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## **S.819**

**Title: A bill to provide for enhanced treatment, support, services, and research for individuals with autism spectrum disorders and their families.**

Sponsor: Sen Durbin, Richard [IL] (introduced 4/2/2009)

Cosponsors (2)

Sen Casey, Robert P., Jr. [PA] - 4/2/2009

Sen Menendez, Robert [NJ] - 4/2/2009

Latest Major Action: 4/2/2009 Referred to Senate committee. Status: Read twice and referred to the Committee on Health, Education, Labor, and Pensions.

As read into the Congressional Record, April 2, 2009.

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Start of text:

By Mr. DURBIN (for himself, Mr. *Casey*, and Mr. *Menendez*):

S. 819. A bill to provide for enhanced treatment, support, services, and research for individuals with autism spectrum disorders and their families; to the Committee on Health, Education, Labor, and Pensions.

Mr. DURBIN. Mr. President, I ask unanimous consent that the text of the bill be printed in the *Record*.

There being no objection, the text of the bill was ordered to be printed in the *Record*, as follows:

S. 819

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

### **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

(a) *Short Title*.--This Act may be cited as the ``Autism Treatment Acceleration Act of 2009''.

(b) *Table of Contents*.--The table of contents for this Act is as follows:

Sec..1..Short title; table of contents.

Sec..2..Findings.

Sec..3..Parental rights rule of construction.

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Sec..4..Definitions; technical amendment to the Public Health Service Act.

Sec..5..Autism Care Centers Demonstration Project.

Sec..6..Planning and demonstration grants for services for adults.

Sec..7..National Registry.

Sec..8..Multimedia campaign.

Sec..9..Interdepartmental Autism Coordinating Committee.

Sec..10..National Network for Autism Spectrum Disorders Research and Services.

Sec..11..National training initiatives on autism spectrum disorders.

Sec..12..Amendments relating to health insurance.

Sec..13..Authorization of appropriations.

## **SEC. 2. FINDINGS.**

Congress makes the following findings:

(1) Autism (sometimes called ``classical autism") is the most common condition in a group of developmental disorders known as autism spectrum disorders.

(2) Autism spectrum disorders include autism as well as Asperger syndrome, Retts syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS), as well as other related developmental disorders.

(3) Individuals with autism spectrum disorders have the same rights as other individuals to exert control and choice over their own lives, to live independently, and to participate fully in, and contribute to, their communities and society through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of society. Individuals with autism spectrum disorders have the right to a life with dignity and purpose.

(4) While there is no uniform prevalence or severity of symptoms associated with autism spectrum disorders, the National Institutes of Health has determined that autism spectrum disorders are characterized by 3 distinctive behaviors: impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests.

(5) Both children and adults with autism spectrum disorders can show difficulties in verbal and nonverbal communication, social interactions, and sensory processing. Individuals with autism spectrum disorders exhibit different symptoms or behaviors, which may range from mild to significant, and require varying degrees of support from friends, families, service providers, and communities.

(6) Individuals with autism spectrum disorders often need assistance in the areas of comprehensive early intervention, health, recreation, job training, employment, housing, transportation, and early, primary, and secondary education. With access to, and assistance with, these types of services and supports, individuals with autism spectrum disorders can live rich, full, and productive lives. Greater coordination and streamlining within the service delivery system will enable individuals with autism spectrum disorders and their families to access assistance from all sectors throughout an individual's

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lifespan.

(7) A 2007 report from the Centers for Disease Control and Prevention found that the prevalence of autism spectrum disorders is estimated to be 1 in 150 people in the United States.

(8) The Harvard School of Public Health reported that the cost of caring for and treating individuals with autism spectrum disorders in the United States is more than \$35,000,000,000 annually (an estimated \$3,200,000 over an individual's lifetime).

(9) Although the overall incidence of autism is consistent around the globe, researchers with the Journal of Paediatrics and Child Health have found that males are 4 times more likely to develop an autism spectrum disorder than females. Autism spectrum disorders know no racial, ethnic, or social boundaries, nor differences in family income, lifestyle, or educational levels, and can affect any child.

(10) Individuals with autism spectrum disorders from low-income, rural, and minority communities often face significant obstacles to accurate diagnosis and necessary specialized services, supports, and education.

(11) There is strong consensus within the research community that intensive treatment as soon as possible following diagnosis not only can reduce the cost of lifelong care by two-thirds, but also yields the most positive life outcomes for children with autism spectrum disorders.

(12) Individuals with autism spectrum disorders and their families experience a wide range of medical issues. Few common standards exist for the diagnosis and management of many aspects of clinical care. Behavioral difficulties may be attributed to the overarching disorder rather than to the pain and discomfort of a medical condition, which may go undetected and untreated. The health care and other treatments available in different communities can vary widely. Many families, lacking access to comprehensive and coordinated health care, must fend for themselves to find the best health care, treatments, and services in a complex clinical world.

(13) Effective health care, treatment, and services for individuals with autism spectrum disorders depends upon a continuous exchange among researchers and caregivers. Evidence-based and promising autism practices should move quickly into communities, allowing individuals with autism spectrum disorders and their families to benefit from the newest research and enabling researchers to learn from the life experiences of the people whom their work most directly affects.

(14) There is a critical shortage of appropriately trained personnel across numerous important disciplines who can assess, diagnose, treat, and support children and adults with autism spectrum disorders and their families. Practicing professionals, as well as those in training to become professionals, need the most up-to-date practices informed by the most current research findings.

(15) The appropriate goals of the Nation regarding individuals with autism spectrum disorder are the same as the appropriate goals of the Nation regarding individuals with disabilities in general, as established in the Americans with Disabilities Act of 1990

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(42 U.S.C. 12101 et seq.): to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.

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(16) Finally, individuals with autism spectrum disorders are often denied health care benefits solely because of their diagnosis, even though proven, effective treatments for autism spectrum disorders do exist.

### **SEC. 3. PARENTAL RIGHTS RULE OF CONSTRUCTION.**

Nothing in this Act shall be construed to modify the legal rights of parents or legal guardians under Federal, State, or local law regarding the care of their children.

