

# Autism Comprehensive Treatment Acceleration Act

## Proposed DRAFT

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

IN THE SENATE OF THE UNITED STATES

A BILL

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

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

SECTION 1. SHORT TITLE.

This Act may be cited as the "Autism Treatment Acceleration Act of 2008".

SEC . 2. FINDINGS.

Congress makes the following findings:

(1) Autism is a neurobiological disorder, categorized under the umbrella of Pervasive Developmental Disorders as outlined in the most recent edition of the DSM-IV. The term Autism Spectrum Disorders (referred to in this section as "ASDs") include Autism, Aspergers syndrome, Retts syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (usually referred to as PDD-NOS).

(2) The National Institutes of Health has determined that ASDs are presently characterized by 3 distinctive behaviors: impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests.

(3) Recent clinical investigations have identified numerous co-morbid disease states in children with autism, including impaired gastrointestinal function, inflammatory bowel disease, immune dysfunction, chronic viral, fungal, and bacterial infections, evidence of increased oxidative stress, severely disordered serum chemistries, decreased elimination of toxins, methylation impairment, mitochondrial dysfunction,

and microglial activation in the brain. This is evidence that while autism is currently defined primarily through behavior, it may potentially be defined by distinct biological changes as biomarkers are found.

(4) Based on data collected in 2002 of eight year olds, the Centers for Disease Control and Prevention found that the prevalence of ASD is estimated to be 1 in 150 Americans.

(5) Autism is presently the fastest-growing neurodevelopmental disorder with a 10 to 17 percent growth annually, according to the Autism Society of America.

(6) The causes and contributing factors for autism are poorly understood. Evidence suggests both genetic and environmental factors appear to play a role but the etiology of autism may vary between individuals.

(7) There is growing concern and increasing scientific evidence that prenatal and postnatal exposure to xenobiotic and biotic factors may act synergistically with unidentified susceptibility-genetic factors to produce autism spectrum disorders.

(8) Many thousands of chemicals used by industry have not been tested for their effects on children's neurodevelopment. Industrial chemicals such as methylmercury, lead, PCBs, organophosphates, pesticides and arsenic are known causes of neurodevelopmental disorders and subclinical brain dysfunction.

(9) Researchers have developed animal models of the regression of neurobehavioral function seen in autism using chemicals that are known to lead to birth defects and autism in the human child, such as thalidomide.

(10) Children with autism are known to have a very high rate (about 30%) of seizure disorder.

(11) Research has determined that children with autism and/or their parents show a higher incidence of at least two newly identified gene deletions or polymorphisms that may make them more susceptible to environmental chemicals.

(12) A study by researchers at the University of California , Davis , [M.I.N.D. Institute](#) and the [NIEHS Center for Children's Environmental Health](#) demonstrate that children with autism have different immune system responses than children who do not have the disorder.

(13) The National Institutes of Mental Health finds that among the many methods available for treatment and education of people with autism, ABA has become widely accepted as an effective treatment and a report from the U.S. Surgeon General states; "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. Parental involvement has emerged as a

major factor in treatment success".

(14) In the report, " Consolidated Analysis of Strengths, Weaknesses, Opportunities, and Gaps in ASD Research", of the NIH Interagency Autism Coordinating Committee, they stated that; " The challenge of meeting the clinical needs of this population is now recognized as a significant public health issue, and research to identify efficacious interventions is a high priority. "

## SEC . 3 DEFINITIONS

(a) GENERAL DEFINITIONS.—In this Act:

(1) ADULT WITH AUTISM.—The term "adult with autism" means an individual with diagnosed with an ASD who has attained 22 years of age.

(2) AFFECTED INDIVIDUAL.—The term "affected individuals" means an individual diagnosed with an ASD.

(3) AUTISM.—The term "autism" means an autism spectrum disorder (referred to in this Act as " ASD ") or a related neurodevelopmental disability.

(4) CHILDREN WITH AUTISM.—The term "children with autism" means individuals diagnosed with an ASD who have not attained 22 years of age.

(5) THERAPEUTIC SERVICES.—The term "therapeutic services" means provision of habilitative or rehabilitative services including but not limited to; psychological care and treatment, applied behavioral analysis, speech, occupational, and physical therapies that provide treatment in the following areas: (i) self care and feeding, (ii) pragmatic, receptive, and expressive language, (iii) cognitive functioning, (iv) behavior (v) motor planning, and (vi) sensory processing.

(6) TREATMENTS. — The term "treatments" means the medically necessary services, including but not limited to therapeutic services, designed to improve or ameliorate symptoms associated with autism.

(8) MEDICALLY NECESSARY – means any care, treatment, intervention, service or item which will or is reasonably expected to do any of the following: (i) prevent the onset of an illness, condition, injury, disease or disability; (ii) reduce or ameliorate the physical, mental or developmental effects of an illness, condition, injury, disease or disability; or (iii) assist to achieve or maintain maximum functional activity in performing daily activities.

