

106TH CONGRESS
2D SESSION

S. 2855

To amend the Public Health Service Act to provide for the establishment of a national program of autism registries.

IN THE SENATE OF THE UNITED STATES

JULY 12, 2000

Mr. TORRICELLI introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act to provide for the establishment of a national program of autism registries.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “National Autism Reg-
5 istry Act”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Autism Spectrum Disorders (ASD), such as
9 classic autism, Asperger’s syndrome and pervasive
10 developmental disorder (also known as atypical au-

1 tism), are defined as developmental and behavioral
2 impairments resulting in impaired social inter-
3 actions, unusual communication styles, and re-
4 stricted or repetitive behaviors.

5 (2) Children with autism are unable to interact
6 appropriately with other people because they lack a
7 fundamental interest in social contact.

8 (3) Autism affects children of every racial, eth-
9 nic, and socioeconomic background.

10 (4) Recent studies have found between 12 and
11 15 children per 10,000 who are affected with au-
12 tism.

13 (5) Studies done in Europe and Asia indicate
14 that as many as 2 out of every 1,000 children have
15 some type of autism.

16 (6) A recent investigation by the Centers for
17 Disease Control and Prevention in Brick Township,
18 New Jersey, found a prevalence rate for autism of
19 4.0 per 1,000 children and a rate of 6.7 per 1,000
20 children for the more broadly defined category of
21 Autistic Spectrum Disorders.

22 (7) It is estimated that there are at least
23 400,000 children and adults in the United States
24 with autism. This rate is 3 to 4 times higher than
25 rates from studies conducted 15 to 20 years ago.

1 (8) Research has indicated that autism is due
2 to an abnormality of brain development.

3 (9) Because there is no biologic marker for au-
4 tism, surveillance for this disability presents several
5 technical and logistic challenges that must be over-
6 come.

7 (10) Reports to the Centers for Disease Control
8 and Prevention of autism clusters are increasing.

9 (11) Families of children with autism experi-
10 ence tremendous psychologic and financial stress re-
11 lated to their child's disability.

12 (12) Children with autism require long-term
13 care and services. Special education costs for a child
14 with autism are more than \$8,000 per year, with
15 some specially structure programs costing about
16 \$30,000, and care in a residential school costing be-
17 tween \$80,000 and \$100,000 per year. These costs
18 continue as children become adults and require
19 round the clock care and assistance. The yearly
20 costs of such care average \$50,000 per person.

21 (13) Little is known about causes of autism, al-
22 though genetic and environmental factors and other
23 early prenatal exposures have been suggested.

1 “(1) establish a baseline level of data that is to
2 be collected by a State (or its designee) for the oper-
3 ation of the autism registry of the State; and

4 “(2) conduct workshops with interested parties
5 including parent groups, physicians, and researchers
6 to reach consensus on the content of the baseline
7 data collection efforts under paragraph (1).

8 “(b) GRANTS.—The Secretary, acting through the
9 Director of the Centers for Disease Control and Preven-
10 tion, may make grants to—

11 “(1) States or their designees for the operation
12 of the State’s autism registry; and

13 “(2) academic institutions to enable such insti-
14 tutions, with respect to autism, to—

15 “(A) conduct population-based surveillance,
16 epidemiologic studies, and possible interventions
17 for developmental disabilities (including au-
18 tism);

19 “(B) conduct epidemiologic case-control
20 studies to examine prenatal, perinatal, and
21 postnatal factors involved in causing autism; or

22 “(C) conduct applied research that will
23 support the development of uniform autism reg-
24 istries, to—

1 “(i) collect demographic information
2 about each case of autism;

3 “(ii) collect administrative information
4 about the source of the information col-
5 lected under clause (i), and the dates of
6 hospitalization, care, and treatment;

7 “(iii) collect information on the out-
8 comes associated with autism (such as im-
9 pairments, functional limitations, and dis-
10 ability);

11 “(iv) collect monitoring information
12 on State trends in developmental disabil-
13 ities (including autism) through the use of
14 well defined and reliable case definitions;

15 “(v) collect information on multiple
16 sites to provide for the conduct of epide-
17 miological studies into the causes of devel-
18 opmental disabilities (including autism);

19 “(vi) conduct evaluations of current
20 and future interventions for developmental
21 disabilities (including autism) prevention;
22 and

23 “(vii) conduct other activities deter-
24 mined appropriate by the Secretary.