### **SEC. 4. DEFINITIONS; TECHNICAL AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT.**

Part R of title III of the Public Health Service Act (42 U.S.C. 280i et seq.) is amended--

(1) by inserting after the header for part R the following:

#### **``Subpart 1--Surveillance and Research Program; Education, Early Detection, and Intervention; and Reporting'';**

(2) in section 399AA(d), by striking ``part" and inserting ``subpart"; and

(3) by adding at the end the following:

#### **``Subpart 2--Care for People With Autism Spectrum Disorders, Registry, and Public Education**

#### **``SEC. 399GG. DEFINITIONS.**

``Except as otherwise provided, in this subpart:

``(1) **AUTISM SPECTRUM DISORDER.**--The term `autism spectrum disorder' means a developmental disability that causes substantial impairments in the areas of social interaction, emotional regulation, communication, and the integration of higher-order cognitive processes and which may be characterized by the presence of unusual behaviors and interests. Such term includes autistic disorder, pervasive developmental disorder (not otherwise specified), Asperger syndrome, Retts disorder, childhood disintegrative disorder, and other related developmental disorders.

``(2) **ADULT WITH AUTISM SPECTRUM DISORDER.**--The term `adult with autism spectrum disorder' means an individual with an autism spectrum disorder who has attained 22 years of age.

``(3) **AFFECTED INDIVIDUAL.**--The term `affected individual' means an individual with an autism spectrum disorder.

``(4) **AUTISM.**--The term `autism' means an autism spectrum disorder or a related developmental disability.

``(5) **AUTISM MANAGEMENT TEAM.**--The term `autism management team' means a group of autism care providers, including behavioral specialists, physicians, psychologists, social workers, family therapists, nurse practitioners, nurses, educators, other appropriate personnel, and family members who work in a coordinated manner to treat individuals with autism spectrum disorders and

their families. Such team shall determine the specific structure and operational model of its specific autism care center, taking into consideration cultural, regional, and geographical factors.

“(6) **CARE MANAGEMENT MODEL.**--The term ‘care management model’ means a model of care that with respect to autism--

“(A) is centered on the relationship between an individual with an autism spectrum disorder and his or her family and their personal autism care coordinator;

“(B) provides services to individuals with autism spectrum disorders to improve the management and coordination of care provided to patients and their families; and

“(C) has established, where practicable, effective referral relationships between the autism care coordinator and the major medical, educational, and behavioral specialties and ancillary services in the region.

“(7) **CHILD WITH AUTISM SPECTRUM DISORDER.**--The term ‘child with autism spectrum disorder’ means an individual with an autism spectrum disorder who has not attained 22 years of age.

“(8) **INTERVENTIONS.**--The term ‘interventions’ means the educational methods and positive behavioral support strategies designed to improve or ameliorate symptoms associated with autism spectrum disorders.

“(9) **NETWORK.**--The term ‘Network’ means the Network for Autism Spectrum Disorders Research and Services described in section 10 of the Autism Treatment Acceleration Act of 2009.

“(10) **PERSONAL PRIMARY CARE COORDINATOR.**--The term ‘personal primary care coordinator’ means a physician, nurse, nurse practitioner, psychologist, social worker, family therapist, educator, or other appropriate personnel (as determined by the Secretary) who has extensive expertise in treatment and services for individuals with autism spectrum disorders, who--

“(A) practices in an autism care center; and

“(B) has been trained to coordinate and manage comprehensive autism care for the whole person.

“(11) **PROJECT.**--The term ‘project’ means the autism care center demonstration project established under section 399HH.

“(12) **SERVICES.**--The term ‘services’ means services to assist individuals with autism spectrum disorders to live more independently in their communities and to improve their quality of life.

“(13) **TREATMENTS.**--The term ‘treatments’ means the health services, including mental health and behavioral therapy services, designed to improve or ameliorate symptoms associated with autism spectrum disorders.

“(14) **AUTISM CARE CENTER.**--In this subpart, the term ‘autism care center’ means a center that is directed by a primary care coordinator who is an expert in autism spectrum disorder treatment and practice and provides an array of medical, psychological, behavioral, educational, and family services to individuals with autism and their families. Such a center shall--

“(A) incorporate the attributes of the care management model;

“(B) offer, through on-site service provision or through detailed referral and coordinated care arrangements, an autism management team of appropriate providers, including behavioral specialists, physicians, psychologists, social workers, family therapists, nurse practitioners, nurses, educators, and other appropriate personnel; and

“(C) have the capability to achieve improvements in the management and coordination of care for targeted beneficiaries.”.

#### **SEC. 5. AUTISM CARE CENTERS DEMONSTRATION PROJECT.**

Part R of title III of the Public Health Service Act (42 U.S.C. 280i), as amended by section 4, is further amended by adding at the end the following:

#### **“SEC. 399HH. AUTISM CARE CENTER DEMONSTRATION PROJECT.**

“(a) *In General.*--Not later than 1 year after the date of enactment of the Autism Treatment Acceleration Act of 2009, the Secretary, acting through the Administrator of the Health Resources and Services Administration, shall establish a demonstration project for the implementation of an Autism Care Center Program (referred to in this section as the ‘Program’) to provide grants and other assistance to improve the effectiveness and efficiency in providing comprehensive care to individuals diagnosed with autism spectrum disorders and their families.

