

VETO MESSAGE:

No

GOVERNOR'S PRESS RELEASE ON SIGNING:

Yes

FOLLOWING WERE PRINTED:

To check for circulating copies, contact New Jersey State Government Publications at the State Library (609) 278-2640 ext.103 or <mailto:refdesk@njstatelib.org>

REPORTS:

No

HEARINGS:

No

NEWSPAPER ARTICLES:

Yes

"Gov. Corzine signs seven autism bills into law," Asbury Park Press, 9-13-07, p.A7

"New laws aim at fighting autism, improving services," Home News Tribune, 9-13-07, p. __

"Corzine OKs laws aimed at autism," Courier-Post, 9-13-07, p. __

"Corzine signs bills to bolster autism fight," The Star-Ledger, 9-13-07, p.22

"New Jersey gives \$4M boost to autism research," The Record, 9-13-07, p.A01

"New Jersey targets nation's highest autism rate," Burlington County Times, p. __

"State probes needs of autistic adults," Courier News, 9-13-07. p. __

IS 5/12/08

P.L. 2007, CHAPTER 168, *approved September 12, 2007*
Senate, No. 698 (*Fourth Reprint*)

1 AN ACT concerning medical research and treatment of autism,
2 amending and supplementing P.L.1999, c.105 and amending
3 P.L.2001, c.338 and P.L.2003, c.144.

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

7
8 1. Section 1 of P.L.1999, c.105 (C.30:6D-56) is amended to
9 read as follows:

10 1. This act shall be known and may be cited as the "New Jersey
11 **[Infantile]** Autism Biomedical Research Act."
12 (cf: P.L.1999, c.105, s.1)

13
14 2. Section 2 of P.L.1999, c.105 (30:6D-57) is amended to read
15 as follows:

16 2. The Legislature finds and declares that:

17 a. **[Infantile autism]** Autism and autism spectrum disorders are
18 biologically-based developmental disorders which cause severe
19 impairments in language and communication and generally manifest
20 in young children sometime during the first two years of life, and
21 the devastation caused by autism lasts a lifetime due to the
22 emotional and financial distress that families experience from the
23 intense support which most individuals with autism require
24 throughout their lives;

25 b. With three quarters of those with **[infantile]** autism
26 spending their adult lives in institutions or group homes, and
27 usually entering institutions by the age of 13, the cost of caring for
28 individuals with autism and autism spectrum disorder is great, and
29 is estimated to be \$.5 billion per year in the State, solely for direct
30 costs;

31 c. ³**[Best estimates indicate that one in 500 children born in the**
32 **State will be diagnosed with an autism spectrum disorder and that**
33 **12,000 individuals in the State have autism or an autism spectrum**
34 **disorder, but these numbers may be understated because current**
35 **diagnostic procedures lack accuracy and sensitivity for those with**
36 **atypical symptoms and because there is a need for epidemiological**
37 **data on incidence and prevalence of this disorder in the State]**
38 According to the federal Centers for Disease Control and
39 Prevention, or CDC, one of every 94 children in this State has
40 autism, which is the highest rate among the states examined by the

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:

¹**Senate floor amendments adopted December 4, 2006.**

²**Assembly AHE committee amendments adopted March 5, 2007.**

³**Assembly floor amendments adopted March 8, 2007.**

⁴**Assembly ABU committee amendments adopted March 12, 2007.**

1 CDC in the most comprehensive study of the prevalence of autism
2 to date³;

3 d. While **[infantile]** autism is the third most common
4 developmental disorder and is more prevalent than Down's
5 syndrome, childhood cancer or cystic fibrosis, autism research
6 receives less than 5% of the funding of these other diseases from
7 the federal government and to date little biomedical research has
8 been done on this disorder, despite the fact that scientists consider
9 autism to be one of the most heritable of all the developmental
10 disorders and the most likely to yield to the latest scientific
11 advancements in genetics and neurology;

12 e. The lack of research was due to 40 years of neglect of
13 autism by the scientific community, arising from the formerly
14 widespread but now discredited belief that autism was an emotional
15 disorder caused by faulty parenting, and thus, few dollars were
16 allocated to researchers, leaving an entire generation of children to
17 be overlooked; however, the rapid advancements in biomedical
18 science suggest that effective treatment and a cure for autism are
19 attainable, if sufficient dollars are allocated to research so that
20 another generation of children in the State is not lost to this
21 disorder;

22 f. While promising findings in the field of autism research
23 have been made in recent years, the diverse symptoms and etiology
24 of autism require a high level of activity in the widest variety of
25 scientific fields, from genetics and neurology to neuroimaging,
26 immunology and gastroenterology, if effective treatments and a
27 cure are to be found quickly;

28 g. Other states such as New York, Connecticut and Maryland
29 have nationally recognized centers for researching and treating
30 autism that attract significant funding from private sources and the
31 National Institutes of Health, but since New Jersey lacks such
32 centers, the State is unable to attract comparable funding, despite
33 the presence of highly regarded medical facilities in the State such
34 as Robert Wood Johnson University Hospital and Hackensack
35 University Medical Center, as well as a higher education medical
36 institution such as the University of Medicine and Dentistry of New
37 Jersey;

38 h. The State's substantial pharmaceutical industry would
39 benefit from having medical centers dedicated to autism research
40 and treatment by gaining access to families for clinical trials and by
41 enabling easy collaboration between public and private scientists;
42 and

43 i. Legislation has been introduced in the United States
44 Congress which, if passed, will increase the level of federal funding
45 for biomedical research on autism; however, in order for State
46 researchers to be eligible for these dollars, funding must be made

1 available for State researchers to carry out preliminary pilot studies.
2 (cf: P.L.1999, c.105, s.2)

3

4 3. Section 3 of P.L.1999, c.105 (C.30:6D-58) is amended to
5 read as follows:

6 3. As used in this act:

7 "Autism" includes autism spectrum disorders to the extent
8 determined by the council to be appropriate.

9 "Center" means the Center of Excellence for Autism established
10 pursuant to this act.

11 "Council" means the "Governor's Council for Medical Research
12 and Treatment of **[Infantile]** Autism" established pursuant to this
13 act. **["President" means the President of the University of
14 Medicine and Dentistry of New Jersey.]**

15 (cf: P.L.1999, c.105, s.3)

16

17 4. Section 4 of P.L.1999, c.105 (C.30:6D-59) is amended to
18 read as follows:

19 4. a. There is established in the ³**[University of Medicine and
20 Dentistry of New Jersey] Department of Health and Senior
21 Services³**, the "Governor's Council for Medical Research and
22 Treatment of **[Infantile]** Autism." The council shall be composed
23 of **[seven] ¹[nine] ²[11¹] ³[13²] 14³** members as follows:
24 ³**[two] seven³** persons to be appointed by the Governor, ³**[one of
25 whom shall be a person with a diagnosis of autism or autism
26 spectrum disorder or the family member of such a person, neither of
27 whom shall occupy a leadership position in any of the organizations
28 represented on the council;] two of whom shall be members of the
29 public who do not occupy a leadership position in any of the
30 organizations represented on the council, of which two members
31 one shall be a person with a diagnosis of autism or autism spectrum
32 disorder or the family member of such a person, four of whom shall
33 be appointed in consultation with the presidents of academic
34 institutions in this State that are engaged in autism research, and
35 one of whom shall be a representative of a health care organization
36 with demonstrated clinical expertise in the evaluation and treatment
37 of autism spectrum disorders;** ³ ²**one person to be appointed by the
38 President of the Senate and one person to be appointed by the
39 Speaker of the General Assembly;** ² ¹**[one person] ³[three persons¹
40 to be appointed by the President of the University of Medicine and
41 Dentistry of New Jersey]³ [, or his designee, the director of the
42 center, and the director of one other treatment center at the
43 University of Medicine and Dentistry of New Jersey that is devoted
44 to biomedical research on autism, to be appointed by the president,
45 all of whom shall serve as ex officio members]; one person to be
46 appointed by the Commissioner of Health and Senior Services;**

1 ³one person to be appointed by the Director of the Environmental
2 and Occupational Health Sciences Institute;³ and four public
3 members from persons ⁴, also to be appointed by the Governor,⁴
4 who represent autism organizations in New Jersey ³as follows:
5 ²one representative designated by the New Jersey chapter of the
6 Cure Autism Now Foundation,² one representative designated by
7 ²the National Alliance for² Autism ²Research Speaks², one
8 representative designated by the The New Jersey Center for
9 Outreach and Services for the Autism Community[, Inc.], ²and²
10 one representative designated by the Autism Autoimmunity
11 Project, Inc.] Asperger Syndrome Education Network², and one
12 person to be selected by the Governor who is a member of an
13 advocacy organization not already named in this subsection², each
14 of whom shall represent no more than one such organization³.

