



State of Wisconsin
2019 - 2020 LEGISLATURE

LRB-5800/1
TJD:cjs

2019 SENATE BILL 908

March 26, 2020 - Introduced by Senator KOOYENGA. Referred to Committee on Health and Human Services.

1 **AN ACT to create** 253.135 of the statutes; **relating to:** information on Down
2 syndrome.

Analysis by the Legislative Reference Bureau

This bill requires certain health care practitioners and genetic counselors who provide prenatal or postnatal care or genetic counseling, who administer or request administration of prenatal or postnatal screening or diagnostic tests that detect Down syndrome, and who receive the results of those tests to deliver certain information to an expectant parent, parent, or guardian whose child has a prenatal screening that indicates or a postnatal diagnosis of Down syndrome. The bill requires the Department of Health Services to make available the information related to Down syndrome specified in the bill in informational support packages and on its Internet site. The bill also requires DHS to establish a grant program to award grants to at least one nonprofit organization for the creation of the information materials on Down syndrome specified in the bill.

For further information see the *state* fiscal estimate, which will be printed as an appendix to this bill.

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

3 **SECTION 1.** 253.135 of the statutes is created to read:

SENATE BILL 908**SECTION 1**

1 **253.135 Down syndrome. (1) DEFINITIONS.** In this section:

2 (a) “Down syndrome” means a chromosomal condition caused in cell division
3 that results in the presence of an extra whole or partial copy of chromosome 21.

4 (b) “Health care practitioner” means any individual with a credential from the
5 department of safety and professional services to provide health or medical care in
6 the ordinary course of business or practice of a profession, including any physician,
7 physician assistant licensed under ch. 448, nurse licensed under ch. 441,
8 nurse-midwife licensed under s. 441.15, or midwife licensed under s. 440.982, or
9 genetic counselor.

10 **(2) DISSEMINATION OF INFORMATIONAL MATERIALS REQUIRED.** Any health care
11 practitioner who provides prenatal or postnatal care or genetic counseling, who
12 administers or requests administration of a prenatal or postnatal screening or
13 diagnostic test of a child that detects Down syndrome, and who receives the test
14 results from such a test shall ensure that all of the following individuals are provided
15 the information described under sub. (3):

16 (a) An expectant parent of a child for whom the results from a prenatal test
17 indicate a high likelihood of or the definite presence of Down syndrome.

18 (b) A parent of a child who is diagnosed with Down syndrome after a postnatal
19 test.

20 (c) A legal guardian of a child who is diagnosed with Down syndrome after a
21 postnatal test.

22 **(3) CREATION OF INFORMATIONAL MATERIALS.** (a) Subject to par. (b), the
23 department shall make available to health care practitioners described in sub. (2) all
24 of the following:

SENATE BILL 908**SECTION 1**

1 1. Current, evidence-based, written information about Down syndrome that
2 has been reviewed by medical experts and national organizations specializing in
3 Down syndrome and that contains all of the following:

4 a. A description of the clinical course of Down syndrome, including possible
5 physical, developmental, educational, and psychosocial outcomes.

6 b. Intellectual and functional development and therapy options for Down
7 syndrome.

8 c. Life expectancy for individuals with a diagnosis of Down syndrome.

9 2. Contact information for local and national Down syndrome organizations
10 that are nonprofit and that provide for parents and guardians of children diagnosed
11 with Down syndrome information and support services, including resources of the
12 Down Syndrome Association of Wisconsin and other informational hotlines specific
13 to Down syndrome, resource centers or clearinghouses, and other educational and
14 support programs related to Down syndrome.

15 (b) The department shall ensure that the information provided under par. (a)
16 is culturally and linguistically appropriate for an expectant parent, parent, or
17 guardian receiving a positive test result indicating a diagnosis of Down syndrome.

18 (c) In addition to providing the information under par. (a) in informational
19 support packages for expectant parents, parents, and guardians, the department
20 shall post the information described in par. (a) on its Internet site. The department
21 may add to its Internet site informational material and contact information from any
22 organization that supports individuals who are diagnosed with Down syndrome or
23 educates individuals on Down syndrome, if the organization requests inclusion.

24 **(4) GRANTS.** The department shall establish a grant program to award grants
25 to at least one nonprofit organization to create the informational materials under

SENATE BILL 908**SECTION 1**

1 sub. (3) (a). The department or the nonprofit organization that receives the grant
2 shall periodically update the informational materials under sub. (3) (a). As a
3 condition of receiving a grant, the department may require the nonprofit
4 organization to distribute the informational materials under sub. (3) (a) to health
5 care practitioners.

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(END)