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LAW/RWH

P.L.2011, CHAPTER 182, *approved January 17, 2012*  
Senate, No. 941 (*First Reprint*)

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

3  
4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

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

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

11 (1) be subjected to any corporal punishment;

12 (2) be administered any medication or chemical restraint, except  
13 upon the written authorization of a physician when necessary and  
14 appropriate as an element of the service being received or as a  
15 treatment of any medical or physical condition in conformity with  
16 accepted standards for such treatment. The nature, amount of, and  
17 reasons for the administration of any medication or chemical  
18 restraint shall be promptly recorded in such person's medical  
19 record;

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

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

39 (4) be subjected to shock treatment, psychosurgery, sterilization  
40 or medical behavioral or pharmacological research without the  
41 express and informed consent of such person, if a competent adult,  
42 or of such person's guardian ad litem specifically appointed by a

**EXPLANATION** – Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

<sup>1</sup>Senate SHH committee amendments adopted May 27, 2010.

1 court for the matter of consent to these proceedings, if a minor or an  
2 incompetent adult or a person administratively determined to be  
3 mentally deficient. Such consent shall be made in writing and shall  
4 be placed in such person's record.

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

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

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

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

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

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

1 Boggs Center on Developmental Disabilities, and Disability Rights  
2 New Jersey.

3 (e) Two years after enactment of P.L. , c. (pending before the  
4 Legislature as this bill) and every two years thereafter, the division  
5 shall provide to the Legislature, pursuant to section 2 of P.L.1991,  
6 c.164 (C.52:14-19.1), and post on the division's Internet website, a  
7 summary of the research proposals reviewed by the committee and  
8 the actions taken<sup>1</sup>.

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

14 c. Every developmentally disabled person between the ages of  
15 5 and 21, inclusive, in residence or full-time attendance at any  
16 facility shall be provided a thorough and efficient education suited  
17 to such person's age and abilities.

18 (cf: P.L.1977, c.82, s.5)

19

20 2. This act shall take effect immediately.

21

22

23

24

25 Clarifies informed consent provisions of "Access to Medical  
26 Research Act" for persons with developmental disabilities.

# SENATE, No. 941

## STATE OF NEW JERSEY 214th LEGISLATURE

INTRODUCED FEBRUARY 4, 2010

**Sponsored by:**

**Senator CHRISTOPHER "KIP" BATEMAN**

**District 16 (Morris and Somerset)**

**Senator ROBERT W. SINGER**

**District 30 (Burlington, Mercer, Monmouth and Ocean)**

**SYNOPSIS**

Clarifies informed consent provisions of "Access to Medical Research Act" for persons with developmental disabilities.

**CURRENT VERSION OF TEXT**

As introduced.



**(Sponsorship Updated As Of: 5/28/2010)**

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

3  
4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

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

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

11 (1) be subjected to any corporal punishment;

12 (2) be administered any medication or chemical restraint, except  
13 upon the written authorization of a physician when necessary and  
14 appropriate as an element of the service being received or as a  
15 treatment of any medical or physical condition in conformity with  
16 accepted standards for such treatment. The nature, amount of, and  
17 reasons for the administration of any medication or chemical  
18 restraint shall be promptly recorded in such person's medical  
19 record;

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

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

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

**EXPLANATION** – Matter enclosed in bold-faced brackets **[thus]** in the above bill is  
not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

1 be placed in such person's record.

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

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

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

27 c. Every developmentally disabled person between the ages of  
28 5 and 21, inclusive, in residence or full-time attendance at any  
29 facility shall be provided a thorough and efficient education suited  
30 to such person's age and abilities.

31 (cf: P.L.1977, c. 82, s. 5)

32

33 2. This act shall take effect immediately.

34

35

36

#### STATEMENT

37

38 This bill amends section 5 of P.L.1977, c. 82 (C.30:6D-5), which  
39 contains, among other measures that protect persons with  
40 developmental disabilities, informed consent provisions in  
41 connection with an individual's participation in medical research.  
42 This law requires informed consent for medical behavioral and  
43 pharmacological research, and requires a court-appointed guardian  
44 ad litem to represent a person who is a minor, incompetent adult, or  
45 person administratively determined to be mentally deficient. The  
46 law prohibits certain research that is not directly related to the  
47 specific goals of the individual's treatment program.



