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Senate Bill 367 (as introduced 5-9-17)

Sponsor: Senator Jim Marleau Committee: Health Policy

Date Completed: 10-17-17

CONTENT

The bill would amend the Public Health Code to do the following:

- -- Allow the Department of Licensing and Regulatory Affairs (LARA) to create, operate, and maintain a prenatal diagnosis clearinghouse containing information regarding prenatally diagnosed conditions, or delegate this activity to an organization or institution of higher learning.
- -- Require a physician to make available to a patient information for perinatal hospice care, at the time the physician informed the patient of the results of a prenatal test that detected a life-limiting condition.
- -- Require a physician to make available to a patient a form containing the website address for the prenatal diagnosis clearinghouse, and inform the patient that the website would contain certain information, at the time the physician informed the patient of prenatal test results that detected a prenatally diagnosed condition.
- -- Require LARA to establish criteria for certifying a hospice that provides perinatal hospice care.
- -- Require LARA to accept and review applications for hospices seeking certification as a prenatal hospice program.

The bill would take effect 90 days after its enactment.

Definitions

The bill would define "life-limiting condition" as a medical condition identified by prenatal diagnostic testing that will, with reasonable certainly, result in the death of the child either before birth or within one year after birth.

"Perinatal hospice care" would mean comprehensive medical and supportive care to a pregnant woman and her family that includes support from the time of diagnosis of a life-limiting condition through the time of birth and death of the child. Perinatal hospice care could include care by maternal-fetal medical specialists, obstetricians, neonatologists, anesthesia specialists, clergy, social workers, and specialty nurses.

"Prenatally diagnosed condition" would mean a medical condition identified by prenatal diagnostic testing that will either temporarily or permanently require medical treatment or other support services after birth, but will not, with reasonable certainty, result in the death of the child within one year after birth.

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Prenatal Diagnosis Clearinghouse

The bill would allow the Department of Licensing and Regulatory Affairs to create, operate, and maintain a prenatal diagnosis clearinghouse that contained information regarding prenatally diagnosed conditions. The clearinghouse would have to be created, operated, and maintained as provided by the bill.

The Department could, by contract, delegate the creation, operation, and maintenance of the clearinghouse to an organization or institution of higher learning. A contracted delegate would have to do all of the following:

- -- Create, and update as needed, a list of medical conditions that can affect a developing unborn child; can be detected by prenatal diagnostic tests; necessitate medical treatment or special services before or at birth; and occur with a frequency of at least one instance per 100,000 births.
- -- Provide the list to LARA and to a prospective qualified contributor upon request.
- -- Develop criteria for approving a qualified contributor who requested authorization to contribute information for posting on the clearinghouse, and provide notice of approval or denial of authorization to an organization or individual who requested authorization as a qualified contributor in accordance with the criteria.
- -- For each medical condition identified on the list, provide directly, or solicit from a qualified contributor, information to be placed on the clearinghouse that described the condition, known treatment options or supportive services, and government agencies or programs and private organizations that provide service or support to individuals with that condition or to their caregivers.
- -- Post on the clearinghouse information on, and website links to, "Early On Michigan" and organizations that maintain registries of families who wish to adopt children with prenatally diagnosed conditions.
- -- At least annually, review the information posted on the clearinghouse to confirm that referral information was still accurate with regard to support organizations and links to other websites.

("Qualified contributor" would mean a licensed medical professional, an academic faculty member, another individual with recognized knowledge or expertise regarding a prenatally diagnosable medical condition, or an organization dedicated to research, treatment, or support for individuals with a specific medical condition.

"Licensed medical professional" would mean an individual who is licensed or otherwise authorized to practice medicine under Article 15 (Occupations).)

The Department would have to create and post on the State's website, in a printable format, a form that prominently displayed the website address of the clearinghouse and that included a statement that the clearinghouse contained information on health outcomes, early intervention services, and referral information (described below).

Physician Requirements

At the time a physician informed a patient of the results of a prenatal test that had detected a life-limiting condition, the physician or a qualified person assisting the physician would have to do both of the following:

-- Make available to the patient referral information for perinatal hospice care offered by a perinatal hospice program certified by LARA.