“(b) *Goals.*--The Program shall be designed--

“(1) to increase--

“(A) comprehensive autism spectrum disorder care delivery;

“(B) access to appropriate health care services, especially wellness and prevention care, at times convenient for patients;

“(C) patient satisfaction;

“(D) communication among autism spectrum disorder health care providers, behaviorists, educators, specialists, hospitals, and other autism spectrum disorder care providers;

“(E) school placement and attendance;

“(F) successful transition to postsecondary education, vocational or job training and placement, and comprehensive adult services for individuals with autism spectrum disorders, focusing in particular upon the transitional period for individuals between the ages of 18 and 25;

“(G) the quality of health care services, taking into account nationally-developed standards and measures;

“(H) development, review, and promulgation of common clinical standards and guidelines for medical care to individuals with autism spectrum disorders;

“(I) development of clinical research projects to support clinical findings in a search for recommended practices; and

“(J) the quality of life of individuals with autism spectrum disorders, including communication abilities, social skills, community integration, and employment and other related services; and

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((2) to decrease--

((A) inappropriate emergency room utilization, which can be accomplished through initiatives such as expanded hours of care;

((B) avoidable hospitalizations;

((C) the duplication of health care services;

((D) the inconvenience of multiple provider locations;

((E) health disparities and inequalities that individuals with autism spectrum disorders face; and

((F) preventable and inappropriate involvement with the juvenile and criminal justice systems.

((c) *Eligible Entities*.--To be eligible to receive assistance under the Program, an entity shall--

((1) be a State or a public or private nonprofit entity;

((2) agree to establish and implement an autism care center that--

((A) enables targeted beneficiaries to designate a personal primary care coordinator in such center to be their source of first contact and to recommend comprehensive and coordinated care for the whole of the individual;

((B) provides for the establishment of a coordination of care committee that is composed of clinicians and practitioners trained in and working in autism spectrum disorder intervention;

((C) establishes a network of physicians, psychologists, family therapists, behavioral specialists, social workers, educators, and health centers that have volunteered to participate as consultants to patient-centered autism care centers to provide high-quality care, focusing on autism spectrum disorder care, at the appropriate times and places and in a cost-effective manner;

((D) works in cooperation with hospitals, local public health departments, and the network of patient-centered autism care centers, to coordinate and provide health care;

((E) utilizes health information technology to facilitate the provision and coordination of health care by network participants; and

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((F) collaborates with other entities to further the goals of the program, particularly by collaborating with entities that provide transitional adult services to individuals between the ages of 18 and 25 with autism spectrum disorder, to ensure successful transition of such individuals to adulthood; and

((3) submit to the Secretary an application, at such time, in such manner, and containing such information as the Secretary may require, including--

((A) a description of the treatments, interventions, or services that the eligible entity proposes to provide under the Program;

((B) a demonstration of the capacity of the eligible entity to provide or establish such treatments,

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interventions, and services within such entity;

((C) a demonstration of the capacity of the eligible entity to monitor and evaluate the outcomes of the treatments, interventions, and services described in subparagraph (A);

((D) estimates of the number of individuals and families who will be served by the eligible entity under the Program, including an estimate of the number of such individuals and families in medically underserved areas;

((E) a description of the ability of the eligible entity to enter into partnerships with community-based or nonprofit providers of treatments, interventions, and services, which may include providers that act as advocates for individuals with autism spectrum disorders and local governments that provide services for individuals with autism spectrum disorders at the community level;

((F) a description of the ways in which access to such treatments and services may be sustained following the Program period;

((G) a description of the ways in which the eligible entity plans to collaborate with other entities to develop and sustain an effective protocol for successful transition from children's services to adult services for individuals with autism spectrum disorder, particularly for individuals between the ages of 18 and 25; and

((H) a description of the compliance of the eligible entity with the integration requirement provided under section 302 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12182).

((d) *Grants.*--The Secretary shall award 3-year grants to eligible entities whose applications are approved under subsection (c). Such grants shall be used to--

((1) carry out a program designed to meet the goals described in subsection (b) and the requirements described in subsection (c); and

((2) facilitate coordination with local communities to be better prepared and positioned to understand and meet the needs of the communities served by autism care centers.

((e) *Advisory Councils.*--

((1) **IN GENERAL.**--Each recipient of a grant under this section shall establish an autism care center advisory council, which shall advise the autism care center regarding policies, priorities, and services.

((2) **MEMBERSHIP.**--Each recipient of a grant shall appoint members of the recipient's advisory council, which shall include a variety of autism care center service providers, individuals from the public who are knowledgeable about autism spectrum disorders, individuals receiving services through the Program, and family members of such individuals. At least 60 percent of the membership shall be comprised of individuals who have received, or are receiving, services through the Program or who are family members of such individuals.

((3) **CHAIRPERSON.**--The recipient of a grant shall appoint a chairperson to the advisory council of the recipient's autism care center who shall be--

((A) an individual with autism spectrum disorder who has received, or is receiving, services through

the Program; or

“(B) a family member of such an individual.

“(f) *Evaluation*.--The Secretary shall enter into a contract with an independent third-party organization with expertise in evaluation activities to conduct an evaluation and, not later than 180 days after the conclusion of the 3-year grant program under this section, submit a report to the Secretary, which may include measures such as whether and to what degree the treatments, interventions, and services provided through the Program have resulted in improved health, educational, employment, and community integration outcomes for individuals with autism spectrum disorders, or other measures, as the Secretary determines appropriate.

“(g) *Administrative Expenses*.--Of the amounts appropriated to carry out this section, the Secretary shall allocate not more than 7 percent for administrative expenses, including the expenses related to carrying out the evaluation described in subsection (f).

“(h) *Supplement Not Supplant*.--Amounts provided to an entity under this section shall be used to supplement, not supplant, amounts otherwise expended for existing treatments, interventions, and services for individuals with autism spectrum disorders.”

## **SEC. 6. PLANNING AND DEMONSTRATION GRANTS FOR SERVICES FOR ADULTS.**

Part R of title III of the Public Health Service Act (42 U.S.C. 280i), as amended by section 5, is further amended by adding at the end the following:

### **“SEC. 399II. PLANNING AND DEMONSTRATION GRANT FOR SERVICES FOR ADULTS.**

“(a) *In General*.--In order to enable selected eligible entities to provide appropriate services to adults with autism spectrum disorders, to enable such adults to be as independent as possible, the Secretary shall establish--

“(1) a one-time, single-year planning grant program for eligible entities; and

“(2) a multiyear service provision demonstration grant program for selected eligible entities.