15 b. The president or his designee shall serve as chairman of
16 At its first meeting of each calendar year, the council shall select,
17 by a simple majority of the members present, a chairperson from
18 among its members, who shall serve as the chairperson until the
19 first meeting held in the next calendar year, at which time the same
20 person may be selected as chairperson or a new chairperson may be
21 selected in the same manner. ³Public The³ members of the
22 council shall serve for three-year terms. Each member shall hold
23 office for the term of appointment and until a successor is appointed
24 and qualified. All vacancies shall be filled in the same manner as
25 the original appointment. Members appointed to fill a vacancy
26 occurring for any reason other than the expiration of the term shall
27 serve for the unexpired term only. ³A public member The
28 members³ of the council shall be eligible for reappointment.

29 c. ³Public The³ members ³of the council³ shall serve without
30 compensation, but shall be reimbursed for necessary expenses
31 incurred in the performance of their duties.

32 d. A majority of the members of the council shall constitute a
33 quorum, but a lesser number may hold hearings.

34 e. The council shall meet periodically at the call of the
35 chairman, but not less than four times in the first year in which the
36 center is established and not less than twice in each subsequent
37 calendar year.

38 f. The president shall appoint a salaried administrator for the
39 council and shall provide the council with additional administrative
40 staff and support as may be necessary to enable the council to carry
41 out its functions ⁴Commissioner of Health and Senior Services, in
42 consultation with the⁴ council ⁴, ⁴ shall ⁴select and⁴ appoint a
43 director ⁴who shall serve, at the pleasure of the council, as
44 administrator⁴ of the council. The director shall be a person
45 qualified by training and experience to perform the duties of that

1 position. The director ⁴ shall be a full-time employee who shall
2 devote his entire time to the duties of the position and shall receive
3 a salary commensurate with the responsibilities thereof. The
4 director shall serve in the State unclassified service of the Civil
5 Service] at the direction of the council, may call upon the
6 commissioner for additional staff assistance and resources as
7 appropriate⁴ .

8 (cf: P.L.1999, c.105, s.4)

9
10 5. Section 5 of P.L.1999, c.105 (C.30:6D-60) is amended to
11 read as follows:

12 5. a. The [University of Medicine and Dentistry of New
13 Jersey, upon the recommendation of the] council[,] shall make
14 awards of grants and contracts to public and nonprofit private
15 entities to pay all or part of the cost of planning, establishing,
16 improving and providing basic operating support for a Center of
17 Excellence for Autism in the State where basic and applied
18 biomedical research, diagnosis and treatment for autism shall take
19 place.

20 b. The council shall define the scope of the programs to be
21 undertaken at the center with the understanding that the center shall
22 conduct:

23 (1) basic and clinical research into the cause, diagnosis, early
24 detection, prevention, control and treatment of autism, including
25 research in the fields of developmental neurobiology, genetics,
26 [psychopharmacology] psychopharmacology, neuroimaging,
27 immunology, infectious diseases, gastroenterology and
28 endocrinology;

29 (2) training programs on biomedical treatments, diagnosis and
30 prevention for autism for physicians, scientists and other health care
31 and allied health care professionals in the State; and

32 (3) information and continuing educational programs on the
33 latest advances in biomedical research on autism for physicians and
34 other health care and allied health care professionals who provide
35 care for patients with autism in the State.

36 c. The center may carry out programs to make individuals in
37 the State aware of opportunities to participate as subjects in
38 research conducted by the center. The program may provide fees to
39 these subjects. The program may, in accordance with guidelines
40 established by the council, provide to these subjects health care,
41 referrals for health and other services and such incidental services
42 as will facilitate the participation of individuals as subjects.

43 d. The center may provide stipends for health care
44 professionals enrolled in training programs established under
45 paragraph (2) of subsection b. of this section.

46 e. The council may require the periodic preparation of reports
47 on the activities of the center and the submission of the reports to

1 the council.

2 f. The center shall use the facilities of a single medical facility
3 or higher education medical institution, or be formed from a
4 consortium of cooperating facilities or institutions, and shall meet
5 any requirements as may be prescribed by the council, with the
6 understanding that the work carried out at the center shall be
7 comprehensive and fully collaborative.

8 (cf: P.L.1999, c.105, s.5)

9

10 6. Section 6 of P.L.1999, c.105 (C.30:6D-61) is amended to
11 read as follows:

12 6. The council shall provide guidance and direction to the
13 director of the council, who shall be responsible for the following
14 duties:

15 a. Carry out a program to provide information and education
16 on advances in the diagnosis and biomedical treatment of autism to
17 families in the State with autistic members and to the general
18 public[.];

19 b. Establish a five-member Scientific Advisory Committee
20 whose members shall serve at the pleasure of the council. The
21 members of the committee shall include: three biomedical research
22 scientists with demonstrated achievements in biomedical research
23 relating to autism; and two medical clinicians whose practice is
24 primarily devoted to the treatment of individuals with autism. The
25 committee shall identify and make recommendations to the council
26 regarding grants for the most promising pilot studies for biomedical
27 research, diagnosis and treatment for autism and autism spectrum
28 disorders [and establish the procedures for soliciting research
29 proposals and applying for grants for pilot studies.];

30 c. **[Select]** Present the recommendations of the Scientific
31 Advisory Committee to the council, which shall select the final
32 grants for pilot studies [based on recommendations of the Scientific
33 Advisory Committee.];

34 d. Establish mechanisms to use the results of biomedical
35 research on autism and autism spectrum disorders, conducted at the
36 center and through the pilot studies in the development of policies
37 and programs to improve the outcomes of individuals in the State
38 with these disorders[.];

39 e. Establish a mechanism for the sharing of information among
40 researchers and clinicians in the State conducting biomedical
41 research on autism and autism spectrum disorders[.];

42 f. Provide for a mechanism that would permit the public to
43 obtain information on the existing and planned programs and
44 activities being conducted through the center and the pilot studies,
45 and the council to receive comments from the public regarding
46 these programs and activities[.];

47 g. Continually seek and apply for funding to supplement and

1 eventually replace the moneys provided pursuant to subsection f. of
2 R.S.39:5-41; and

3 h. Report not later than March 1 of each year to the Governor
4 and ², pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to²
5 the Legislature on the status of the Center of Excellence for Autism
6 and other activities of the council.

7 (cf: P.L.1999, c.105, s.6)

8

9 7. (New section) Whenever the term "Governor's Council for
10 Medical Research and Treatment of Infantile Autism" occurs or any
11 reference is made thereto in any law, contract or document, the
12 same shall be deemed to mean or refer to the "Governor's Council
13 for Medical Research and Treatment of Autism."

14

15 8. Section 1 of P.L.2001, c.338 (C.30:6D-62.1) is amended to
16 read as follows:

17 1. Beginning in Fiscal Year 2001 and in each fiscal year
18 thereafter, the Governor shall recommend and the Legislature shall
19 appropriate \$1,500,000 from the General Fund to the Governor's
20 Council for Medical Research and Treatment of **[Infantile]** Autism
21 established pursuant to P.L.1999, c.105 (C.30:6D-56 et seq.).

22 (cf: P.L.2001, c.338, s.1)

23

24 9. Section 1 of P.L.2003, c.144 (C.30:6D-62.2) is amended to
25 read as follows:

26 1. a. There is established in the Department of the Treasury a
27 nonlapsing fund to be known as the "Autism Medical Research and
28 Treatment Fund." This fund shall be the repository for moneys
29 provided pursuant to subsection f. of R.S.39:5-41. Moneys
30 deposited in the fund, and any interest earned thereon, shall be
31 allocated to the Governor's Council for Medical Research and
32 Treatment of **[Infantile]** Autism established pursuant to P.L.1999,
33 c.105 (C.30:6D-56 et seq.), to support grants and contracts awarded
34 under subsection a. of section 5 of P.L.1999, c.105 (C.30:6D-60),
35 and any grants for pilot studies selected under subsection c. of
36 section 6 of that P.L.1999, c.105 (C.30:6D-61), provided that, if
37 federal funds are available for the purpose, the grantee or contractor
38 shall, as a condition of receiving any such grant or contract from the
39 fund, apply for an amount of federal funds in support of that grant
40 or contract.

41 b. Any costs incurred by the department in the collection or
42 administration of the fund may be deducted from the funds
43 deposited therein, as determined by the Director of the Division of
44 Budget and Accounting.

45 (cf: P.L.2003, c.144, s.1)

46

47 10. This act shall take effect immediately.

1

2

3 Makes changes concerning Governor's Council for Medical

4 Research and Treatment of Autism.

SENATE, No. 698

STATE OF NEW JERSEY 212th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2006 SESSION

Sponsored by:

Senator LORETTA WEINBERG

District 37 (Bergen)

Senator JOSEPH F. VITALE

District 19 (Middlesex)

Co-Sponsored by:

Senators Karcher, Buono, T.Kean and Madden

SYNOPSIS

Makes changes concerning Governor's Council for Medical Research and Treatment of Autism.

CURRENT VERSION OF TEXT

Introduced Pending Technical Review by Legislative Counsel



(Sponsorship Updated As Of: 10/17/2006)

1 AN ACT concerning medical research and treatment of autism,
2 amending and supplementing P.L.1999, c.105 and amending
3 P.L.2001, c.338 and P.L.2003, c.144.

