

ACT 192

S.B. NO. 318

A Bill for an Act Relating to Fetal Alcohol Spectrum Disorders.

Be It Enacted by the Legislature of the State of Hawaii:

SECTION 1. In accordance with section 9 of article VII of the Hawaii State Constitution and sections 37 91 and 37 93, Hawaii Revised Statutes, the legislature has determined that the appropriations contained in H.B. No. 300,

H.D. 1, S.D. 1, C.D. 1,¹ and this Act will cause the state general fund expenditure ceiling for fiscal year 2023 2024 to be exceeded by \$1,064,252,367 or 11.0 per cent. This current declaration takes into account general fund appropriations authorized for fiscal year 2023 2024 in H.B. No. 300, H.D. 1, S.D. 1, C.D. 1,¹ and this Act only. The reasons for exceeding the general fund expenditure ceiling are that:

- (1) The appropriations made in this Act are necessary to serve the public interest; and
- (2) The appropriations made in this Act meet the needs addressed by this Act.

SECTION 2. The legislature finds that fetal alcohol spectrum disorders are lifelong physical, developmental, behavioral, and intellectual conditions caused by prenatal exposure to alcohol. According to the Centers for Disease Control and Prevention, up to one in five school children in the United States may have a fetal alcohol spectrum disorder. Fetal alcohol spectrum disorders are more prevalent than autism disorders, spina bifida, cerebral palsy, and Down syndrome combined.

The legislature recognizes that individuals with fetal alcohol spectrum disorders face unique challenges. For example, while children with autism spectrum disorders share many of the same behavioral characteristics and related mental health diagnoses as children with fetal alcohol spectrum disorders, the latter tend to also struggle with feelings of being different from others, difficulties following through with instructions, emotional dysregulation, sleep disturbance, indiscriminate affection with strangers, dishonesty, learning difficulties, and difficulties in understanding the causes and consequences of behaviors. Further, due to diffuse brain damage, children with fetal alcohol spectrum disorders may also exhibit startled responses; suffer from depression, often in teenage years; be unable to take initiative; be unable to manage or comprehend time; lose their temper; be argumentative with those in authority; and appear defiant. Although many of these behaviors may appear to resemble typical teenage behaviors, many individuals with fetal alcohol spectrum disorders retain these behaviors through adulthood.

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

Of the 174,000 students in Hawaii schools, as many as eight thousand seven hundred may have fetal alcohol spectrum disorders, yet far fewer are diagnosed. Many individuals with fetal alcohol spectrum disorders have normal intelligence quotient scores but function below their chronological age, and many students with fetal alcohol spectrum disorders do not qualify for services dedicated to those with developmental disabilities, even when the students are correctly diagnosed. Fetal alcohol spectrum disorders are not tracked in special education, and most schools lack trained staff and the ability to support students with fetal alcohol spectrum disorders. By age thirteen, more than sixty per cent of students with fetal alcohol spectrum disorders may experience trouble with law enforcement, and individuals with fetal alcohol spectrum disorder

ders face high rates of incarceration and recidivism. A high percentage of older youths and adults with fetal alcohol spectrum disorders struggle with independent living and unemployment. More than ninety per cent of 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.

Accordingly, the purpose of this Act is to:

- (1) Require 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 individuals with fetal alcohol spectrum disorders; and
- (2) Appropriate funds for the pilot program and an annual public awareness campaign.

SECTION 3. (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 provider; behavioral health provider; and fetal alcohol spectrum disorders specialist with a specialization in genetics, pediatric neurology, developmental-behavioral, or other applicable field; each plays a role.

(b) The co-management system shall operate as follows:

- (1) The primary care provider shall refer a patient who screens positive for a fetal alcohol spectrum disorder to a fetal alcohol spectrum disorders specialist;
- (2) At least one fetal alcohol spectrum disorders specialist shall make a diagnosis, establish a treatment plan, and refer the patient back to the primary care provider. The diagnostic assessment and written treatment plan shall be provided to the primary care provider;
- (3) The primary care provider shall refer the patient to a behavioral health provider in accordance with the treatment plan and provide appropriate information, including the diagnostic assessment and treatment plan, to the behavioral health provider;
- (4) The primary care provider, behavioral health provider, or both, shall involve the patient's family and school in accordance with the recommendations of the treatment plan;
- (5) The behavioral health provider shall provide the recommended treatment, including medication and other modalities, and shall provide periodic reports to the primary care provider;
- (6) The primary care provider shall monitor the patient's progress via contact with the patient and communication from the family, school, and behavioral health provider, in accordance with the treatment plan;
- (7) If the patient's progress is not satisfactory, the primary care provider shall refer the patient back to the fetal alcohol spectrum disorders specialist; and
- (8) The fetal alcohol spectrum disorders specialist shall reassess the patient, make any necessary modifications to the treatment plan with input from the primary care provider and behavioral health provider, and refer the patient back to the primary care provider.

ACT 192

SECTION 4. There is appropriated out of the general revenues of the State of Hawaii the sum of \$450,000 or so much thereof as may be necessary for fiscal year 2023-2024 for the establishment and administration of a three-year pilot program to implement a co-management system of care for the diagnosis and treatment of individuals with fetal alcohol spectrum disorders; provided that the appropriation shall not lapse at the end of the fiscal biennium for which the appropriation is made; provided further that all moneys from the appropriation unencumbered as of June 30, 2026, shall lapse as of that date.

The sum appropriated shall be expended by the department of health for the purposes of this Act.

SECTION 5. There is appropriated out of the general revenues of the State of Hawaii the sum of \$35,000 or so much thereof as may be necessary for fiscal year 2023-2024 for the establishment of an annual public awareness campaign on preventing fetal alcohol spectrum disorder.

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

SECTION 6. This Act shall take effect on July 1, 2023.

(Approved July 3, 2023.)

Note

1. Act 164.