“(b) *Purpose of Grants*.--Grants shall be awarded to eligible entities to provide all or part of the funding needed to carry out programs that focus on critical aspects of adult life, such as--

“(1) postsecondary education, vocational training, self-advocacy skills, and employment;

“(2) residential services and supports, housing, and transportation;

“(3) nutrition, health and wellness, recreational and social activities; and

“(4) personal safety and the needs of individuals with autism spectrum disorders who become involved with the criminal justice system.

“(c) *Eligible Entity*.--An eligible entity desiring to receive a grant under this section shall be a State or other public or private nonprofit organization, including an autism care center.

“(d) *Planning Grants*.--

“(1) **IN GENERAL.**--The Secretary shall award one-time grants to eligible entities to support the planning and development of initiatives that will expand and enhance service delivery systems for adults with autism spectrum disorders.

“(2) **APPLICATION.**--In order to receive such a grant, an eligible entity shall--

“(A) submit an application at such time and containing such information as the Secretary may require; and

“(B) demonstrate the ability to carry out such planning grant in coordination with the State Developmental Disabilities Council and organizations representing or serving individuals with autism spectrum disorders and their families.

“(e) *Implementation Grants.*--

“(1) **IN GENERAL.**--The Secretary shall award grants to eligible entities that have received a planning grant under subsection (d) to enable such entities to provide appropriate services to adults with autism spectrum disorders.

“(2) **APPLICATION.**--In order to receive a grant under paragraph (1), the eligible entity shall submit an application at such time and containing such information as the Secretary may require, including--

“(A) the services that the eligible entity proposes to provide and the expected outcomes for adults with autism spectrum disorders who receive such services;

“(B) the number of adults and families who will be served by such grant, including an estimate of the adults and families in underserved areas who will be served by such grant;

“(C) the ways in which services will be coordinated among both public and nonprofit providers of services for adults with disabilities, including community-based services;

“(D) where applicable, the process through which the eligible entity will distribute funds to a range of community-based or nonprofit providers of services, including local governments, and such entity's capacity to provide such services;

“(E) the process through which the eligible entity will monitor and evaluate the outcome of activities funded through the grant, including the effect of the activities upon adults with autism spectrum disorders who receive such services;

“(F) the plans of the eligible entity to coordinate and streamline transitions from youth to adult services;

“(G) the process by which the eligible entity will ensure compliance with the integration requirement provided under section 302 of the Americans With Disabilities Act of 1990 (42 U.S.C. 12182); and

“(H) a description of how such services may be sustained following the grant period.

“(f) *Evaluation.*--The Secretary shall contract with a third-party organization with expertise in evaluation to evaluate such demonstration grant program and, not later than 180 days after the conclusion of the grant program under subsection (e), submit a report to the Secretary. The evaluation

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and report may include an analysis of whether and to what extent the services provided through the grant program described in this section resulted in improved health, education, employment, and community integration outcomes for adults with autism spectrum disorders, or other measures, as the Secretary determines appropriate.

“(g) *Administrative Expenses.*--Of the amounts appropriated to carry out this section, the Secretary shall set aside not more than 7 percent for administrative expenses, including the expenses related to carrying out the evaluation described in subsection (f).

“(h) *Supplement, Not Supplant.*--Demonstration grant funds provided under this section shall supplement, not supplant, existing treatments, interventions, and services for individuals with autism spectrum disorders.”.

## **SEC. 7. NATIONAL REGISTRY.**

Part R of title III of the Public Health Service Act (42 U.S.C. 280i), as amended by

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section 6, is further amended by adding at the end the following:

### **“SEC. 399JJ. NATIONAL REGISTRY FOR AUTISM SPECTRUM DISORDERS.**

“(a) *Establishment.*--The Secretary, in consultation with national health organizations and professional societies with experience and expertise relating to autism spectrum disorders, shall establish a voluntary population-based registry of cases of autism spectrum disorders. Such registry shall be known as the ‘National Registry for Autism Spectrum Disorders’ (referred to in this section as the ‘Registry’). The Secretary shall ensure that the Registry maintains the privacy of individuals and the highest level of medical and scientific research ethics.

“(b) *Purpose.*--The purpose of the Registry is to facilitate the collection, analysis, and dissemination of data related to autism spectrum disorders that can increase understanding of causal factors, rates, and trends of autism spectrum disorders.

“(c) *Activities.*--In carrying out the Registry, the Secretary may--

“(1) implement a surveillance and monitoring system that is based on thorough and complete medical diagnosis data, clinical history, and medical findings;

“(2) collect standardized information concerning the environmental, medical, social, and genetic circumstances that may correlate with diagnosis of autism spectrum disorders;

“(3) promote the use of standardized autism spectrum disorder investigation and reporting tools of the Centers for Disease Control and Prevention, as well as standardized autism spectrum disorder protocols;

“(4) establish a standardized classification system for defining subcategories of autism spectrum disorders for surveillance research activities; and

“(5) support multidisciplinary reviews of autism spectrum disorders.”.

## **SEC. 8. MULTIMEDIA CAMPAIGN.**

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Part R of title III of the Public Health Service Act (42 U.S.C. 280i), as amended by section 7, is further amended by adding at the end the following:

**SEC. 399KK. MULTIMEDIA CAMPAIGN.**

*(a) In General.*--The Secretary, in order to enhance existing awareness campaigns and provide for the implementation of new campaigns, shall award grants to public and nonprofit private entities for the purpose of carrying out multimedia campaigns to increase public education and awareness and reduce stigma concerning--

(1) healthy developmental milestones for infants and children that may assist in the early identification of the signs and symptoms of autism spectrum disorders; and

(2) autism spectrum disorders through the lifespan and the challenges that individuals with autism spectrum disorders face, which may include transitioning into adulthood, securing appropriate job training or postsecondary education, securing and holding jobs, finding suitable housing, interacting with the correctional system, increasing independence, and attaining a good quality of life.