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

7
8 1. Section 1 of P.L.1999, c.105 (C.30:6D-56) is amended to read
9 as follows:

10 1. This act shall be known and may be cited as the "New Jersey
11 **【Infantile】** Autism Biomedical Research Act."
12 (cf: P.L.1999, c.105, s.1)

13
14 2. Section 2 of P.L.1999, c.105 (30:6D-57) is amended to read
15 as follows:

16 2. The Legislature finds and declares that:

17 a. **【Infantile autism】** Autism and autism spectrum disorders are
18 biologically-based developmental disorders which cause severe
19 impairments in language and communication and generally manifest
20 in young children sometime during the first two years of life, and
21 the devastation caused by autism lasts a lifetime due to the
22 emotional and financial distress that families experience from the
23 intense support which most individuals with autism require
24 throughout their lives;

25 b. With three quarters of those with **【infantile】** autism spending
26 their adult lives in institutions or group homes, and usually entering
27 institutions by the age of 13, the cost of caring for individuals with
28 autism and autism spectrum disorder is great, and is estimated to be
29 \$.5 billion per year in the State, solely for direct costs;

30 c. Best estimates indicate that one in 500 children born in the
31 State will be diagnosed with an autism spectrum disorder and that
32 12,000 individuals in the State have autism or an autism spectrum
33 disorder, but these numbers may be understated because current
34 diagnostic procedures lack accuracy and sensitivity for those with
35 atypical symptoms and because there is a need for epidemiological
36 data on incidence and prevalence of this disorder in the State;

37 d. While **【infantile】** autism is the third most common
38 developmental disorder and is more prevalent than Down's
39 syndrome, childhood cancer or cystic fibrosis, autism research
40 receives less than 5% of the funding of these other diseases from
41 the federal government and to date little biomedical research has
42 been done on this disorder, despite the fact that scientists consider
43 autism to be one of the most heritable of all the developmental
44 disorders and the most likely to yield to the latest scientific
45 advancements in genetics and neurology;

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 e. The lack of research was due to 40 years of neglect of autism
2 by the scientific community, arising from the formerly widespread
3 but now discredited belief that autism was an emotional disorder
4 caused by faulty parenting, and thus, few dollars were allocated to
5 researchers, leaving an entire generation of children to be
6 overlooked; however, the rapid advancements in biomedical
7 science suggest that effective treatment and a cure for autism are
8 attainable, if sufficient dollars are allocated to research so that
9 another generation of children in the State is not lost to this
10 disorder;

11 f. While promising findings in the field of autism research have
12 been made in recent years, the diverse symptoms and etiology of
13 autism require a high level of activity in the widest variety of
14 scientific fields, from genetics and neurology to neuroimaging,
15 immunology and gastroenterology, if effective treatments and a
16 cure are to be found quickly;

17 g. Other states such as New York, Connecticut and Maryland
18 have nationally recognized centers for researching and treating
19 autism that attract significant funding from private sources and the
20 National Institutes of Health, but since New Jersey lacks such
21 centers, the State is unable to attract comparable funding, despite
22 the presence of highly regarded medical facilities in the State such
23 as Robert Wood Johnson University Hospital and Hackensack
24 University Medical Center, as well as a higher education medical
25 institution such as the University of Medicine and Dentistry of New
26 Jersey;

27 h. The State's substantial pharmaceutical industry would benefit
28 from having medical centers dedicated to autism research and
29 treatment by gaining access to families for clinical trials and by
30 enabling easy collaboration between public and private scientists;
31 and

32 i. Legislation has been introduced in the United States Congress
33 which, if passed, will increase the level of federal funding for
34 biomedical research on autism; however, in order for State
35 researchers to be eligible for these dollars, funding must be made
36 available for State researchers to carry out preliminary pilot studies.
37 (cf: P.L.1999, c.105, s.2)

38

39 3. Section 3 of P.L.1999, c.105 (C.30:6D-58) is amended to read
40 as follows:

41 3. As used in this act:

42 "Autism" includes autism spectrum disorders to the extent
43 determined by the council to be appropriate.

44 "Center" means the Center of Excellence for Autism established
45 pursuant to this act.

46 "Council" means the "Governor's Council for Medical Research
47 and Treatment of **[Infantile]** Autism" established pursuant to this

1 act. **["President" means the President of the University of**
2 **Medicine and Dentistry of New Jersey.]**
3 (cf: P.L.1999, c.105, s.3)
4

5 4. Section 4 of P.L.1999, c.105 (C.30:6D-59) is amended to read
6 as follows:

7 4. a. There is established in the University of Medicine and
8 Dentistry of New Jersey, the "Governor's Council for Medical
9 Research and Treatment of **[Infantile] Autism.**" The council shall
10 be composed of **[seven] nine** members as follows: two persons to
11 be appointed by the Governor, one of whom shall be a person with a
12 diagnosis of autism or autism spectrum disorder or the family
13 member of such a person, neither of whom shall occupy a
14 leadership position in any of the organizations represented on the
15 council; one person to be appointed by the President of the
16 University of Medicine and Dentistry of New Jersey[, or his
17 designee, the director of the center, and the director of one other
18 treatment center at the University of Medicine and Dentistry of New
19 Jersey that is devoted to biomedical research on autism, to be
20 appointed by the president, all of whom shall serve as ex officio
21 members]; one person to be appointed by the Commissioner of
22 Health and Senior Services; one person to be appointed by the
23 Director of the Environmental and Occupational Health Sciences
24 Institute; and four **[public members from] persons who represent**
25 autism organizations in New Jersey as follows: one representative
26 designated by the New Jersey chapter of the Cure Autism Now
27 Foundation, one representative designated by the National Alliance
28 for Autism Research, one representative designated by **[the] The**
29 New Jersey Center for Outreach and Services for the Autism
30 Community[, Inc.], and one representative designated by the
31 **[Autism Autoimmunity Project, Inc.] Asperger Syndrome**
32 Education Network.

33 b. **[The president or his designee shall serve as chairman of] At**
34 its first meeting of each calendar year, the council shall select, by a
35 simple majority of the members present, a chairperson from among
36 its members, who shall serve as the chairperson until the first
37 meeting held in the next calendar year, at which time the same
38 person may be selected as chairperson or a new chairperson may be
39 selected in the same manner. Public members of the council shall
40 serve for three-year terms. Each member shall hold office for the
41 term of appointment and until a successor is appointed and
42 qualified. All vacancies shall be filled in the same manner as the
43 original appointment. Members appointed to fill a vacancy
44 occurring for any reason other than the expiration of the term shall
45 serve for the unexpired term only. A public member of the council
46 shall be eligible for reappointment.

1 c. Public members shall serve without compensation, but shall
2 be reimbursed for necessary expenses incurred in the performance
3 of their duties.

4 d. A majority of the members of the council shall constitute a
5 quorum, but a lesser number may hold hearings.

6 e. The council shall meet periodically at the call of the
7 chairman, but not less than four times in **[the first year in which the**
8 **center is established and not less than twice in]** each **[subsequent]**
9 calendar year.

10 f. The **[president shall appoint a salaried administrator for the**
11 **council and shall provide the council with additional administrative**
12 **staff and support as may be necessary to enable the council to carry**
13 **out its functions]** council shall select and appoint a director who
14 shall serve, at the pleasure of the council, as administrator of the
15 council. The director shall be a person qualified by training and
16 experience to perform the duties of that position. The director shall
17 be a full-time employee who shall devote his entire time to the
18 duties of the position and shall receive a salary commensurate with
19 the responsibilities thereof. The director shall serve in the State
20 unclassified service of the Civil Service.

21 (cf: P.L.1999, c.105, s.4)

22

23 5. Section 5 of P.L.1999, c.105 (C.30:6D-60) is amended to read
24 as follows:

25 5. a. The **[University of Medicine and Dentistry of New Jersey,**
26 **upon the recommendation of the]** council**[,]** shall make awards of
27 grants and contracts to public and nonprofit private entities to pay
28 all or part of the cost of planning, establishing, improving and
29 providing basic operating support for a Center of Excellence for
30 Autism in the State where basic and applied biomedical research,
31 diagnosis and treatment for autism shall take place.

32 b. The council shall define the scope of the programs to be
33 undertaken at the center with the understanding that the center shall
34 conduct:

35 (1) basic and clinical research into the cause, diagnosis, early
36 detection, prevention, control and treatment of autism, including
37 research in the fields of developmental neurobiology, genetics,
38 **[psychopharmacology]** psychopharmacology, neuroimaging,
39 immunology, infectious diseases, gastroenterology and
40 endocrinology;

41 (2) training programs on biomedical treatments, diagnosis and
42 prevention for autism for physicians, scientists and other health care
43 and allied health care professionals in the State; and

44 (3) information and continuing educational programs on the
45 latest advances in biomedical research on autism for physicians and
46 other health care and allied health care professionals who provide
47 care for patients with autism in the State.

1 c. The center may carry out programs to make individuals in the
2 State aware of opportunities to participate as subjects in research
3 conducted by the center. The program may provide fees to these
4 subjects. The program may, in accordance with guidelines
5 established by the council, provide to these subjects health care,
6 referrals for health and other services and such incidental services
7 as will facilitate the participation of individuals as subjects.

