AN ACT concerning health.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 1. Short title. This Act may be cited as the Autism and Co-Occurring Medical Conditions Awareness Act.

Section 5. Findings. The General Assembly finds the following:

(1) The medical consensus is that autism is an idiopathic disorder that has complex and multiple etiologies. The development of autism appears to be a complex interaction of multiple genetic and environmental factors. Both the prevalence and incidence of autism has risen in recent decades.

(2) The Centers for Disease Control estimates that one in 68 children born in 2002 and one in 42 boys have been identified as living with autism.

(3) A 2012 survey conducted by the Centers for Disease Control of U.S. households estimated one in 50 children ages 6 to 17 has an autism spectrum disorder.

(4) Autism spectrum disorders occur among all racial, ethnic, and socioeconomic groups.

(5) Autism spectrum disorders are almost 5 times more common among boys than among girls.

(6) According to the Centers for Disease Control, autism rates increased 78% between 2002 and 2008. The most recent estimate is roughly 30% higher than the estimate for 2008 (one in 88), 60% higher than the estimate for 2006 (one in 110), and 120% higher than the estimates for 2000 and 2002 (one in 150).

(7) While autism spectrum disorders have primarily been diagnosed in measuring deficits in the areas of communication, socialization, and behavior, recent clinical and scientific investigations have determined that co-occurring pathophysiological conditions may occur more commonly in persons also diagnosed with autism. These pathologies include, but are not limited to, allergies, autoimmune conditions, gastrointestinal diseases, immune dysregulation, metabolic disturbances, mitochondrial abnormalities, oxidative stress, neuroinflammation, and seizure disorders.

(8) Scientific inquiry is providing evidence of biological markers, including, but not limited to, single nucleotide polymorphisms, indications of cellular inflammation, increased cellular oxidation and damage, and abnormal DNA methylation, that may be clinically significant in the provision of appropriate medical care for persons also diagnosed with an autism spectrum disorder.

Therefore, it is the intention of the General Assembly to

promote a greater awareness and the detection, diagnosis, and treatment of underlying and co-occurring medical conditions that occur more commonly in persons with autism to further awareness, scientific understanding, and health outcomes for persons living with autism.

Section 10. Definitions. In this Act:

"Autism spectrum disorder" means a neurobiological disorder, including autism, regressive autism, Asperger Syndrome, and pervasive developmental disorders not otherwise specified.

"Clinical symptomatology" means any indication of disorder or disease when experienced by an individual as a change from normal function, sensation, or appearance.

"Co-occurring or otherwise diagnosed medical condition" means a simultaneous illness, condition, injury, disease, pathology, or disability that is not primarily diagnosed as an autism spectrum disorder.

"Department" means the Department of Financial and Professional Regulation.

"Pathophysiological" means the functional alterations in the body related to a disease or syndrome.

"Provider" means any provider of healthcare services in this State.

Section 15. Study and education. Public partnerships and

private partnerships supporting the discovery of biomarkers and their implications in pathophysiological conditions shall be encouraged and information derived from such discoveries shall be disseminated to providers and made available to the general public through research initiatives that may be promoted by universities, medical clinics, health care providers, consortiums, State agencies, private organizations, public organizations, and any party that may contribute to the scientific understanding of medical conditions associated or occurring more often in persons also diagnosed with an autism spectrum disorder than in the general population.

Universities, private organizations, public organizations, and associations are encouraged to develop for providers who treat persons with autism spectrum disorders continuing education courses which address training in evaluation, diagnosis, and treatments for co-occurring and otherwise diagnosed pathophysiological conditions in autism spectrum disorders to promote and align standard of care practices to reflect emerging clinical findings and promising practices derived from improved patient outcomes.

Section 20. Treatment or service of persons with an autism spectrum disorder. Providers are strongly encouraged to evaluate persons diagnosed with an autism spectrum disorder for co-occurring or otherwise diagnosed medical conditions when clinical symptomatology is present or suspected and prescribe

appropriate treatments or services in alignment with care practices for the condition, illness, injury, disease, or disability. Providers may consider, without limitation, whether or not a medication or any ingredient, allergen, potential toxicant, or artificial agent may exacerbate clinical symptomatology of autism spectrum disorder or a related or co-occurring or otherwise diagnosed medical condition and, if so, may consider adopting measures that would result in the reduction or elimination of risk to the patient.

Section 25. Complaints. Any person with an autism spectrum disorder, or the person's parent or legal guardian on his or her behalf, who believes they have not received an appropriate medical assessment, evaluation, diagnosis, service or treatment from a provider because he or she is also diagnosed with an autism spectrum disorder may report the incident to the Department.

Section 30. Right to seek new care. A person with an autism spectrum disorder, or the person's parent or legal guardian on his or her behalf, retains the right to seek further medical opinions or care from other providers.

