

IC 16-38-4

Chapter 4. Birth Problems Registry

IC 16-38-4-1

"Birth problems" defined

Sec. 1. As used in this chapter, "birth problems" means one (1) or more of the following conditions:

- (1) A structural deformation.
- (2) A developmental malformation.
- (3) A genetic, inherited, or biochemical disease.
- (4) A condition of a chronic nature, including central nervous system hemorrhage or infection of the central nervous system, that may result in a need for long term health care.
- (5) A pervasive developmental disorder that is recognized in a child before the child becomes five (5) years of age.
- (6) A fetal alcohol spectrum disorder that is recognized before a child becomes five (5) years of age.
- (7) Any other severe disability that is:
 - (A) designated in a rule adopted by the state department; and
 - (B) recognized in a child after birth and before the child becomes three (3) years of age.

As added by P.L.180-1993, SEC.2. Amended by P.L.93-2001, SEC.3; P.L.17-2004, SEC.5.

IC 16-38-4-2

"Other severe disability" defined

Sec. 2. As used in this chapter, "other severe disability" means a severe physical disability or developmental delay that results from injury, infection, or disease, is chronic in nature, and requires long term health care.

As added by P.L.180-1993, SEC.2. Amended by P.L.23-1993, SEC.76.

IC 16-38-4-3

"Patient" defined

Sec. 3. As used in this chapter, "patient" means:

- (1) a child born with a birth problem; or
- (2) a parent or a guardian of a child born with a birth problem.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-4

"Person" defined

Sec. 4. As used in this chapter, "person" means an individual, association, partnership, corporation, or governmental entity.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-5

"Registry" defined

Sec. 5. As used in this chapter, "registry" refers to the birth problems registry established under this chapter.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-6

"State department" defined

Sec. 6. As used in this chapter, "state department" refers to the state department of health.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-7

Rules to define birth problems; reporting requirements

Sec. 7. (a) The state department shall adopt rules under IC 4-22-2 to:

- (1) define a birth problem; and
- (2) establish reporting requirements regarding birth problems for:
 - (A) hospitals;
 - (B) physicians;
 - (C) local health departments; and
 - (D) other health care providers designated by the state department.

(b) In adopting rules regarding the reporting of birth problems, the state department shall give consideration to the following factors:

- (1) The extent to which a condition can be measured or identified.
- (2) The extent to which there is a known intervention for a condition.
- (3) The significance of the burden imposed on the life of the individual by a condition.
- (4) Other factors that the state department determines appropriate.

As added by P.L.180-1993, SEC.2. Amended by P.L.93-2001, SEC.4.

IC 16-38-4-8

Department to establish birth problems registry; rationale; sources of data; report

Sec. 8. (a) The state department shall establish a birth problems registry for the purpose of recording all cases of birth problems that occur in Indiana residents and compiling necessary and appropriate information concerning those cases, as determined by the state department, in order to:

- (1) conduct epidemiologic and environmental studies and to apply appropriate preventive and control measures;
- (2) inform the parents of children with birth problems:
 - (A) at the time of discharge from the hospital; or
 - (B) if a birth problem is diagnosed during a physician or hospital visit that occurs before the child is:
 - (i) except as provided in item (ii), three (3) years of age at the time of diagnosis; or
 - (ii) five (5) years of age at the time of diagnosis if the disorder is a pervasive developmental disorder or a fetal

- alcohol spectrum disorder;
- about physicians, care facilities, and appropriate community resources, including local step ahead agencies and the infants and toddlers with disabilities program (IC 12-12.7-2); or
- (3) inform citizens regarding programs designed to prevent or reduce birth problems.

(b) The state department shall record in the birth problems registry:

- (1) all data concerning birth problems of children that are provided from the certificate of live birth; and
- (2) any additional information that may be provided by an individual or entity described in section 7(a)(2) of this chapter concerning a birth problem that is:
 - (A) designated in a rule adopted by the state department; and
 - (B) recognized:
 - (i) after the child is discharged from the hospital as a newborn;
 - (ii) before the child is five (5) years of age if the child is diagnosed with a pervasive developmental disorder or a fetal alcohol spectrum disorder; and
 - (iii) before the child is three (3) years of age for any diagnosis not specified in item (ii).

(c) The state department shall:

- (1) provide a physician and a local health department with necessary forms for reporting under this chapter; and
- (2) report in an electronic format under IC 5-14-6 to the legislative council any birth problem trends that are identified through the data collected under this chapter.

As added by P.L.180-1993, SEC.2. Amended by P.L.93-2001, SEC.5; P.L.11-2002, SEC.1; P.L.28-2004, SEC.138; P.L.17-2004, SEC.6; P.L.2-2005, SEC.57; P.L.93-2006, SEC.14.

