

110TH CONGRESS  
2D SESSION

**S.** \_\_\_\_\_

To provide for enhanced research, treatment, and services for autism.

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IN THE SENATE OF THE UNITED STATES

Mr. OBAMA (for himself and Mr. DURBIN) introduced the following bill; which was read twice and referred to the Committee on \_\_\_\_\_

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**A BILL**

To provide for enhanced research, treatment, and services for autism.

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 “Autism Treatment Ac-  
5 celeration Act of 2008”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Autism (sometimes called “classical au-  
9 tism”) is the most common condition in a group of  
10 developmental disorders known as the autism spec-

1       trum disorders (referred to in this section as  
2       “ASDs”).

3           (2) Other ASDs include Aspergers syndrome,  
4       Retts syndrome, childhood disintegrative disorder,  
5       and pervasive developmental disorder not otherwise  
6       specified (usually referred to as PDD-NOS).

7           (3) The National Institutes of Health has de-  
8       termined that ASDs are characterized by 3 distine-  
9       tive behaviors: impaired social interaction, problems  
10      with verbal and nonverbal communication, and un-  
11      usual, repetitive, or severely limited activities and in-  
12      terests.

13          (4) A 2007 report from the Centers for Disease  
14      Control and Prevention found that across the spec-  
15      trum of ASD, the prevalence of ASD is estimated to  
16      be 1 in 150 Americans.

17          (5) Autism is the fastest-growing developmental  
18      disability with a 10 to 17 percent growth expected  
19      annually, according to the Autism Society of Amer-  
20      ica.

21          (6) The Harvard School of Public Health re-  
22      ported that autism costs the United States over  
23      \$35,000,000,000 annually (an estimated \$3,200,000  
24      over an individual’s lifetime).

1           (7) Researchers from the Journal of Paediatrics  
2           and Child Health have discovered that males are 4  
3           times more likely to develop an ASD than females.

4           (8) According to the National Institute of Neu-  
5           rological Disorders and Stroke, there is no cure for  
6           autism. However, early intensive treatment can not  
7           only reduce the cost of lifelong care by two-thirds,  
8           but may also support improved communication  
9           skills, enhanced intellectual development, greater  
10          independence and community integration, and fore-  
11          stall the emergence of challenging secondary symp-  
12          toms such as self-injurious behavior and aggression.

13          (9) Through Autism Centers of Excellence, the  
14          National Institutes of Health has proffered a re-  
15          search program investigating the etiology and pos-  
16          sible treatments of ASDs.

17          (10) The University of Wisconsin's Waisman  
18          Center recently completed a report endorsing and  
19          detailing ways that the concepts and principles of  
20          the medical home can be utilized by clinicians, edu-  
21          cators, administrators, policymakers, families, and  
22          individuals with ASD and others to improve the  
23          early identification, intervention, treatment, and  
24          services for individuals with autism and their fami-  
25          lies.

1           (11) According to the American Academy of  
2           Pediatrics, medical homes help patients and their  
3           families better manage chronic diseases, including  
4           ASDs, and maintain basic preventive care, resulting  
5           in better health outcomes than those who lack med-  
6           ical homes. An investigation of the Chronic Care  
7           Model discovered that the medical home reduced the  
8           risk of the exacerbation of disease conditions in pa-  
9           tients, helped patients become more knowledgeable  
10          and stay on recommended therapy, and increased  
11          the likelihood that patients would receive appropriate  
12          therapy.

13          (12) Finally, individuals with autism are often  
14          denied health care benefits solely because of their di-  
15          agnosis, even though effective treatments for autism  
16          do exist, according to a 2007 study by Autism  
17          Speaks.

18 **SEC. 3. DEFINITIONS.**

19          (a) GENERAL DEFINITIONS.—In this Act:

20               (1) ADULT WITH AUTISM.—The term “adult  
21               with autism” means an individual with autism who  
22               has attained 22 years of age.

23               (2) AFFECTED INDIVIDUAL.—The term “af-  
24               fected individuals” means an individual with autism.

1           (3) AUTISM.—The term “autism” means an au-  
2           tism spectrum disorder (referred to in this Act as  
3           “ASD”) or a related developmental disability.

4           (4) AUTISM MANAGEMENT TEAM.—The term  
5           “autism management team” means a group of au-  
6           tism care providers, including behavioral specialists,  
7           physicians, psychologists, social workers, family  
8           therapists, nurse practitioners, nurses, educators,  
9           and other appropriate personnel who work in a co-  
10          ordinated manner to treat individuals with autism  
11          and their families. Such team shall determine the  
12          specific structure and operational model of their spe-  
13          cific autism care center, including cultural, regional,  
14          and geographical considerations.

15          (5) CARE MANAGEMENT MODEL.—The term  
16          “care management model” means a model of care  
17          that with respect to autism—

18                 (A) is centered on the relationship between  
19                 an individual with autism and his or her family  
20                 and their personal autism care coordinator;

21                 (B) uses innovations in autism treatment  
22                 to improve the management and coordination of  
23                 care provided to patients and their families; and

24                 (C) has established, where practicable, ef-  
25                 fective referral relationships between the autism

1           care coordinator and the major medical, edu-  
2           cational, and behavioral specialties and ancillary  
3           services in the region.

4           (6) CHILDREN WITH AUTISM.—The term “chil-  
5           dren with autism” means individuals with autism  
6           who have not attained 22 years of age.

