

IN THE SENATE

SENATE BILL NO. 1270

BY HEALTH AND WELFARE COMMITTEE

AN ACT

1 RELATING TO THE DOWN SYNDROME DIAGNOSIS INFORMATION ACT; AMENDING TITLE 39,  
2 IDAHO CODE, BY THE ADDITION OF A NEW CHAPTER 97, TITLE 39, IDAHO CODE, TO  
3 PROVIDE A SHORT TITLE, TO DEFINE TERMS, TO PROVIDE APPLICABILITY, AND TO  
4 PROVIDE DUTIES OF THE DEPARTMENT OF HEALTH AND WELFARE; AND DECLARING AN  
5 EMERGENCY AND PROVIDING AN EFFECTIVE DATE.  
6

7 Be It Enacted by the Legislature of the State of Idaho:

8 SECTION 1. That Title 39, Idaho Code, be, and the same is hereby amended  
9 by the addition thereto of a NEW CHAPTER, to be known and designated as Chap-  
10 ter 97, Title 39, Idaho Code, and to read as follows:

11 CHAPTER 97

12 DOWN SYNDROME DIAGNOSIS INFORMATION ACT

13 39-9701. SHORT TITLE. This chapter shall be known and may be cited as  
14 the "Down Syndrome Diagnosis Information Act."

15 39-9702. DEFINITIONS. For purposes of this chapter:

16 (1) "Department" means the department of health and welfare.

17 (2) "Down syndrome" means a chromosomal condition associated with ei-  
18 ther an extra chromosome 21, in whole or in part, or an effective trisomy for  
19 chromosome 21. Trisomy 21 is the medical term for Down syndrome.

20 (3) "Down syndrome organization" means any state or local nonprofit or-  
21 ganization primarily involved in providing advocacy, support, and education  
22 to individuals with Down syndrome and their support community.

23 (4) "Health care practitioner" means a physician or other health care  
24 practitioner licensed, accredited, or certified to perform specified health  
25 care services consistent with state law. "Health care practitioner" in-  
26 cludes a genetic counselor.

27 (5) "Parent" means any person expecting a child who has received a test  
28 result from a prenatal screening or diagnostic test that indicates a high  
29 likelihood or the definite presence of Down syndrome, or the parent or legal  
30 guardian of a child diagnosed with Down syndrome.

31 39-9703. APPLICABILITY. A health care practitioner who provides pre-  
32 natal or postnatal care and who administers or requests administration of  
33 a prenatal or postnatal screening or diagnostic test that detects Down syn-  
34 drome or receives a result from such test that indicates a high likelihood or  
35 the definite presence of Down syndrome shall deliver to the parents the in-  
36 formation support sheet provided by the department under section 39-9704,  
37 Idaho Code.

1           39-9704. SUPPORT SHEET. (1) The department shall create an up-to-  
2 date, evidence-based support sheet about Down syndrome that has been re-  
3 viewed by medical experts and the Idaho Down syndrome council. The support  
4 sheet shall be provided at the time of diagnosis or when an ultrasound or  
5 test detects a high likelihood of Down syndrome. The support sheet shall be  
6 readily accessible and include the following:

7           (a) A clinical course description of Down syndrome, including possible  
8 physical, developmental, educational, and psychosocial outcomes;

9           (b) Options available for treatment and therapy for conditions related  
10 to Down syndrome;

11           (c) Life expectancy for individuals with Down syndrome; and

12           (d) Contact information for nonprofit Idaho Down syndrome organiza-  
13 tions that provide information and support services for caregivers,  
14 including first-call programs and information hotlines specific to  
15 Down syndrome, resource centers, and other education and support pro-  
16 grams for Down syndrome.

17           (2) The department shall post the information required in this section  
18 on its website and shall include an information support sheet, in a print-  
19 friendly format, to be delivered by health care practitioners to parents as  
20 prescribed in section 39-9703, Idaho Code.

21           (3) The department shall ensure that the information on the support  
22 sheet required in this section is culturally and linguistically appropriate  
23 for caregivers.

24           (4) A Down syndrome organization may request that the department in-  
25 clude the organization's informational material and contact information on  
26 the department's website. The department may add the information to the web-  
27 site upon request.

28           (5) The department shall meet annually with representatives of the  
29 Idaho Down syndrome council to ensure the information in the support sheet  
30 that is made available by the department is current.

31           SECTION 2. An emergency existing therefor, which emergency is hereby  
32 declared to exist, this act shall be in full force and effect on and after  
33 July 1, 2022.