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# 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, while fetal alcohol  
2 exposure is one of the leading known causes of mental  
3 retardation in industrialized nations, the majority of those so  
4 exposed are not mentally retarded. Individuals with diagnosed  
5 or undiagnosed fetal alcohol exposure suffer substantially from  
6 secondary disabilities, such as child abuse and neglect,  
7 separation from families, multiple foster placements, school  
8 failure, juvenile detention, job instability, depression,  
9 aggression, and other serious mental disorders. These secondary  
10 disabilities come at a high cost to the individuals, their  
11 families, and society. The legislature finds that these  
12 problems can be reduced substantially by early diagnosis and  
13 receipt of appropriate, effective intervention.

14           Fetal alcohol spectrum disorder is an umbrella term  
15 describing the range of effects that can occur in an individual  
16 whose mother consumed alcohol during pregnancy. These effects  
17 may include physical, mental, behavioral, and learning  
18 disabilities with possible lifelong implications.



1           Nationwide, the incidence of fetal alcohol spectrum  
2 disorder is estimated to be ten per one thousand live births.  
3 Nationally, more children are born each year with fetal alcohol  
4 spectrum disorder than those born with spina bifida, multiple  
5 sclerosis, Down Syndrome, and HIV combined. There are an  
6 estimated one hundred seventy-five children born each year in  
7 Hawaii with fetal alcohol spectrum disorder. Human costs of  
8 prenatal alcohol exposure are great, as are the economic costs.  
9 Caring for someone with fetal alcohol spectrum disorder may cost  
10 as much as \$5,000,000. Nationally, as many as forty thousand  
11 babies are born each year with fetal alcohol spectrum disorder,  
12 costing the United States about \$4,000,000,000.

13           Fetal alcohol spectrum disorder is the most underdiagnosed  
14 developmental disability, both in Hawaii and across the United  
15 States. The effect of prenatal alcohol exposure lasts a  
16 lifetime, yet it is totally preventable. The effects of the  
17 known risk factors may be ameliorated with early intervention  
18 and through effective systems of care and services.

19           Most persons with fetal alcohol spectrum disorder are  
20 undiagnosed or misdiagnosed and frequently do not follow  
21 treatment plans, even when properly diagnosed. Persons with  
22 fetal alcohol spectrum disorder frequently fail in traditional



1 treatment and other service systems and are commonly identified  
2 as being noncompliant, uncooperative, and unmotivated in all  
3 systems of services and care.

4 There are currently few fetal alcohol spectrum disorder-  
5 specific services in Hawaii, and only eighty-nine cases of fetal  
6 alcohol spectrum disorder have been documented and reported to  
7 Hawaii's birth defects registry from 1966 to 2002. Department  
8 of health data from 2002 indicated that forty per cent of  
9 pregnant women surveyed consumed alcohol prior to becoming  
10 pregnant, and almost four per cent indicated that they consumed  
11 alcohol during pregnancy, which put their infants at risk for  
12 fetal alcohol spectrum disorder.

13 Information from a 2003 department of health behavioral  
14 risk prevalence survey shows that almost eighty-two per cent of  
15 the women surveyed consumed alcohol one month prior to the  
16 survey, and almost four per cent indicated that they engage in  
17 binge drinking. Because fetal alcohol spectrum disorder can  
18 occur in any community where women consume alcohol during  
19 pregnancy, it is a statewide public health concern that has  
20 service, policy, and economic implications for virtually all  
21 state departments.



1           Because fetal alcohol spectrum disorder is underdiagnosed  
2 and families as well as providers have significant problems in  
3 addressing the multiple, challenging needs of persons with this  
4 disorder, fourteen states already have state fetal alcohol  
5 spectrum disorder coordinators. These fetal alcohol spectrum  
6 disorder coordinators serve as a key educational, informational,  
7 and coordination link between departments and agencies dealing  
8 with persons with fetal alcohol spectrum disorder.

9           Poor coordination hampers prevention, diagnosis, and  
10 service delivery. A state fetal alcohol spectrum disorder  
11 coordinator would organize all fetal alcohol syndrome activities  
12 and would ensure that a comprehensive state strategic plan to  
13 address fetal alcohol spectrum disorder is drafted and  
14 implemented.

15           The purpose of this Act is to coordinate and develop fetal  
16 alcohol spectrum disorder information, education, policies, and  
17 support services statewide by establishing a state fetal alcohol  
18 spectrum disorder coordinator position within the department of  
19 health's family health services division.

20           SECTION 2. There is established within the family health  
21 services division of the department of health one full-time  
22 equivalent permanent professional fetal alcohol spectrum



1 disorder coordinator position. The fetal alcohol spectrum  
2 disorder coordinator shall act as a public point of contact for  
3 individuals and families affected by fetal alcohol spectrum  
4 disorder and shall help to coordinate a statewide system of  
5 services for persons with fetal alcohol spectrum disorder by:

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

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

3 (7) Facilitating 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.

7 SECTION 3. There is appropriated out of the general  
8 revenues of the State of Hawaii the sum of \$ , or so  
9 much thereof as may be necessary for fiscal year 2006-2007 for  
10 operating expenses and to establish a full-time equivalent  
11 permanent professional fetal alcohol spectrum disorder  
12 coordinator position in the family health services division at  
13 the department of health.

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

16 SECTION 4. This Act shall take effect on July 1, 2050.

**Report Title:**

Fetal Alcohol Spectrum Disorder; Coordinator

**Description:**

Establishes a fetal alcohol spectrum disorder coordinator position within the Department of Health. (SD2)