7           (7) INTERVENTIONS.—The term “interven-  
8           tions” means the educational methods and positive  
9           behavioral support strategies designed to improve or  
10          ameliorate symptoms associated with autism.

11          (8) MEDICAL HOME.—The term “medical  
12          home” means a concept or model of care delivery  
13          that includes an ongoing relationship between a pro-  
14          vider and a patient, around-the-clock access to med-  
15          ical consultation, respect for a patient’s cultural and  
16          religious beliefs, and a comprehensive approach to  
17          care and coordination of care through providers and  
18          community services, as defined by the American  
19          Academy of Pediatrics.

20          (9) NETWORK.—The term “Network” means  
21          the National Autism Translational “Research to  
22          Services” Network described in section 4.

23          (10) PERSONAL PRIMARY CARE COORDI-  
24          NATOR.—The term “personal primary care provider”  
25          means—

1 (A) a physician, nurse, nurse practitioner,  
2 psychologist, social worker, family therapist, ed-  
3 ucator, or other appropriate personnel (as de-  
4 termined by the Secretary) who has extensive  
5 expertise in autism treatment and services,  
6 who—

7 (i) practices in an autism care center;

8 and

9 (ii) has been trained to coordinate and  
10 manage comprehensive autism care for the  
11 whole person; or

12 (B) a health center that—

13 (i) is a patient-centered autism care  
14 center; and

15 (ii) has providers on staff that have  
16 received the training described in subpara-  
17 graph (a)(ii).

18 (11) PROJECT.—The term “project” means the  
19 demonstration project established under section 4.

20 (12) SERVICES.—The term “services” means  
21 services to assist individuals with autism to live  
22 more independently in their communities.

23 (13) SECRETARY.—The term “Secretary”  
24 means the Secretary of Health and Human Services.

- 1           (14) STEERING COMMITTEE.—The term “steer-
- 2           ing committee” means a local management group
- 3           that is composed of collaborating local health care
- 4           practitioners or a local not-for-profit network of
- 5           health care practitioners, with respect to autism—
- 6                   (A) that implements State-level initiatives;
- 7                   (B) that develops local improvement initia-
- 8           tives;
- 9                   (C) whose mission is to—
- 10                   (i) investigate questions related to
- 11                   community-based practice; and
- 12                   (ii) improve the quality of primary
- 13                   care; and
- 14                   (D) whose membership—
- 15                   (i) represents the health care delivery
- 16                   system of the community it serves; and
- 17                   (ii) includes autism care coordinators
- 18                   and 1 representative from each part of the
- 19                   collaborative or network (such as a rep-
- 20                   resentative from a health center, a rep-
- 21                   resentative from the health department, a
- 22                   representative from social services, and a
- 23                   representative from each public and private
- 24                   hospital in the collaborative or the net-
- 25                   work).



1           (15) TREATMENTS.—The term “treatments”  
2 means the health services, including mental health  
3 services, designed to improve or ameliorate symp-  
4 toms associated with autism.

5           (b) AUTISM CARE CENTERS.—

6           (1) IN GENERAL.—In this Act, the term “au-  
7 tism care center” means a comprehensive health  
8 center that is directed by a primary care coordinator  
9 who is an expert in autism treatment and practice  
10 and provides a full array of medical, psychological,  
11 behavioral, educational, and family services to indi-  
12 viduals with autism and their families. Such center  
13 shall—

14                   (A) incorporate the attributes of the care  
15 management model;

16                   (B) offer, through on-site service provision  
17 or through detailed referral and coordinated  
18 care arrangements, an autism management  
19 team of appropriate providers, including behav-  
20 ioral specialists, physicians, psychologists, social  
21 workers, family therapists, nurse practitioners,  
22 nurses, educators, and other appropriate per-  
23 sonnel; and

24                   (C) have the capability to achieve improve-  
25 ments in the management and coordination of

1 care for targeted beneficiaries (as determined in  
2 accordance with paragraph (2)).

3 (2) CONSIDERATIONS.—In determining whether  
4 an entity meets the requirement of paragraph  
5 (1)(C), an autism management team shall consider  
6 the following:

7 (A) ACCESS AND COMMUNICATION WITH  
8 PATIENTS AND THEIR FAMILIES.—Whether the  
9 autism care center applies access to care stand-  
10 ards for affected individuals and their families  
11 as well as establishes and maintains ongoing  
12 communication and services to the recipients of  
13 care.

14 (B) MANAGING PATIENT INFORMATION  
15 AND USING INFORMATION MANAGEMENT TO  
16 SUPPORT PATIENT CARE.—Whether the autism  
17 care center has readily accessible, clinically use-  
18 ful information on affected individuals that en-  
19 ables the autism care center to comprehensively  
20 and systematically treat such individuals.

21 (C) MANAGING AND COORDINATING CARE  
22 ACCORDING TO INDIVIDUAL NEEDS.—Whether  
23 the autism care center—

24 (i) maintains continuous relationships  
25 with affected individuals by implementing

1 evidence-based guidelines and applying  
2 such guidelines to the identified needs of  
3 such individuals over time and with the in-  
4 tensity needed by such individuals;

5 (ii) assists in the early identification  
6 of the comprehensive health needs of af-  
7 fected individuals;

8 (iii) provides ongoing primary care;  
9 and

10 (iv) coordinates with a broad range of  
11 other specialty, ancillary, and related serv-  
12 ices.

