

Senate Bill No. 1800

CHAPTER 897

An act to amend Section 124980 of the Health and Safety Code, relating to hereditary disorders.

[Approved by Governor September 27, 1998. Filed
with Secretary of State September 28, 1998.]

LEGISLATIVE COUNSEL'S DIGEST

SB 1800, Johnston. Hereditary disorders: genetic counselors.

Existing law requires the Director of Health Services to establish any regulations and standards for hereditary disorders programs as the director deems necessary to promote and protect the public health and safety in accordance with certain principles.

This bill would require the State Department of Health Services to recommend appropriate criteria and standards for licensing genetic counselors, and would require the department to consult with a group of medical experts representing medical professional organizations during the process of developing and recommending the criteria and standards. It would further require the department to report its recommendations to the Legislature by January 1, 2000.

The people of the State of California do enact as follows:

SECTION 1. Section 124980 of the Health and Safety Code is amended to read:

124980. (a) The director shall establish any regulations and standards for hereditary disorders programs as the director deems necessary to promote and protect the public health and safety, in accordance with the principles established pursuant to this section. These principles shall include, but not be limited to, the following:

(1) The public, especially communities and groups particularly affected by programs on hereditary disorders, should be consulted before any regulations and standards are adopted by the department.

(2) The incidence, severity and treatment costs of each hereditary disorder and its perceived burden by the affected community should be considered; and that where appropriate, state and national experts in the medical, psychological, ethical, social, and economic effects or programs for the detection and management of hereditary disorders be consulted by the department.

(3) Information on the operation of all programs on hereditary disorders within the state, except for confidential information obtained from participants in the programs, be open and freely available to the public.

(4) Clinical testing procedures established for use in programs, facilities, and projects be accurate, provide maximum information, and that the testing procedures selected produce results that are subject to minimum misinterpretation.

(5) No test or tests shall be performed on any minor over the objection of the minor's parents or guardian, nor may any tests be performed unless the parent or guardian is fully informed of the purposes of testing for hereditary disorders, and is given reasonable opportunity to object to the testing.

(6) No testing, except initial screening for PKU and other diseases that may be added to the newborn screening program, shall require mandatory participation, and no testing programs shall require restriction of childbearing, and participation in a testing program shall not be a prerequisite to eligibility for, or receipt of, any other service or assistance from, or to participate in, any other program, except where necessary to determine eligibility for further programs of diagnoses of or therapy for hereditary conditions.

(7) Counseling services for hereditary disorders be available through the program or a referral source for all persons determined to be or who believe themselves to be at risk for a hereditary disorder as a result of screening programs; the counseling is nondirective, emphasizes informing the client, and not require restriction of childbearing.

(8) All participants in programs on hereditary disorders be protected from undue physical and mental harm, and except for initial screening for PKU and other diseases that may be added to newborn screening programs, be informed of the nature of risks involved in participation in the programs, and those determined to be affected with genetic disease be informed of the nature, and where possible, the cost of available therapies or maintenance programs, and be informed of the possible benefits and risks associated with such therapies and programs.

(9) All testing results and personal information generated from hereditary disorders programs be made available to an individual over 18 years of age, or to the individual's parent or guardian. If the individual is a minor or incompetent, all testing results that have positively determined the individual to either have, or be a carrier of, a heredity disorder shall be given through a physician or other source of health care.

(10) All testing results and personal information from hereditary disorders programs obtained from any individual, or from specimens from any individual, be held confidential and be considered a confidential medical record except for such information as the individual, parent, or guardian consents to be released; provided that the individual is first fully informed of the scope of the information requested to be released, of all of the risks, benefits, and purposes for the release, and of the identity of those to whom the information will



be released or made available, except for statistical data compiled without reference to the identity of any individual, and except for research purposes, provided that pursuant to 45 Code of Federal Regulations Section 46.101 et seq. entitled "Protection of Human Subjects," the research has first been reviewed and approved by an institutional review board that certifies the approval to the custodian of the information and further certifies that in its judgment the information is of such potentially substantial public health value that modification of the requirement for legally effective prior informed consent of the individual is ethically justifiable.

(11) An individual whose confidentiality has been breached as a result of any violation of the provisions of the Hereditary Disorders Act (Section 27) may recover compensatory damages, and in addition, may recover civil damages not to exceed ten thousand dollars (\$10,000), reasonable attorney's fees, and the costs of litigation.

(b) The department shall recommend appropriate criteria and standards for licensing genetic counselors. In the process of developing the recommended criteria and standards, the department shall consult with a group of medical experts representing medical professional organizations including, but not limited to, the Medical Board of California, the California Medical Association, and organizations representing genetic counselors in California. The department shall report its recommendations to the Legislature by January 1, 2000.

