The Florida Senate

BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Health Regulation Committee

BILL: SB 100

INTRODUCER: Senator Ring

SUBJECT: Autism

DATE: March 18, 2011 REVISED:

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Fernandez/Brown	Stovall	HR	**Pre-meeting**
2.			BI	
3.			BC	
4.				
5.				
6.				

I. Summary:

The bill requires a licensed physician, other than one providing emergency services and care, to screen a minor for autism spectrum disorder (ASD) when the parent or legal guardian of that minor believes the minor exhibits symptoms of ASD and notifies the physician. Based on a determination by the physician of medical necessity or lack thereof, the physician must refer the minor for additional ASD screening or inform the parent or legal guardian of other available ASD screening options.

The bill requires health insurers and health maintenance organizations (HMOs) to provide coverage for "direct patient access," as defined in the bill, to an appropriate specialist for screening for or evaluation or diagnosis of ASD. The bill mandates that health insurance policies and HMO contracts provide coverage for a minimum of three visits per policy year for that purpose.

The bill substantially amends the following sections of the Florida Statutes: 627.6686 and 641.31098.

The bill creates the following section of the Florida Statutes: 381.986.

II. Present Situation:

What is Autism?

Autism is a term used to describe a group of complex developmental disabilities that many researchers believe are the result of a neurological disorder that affects the functioning of the

brain. Individuals with autism often have problems communicating with others through spoken language and nonverbal communication. The early signs of autism usually appear in the form of developmental delays before a child turns 3 years old.[1]

Section 393.063(3), F.S., defines autism to mean: ". . . a pervasive, neurologically based developmental disability of extended duration which causes severe learning, communication, and behavior disorders with age of onset during infancy or childhood. Individuals with autism exhibit impairment in reciprocal social interaction, impairment in verbal and nonverbal communication and imaginative ability, and a markedly restricted repertoire of activities and interests."

The various forms of autism are referred to as the autism spectrum disorders, meaning that autism can be manifested in a wide variety of combinations, from mild to severe. Thus, many different behaviors can indicate that a person should be diagnosed as autistic.

According to the National Institute of Mental Health (NIMH),[2] the pervasive developmental disorders, or ASDs, range from a severe form, called autistic disorder, to a milder form, Asperger's syndrome.[3] If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, severe disorders that are included in the autism spectrum are Rett syndrome[4] and childhood disintegrative disorder.[5]

The NIMH states that all children with an ASD demonstrate deficits in:

- *Social Interaction* – Most children with an ASD have difficulty learning to engage in everyday human interaction. Children with an ASD are also slower in understanding subtle social cues (nonverbal communication) and thus struggle to interpret what others are thinking

[1] Centers for Disease Control and Prevention website, Found at: <http://www.cdc.gov/ncbddd/autism/signs.html> (Last visited on March 17, 2011).

[2] Department of Health and Human Services, National Institute of Mental Health. *Autism Spectrum Disorders: Pervasive Developmental Disorders.* Printed 2004 Reprinted 2008. Found at: <http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf> (Last visited on March 17, 2011).

[3] The NIMH states that children with Asperger's syndrome are similar to high-functioning children with autism in that their language and intelligence remain intact. Like autistic children, persons with Asperger's syndrome have repetitive behaviors, severe social problems, and clumsy movements. The symptoms of Asperger's syndrome usually appear later in childhood than those of autism.

[4] The NIMH provides the following explanation of Rett syndrome: Rett syndrome is relatively rare, affecting almost exclusively females, one out of 10,000 to 15,000. After a period of normal development, sometime between 6 and 18 months, autism-like symptoms begin to appear. The little girl's mental and social development regresses—she no longer responds to her parents and pulls away from any social contact. If she has been talking, she stops; she cannot control her feet; she wrings her hands. Some of the problems associated with Rett syndrome can be treated. Physical, occupational, and speech therapy can help with problems of coordination, movement, and speech.