13 (D) PROVIDING ONGOING ASSISTANCE AND  
14 ENCOURAGEMENT IN PATIENT/FAMILY SELF-  
15 MANAGEMENT.—Whether the autism care cen-  
16 ter—

17 (i) collaborates with affected individ-  
18 uals who receive care through the autism  
19 care center to pursue their goals for opti-  
20 mal achievable health;

21 (ii) assesses patient-specific barriers;  
22 and

23 (iii) conducts activities to support pa-  
24 tient/family self-management.

1 (E) RESOURCES FOR MANAGED CARE.—

2 Whether the autism care center has in place the  
3 resources and processes necessary to achieve  
4 improvements in the management and coordina-  
5 tion of care for affected individuals who receive  
6 care through the autism care center.

7 (F) MONITORING PERFORMANCE.—Wheth-  
8 er the autism care center—

9 (i) monitors its clinical process and  
10 performance (including process and out-  
11 come measures) in meeting the applicable  
12 standards; and

13 (ii) provides information in a form  
14 and manner that provides transparent  
15 evaluation of process and performance.

16 **SEC. 4. NATIONAL AUTISM TRANSLATIONAL “RESEARCH TO**  
17 **SERVICES” NETWORK.**

18 (a) ESTABLISHMENT AND PURPOSE.—The Secretary  
19 shall establish a National Autism Translational “Research  
20 to Services” Network for the purpose of leveraging and  
21 enhancing the autism treatment and service capacity of  
22 Federal, regional, State, and local agencies and inte-  
23 grating regional, State and local agencies as fully as pos-  
24 sible into national autism treatment and service efforts.  
25 Such Network shall—

1           (1) build upon the autism infrastructure exist-  
2           ing on the date of enactment of this Act (including  
3           Autism Centers of Excellence);

4           (2) strengthen linkages between autism re-  
5           search and service initiatives at Federal, regional,  
6           State, and community levels;

7           (3) ensure the rapid dissemination of evidence-  
8           based and promising autism practices;

9           (4) increase coordination of autism data track-  
10          ing initiatives that can support broad program eval-  
11          uation and research; and

12          (5) facilitate the establishment of comprehen-  
13          sive autism treatment facilities that integrate and  
14          coordinate research and services efforts that can—

15                (A) reduce the fragmentation of care and  
16                duplication of services;

17                (B) provide a fertile environment for the  
18                implementation and evaluation of emerging  
19                practices;

20                (C) offer a full array of medical, behav-  
21                ioral, mental health, and family care services to  
22                individuals with ASD and their families; and

23                (D) ensure accessibility, continuity of care,  
24                comprehensive services, case coordination and

1 transition services, compassionate and family/  
2 person centered focus, and cultural relevance.

3 (b) ORGANIZATION OF THE NETWORK.—

4 (1) IN GENERAL.—In establishing the Network,  
5 the Secretary, acting through Administrator of the  
6 Health Resources and Services Administration, shall  
7 upgrade and unify autism treatment and services ef-  
8 forts that are ongoing on the date of enactment of  
9 this Act and shall promote Federal, regional, State,  
10 and local integration where practicable.

11 (2) COMPOSITION.—The Secretary shall ensure  
12 that the Network is composed of entities from the  
13 Federal, regional, State, and local levels.

14 (3) FEDERAL LEADERSHIP AND ORGANIZA-  
15 TION.—

16 (A) COORDINATING COMMITTEE.—The  
17 Secretary shall establish an ASD Coordinating  
18 Committee (referred to in this section as the  
19 “Committee”) to carry out the duties described  
20 in subparagraph (B). The membership of such  
21 Committee shall be composed of individuals ap-  
22 pointed by the Secretary, including leading rep-  
23 resentatives from relevant governmental agen-  
24 cies, researchers, service providers, and the  
25 public.

1 (B) DUTIES.—The Committee shall—

2 (i) coordinate the Autism efforts de-  
3 scribed in this Act;

4 (ii) serve as the principal advisor to  
5 the Administrator of the Health Resources  
6 and Services Administration concerning  
7 autism;

8 (iii) conduct evaluations concerning—

9 (I) barriers to the development of  
10 effective treatment and services for in-  
11 dividuals with ASDs;

12 (II) the development and imple-  
13 mentation of a comprehensive network  
14 structure for autism research and  
15 service delivery; and

16 (III) emerging opportunities for  
17 ongoing autism network expansion;

18 (iv) submit to Congress periodic re-  
19 ports concerning the findings and rec-  
20 ommendations of the Committee; and

21 (v) provide oversight to the Network,  
22 including—

23 (I) oversight of the development,  
24 issuance, and ongoing monitoring of  
25 regional and State specific grant pro-

1                   grams to support Network develop-  
2                   ment and evaluation; and

3                               (II) oversight of the National  
4                   Center for Project Access under sec-  
5                   tion 5.

