



Sen. Don Harmon

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1 AMENDMENT TO SENATE BILL 345

2 AMENDMENT NO. \_\_\_\_\_. Amend Senate Bill 345 by replacing  
3 everything after the enacting clause with the following:

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

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

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

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

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

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

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

8           (6) According to the Centers for Disease Control,  
9 autism rates increased 78% between 2002 and 2008. The most  
10 recent estimate is roughly 30% higher than the estimate for  
11 2008 (one in 88), 60% higher than the estimate for 2006  
12 (one in 110), and 120% higher than the estimates for 2000  
13 and 2002 (one in 150).

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

25           (8) Scientific inquiry is providing evidence of  
26 biological markers, including, but not limited to, single

1 nucleotide polymorphisms, indications of cellular  
2 inflammation, increased cellular oxidation and damage, and  
3 abnormal DNA methylation, that may be clinically  
4 significant in the provision of appropriate medical care  
5 for persons also diagnosed with an autism spectrum  
6 disorder.

7 Therefore, it is the intention of the General Assembly to  
8 promote a greater awareness and the detection, diagnosis, and  
9 treatment of underlying and co-occurring medical conditions  
10 that occur more commonly in persons with autism to further  
11 awareness, scientific understanding, and health outcomes for  
12 persons living with autism.

13 Section 10. Definitions. In this Act:

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

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

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

25 "Department" means the Department of Financial and

1 Professional Regulation.

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

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

6 Section 15. Study and education. Public partnerships and  
7 private partnerships supporting the discovery of biomarkers  
8 and their implications in pathophysiological conditions shall  
9 be encouraged and information derived from such discoveries  
10 shall be disseminated to providers and made available to the  
11 general public through research initiatives that may be  
12 promoted by universities, medical clinics, health care  
13 providers, consortiums, State agencies, private organizations,  
14 public organizations, and any party that may contribute to the  
15 scientific understanding of medical conditions associated or  
16 occurring more often in persons also diagnosed with an autism  
17 spectrum disorder than in the general population.

18 Universities, private organizations, public organizations,  
19 and associations are encouraged to develop for providers who  
20 treat persons with autism spectrum disorders continuing  
21 education courses which address training in evaluation,  
22 diagnosis, and treatments for co-occurring and otherwise  
23 diagnosed pathophysiological conditions in autism spectrum  
24 disorders to promote and align standard of care practices to  
25 reflect emerging clinical findings and promising practices

1 derived from improved patient outcomes.

2 Section 20. Treatment or service of persons with an autism  
3 spectrum disorder. Providers are strongly encouraged to  
4 evaluate persons diagnosed with an autism spectrum disorder for  
5 co-occurring or otherwise diagnosed medical conditions when  
6 clinical symptomatology is present or suspected and prescribe  
7 appropriate treatments or services in alignment with care  
8 practices for the condition, illness, injury, disease, or  
9 disability. Providers may consider, without limitation,  
10 whether or not a medication or any ingredient, allergen,  
11 potential toxicant, or artificial agent may exacerbate  
12 clinical symptomatology of autism spectrum disorder or a  
13 related or co-occurring or otherwise diagnosed medical  
14 condition and, if so, may consider adopting measures that would  
15 result in the reduction or elimination of risk to the patient.

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

23 Section 30. Right to seek new care. A person with an autism

1 spectrum disorder, or the person's parent or legal guardian on  
2 his or her behalf, retains the right to seek further medical  
3 opinions or care from other providers.

4 A parent or legal guardian shall not be threatened with  
5 loss of parental or legal guardianship rights for a person with  
6 autism spectrum disorder for pursuing additional medical  
7 expertise, especially in the case of trying to ascertain  
8 appropriate identification and diagnosis of underlying or  
9 co-occurring medical conditions that may or may not be  
10 exacerbating symptoms primarily associated with an autism  
11 spectrum disorder. This Section does not abrogate or restrict  
12 any responsibilities set forth under the Abused and Neglected  
13 Child Reporting Act.