(9) ENVIRONMENTAL FACTORS – means viruses, medications, lifestyle factors,

chemicals, heavy metals and other influences that children are exposed to irregardless of mechanism of exposure.

(10) CO-MORBID – means other states or condition of disease, disorder or pathology present in an individual which are not primarily symptoms of ASD .

#### SEC . 4. ACCELERATION OF RESEARCH TO MEDICAL TREATMENTS FOR AUTISM SPECTRUM DISORDERS

(a) In accordance with the Findings contained in Sec. 2 of this ACT of Congress, the following activities shall be prioritized by the Secretary of NIH, as appropriations are made available through the authorization contained within the Combating Autism Act 2006, 42 USC 201 section 399CC, 409C, and section 404H;

(1) Since the etiology of autism is not fully understood, efforts to expedite the investigation into the prenatal and postnatal susceptibility factors to developing an ASD considering heritability factors, de novo genetic and environmental implications.

(2) Additional investigations into associated pathological states offer the promise of the identification of biomarkers, therefore studies, clinical trials and research designed to increase the understanding of co-morbid disease states, biomarkers and identification of sub- cohort populations diagnosed with ASD .

(3) Since many biomedical imbalances are amenable to medical and nutritional interventions, the information elicited from such findings shall be made readily available through pertinent governmental agencies and non-governmental organizations to clinicians treating persons with ASD through the development and promotion of continuing medical education requirements promulgated at the State level.

(4) Funding for animal studies shall be prioritized for which targeted environmental agents can be tested to evaluate mechanisms and identify susceptibility genes that may interact with environmental factors.

(5) Efforts to ensure the rapid dissemination of promising autism treatments and associated co-morbid disorders to medical practitioners, autism service providers and pertinent policy makers at all levels of government, including but not limited to State Directors of Public Health, and Human Services agencies and the incorporation of this information into clinical practice guidelines for diagnosis and treatment of ASDs.

(6) Studies which examine children who formerly were classified as having an ASD

but no longer meet the diagnostic criteria. Both biological and educational interventions should be considered.

## SEC . 5. RIGHT TO RECEIVE MEDICALLY NECESSARY TREATMENTS FOR PERSONS DIAGNOSED WITH ASD

- The standard of care for persons diagnosed with an ASD shall include that appropriate medical care is individualized and considers the varying affectations of ASD and the presence of co-morbid disease states.
- Treatment or evaluation of co-morbid conditions, not diagnosed as an ASD shall not be denied because a person also has an ASD .

## Sec. 6. NATIONAL AUTISM EXECUTIVE COMMITTEE

• ESTABLISHMENT AND PURPOSE.—The Secretary shall establish a National Autism Executive Committee (referred to in this section as the "Committee") for the purpose of leveraging and enhancing the autism research and treatment capacity of Federal, regional, State, and local agencies and to oversee development and coordination of activities outlined in Sec. 4 of this ACT.

• Such Committee shall—

(1) expand, intensify, and coordinate activities with respect to research on autism spectrum disorder, including basic and clinical research in various fields including; etiology, pathology, developmental pediatrics, neurobiology, genetic, epigenetic, pharmacology, nutrition, immunology, neuroimmunology, endocrinology, gastroenterology, and toxicology;

(2) strengthen linkages between autism research and service initiatives at Federal, regional, State, and community levels;

(3) ensure the rapid dissemination of promising autism treatments, biomarkers, pathology and associated co-morbid disorders to medical practitioners, autism service providers and pertinent policy makers at all levels of government, including but not limited to State Directors of Public Health, and Human Services agencies and the incorporation of this information into clinical practice guidelines for diagnosis and treatment of ASDs;

(4) support coordination of autism epidemiological initiatives and monitoring activities especially those which may help to identify birth co-horts, sub-cohorts and environmental exposures;

(5) facilitate communication between families of persons with autism and governmental agencies and other facilities that integrate or coordinate research and

services, promoting efforts that can—

- (A) reduce the fragmentation of care and provide appropriate services;
- (B) provide a fertile environment for the sharing, implementation and evaluation of emerging medical and therapeutic practices;
- (C) offer a full array of medical, behavioral, developmental, mental health, and family support services responsive to the needs of to individuals with ASD and their families; and
- (D) provide accessibility to comprehensive services expressing compassionate and family/person centered focus, and cultural relevance.

(6) a report will be submitted annually, one year from the passage of this Act, and every year thereafter, to the Congress and the Office of the President, detailing the Committee's activities outlined herein.

(c) ORGANIZATION OF THE COMMITTEE.—(1) IN GENERAL.—In establishing the Committee, the Secretary, shall upgrade and coordinate autism treatments and services efforts that are ongoing on the date of enactment of this Act and shall promote Federal, regional, State, and local integration where practicable. The Committee may be divided into subcommittees in efforts to best utilize the expertise of the various members to address the Network activities. Subcommittees will be determined by the Executive Committee.