[5] The NIMH provides the following explanation of childhood disintegrative disorder: Very few children who have an ASD diagnosis meet the criteria for childhood disintegrative disorder (CDD). An estimate based on four surveys of ASD found fewer than two children per 100,000 with an ASD could be classified as having CDD. This suggests that CDD is a very rare form of ASD. It has a strong male preponderance. Symptoms may appear by age 2, but the average age of onset is between 3 and 4 years. Until this time, the child has age-appropriate skills in communication and social relationships. The long period of normal development before regression helps differentiate CDD from Rett syndrome. The loss of such skills as vocabulary is more dramatic in CDD than they are in classical autism. The diagnosis requires extensive and pronounced losses involving motor, language, and social skills. CDD is also accompanied by loss of bowel and bladder control and oftentimes seizures and a very low IQ.

and feeling. This causes them to often find social interaction confusing and frustrating. It is also common for people with an ASD to have difficulty controlling their emotions. Examples include episodes of disruptive behavior such as crying or verbal outbursts at inappropriate times or physical aggression. Autistics often can lose self control when exposed to a strange or overwhelming environment or when angry or frustrated.

- *Verbal and nonverbal communication* – Autistics have difficulty developing standard communication skills. Some children with an ASD remain mute, while others do not develop language until ages 5 to 9. Others use language in unusual ways or utilize sign language or pictures to communicate. The body language of autistics can be difficult to understand because it is not always consistent with the words they are saying. As they grow older, persons with an ASD often become more aware of their difficulties in communication, which can lead to anxiety or depression.
- *Repetitive behaviors or interests* – Children with an ASD often perform odd repetitive motions that set them apart from their peers. For example, some children and adults repeatedly flap their arms or walk on their toes while others freeze in position. Children with an ASD exhibit the need for consistency in their environment. Changes in daily routines—such as mealtimes, dressing, bathing, going to school at a certain time and by the same route—can cause autistics to become extremely disturbed. As children, they might spend hours lining up their toys in a certain way and if the toys are moved, they become upset. Additionally, autistics often form intense, obsessive preoccupations with certain objects or topics on which they focus much of their energy.

Another common difficulty is that children with an ASD often have unusual responses to sensory experiences, such as certain sounds or the way objects look.

The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, is the primary system used to classify and diagnose mental disorders. The 4th edition of the DSM was released in 1994. On February 10, 2010, the American Psychiatric Association released its draft criteria for the fifth edition of the DSM on its website.[6] The draft DSM-5 includes collapsing all autism related diagnoses into one single category, “autism spectrum disorder” that would incorporate autistic disorder, Asperger’s syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. The final DSM-5 is not scheduled for release until May 2013.

Sections 627.6686(2)(b) and 641.31098(2)(b), F.S., define the term “autism spectrum disorder” as any of the following disorders as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association:

- Autistic disorder.
- Asperger’s syndrome.
- Pervasive developmental disorder not otherwise specified.

The law requires certain insurance coverage for diagnostic screening, intervention, and treatment of autism spectrum disorder for eligible individuals and defines an eligible individual as:

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[6] Proposed Draft Revisions to DSM Disorders and Criteria. Found at: <http://www.dsm5.org/Pages/Default.aspx> (Last visited on March 17, 2011).

> . . .an individual under 18 years of age or an individual 18 years of age or older who is in high school who has been diagnosed as having a developmental disability at 8 years of age or younger.[7]

Diagnosis of Autism Spectrum Disorders

There is no medical test for ASDs. Instead, doctors look at behavioral symptoms to make a diagnosis. These symptoms may show up within the first few months of life or may appear at any time before the age of 3.[8]

According to the Centers for Disease Control and Prevention (CDC), research shows that the diagnosis of autism at age 2 can be reliable, valid, and stable. However, many children do not receive final diagnosis until they are much older. This delay in diagnosis may result in lost opportunities for specialized early intervention.[9]

The diagnosis of an ASD is a two-stage process. The first stage involves developmental screening during "well child" check-ups. These screening tests are used solely for identifying children with developmental disabilities. Additional screening may be needed if a child is at high risk[10] for an ASD or if the symptoms warrant it.[11]

The second stage of diagnosis is a comprehensive evaluation. If the initial screening tests indicate the possibility of an ASD, then further comprehensive testing is performed. Comprehensive testing is done by health care practitioners from multiple disciplines (psychologists, psychiatrists, neurologists, speech therapists, and other professions with experience in diagnosing children with an ASD) who evaluate the child in depth and determine if there is a developmental disorder, and if so, render a diagnosis. This may include:[12]

- Clinical observations;
- Parent interviews;
- Developmental histories;
- Psychological testing;
- Speech and language assessments;
- The possibility of the use of one or more autism diagnostic scales; and
- The possibility of physical, neurological, and genetic testing.