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

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

24 Section 35. Repeal. In order to consider the most  
25 innovative medical study and research involving autism and

1 co-occurring medical conditions, this Act is repealed 5 year  
2 after the effective date of this Act of the 99th General  
3 Assembly.

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

7 (215 ILCS 5/356z.14)

8 Sec. 356z.14. Autism spectrum disorders.

9 (a) A group or individual policy of accident and health  
10 insurance or managed care plan amended, delivered, issued, or  
11 renewed after the effective date of this amendatory Act of the  
12 95th General Assembly must provide individuals under 21 years  
13 of age coverage for the diagnosis of autism spectrum disorders  
14 and for the treatment of autism spectrum disorders to the  
15 extent that the diagnosis and treatment of autism spectrum  
16 disorders are not already covered by the policy of accident and  
17 health insurance or managed care plan.

18 (b) Coverage provided under this Section shall be subject  
19 to a maximum benefit of \$36,000 per year, but shall not be  
20 subject to any limits on the number of visits to a service  
21 provider. After December 30, 2009, the Director of the Division  
22 of Insurance shall, on an annual basis, adjust the maximum  
23 benefit for inflation using the Medical Care Component of the  
24 United States Department of Labor Consumer Price Index for All

1 Urban Consumers. Payments made by an insurer on behalf of a  
2 covered individual for any care, treatment, intervention,  
3 service, or item, the provision of which was for the treatment  
4 of a health condition not diagnosed as an autism spectrum  
5 disorder, shall not be applied toward any maximum benefit  
6 established under this subsection.

7 (c) Coverage under this Section shall be subject to  
8 copayment, deductible, and coinsurance provisions of a policy  
9 of accident and health insurance or managed care plan to the  
10 extent that other medical services covered by the policy of  
11 accident and health insurance or managed care plan are subject  
12 to these provisions.

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

21 (e) An insurer may not deny or refuse to provide otherwise  
22 covered services, or refuse to renew, refuse to reissue, or  
23 otherwise terminate or restrict coverage under an individual  
24 contract to provide services to an individual because the  
25 individual or their dependent is diagnosed with an autism  
26 spectrum disorder or due to the individual utilizing benefits



1 in this Section.

2 (f) Upon request of the reimbursing insurer, a provider of  
3 treatment for autism spectrum disorders shall furnish medical  
4 records, clinical notes, or other necessary data that  
5 substantiate that initial or continued medical treatment is  
6 medically necessary and is resulting in improved clinical  
7 status. When treatment is anticipated to require continued  
8 services to achieve demonstrable progress, the insurer may  
9 request a treatment plan consisting of diagnosis, proposed  
10 treatment by type, frequency, anticipated duration of  
11 treatment, the anticipated outcomes stated as goals, and the  
12 frequency by which the treatment plan will be updated.

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

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

1 (h-5) If an individual has been diagnosed as having an  
2 autism spectrum disorder, meeting the diagnostic criteria in  
3 place at the time of diagnosis, and treatment is determined  
4 medically necessary, then that individual shall remain  
5 eligible for coverage under this Section even if subsequent  
6 changes to the diagnostic criteria are adopted by the American  
7 Psychiatric Association. If no changes to the diagnostic  
8 criteria are adopted after April 1, 2012, and before December  
9 31, 2014, then this subsection (h-5) shall be of no further  
10 force and effect.

11 (h-10) An insurer may not require, as a condition for  
12 coverage of other covered services, that an individual  
13 diagnosed with an autism spectrum disorder receive any  
14 medication or intervention that has been determined by the  
15 individual's health care provider to be medically  
16 contraindicated for the individual. An insurer may not deny or  
17 refuse to provide covered services, or refuse to renew, refuse  
18 to reissue, or otherwise terminate or restrict coverage under  
19 an individual contract, for a person diagnosed with an autism  
20 spectrum disorder on the basis that the individual declined an  
21 alternative medication or covered service when the  
22 individual's health care provider determined that such  
23 medication or covered service may exacerbate clinical  
24 symptomatology and is medically contraindicated for the  
25 individual. For the purposes of this subsection (h-10),  
26 "clinical symptomatology" means any indication of disorder or

1 disease when experienced by an individual as a change from  
2 normal function, sensation, or appearance.