6       (c) NATIONAL CENTER FOR PROJECT ACCESS.—

7               (1) IN GENERAL.—Not later than 12 months  
8       after the date of enactment of this Act, the Sec-  
9       retary, acting through the Director of the Centers  
10      for Disease Control and Prevention and the Admin-  
11      istrator of the Health Resources and Services Ad-  
12      ministration, shall establish a National Center for  
13      Project Access (referred to in this Act as the “Na-  
14      tional Center”) to—

15                   (A) provide training and technical assist-  
16                   ance to frontline autism service providers; and

17                   (B) enhance autism program evaluation  
18                   support in order to—

19                               (i) facilitate the rapid dissemination  
20                   of evidence-based and promising practices;

21                               (ii) facilitate the integration of emerg-  
22                   ing data and findings from the Network  
23                   and other clinical trials as appropriate with  
24                   the findings of the National Institutes of  
25                   Health; and



1 (iii) enhance the utilization of a na-  
2 tional data repository to support basic and  
3 applied autism research.

4 (2) DATA REPOSITORY.—The data repository  
5 utilized under subsection (a)(2)(C) shall be acces-  
6 sible to health care providers, educators, and other  
7 eligible entities (including researchers and diagnosti-  
8 cians engaged in the care of individuals with autism  
9 and their family members) to facilitate the coordina-  
10 tion of care and multi-site research. All data con-  
11 tained in the repository shall be maintained in a  
12 manner that does not personally identify individuals.

13 (d) REGIONAL LEADERSHIP AND ORGANIZATION.—

14 (1) IN GENERAL.—In establishing the Network,  
15 the Secretary, acting through the Committee, shall  
16 ensure that regional participation is provided  
17 through the appointment of regional leadership that  
18 is composed of university and community-based  
19 partnerships that will represent the needs and inter-  
20 ests of regional stakeholders (including individuals  
21 with ASD and their families, providers, and re-  
22 searchers).

23 (2) PARTICIPATION OF STAKEHOLDERS.—The  
24 Committee shall engage a variety of autism stake-  
25 holders, including the National Institutes of Health,

1 Autism Centers of Excellence, autism networks, au-  
2 tism researchers, community service agencies, indi-  
3 viduals, and families, in the establishment and im-  
4 plementation of regional autism research and service  
5 initiatives consistent with Network goals and the  
6 goals of this Act.

7 (e) STATE AND COMMUNITY LEVEL LEADERSHIP  
8 AND ORGANIZATION.—

9 (1) COORDINATION.—Activities of the Network  
10 at the State and community level shall be coordi-  
11 nated through State directors who are appointed by  
12 the regional leadership under subsection (c).

13 (2) ACTIVITIES.—In implementing the Net-  
14 work, the Secretary shall ensure that State and com-  
15 munity autism subnetworks are established to en-  
16 gage in a variety of frontline autism activities pro-  
17 viding evidence-based services, including comprehen-  
18 sive diagnostics, treatment, resource and referral,  
19 and support programs.

20 (3) EVALUATIONS.—The Secretary shall solicit  
21 the participation of State and local agencies in Fed-  
22 eral and State Network evaluation efforts, including  
23 participation in national clinical trials initiatives, as  
24 practicable.

1           (4) WORKFORCE.—In implementing the Net-  
2           work, the Secretary shall provide incentives to State  
3           specific university partners to encourage such part-  
4           ners to advance autism workforce development ini-  
5           tiatives to secure and maintain a trained autism  
6           workforce.

7           (5) SUPPLEMENT NOT SUPPLANT.—Amounts  
8           provided under this section shall be used to supple-  
9           ment, not supplant, amounts otherwise expended for  
10          existing network or organizational structures.

11          (6) AUTHORIZATION OF APPROPRIATIONS.—  
12          There is authorized to be appropriated to carry out  
13          this section, such sums as may be necessary for each  
14          of fiscal years 2009 through 2012.

15 **SEC. 5. AUTISM CARE CENTER DEMONSTRATION PROJECT.**

16          (a) IN GENERAL.—Not later than 18 months after  
17          the date of enactment of this Act, the Secretary, acting  
18          through the Administrator of the Health Resources and  
19          Services Administration, shall establish a 5 year dem-  
20          onstration project for the implementation of an Autism  
21          Care Center Program (referred to in this section as the  
22          “Program”) to provide grants and other assistance to im-  
23          prove the effectiveness and efficiency in providing com-  
24          prehensive care to individuals diagnosed with ASD and  
25          their families.

1 (b) GOALS.—The Program shall be designed—

2 (1) to increase—

3 (A) comprehensive ASD care delivery;

4 (B) access to appropriate health care serv-  
5 ices, especially wellness and prevention care, at  
6 times convenient for patients;

7 (C) patient satisfaction;

8 (D) communication among ASD healthcare  
9 providers, behaviorists, educators, specialists,  
10 hospitals, and other ASD care providers;

11 (E) school placement and attendance; and

12 (F) the quality of health care services tak-  
13 ing into account nationally-developed standards  
14 and measures; and

15 (2) to decrease—

16 (A) inappropriate emergency room utiliza-  
17 tion, which can be accomplished through initia-  
18 tives such as expanded hours of care;

19 (B) avoidable hospitalizations;

20 (C) the duplication of health care services;

21 and

22 (D) the inconvenience of multiple provider  
23 locations.

24 (c) PARTICIPATING STATES AND ELIGIBLE ENTI-

25 TIES.—

1           (1) PARTICIPATING STATES.—The Secretary  
2 shall select at least 8 States, that are diverse in ge-  
3 ography and community served, to participate in the  
4 Program.