**S941 BATEMAN, SINGER**

4

1       The amendment in this bill is intended to eliminate confusion  
2 and potential statutory conflict with the “Access to Medical  
3 Research Act,” P.L. 2007, c.316 (C.26:14-1 et seq.), which permits  
4 a broader range of research, provided that an institutional review  
5 board approves and oversees the research, and which authorizes  
6 certain individuals other than a guardian ad litem to provide  
7 surrogate consent for medical research when specific protective  
8 criteria are met. Those individuals, in descending order of priority,  
9 are:

- 10       • a guardian with authority to make health care decisions;
- 11       • the person’s health care representative under an advance  
12       directive for health care;
- 13       • the spouse or civil union partner, as applicable;
- 14       • the person’s domestic partner;
- 15       • the person’s adult son or daughter;
- 16       • a custodial parent;
- 17       • an adult brother or sister;
- 18       • an adult grandchild; and
- 19       • an available adult relative with the closest degree of kinship  
20       to the person.

21       This bill would take effect immediately.

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.

# ASSEMBLY HUMAN SERVICES COMMITTEE

## STATEMENT TO

[First Reprint]

**SENATE, No. 941**

# **STATE OF NEW JERSEY**

DATED: JANUARY 5, 2012

The Assembly Human Services Committee reports favorably Senate Bill No. 941(1R).

This bill amends current law, which protects persons with developmental disabilities by requiring consent of the person's guardian ad litem when they are participants in medical research, so that it conforms with the State's "Access to Medical Research Act" (AMRA), which authorizes other specified individuals to provide surrogate consent for medical research and permits research when an institutional review board approves and oversees the research.

Specifically, current law is amended to add that consent may be obtained or research conducted pursuant to AMRA, under which consent is obtained, in descending order of priority, from: a guardian with authority to make health care decisions; the person's health care representative under an advance directive for health care; the spouse or civil union partner, as applicable; the person's domestic partner; the person's adult son or daughter; a custodial parent; an adult brother or sister; an adult grandchild; and an available adult relative with the closest degree of kinship to the person.

The bill also establishes an Interdisciplinary Research Committee (IRC). The members of the IRC would be appointed by the Assistant Commissioner of the Division of Developmental Disabilities (division) in the Department of Human Services (DHS), would represent diverse backgrounds, and would include at least one self-advocate and one family member who are not employees of DHS.

The IRC would independently determine whether protective measures and consent requirements have been met, and could impose other conditions on approval as it determines are necessary.

The bill requires the division to post on its 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. In addition, two years after enactment of the bill and every two years thereafter, the division is to post on its website a summary of the

research proposals reviewed and the actions taken by the IRC, and also provide the summary to the Legislature.

As reported, the bill is identical to Assembly Bill No. 3940 (Jasey), which the committee also reported favorably on this date.

# ASSEMBLY, No. 3940

## STATE OF NEW JERSEY 214th LEGISLATURE

INTRODUCED MAY 5, 2011

**Sponsored by:**

**Assemblywoman MILA M. JASEY**

**District 27 (Essex)**

**SYNOPSIS**

Clarifies informed consent provisions of “Access to Medical Research Act” for persons with developmental disabilities.

**CURRENT VERSION OF TEXT**

As introduced.



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

3  
4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

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

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

11 (1) be subjected to any corporal punishment;

12 (2) be administered any medication or chemical restraint, except  
13 upon the written authorization of a physician when necessary and  
14 appropriate as an element of the service being received or as a  
15 treatment of any medical or physical condition in conformity with  
16 accepted standards for such treatment. The nature, amount of, and  
17 reasons for the administration of any medication or chemical  
18 restraint shall be promptly recorded in such person's medical  
19 record;

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

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

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

**EXPLANATION** – Matter enclosed in bold-faced brackets **[thus]** in the above bill is  
not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

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

17        (5) Notwithstanding the provisions of paragraph (4) of this  
18 subsection to the contrary, nothing in this section shall prohibit  
19 consent obtained or research conducted pursuant to the provisions  
20 of P.L. 2007, c.316 (C.26:14-1 et seq.) as provided in this paragraph  
21 (5).

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

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

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

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

47        (e) Two years after enactment of P.L. , c. (pending before the  
48 Legislature as this bill) and every two years thereafter, the division



1 shall provide to the Legislature, pursuant to section 2 of P.L.1991,  
2 c.164 (C.52:14-19.1), and post on the division's Internet website, a  
3 summary of the research proposals reviewed by the committee and  
4 the actions taken.