8 d. The center may provide stipends for health care professionals
9 enrolled in training programs established under paragraph (2) of
10 subsection b. of this section.

11 e. The council may require the periodic preparation of reports on
12 the activities of the center and the submission of the reports to the
13 council.

14 f. The center shall use the facilities of a single medical facility
15 or higher education medical institution, or be formed from a
16 consortium of cooperating facilities or institutions, and shall meet
17 any requirements as may be prescribed by the council, with the
18 understanding that the work carried out at the center shall be
19 comprehensive and fully collaborative.

20 (cf: P.L.1999, c.105, s.5)

21

22 6. Section 6 of P.L.1999, c.105 (C.30:6D-61) is amended to read
23 as follows:

24 6. The council shall provide guidance and direction to the
25 director of the council, who shall be responsible for the following
26 duties:

27 a. Carry out a program to provide information and education on
28 advances in the diagnosis and biomedical treatment of autism to
29 families in the State with autistic members and to the general
30 public~~].~~;

31 b. Establish a five-member Scientific Advisory Committee
32 whose members shall serve at the pleasure of the council. The
33 members of the committee shall include: three biomedical research
34 scientists with demonstrated achievements in biomedical research
35 relating to autism; and two medical clinicians whose practice is
36 primarily devoted to the treatment of individuals with autism. The
37 committee shall identify and make recommendations to the council
38 regarding grants for the most promising pilot studies for biomedical
39 research, diagnosis and treatment for autism and autism spectrum
40 disorders ~~and establish the procedures for soliciting research~~
41 ~~proposals and applying for grants for pilot studies.~~];

42 c. ~~Select~~ Present the recommendations of the Scientific
43 Advisory Committee to the council, which shall select the final
44 grants for pilot studies ~~based on recommendations of the Scientific~~
45 ~~Advisory Committee.~~];

46 d. Establish mechanisms to use the results of biomedical
47 research on autism and autism spectrum disorders, conducted at the

1 center and through the pilot studies in the development of policies
2 and programs to improve the outcomes of individuals in the State
3 with these disorders[.];

4 e. Establish a mechanism for the sharing of information among
5 researchers and clinicians in the State conducting biomedical
6 research on autism and autism spectrum disorders[.];

7 f. Provide for a mechanism that would permit the public to
8 obtain information on the existing and planned programs and
9 activities being conducted through the center and the pilot studies,
10 and the council to receive comments from the public regarding
11 these programs and activities[.];

12 g. Continually seek and apply for funding to supplement and
13 eventually replace the moneys provided pursuant to subsection f. of
14 R.S.39:5-41; and

15 h. Report not later than March 1 of each year to the Governor
16 and the Legislature on the status of the Center of Excellence for
17 Autism and other activities of the council.

18 (cf: P.L.1999, c.105, s.6)

19

20 7. (New section) Whenever the term "Governor's Council for
21 Medical Research and Treatment of Infantile Autism" occurs or any
22 reference is made thereto in any law, contract or document, the
23 same shall be deemed to mean or refer to the "Governor's Council
24 for Medical Research and Treatment of Autism."

25

26 8. Section 1 of P.L.2001, c.338 (C.30:6D-62.1) is amended to
27 read as follows:

28 1. Beginning in Fiscal Year 2001 and in each fiscal year
29 thereafter, the Governor shall recommend and the Legislature shall
30 appropriate \$1,500,000 from the General Fund to the Governor's
31 Council for Medical Research and Treatment of **[Infantile]** Autism
32 established pursuant to P.L.1999, c.105 (C.30:6D-56 et seq.).

33 (cf: P.L.2001, c.338, s.1)

34

35 9. Section 1 of P.L.2003, c.144 (C.30:6D-62.2) is amended to
36 read as follows:

37 1. a. There is established in the Department of the Treasury a
38 nonlapsing fund to be known as the "Autism Medical Research and
39 Treatment Fund." This fund shall be the repository for moneys
40 provided pursuant to subsection f. of R.S.39:5-41. Moneys
41 deposited in the fund, and any interest earned thereon, shall be
42 allocated to the Governor's Council for Medical Research and
43 Treatment of **[Infantile]** Autism established pursuant to P.L.1999,
44 c.105 (C.30:6D-56 et seq.), to support grants and contracts awarded
45 under subsection a. of section 5 of P.L.1999, c.105 (C.30:6D-60),
46 and any grants for pilot studies selected under subsection c. of
47 section 6 of that P.L.1999, c.105 (C.30:6D-61), provided that, if

1 federal funds are available for the purpose, the grantee or contractor
2 shall, as a condition of receiving any such grant or contract from the
3 fund, apply for an amount of federal funds in support of that grant
4 or contract.

5 b. Any costs incurred by the department in the collection or
6 administration of the fund may be deducted from the funds
7 deposited therein, as determined by the Director of the Division of
8 Budget and Accounting.
9 (cf: P.L.2003, c.144, s.1)

10

11 10. This act shall take effect immediately.

12

13

14

STATEMENT

15

16 This bill renames the Governor's Council for Medical Research
17 and Treatment of Infantile Autism, which was established pursuant
18 to P.L.1999, c.105 (N.J.S.A.30:6D-56 et seq.), as the Governor's
19 Council for Medical Research and Treatment of Autism, and retitles
20 that statute accordingly as the "New Jersey Autism Biomedical
21 Research Act."

22 The bill also:

23 • expands the membership of the council from seven to nine
24 members and changes its composition to include:

25 -- two persons appointed by the Governor, one of whom is a
26 person with a diagnosis of autism or autism spectrum disorder or
27 the family member of such a person, neither of whom occupies a
28 leadership position in any of the organizations represented on the
29 council;

30 -- one person appointed by the President of UMDNJ;

31 -- one person appointed by the Commissioner of Health and
32 Senior Services;

33 -- one person appointed by the Director of the Environmental
34 and Occupational Health Sciences Institute; and

35 -- four persons who represent autism organizations in New
36 Jersey as provided in the current statute (updating the names of
37 those organizations);

38 • directs the council, at its first meeting of each calendar year, to
39 select, by a simple majority of the members present, a
40 chairperson from among its members, who will serve as the
41 chairperson until the first meeting held in the next calendar year,
42 at which time the same person may be selected as chairperson or
43 a new chairperson may be selected in the same manner;

44 • provides for the appointment by the council of a director to serve
45 as administrator of the council, who is to be a full-time employee
46 and serve in the State unclassified service of the Civil Service;
47 and

48 • requires the director of the council to (in addition to the duties

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9

1 enumerated in the current statute):

2 -- continually seek and apply for funding to supplement and
3 eventually replace the moneys provided to the council pursuant to
4 subsection f. of N.J.S.A.39:5-41 (through a \$1 surcharge on motor
5 vehicle fines and penalties); and

6 -- report not later than March 1 of each year to the Governor and
7 the Legislature on the status of the Center of Excellence for Autism
8 and other activities of the council.

ASSEMBLY HEALTH AND SENIOR SERVICES COMMITTEE

STATEMENT TO

[First Reprint]

SENATE, No. 698

with committee amendments

STATE OF NEW JERSEY

DATED: MARCH 5, 2007

The Assembly Health and Senior Services Committee reports favorably and with amendments Senate Bill No. 698 (1R).

As amended by the committee, this bill renames the Governor's Council for Medical Research and Treatment of Infantile Autism, established pursuant to N.J.S.A.30:6D-56 et seq., to delete the term "infantile." The title of that law is likewise changed to the "New Jersey Autism Biomedical Research Act."

The bill also makes the following changes:

- expands the council membership from seven to 13, to include:
 - two persons appointed by the Governor, one of whom is a person with a diagnosis of autism or autism spectrum disorder or the family member of such a person, neither of whom occupies a leadership position in an organization represented on the council;
 - one person appointed by the President of the Senate and one by the Speaker of the General Assembly;
 - three persons appointed by the President of the University of Medicine and Dentistry of New Jersey;
 - one person appointed by the Commissioner of Health and Senior Services;
 - one person appointed by the Director of the Environmental and Occupational Health Sciences Institute;
 - three persons representing specified autism organizations in New Jersey (Autism Speaks, The New Jersey Center for Outreach and Services for the Autism Community, and the Asperger Syndrome Education Network); and
 - one person, to be selected by the Governor, who is a member of an advocacy organization not already named in the bill.
- directs the council, at its first meeting of each calendar year, to select a chairperson from among its members to serve until the first meeting held the following calendar year;
- deletes the provision whereby the council president appoints a salaried administrator, and instead provides for the appointment by the council of a director to serve as a full-time administrator in an

unclassified Civil Service capacity; and

- requires the director (in addition to the duties enumerated in the current law) to continually seek and apply for funding to supplement and eventually replace the moneys provided to the council through a \$1 surcharge on motor vehicle fines and penalties pursuant to R.S.39:5-41, and report by March 1 of each year to the Governor and the Legislature on the status of the Center of Excellence for Autism and other activities of the council.