A parent or legal guardian shall not be threatened with loss of parental or legal guardianship rights for a person with autism spectrum disorder for pursuing additional medical expertise, especially in the case of trying to ascertain

appropriate identification and diagnosis of underlying or co-occurring medical conditions that may or may not be exacerbating symptoms primarily associated with an autism spectrum disorder. This Section does not abrogate or restrict any responsibilities set forth under the Abused and Neglected Child Reporting Act.

Any person diagnosed as having an autism spectrum disorder or his or her parent or legal guardian shall not be denied the right to pursue appropriate and available medical interventions or treatments that may help to ameliorate or improve the symptoms primarily associated with an autism spectrum disorder or co-occurring or otherwise diagnosed medical condition.

Any person diagnosed as having an autism spectrum disorder or his or her parent or legal guardian shall not be denied the right to decline a medical treatment or intervention.

Section 35. Repeal. In order to consider the most innovative medical study and research involving autism and co-occurring medical conditions, this Act is repealed 5 years after the effective date of this Act.

Section 90. The Illinois Insurance Code is amended by changing Section 356z.14 and by adding Section 356z.24 as follows:

(215 ILCS 5/356z.14)

Sec. 356z.14. Autism spectrum disorders.

(a) A group or individual policy of accident and health insurance or managed care plan amended, delivered, issued, or renewed after the effective date of this amendatory Act of the 95th General Assembly must provide individuals under 21 years of age coverage for the diagnosis of autism spectrum disorders and for the treatment of autism spectrum disorders to the extent that the diagnosis and treatment of autism spectrum disorders are not already covered by the policy of accident and health insurance or managed care plan.

(b) Coverage provided under this Section shall be subject to a maximum benefit of $36,000 per year, but shall not be subject to any limits on the number of visits to a service provider. After December 30, 2009, the Director of the Division of Insurance shall, on an annual basis, adjust the maximum benefit for inflation using the Medical Care Component of the United States Department of Labor Consumer Price Index for All Urban Consumers. Payments made by an insurer on behalf of a covered individual for any care, treatment, intervention, service, or item, the provision of which was for the treatment of a health condition not diagnosed as an autism spectrum disorder, shall not be applied toward any maximum benefit established under this subsection.

(c) Coverage under this Section shall be subject to copayment, deductible, and coinsurance provisions of a policy

of accident and health insurance or managed care plan to the extent that other medical services covered by the policy of accident and health insurance or managed care plan are subject to these provisions.

(d) This Section shall not be construed as limiting benefits that are otherwise available to an individual under a policy of accident and health insurance or managed care plan and benefits provided under this Section may not be subject to dollar limits, deductibles, copayments, or coinsurance provisions that are less favorable to the insured than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally.

(e) An insurer may not deny or refuse to provide otherwise covered services, or refuse to renew, refuse to reissue, or otherwise terminate or restrict coverage under an individual contract to provide services to an individual because the individual or their dependent is diagnosed with an autism spectrum disorder or due to the individual utilizing benefits in this Section.

(f) Upon request of the reimbursing insurer, a provider of treatment for autism spectrum disorders shall furnish medical records, clinical notes, or other necessary data that substantiate that initial or continued medical treatment is medically necessary and is resulting in improved clinical status. When treatment is anticipated to require continued services to achieve demonstrable progress, the insurer may

request a treatment plan consisting of diagnosis, proposed treatment by type, frequency, anticipated duration of treatment, the anticipated outcomes stated as goals, and the frequency by which the treatment plan will be updated.

(g) When making a determination of medical necessity for a treatment modality for autism spectrum disorders, an insurer must make the determination in a manner that is consistent with the manner used to make that determination with respect to other diseases or illnesses covered under the policy, including an appeals process. During the appeals process, any challenge to medical necessity must be viewed as reasonable only if the review includes a physician with expertise in the most current and effective treatment modalities for autism spectrum disorders.

(h) Coverage for medically necessary early intervention services must be delivered by certified early intervention specialists, as defined in 89 Ill. Admin. Code 500 and any subsequent amendments thereto.

(h-5) If an individual has been diagnosed as having an autism spectrum disorder, meeting the diagnostic criteria in place at the time of diagnosis, and treatment is determined medically necessary, then that individual shall remain eligible for coverage under this Section even if subsequent changes to the diagnostic criteria are adopted by the American Psychiatric Association. If no changes to the diagnostic criteria are adopted after April 1, 2012, and before December

31, 2014, then this subsection (h-5) shall be of no further force and effect.

(h-10) An insurer may not deny or refuse to provide covered services, or refuse to renew, refuse to reissue, or otherwise terminate or restrict coverage under an individual contract, for a person diagnosed with an autism spectrum disorder on the basis that the individual declined an alternative medication or covered service when the individual's health care provider has determined that such medication or covered service may exacerbate clinical symptomatology and is medically contraindicated for the individual and the individual has requested and received a medical exception as provided for under Section 45.1 of the Managed Care Reform and Patient Rights Act. For the purposes of this subsection (h-10), "clinical symptomatology" means any indication of disorder or disease when experienced by an individual as a change from normal function, sensation, or appearance.

