

JAN 23 2015

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 the most underdiagnosed and preventable
3 developmental disability in Hawaii and across the United States.
4 The effects of prenatal alcohol exposure are lifelong, yet fetal
5 alcohol spectrum disorder is completely preventable. The
6 effects of fetal alcohol exposure can be ameliorated through
7 early intervention and effective systems of care and service.
8 The devastating effects of prenatal alcohol exposure are
9 manifested in youth, and barring the effective care and services
10 of a qualified practitioner, continue for the duration of the
11 individual's lifetime.

12 Fetal alcohol spectrum disorder is an umbrella term
13 describing the range of effects that can occur to an individual
14 as a result of the individual's mother consuming alcohol during
15 pregnancy. These effects typically include physical, mental,
16 behavioral, and learning disabilities with lifelong
17 implications.



1 Although fetal alcohol exposure is a leading cause of
2 intellectual disabilities in the United States, the majority of
3 those exposed do not exhibit noticeable delays in intellectual
4 development. Individuals with diagnosed or undiagnosed fetal
5 alcohol exposure often suffer from secondary disabilities and
6 other areas of concern, such as child abuse, neglect, family
7 separation or disjointment, multiple foster placements, school
8 related failure, juvenile delinquency, job instability,
9 depression, aggression, and other serious mental health
10 disorders. These secondary concerns and intellectual
11 disabilities come at a high cost to the individual, their
12 families, and society. These problems can be substantially
13 reduced, however, by early diagnosis and appropriate, effective
14 intervention undertaken by qualified persons that have
15 experience and established knowledge of the disorder.

16 Further illustrating the prevalence of this disorder in the
17 United States, a 2014 study reported that in one typical
18 Midwestern city, the estimated rate of fetal alcohol spectrum
19 disorder occurs in the range of twenty-four to forty-eight
20 children per every one thousand children in the city. In other
21 words, out of the total city population of children, there are



1 2.4 to 4.8 per cent that are affected with this disorder. These
2 results further indicate that children diagnosed with fetal
3 alcohol spectrum disorder represent a larger percent of the
4 population than previously projected percentages set forth in
5 commonly accepted studies.

6 The annual birth rate of those affected with fetal alcohol
7 spectrum disorder across the nation constitutes 1 per cent of
8 total live births annually in the United States. This figure
9 means that forty thousand newborns every year are born and
10 already struggling with the effects of fetal alcohol spectrum
11 disorder. This figure further means that there are more annual
12 cases of fetal alcohol spectrum disorder than the combined
13 annual births of newborns diagnosed with spina bifida, multiple
14 sclerosis, down syndrome, and HIV combined.

15 Human costs of prenatal alcohol exposure are significant,
16 as are the projected economic and financial costs to ensure
17 appropriate health care and treatment for affected and at-risk
18 persons. Costs associated with the care of one person diagnosed
19 with fetal alcohol spectrum disorder are currently estimated at
20 approximately \$5,000,000. The generally accepted figure that
21 forty thousand children are born annually with this disorder



1 nationwide likely to require additional health care treatment
2 means that the total amount of expenses for one year of
3 treatment for affected newborns is \$4,000,000,000.

4 The legislature further finds that there is a disturbing
5 disparity between the considerable costs of future care and the
6 absence of a mandatory or uniform documentation of new
7 diagnoses. In the absence of a reliable source of current
8 figures, the State remains unprepared to handle the growing
9 numbers of those needing care. As there is no mandatory
10 reporting for fetal alcohol spectrum disorder, the current
11 number of individuals documented with a fetal alcohol spectrum
12 disorder remains well below the number of those in fact
13 affected. For example, only ninety cases were documented and
14 reported to Hawaii's birth defects registry between 1966 and
15 2005. Most children that are diagnosed with fetal alcohol
16 spectrum disorder are only diagnosed around twelve years of age.
17 This ongoing scarcity of documentation and delayed diagnoses
18 highlights the juxtaposition of notably absent services against
19 the significant presence of mothers that drink during pregnancy.

20 Additional research has revealed that alcohol is a major
21 substance that is frequently used by pregnant women in Hawaii



1 county. Approximately 35 per cent of women surveyed stated they
2 had drunk alcohol in the month prior to learning of their
3 pregnancy. Even in the early days of pregnancy, the use of
4 alcohol places the newborn at risk of developing intellectual
5 behavioral disorders. Although more than half the women
6 reported that they stopped drinking alcohol after learning they
7 were pregnant, 42 per cent reported that they continued to drink
8 during their pregnancy. Of this 42 per cent, only 10 per cent
9 responded to a decrease in alcohol intake after learning of
10 their pregnancy. In other words, alcohol consumption by the
11 women surveyed is so significant or occurred so frequently that
12 this reduced rate of consumption means that they still consumed
13 alcohol daily in a range between three to six days per week.
14 Any future children born to these women face an elevated risk
15 for the sequelae of prenatal alcohol exposure.