As reported by the committee, this bill is identical to Assembly Bill No. 4054 ACA (Voss/Schaer/Roberts/McKeon), which the committee also reported on this date.

COMMITTEE AMENDMENTS

The committee amendments to the bill:

- update the names of organizations represented on the council, and provide that one member is to be from an advocacy organization not already named in the bill;
- add a member to the council to be appointed by the President of the Senate and a member to be appointed by the Speaker of the General Assembly; and
- include a reference to P.L.1991, c.164 (C.52:14-19.1), concerning the council reports to the Legislature.

ASSEMBLY BUDGET COMMITTEE

STATEMENT TO

[Third Reprint]

SENATE, No. 698

with committee amendments

STATE OF NEW JERSEY

DATED: MARCH 12, 2007

The Assembly Budget Committee reports favorably Senate Bill No. 698 (3R), with committee amendments.

The bill, as amended, renames the Governor's Council for Medical Research and Treatment of Infantile Autism, established pursuant to N.J.S.A.30:6D-56 et seq., to delete the term "infantile." The title of that law is likewise changed to the "New Jersey Autism Biomedical Research Act."

The bill transfers the "Governor's Council for Medical Research and Treatment of Autism" from the University of Medicine and Dentistry of New Jersey to the Department of Health and Senior Services.

The bill expands the council membership from seven to 14, to include:

-- seven persons appointed by the Governor:

two of whom are persons who do not occupy a leadership position in an organization represented on the council, of whom one is a person with a diagnosis of autism or autism spectrum disorder or the family member of such a person,

four of whom shall be appointed in consultation with the presidents of academic institutions in this State that are engaged in autism research, and

one of whom be a representative of a health care organization with demonstrated clinical expertise in the evaluation and treatment of autism spectrum disorders ;

-- two Legislative appointments, one person appointed by the President of the Senate and one by the Speaker of the General Assembly;

-- one person appointed by the Commissioner of Health and Senior Services; and

-- four persons, appointed by the Governor, who represent autism organizations in New Jersey, each of whom represents no more than one such organization.

The bill directs the council, at its first meeting of each calendar year, to select a chairperson from among its members to serve until the first meeting held the following calendar year;

The bill removes from law a provision whereby the council president appoints a salaried administrator, and instead provides for the appointment by the Commissioner of Health and Senior Services, in consultation with the council, of a director of the council. and

The bill requires the director (in addition to the duties enumerated in the current law) to continually seek and apply for funding to supplement and eventually replace the moneys provided to the council through a \$1 surcharge on motor vehicle fines and penalties pursuant to R.S.39:5-41, and report by March 1 of each year to the Governor and the Legislature on the status of the Center of Excellence for Autism and other activities of the council.

FISCAL IMPACT:

The bill has not yet been certified for a fiscal note, nor has the Department indicated any resulting costs at this time. The Office of Legislative Services has no information available to it which would allow it to estimate the costs of the bill.

COMMITTEE AMENDMENTS:

The amendments: clarify that the four council members who represent autism organizations in New Jersey will be appointed by the Governor; and delete a provision authorizing the council to appoint a director to serve as a full-time administrator in the unclassified service of the Civil Service and instead provides for the appointment by the Commissioner of Health and Senior Services, in consultation with the council, of a director of the council.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE, No. 698

STATE OF NEW JERSEY

DATED: OCTOBER 16, 2006

The Senate Health, Human Services and Senior Citizens Committee reports favorably Senate Bill No. 698.

This bill renames the Governor's Council for Medical Research and Treatment of Infantile Autism, established pursuant to N.J.S.A.30:6D-56 et seq., to delete the term "infantile." The title of the law is likewise changed to the "New Jersey Autism Biomedical Research Act."

The bill also makes the following changes:

- expands the council membership from seven to nine, to include two persons appointed by the Governor, one of whom is a person with a diagnosis of autism or autism spectrum disorder or the family member of such a person, neither of whom occupies a leadership position in an organization represented on the council;
- changes the composition of the council to include one person appointed by the President of UMDNJ, one person appointed by the Commissioner of Health and Senior Services, and one person appointed by the Director of the Environmental and Occupational Health Sciences Institute;
- updates the names of organizations represented by four of the council members;
- directs the council, at its first meeting of each calendar year, to select a chairperson from among its members to serve until the first meeting held the following calendar year;
- deletes the provision whereby the council president appoints a salaried administrator, and instead provides for the appointment by the council of a director to serve as a full-time administrator in an unclassified Civil Service capacity; and
- requires the director (in addition to the duties enumerated in the current statute) to continually seek and apply for funding to supplement and eventually replace the moneys provided to the council through a \$1 surcharge on motor vehicle fines and penalties, and report by March 1 of each year to the Governor and the Legislature on the status of the Center of Excellence for Autism and other activities of the council.

This bill was pre-filed for introduction in the 2006-2007 session pending technical review. As reported, the bill includes the changes required by technical review, which has been performed.

STATEMENT TO

SENATE, No. 698

with Senate Floor Amendments
(Proposed By Senator WEINBERG)

ADOPTED: DECEMBER 4, 2006

These amendments add two additional members to the Governor's Council for Medical Research and Treatment of Infantile Autism. The President of UMDNJ would appoint three members instead of one member. The council membership will total 11.

STATEMENT TO
[Second Reprint]
SENATE, No. 698

with Assembly Floor Amendments
(Proposed By Assemblywoman Voss)

ADOPTED: MARCH 8, 2007

These amendments:

- incorporate updated information about the rate of autism among children in New Jersey within the findings and declarations language of section 2 of P.L.1999, c.105 (C.30:6D-57);
- establish the “Governor’s Council for Medical Research and Treatment of Autism” in the Department of Health and Senior Services, thereby transferring it from the University of Medicine and Dentistry of New Jersey (UMDNJ) in which it was established under section 4 of P.L.1999, c.105 (C.30:6D-59);
- increase the number of gubernatorial appointments to the council from two to seven members, and require that four of those be appointed in consultation with the presidents of academic institutions in this State that are engaged in autism research and one be a representative of a health care organization with demonstrated clinical expertise in the evaluation and treatment of autism spectrum disorders;
- delete the requirement that three members of the council be appointed by the President of UMDNJ;
- delete the requirement that a member of the council be appointed by the Director of the Environmental and Occupational Health Sciences Institute; and
- delete references to the names of specific autism organizations represented on the council and provide, instead, that the council is to include four persons who represent autism organizations in New Jersey, each of whom represents no more than one such organization.

ASSEMBLY, No. 4054

STATE OF NEW JERSEY

212th LEGISLATURE

INTRODUCED FEBRUARY 26, 2007

Sponsored by:

Assemblywoman JOAN M. VOSS

District 38 (Bergen)

Assemblyman GARY S. SCHAER

District 36 (Bergen, Essex and Passaic)

Assemblyman JOSEPH J. ROBERTS, JR.

District 5 (Camden and Gloucester)

Assemblyman JOHN F. MCKEON

District 27 (Essex)

Co-Sponsored by:

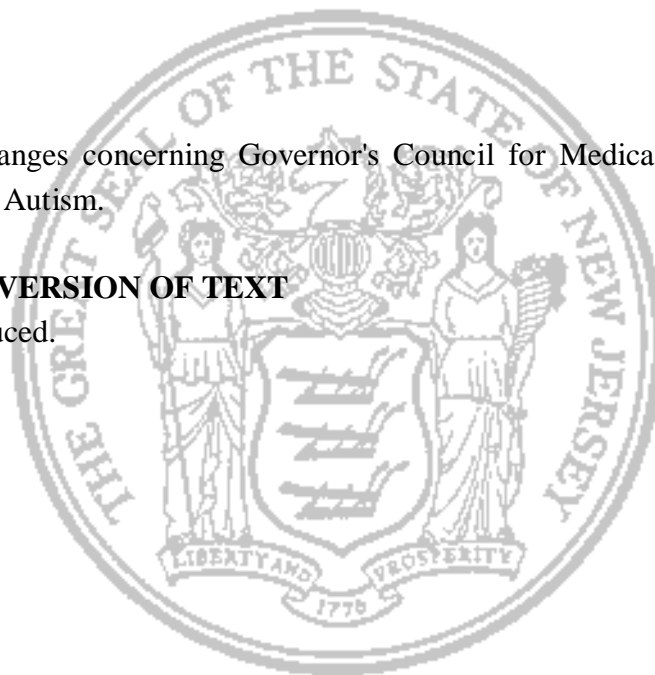
**Assemblywoman Vainieri Huttie, Assemblymen Whelan, Mayer,
Assemblywoman Greenstein, Assemblymen Wolfe, Holzapfel, Conaway,
Thompson, Scalera, Epps, Assemblywomen Quigley, Stender,
Assemblymen Munoz, Manzo and Gordon**

SYNOPSIS

Makes changes concerning Governor's Council for Medical Research and Treatment of Autism.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 3/6/2007)

1 AN ACT concerning medical research and treatment of autism,
2 amending and supplementing P.L.1999, c.105 and amending
3 P.L.2001, c.338 and P.L.2003, c.144.

