WEST VIRGINIA CODE CHAPTER 16 ARTICLE 40

WV Legislature

§16-40-1. Definitions.

As used in this article:

(1) "Commissioner" means the commissioner of the Bureau for Public Health.

(2) "Freestanding birthing center" means any health care facility in which births routinely occur, regardless of whether the facility is located on the campus of another health care facility, and which is not licensed under article five-b of this chapter.

(3) "Hospital" means a hospital licensed under the provisions of article five-b of this chapter.

(4) "Nurse-midwife" means an individual authorized under article fifteen, chapter thirty of this code to practice nurse-midwifery.

(5) "Physician" means an individual authorized under article three or fourteen, chapter thirty of this code to practice medicine and surgery or osteopathic medicine and surgery.

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§16-40-2. Expansion and implementation of statewide birth defects information system.

(a) The commissioner shall establish and implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths and abnormal conditions of newborns.

(b) The commissioner may require each physician, nurse-midwife, hospital and freestanding birthing center to report to the system information concerning all patients under six years of age with a primary diagnosis of a congenital anomaly or abnormal condition: Provided, That the commissioner may not require the reporting of personal identifying information or enter into the system any personal identifying information regarding congenital anomalies or abnormal conditions of a child whose parent or legal guardian objects on the basis of religious belief. The commissioner may not require a hospital, freestanding birthing center, nurse-midwife or physician to report to the system any information that is required to be reported to the commissioner or the Bureau for Public Health under another provision of this code.

(c) On request, each physician, nurse-midwife, hospital and freestanding birthing center shall give the commissioner or authorized employees of the bureau access to the medical records of any patient described in subsection (b) of this section. The bureau shall pay the costs of copying any medical records pursuant to this section.

(d) A physician, nurse-midwife, hospital or freestanding birthing center that provides information to the system under subsection (b) of this section is not subject to criminal or civil liability for providing the information.

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§16-40-3. Purposes of system.

The birth defects information system may be used for all of the following purposes:

(1) To identify and describe congenital anomalies, stillbirths and abnormal conditions of newborns;

(2) To detect trends and epidemics in congenital anomalies, stillbirths and abnormal conditions of newborns;

(3) To quantify morbidity and mortality of congenital anomalies and abnormal conditions of newborns;

(4) To stimulate epidemiological research regarding congenital anomalies, stillbirths and abnormal conditions of newborns;

(5) To identify risk factors for congenital anomalies, stillbirths and abnormal conditions of newborns;

(6) To facilitate intervention in and prevention of congenital anomalies, stillbirths and abnormal conditions of newborns;

(7) To facilitate access to treatment for congenital anomalies and abnormal conditions of newborns;

(8) To inform and educate the public about congenital anomalies, stillbirths and abnormal conditions of newborns.

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§16-40-4. Confidentiality of information.

(a) Except as provided in this section, records received and information assembled by the birth defects information system pursuant to section two of this article are confidential medical records.

(b) (1) The commissioner may use information assembled by the system to notify parents, guardians and custodians of children with congenital anomalies or abnormal conditions of medical care and other services available for the child and family.

(2) The commissioner may disclose information assembled by the system with the written consent of the parent or legal guardian of the child who is the subject of the information.

(c) (1) Access to information assembled by the system is limited to the following persons and government entities:

(A) The commissioner;

(B) Authorized employees of the bureau; and

(C) Qualified persons or government entities that are engaged in demographic, epidemiological or similar studies related to health and health care provision.

(2) The commissioner shall give a person or government entity described in subparagraph (C), subdivision (1) of this subsection access to the system only for informational requests of data and only if the person or a representative of the person or government entity signs an agreement to maintain the system's confidentiality.

(3) The commissioner shall maintain a record of all persons and government entities given access to the information in the system. The record shall include all of the following information:

(A) The name of the person who authorized access to the system;

(B) The name, title and organizational affiliation of the person or government entity given access to the system;

(C) The dates the person or government entity was given access to the system; and

(D) The specific purpose for which the person or government entity intends to use the information.

(4) The record maintained pursuant to subdivision (3) of this subsection is a public record as defined in chapter twenty-nine-b of this code.

(5) A person who violates an agreement described in subdivision (2) of this subsection shall

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be denied further access to confidential information maintained by the commissioner.

(d) The commissioner may disclose information assembled by the system in summary, statistical or other form that does not identify particular individuals or individual sources of information.

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§16-40-5. Parent or legal guardian may require removal of information concerning child from system.

(a) As used in this section, "local board of health" means a local board of health established under the provisions of article two of this chapter.

(b) A child's parent or legal guardian who wants information concerning the child removed from the birth defects information system shall request from the local board of health or the child's physician a form prepared by the commissioner. On request, a local board of health or physician shall provide the form to the child's parent or legal guardian. The individual providing the form shall discuss with the child's parent or legal guardian the information contained in the system. If the child's parent or legal guardian signs the form, the local board of health or physician shall forward it to the commissioner. On receipt of the signed form, the commissioner shall remove from the follow-up system any information that identifies the child. All personal identifying information may be removed from the record: Provided, That the record itself shall remain in the system for reporting and analysis purposes.

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§16-40-6. Advisory council.

[Repealed.]

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§16-40-7. Rules.

Not later than July 1, 2003, the commissioner shall propose rules for legislative approval in accordance with the provisions of §29A-3-1 *et seq.* of this code to do all of the following:

(1) Implement the birth defects information system;

(2) Specify the types of congenital anomalies and abnormal conditions of newborns to be reported to the system under section two of this article;

(3) Establish reporting requirements for information concerning diagnosed congenital anomalies and abnormal conditions of newborns;

(4) Establish standards that are required to be met by persons or government entities that seek access to the system; and

(5) Establish a form for use by parents or legal guardians who seek to have information regarding their children removed from the system and a method of distributing the form to local boards of health and to physicians. The method of distribution must include making the form available on the Internet.

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§16-40-8. Reports by commissioner.

The commissioner shall include an update on the birth defects information system in the annual report the commissioner submits pursuant to §5-1-20(a) of this code.

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