3 (h-15) If, at any time, the Secretary of the United States  
4 Department of Health and Human Services, or its successor  
5 agency, promulgates rules or regulations to be published in the  
6 Federal Register or publishes a comment in the Federal Register  
7 or issues an opinion, guidance, or other action that would  
8 require the State, pursuant to any provision of the Patient  
9 Protection and Affordable Care Act (Public Law 111-148),  
10 including, but not limited to, 42 U.S.C. 18031(d)(3)(B) or any  
11 successor provision, to defray the cost of any coverage  
12 outlined in subsection (h-10), then subsection (h-10) is  
13 inoperative with respect to all coverage outlined in subsection  
14 (h-10) other than that authorized under Section 1902 of the  
15 Social Security Act, 42 U.S.C. 1396a, and the State shall not  
16 assume any obligation for the cost of the coverage set forth in  
17 subsection (h-10).

18 (i) As used in this Section:

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

24 "Diagnosis of autism spectrum disorders" means one or more  
25 tests, evaluations, or assessments to diagnose whether an  
26 individual has autism spectrum disorder that is prescribed,

1 performed, or ordered by (A) a physician licensed to practice  
2 medicine in all its branches or (B) a licensed clinical  
3 psychologist with expertise in diagnosing autism spectrum  
4 disorders.

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

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

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

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

26 (3) Habilitative or rehabilitative care, meaning

1 professional, counseling, and guidance services and  
2 treatment programs, including applied behavior analysis,  
3 that are intended to develop, maintain, and restore the  
4 functioning of an individual. As used in this subsection  
5 (i), "applied behavior analysis" means the design,  
6 implementation, and evaluation of environmental  
7 modifications using behavioral stimuli and consequences to  
8 produce socially significant improvement in human  
9 behavior, including the use of direct observation,  
10 measurement, and functional analysis of the relations  
11 between environment and behavior.

12 (4) Therapeutic care, including behavioral, speech,  
13 occupational, and physical therapies that provide  
14 treatment in the following areas: (i) self care and  
15 feeding, (ii) pragmatic, receptive, and expressive  
16 language, (iii) cognitive functioning, (iv) applied  
17 behavior analysis, intervention, and modification, (v)  
18 motor planning, and (vi) sensory processing.

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

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

1 (215 ILCS 5/356z.24 new)

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

3 (a) Patients with primary immunodeficiency are susceptible  
4 to the ravages of infection because they have impaired antibody  
5 response and quality. Immune gamma globulin therapy is intended  
6 for continuous replacement therapy for primary  
7 immunodeficiency and may be delivered through intravenous  
8 immunoglobulin or subcutaneous immunoglobulin. For patients  
9 with a primary immunodeficiency, immune gamma globulin therapy  
10 protects against life-threatening infections, reduces  
11 hospitalizations, preserves organ function, increases life  
12 span, and is lifesaving. Immune gamma globulin is a human  
13 plasma product regulated by the United States Food and Drug  
14 Administration and approved for the treatment of primary  
15 immunodeficiency. No generic immune gamma globulin product  
16 exists. Patients diagnosed with primary immunodeficiency may  
17 have varying clinical responses to a prescribed drug, including  
18 those that may qualify as a serious medical contraindication.  
19 Infusions should not be interrupted to learn about a patient's  
20 tolerance for frequency of infusion as this will put the  
21 patient's life at risk and to do so would be consistent with  
22 medical malpractice. Some patients with primary  
23 immunodeficiency have normal levels of immunoglobulins at  
24 diagnosis but cannot make the antibodies that will neutralize  
25 infection. In these cases, trough dosing is not clinically

1 appropriate.

