## LEGISLATIVE BILL 506

Approved by the Governor April 26, 2017

A BILL FOR AN ACT relating to health and human services; to amend section 71-3407, Revised Statutes Cumulative Supplement, 2016; to adopt the Compassion and Care for Medically Challenging Pregnancies Act; to provide duties for the State Child and Maternal Death Review Team; and to repeal the original section.

Be it enacted by the people of the State of Nebraska,

Sections 1 to 4 of this act shall be known and may be cited as the Compassion and Care for Medically Challenging Pregnancies Act.

For purposes of the Compassion and Care for Medically Challenging Pregnancies Act:

(1) Department means the Department of Health and Human Services;

- (2) Lethal fetal anomaly means a fetal condition diagnosed before birth that will, with reasonable certainty, result in the death of the unborn child within three months after birth;
- (3) Nurse practitioner means any person licensed to practice as a nurse practitioner in this state;
- (4) Perinatal hospice means comprehensive support to the pregnant woman her family that includes support from the time of diagnosis, through the time of birth and the death of the infant, and through the postpartum period. Supportive care may include, but is not limited to, counseling and medical care by maternal-fetal medical specialists, obstetricians, neonatologists, anesthesia specialists, clergy, social workers, and specialty nurses focused on alleviating fear and ensuring that the woman and her family experience the life and death of their child in a comfortable and supportive environment; and
- (5) Physician means any person licensed to practice medicine and surgery <u>in this state and includes osteopathic physicians.</u>
- A physician or nurse practitioner who diagnoses an unborn child as having a lethal fetal anomaly may:
  (1) Inform the pregnant woman,
- orally <u>and in person, that</u> hospice services are available and offer or refer for this care; and
- (2) Deliver to the pregnant woman in writing the information support sheet provided by the department under section 4 of this act.
- Sec. 4. (1) The department shall create and organize geographically a of perinatal hospice programs available in Nebraska and nationally. The department shall post such information on its web site and shall include an <u>information</u> support sheet in English and Spanish on the web site that can be printed and delivered by physicians and nurse practitioners to the pregnant woman as provided in section 3 of this act. The web site and information support sheet shall be completed and available within ninety days after the effective date of this act. The web site and information support sheet shall <u>include:</u>
- (a) A statement indicating that perinatal hospice is an innovative and compassionate model of support for the pregnant woman who finds out that her baby has a life-limiting condition and who chooses to continue her pregnancy;

(b) A general description of the health care services available perinatal hospice programs; and

- (c) Pertinent contact information that includes any twenty-four-hour perinatal hospice services available.
- (2) A perinatal hospice program may request that the department include the program's informational material and contact information on the web site. The department may add the information to the web site upon request.
- Sec. 5. Section 71-3407, Revised Statutes Cumulative Supplement, 2016, is amended to read:
- 71-3407 (1) The purposes of the team shall be to (a) develop an understanding of the causes and incidence of child or maternal deaths in this state, (b) develop recommendations for changes within relevant agencies and organizations which may serve to prevent child or maternal deaths, and (c) advise the Governor, the Legislature, and the public on changes to law, policy, and practice which will prevent child or maternal deaths.
  - (2) The team shall:
- (a) Undertake annual statistical studies of the causes and incidence of child or maternal deaths in this state. The studies shall include, but not be limited to, an analysis of the records of community, public, and private agency involvement with the children, the pregnant or postpartum women, and their families prior to and subsequent to the child or maternal deaths;
- (b) Develop a protocol for retrospective investigation of child or
- maternal deaths by the team;
  (c) Develop a protocol for collection of data regarding child or maternal deaths by the team;
  - (d) Consider training needs, including cross-agency training, and service

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gaps;

(e) Include in its annual report recommended changes to any law, rule, regulation, or policy needed to decrease the incidence of preventable child or maternal deaths;

- (f) Educate the public regarding the incidence and causes of child or maternal deaths, the public role in preventing child or maternal deaths, and specific steps the public can undertake to prevent child or maternal deaths. The team may enlist the support of civic, philanthropic, and public service organizations in the performance of its educational duties;
- (g) Provide the Governor, the Legislature, and the public with annual reports which shall include the team's findings and recommendations for each of its duties. The team shall provide the annual report on or before each September 15. For 2013 and 2014, the team shall also provide the report to the Health and Human Services Committee of the Legislature on or before September 15. The reports submitted to the Legislature shall be submitted electronically; and
- (h) When appropriate, make referrals to those agencies as required in section 28-711 or as otherwise required by state law.
- (3) The team may enter into consultation agreements with relevant experts to evaluate the information and records collected by the team. All of the confidentiality provisions of section 71-3411 shall apply to the activities of a consulting expert.
- (4) The team may enter into written agreements with entities to provide for the secure storage of electronic data based on information and records collected by the team, including data that contains personal or incident identifiers. Such agreements shall provide for the protection of the security and confidentiality of the content of the information, including access limitations, storage of the information, and destruction of the information. All of the confidentiality provisions of section 71-3411 shall apply to the activities of the data storage entity.
- (5) (4) The team may enter into agreements with a local public health department as defined in section 71-1626 to act as the agent of the team in conducting all information gathering and investigation necessary for the purposes of the Child and Maternal Death Review Act. All of the confidentiality provisions of section 71-3411 shall apply to the activities of the agent.

  (6) For purposes of this section, entity means an organization which
- (6) For purposes of this section, entity means an organization which provides collection and storage of data from multiple agencies but is not solely controlled by the agencies providing the data.
- Sec. 6. Original section 71-3407, Revised Statutes Cumulative Supplement, 2016, is repealed.