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

7
8 1. Section 1 of P.L.1999, c.105 (C.30:6D-56) is amended to read
9 as follows:

10 1. This act shall be known and may be cited as the "New Jersey
11 **【Infantile】** Autism Biomedical Research Act."
12 (cf: P.L.1999, c.105, s.1)

13
14 2. Section 2 of P.L.1999, c.105 (30:6D-57) is amended to read
15 as follows:

16 2. The Legislature finds and declares that:

17 a. **【Infantile autism】** Autism and autism spectrum disorders are
18 biologically-based developmental disorders which cause severe
19 impairments in language and communication and generally manifest
20 in young children sometime during the first two years of life, and
21 the devastation caused by autism lasts a lifetime due to the
22 emotional and financial distress that families experience from the
23 intense support which most individuals with autism require
24 throughout their lives;

25 b. With three quarters of those with **【infantile】** autism spending
26 their adult lives in institutions or group homes, and usually entering
27 institutions by the age of 13, the cost of caring for individuals with
28 autism and autism spectrum disorder is great, and is estimated to be
29 \$.5 billion per year in the State, solely for direct costs;

30 c. Best estimates indicate that one in 500 children born in the
31 State will be diagnosed with an autism spectrum disorder and that
32 12,000 individuals in the State have autism or an autism spectrum
33 disorder, but these numbers may be understated because current
34 diagnostic procedures lack accuracy and sensitivity for those with
35 atypical symptoms and because there is a need for epidemiological
36 data on incidence and prevalence of this disorder in the State;

37 d. While **【infantile】** autism is the third most common
38 developmental disorder and is more prevalent than Down's
39 syndrome, childhood cancer or cystic fibrosis, autism research
40 receives less than 5% of the funding of these other diseases from
41 the federal government and to date little biomedical research has
42 been done on this disorder, despite the fact that scientists consider
43 autism to be one of the most heritable of all the developmental
44 disorders and the most likely to yield to the latest scientific
45 advancements in genetics and neurology;

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 e. The lack of research was due to 40 years of neglect of autism
2 by the scientific community, arising from the formerly widespread
3 but now discredited belief that autism was an emotional disorder
4 caused by faulty parenting, and thus, few dollars were allocated to
5 researchers, leaving an entire generation of children to be
6 overlooked; however, the rapid advancements in biomedical
7 science suggest that effective treatment and a cure for autism are
8 attainable, if sufficient dollars are allocated to research so that
9 another generation of children in the State is not lost to this
10 disorder;

11 f. While promising findings in the field of autism research have
12 been made in recent years, the diverse symptoms and etiology of
13 autism require a high level of activity in the widest variety of
14 scientific fields, from genetics and neurology to neuroimaging,
15 immunology and gastroenterology, if effective treatments and a
16 cure are to be found quickly;

17 g. Other states such as New York, Connecticut and Maryland
18 have nationally recognized centers for researching and treating
19 autism that attract significant funding from private sources and the
20 National Institutes of Health, but since New Jersey lacks such
21 centers, the State is unable to attract comparable funding, despite
22 the presence of highly regarded medical facilities in the State such
23 as Robert Wood Johnson University Hospital and Hackensack
24 University Medical Center, as well as a higher education medical
25 institution such as the University of Medicine and Dentistry of New
26 Jersey;

27 h. The State's substantial pharmaceutical industry would benefit
28 from having medical centers dedicated to autism research and
29 treatment by gaining access to families for clinical trials and by
30 enabling easy collaboration between public and private scientists;
31 and

32 i. Legislation has been introduced in the United States Congress
33 which, if passed, will increase the level of federal funding for
34 biomedical research on autism; however, in order for State
35 researchers to be eligible for these dollars, funding must be made
36 available for State researchers to carry out preliminary pilot studies.
37 (cf: P.L.1999, c.105, s.2)

38
39 3. Section 3 of P.L.1999, c.105 (C.30:6D-58) is amended to read
40 as follows:

41 3. As used in this act:

42 "Autism" includes autism spectrum disorders to the extent
43 determined by the council to be appropriate.

44 "Center" means the Center of Excellence for Autism established
45 pursuant to this act.

46 "Council" means the "Governor's Council for Medical Research
47 and Treatment of **【Infantile】** Autism" established pursuant to this
48 act. **【**"President" means the President of the University of Medicine

1 and Dentistry of New Jersey.]

2 (cf: P.L.1999, c.105, s.3)

3

4 4. Section 4 of P.L.1999, c.105 (C.30:6D-59) is amended to read
5 as follows:

6 4. a. There is established in the University of Medicine and
7 Dentistry of New Jersey, the "Governor's Council for Medical
8 Research and Treatment of **【Infantile】** Autism." The council shall
9 be composed of **【seven】** 11 members as follows: two persons to be
10 appointed by the Governor, one of whom shall be a person with a
11 diagnosis of autism or autism spectrum disorder or the family
12 member of such a person, neither of whom shall occupy a
13 leadership position in any of the organizations represented on the
14 council; three persons to be appointed by the President of the
15 University of Medicine and Dentistry of New Jersey【, or his
16 designee, the director of the center, and the director of one other
17 treatment center at the University of Medicine and Dentistry of New
18 Jersey that is devoted to biomedical research on autism, to be
19 appointed by the president, all of whom shall serve as ex officio
20 members】; one person to be appointed by the Commissioner of
21 Health and Senior Services; one person to be appointed by the
22 Director of the Environmental and Occupational Health Sciences
23 Institute; and four **【public members from】** persons who represent
24 autism organizations in New Jersey as follows: one representative
25 designated by the New Jersey chapter of the Cure Autism Now
26 Foundation, one representative designated by the National Alliance
27 for Autism Research, one representative designated by **【the】** The
28 New Jersey Center for Outreach and Services for the Autism
29 Community【, Inc.】, and one representative designated by the
30 **【Autism Autoimmunity Project, Inc.】** Asperger Syndrome
31 Education Network.

32 b. **【The president or his designee shall serve as chairman of】** At
33 its first meeting of each calendar year, the council shall select, by a
34 simple majority of the members present, a chairperson from among
35 its members, who shall serve as the chairperson until the first
36 meeting held in the next calendar year, at which time the same
37 person may be selected as chairperson or a new chairperson may be
38 selected in the same manner. Public members of the council shall
39 serve for three-year terms. Each member shall hold office for the
40 term of appointment and until a successor is appointed and
41 qualified. All vacancies shall be filled in the same manner as the
42 original appointment. Members appointed to fill a vacancy
43 occurring for any reason other than the expiration of the term shall
44 serve for the unexpired term only. A public member of the council
45 shall be eligible for reappointment.

46 c. Public members shall serve without compensation, but shall
47 be reimbursed for necessary expenses incurred in the performance

1 of their duties.

2 d. A majority of the members of the council shall constitute a
3 quorum, but a lesser number may hold hearings.

4 e. The council shall meet periodically at the call of the
5 chairman, but not less than four times in [the first year in which the
6 center is established and not less than twice in] each [subsequent]
7 calendar year.

8 f. The [president shall appoint a salaried administrator for the
9 council and shall provide the council with additional administrative
10 staff and support as may be necessary to enable the council to carry
11 out its functions] council shall select and appoint a director who
12 shall serve, at the pleasure of the council, as administrator of the
13 council. The director shall be a person qualified by training and
14 experience to perform the duties of that position. The director shall
15 be a full-time employee who shall devote his entire time to the
16 duties of the position and shall receive a salary commensurate with
17 the responsibilities thereof. The director shall serve in the State
18 unclassified service of the Civil Service.

19 (cf: P.L.1999, c.105, s.4)

20

21 5. Section 5 of P.L.1999, c.105 (C.30:6D-60) is amended to read
22 as follows:

23 5. a. The [University of Medicine and Dentistry of New Jersey,
24 upon the recommendation of the] council[,] shall make awards of
25 grants and contracts to public and nonprofit private entities to pay
26 all or part of the cost of planning, establishing, improving and
27 providing basic operating support for a Center of Excellence for
28 Autism in the State where basic and applied biomedical research,
29 diagnosis and treatment for autism shall take place.

30 b. The council shall define the scope of the programs to be
31 undertaken at the center with the understanding that the center shall
32 conduct:

33 (1) basic and clinical research into the cause, diagnosis, early
34 detection, prevention, control and treatment of autism, including
35 research in the fields of developmental neurobiology, genetics,
36 [psychopharmacology] psychopharmacology, neuroimaging,
37 immunology, infectious diseases, gastroenterology and
38 endocrinology;

39 (2) training programs on biomedical treatments, diagnosis and
40 prevention for autism for physicians, scientists and other health care
41 and allied health care professionals in the State; and

42 (3) information and continuing educational programs on the
43 latest advances in biomedical research on autism for physicians and
44 other health care and allied health care professionals who provide
45 care for patients with autism in the State.

46 c. The center may carry out programs to make individuals in the
47 State aware of opportunities to participate as subjects in research

1 conducted by the center. The program may provide fees to these
2 subjects. The program may, in accordance with guidelines
3 established by the council, provide to these subjects health care,
4 referrals for health and other services and such incidental services
5 as will facilitate the participation of individuals as subjects.