2 (b) A group or individual policy of accident and health  
3 insurance or managed care plan amended, delivered, issued, or  
4 renewed after the effective date of this amendatory Act of the  
5 99th General Assembly may not allow for the delay,  
6 discontinuation, or interruption of immune gamma globulin  
7 therapy for persons who are diagnosed with a primary  
8 immunodeficiency when prescribed immune gamma globulin therapy  
9 by a physician licensed to practice medicine in all of its  
10 branches. Administration of immune gamma globulin therapy  
11 shall not be delayed or interrupted by an insurer once a  
12 diagnosis is established and immune gamma globulin is  
13 prescribed. For the purposes of this Section, delay,  
14 interruption, or discontinuation of therapy means interfering  
15 with treatment as prescribed by the licensed physician by  
16 altering the prescribed dose, frequency, route, venue,  
17 product, or administration, which is determined by the  
18 physician based on patient tolerability, individual patient  
19 characteristics, needs, and clinical response. Product  
20 interchangeability not authorized by a prescribing physician  
21 is prohibited.

22 (c) Upon the diagnosis of primary immunodeficiency by the  
23 prescribing physician, authorization or reauthorization by  
24 insurers of immune gamma globulin therapy shall be expedited by  
25 insurers. Due to the potential lifesaving necessity of immune  
26 gamma globulin, determination of authorization or

1 reauthorization may not take more than 2 weeks and  
2 reauthorization may not be required more frequently than every  
3 12 months unless a more frequent duration has been indicated by  
4 the prescribing physician. Since immune gamma globulin therapy  
5 is intended for continuous replacement of antibodies, once a  
6 diagnosis of primary immunodeficiency is made, the previous  
7 diagnosis and current clinical judgment of the prescribing  
8 physician shall be sufficient for renewed authorization or  
9 authorization for continuation of care if the patient requires  
10 new authorization due to change in insurers.

11 (d) Review of a patient's clinical history for meaningful  
12 infections and the available laboratory findings, genetic  
13 findings, and imaging studies, along with physical evidence of  
14 end-organ damage from recurrent infections and the favorable  
15 effect of immune gamma globulin replacement on clinical course  
16 and the treating physician's clinical judgment is sufficient to  
17 validate an antibody deficiency diagnosis. Trough levels of  
18 antibodies and normal immune globulin levels may be used by  
19 clinicians to monitor treatment and shall not be used to  
20 discontinue or otherwise deny coverage of immune gamma globulin  
21 therapy for a patient determined by a physician to have a  
22 primary immunodeficiency.

23 (e) Any standards, policies, provisions, or practices by  
24 insurers that require a person who is diagnosed with a primary  
25 immunodeficiency to delay, discontinue, or interrupt immune  
26 gamma globulin therapy that could result in a potentially life



1 threatening situation are prohibited when prescribed by a  
2 physician licensed to practice medicine in all its branches.

3 (f) If, at any time, the Secretary of the United States  
4 Department of Health and Human Services, or its successor  
5 agency, promulgates rules or regulations to be published in the  
6 Federal Register or publishes a comment in the Federal Register  
7 or issues an opinion, guidance, or other action that would  
8 require the State, pursuant to any provision of the Patient  
9 Protection and Affordable Care Act (Public Law 111-148),  
10 including, but not limited to, 42 U.S.C. 18031(d)(3)(B) or any  
11 successor provision, to defray the cost of any coverage  
12 outlined in subsections (b) and (c), then subsections (b) and  
13 (c) are inoperative with respect to all coverage outlined in  
14 subsections (b) and (c) other than that authorized under  
15 Section 1902 of the Social Security Act, 42 U.S.C. 1396a, and  
16 the State shall not assume any obligation for the cost of the  
17 coverage set forth in subsections (b) and (c).

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