(2) COMPOSITION.—The Secretary shall ensure that the Committee is composed of stakeholders; (A) A minimum of 25% of the Committee membership shall include family members of a person with an ASD , who are not acting as a designated representative of a government agency or non-governmental organization. (B) Additionally, 25% of the membership of the Committee shall be representatives of non-governmental organizations that provide advocacy, direct services or other support to persons with ASD and their families. No more than two representatives affiliated with the same organization shall be able to serve at a time (C) A minimum of 25% of the membership shall be representative of clinicians who treat children with ASD or who specialize in the co-morbid disorders occurring with ASD and scientific researchers studying the underlying pathology contributing to ASD . (D) A minimum of thirty-two members will serve on the Committee, with a maximum of 40; terms will be for three years and an appointee may serve no more than two consecutive terms, unless fulfilling an official governmental role.

(E) Public appointees may not serve consecutively on the Committee while also fulfilling an appointment on another governmental body or in serving the federal government in any other official capacity related to ASD .

(3) FEDERAL LEADERSHIP AND ORGANIZATION.— (A) The Secretary shall establish

an ASD Committee (referred to in this section as the "Committee") to coordinate and carry out the duties described in subparagraph (a) of this Section.

(B). The membership of such Committee shall be composed of individuals appointed by the Secretary, including leading representatives from relevant governmental agencies, including representatives from NIH, NIEHS, NICHE, NIMH, CDC, EPA and other pertinent agencies whose participation is integral to implementation of the provisions of this Act.

(C) When appropriate government agencies or other official bodies with existing responsibilities for areas of ASD research or services will cooperate with the Committee in efforts to carry out the stated duties and the Committee will provide input to appropriate government agencies regarding allocations for autism research funding as prioritized in Section 4 of this Act.

## SEC . 7. AMENDMENTS RELATING TO HEALTH INSURANCE.

(a) ERISA.— (1) IN GENERAL.—Subpart B of part 7 of sub title 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 . 714. 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. Persons diagnosed with an ASD shall receive medically necessary care for otherwise diagnosed conditions, in accordance with their health plan, and otherwise covered medical services shall not be denied because a person is diagnosed with an ASD or due to utilization of benefits under this section.

"(b) RULE OF CONSTRUCTION.—Nothing in this section shall be construed— "(1) as preventing a group health plan or health insurance issuer from imposing deductibles, coinsurance, or other cost-sharing in relation to benefits for the diagnosis and treatment of autism spectrum disorders, except that such coinsurance or other cost-sharing for any such benefits may not be greater than such coinsurance or cost-sharing for any other benefit; 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) by not later than 60 days after the first day of the first plan year in which such requirements apply; “(2) in the next mailing made by the plan or issuer to the participant or beneficiary; or “(3) January 1, 2010 . “(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 “(2) deny coverage otherwise available under this section on the basis that coverage is necessary to develop, maintain, or restore skills or functioning, or to 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 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 with respect to group health plans. “(f) DEFINITIONS.—In this section:

“(1) AUTISM SPECTRUM DISORDERS.—The term ‘autism spectrum disorders’ means a neurobiological disease that may cause substantial impairments in the areas of social interaction, communication, and the presence of unusual or stereotypical behaviors and interests. Such term includes autistic disorder, pervasive developmental disorder (not otherwise specified), Asperger’s syndrome, Retts 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 physician or psychologist. “(D) Professional, counseling, and guidance services and treatment programs, including but not limited to, 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 relations between environment and behavior.”.

(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 713 the following:

“Sec. 714. 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 . 2707. 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 deductibles, coinsurance, or other cost-sharing in relation to benefits for the diagnosis and treatment of autism spectrum disorders, except that such coinsurance or other cost-sharing for any such benefits may not be greater than such coinsurance or cost-sharing for any other benefit; 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 “(1) by not later than 60 days after the first day of the first plan year in which such requirements apply; “(2) in the next mailing made by the plan or issuer to the enrollee; or “(3) January 1, 2010 . “(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 “(2) deny coverage otherwise available under this section on the basis that coverage is medically necessary to develop, maintain, or restore health, skills or functioning, or to prevent the loss of health, skills or functioning. “(e) PREEMPTION; RELATION TO STATE LAW.— “(1) IN GENERAL.—Nothing in this section shall be construed to preempt any 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 with respect to group health plans. “(f) DEFINITIONS.—In this section: “(1) AUTISM SPECTRUM DISORDERS.—The term ‘autism spectrum disorders’ means neurodevelop

mental disorders that cause substantial impairments in the areas of social interaction, communication, and the presence of unusual behaviors and interests. Such term includes autistic disorder, pervasive developmental disorder (not otherwise specified), and Asperger's 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 relations between environment and behavior.”.

(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 2707 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 1 or more collective bargaining agreements between employee representatives and 1 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 subsection (a) shall not be treated as a termination of such collective bargaining agreement. (2) INDIVIDUAL PLANS.—The amendment made by subsection (b) 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.