

STATE OF NEW YORK

197

2019-2020 Regular Sessions

IN SENATE

(Prefiled)

January 9, 2019

Introduced by Sen. ORTT -- read twice and ordered printed, and when printed to be committed to the Committee on Mental Health and Developmental Disabilities

AN ACT to amend the mental hygiene law, in relation to Down syndrome diagnosis awareness

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

- 1 Section 1. The mental hygiene law is amended by adding a new section
2 13.44 to read as follows:
3 § 13.44 Down syndrome diagnosis awareness.
4 (a) For purposes of this section, the following terms shall have the
5 following meanings:
6 (1) "Health care practitioner" means a medical professional that
7 provides prenatal or postnatal care and administers or requests adminis-
8 tration of a diagnostic or screening test to a pregnant woman or infant
9 that detects for Down syndrome; and
10 (2) "Down syndrome" means a chromosomal condition caused by an error
11 in cell division that results in the presence of an extra or partial
12 copy of chromosome twenty-one.
13 (b) A health care practitioner who orders tests for a pregnant woman
14 or infant to screen for Down syndrome shall provide the following infor-
15 mation to such pregnant woman or the infant's parent if such test
16 reveals a positive result:
17 (1) Up-to-date and evidence-based information about Down syndrome that
18 has been reviewed by medical experts and national Down syndrome organ-
19 izations. The information must be provided in a written or an alterna-
20 tive format and must include the following:
21 (i) expected physical, developmental, educational, and psychosocial
22 outcomes;
23 (ii) life expectancy;

EXPLANATION--Matter in italics (underscored) is new; matter in brackets [-] is old law to be omitted.

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1 (iii) the clinical course description;
2 (iv) expected intellectual and functional development;
3 (v) treatment options available for the particular syndrome for which
4 the test was positive; and
5 (vi) any other information the office deems necessary.

6 (2) Contact information for nonprofit organizations that provide
7 information and support services for Down syndrome including but not
8 limited to:

9 (i) information hotlines specific to Down syndrome;

10 (ii) relevant resource centers or clearinghouses; and

11 (iii) national and local Down syndrome organizations.

12 (c) (1) The commissioner shall provide written information to health
13 care practitioners necessary to implement subdivision (b) of this
14 section.

15 (2) Additionally, the commissioner shall post such information on the
16 office's website.

17 (3) The commissioner shall follow existing practices to ensure that
18 the information is culturally and linguistically appropriate for all
19 recipients.

20 (4) Any local or national organization that provides education or
21 services related to Down syndrome, may request that the commissioner
22 include the organization's informational material and contact informa-
23 tion on the office's website. Once a request is made, the commissioner
24 may add the information to the website.

25 § 2. This act shall take effect on the ninetieth day after it shall
26 have become a law. Effective immediately, the addition, amendment and/or
27 repeal of any rule or regulation necessary for the implementation of
28 this act on its effective date are authorized to be made and completed
29 on or before such effective date.