STATE OF NEW YORK

2163

2021-2022 Regular Sessions

IN SENATE

January 20, 2021

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

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:

Section 1. The mental hygiene law is amended by adding a new section 13.44 to read as follows:

§ 13.44 Down syndrome diagnosis awareness.

(a) For purposes of this section, the following terms shall have the following meanings:

(1) "Health care practitioner" means a medical professional that provides prenatal or postnatal care and administers or requests administration of a diagnostic or screening test to a pregnant woman or infant that detects for Down syndrome; and

(2) "Down syndrome" means a chromosomal condition caused by an error in cell division that results in the presence of an extra or partial copy of chromosome twenty-one.

(b) A health care practitioner who orders tests for a pregnant woman or infant to screen for Down syndrome shall provide the following information to such pregnant woman or the infant's parent if such test reveals a positive result:

(1) Up-to-date and evidence-based information about Down syndrome that has been reviewed by medical experts and national Down syndrome organizations. The information must be provided in a written or an alternative format and must include the following:

(i) expected physical, developmental, educational, and psychosocial outcomes;

(ii) life expectancy;

(iii) the clinical course description;

(iv) expected intellectual and functional development;

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

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

(vi) any other information the office deems necessary.

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

(i) information hotlines specific to Down syndrome;

(ii) relevant resource centers or clearinghouses; and

(iii) national and local Down syndrome organizations.

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

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

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

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

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