



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.

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

6 (215 ILCS 5/356z.14)

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

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

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

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

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

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

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



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

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

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

26 (h-5) If an individual has been diagnosed as having an

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

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

25 (h-15) If, at any time, the Secretary of the United States  
26 Department of Health and Human Services, or its successor

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

14 (i) As used in this Section:

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

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

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

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

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

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

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

1 (i), "applied behavior analysis" means the design,  
2 implementation, and evaluation of environmental  
3 modifications using behavioral stimuli and consequences to  
4 produce socially significant improvement in human  
5 behavior, including the use of direct observation,  
6 measurement, and functional analysis of the relations  
7 between environment and behavior.

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

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

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

23 (215 ILCS 5/356z.24 new)

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

25 (a) A group or individual policy of accident and health

1 insurance or managed care plan amended, delivered, issued, or  
2 renewed after the effective date of this amendatory Act of the  
3 99th General Assembly may not allow for the delay,  
4 discontinuation, or interruption of immune gamma globulin  
5 therapy for persons who are diagnosed with a primary  
6 immunodeficiency when prescribed as medically necessary by a  
7 physician licensed to practice medicine in all of its branches,  
8 based on documented immunopathological findings and a  
9 provider's clinical judgment, and if provided as a covered  
10 benefit under the plan. Nothing in this Section shall prevent  
11 an insurer from applying appropriate utilization review  
12 standards to the ongoing coverage of immune gamma globulin  
13 therapy for persons diagnosed with a primary immunodeficiency  
14 by a physician licensed to practice medicine in all of its  
15 branches. For the purposes of this subsection (a),  
16 "immunopathological findings" means clinical findings related  
17 to the structural and functional manifestations associated  
18 with immune responses to disease or function of antibodies.

19 (b) Upon diagnosis of primary immunodeficiency by the  
20 prescribing physician, determination of an initial  
21 authorization for immune gamma globulin therapy shall be no  
22 less than 3 months. Reauthorization for immune gamma globulin  
23 therapy for patients with a primary immunodeficiency diagnosis  
24 may occur every 6 months thereafter. For patients with a  
25 diagnosis of primary immunodeficiency who have been receiving  
26 immune gamma globulin therapy for at least 2 years with

1 sustained beneficial response based on the treatment notes or  
2 clinical narrative detailing progress to date, reauthorization  
3 shall be no less than 12 months unless a more frequent duration  
4 has been indicated by the prescribing physician.

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

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