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 exposure is one of the leading known causes of mental 2 retardation in industrialized nations, the majority of those so 3 exposed are not mentally retarded. Individuals with diagnosed 4 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 disabilities come at a high cost to the individuals, their 10 11 families, and society. The legislature finds that these 12 problems can be reduced substantially by early diagnosis and receipt of appropriate, effective intervention. 13 14 Fetal alcohol spectrum disorders is an umbrella term describing the range of effects that can occur in an individual 15 whose mother drank alcohol during pregnancy. These effects may 16 include physical, mental, behavioral, and learning disabilities 17

with possible lifelong implications.

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Nationwide, the incidence of fetal alcohol spectrum 1 disorder is estimated to be ten per one thousand live births. 2 Nationally, more children are born each year with fetal alcohol 3 spectrum disorder than those born with spina bifida, multiple 4 sclerosis, Down Syndrome, and HIV combined. There are an 5 estimated one hundred seventy-five children born each year in 6 Hawaii with a fetal alcohol spectrum disorder. Human costs of 7 prenatal alcohol exposure are great, as are the economic costs. 8 Caring for someone with a fetal alcohol spectrum disorder may 9 cost as much as \$5,000,000. Nationally, as many as forty 10 thousand babies are born each year with a fetal alcohol spectrum 11 disorder, costing the United States about \$4,000,000,000. 12 Fetal alcohol spectrum disorders are the most 13 underdiagnosed developmental disabilities, both in Hawaii and 14 across the United States. The effect of prenatal alcohol 15 exposure lasts a lifetime, yet fetal alcohol spectrum disorder 16 is totally preventable. The effects of the known risk factors 17 may be ameliorated with early intervention and through effective 18 systems of care and services. 19 Most persons with a fetal alcohol spectrum disorder are **20**

undiagnosed or misdiagnosed and frequently do not follow

treatment plans, even when properly diagnosed. Persons with

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- 1 fetal alcohol spectrum disorder frequently fail in traditional
- 2 treatment and other service systems and are commonly identified
- 3 as being noncompliant, uncooperative, and unmotivated in all
- 4 systems of services and care.
- 5 There are currently few fetal alcohol spectrum disorder-
- 6 specific services in Hawaii, and only eighty-nine cases of fetal
- 7 alcohol spectrum disorder have been documented and reported to
- 8 Hawaii's birth defects registry from 1966 to 2002. Hawaii
- 9 department of health data from 2002 indicate that forty per cent
- 10 of pregnant women surveyed consumed alcohol prior to becoming
- 11 pregnant, and almost four per cent indicated that they consumed
- 12 alcohol during pregnancy, which put their infants at risk for
- 13 fetal alcohol spectrum disorder.
- 14 Information from a 2003 department of health behavioral
- 15 risk prevalence survey shows that almost eighty-two per cent of
- 16 the women surveyed consumed alcohol one month prior to the
- 17 survey, and almost four per cent indicated that they engage in
- 18 binge drinking. Because fetal alcohol spectrum disorder can
- 19 occur in any community where women drink alcohol during
- 20 pregnancy, it is a statewide public health concern that has
- 21 service, policy, and economic implications for virtually all
- 22 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 disorder, there are currently fourteen states that already have 4 5 state fetal alcohol spectrum disorder coordinators. The state fetal alcohol spectrum disorder coordinators serve as a key 6 7 educational, informational and coordination link between departments and agencies dealing with persons with a fetal 8 9 alcohol spectrum disorder. Poor coordination hampers prevention, diagnosis, and 10 service delivery. A state fetal alcohol spectrum disorder 11 12 coordinator would organize all fetal alcohol syndrome activities and would ensure that a comprehensive state strategic plan to 13 address fetal alcohol spectrum disorder is drafted and 14 15 implemented. 16 The purpose of this Act is to coordinate and develop fetal alcohol spectrum disorder information, education, policies, and 17 support services statewide by authorizing the lieutenant 18 19 governor to establish a state fetal alcohol spectrum disorder 20 coordinator position within the office of the lieutenant 21 governor.

1	SECTION 2. There is to be established within the office of	
2	the lieutenant governor one full-time equivalent permanent	
3	professional fetal alcohol spectrum disorder coordinator	
4	position.	The fetal alcohol spectrum disorder coordinator shall
5	act as a	public point of contact for individuals and families
6	affected	by fetal alcohol spectrum disorder and shall help to
7	coordinat	e a statewide system of services for persons with fetal
8	alcohol s	pectrum disorder by:
9	(1)	Increasing statewide awareness of fetal alcohol
10		spectrum disorder both in the general public and in
11		at-risk populations;
12	(2)	Expanding statewide capacity to identify and intervene
13		with at-risk pregnant and parenting women;
14	(3)	Advocating, mobilizing, and coordinating state and
15		community resources to assist persons and families
16		affected by fetal alcohol spectrum disorder to get the
17		support they need;
18	(4)	Improving statewide service delivery to individuals
19		and families affected by fetal alcohol spectrum
20		disorder;
21	(5)	Coordinating a statewide strategic plan to address the
22		full range of cradle-to-grave fetal alcohol spectrum

disorder care, treatment, education, and prevention 1 2 issues; Facilitating and coordinating state fetal alcohol 3 (6) spectrum disorder task force meetings; and Facilitating development and implementation of a 5 (7)comprehensive, statewide system of care for the 6 7 prevention, identification, surveillance, and treatment of fetal alcohol spectrum disorders. 8 SECTION 3. There is appropriated out of the general 9 revenues of the State of Hawaii the sum of \$ 10 , or so much thereof as may be necessary, for fiscal year 2006-2007, to 11 establish a full-time equivalent permanent professional fetal 12 alcohol spectrum disorder coordinator position in the office of 13 14 the lieutenant governor. SECTION 4. The sum appropriated shall be expended by the 15 office of the lieutenant governor for the purposes of this Act. 16 SECTION 5. This Act shall take effect on July 1, 2006. 17 **18**

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HB 2109

Report Title:

Fetal Alcohol Spectrum Disorder; Coordinator

Description:

Establishes a fetal alcohol spectrum disorder coordinator position within the office of the lieutenant governor.