6 d. The center may provide stipends for health care professionals
7 enrolled in training programs established under paragraph (2) of
8 subsection b. of this section.

9 e. The council may require the periodic preparation of reports on
10 the activities of the center and the submission of the reports to the
11 council.

12 f. The center shall use the facilities of a single medical facility
13 or higher education medical institution, or be formed from a
14 consortium of cooperating facilities or institutions, and shall meet
15 any requirements as may be prescribed by the council, with the
16 understanding that the work carried out at the center shall be
17 comprehensive and fully collaborative.

18 (cf: P.L.1999, c.105, s.5)

19

20 6. Section 6 of P.L.1999, c.105 (C.30:6D-61) is amended to read
21 as follows:

22 6. The council shall provide guidance and direction to the
23 director of the council, who shall be responsible for the following
24 duties:

25 a. Carry out a program to provide information and education on
26 advances in the diagnosis and biomedical treatment of autism to
27 families in the State with autistic members and to the general
28 public~~].~~];

29 b. Establish a five-member Scientific Advisory Committee
30 whose members shall serve at the pleasure of the council. The
31 members of the committee shall include: three biomedical research
32 scientists with demonstrated achievements in biomedical research
33 relating to autism; and two medical clinicians whose practice is
34 primarily devoted to the treatment of individuals with autism. The
35 committee shall identify and make recommendations to the council
36 regarding grants for the most promising pilot studies for biomedical
37 research, diagnosis and treatment for autism and autism spectrum
38 disorders ~~and establish the procedures for soliciting research~~
39 ~~proposals and applying for grants for pilot studies.~~];

40 c. ~~Select~~ Present the recommendations of the Scientific
41 Advisory Committee to the council, which shall select the final
42 grants for pilot studies ~~based on recommendations of the Scientific~~
43 ~~Advisory Committee.~~];

44 d. Establish mechanisms to use the results of biomedical
45 research on autism and autism spectrum disorders, conducted at the
46 center and through the pilot studies in the development of policies
47 and programs to improve the outcomes of individuals in the State

1 with these disorders[.];

2 e. Establish a mechanism for the sharing of information among
3 researchers and clinicians in the State conducting biomedical
4 research on autism and autism spectrum disorders[.];

5 f. Provide for a mechanism that would permit the public to
6 obtain information on the existing and planned programs and
7 activities being conducted through the center and the pilot studies,
8 and the council to receive comments from the public regarding
9 these programs and activities[.];

10 g. Continually seek and apply for funding to supplement and
11 eventually replace the moneys provided pursuant to subsection f. of
12 R.S.39:5-41; and

13 h. Report not later than March 1 of each year to the Governor
14 and the Legislature on the status of the Center of Excellence for
15 Autism and other activities of the council.

16 (cf: P.L.1999, c.105, s.6)

17

18 7. (New section) Whenever the term "Governor's Council for
19 Medical Research and Treatment of Infantile Autism" occurs or any
20 reference is made thereto in any law, contract or document, the
21 same shall be deemed to mean or refer to the "Governor's Council
22 for Medical Research and Treatment of Autism."

23

24 8. Section 1 of P.L.2001, c.338 (C.30:6D-62.1) is amended to
25 read as follows:

26 1. Beginning in Fiscal Year 2001 and in each fiscal year
27 thereafter, the Governor shall recommend and the Legislature shall
28 appropriate \$1,500,000 from the General Fund to the Governor's
29 Council for Medical Research and Treatment of **[Infantile]** Autism
30 established pursuant to P.L.1999, c.105 (C.30:6D-56 et seq.).

31 (cf: P.L.2001, c.338, s.1)

32

33 9. Section 1 of P.L.2003, c.144 (C.30:6D-62.2) is amended to
34 read as follows:

35 1. a. There is established in the Department of the Treasury a
36 nonlapsing fund to be known as the "Autism Medical Research and
37 Treatment Fund." This fund shall be the repository for moneys
38 provided pursuant to subsection f. of R.S.39:5-41. Moneys
39 deposited in the fund, and any interest earned thereon, shall be
40 allocated to the Governor's Council for Medical Research and
41 Treatment of **[Infantile]** Autism established pursuant to P.L.1999,
42 c.105 (C.30:6D-56 et seq.), to support grants and contracts awarded
43 under subsection a. of section 5 of P.L.1999, c.105 (C.30:6D-60),
44 and any grants for pilot studies selected under subsection c. of
45 section 6 of that P.L.1999, c.105 (C.30:6D-61), provided that, if
46 federal funds are available for the purpose, the grantee or contractor
47 shall, as a condition of receiving any such grant or contract from the
48 fund, apply for an amount of federal funds in support of that grant

1 or contract.

2 b. Any costs incurred by the department in the collection or
3 administration of the fund may be deducted from the funds
4 deposited therein, as determined by the Director of the Division of
5 Budget and Accounting.

6 (cf: P.L.2003, c.144, s.1)

7

8 10. This act shall take effect immediately.

9

10

11

STATEMENT

12

13 This bill renames the Governor's Council for Medical Research
14 and Treatment of Infantile Autism, established pursuant to
15 N.J.S.A.30:6D-56 et seq., to delete the term "infantile." The title of
16 the law is likewise changed to the "New Jersey Autism Biomedical
17 Research Act."

18 The bill also makes the following changes:

- 19 • expands the council membership from seven to nine, to include
20 two persons appointed by the Governor, one of whom is a person
21 with a diagnosis of autism or autism spectrum disorder or the
22 family member of such a person, neither of whom occupies a
23 leadership position in an organization represented on the council;
- 24 • changes the composition of the council to include three persons
25 appointed by the President of UMDNJ, one person appointed by
26 the Commissioner of Health and Senior Services, and one person
27 appointed by the Director of the Environmental and Occupational
28 Health Sciences Institute;
- 29 • updates the names of organizations represented by four of the
30 council members;
- 31 • directs the council, at its first meeting of each calendar year, to
32 select a chairperson from among its members to serve until the
33 first meeting held the following calendar year;
- 34 • deletes the provision whereby the council president appoints a
35 salaried administrator, and instead provides for the appointment
36 by the council of a director to serve as a full-time administrator in
37 an unclassified Civil Service capacity; and
- 38 • requires the director (in addition to the duties enumerated in the
39 current statute) to continually seek and apply for funding to
40 supplement and eventually replace the moneys provided to the
41 council through a \$1 surcharge on motor vehicle fines and
42 penalties, and report by March 1 of each year to the Governor and
43 the Legislature on the status of the Center of Excellence for
44 Autism and other activities of the council.

ASSEMBLY HEALTH AND SENIOR SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4054

with committee amendments

STATE OF NEW JERSEY

DATED: MARCH 5, 2007

The Assembly Health and Senior Services Committee reports favorably and with amendments Assembly Bill No. 4054.

As amended by the committee, this bill renames the Governor's Council for Medical Research and Treatment of Infantile Autism, established pursuant to N.J.S.A.30:6D-56 et seq., to delete the term "infantile." The title of that law is likewise changed to the "New Jersey Autism Biomedical Research Act."

The bill also makes the following changes:

- expands the council membership from seven to 13, to include:
 - two persons appointed by the Governor, one of whom is a person with a diagnosis of autism or autism spectrum disorder or the family member of such a person, neither of whom occupies a leadership position in an organization represented on the council;
 - one person appointed by the President of the Senate and one by the Speaker of the General Assembly;
 - three persons appointed by the President of the University of Medicine and Dentistry of New Jersey;
 - one person appointed by the Commissioner of Health and Senior Services;
 - one person appointed by the Director of the Environmental and Occupational Health Sciences Institute;
 - three persons representing specified autism organizations in New Jersey (Autism Speaks, The New Jersey Center for Outreach and Services for the Autism Community, and the Asperger Syndrome Education Network); and
 - one person, to be selected by the Governor, who is a member of an advocacy organization not already named in the bill.
- directs the council, at its first meeting of each calendar year, to select a chairperson from among its members to serve until the first meeting held the following calendar year;
- deletes the provision whereby the council president appoints a salaried administrator, and instead provides for the appointment by the council of a director to serve as a full-time administrator in an unclassified Civil Service capacity; and
- requires the director (in addition to the duties enumerated in the

current law) to continually seek and apply for funding to supplement and eventually replace the moneys provided to the council through a \$1 surcharge on motor vehicle fines and penalties pursuant to R.S.39:5-41, and report by March 1 of each year to the Governor and the Legislature on the status of the Center of Excellence for Autism and other activities of the council.

As reported by the committee, this bill is identical to Senate Bill No. 698 (1R) ACA (Weinberg/Vitale), which the committee also reported on this date.

COMMITTEE AMENDMENTS

The committee amendments to the bill:

- update the names of organizations represented on the council, and provide that one member is to be from an advocacy organization not already named in the bill;
- add a member to the council to be appointed by the President of the Senate and a member to be appointed by the Speaker of the General Assembly; and
- include a reference to P.L.1991, c.164 (C.52:14-19.1), concerning the council reports to the Legislature.

