

# STATE OF NEW YORK

7345

## IN SENATE

January 8, 2018

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 13.43 to read as follows:

3 § 13.43 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;

24 (iii) the clinical course description;

25 (iv) expected intellectual and functional development;

26 (v) treatment options available for the particular syndrome for which  
27 the test was positive; and

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

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1     (vi) any other information the office deems necessary.

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

5         (i) information hotlines specific to Down syndrome;

6         (ii) relevant resource centers or clearinghouses; and

7         (iii) national and local Down syndrome organizations.

8     (c) (1) The commissioner shall provide written information to health  
9 care practitioners necessary to implement subdivision (b) of this  
10 section.

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

13     (3) The commissioner shall follow existing practices to ensure that  
14 the information is culturally and linguistically appropriate for all  
15 recipients.

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

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