## A BILL FOR AN ACT

RELATING TO FETAL ALCOHOL SPECTRUM DISORDERS.

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

- 1 SECTION 1. The legislature finds that fetal alcohol
- 2 spectrum disorders (FASDs) are lifelong physical, developmental,
- 3 behavioral, and intellectual conditions caused by prenatal
- 4 exposure to alcohol. According to the Centers for Disease
- 5 Control and Prevention, up to one in five school children in the
- 6 United States may have a FASD. FASDs are more prevalent than
- 7 autism disorders, spina bifida, cerebral palsy, and Down
- 8 syndrome combined.
- 9 The legislature recognizes that individuals with FASDs face
- 10 unique challenges. For example, while children with autism
- 11 spectrum disorders share many of the same behavioral
- 12 characteristics and related mental health diagnoses of children
- 13 with FASDs, the latter tend to also struggle with feelings of
- 14 being different from others, difficulties following through with
- 15 instructions, emotional dysregulation, sleep disturbance,
- 16 indiscriminate affection with strangers, dishonesty, learning
- 17 difficulties, and difficulties in understanding the causes and



- 1 consequences of behaviors. Further, due to diffuse brain
- 2 damage, children with FASDs may also exhibit startled responses;
- 3 suffer from depression, often in teenage years; be unable to
- 4 take initiative; be unable to manage or comprehend time; lose
- 5 their temper; be argumentative with those in authority; and
- 6 appear defiant. Although many of these behaviors may appear to
- 7 resemble typical teenage behaviors, many individuals with FASDs
- 8 retain these behaviors through adulthood.
- 9 The legislature also finds that FASDs may impact an
- 10 estimated seventy thousand eight hundred people living in
- 11 Hawaii. Of the nearly seventeen thousand babies born annually
- 12 in the State, as many as eight hundred forty are estimated to
- 13 have FASDs. However, few children in Hawaii are diagnosed even
- 14 by using best practices. Within foster care and adoptive
- 15 families, eighty-five per cent of children are not diagnosed, or
- 16 are misdiagnosed. Raising a child with a FASD costs thirty
- 17 times more than the cost of successful prevention efforts, and
- 18 FASDs cost the State an estimated \$876,000,000 annually.
- 19 Of the 174,000 students in Hawaii schools, as many as eight
- 20 thousand seven hundred may have FASDs, yet far fewer are
- 21 diagnosed. Many individuals with FASDs have normal intelligence

- 1 quotient scores but function below their chronological age, and
- 2 many students with FASDs do not qualify for services dedicated
- 3 to those with developmental disabilities, even when the students
- 4 are correctly diagnosed. FASDs are not tracked in special
- 5 education, and most schools lack trained staff and the ability
- 6 to support students with FASDs. By age thirteen, more than
- 7 sixty per cent of students with FASDs may experience trouble
- 8 with law enforcement, and individuals with FASDs, with or
- 9 without a diagnosis, face high rates of incarceration and
- 10 recidivism. A high proportion of older youths and adults with
- 11 FASDs struggle with independent living and unemployment. More
- 12 than ninety per cent of individuals with FASDs will develop
- 13 comorbid mental health conditions.
- 14 The legislature further finds that a multidisciplinary
- 15 system of care is necessary to improve outcomes for individuals
- 16 with FASDs and promote health equity. This system of care must
- 17 leverage existing resources to make a definitive diagnosis,
- 18 provide appropriate therapy, and modify a treatment plan in
- 19 accordance with reassessment results.
- 20 Accordingly, the purpose of this Act is to:

1	(1)	Require the department of health to establish and
2		administer a five-year pilot program to implement a
3		co-management system of care for the diagnosis and
4		treatment of individuals with fetal alcohol spectrum
5		disorders; and
6	(2)	Appropriate funds to the department of health for the
7		establishment and administration of the pilot program.
8	SECT	ION 2. (a) The department of health shall establish
9	and admin	ister a five-year pilot program to implement a co-
10	managemen	t system of care in which the primary care provider;
11	behaviora	l health provider; and fetal alcohol spectrum disorders
12	specialis	t with a specialization in genetics, pediatric
13	neurology	, developmental-behavioral, or other applicable field;
14	each play	s a role.
15	(b)	The co-management system shall operate as follows:
16	(1)	The primary care provider shall refer a patient who
17		screens positive for a fetal alcohol spectrum disorder
18		to a fetal alcohol spectrum disorders specialist;
19	(2)	At least one fetal alcohol spectrum disorders
20		specialist shall make a diagnosis, establish a
21		treatment plan, and refer the patient back to the

1		primary care provider. The diagnostic assessment and
2		written treatment plan shall be provided to the
3		primary care provider;
4	(3)	The primary care provider shall refer the patient to a
5		behavioral health provider in accordance with the
6		treatment plan and provide appropriate information,
7		including the diagnostic assessment and treatment
8		plan, to the behavioral health provider;
9	(4)	The primary care provider or behavioral health
10		provider servicing the patient, or both, shall involve
11		the patient's family and school in accordance with the
12		recommendations of the treatment plan;
13	(5)	The behavioral health provider shall provide the
14		recommended treatment, including medication and other
15		modalities, and shall provide periodic reports to the
16		<pre>primary care provider;</pre>
17	(6)	The primary care provider shall monitor the patient's
18		progress via contact with the patient and
19		communication from the family, school, and behavioral
20		health provider, in accordance with the treatment
21		plan;

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1	(7)	If the patient's progress is not satisfactory,	the
2		primary care provider shall refer the patient b	ack to
3		the fetal alcohol spectrum disorders specialist	; and
4	(8)	The fetal alcohol spectrum disorders specialist	shall
5		reassess the patient, make any necessary modifi	cations.
6		to the treatment plan with input from the prima	ry care
7		provider and behavioral health provider, and re	fer the
8		patient back to the primary care provider.	
9	SECT	TION 3. There is appropriated out of the general	
10	revenues	of the State of Hawaii the sum of \$ or	so
11	much there	eof as may be necessary for fiscal year 2023-202	4 and
12	the same s	sum or so much thereof as may be necessary for f	iscal
13	year 2024	-2025 for the establishment and administration o	f a
14	five-year	pilot program to implement a co-management syst	em of
15	care for t	the diagnosis and treatment of individuals with	fetal
16	alcohol sp	pectrum disorders.	
17	The s	sums appropriated shall be expended by the depar	tment
18	of health	for the purposes of this Act.	
19	SECT	TON 4. This Act shall take effect on July 1, 20	23.

#### Report Title:

Fetal Alcohol Spectrum Disorders; Pilot Program; Department of Health; Appropriation

### Description:

Requires the Department of Health to establish and administer a five-year pilot program to implement a co-management system of care for the diagnosis and treatment of individuals with fetal alcohol spectrum disorders. Appropriates funds. (SD1)

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