## 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 (FASD) 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			

disabilities with possible lifelong implications.

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- 1 Nationwide, the incidence of FASD is estimated to be ten
- 2 per one thousand live births. Nationally, more children are
- 3 born each year with FASD than those born with spina bifida,
- 4 multiple sclerosis, Down Syndrome, and HIV combined. There are
- 5 an estimated one hundred seventy-five children born each year in
- 6 Hawaii with FASD. Human costs of prenatal alcohol exposure are
- 7 great, as are the economic costs. Caring for someone with FASD
- 8 may cost as much as \$5,000,000. Nationally, as many as forty
- 9 thousand babies are born each year with FASD, costing the United
- 10 States about \$4,000,000,000.
- 11 FASD is the most underdiagnosed developmental disability,
- 12 both in Hawaii and across the United States. The effect of
- 13 prenatal alcohol exposure lasts a lifetime, yet FASD is totally
- 14 preventable. The effects of the known risk factors may be
- 15 ameliorated with early intervention and through effective
- 16 systems of care and services.
- Most persons with FASD are undiagnosed or misdiagnosed and
- 18 frequently do not follow treatment plans, even when properly
- 19 diagnosed. Persons with FASD frequently fail in traditional
- 20 treatment and other service systems and are commonly identified
- 21 as being noncompliant, uncooperative, and unmotivated in all
- 22 systems of services and care.

1 There are currently few FASD-specific services in Hawaii, 2 and only eighty-nine cases of FASD have been documented and 3 reported to Hawaii's birth defects registry from 1966 to 2002. 4 Department of health data from 2002 indicated that forty per 5 cent of pregnant women surveyed consumed alcohol prior to becoming pregnant, and almost four per cent indicated that they 6 7 consumed alcohol during pregnancy, which put their infants at 8 risk for FASD. 9 Information from a 2003 department of health behavioral 10 risk prevalence survey shows that almost eighty-two per cent of 11 the women surveyed consumed alcohol one month prior to the 12 survey, and almost four per cent indicated that they engage in 13 binge drinking. Because FASD can occur in any community where 14 women consume alcohol during pregnancy, it is a statewide public 15 health concern that has service, policy, and economic implications for virtually all state departments. 16 17 Because FASD is underdiagnosed and families as well as 18 providers have significant problems in addressing the multiple, 19 challenging needs of persons with this disorder, fourteen states 20 already have state FASD coordinators. These FASD coordinators 21 serve as a key educational, informational, and coordination link

between departments and agencies dealing with persons with FASD.

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1	Poor coordination hampers prevention, diagnosis, and			
2	service delivery. A state FASD coordinator would organize all			
3	fetal alcohol syndrome activities and would ensure that a			
4	comprehensive state strategi'c plan to address FASD is drafted			
5	and implemented.			
6	The purpose of this Act is to coordinate and develop FASD			
7	information, education, policies, and support services statewid			
8	by establishing a state FASD coordinator position within the			
9	department of health's family health services division.			
10	SECTION 2. There is established within the family health			
11	services division of the department of health one full-time			
12	equivalent permanent professional fetal alcohol spectrum			
13	disorder coordinator position. The fetal alcohol spectrum			
14	disorder coordinator shall act as a public point of contact for			
15	individuals and families affected by fetal alcohol spectrum			
16	disorder and shall help to coordinate a statewide system of			
17	services for persons with fetal alcohol spectrum disorder by:			
18	(1) Increasing statewide awareness of fetal alcohol			
19	spectrum disorder both in the general public and in			
20	at-risk populations;			
21	(2) Expanding statewide capacity to identify and intervene			
22	with at-risk pregnant and parenting women;			

1	(3)	Advocating, mobilizing, and coordinating state and
2		community resources to assist persons and families
3		affected by fetal alcohol spectrum disorder to receive
4		the support they need;
5	(4)	Improving statewide service delivery to individuals
6		and families affected by fetal alcohol spectrum
7		disorder;
8	(5)	Coordinating a statewide strategic plan to address the
9		full range of cradle-to-grave fetal alcohol spectrum
10		disorder care, treatment, education, and prevention
11		issues;
12	(6)	Facilitating and coordinating state fetal alcohol
13		spectrum disorder task force meetings; and
14	(7)	Facilitating development and implementation of a
15	*	comprehensive, statewide system of care for the
16		prevention, identification, surveillance, and
17		treatment of fetal alcohol spectrum disorders.
18	SECT	ION 3. There is appropriated out of the general
19	revenues	of the State of Hawaii the sum of \$1 or so much thereof
20	as may be	necessary for fiscal year 2006-2007 to establish a
21	full-time	equivalent permanent professional fetal alcohol

- 1 spectrum disorder coordinator position in the family health
- 2 services division at the department of health.
- 3 The sum appropriated shall be expended by the department of
- 4 health for the purposes of this Act.
- 5 SECTION 4. This Act shall take effect on July 1, 2006.

HB 2109

## Report Title:

Fetal Alcohol Spectrum Disorder; Coordinator

## Description:

Establishes a fetal alcohol spectrum disorder coordinator position within the Department of Health. (HB2109 HD1)