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[7] ss. 627.6686(2)(c) and 641.31098(2)(c), F.S.
[8] Centers for Disease Control and Prevention website. Found at: <http://www.cdc.gov/ncbddd/autism/screening.html> (Last visited on March 17, 2011).
[9] Centers for Disease Control and Prevention website. Found at <http://www.cdc.gov/ncbddd/autism/screening.html> (Last visited on March 17, 2011).
[10] The CDC considers a child with a sibling or parent with an ASD to be at high risk.
[11] Centers for Disease Control and Prevention website, Found at <http://www.cdc.gov/ncbddd/autism/screening.html> (Last visited on March 17, 2011).
[12] Centers for Disease Control and Prevention website, Found at <http://www.cdc.gov/ncbddd/autism/screening.html> (Last visited on March 17, 2011).

Treatment Approaches

Much of the scientific and clinical evidence indicates that early treatment of autism during preschool years (ages 3 to 5) often yields positive results in mitigating the effects of ASDs. According to the National Institute of Neurological Disorders and Stroke (NINDS), therapies for autism are designed to remedy specific symptoms.[13] Educational and behavioral interventions are highly-structured and usually aimed at the development of skills such as language and social skills. Medication may be prescribed to reduce self-injurious behavior or other behavioral symptoms of autism. Early intervention is important for children because children learn most rapidly when they are very young. If begun early enough, such intervention has a chance of favorably influencing brain development. In a 2001 report, the Commission on Behavioral and Social Sciences and Education recommended that treatment "services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives."[14]

The Center for Autism and Related Disabilities provided the following information concerning the application of speech-language therapy, occupational therapy, and physical therapy for individuals with autism:

- *Speech-Language Therapy:* People with autism usually have delays in communication. Speech therapists look for a system of communication that will work for an individual with autism and may consider alternatives to the spoken word such as signing, typing, or a picture board with words.
- *Occupational Therapy:* Commonly, this therapy focuses on improving fine motor skills, such as brushing teeth, feeding, and writing, or sensory motor skills that include balance, awareness of body position, and touch.
- *Physical Therapy:* This therapy specializes in developing strength, coordination, and movement.

According to the NIMH, a number of treatment approaches have evolved in the decades since autism was first identified. These approaches include developmental, behaviorist, and nonstandard. Developmental approaches provide consistency and structure along with appropriate levels of stimulation.

Behaviorist training approaches are based on rewarding individuals for a certain type of behavior. Dr. Ivar Lovaas pioneered the use of behaviorist methods for children with autism more than 25 years ago. Lovaas therapy involves time-intensive, highly structured, repetitive sequences in which a child is given a command and rewarded each time he responds correctly. Using this approach for up to 40 hours a week, some children may be brought to the point of near-normal behavior. Others are much less responsive to the treatment. However, some researchers and therapists believe that less intensive treatments, particularly those begun early in a child's life, may provide the same level of efficacy.

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[13] National Institutes of Health, National Institute of Neurological Disorders and Stroke, Autism Information Page. Found at: <http://www.ninds.nih.gov/disorders/autism/autism.htm#Is_there_any_treatment> (Last visited on March 18, 2011).

[14] Commission on Behavioral and Social Sciences and Education, *Educating Children with Autism* 6, 2001. Found at: <http://www.nap.edu/openbook.php?record_id=10017&page=66> (Last visited on March 18, 2011).