(h-15) If, at any time, the Secretary of the United States Department of Health and Human Services, or its successor agency, promulgates rules or regulations to be published in the Federal Register or publishes a comment in the Federal Register or issues an opinion, guidance, or other action that would require the State, pursuant to any provision of the Patient Protection and Affordable Care Act (Public Law 111-148), including, but not limited to, 42 U.S.C. 18031(d)(3)(B) or any successor provision, to defray the cost of any coverage

outlined in subsection (h-10), then subsection (h-10) is inoperative with respect to all coverage outlined in subsection (h-10) other than that authorized under Section 1902 of the Social Security Act, 42 U.S.C. 1396a, and the State shall not assume any obligation for the cost of the coverage set forth in subsection (h-10).

(i) As used in this Section:

"Autism spectrum disorders" means pervasive developmental disorders as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, including autism, Asperger's disorder, and pervasive developmental disorder not otherwise specified.

"Diagnosis of autism spectrum disorders" means one or more tests, evaluations, or assessments to diagnose whether an individual has autism spectrum disorder that is prescribed, performed, or ordered by (A) a physician licensed to practice medicine in all its branches or (B) a licensed clinical psychologist with expertise in diagnosing autism spectrum disorders.

"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.

"Treatment for autism spectrum disorders" shall include the following care prescribed, provided, or ordered for an individual diagnosed with an autism spectrum disorder by (A) a physician licensed to practice medicine in all its branches or (B) a certified, registered, or licensed health care professional with expertise in treating effects of autism spectrum disorders when the care is determined to be medically necessary and ordered by a physician licensed to practice medicine in all its branches:

(1) Psychiatric care, meaning direct, consultative, or diagnostic services provided by a licensed psychiatrist.

(2) Psychological care, meaning direct or consultative services provided by a licensed psychologist.

(3) Habilitative or rehabilitative care, meaning professional, counseling, and guidance services and treatment programs, including applied behavior analysis, that are intended to develop, maintain, and restore the functioning of an individual. As used in this subsection (i), "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.

(4) Therapeutic care, including behavioral, 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) applied behavior analysis, intervention, and modification, (v) motor planning, and (vi) sensory processing.

(j) Rulemaking authority to implement this amendatory Act of the 95th General Assembly, if any, is conditioned on the rules being adopted in accordance with all provisions of the Illinois Administrative Procedure Act and all rules and procedures of the Joint Committee on Administrative Rules; any purported rule not so adopted, for whatever reason, is unauthorized.

(Source: P.A. 96-1000, eff. 7-2-10; 97-972, eff. 1-1-13.)

(215 ILCS 5/356z.24 new)

Sec. 356z.24. Immune gamma globulin therapy.

(a) A group or individual policy of accident and health insurance or managed care plan amended, delivered, issued, or renewed after the effective date of this amendatory Act of the 99th General Assembly may not allow for the delay, discontinuation, or interruption of immune gamma globulin therapy for persons who are diagnosed with a primary immunodeficiency when prescribed as medically necessary by a physician licensed to practice medicine in all of its branches

and if provided as a covered benefit under the plan. Nothing in this Section shall prevent an insurer from applying appropriate utilization review standards to the ongoing coverage of immune gamma globulin therapy for persons diagnosed with a primary immunodeficiency by a physician licensed to practice medicine in all of its branches.

(b) Upon diagnosis of primary immunodeficiency by the prescribing physician, determination of an initial authorization for immune gamma globulin therapy shall be no less than 3 months. Reauthorization for immune gamma globulin therapy for patients with a primary immunodeficiency diagnosis may occur every 6 months thereafter. For patients with a diagnosis of primary immunodeficiency who have been receiving immune gamma globulin therapy for at least 2 years with sustained beneficial response based on the treatment notes or clinical narrative detailing progress to date, reauthorization shall be no less than 12 months unless a more frequent duration has been indicated by the prescribing physician.

(c) If, at any time, the Secretary of the United States Department of Health and Human Services, or its successor agency, promulgates rules or regulations to be published in the Federal Register or publishes a comment in the Federal Register or issues an opinion, guidance, or other action that would require the State, pursuant to any provision of the Patient Protection and Affordable Care Act (Public Law 111-148), including, but not limited to, 42 U.S.C. 18031(d)(3)(B) or any

successor provision, to defray the cost of any coverage outlined in subsections (a) and (b), then subsections (a) and (b) are inoperative with respect to all coverage outlined in subsections (a) and (b) other than that authorized under Section 1902 of the Social Security Act, 42 U.S.C. 1396a, and the State shall not assume any obligation for the cost of the coverage set forth in subsections (a) and (b).

Section 99. Effective date. This Act takes effect upon becoming law.