IC 16-38-4-9

Reports of birth problems to registry

Sec. 9. (a) Nurse midwives and individuals and entities described in section 7(a)(2) of this chapter shall report each confirmed case of a birth problem that is recognized at the time of birth to the registry not later than sixty (60) days after the birth. An individual or entity described in section 7(a)(2) of this chapter who recognizes a birth problem in a child after birth but before the child is five (5) years of age shall report the birth problem to the registry not later than sixty (60) days after recognizing the birth problem. Information may be provided to amend or clarify an earlier reported case.

(b) A person required to report information to the registry under this section may use, when completing reports required by this chapter, information submitted to any other public or private registry or required to be filed with federal, state, or local agencies. However, the state department may require additional, definitive information.

(c) Exchange of information between state department registries is authorized. The state department may use information from

another registry administered by the state department. Information used from other registries remains subject to the confidentiality restrictions on the other registries.

As added by P.L.180-1993, SEC.2. Amended by P.L.93-2001, SEC.6; P.L.17-2004, SEC.7.

IC 16-38-4-10

Confidentiality of information

Sec. 10. Except as provided in sections 11, 12, and 13 of this chapter, information that:

(1) is obtained under this chapter by the state department concerning individual patients; and

(2) is not otherwise a matter of public record;

is for the confidential use of the state department only.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-11

Access to confidential information for research

Sec. 11. The state department shall grant any person involved in a legitimate research activity access to confidential information concerning individual patients obtained by the state department under this chapter if:

(1) the person conducting the research provides written information about the purpose of the research project, the nature of the data to be collected and how the researcher intends to analyze it, the records the researcher wishes to review, and the safeguards the researcher will take to protect the identity of the patients whose records the researcher will be reviewing;

(2) the proposed safeguards are adequate to protect the identity of each patient whose records will be reviewed; and

(3) an agreement is executed between the state department and the researcher that specifies the terms of the researcher's use of the records and that prohibits the publication or release of the names of individual patients or any facts tending to lead to the identification of individual patients.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-12

Requests for additional information

Sec. 12. Researchers may, with the approval of the state department, use the names of individual patients when requesting additional information for research purposes. However, if a researcher requests additional information, the researcher must then obtain the individual patient's written consent by having the patient complete a release of confidential medical information form.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-13

Release of confidential information

Sec. 13. The state department may release confidential

information concerning individual patients to:

- (1) the birth problems registry of another state; and
- (2) physicians and local health officers for diagnostic and treatment purposes;

if the patient gives written consent by completing a release of confidential medical information form.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-14

Persons reporting to registry; immunity from liability for released information

Sec. 14. A person who reports information to the registry under this chapter is immune from any civil or criminal liability that might otherwise be imposed because of the release of what is otherwise confidential information.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-15

Epidemiological and environmental information; release permitted

Sec. 15. This chapter does not prevent the release to any interested person of epidemiological and environmental information that does not identify individual patients.

As added by P.L.180-1993, SEC.2.

IC 16-38-4-16

Educational programs

Sec. 16. (a) The state department shall conduct intensive educational programs for health professionals and members of the public concerning the nature and purpose of the birth problems registry, the reporting and informational requirements, and the causes and detection of birth problems.

(b) The state department shall develop educational program materials appropriate for use in education concerning the transmission of HIV prenatally and neonatally. The state department shall promote the use of the educational program materials by health care providers that furnish prenatal health care services.

As added by P.L.180-1993, SEC.2. Amended by P.L.126-1995, SEC.3.

IC 16-38-4-16.5

Review of medical records

Sec. 16.5. To assure accurate, complete, and timely reporting of birth problems to the registry, the state department may review the medical records of an individual or entity required to report birth problems under this chapter.

As added by P.L.93-2001, SEC.7.

IC 16-38-4-17

Birth problems registry fund

Sec. 17. (a) The birth problems registry fund is established for the

purpose of carrying out this chapter. The fund shall be administered by the state department.

(b) The expenses of administering the fund shall be paid from money in the fund.

(c) Money in the fund at the end of a particular fiscal year does not revert to the state general fund.

(d) The state department is not required to implement the provisions of this chapter regarding birth problems described in section 1(7) of this chapter until the state department receives the funding necessary for implementation.

As added by P.L.180-1993, SEC.2. Amended by P.L.93-2001, SEC.8.

IC 16-38-4-18

Reports by department

Sec. 18. The state department shall report to the legislative council and the governor each year before November 1, the following:

(1) The numbers and types of birth problems occurring in Indiana by county.

(2) The amount of use of the birth problems registry by researchers.

(3) Proposals for the prevention of birth problems occurring in Indiana.

A report under this section to the legislative council must be in an electronic format under IC 5-14-6.

As added by P.L.180-1993, SEC.2. Amended by P.L.28-2004, SEC.139.

IC 16-38-4-19

Abolition of registry

Sec. 19. The registry is abolished July 1, 2017.

As added by P.L.180-1993, SEC.2. Amended by P.L.28-2004, SEC.140; P.L.193-2007, SEC.2.