5           (2) ELIGIBLE ENTITIES.—

6           (A) IN GENERAL.—To be eligible to receive  
7 assistance under the Program, an entity shall—

8                   (i) be located in a participating State;

9                   (ii) submit an application that meets  
10 the requirements of subsection (d); and

11                   (iii) meet the requirements of sub-  
12 paragraph (B).

13           (B) REQUIREMENTS.—To be eligible to re-  
14 ceive assistance under the Program, an entity  
15 shall agree to establish and implement an au-  
16 tism care center that—

17                   (i) enables targeted beneficiaries to  
18 designate a personal primary care coordi-  
19 nator in such center to be their source of  
20 first contact and to provide comprehensive  
21 and coordinated care for the whole of the  
22 individual;

23                   (ii) provides for the establishment of a  
24 coordination of care committee that is

1 composed of ASD clinicians and practi-  
2 tioners trained in ASD intervention;

3 (iii) provides for primary care case  
4 managers to lead care coordination;

5 (iv) establishes a network of physi-  
6 cians, psychologists, family therapists, so-  
7 cial workers, educators, and health centers  
8 that have volunteered to participate as con-  
9 sultants to patient-centered autism care  
10 centers to provide high-quality care, focus-  
11 ing on ASD care, at the appropriate times  
12 and places in a cost-effective manner;

13 (v) works in cooperation with hos-  
14 pitals and local public health departments  
15 and with the network of patient-centered  
16 autism care centers, to coordinate and pro-  
17 vide health care; and

18 (vi) utilizes health information tech-  
19 nology to facilitate the provision and co-  
20 ordination of health care by network par-  
21 ticipants.

22 (d) APPLICATION.—To be eligible to receive assist-  
23 ance under the Project, an entity (in consultation with the  
24 appropriate State Developmental Disabilities Council and  
25 organizations representing or serving individuals with au-

1 tism and their families) shall submit to the Secretary an  
2 application, at such time, in such manner, and containing  
3 such information as the Secretary may require, includ-  
4 ing—

5           (1) a description of the treatments, interven-  
6           tions, or services that the entity proposes to provide  
7           under the Program;

8           (2) a demonstration of the capacity of the enti-  
9           ty to provide or establish such treatments, interven-  
10          tions, and services within the entity;

11          (3) a demonstration of the capacity of the enti-  
12          ty to monitor and evaluate the outcomes of such  
13          treatments, interventions, and services with respect  
14          to individuals with autism;

15          (4) estimates of the number of individuals and  
16          families who will be served by the entity under the  
17          Program, including an estimate of the number of  
18          such individuals and families in medically under-  
19          served areas;

20          (5) a description of the ability of the entity to  
21          enter into partnerships with community-based or  
22          nonprofit providers of treatments, interventions, and  
23          services, including providers that act as advocates  
24          for individuals with autism, and local governments

1 that provide services for individuals with autism at  
2 the community level;

3 (6) a description of the ways in which access to  
4 such treatments and services may be sustained fol-  
5 lowing the Program period; and

6 (7) a description of the compliance of the entity  
7 with the integration requirement provided under sec-  
8 tion 302 of the Americans with Disabilities Act of  
9 1990 (42 U.S.C. 12182).

10 (e) GRANTS.—

11 (1) DEVELOPMENTAL GRANTS.—During the ini-  
12 tial year in which the Program is in operation, the  
13 Secretary shall award developmental grants to enti-  
14 ties with applications approved under subsection (d).  
15 Such grants shall be used to—

16 (A) assist with the development of na-  
17 tional, regional, State and local autism coordi-  
18 nation committees, and local networks of ASD  
19 healthcare providers; and

20 (i) facilitate coordination with local  
21 communities to be better prepared and po-  
22 sitioned to understand and meet the needs  
23 of the communities served by patient-cen-  
24 tered medical homes and autism care cen-  
25 ters.



1           (2) FUNDING AFTER THE FIRST YEAR.—In the  
2           second and subsequent years in which the Program  
3           is in operation, the Secretary shall award additional  
4           grant funds to entities that receive a development  
5           grant under paragraph (1) if the Secretary deter-  
6           mines such funds are necessary to ensure the contin-  
7           ued participation of the entity in the Program.

8           (f) EVALUATION AND REPORT.—

9           (1) EVALUATIONS.—Not later than 12 months  
10          after the establishment of the Program under this  
11          section, the Secretary shall enter into a contract  
12          with an independent third-party organization with  
13          expertise in evaluation activities, for the evaluation  
14          of the Program under this section.

15          (2) REPORT.—Not later than 1 year after the  
16          completion of the Program, the independent third-  
17          party organization described in paragraph (1) shall  
18          submit to the Secretary a report concerning the  
19          ways in which the treatments, interventions, and  
20          services provided for through the Program have re-  
21          sulted in improved health, educational, employment,  
22          and community integration outcomes for individuals  
23          with autism.

24          (g) SUPPLEMENT NOT SUPPLANT.—Amount pro-  
25          vided to an entity under this section shall be used to sup-

1 plement, not supplant, amounts otherwise expended for  
2 existing treatments, interventions, and services for individ-  
3 uals with autism.

4 (h) **AUTHORIZATION OF APPROPRIATIONS.**—There is  
5 authorized to be appropriated to carry out this section,  
6 such sums as may be necessary for each of fiscal years  
7 2009 through 2012. Amounts not expended in 1 fiscal  
8 year shall remaining available for use in the succeeding  
9 fiscal year.