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Sep-12-07 Governor Corzine Signs Bills On Autism

NEWS RELEASE

Governor Jon S. Corzine
September 12, 2007

FOR MORE INFORMATION:

Press Office
609-777-2600

GOVERNOR CORZINE SIGNS BILLS ON AUTISM

West Windsor - Governor Jon S. Corzine today signed a package of seven bills relating to autism spectrum disorders. These disorders are often characterized by substantial impairments in social interaction and communication and the presence of unusual behaviors and interests.

“Today, we are enhancing New Jersey’s pioneer status in the fight against autism spectrum disorders by bolstering our arsenal of programs, training, education, and research,” said Governor Jon S. Corzine. “This is an opportunity for New Jersey to become a model for other states in researching the nature of autism and its causes as well as in treating those with these disorders.

“More importantly, through these initiatives, we will be enabling those impacted by autism spectrum disorders to function as independent, productive, and empowered individuals.”

The rate and diagnosis of autism spectrum disorders in New Jersey is disproportionately high. While experts estimate the national rate has increased to about 1 in 150 children, the incidence in New Jersey is approximately 1 in 95.

“With new studies showing New Jersey with the highest reported autism rates in the country, it is critically important that the state do all it can to help the growing number of individuals and families confronting autism spectrum

disorders,” said Assembly Speaker Joseph J. Roberts, Jr. (D-Camden) who championed the legislative effort to improve the detection, treatment and awareness of autism in New Jersey.

“For families whose loved ones are locked in the grasp of this disorder, today’s action sends a reassuring message of hope that New Jersey is working to do more to improve its safety net of services and care,” Roberts said. “These measures will enable New Jersey to address the startling number of children being diagnosed with autism and they will allow us to extend a helping hand to countless autistic young adults and others who have aged out of the state’s special education system.”

“A diagnosis of autism or developmental disability presents real challenges for parents and caregivers,” said Senator Ellen Karcher (D-Mercer/Monmouth). “While the medical community seeks to find answers to the causes of autism and developmental disability, states have an obligation to promote programs which help those living with the disability. These new lifesaving laws will help families deal with the hardships of caring for individuals with autism.”

“According to federal statistics, New Jersey has the highest number of autism cases in the nation,” said Senator Loretta Weinberg, (D-Bergen). “We are still learning about the autism spectrum disorders, but while we are learning, we must be able to provide much-needed assistance to families living with autism. As the number of residents living with autism increases, we must have the resources in place to provide them with support programs and work to find ways to decrease the incidence of autism in New Jersey.”

The Governor signed A4055/S2558, providing for teacher training in awareness and instruction methods for students with autism and other developmental disabilities for candidates for teaching certificates, current teachers and paraprofessionals. The Commissioner of Education will develop recommendations to address a variety of issues including the characteristics of students with autism and other developmental disabilities; curriculum planning, assistive technology; and inclusive educational practices.

“In a state with high autism rates, it’s imperative that educators have the tools to recognize autism and help children with this confounding disorder,” said Assemblyman Jim Whelan (D-Atlantic), a veteran teacher with a master’s in education. “Teachers are an untapped resource in this state’s growing efforts to help children and adults with autism.”

Other primary bill sponsors in the Assembly were: Assemblywoman Valerie Vainieri Huttle (District 37) and Assemblywoman Joan Voss (District 38). Primary Senate sponsors were: Senator Loretta Weinberg (District 37) and Senator Ellen Karcher (District 12).

Governor Corzine also signed A4056/S2568, requiring the Early Intervention Program in the Department of Health and Senior Services to address the specific needs of children with autism spectrum disorders and their families. These activities involve developing guidelines for health care professionals to use in evaluating infants and toddlers for autism, ensuring the timely referral by health care professionals of infants and toddlers suspected of being on the autism spectrum to the Early Intervention Program and collecting data on statewide autism screening, diagnosis, and intervention programs and systems.

“By establishing comprehensive guidelines for New Jersey pediatricians to use in the evaluation and referral of autistic children, we can ensure appropriate treatment for infants and toddlers as soon as possible,” said Assemblyman Herb Conaway, M.D. (D-Burlington/Camden). “For autistic children, early detection is the key to ensuring proper care.”

Other primary bill sponsors in the Assembly were: Assemblyman Michael Panter (District 12); Assemblywoman Valerie Vainieri Huttle (District 37) and Assemblyman Lou Greenwald (District 6). Primary Senate sponsors were: Senator Loretta Weinberg (District 37) and Senator Ellen Karcher (District 12)

Governor Corzine signed A4057/S2559, establishing the New Jersey Adults with Autism Task Force in the Department of Human Services (DHS). The purpose of the task force is to study, evaluate, and develop recommendations relating to specific actionable measures to support and meet the needs of adults with autism. These include job training and placement, housing, and long-term care.

“New Jersey faces new challenges created by the rise in adults classified with autism including the need for job training

and placement, housing and long-term care,” said Assemblyman Gary Schaer (D-Passaic/Bergen/Essex). “It’s critical that we strengthen the community of support for adults living with this lifelong disease.”

Other primary Assembly sponsors were: Assemblywoman Joan Voss (District 38) and Assemblyman John McKeon (District 27). Primary sponsors in the Senate were: Senator Loretta Weinberg (District 37) and Senator Ellen Karcher (District 12).

In addition, Governor Corzine signed S/698A4054, which makes changes to the Governor's Council for Medical Research and Treatment of Infantile Autism, renaming it the Governor's Council for Medical Research and Treatment of Autism.

“There are going to be new challenges created by a growing number of adults who are being classified with autism,” said Assemblywoman Joan Voss (D-Bergen). “The numbers clearly indicate that we need to step up our efforts to help the thousands of families in this state that have loved ones with autism disorders.”

Other primary sponsors in the Assembly were: Assemblyman Gary Schaer (District 36); and Assemblyman John McKeon (District 27). Primary sponsors in the Senate were: Senator Loretta Weinberg (District 37) and Senator Joe Vitale (District 19).

Governor Corzine signed A4059/S2569, extending funding for autism medical research and treatment. The bill eliminates the five-year “sunset” for the \$1 surcharge established under P.L.2003, c.144 for each motor vehicle fine and penalty imposed by the court, which is deposited in the “Autism Medical Research and Treatment Fund.” The fund provides the financial support funding for the grant and contract awards of the Governor’s Council for Medical Research and Treatment of Autism.

“More than ever, New Jersey needs to muster more attention and resources to help families, school districts, communities, and health care providers deal with the challenge of rising autism diagnosis rates,” said Assemblyman David Mayer (D-Gloucester/Camden).

Other primary Assembly sponsors were: Assemblywoman Joan Voss (District 38); Assemblyman Jim Whelan (District 2) and Assemblyman Lou Greenwald (District 6). Primary Senate sponsors were Senator Loretta Weinberg (District 37) and Senator Joseph Coniglio (District 38).

The Governor also signed A2306/S2723 requiring the Department of Health and Senior Services (DHSS) to maintain a registry of reported autism diagnoses. The DHSS, in consultation with the Department of Human Services, will maintain an up-to-date registry to include a record of all reported cases of autism that occur in New Jersey; each reported case of autism in which the initial diagnosis is changed, lost, or considered misdiagnosed; and any other information DHSS deems relevant and appropriate to conduct thorough and complete epidemiologic surveys of autism, to enable analysis of this problem, and to plan for and provide services to children with autism and their families.

“New Jersey has the nation’s highest reported rates of autism and this presents new challenges for families, schools and our state’s health-care network,” said John Assemblyman McKeon (D-Essex). “This registry will serve as an invaluable tool for the state to monitor autism cases while ensuring that New Jersey continues to provide services to meet the needs of the state’s growing autism community.”

Other primary bill sponsors in the Assembly were Assemblyman Nelson Albano (District 1) and Assemblywoman Joan Voss (District 38). Primary sponsors in the Senate were: Senator Andrew Ciesla (District 10) and Senator Diane Allen (District 7).

Governor Corzine also signed A2291/S690, which establishes an Asperger's Syndrome Pilot Initiative in the Department of Human Services. The initiative will provide vocational, educational and social training services to persons with Asperger's Syndrome. This will be accomplished through community-based service sites which offer appropriate support; guidance and education that will enable these individuals to further their education achieve gainful employment and become broadly competent adults who are able to lead fulfilling lives.

“Asperger’s Syndrome was only recognized in the United States in 1994, 60 years after many European countries confirmed its existence,” said Assemblywoman Joan Voss (D-Bergen), whose adult son has Asperger’s. “There are so many adults and young adults who were misdiagnosed over the years because there wasn’t a correct diagnosis for what was troubling them and there were no programs to meet their needs. This pilot program will be a model to help people with Asperger's acquire the socialization skills they need so they can enjoy productive and happy lives.”

Other primary bill sponsors in the Assembly were: Assemblyman Robert Gordon (District 38) and Assemblyman Eric Munoz (District 21). Primary sponsors in the Senate were: Senator Loretta Weinberg (District 37) and Senator Ellen Karcher (District 12).

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