

SECOND REGULAR SESSION
HOUSE COMMITTEE SUBSTITUTE FOR
HOUSE BILL NO. 3457
103RD GENERAL ASSEMBLY

7419H.03C

JOSEPH ENGLER, Chief Clerk

AN ACT

To amend chapter 197, RSMo, by adding thereto one new section relating to medically complex pediatric patients.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Chapter 197, RSMo, is amended by adding thereto one new section, to be known as section 197.181, to read as follows:

197.181. 1. This section shall be known and may be cited as "Maddie's Law: The Rare Pediatric Disease Care and Protocol Protection Act".

2. As used in this section, the following terms mean:

(1) "Care plan", a patient-specific electronic document that may include diagnoses, baseline clinical status, medications and allergies, medical devices, emergency treatment recommendations, treating providers, and communication needs and that is developed by the primary physician providing care to the patient;

(2) "Department", the department of health and senior services;

(3) "Emergency department", an emergency department in a hospital licensed under this chapter;

(4) "Medically complex pediatric patient", a person under eighteen years of age who has one or more chronic medical conditions expected to last at least twelve months and who requires multiple medication updates, medical technology, or care coordination across multiple providers.

3. (1) Each hospital that operates an emergency department in this state may implement, within its existing electronic health record system, a clearly visible electronic alert or flag for a medically complex pediatric patient.

(2) The alert shall:

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in bold-face type in the above bill is proposed language.

19 **(a) Appear in a manner that is immediately identifiable to emergency**
20 **department personnel on the patient tracking screen or within the patient's electronic**
21 **chart;**

22 **(b) Provide rapid, one-click access to the patient's care plan, if available; and**

23 **(c) Function in a manner that does not delay triage or treatment.**

24 **4. A hospital shall be considered in compliance with this section if the hospital**
25 **utilizes existing alert, flagging, or patient notification functionality within its current**
26 **electronic health record system.**

27 **5. Nothing in this section shall be construed to require a hospital to:**

28 **(1) Purchase a new electronic health record system;**

29 **(2) Develop a separate technology platform; or**

30 **(3) Create a new full-time position.**

31 **6. A parent or legal guardian of a medically complex pediatric patient may**
32 **request that the patient's care plan be sent by the patient's licensed health care provider**
33 **to the hospital for inclusion in the hospital's electronic health record and alert system.**

34 **7. Any approved care plan for a medically complex pediatric patient shall be**
35 **entered into the system under the direction of a licensed health care provider at the**
36 **hospital where the child may receive emergency care.**

37 **8. Participation in the alert system shall be voluntary and shall require the**
38 **consent of the parent or legal guardian of the medically complex pediatric patient. A**
39 **care plan for a medically complex pediatric patient shall not be considered approved**
40 **and placed in the alert system unless the primary physician of the patient confirms the**
41 **care plan.**

42 **9. All information maintained under this section shall comply with applicable**
43 **state and federal privacy laws, including the federal Health Insurance Portability and**
44 **Accountability Act (HIPAA).**

45 **10. Any hospital or health care provider acting in good-faith reliance on a care**
46 **plan accessed in accordance with this section shall not be subject to additional civil**
47 **liability solely for such reliance.**

48 **11. The department shall administer the provisions of this section within existing**
49 **appropriations.**

50 **12. The department may issue model guidelines to assist hospitals in**
51 **implementation of the requirements of this section. Such guidelines shall be advisory**
52 **and shall not require formal rulemaking unless necessary.**

53 **13. Nothing in this section shall be construed to:**

54 **(1) Establish a state registry;**

55 **(2) Require the creation of a state database; or**

56 **(3) Require the department to collect or store patient-specific medical**
57 **information.**

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