

SENATE HEALTH, HUMAN SERVICES AND SENIOR  
CITIZENS COMMITTEE

STATEMENT TO

**SENATE, No. 941**

with committee amendments

**STATE OF NEW JERSEY**

DATED: MAY 27, 2010

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with amendments Senate Bill No. 941.

As amended by the committee, this bill amends section 5 of P.L.1977, c.82 (C.30:6D-5), which protects persons with developmental disabilities when they are participants in medical research. This law requires informed consent and requires a court-appointed guardian ad litem to represent a minor, incompetent adult, or person administratively determined to be mentally deficient. The law prohibits certain research that is not directly related to the specific goals of the individual's treatment program.

The purpose of this bill is to eliminate confusion and potential statutory conflict with the "Access to Medical Research Act," P.L. 2007, c.316 (C.26:14-1 et seq.), which permits a broader range of research when an institutional review board approves and oversees the research, and which authorizes specified individuals other than a guardian ad litem to provide surrogate consent for medical research when specific protective criteria are met.

The committee amendments add the following requirements:

- Medical research also shall be approved by an Interdisciplinary Research Committee (IRC), the members of which would be appointed by the Assistant Commissioner of the Division of Developmental Disabilities. The IRC members are to represent diverse backgrounds, and include at least one self-advocate and one family member who are not employees of the department.
- The ICR would independently determine whether the above protective measures and consent requirements have been met, and could impose such other conditions on approval as it determines are necessary.
- The division is to post on its Internet website notices of proposals for medical research received by the IRC as well as the IRC's actions on those proposals, and forward them to the New Jersey Council on Developmental Disabilities, The

Elizabeth M. Boggs Center on Developmental Disabilities, and Disability Rights New Jersey.

- Two years after enactment of the bill and every two years thereafter, the division is to post a summary of the research proposals reviewed by the IRC and the actions taken by the IRC on the division's Internet website and provide the summary to the Legislature.