S.B. NO. ³¹⁸ ^{S.D. 2} ^{H.D. 1}

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 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 fetal alcohol spectrum disorder. Fetal 7 alcohol spectrum disorders are more prevalent than autism 8 disorders, spina bifida, cerebral palsy, and Down syndrome 9 combined.

10 The legislature recognizes that individuals with fetal 11 alcohol spectrum disorders face unique challenges. For example, 12 while children with autism spectrum disorders share many of the 13 same behavioral characteristics and related mental health 14 diagnoses as children with fetal alcohol spectrum disorders, the 15 latter tend to also struggle with feelings of being different 16 from others, difficulties following through with instructions, 17 emotional dysregulation, sleep disturbance, indiscriminate

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1 affection with strangers, dishonesty, learning difficulties, and 2 difficulties in understanding the causes and consequences of behaviors. Further, due to diffuse brain damage, children with 3 4 fetal alcohol spectrum disorders may also exhibit startled 5 responses; suffer from depression, often in teenage years; be 6 unable to take initiative; be unable to manage or comprehend 7 time; lose their temper; be argumentative with those in 8 authority; and appear defiant. Although many of these behaviors 9 may appear to resemble typical teenage behaviors, many 10 individuals with fetal alcohol spectrum disorders retain these 11 behaviors through adulthood.

12 The legislature also finds that fetal alcohol spectrum 13 disorders may impact an estimated seventy thousand eight hundred people living in Hawaii. Of the nearly seventeen thousand 14 15 babies born annually in the State, as many as eight hundred 16 forty are estimated to have fetal alcohol spectrum disorders. 17 However, even using best practices, few children in Hawaii are 18 diagnosed with fetal alcohol spectrum disorder. Within foster 19 care and adoptive families, eighty-five per cent of children 20 with fetal alcohol spectrum disorders are not diagnosed, or are 21 misdiagnosed. Raising a child with a fetal alcohol spectrum

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disorder costs thirty times more than the cost of successful
 prevention efforts, and fetal alcohol spectrum disorders cost
 the State an estimated \$876,000,000 annually.

4 Of the one hundred seventy-four thousand students in Hawaii 5 schools, as many as eight thousand seven hundred may have fetal 6 alcohol spectrum disorders, yet far fewer are diagnosed. Many 7 individuals with fetal alcohol spectrum disorders have normal 8 intelligence quotient scores but function below their 9 chronological age, and many students with fetal alcohol spectrum 10 disorders do not qualify for services dedicated to those with 11 developmental disabilities, even when the students are correctly 12 diagnosed. Fetal alcohol spectrum disorders are not tracked in 13 special education, and most schools lack trained staff and the 14 ability to support students with fetal alcohol spectrum 15 disorders. By age thirteen, more than sixty per cent of 16 students with fetal alcohol spectrum disorders may experience 17 trouble with law enforcement, and individuals with fetal alcohol 18 spectrum disorders face high rates of incarceration and 19 recidivism. A high percentage of older youths and adults with 20 fetal alcohol spectrum disorders struggle with independent 21 living and unemployment. More than ninety per cent of

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individuals with fetal alcohol spectrum disorders will develop
 comorbid mental health conditions.

The legislature further finds that a multidisciplinary system of care is necessary to improve outcomes for individuals with fetal alcohol spectrum disorders and promote health equity. This system of care must leverage existing resources to make a definitive diagnosis, provide appropriate therapy, and modify a treatment plan in accordance with reassessment results.

9 Accordingly, the purpose of this Act is to:

10 (1) Require the department of health to establish and 11 administer a three-year pilot program to implement a 12 co-management system of care for the diagnosis and 13 treatment of individuals with fetal alcohol spectrum 14 disorders; and

15 (2) Appropriate funds for the pilot program and an annual16 public awareness campaign.

SECTION 2. (a) The department of health shall establish and administer a three-year pilot program with a primary and secondary prevention component and tertiary prevention component that implements a co-management system of care for persons with a fetal alcohol spectrum disorder in which the primary care

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1	provider:	behavioral health provider; and fetal alcohol spectrum
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2	disorders	specialist with a specialization in genetics,
3	pediatric	neurology, developmental-behavioral, or other
4	applicabl	e field; each plays a role.
5	(b)	The co-management system shall operate as follows:
6	(1)	The primary care provider shall refer a patient who
7		screens positive for a fetal alcohol spectrum disorder
8		to a fetal alcohol spectrum disorders specialist;
9	(2)	At least one fetal alcohol spectrum disorders
10		specialist shall make a diagnosis, establish a
11		treatment plan, and refer the patient back to the
12		primary care provider. The diagnostic assessment and
13		written treatment plan shall be provided to the
14		primary care provider;
15	(3)	The primary care provider shall refer the patient to a
16		behavioral health provider in accordance with the
17		treatment plan and provide appropriate information,
18		including the diagnostic assessment and treatment
19		plan, to the behavioral health provider;
20	(4)	The primary care provider, behavioral health provider,
21		or both, shall involve the patient's family and school

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1		in accordance with the recommendations of the
2		treatment plan;
3	(5)	The behavioral health provider shall provide the
4		recommended treatment, including medication and other
5		modalities, and shall provide periodic reports to the
6		primary care provider;
7	(6)	The primary care provider shall monitor the patient's
8		progress via contact with the patient and
9		communication from the family, school, and behavioral
10		health provider, in accordance with the treatment
11		plan;
12	(7)	If the patient's progress is not satisfactory, the
13		primary care provider shall refer the patient back to
14		the fetal alcohol spectrum disorders specialist; and
15	(8)	The fetal alcohol spectrum disorders specialist shall
16		reassess the patient, make any necessary modifications
17		to the treatment plan with input from the primary care
18		provider and behavioral health provider, and refer the
19		patient back to the primary care provider.
20	SECT	ION 3. There is appropriated out of the general
21	revenues	of the State of Hawaii the sum of \$ or so

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1 much thereof as may be necessary for fiscal year 2023-2024 and 2 the same sum or so much thereof as may be necessary for fiscal 3 year 2024-2025 for the establishment and administration of a 4 three-year pilot program to implement a co-management system of 5 care for the diagnosis and treatment of individuals with fetal 6 alcohol spectrum disorders; provided that the appropriation 7 shall not lapse at the end of the fiscal biennium for which the 8 appropriation is made; provided further that all moneys from the 9 appropriation unencumbered as of June 30, 2026, shall lapse as 10 of that date.

11 The sums appropriated shall be expended by the department
12 of health for the purposes of this Act.

13 SECTION 4. There is appropriated out of the general 14 revenues of the State of Hawaii the sum of \$ or so 15 much thereof as may be necessary for fiscal year 2023-2024 and 16 the same sum or so much thereof as may be necessary for fiscal 17 year 2024-2025 for the establishment of an annual public 18 awareness campaign on preventing fetal alcohol spectrum 19 disorder.

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The sums appropriated shall be expended by the state
 council on developmental disabilities for the purposes of this
 Act.

4 SECTION 5. This Act shall take effect on June 30, 3000.



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Report Title:

DOH; Fetal Alcohol Spectrum Disorder; Pilot Program; Public Awareness Campaign; Appropriation

Description:

Requires the Department of Health to establish and administer a three-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders. Appropriates funds. Effective 6/30/3000. (HD1)

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