



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

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

26 (c) If, at any time, the Secretary of the United States

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

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