

## CHAPTER 182

AN ACT concerning informed consent for medical research and amending P.L.1977, c. 82.

**BE IT ENACTED** by the Senate and General Assembly of the State of New Jersey:

1. Section 5 of P.L.1977, c. 82 (C.30:6D-5) is amended to read as follows:

C.30:6D-5 Rights of person receiving services for developmentally disabled at facility.

5. a. No person receiving services for the developmentally disabled at any facility shall:

- (1) be subjected to any corporal punishment;
- (2) be administered any medication or chemical restraint, except upon the written authorization of a physician when necessary and appropriate as an element of the service being received or as a treatment of any medical or physical condition in conformity with accepted standards for such treatment. The nature, amount of, and reasons for the administration of any medication or chemical restraint shall be promptly recorded in such person's medical record;

- (3) be physically or chemically restrained or isolated in any manner, except in emergency situations for the control of violent, disturbed or depressed behavior which may immediately result in or has resulted in harm to such person or other person or in substantial property damage.

The chief administrator of the facility, or his designee, shall be notified immediately upon the application of any such restraint or isolation, and thereafter such restraint or isolation shall be continued only upon the written order of the administrator or designee. Such order shall be effective for not more than 24 hours, and may be renewed for additional periods of not more than 24 hours each if the administrator or designee shall determine that such continued restraint or isolation is necessary. While in restraint or isolation, such person shall be checked by an attendant every 15 minutes, and bathed every 24 hours. Such restraint or isolation shall be terminated at any time if an attending physician shall find such restraint or isolation to be medically contraindicated. The nature, duration of, reasons for and notation of attendant checks shall be promptly recorded in such person's medical record;

- (4) be subjected to shock treatment, psychosurgery, sterilization or medical behavioral or pharmacological research without the express and informed consent of such person, if a competent adult, or of such person's guardian ad litem specifically appointed by a court for the matter of consent to these proceedings, if a minor or an incompetent adult or a person administratively determined to be mentally deficient. Such consent shall be made in writing and shall be placed in such person's record.

Either the party alleging the necessity of such procedure or such person or such person's guardian ad litem may petition a court of competent jurisdiction to hold a hearing to determine the necessity of such procedure at which the client is physically present, represented by counsel, and provided the right and opportunity to be confronted with and to cross-examine all witnesses alleging the necessity of such procedure. In such proceedings, the burden of proof shall be on the party alleging the necessity of such procedure. In the event that a person cannot afford counsel, the court shall appoint an attorney not less than 10 days before the hearing. An attorney so appointed shall be entitled to a reasonable fee to be determined by the court and paid by the county from which the person was admitted. Under no circumstances may a person in treatment be subjected to hazardous or intrusive experimental research which is not directly related to the specific goals of his treatment program;

(5) Notwithstanding the provisions of paragraph (4) of this subsection to the contrary, nothing in this section shall prohibit consent obtained or research conducted pursuant to the provisions of P.L.2007, c.316 (C.26:14-1 et seq.) as provided in this paragraph (5).

(a) In addition to meeting the requirements of sections 4 and 5 of P.L.2007, c.316 (C.26:14-4 and 26:14-5), medical research involving persons who are protected by the provisions of this subsection shall also meet the approval of the Interdisciplinary Research Committee established herein.

(b) The members of the Interdisciplinary Research Committee shall be appointed by the Assistant Commissioner of the Division of Developmental Disabilities in the Department of Human Services, and shall serve at the pleasure of the Assistant Commissioner. The members shall have diverse backgrounds, represent a variety of professions, and include at least one self-advocate and one family member, neither of whom shall be an employee of the department.

(c) The committee shall independently determine whether the criteria set forth in section 3 of P.L.2007, c.316 (C.26:14-3), and where required, the informed consent provisions of section 4 of P.L.2007, c.316 (C.26:14-4), have been met. In addition, the committee may impose such other conditions on approval as it determines are necessary to protect the health, safety, and autonomy of the individuals participating in the medical research.

(d) Notices of proposals for medical research received by the committee, and the committee's action on the proposals, shall be posted on the department's website and forwarded to the New Jersey Council on Developmental Disabilities, The Elizabeth M. Boggs Center on Developmental Disabilities, and Disability Rights of New Jersey.

(e) Two years after enactment of P.L.2011, c.182 and every two years thereafter, the division shall provide to the Legislature, pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), and post on the division's Internet website, a summary of the research proposals reviewed by the committee and the actions taken.

b. Every developmentally disabled person in residence at any facility shall be provided with a nutritionally adequate and sufficient diet and shall receive appropriate and sufficient medical and dental care on a regular basis and whenever otherwise necessary.

c. Every developmentally disabled person between the ages of 5 and 21, inclusive, in residence or full-time attendance at any facility shall be provided a thorough and efficient education suited to such person's age and abilities.

2. This act shall take effect immediately.

Approved January 17, 2012.