10 **SEC. 6. NATIONAL REGISTRY FOR AUTISM SPECTRUM DIS-**  
11 **ORDER .**

12 (a) **ESTABLISHMENT.**—The Secretary, in consulta-  
13 tion with national health organizations and professional  
14 societies with experience and expertise relating to pre-  
15 venting, treating, and reducing ASD, shall establish a pop-  
16 ulation-based ASD case registry that can facilitate the un-  
17 derstanding of the root causes, rates, and trends of ASD.  
18 Such registry shall be known as the “National Registry  
19 for Autism Spectrum Disorder” (referred to in this section  
20 as the “Registry”).

21 (b) **REQUIREMENTS.**—The Registry shall be designed  
22 to facilitate the collection, analysis, and dissemination of  
23 ASD-related data by—

24 (1) implementing a surveillance and monitoring  
25 system that is based on thorough and complete med-

1 ical diagnosis data, clinical history, and medical  
2 findings;

3 (2) collecting standardized information con-  
4 cerning the environmental, medical, social, and ge-  
5 netic circumstances that may correlate with ASD di-  
6 agnosis;

7 (3) promoting the use of Centers for Disease  
8 Control and Prevention standardized ASD investiga-  
9 tion and reporting tools as well as standardized ASD  
10 protocols;

11 (4) establishing a standardized classification  
12 system for defining subcategories of ASD for surveil-  
13 lance and prevention research activities;

14 (5) supporting multidisciplinary ASD reviews;  
15 and

16 (6) improving the public reporting of surveil-  
17 lance and descriptive epidemiology of ASD by  
18 supplementing vital statistics data.

19 (c) AUTHORIZATION OF APPROPRIATIONS.—There is  
20 authorized to be appropriated to carry out this section,  
21 such sums as may be necessary for each of fiscal years  
22 2009 through 2012.

23 **SEC. 7. MULTIMEDIA CAMPAIGN.**

24 (a) IN GENERAL.—The Secretary, in order to en-  
25 hance existing awareness campaigns provide for the imple-

1 mentation of new campaigns, shall award grants to public  
2 and nonprofit private entities for the purpose of carrying  
3 out multimedia campaigns to increase public education  
4 and awareness concerning healthy developmental mile-  
5 stones for infants and children that may assist in the early  
6 identification of the signs and symptoms of ASD.

7 (b) APPLICATION.—To be eligible to receive a grant  
8 under subsection (a), an entity shall submit to the Sec-  
9 retary an application at such time, in such manner, and  
10 containing such information as the Secretary may require.

11 (c) REQUIREMENTS.—To be eligible for a grant  
12 under subsection (a), an entity subsection (a) shall provide  
13 assurance in the application submitted under subsection  
14 (b) that the multimedia campaign implemented under  
15 such grant will—

16 (1) provide information that is tailored to a di-  
17 verse public audience, including health professionals,  
18 concerning normal developmental milestones for in-  
19 fants and children; and

20 (2) identify national and State organizations  
21 that can facilitate the provision of ASD-related serv-  
22 ices regarding diagnosis and treatment.

23 (d) AUTHORIZATION OF APPROPRIATIONS.—There  
24 are authorized to be appropriated to carry out this section,

1 such sums as may be necessary for each of fiscal years  
2 2009 through 2012.

3 **SEC. 8. AMENDMENTS RELATING TO HEALTH INSURANCE.**

4 (a) ERISA.—

5 (1) IN GENERAL.—Subpart B of part 7 of sub-  
6 title B of title I of the Employee Retirement Income  
7 Security Act of 1974 (29 U.S.C. 1185 et seq.) is  
8 amended by adding at the end the following:

9 **“SEC. 714. REQUIRED COVERAGE FOR AUTISM SPECTRUM**  
10 **DISORDERS.**

11 “(a) IN GENERAL.—A group health plan, and a  
12 health insurance issuer providing health insurance cov-  
13 erage in connection with a group health plan, shall provide  
14 coverage for the diagnosis of autism spectrum disorders  
15 and the treatment of autism spectrum disorders.

16 “(b) RULE OF CONSTRUCTION.—Nothing in this sec-  
17 tion shall be construed—

18 “(1) as preventing a group health plan or  
19 health insurance issuer from imposing deductibles,  
20 coinsurance, or other cost-sharing in relation to ben-  
21 efits for the diagnosis and treatment of autism spec-  
22 trum disorders, except that such coinsurance or  
23 other cost-sharing for any such benefits may not be  
24 greater than such coinsurance or cost-sharing for  
25 any other benefit; and

1           “(2) to prevent a group health plan or a health  
2           insurance issuer from negotiating the level and type  
3           of reimbursement with a provider for care provided  
4           in accordance with this section.

5           “(c) NOTICE UNDER GROUP HEALTH PLAN.—The  
6           imposition of the requirements of this section shall be  
7           treated as a material modification in the terms of the plan  
8           described in section 102(a)(1), for purposes of assuring  
9           notice of such requirements under the plan, except that  
10          the summary description required to be provided under the  
11          last sentence of section 104(b)(1) with respect to such  
12          modification shall be provided not later than the earlier  
13          of—

14                 “(1) by not later than 60 days after the first  
15                 day of the first plan year in which such require-  
16                 ments apply;

17                 “(2) in the next mailing made by the plan or  
18                 issuer to the participant or beneficiary; or

19                 “(3) January 1, 2010.

