A BILL FOR AN ACT

RELATING TO HEALTH.

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

- SECTION 1. The legislature finds that, while fetal alcohol 1 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 or undiagnosed fetal alcohol exposure suffer substantially from 5 secondary disabilities, such as child abuse and neglect, 6 separation from families, multiple foster placements, school 7 failure, juvenile detention, job instability, depression, 8 aggression, and other serious mental disorders. These secondary 9 disabilities come at a high cost to the individuals, their 10 families, and society. The legislature finds that these 11 problems can be reduced substantially by early diagnosis and 12 receipt of appropriate, effective intervention. 13 Fetal alcohol spectrum disorders is an umbrella term 14 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
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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 40,000 10 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 21 treatment plans, even when properly diagnosed. Persons with 22

- 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.

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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, there are currently fourteen states that already have		
5	state fetal alcohol spectrum disorder coordinators. The state		
6	fetal alcohol spectrum disorder coordinators serve as a key		
7	educational, informational and coordination link between		
8	departments and agencies dealing with persons with a fetal		
9	alcohol spectrum disorder.		
10	Poor coordination hampers prevention, diagnosis, and		
11	service delivery. A state fetal alcohol spectrum disorder		
12	coordinator would organize all fetal alcohol syndrome activities		
13	and would ensure that a comprehensive state strategic plan to		
14	address fetal alcohol spectrum disorder is drafted and		
15	implemented.		
16	The purpose of this Act is to coordinate and develop fetal		
17	alcohol spectrum disorder information, education, policies, and		
18	support services statewide by authorizing the lieutenant		
19	governor to establish a state fetal alcohol spectrum disorder		
20	coordinator position within the office of the lieutenant		
21	governor.		

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1	SECTION 2. There is to be established within the office o		
2	the lieute	enant governor one full-time equivalent permanent	
3	profession	nal 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 l	oy fetal alcohol spectrum disorder and shall help to	
7	coordinate a statewide system of services for persons with feta		
8	alcohol spectrum 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	

1		disorder care, treatment, education, and prevention		
2		issues;		
3	(6)	Facilitating and coordinating state fetal alcohol		
4		spectrum disorder task force meetings; and		
5	(7)	Facilitating development and implementation of a		
6		comprehensive, statewide system of care for the		
7		prevention, identification, surveillance, and		
8		treatment of fetal alcohol spectrum disorders.		
9	SECT	ION 3. There is appropriated out of the general		
10	revenues of the State of Hawaii the sum of \$, or so			
11	much thereof as may be necessary, for fiscal year 2006-2007, to			
12	establish a full-time equivalent permanent professional fetal			
13	alcohol spectrum disorder coordinator position in the office of			
14	the lieutenant governor.			
15	SECTION 4. The sums appropriated shall be expended by the			
16	office of the lieutenant governor for the purposes of this Act.			
17	SECT	ION 5. This Act shall take effect on July 1, 2006.		
18		INTRODUCED BY: Colon K. Y. Am		
		BY REQUEST		
		JAN 2 0 2006		

HB 2153

Report Title:

Fetal Alcohol Spectrum Disorder; Coordinator

Description:

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

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