

1 AN ACT concerning health.

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

4 Section 1. Short title. This Act may be cited as the Autism
5 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.

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

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

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

1 (6) According to the Centers for Disease Control,
2 autism rates increased 78% between 2002 and 2008. The most
3 recent estimate is roughly 30% higher than the estimate for
4 2008 (one in 88), 60% higher than the estimate for 2006
5 (one in 110), and 120% higher than the estimates for 2000
6 and 2002 (one in 150).

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

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

26 Therefore, it is the intention of the General Assembly to

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

6 Section 10. Definitions. In this Act:

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

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

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

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

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

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

24 Section 15. Study and education. Public partnerships and

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

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

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

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

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

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

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

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

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

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 decline a medical treatment or intervention.

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

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

1 (215 ILCS 5/356z.14)

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

3 (a) A group or individual policy of accident and health
4 insurance or managed care plan amended, delivered, issued, or
5 renewed after the effective date of this amendatory Act of the
6 95th General Assembly must provide individuals under 21 years
7 of age coverage for the diagnosis of autism spectrum disorders
8 and for the treatment of autism spectrum disorders to the
9 extent that the diagnosis and treatment of autism spectrum
10 disorders are not already covered by the policy of accident and
11 health insurance or managed care plan.

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

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

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

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

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

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

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

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

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

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

1 31, 2014, then this subsection (h-5) shall be of no further
2 force and effect.

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

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

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

7 (i) As used in this Section:

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

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

20 "Medically necessary" means any care, treatment,
21 intervention, service or item which will or is reasonably
22 expected to do any of the following: (i) prevent the onset of
23 an illness, condition, injury, disease or disability; (ii)
24 reduce or ameliorate the physical, mental or developmental
25 effects of an illness, condition, injury, disease or
26 disability; or (iii) assist to achieve or maintain maximum

1 functional activity in performing daily activities.

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

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

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

15 (3) Habilitative or rehabilitative care, meaning
16 professional, counseling, and guidance services and
17 treatment programs, including applied behavior analysis,
18 that are intended to develop, maintain, and restore the
19 functioning of an individual. As used in this subsection
20 (i), "applied behavior analysis" means the design,
21 implementation, and evaluation of environmental
22 modifications using behavioral stimuli and consequences to
23 produce socially significant improvement in human
24 behavior, including the use of direct observation,
25 measurement, and functional analysis of the relations
26 between environment and behavior.

1 (4) Therapeutic care, including behavioral, speech,
2 occupational, and physical therapies that provide
3 treatment in the following areas: (i) self care and
4 feeding, (ii) pragmatic, receptive, and expressive
5 language, (iii) cognitive functioning, (iv) applied
6 behavior analysis, intervention, and modification, (v)
7 motor planning, and (vi) sensory processing.

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

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

16 (215 ILCS 5/356z.24 new)

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

18 (a) A group or individual policy of accident and health
19 insurance or managed care plan amended, delivered, issued, or
20 renewed after the effective date of this amendatory Act of the
21 99th General Assembly may not allow for the delay,
22 discontinuation, or interruption of immune gamma globulin
23 therapy for persons who are diagnosed with a primary
24 immunodeficiency when prescribed as medically necessary by a
25 physician licensed to practice medicine in all of its branches

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

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

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

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

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