20           “(d) PROHIBITIONS.—A group health plan, and a  
21           health insurance issuer offering group health insurance  
22           coverage in connection with a group health plan, shall  
23           not—

24                 “(1) deny to an individual eligibility, or contin-  
25                 ued eligibility, to enroll or to renew coverage under

1 the terms of the plan, solely for the purpose of  
2 avoiding the requirements of this section; or

3 “(2) deny coverage otherwise available under  
4 this section on the basis that coverage is necessary  
5 to develop, maintain, or restore skills or functioning,  
6 or to prevent the loss of skills or functioning.

7 “(e) PREEMPTION; RELATION TO STATE LAW.—

8 “(1) IN GENERAL.—Nothing in this section  
9 shall be construed to preempt any State law with re-  
10 spect to health insurance coverage that requires cov-  
11 erage of at least the coverage for autism spectrum  
12 disorders otherwise required under this section.

13 “(2) ERISA.—Nothing in this section shall be  
14 construed to affect or modify the provisions of sec-  
15 tion 514 with respect to group health plans.

16 “(f) DEFINITIONS.—In this section:

17 “(1) AUTISM SPECTRUM DISORDERS.—The  
18 term ‘autism spectrum disorders’ means develop-  
19 mental disabilities that cause substantial impair-  
20 ments in the areas of social interaction, emotional  
21 regulation, communication, and the integration of  
22 higher-order cognitive processes and are often char-  
23 acterized by the presence of unusual behaviors and  
24 interests. Such term includes autistic disorder, per-  
25 vasive developmental disorder (not otherwise speci-

1       fied), Asperger’s syndrome, Retts disorder, and  
2       childhood disintegrative disorder.

3               “(2) DIAGNOSIS OF AUTISM SPECTRUM DIS-  
4       ORDERS.—The term ‘diagnosis of autism spectrum  
5       disorders’ means medically necessary assessments,  
6       evaluations, or tests to diagnose whether an indi-  
7       vidual has an autism spectrum disorder.

8               “(3) TREATMENT OF AUTISM SPECTRUM DIS-  
9       ORDERS.—The term ‘treatment of autism spectrum  
10      disorders’ means the following care prescribed, pro-  
11      vided, or ordered for an individual diagnosed with an  
12      autism spectrum disorder by a physician, psycholo-  
13      gist, or other qualified professional who determines  
14      the care to be medically necessary:

15              “(A) Medications prescribed by a physician  
16              and any health-related services necessary to de-  
17              termine the need or effectiveness of the medica-  
18              tions.

19              “(B) Occupational therapy, physical ther-  
20              apy, and speech therapy.

21              “(C) Direct or consultative services pro-  
22              vided by a psychiatrist or psychologist.

23              “(D) Professional, counseling, and guid-  
24              ance services and treatment programs, includ-  
25              ing applied behavior analysis and other struc-



1           tured behavioral programs. In this subpara-  
2           graph, the term ‘applied behavior analysis’  
3           means the design, implementation and evalua-  
4           tion of environmental modifications, using be-  
5           havioral stimuli and consequences, to produce  
6           socially significant improvement in human be-  
7           havior, including the use of direct observation,  
8           measurement, and functional analysis of the re-  
9           lations between environment and behavior.”.

10           (2) CLERICAL AMENDMENT.—The table of con-  
11           tents in section 1 of the Employee Retirement In-  
12           come Security Act of 1974 (29 U.S.C. 1001 note) is  
13           amended by inserting after the item relating to sec-  
14           tion 713 the following:

“Sec. 714. Required coverage for autism spectrum disorders.”.

15           (b) PUBLIC HEALTH SERVICE ACT.—

16           (1) GROUP MARKET.—Subpart 2 of part A of  
17           title XXVII of the Public Health Service Act (42  
18           U.S.C. 300gg-4 et seq.) is amended by adding at the  
19           end the following:

20           **“SEC. 2707. REQUIRED COVERAGE FOR AUTISM SPECTRUM**  
21           **DISORDERS.**

22           “(a) IN GENERAL.—A group health plan, and a  
23           health insurance issuer providing health insurance cov-  
24           erage in connection with a group health plan, shall provide

1 coverage for the diagnosis of autism spectrum disorders  
2 and the treatment of autism spectrum disorders.

3 “(b) RULE OF CONSTRUCTION.—Nothing in this sec-  
4 tion shall be construed—

5 “(1) as preventing a group health plan or  
6 health insurance issuer from imposing deductibles,  
7 coinsurance, or other cost-sharing in relation to ben-  
8 efits for the diagnosis and treatment of autism spec-  
9 trum disorders, except that such coinsurance or  
10 other cost-sharing for any such benefits may not be  
11 greater than such coinsurance or cost-sharing for  
12 any other benefit; and

13 “(2) to prevent a group health plan or a health  
14 insurance issuer from negotiating the level and type  
15 of reimbursement with a provider for care provided  
16 in accordance with this section.