*(b) Eligibility.*--To be eligible to receive a grant under subsection (a), an entity shall--

(1) submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require; and

(2) provide assurance that the multimedia campaign implemented under such grant will provide information that is tailored to the intended audience, which may be a diverse public audience or a specific audience, such as health professionals, criminal justice professionals, or emergency response professionals."

**SEC. 9. INTERDEPARTMENTAL AUTISM COORDINATING COMMITTEE.**

*(a) Establishment.*--There is established a committee, to be known as the "Interdepartmental Autism Coordinating Committee," (referred to in this section as the "Committee") to coordinate all Federal efforts concerning autism spectrum disorders.

*(b) Responsibilities.*--In carrying out its duties under this section, the Committee shall--

(1) develop and annually update a summary of developments in research on autism spectrum disorders, services for people on the autism spectrum and their families, and programs that focus on people on the autism spectrum;

(2) monitor governmental and nongovernmental activities with respect to autism spectrum disorders;

(3) make recommendations to the Secretary of Health and Human Services and other relevant heads of agencies (referred to in this subsection as the "agency heads") regarding any appropriate changes to such activities and any ethical considerations relating to those activities;

(4) make recommendations to the agency heads regarding public participation in decisions relating to autism spectrum disorders;

(5) develop and annually update a strategic plan, including proposed budgetary requirements, for conducting and supporting research related to autism spectrum disorders, services for individuals on the autism spectrum and their families, and programs that focus on such individuals and their families; and

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(6) annually submit to Congress and the President such strategic plan and any updates to such plan.

(c) *Membership.*--

(1) **FEDERAL MEMBERS.**--The Committee shall be composed of--

(A) the Director of the National Institutes of Health, and the directors of such national research institutes of the National Institutes of Health as the Director determines appropriate;

(B) the heads of other agencies within the Department of Health and Human Services, as the Secretary determines appropriate; and

(C) representatives of the Department of Education, the Department of Defense, and other Federal agencies that provide services to individuals with autism spectrum disorders and their families or that have programs that affect individuals with autism spectrum disorders, as the Secretary determines appropriate.

(2) **NON-FEDERAL MEMBERS.**--Not less than 2/5 of the total membership of the Committee shall be composed of public members to be appointed by the Secretary, of which--

(A) at least one such member shall be an individual with an autism spectrum disorder;

(B) at least one such member shall be a parent or legal guardian of an individual with an autism spectrum disorder;

(C) at least one such member shall be a representative of a nongovernmental organization that provides services to individuals with autism spectrum disorders or their families; and

(D) at least one such member shall be a representative of a leading research, advocacy, and service organization for individuals with autism spectrum disorders and their families.

(d) *Administrative Support; Terms of Service; Other Provisions.*--The following provisions shall apply with respect to the Committee:

(1) The Committee shall receive necessary and appropriate administrative support from the Secretary.

(2) Members of the Committee appointed under subsection (c)(2) shall serve for a term of 4 years and may be reappointed for one or more additional 4-year terms. The term of any member appointed under subsection (c)(2)(C) or subsection (c)(2)(D) shall expire if the member no longer represents the organization described in such subsections. Any member appointed to fill a vacancy for an unexpired term shall be appointed for the remainder of such term. A member may serve after the expiration of the member's term until a successor has taken office.

(3) The Committee shall be chaired by the Secretary or the Secretary's designee. The Committee shall meet at the call of the chairperson and not fewer than 2 times each year.

(4) All meetings of the Committee or its subcommittees shall be public and shall include appropriate time periods for questions and presentations by the public.

(5) The Committee may convene workshops and conferences.

(e) *Subcommittees: Establishment and Membership.*--

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(1) **ESTABLISHMENT OF SUBCOMMITTEES.**--In carrying out its functions, the Committee may establish--

(A) a subcommittee on research on autism spectrum disorders;

(B) a subcommittee on services for individuals with autism spectrum disorders and their families and programs that focus on individuals with autism spectrum disorders; and

(C) such other subcommittees as the Committee determines appropriate.

(2) **MEMBERSHIP.**--Subcommittees may include as members individuals who are not members of the Committee.

(3) **MEETINGS.**--Subcommittees may hold such meetings as are necessary.

(f) *Interagency Autism Coordinating Committee.*--Part R of title III of the Public Health Service Act (42 U.S.C. 280i) is amended by striking section 399CC (42 U.S.C. 284i-2).

## **SEC. 10. NATIONAL NETWORK FOR AUTISM SPECTRUM DISORDERS RESEARCH AND SERVICES.**

(a) *Definitions.*--In this section:

(1) **SERVICES.**--The term ``services" means services to assist individuals with autism spectrum disorders to live more independently in their communities and improve the quality of life of such individuals.

(2) **SECRETARY.**--The term ``Secretary" means the Secretary of Health and Human Services.

(3) **TREATMENTS.**--The term ``treatments" means the health services, including mental health and behavioral therapy services, designed to improve or ameliorate symptoms associated with autism spectrum disorders.

(4) **AUTISM CARE CENTER.**--In this subpart, the term ``autism care center" means a center that is directed by a primary care coordinator who is an expert in autism spectrum disorder treatment and practice and provides an array of medical, psychological, behavioral, educational, and family services to individuals with autism and their families. Such a center shall--

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

(B) offer, through on-site service provision or through detailed referral and coordinated care arrangements, an autism management team of appropriate providers, including behavioral specialists, physicians, psychologists, social workers, family therapists, nurse practitioners, nurses, educators, and other appropriate personnel; and

(C) have the capability to achieve improvements in the management and coordination of care for targeted beneficiaries.

(b) *Establishment of the National Network for Autism Spectrum Disorders Research and Services.*--  
Not later than 1 year

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after the date of enactment of this Act, the Secretary shall establish the National Network for Autism Spectrum Disorders Research and Services (referred to in this section as the "National Network"). The National Network shall provide resources for, and facilitate communication between, autism spectrum disorder researchers and service providers for individuals with autism spectrum disorders and their families.