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-- In a case in which a life-limiting condition would cause, or had a reasonable probability of causing, a stillbirth, inform the patient that Michigan recognizes the death of a fetus that has completed at least 20 weeks of gestation or weighs at least 400 grams with a certificate of stillbirth.

At the time a physician informed a patient of the results of a prenatal test that had detected a prenatally diagnosed condition, the physician or qualified person assisting the physician would have to provide the patient with a form containing the website address for the prenatal diagnosis clearinghouse and inform the patient that the website address identified on the form contained the following information:

- -- Up-to-date and scientifically accurate information on health outcomes, including clinical course, life expectancy, and development potential for individuals with the prenatally diagnosed condition.
- -- Information on early intervention services for the functional development and education of a child born with a prenatally diagnosed condition referral information for "Early On Michigan".
- -- Referral information for peer support groups, including support groups for parents of children with the prenatally diagnosed condition and advocacy organizations for individuals with that condition.
- -- Referral information for adoption, including adoption agencies that place children with prenatally diagnosed conditions and organizations that maintain registries of families who wish to adopt children with prenatally diagnosed conditions.

"Qualified person assisting the physician" would mean that term as defined in Section 17015 of the Code: another physician or a physician's assistant licensed under Part 170 (Medicine) or Part 175 (Osteopathic Medicine and Surgery), a fully licensed or limited licensed psychologist licensed under Part 182, a professional counselor licensed under Part 181 (Counseling), a registered professional nurse or a licensed practice nurse licensed under Part 172 (Nursing), or a social worker licensed under Part 185 (Social Work).)

Perinatal Hospice Program

The Department would have establish criteria for certifying as a perinatal hospice program a hospice that provides perinatal hospice care. In establishing criteria for the certification of a perinatal hospice program, LARA could refer to existing criteria established by recognized medical authorities or associations that specialize in hospice care.

The Department also would have to accept and review applications for certification from a hospice seeking certification as a prenatal hospice program. If LARA rejected an application for certification, the Department would have to provide a written explanation as to the reason the application was rejected.

Additionally, LARA would have to post on the State's website, in a printable format, a list of hospices in the State that had been certified by the Department for providing perinatal hospice care.

A health facility or agency providing obstetric care and social work or chaplaincy services in conjunction with its health services would have to provide its social workers and chaplains, as appropriate, with information about perinatal hospice programs certified by LARA.

Proposed MCL 333.17019 et al.

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BACKGROUND

Early On Michigan is a system offered by the Michigan Department of Education, in conjunction with the Michigan Department of Health and Human Services, that provides early intervention services for infants and toddlers, from birth to 36 months, who have developmental delays or conditions that could lead to delays, and their families. According to its website, "*Early On* specializes in evaluating and treating children that are not developing at the same rate as other children. This can include physical, mental, communication, adaptive, social or emotional development."

Legislative Analyst: Stephen Jackson

FISCAL IMPACT

The bill would have a small to moderate negative impact on the Department of Licensing and Regulatory Affairs. The bill would require LARA to create a new perinatal certification for hospices, develop a criteria for certification, create application forms and a review process, and post a list of hospices with perinatal certification on its website. It is probable that the costs associated with these activities would be absorbed by LARA.

The bill also would authorize LARA to create, operate, and maintain an informational prenatal diagnosis clearinghouse that would contain information regarding prenatally diagnosed conditions. Assuming the creation of this clearinghouse were required, either by LARA or an organization or institution of higher learning under contract, the creation and maintenance of the clearinghouse could cost over \$100,000. One-time funding amounting to \$150,000 was allocated for the creation of a prenatal diagnosis clearinghouse website in the most recent omnibus appropriations bill, Public Act 107 of 2017, but those funds were provided for the Department of Health and Human Services, not for LARA. Assuming LARA could gain access to those funds, the cost to LARA to create the clearinghouse would be minimal.

The bill would have no fiscal impact on local government.

Fiscal Analyst: Michael Siracuse

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This analysis was prepared by nonpartisan Senate staff for use by the Senate in its deliberations and does not constitute an official statement of legislative intent.