacancy on the council shall be filled in the same
16 manner in which the original position was filled.

17 (b) The council shall elect its officers, and fifty per
18 cent of the members shall constitute a quorum. Members shall
19 serve without compensation but shall be reimbursed for
20 authorized expenses, including travel expenses, necessary for
21 the performance of their duties. No member shall cast a vote on
22 any matter that is likely to provide a direct financial benefit



1 to that member or otherwise give the appearance of a conflict of
2 interest.

3 (c) The council and coordinator shall meet at least
4 quarterly and in such places as it deems necessary.

5 (d) For the purpose of minimizing travel and per diem
6 expenses for parties who are not located on Oahu, the board
7 shall utilize cost efficient means, such as teleconferencing or
8 videoconferencing, that do not require appearances on Oahu,
9 whenever practicable, to conduct its proceedings.

10 (e) The council and coordinator shall perform the
11 following functions:

12 (1) Increase statewide awareness of fetal alcohol spectrum
13 disorder in the general public and in at-risk
14 populations;

15 (2) Expand the statewide capacity to identify and
16 intervene with at-risk women who are pregnant and
17 parenting;

18 (3) Advocate, mobilize, and coordinate state and community
19 resources to assist persons and families affected by
20 fetal alcohol spectrum disorder to receive the support
21 they need;



- 1 (4) Improve statewide service delivery to individuals and
- 2 families affected by fetal alcohol spectrum disorder;
- 3 (5) Facilitate development and implementation of a
- 4 comprehensive, statewide system of care for the
- 5 prevention, identification, surveillance, and
- 6 treatment of fetal alcohol spectrum disorders; and
- 7 (6) Develop and implement a statewide strategic plan to
- 8 address the full range of lifelong fetal alcohol
- 9 spectrum disorder prevention, identification, care,
- 10 treatment, and education.

11 SECTION 3. There is appropriated out of the general
12 revenues of the State of Hawaii the sum of \$ or so
13 much thereof as may be necessary for fiscal year 2014-2015 to
14 establish a fetal alcohol spectrum disorder interagency
15 coordinating council and a permanent fetal alcohol spectrum
16 disorder coordinator position in the family health services
17 division of the department of health.

18 The sum appropriated shall be expended by the department of
19 health for the purposes of this Act.


20 SECTION 4. This Act shall take effect on July 1, 2014.

21

INTRODUCED BY: *Theranne Chun Oakland*



S.B. NO. 2218


George de Beken



S.B. NO. 2218

Report Title:

Fetal Alcohol Spectrum Disorder; Appropriation

Description:

Creates a coordinating council and coordinator position within the department of health's family health services division to coordinate and develop information, education, policy, and support services for fetal alcohol spectrum disorder.

The summary description of legislation appearing on this page is for informational purposes only and is not legislation or evidence of legislative intent.