(c) *Purposes.*--The purposes of the National Network are to--

(1) build upon the infrastructure relating to autism spectrum disorders that exists on the date of enactment of this Act;

(2) strengthen linkages between autism spectrum disorders research and service initiatives at the Federal, regional, State, and local levels;

(3) facilitate the translation of research on autism spectrum disorders into services and treatments to improve the quality of life for individuals with autism and their families; and

(4) ensure the rapid dissemination of evidence-based or promising autism spectrum disorder practices through the National Data Repository for Autism Spectrum Disorders Research and Services described in subsection (e).

(d) *Organization and Activities of the National Network.*--

(1) **IN GENERAL.**--In establishing the National Network, the Secretary, acting through Administrator of the Health Resources and Services Administration, shall ensure that the National Network is composed of entities at the Federal, regional, State, and local levels.

(2) **REGIONAL LEADERSHIP AND ORGANIZATION.**--In establishing the National Network, the Secretary shall establish a Committee of Regional Leaders, which shall ensure that regional participation is provided through the appointment of regional leaders such as university- and community-based partnerships that represent the needs and interests of regional stakeholders (including individuals with autism spectrum disorders and their families, providers, and researchers). The Committee of Regional Leaders shall be responsible for monitoring, reporting, analyzing, and disseminating information in the Data Repository described in subsection (e) to other stakeholders to ensure that the information contained in such Data Repository is widely available to policymakers and service providers at the State and local levels, and to facilitate communication between various members of the National Network.

(3) **STATE AND COMMUNITY LEVEL LEADERSHIP AND ORGANIZATION.**--

(A) **STATE DIRECTORS.**--The regional leaders appointed under paragraph (2) shall appoint State directors who shall coordinate the activities of the National Network at the State and community levels.

(B) **STATE AND COMMUNITY SUBNETWORKS.**--The Secretary shall ensure that the State directors establish State and community autism subnetworks, which shall engage in a variety of frontline autism activities and provide services, including comprehensive diagnostics, treatment,

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resource and referral, and support programs, for individuals with autism spectrum disorders.

(e) *National Data Repository for Autism Spectrum Disorders Research and Services*.--

(1) **IN GENERAL**.--The Secretary shall establish a National Data Repository for Autism Spectrum Disorders Research and Services (referred to in this section as the "Data Repository") and shall contract with one eligible third-party entity to develop and administer such repository (referred to in this section as the "Data Repository Administrator"). The Data Repository shall be used to collect, store, and disseminate information regarding research, data, findings, models of treatment, training modules, and technical assistance materials related to autism spectrum disorders in order to facilitate the development and rapid dissemination of research into best practices that improve care.

(2) **ELIGIBILITY**.--To be eligible to receive the contract described in paragraph (1), an entity shall--

(A) be a public or private nonprofit entity; and

(B) have experience--

(i) collecting data;

(ii) developing systems to store data in a secure manner that does not personally identify individuals;

(iii) developing internet web portals and other means of communicating with a wide audience; and

(iv) making information available to the public.

(3) **CONTENTS**.--The Data Repository shall include--

(A) emerging research, data, and findings regarding autism spectrum disorders from basic and applied researchers and service providers;

(B) emerging or promising models of treatment, service provision, and training related to autism spectrum disorders that are developed in individual care centers or programs; and

(C) training modules and technical assistance materials.

(4) **DUTIES OF THE ADMINISTRATOR**.--The Data Repository Administrator shall--

(A) collect information from autism spectrum disorders research and service provision agencies and organizations including--

(i) Centers of Excellence in Autism Spectrum Disorder Epidemiology under section 399AA(b) of the Public Health Service Act (42 U.S.C. 280i(b));

(ii) autism care centers;

(iii) recipients of grants through the grant program for adult services under section 399II of the Public Health Service Act, as added by section 6 of this Act;

(iv) members and recipients of the national training initiatives on autism spectrum disorders under section 399LL of the Public Health Service Act, as added by section 11 of this Act; and

(v) the Committee of Regional Leaders, regional leaders, State directors, members of State and community autism subnetworks, and other entities, as determined by the Secretary;

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(B) securely store and maintain information in the Data Repository in a manner that does not personally identify individuals;

(C) make information in the Data Repository accessible through an Internet web portal or other appropriate means of sharing information;

(D) ensure that the information contained in the Data Repository is accessible to the National Network, including health care providers, educators, and other autism spectrum disorders service providers at the national, State, and local levels; and

(E) provide a means through the Internet web portal, or through other means, for members of the National Network to share information, research, and best practices on autism spectrum disorders.

(f) *Supplement Not Supplant.*--Amounts provided under this section shall be used to supplement, not supplant, amounts otherwise expended for existing network or organizational structures relating to autism spectrum disorders.

#### **SEC. 11. NATIONAL TRAINING INITIATIVES ON AUTISM SPECTRUM DISORDERS.**

Part R of title III of the Public Health Service Act (42 U.S.C. 280i), as amended by section 8, is further amended by adding at the end the following:

#### **``SEC. 399LL. NATIONAL TRAINING INITIATIVES ON AUTISM SPECTRUM DISORDERS.**

``(a) *National Training Initiative Supplemental Grants.*--

``(1) **IN GENERAL.**--The Secretary shall award multiyear national training initiative supplemental grants to eligible entities so that such entities may provide training and technical assistance and to disseminate information, in order to enable such entities to address the unmet needs of individuals with autism spectrum disorders and their families.

``(2) **ELIGIBLE ENTITY.**--To be eligible to receive assistance under this section an entity shall--

``(A) be a public or private nonprofit entity, including University Centers for Excellence in Developmental Disabilities and other service, training, and academic entities; and

``(B) submit an application as described in paragraph (3).