16 Further illustrating the severity of alcohol exposure to
17 future newborns is a conclusion reached in the recent State
18 survey on alcohol use by pregnant or recently pregnant women,
19 "Pregnancy Risk Assessment Monitoring" (2011). The most
20 disturbing conclusion that highlighted the higher than national
21 average consumption of alcohol of women statewide on a regular



1 basis, including the period prior to learning of their
2 pregnancy. Specifically, this data revealed that 7 per cent of
3 women surveyed reported that they had drunk alcohol in the final
4 trimester of their most recent pregnancy. In addition, 1.2 per
5 cent of women who had given birth in the same period had engaged
6 in binge drinking in the final trimester of their most recent
7 pregnancy.

8 There are approximately eighteen thousand nine hundred
9 annual live births in Hawaii. By calculating this figure of
10 live births together with the reported figure in the 2011 survey
11 of 7 per cent of women who consumed alcohol during their final
12 trimester, there are an estimated one thousand three hundred
13 newborns that face possible exposure to alcohol and risk to
14 lifelong effects of fetal alcohol spectrum disorder.

15 Most persons currently affected with fetal alcohol spectrum
16 disorder are undiagnosed or misdiagnosed. Even properly
17 diagnosed patients have been reported by service providers as
18 unable or unwilling to follow individual treatment plans or to
19 follow traditional treatment methods and other state service
20 systems.



1 In situations where fetal alcohol spectrum disorder is
2 underdiagnosed, families and providers have generally faced
3 significant difficulties in comprehensively addressing the
4 multiple and challenging needs of patients. These difficulties
5 may grow with the growing population of those affected and at-
6 risk. In response to this burgeoning state and national health
7 crisis, twenty states have recently established a fetal alcohol
8 spectrum disorder coordinator position within their respective
9 state agencies. This fetal alcohol spectrum disorder
10 coordinator serves primarily as a key educational,
11 informational, and public access point for relevant state
12 departments, agencies and public at large.

13 In contrast to these twenty states that have already
14 affirmatively acted to establish effective and multi-
15 comprehensive processes by which to treat current patients and
16 prevent an unchecked increase of affected persons in the future,
17 Hawaii's own efforts continue to be hampered by poor
18 coordination, thereby obstructing movement toward state uniform
19 diagnosis methods and service of care. The legislature further
20 finds there is an urgent need to establish a fetal alcohol
21 spectrum disorder coordinator position in the interest of



1 serving both current and future populations affected by this
2 disorder.

3 The fetal alcohol spectrum disorder coordinator shall
4 organize State-sponsored activities relating to fetal alcohol
5 syndrome, such as informational and prevention promotional
6 activities. The role of this coordinator shall include the duty
7 to oversee establishment, drafting, and implementation of a
8 State-based comprehensive strategic plan to effectively address
9 the multi-faceted issues arising in preventive planning, such as
10 identifying populations historically evidenced as particularly
11 vulnerable to fetal alcohol exposure, and evaluating cost-
12 effective, appropriate responses to continued occurrences.

13 The purpose of this Act is to establish one permanent full-
14 time equivalent (1.00 FTE) fetal alcohol spectrum disorder
15 coordinator position in the family health services division of
16 the department of health.

17 SECTION 2. There is established in the family health
18 services division of the department of health one permanent
19 full-time equivalent (1.00 FTE) fetal alcohol spectrum disorder
20 coordinator position. This coordinator shall serve as the
21 public point of contact for individuals and families affected by



1 fetal alcohol spectrum disorder. The coordinator shall
2 additionally coordinate a statewide system of service for those
3 affected with fetal alcohol spectrum disorder by undertaking the
4 following:

- 5 (1) Increasing statewide awareness of fetal alcohol
6 spectrum disorder for the general public and at-risk
7 populations;
- 8 (2) Expanding statewide capacity to identify and intervene
9 with at-risk pregnant and parenting women;
- 10 (3) Advocating, mobilizing, and coordinating state and
11 community resources to provide necessary assistance
12 for persons and families affected by fetal alcohol
13 spectrum disorder to receive the support they need;
- 14 (4) Improving statewide service delivery to individuals
15 and families affected by fetal alcohol spectrum
16 disorder;
- 17 (5) Coordinating the state comprehensive strategic plan
18 that addresses the full range of fetal alcohol
19 spectrum disorder care, treatment, education, and
20 prevention issues and possible solutions;



(6) Facilitating and coordinating fetal alcohol spectrum disorder task force meetings;

(7) Facilitating development and implementation of a comprehensive, statewide system of care for the prevention, identification, surveillance, and treatment of fetal alcohol spectrum disorders; and

(8) Assisting state department and agency efforts to collect, analyze, and share available data on rates of diagnosis and prevalence.

SECTION 3. There is appropriated out of the general revenues of the State of Hawaii the sum of \$150,000 or so much thereof as may be necessary for fiscal year 2015-2016 to establish one permanent full-time equivalent (1.00 FTE) fetal alcohol spectrum disorder coordinator position within the family health services division of the department of health and the operating expenses necessary to facilitate the coordinator's duties.

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



1 SECTION 4. This Act shall take effect on July 1, 2015.

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S.B. NO. 925

Report Title:

Fetal Alcohol Spectrum Disorder; Fetal Alcohol Spectrum Disorder Coordinator; Family Health Services; Department of Health; Appropriation

Description:

Establishes one permanent full-time equivalent (1.00 FTE) fetal alcohol spectrum disorder coordinator position in the family services division of the department of health. Makes an appropriation.

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