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

10 c. Every developmentally disabled person between the ages of  
11 5 and 21, inclusive, in residence or full-time attendance at any  
12 facility shall be provided a thorough and efficient education suited  
13 to such person's age and abilities.

14 (cf: P.L.1977, c.82, s.5)

15

16 2. This act shall take effect immediately.

17

18

19

STATEMENT

20

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

29 The purpose of this bill is to eliminate confusion and potential  
30 statutory conflict with the "Access to Medical Research Act," P.L.  
31 2007, c.316 (C.26:14-1 et seq.), which permits a broader range of  
32 research when an institutional review board approves and oversees  
33 the research, and which authorizes specified individuals other than a  
34 guardian ad litem to provide surrogate consent for medical research  
35 when specific protective criteria are met. Those individuals, in  
36 descending order of priority, are:

- 37 • a guardian with authority to make health care decisions;
- 38 • the person's health care representative under an advance  
39 directive for health care;
- 40 • the spouse or civil union partner, as applicable;
- 41 • the person's domestic partner;
- 42 • the person's adult son or daughter;
- 43 • a custodial parent;
- 44 • an adult brother or sister;
- 45 • an adult grandchild; and
- 46 • an available adult relative with the closest degree of kinship  
47 to the person.

48 In addition, this bill provides that:

- 1       • Medical research also shall be approved by an  
2       Interdisciplinary Research Committee (IRC), the members of  
3       which would be appointed by the Assistant Commissioner of  
4       the Division of Developmental Disabilities. The IRC  
5       members are to represent diverse backgrounds, and include  
6       at least one self-advocate and one family member who are  
7       not employees of the department.
- 8       • The ICR would independently determine whether the above  
9       protective measures and consent requirements have been  
10      met, and could impose such other conditions on approval as  
11      it determines are necessary.
- 12     • The division is to post on its Internet website notices of  
13      proposals for medical research received by the IRC as well  
14      as the IRC's actions on those proposals, and forward them to  
15      the New Jersey Council on Developmental Disabilities, The  
16      Elizabeth M. Boggs Center on Developmental Disabilities,  
17      and Disability Rights New Jersey.
- 18     • Two years after enactment of the bill and every two years  
19      thereafter, the division is to post a summary of the research  
20      proposals reviewed by the IRC and the actions taken by the  
21      IRC on the division's Internet website and provide the  
22      summary to the Legislature.
- 23     The bill takes effect immediately.

# ASSEMBLY HUMAN SERVICES COMMITTEE

## STATEMENT TO

### ASSEMBLY, No. 3940

# STATE OF NEW JERSEY

DATED: JANUARY 5, 2012

The Assembly Human Services Committee reports favorably Assembly Bill No. 3940.

This bill amends current law, which protects persons with developmental disabilities by requiring consent of the person's guardian ad litem when they are participants in medical research, so that it conforms with the State's "Access to Medical Research Act" (AMRA), which authorizes other specified individuals to provide surrogate consent for medical research and permits research when an institutional review board approves and oversees the research.

Specifically, current law is amended to add that consent may be obtained or research conducted pursuant to AMRA, under which consent is obtained, in descending order of priority, from: a guardian with authority to make health care decisions; the person's health care representative under an advance directive for health care; the spouse or civil union partner, as applicable; the person's domestic partner; the person's adult son or daughter; a custodial parent; an adult brother or sister; an adult grandchild; and an available adult relative with the closest degree of kinship to the person.

The bill also establishes an Interdisciplinary Research Committee (IRC). The members of the IRC would be appointed by the Assistant Commissioner of the Division of Developmental Disabilities (division) in the Department of Human Services (DHS), would represent diverse backgrounds, and would include at least one self-advocate and one family member who are not employees of DHS.

The IRC would independently determine whether protective measures and consent requirements have been met, and could impose other conditions on approval as it determines are necessary.

The bill requires the division to post on its 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. In addition, two years after enactment of the bill and every two years thereafter, the division is to post on its website a summary of the research proposals reviewed and the actions taken by the IRC, and also provide the summary to the Legislature.

As reported, the bill is identical to Senate Bill No. 941 (1R) (Bateman/Singer), which the committee also reported favorably on this date.