``(3) **REQUIREMENTS.**--An eligible entity that desires to receive a grant under this paragraph shall submit to the Secretary an application containing such agreements and information as the Secretary may require, including agreements that the training program shall--

``(A) provide trainees with an appropriate balance of interdisciplinary academic and community-based experiences;

``(B) have a demonstrated capacity to include individuals with autism spectrum disorders, parents, and family members as part of the training program to ensure that a person and family-centered approach is used;

``(C) provide to the Secretary, in the manner prescribed by the Secretary, data regarding the outcomes of the provision of training and technical assistance;

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((D) demonstrate a capacity to share and disseminate materials and practices that are developed and evaluated to be effective in the provision of training and technical assistance; and

((E) provide assurances that training, technical assistance, and information dissemination performed under grants made pursuant to this paragraph shall be consistent with the goals established under already existing disability programs authorized under Federal law and conducted in coordination with other relevant State agencies and service providers.

((4) **ACTIVITIES.**--An entity that receives a grant under this section shall expand and develop interdisciplinary training and continuing education initiatives for health, allied health, and educational professionals by engaging in the following activities:

((A) Promoting and engaging in training for health, allied health, and educational professionals to identify, diagnose, and develop interventions for individuals with, or at risk of developing, autism spectrum disorders.

((B) Working to expand the availability of training and information regarding effective, lifelong interventions, educational services, and community supports, including specific training for criminal justice system, emergency health care, legal, and other mainstream first responder professionals, to identify characteristics of individuals with autism spectrum disorders and to develop appropriate responses and interventions.

((C) Providing technical assistance in collaboration with relevant State, regional, or national agencies, institutions of higher education, advocacy groups for individuals with autism spectrum disorders and their families, or community-based service providers.

((D) Developing mechanisms to provide training and technical assistance, including

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for-credit courses, intensive summer institutes, continuing education programs, distance-based programs, and web-based information dissemination strategies.

((E) Collecting data on the outcomes of training and technical assistance programs to meet statewide needs for the expansion of services to children with autism spectrum disorders and adults with autism spectrum disorders.

((b) *Technical Assistance.*--The Secretary shall reserve 2 percent of the appropriated funds to make a grant to a national organization with demonstrated capacity for providing training and technical assistance to the entities receiving grants under subsection (a) to enable such entities to--

((1) assist in national dissemination of specific information, including evidence-based and promising best practices, from interdisciplinary training programs, and when appropriate, other entities whose findings would inform the work performed by entities awarded grants;

((2) compile and disseminate strategies and materials that prove to be effective in the provision of training and technical assistance so that the entire network can benefit from the models, materials, and practices developed in individual centers;

((3) assist in the coordination of activities of grantees under this section;

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((4) develop an Internet web portal that will provide linkages to each of the individual training initiatives and provide access to training modules, promising training, and technical assistance practices and other materials developed by grantees;

((5) convene experts from multiple interdisciplinary training programs and individuals with autism spectrum disorders and their families to discuss and make recommendations with regard to training issues related to the assessment, diagnosis of, treatment, interventions and services for, children with autism spectrum disorders and adults with autism spectrum disorders; and

((6) undertake any other functions that the Secretary determines to be appropriate.

((c) *Supplement Not Supplant.*--Amounts provided under this section shall be used to supplement, not supplant, amounts otherwise expended for existing network or organizational structures."

## **SEC. 12. AMENDMENTS RELATING TO HEALTH INSURANCE.**

(a) *ERISA.*--

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

### **((SEC. 715. REQUIRED COVERAGE FOR AUTISM SPECTRUM DISORDERS.**

((a) *In General.*--A group health plan, and a health insurance issuer providing health insurance coverage in connection with a group health plan, shall provide coverage for the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders.

((b) *Rule of Construction.*--Nothing in this section shall be construed--

((1) as preventing a group health plan or health insurance issuer from imposing financial requirements or limits in relation to benefits for the diagnosis and treatment of autism spectrum disorders, except that such financial requirements or limits for any such benefits may not be less favorable to the individual than such financial requirements or limits for substantially all other medical and surgical benefits covered by the plan, and there shall be no separate financial requirements or limits that are applicable only with respect to benefits for the diagnosis or treatment of autism spectrum disorders; and

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

((c) *Notice Under Group Health Plan.*--The imposition of the requirements of this section shall be treated as a material modification in the terms of the plan described in section 102(a)(1), for purposes of assuring notice of such requirements under the plan, except that the summary description required to be provided under the last sentence of section 104(b)(1) with respect to such modification shall be provided not later than the earlier of--

((1) 60 days after the first day of the first plan year in which such requirements apply; or

((2) in the first mailing after the date of enactment of the Autism Treatment Acceleration Act of 2009 made by the plan or issuer to the participant or beneficiary.

((d) *Prohibitions.*--A group health plan, and a health insurance issuer offering group health

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insurance coverage in connection with a group health plan, shall not--

((1) deny to an individual eligibility, or continued eligibility, to enroll or to renew coverage under the terms of the plan, solely for the purpose of avoiding the requirements of this section; or

((2) deny coverage otherwise available under this section on the basis that such coverage will not--

((A) develop skills or functioning;

((B) maintain skills or functioning;

((C) restore skills or functioning; or

((D) prevent the loss of skills or functioning.

((e) *Preemption; Relation to State Law.*--

((1) **IN GENERAL.**--Nothing in this section shall be construed to preempt any State law (or cost sharing requirements under State law) with respect to health insurance coverage that requires coverage of at least the coverage for autism spectrum disorders otherwise required under this section.

((2) **EFFECT ON OTHER LAWS.**--Nothing in this section shall be construed to affect or modify the provisions of section 514 with respect to group health plans.

((f) *Definitions.*--In this section:

((1) **AUTISM SPECTRUM DISORDERS.**--The term 'autism spectrum disorders' means developmental disabilities that cause substantial impairments in the areas of social interaction, emotional regulation, communication, and the integration of higher-order cognitive processes and which may be characterized by the presence of unusual behaviors and interests. Such term includes autistic disorder, pervasive developmental disorder (not otherwise specified), Asperger syndrome, Rett's disorder, and childhood disintegrative disorder.

((2) **DIAGNOSIS OF AUTISM SPECTRUM DISORDERS.**--The term 'diagnosis of autism spectrum disorders' means medically necessary assessments, evaluations, or tests to diagnose whether an individual has an autism spectrum disorder.