17 “(c) NOTICE UNDER GROUP HEALTH PLAN.—The  
18 imposition of the requirements of this section shall be  
19 treated as a material modification in the terms of the plan  
20 described in section 102(a)(1), for purposes of assuring  
21 notice of such requirements under the plan, except that  
22 the summary description required to be provided under the  
23 last sentence of section 104(b)(1) with respect to such  
24 modification shall be provided not later than the earlier  
25 of—

1           “(1) by not later than 60 days after the first  
2 day of the first plan year in which such require-  
3 ments apply;

4           “(2) in the next mailing made by the plan or  
5 issuer to the enrollee; or

6           “(3) January 1, 2010.

7           “(d) PROHIBITIONS.—A group health plan, and a  
8 health insurance issuer offering group health insurance  
9 coverage in connection with a group health plan, shall  
10 not—

11           “(1) deny to an individual eligibility, or contin-  
12 ued eligibility, to enroll or to renew coverage under  
13 the terms of the plan, solely for the purpose of  
14 avoiding the requirements of this section; or

15           “(2) deny coverage otherwise available under  
16 this section on the basis that coverage is necessary  
17 to develop, maintain, or restore skills or functioning,  
18 or to prevent the loss of skills or functioning.

19           “(e) PREEMPTION; RELATION TO STATE LAW.—

20           “(1) IN GENERAL.—Nothing in this section  
21 shall be construed to preempt any State law with re-  
22 spect to health insurance coverage that requires cov-  
23 erage of at least the coverage for autism spectrum  
24 disorders otherwise required under this section.

1           “(2) ERISA.—Nothing in this section shall be  
2           construed to affect or modify the provisions of sec-  
3           tion 514 with respect to group health plans.

4           “(f) DEFINITIONS.—In this section:

5           “(1) AUTISM SPECTRUM DISORDERS.—The  
6           term ‘autism spectrum disorders’ means develop-  
7           mental disabilities that cause substantial impair-  
8           ments in the areas of social interaction, emotional  
9           regulation, communication, and the integration of  
10          higher-order cognitive processes and are often char-  
11          acterized by the presence of unusual behaviors and  
12          interests. Such term includes autistic disorder, per-  
13          vasive developmental disorder (not otherwise speci-  
14          fied), and Asperger’s syndrome.

15          “(2) DIAGNOSIS OF AUTISM SPECTRUM DIS-  
16          ORDERS.—The term ‘diagnosis of autism spectrum  
17          disorders’ means medically necessary assessments,  
18          evaluations, or tests to diagnose whether an indi-  
19          vidual has an autism spectrum disorder.

20          “(3) TREATMENT OF AUTISM SPECTRUM DIS-  
21          ORDERS.—The term ‘treatment of autism spectrum  
22          disorders’ means the following care prescribed, pro-  
23          vided, or ordered for an individual diagnosed with an  
24          autism spectrum disorder by a physician, psycholo-

1       gist, or other qualified professional who determines  
2       the care to be medically necessary:

3               “(A) Medications prescribed by a physician  
4               and any health-related services necessary to de-  
5               termine the need or effectiveness of the medica-  
6               tions.

7               “(B) Occupational therapy, physical ther-  
8               apy, and speech therapy.

9               “(C) Direct or consultative services pro-  
10              vided by a psychiatrist or psychologist.

11              “(D) Professional, counseling, and guid-  
12              ance services and treatment programs, includ-  
13              ing applied behavior analysis and other struc-  
14              tured behavioral programs. In this subpara-  
15              graph, the term ‘applied behavior analysis’  
16              means the design, implementation and evalua-  
17              tion of environmental modifications, using be-  
18              havioral stimuli and consequences, to produce  
19              socially significant improvement in human be-  
20              havior, including the use of direct observation,  
21              measurement, and functional analysis of the re-  
22              lations between environment and behavior.”.

23              (2) INDIVIDUAL MARKET.—Subpart 3 of part B  
24              of title XXVII of the Public Health Service Act (42

1 U.S.C. 300gg-51 et seq.) is amended by adding at  
2 the end the following:

3 **“SEC. 2754. REQUIRED COVERAGE FOR AUTISM SPECTRUM**  
4 **DISORDERS.**

5 “The provisions of section 2707 shall apply to health  
6 insurance coverage offered by a health insurance issuer  
7 in the individual market in the same manner as they apply  
8 to health insurance coverage offered by a health insurance  
9 issuer in connection with a group health plan in the small  
10 or large group market.”.

11 (c) EFFECTIVE DATES.—

12 (1) GROUP HEALTH PLANS.—

13 (A) IN GENERAL.—The amendment made  
14 by subsection (a) shall apply to group health  
15 plans for plan years beginning on or after the  
16 date of enactment of this Act.

17 (B) SPECIAL RULE FOR COLLECTIVE BAR-  
18 GAINING AGREEMENTS.—In the case of a group  
19 health plan maintained pursuant to 1 or more  
20 collective bargaining agreements between em-  
21 ployee representatives and 1 or more employers,  
22 any plan amendment made pursuant to a collec-  
23 tive bargaining agreement relating to the plan  
24 which amends the plan solely to conform to any  
25 requirement added by the amendment made by

1 subsection (a) shall not be treated as a termi-  
2 nation of such collective bargaining agreement.

3 (2) INDIVIDUAL PLANS.—The amendment made  
4 by subsection (b) shall apply with respect to health  
5 insurance coverage offered, sold, issued, renewed, in  
6 effect, or operated in the individual market on or  
7 after the date of enactment of this Act.