25 “(c) ELIGIBILITY FOR GRANTS.—

1 “(1) IN GENERAL.—No grant shall be made by
2 the Secretary under subsection (b) unless an appli-
3 cation has been submitted to, and approved by, the
4 Secretary. Such application shall be in such form,
5 submitted in such a manner, and be accompanied by
6 such information, as the Secretary may specify. No
7 such application may be approved unless it contains
8 assurances that the applicant will use the funds pro-
9 vided only for the purposes specified in the approved
10 application and in accordance with the requirements
11 of subsection (b), that the application will establish
12 such fiscal control and fund accounting procedures
13 as may be necessary to assure proper disbursement
14 and accounting of Federal funds paid to the appli-
15 cant under subsection (b), and that the applicant
16 will comply with review requirements under sections
17 491 and 492.

18 “(2) ESTABLISHMENT OF REGISTRIES.—Each
19 applicant, prior to receiving Federal funds under
20 subsection (b), shall provide for the establishment of
21 a registry that will—

22 “(A) comply with the uniform data collec-
23 tion methods established under subsection (a);

1 “(B) comply with appropriate standards of
2 completeness, timeliness, and quality of data
3 collection;

4 “(C) provide for periodic reports of autism
5 registry data; and

6 “(D) provide for the authorization under
7 State law of the statewide autism registry, in-
8 cluding the promulgation of regulations
9 providing—

10 “(i) a means to assure timely and
11 complete reporting of autism cases (as de-
12 scribed in subsection (b)) to the statewide
13 autism registry by hospitals or other facili-
14 ties providing care or social services to pa-
15 tients with autism;

16 “(ii) a means to assure the complete
17 reporting of autism cases (as defined in
18 subsection (b)) to the statewide autism
19 registry by physicians, and all other health
20 care practitioners diagnosing or providing
21 treatment for autistic patients, except for
22 cases directly referred to or previously ad-
23 mitted to a hospital or other facility pro-
24 viding care or services to patients in that
25 State and reported by those facilities;

1 “(iii) a means for the statewide au-
2 tism registry to access all records of physi-
3 cians, hospitals, clinics, treatment centers,
4 and all other facilities, individuals, or
5 agencies providing such services to patients
6 or individuals who care for autistic individ-
7 uals, or that identify cases of autism or
8 would establish characteristics of autism,
9 treatment of autism, or medical status of
10 any identified patient; and

11 “(iv) for the reporting of autism case
12 data to the statewide autism registry in
13 such a format, with such data elements,
14 and in accordance with such standards of
15 quality timeliness and completeness, as
16 may be established by the Secretary.

17 “(3) APPLIED RESEARCH.—Applicants for ap-
18 plied research shall conduct applied research as de-
19 termined by the Secretary, acting through the Direc-
20 tor of the Centers for Disease Control and Preven-
21 tion, to be necessary to support the development of
22 registry activities as defined in this section.

23 “(4) ASSURANCES FOR CONFIDENTIALITY OF
24 REGISTRY DATA.—Each applicant shall provide to
25 the satisfaction of the Secretary for—

1 “(A) a means by which confidential case
2 data may, in accordance with State law, be dis-
3 closed to autism researchers for the purposes of
4 the prevention, control and research of autism;

5 “(B) the authorization or the conduct, by
6 the statewide autism registry or other persons
7 and organizations, of studies utilizing statewide
8 autism registry data, including studies of the
9 sources and causes of autism, evaluations of the
10 cost, quality, efficacy, and appropriateness of
11 preventative and other services and programs
12 relating to autism, and any other clinical, epide-
13 miological, or other autism research;

14 “(C) the protection of individuals com-
15 plying with the law, including provisions speci-
16 fying that no person shall be held liable in any
17 civil action with respect to an autism case re-
18 port provided to the statewide autism registry,
19 or with respect to access to autism case infor-
20 mation provided to the statewide autism reg-
21 istry; and

22 “(D) the protection of individual privacy
23 and confidentiality consistent with Federal and
24 State laws.

1 **“SEC. 399P. TECHNICAL ASSISTANCE IN OPERATIONS OF**
2 **STATEWIDE REGISTRIES.**

3 “The Secretary, acting through the Director of the
4 Centers for Disease Control and Prevention, may, directly
5 or through grants and contracts, or both, provide technical
6 assistance to the States in the establishment and operation
7 of statewide registries, including assistance in the develop-
8 ment of model legislation for statewide autism registries
9 and assistance in establishing a computerized reporting
10 and data processing system. In providing such assistance,
11 the Secretary shall encourage States to utilize standard-
12 ized procedures where appropriate.

13 **“SEC. 399Q. AUTHORIZATION OF APPROPRIATIONS.**

14 “For the purpose of carrying out this part, there are
15 authorized to be appropriated \$50,000,000 for fiscal year
16 2001, and such sums as may be necessary for each of the
17 fiscal years 2002 through 2006.”

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