((3) **TREATMENT OF AUTISM SPECTRUM DISORDERS.**--The term 'treatment of autism spectrum disorders' means the following care prescribed, provided, or ordered for an individual diagnosed with an autism spectrum disorder by a physician, psychologist, or other qualified professional who determines the care to be medically necessary:

((A) Medications prescribed by a physician and any health-related services necessary to determine the need or effectiveness of the medications.

((B) Occupational therapy, physical therapy, and speech therapy.

((C) Direct or consultative services provided by a psychiatrist or psychologist.

((D) Professional, counseling, and guidance services and treatment programs, including applied behavior analysis and other structured behavioral programs. In this subparagraph, the term 'applied behavior analysis' means the design, implementation and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human

behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.

“(E) Augmentative communication devices and other assistive technology devices.”

(2) **CLERICAL AMENDMENT.**--The table of contents in section 1 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1001 note) is amended by inserting after the item relating to section 714 the following:

“Sec. 715. Required coverage for autism spectrum disorders.”

(b) *Public Health Service Act.*--

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

“**SEC. 2708. REQUIRED COVERAGE FOR AUTISM SPECTRUM DISORDERS.**

“(a) *In General.*--A group health plan, and a health insurance issuer providing health insurance coverage in connection with a group health plan, shall provide coverage for the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders.

“(b) *Rule of Construction.*--Nothing in this section shall be construed--

“(1) as preventing a group health plan or health insurance issuer from imposing financial requirements or limits in relation to benefits for the diagnosis and treatment of autism spectrum disorders, except that such financial requirements or limits for any such benefits may not be less favorable to the individual than such financial requirements or limits for substantially all other medical and surgical benefits covered by the plan, and there shall be no separate financial requirements or limits that are applicable only with respect to benefits for the diagnosis or treatment of autism spectrum disorders; or

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

“(c) *Notice Under Group Health Plan.*--The imposition of the requirements of this section shall be treated as a material modification in the terms of the plan described in section 102(a)(1), for purposes of assuring notice of such requirements under the plan, except that the summary description required to be provided under the last sentence of section 104(b)(1) with respect to such modification shall be provided not later than the earlier of--

“(1) 60 days after the first day of the first plan year in which such requirements apply; or

“(2) in the first mailing after the date of enactment of the Autism Treatment Acceleration Act of 2009 made by the plan or issuer to the enrollee.

“(d) *Prohibitions.*--A group health plan, and a health insurance issuer offering group health insurance coverage in connection with a group health plan, shall not--

“(1) deny to an individual eligibility, or continued eligibility, to enroll or to renew coverage under the terms of the plan, solely for the purpose of avoiding the requirements of this section; or

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``(2) deny coverage otherwise available under this section on the basis that such coverage will not--

``(A) develop skills or functioning;

``(B) maintain skills or functioning;

``(C) restore skills or functioning; or

``(D) prevent the loss of skills or functioning.

``(e) *Preemption; Relation to State Law.*--

``(1) **IN GENERAL.**--Nothing in this section shall be construed to preempt any State law (or cost sharing requirements under State law) with respect to health insurance coverage that requires coverage of at least the coverage for autism spectrum disorders otherwise required under this section.

``(2) **ERISA.**--Nothing in this section shall be construed to affect or modify the provisions of section 514 of the Employee Income Retirement Security Act of 1974 with respect to group health plans.

``(f) *Definitions.*--In this section:

``(1) **AUTISM SPECTRUM DISORDERS.**--The term `autism spectrum disorders' means developmental disabilities that cause substantial impairments in the areas of social interaction, emotional regulation, communication, and the integration of higher-order cognitive processes and which may be characterized by the presence of unusual behaviors and interests. Such term includes autistic disorder, pervasive developmental disorder (not otherwise specified), and Asperger syndrome.

``(2) **DIAGNOSIS OF AUTISM SPECTRUM DISORDERS.**--The term `diagnosis of autism spectrum disorders' means medically necessary assessments, evaluations, or tests to diagnose whether an individual has an autism spectrum disorder.

``(3) **TREATMENT OF AUTISM SPECTRUM DISORDERS.**--The term `treatment of autism spectrum disorders' means the following care prescribed, provided, or ordered for an individual diagnosed with an autism spectrum disorder by a physician, psychologist, or other qualified professional who determines the care to be medically necessary:

``(A) Medications prescribed by a physician and any health-related services necessary to determine the need or effectiveness of the medications.

``(B) Occupational therapy, physical therapy, and speech therapy.

``(C) Direct or consultative services provided by a psychiatrist or psychologist.

``(D) Professional, counseling, and guidance services and treatment programs, including applied behavior analysis and other structured behavioral programs. In this subparagraph, the term `applied behavior analysis' means the design, implementation and evaluation of environmental modifications,

using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.

“(E) Augmentative communication devices and other assistive technology devices.”.

(2) **INDIVIDUAL MARKET.**--Subpart 3 of part B of title XXVII of the Public Health Service Act (42 U.S.C. 300gg-51 et seq.) is amended by adding at the end the following:

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

“The provisions of section 2708 shall apply to health insurance coverage offered by a health insurance issuer in the individual market in the same manner as they apply to health insurance coverage offered by a health insurance issuer in connection with a group health plan in the small or large group market.”.

(c) *Effective Dates.*--

(1) **GROUP HEALTH PLANS.**--

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

(B) **SPECIAL RULE FOR COLLECTIVE BARGAINING AGREEMENTS.**--In the case of a group health plan maintained pursuant to one or more collective bargaining agreements between employee representatives and one or more employers, any plan amendment made pursuant to a collective bargaining agreement relating to the plan which amends the plan solely to conform to any requirement added by the amendment made by subsections (a) and (b)(1) shall not be treated as a termination of such collective bargaining agreement.

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

**SEC. 13. AUTHORIZATION OF APPROPRIATIONS.**

There are authorized to be appropriated for fiscal years 2010 through 2014 such sums as may be necessary to carry out this Act.

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End of Record