Health Insurance Coverage for Autism Spectrum Disorders in Florida

In 2008, the Legislature passed CS/CS/SB 2654, which included the *Steven A. Geller Autism Coverage Act* and the *Window of Opportunity Act*.[15]

The Window of Opportunity Act required the Office of Insurance Regulation (OIR) to convene a workgroup of stakeholders by August 31, 2008, to negotiate a compact for a binding agreement among the participants relating to insurance coverage and access to services for persons with developmental disabilities. The law required the compact to include coverage for behavioral analysis and behavior assistant services, speech therapy, physical therapy, and occupational therapy when medically necessary; policies and procedures for notifying policy holders of the amount, scope, and developmental disability conditions covered; penalties for documented cases of denial of claims for medically necessary services due to the presence of a developmental disability; and proposals for new product lines that may be offered in conjunction with traditional health insurance to provide a more appropriate means of spreading risk, financing costs, and accessing favorable prices.

In September 2008, the OIR convened the Developmental Disabilities Compact Workgroup to develop the compact required in law. A compact was developed by the workgroup and adopted on December 17, 2008.[16] Insurers and HMOs that sign onto the compact agreement must provide coverage for developmental disabilities as specified in the compact for all plans issued or renewed after January 1, 2010. The OIR reports that Total Health Choice is the only health insurer that has signed onto the autism compact.[17]

All insurers and HMOs that did not sign the Developmental Disabilities Compact Workgroup by April 1, 2009, are subject to the requirements of the Steven A. Gellar Autism Act. The Act requires insurers, including the state group insurance plan, to provide coverage for well-baby and child screening for diagnosing the presence of autism and to cover the treatment of autism through applied behavioral analysis and assistant services, physical therapy, speech therapy, and occupational therapy.[18] The autism disorders covered in the law are: autistic disorder, Asperger's syndrome, and pervasive developmental disorder not otherwise specified. The insurance coverage is limited to $36,000 annually with a $200,000 total lifetime benefit. Beginning January 1, 2011, the coverage maximum will increase with inflation.

State Group Health Insurance Program

Florida law provides for the State Group Health Insurance Program for the purpose of offering health insurance benefits for state and political subdivision employees in a cost-efficient and

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[15] *See* ch. 2008-30, L.O.F.

[16] Developmental Disabilities Compact. Found at: <http://www.floir.com/pdf/DDCProposal-A.pdf> (Last visited on March 18, 2011).

[17] Florida Department of Financial Services Library. Found at: http://www.myfloridacfo.com/consumers/insurancelibrary/index.htm#insurance/l_and_h/health_coverages/health_coverage_-_autism_and_developmental_disabilities.htm (last visited on March 18, 2011).

[18] ss. 627.6686 and 641.31098, F.S.

prudent manner.[19] On January 1, 2010, the State Group Health Insurance Program implemented the requirements of the Steven A. Geller Autism Coverage Act, which requires comprehensive coverage for the screening, diagnosis and treatment of autism spectrum disorder. The State Group Insurance Plan is required to cover well-baby and child screening for diagnosing the presence of autism and to cover the treatment of autism through applied behavior analysis and assistant services, physical therapy, speech therapy and occupational therapy. The disorders covered are autistic disorder, Asperger's syndrome and pervasive developmental disorder not otherwise specified. Children under age 18 or in high school are covered.

III. Effect of Proposed Changes:

Section 1 creates s. 381.986, F.S., to require a licensed physician to screen a minor for ASD, in accordance with the American Academy of Pediatrics' guidelines,[20] when the parent or legal guardian of that minor believes the minor exhibits symptoms of ASD and notifies the physician. If the physician determines that a referral to a specialist is medically necessary, he or she must refer the minor to an appropriate specialist to determine whether the minor meets diagnostic criteria for ASD. If the physician determines that a referral to a specialist is not medically necessary, the physician must inform the parent or guardian that he or she can self-refer to the Early Steps Program[21] or other specialist in autism. The bill exempts physicians providing emergency services and care[22] from this requirement.

An "appropriate specialist" is defined in the bill as a qualified professional who is experienced in the evaluation of autism spectrum disorder, is licensed in this state, and has training in validated diagnostic tools. The term includes, but is not limited to:

- A psychologist;
- A psychiatrist;
- A neurologist;
- A developmental or behavioral pediatrician; or
- A professional whose licensure is deemed appropriate by the Children's Medical Services Early Steps Program within the Department of Health.

