

AMENDMENTS TO LB891

Introduced by Health and Human Services.

1 1. Strike the original sections and insert the following new
2 sections:

3 Section 1. Sections 1 to 4 of this act shall be known and may be
4 cited as the Down Syndrome Diagnosis Information and Support Act.

5 Sec. 2. For purposes of the Down Syndrome Diagnosis Information and
6 Support Act:

7 (1) Department means the Division of Public Health of the Department
8 of Health and Human Services;

9 (2) Down syndrome means a chromosomal condition caused by cell
10 division that results in the presence of an extra whole or partial copy
11 of chromosome 21;

12 (3) Down syndrome organization means any national, state, or local
13 nonprofit organization primarily involved in providing advocacy, support,
14 and education to individuals with Down syndrome and their parents;

15 (4) Health care practitioner means any person who is credentialed
16 under the Uniform Credentialing Act to provide health or medical care in
17 the ordinary course of business or practice of a profession, including a
18 genetic counselor; and

19 (5) Parents means (a) expectant parents of a child who receive a
20 test result from a prenatal screening or diagnostic test that indicates a
21 high likelihood or the definite presence of Down syndrome, (b) parents of
22 a child postnatally diagnosed with Down syndrome, and (c) a legal
23 guardian of a child diagnosed with Down syndrome.

24 Sec. 3. A health care practitioner who provides prenatal or
25 postnatal care, who administers or requests administration of a prenatal
26 or postnatal screening or diagnostic test that detects Down syndrome, and
27 who receives a test result from such test that indicates a high

1 likelihood or the definite presence of Down syndrome shall deliver to the
2 parents the information support sheet provided by the department under
3 section 4 of this act.

4 Sec. 4. (1) The department shall make the following information
5 available:

6 (a) Up-to-date information about Down syndrome that has been
7 reviewed by medical experts and Down syndrome organizations. The
8 information shall be provided in a written format and shall include the
9 following:

10 (i) A clinical course description, including possible physical,
11 developmental, educational, and psychosocial outcomes;

12 (ii) Treatment and therapy options; and

13 (iii) Life expectancy; and

14 (b) Contact information for Down syndrome organizations that are
15 nonprofit and that provide information and support services for parents,
16 including first-call programs and information hotlines specific to Down
17 syndrome, resource centers or clearinghouses, and other education and
18 support programs for Down syndrome.

19 (2) The department shall post the information required in subsection
20 (1) of this section on its web site and shall include an information
21 support sheet to be delivered by health care practitioners to parents as
22 prescribed in section 3 of this act.

23 (3) The department shall ensure that the information required in
24 subsection (1) of this section is culturally and linguistically
25 appropriate for parents.

26 (4) A Down syndrome organization may request that the department
27 include the organization's informational material and contact information
28 on the web site. The department may add the information to the web site
29 upon request.