
DIGEST

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Harrison

HB No. 1058

Abstract: Requires the Department of Health and Hospitals to provide information concerning Down syndrome to healthcare providers and on its website.

Proposed law provides relative to public information concerning Down syndrome, a chromosomal condition caused by the presence of an extra whole or partial copy of chromosome 21.

Proposed law requires the Department of Health and Hospitals (DHH) to identify current, evidence-based, written information concerning Down syndrome that meets all of the following criteria:

- (1) Has been reviewed by medical experts and national and local Down syndrome organizations.
- (2) Is designed for use by an expectant parent who receives a prenatal test result for Down syndrome or a parent of a child who receives a diagnosis of Down syndrome.
- (3) Does not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.
- (4) Is culturally and linguistically appropriate for potential recipients of the information and includes all of the following:
 - (a) Information addressing physical, developmental, educational, and psychosocial outcomes, life expectancy, clinical course, and intellectual and functional development and treatment options for individuals with Down syndrome.
 - (b) Contact information for national and local Down syndrome education and support programs and services, including information hotlines, resource centers, and clearinghouses.

Proposed law requires DHH to do all of the following:

- (1) Provide the information identified pursuant to proposed law to healthcare facilities and

healthcare providers that furnish prenatal care, postnatal care, or genetic counseling to expectant parents who receive a prenatal test result for Down syndrome and parents of a child diagnosed with Down syndrome.

- (2) Make available the information identified pursuant to proposed law on its website.

Proposed law provides that upon receipt of a positive test result from a test for Down syndrome, a healthcare facility or healthcare provider shall provide to the expectant parent or the parent of the child diagnosed with Down syndrome the written information provided or made available by DHH pursuant to proposed law.

Proposed law stipulates that all information provided pursuant thereto shall be culturally and linguistically appropriate for recipients, and that such information not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.

(Adds R.S. 40:1300.381-1300.382)

Summary of Amendments Adopted by House

Committee Amendments Proposed by House Committee on Health and Welfare to the original bill.

1. Deleted reference to an error in cell division as a cause of Down syndrome.
2. Among criteria for information on Down syndrome that DHH is required to identify for publication, added a requirement that such information not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.
3. Added a requirement that information provided pursuant to proposed law not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.