Sections 2 and 3 amend the Steven A. Geller Autism Coverage Act, under ss. 627.6686 and 641.31098, F.S., to mandate that health insurance plans and health maintenance contracts provide coverage for direct patient access to an appropriate specialist, as defined by the bill in s. 381.986, F.S, (see above) for a minimum of three visits per policy year for screening for or evaluation or diagnosis of ASD.

The bill defines "direct patient access" as the ability of an insured to obtain services from an in-network provider without a referral or other authorization before receiving services.

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[19] *See* s. 110.123(3)(b), F.S.

[20] Greenspan et. al., "Guidelines for Early Identification, Screening, and Clinical Management of Children With Autism Spectrum Disorders," *Pediatrics: Official Journal of the American Academy of Pediatrics,* April 2008, vol. 121, no. 4, p. 828.

[21] Early Steps is Florida's early intervention system that offers services to eligible infants and toddlers (birth to thirty-six months) with significant delays or a condition likely to result in a developmental delay. Early intervention is provided to support families and caregivers in developing the competence and confidence to help their child learn and develop. *See* http://www.doh.state.fl.us/alternatesites/cms-kids/families/early_steps/early_steps.html

[22] *See* s. 395.1041, F.S.

Section 4 provides an effective date for the bill of July 1, 2011.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

The provisions of this bill have no impact on municipalities and the counties under the requirements of Article VII, Section 18 of the Florida Constitution.

B. Public Records/Open Meetings Issues:

The provisions of the bill have no impact on public records or open meetings issues under the requirements of Article I, Section 24(a) and (b) of the Florida Constitution.

C. Trust Funds Restrictions:

The provisions of this bill have no impact on the trust fund restrictions under the requirements of article III, Subsection 19(f) of the Florida Constitution.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

The bill may increase the total number and cost of claims incurred by insurers and HMOs for evaluations because more minors may be referred for ASD screening or visit specialists under the direct patient access provision. If so, the bill may cause health insurance costs to increase by an indeterminate amount.

C. Government Sector Impact:

The Division of State Group Insurance within the Department of Management Services (DMS) examined the bill for fiscal impact on the State Group Health Insurance Program. DMS advises that because the bill requires coverage for direct patient access and a minimum of three visits per policy year for autism spectrum screenings (in addition to the non-specialist opinion of the primary care physician), the bill could result in marginally higher cost if medically unnecessary repetition of valid screenings occurs. The fiscal impact is indeterminate but is not expected by DMS to be significant.

The Department of Health has provided the following fiscal analysis:

- The bill could result in additional families seeking ASD screening from the Early Steps Program, which would increase the program’s screening costs.
- The bill could increase the number children in the program who need early intervention services, which could result in further increased costs and in the inability

of the Early Steps Program to ensure that appropriate early intervention services are available to eligible children.

- The exact fiscal impact is indeterminate.

VI. Technical Deficiencies:

Section 1 refers to "a physician licensed in this state." It may be more appropriate to specify a physician licensed under ch. 458 or ch. 459, F.S.

Section 1 defines the term "appropriate specialist," in part, with the phrase "has training in validated diagnostic tools." However, the term "validated diagnostic tools" is defined neither in the bill nor in existing Florida law, leaving ambiguous the standard(s) by which a diagnostic tool may be considered "validated."

Section 2, which amends s. 627.6686, F.S., defines "direct patient access" using the term "in-network" provider. The OIR advises that not all health plans governed by this statute have "networks" or "in-network" providers. A more appropriate term would be "contracted" provider.

VII. Related Issues:

Section 624.215, F.S., requires every person or organization seeking consideration of a legislative proposal mandating health coverage to submit to the Agency for Health Care Administration and the appropriate legislative committees having jurisdiction a report assessing the social and financial impacts of the proposed coverage. The Senate Committee on Health Regulation has not received a report analyzing the mandated coverage for direct patient access to an appropriate specialist for a minimum of three visits per policy year as created by the bill.

VIII. Additional Information:

A. Committee Substitute – Statement of Substantial Changes:

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

B. Amendments:

None.

This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.