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 242
INTRODUCER:	Senators Ring and Fasano
SUBJECT:	Autism Spectrum Disorder Screening/Minors
DATE:	March 28, 2009 REVISED: 04/02/09

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Ray	Walsh	CF	**Fav/1 amendment**
2.	Bell/Munroe	Wilson	HR	**Fav/1 amendment**
3.			BI	
4.			HA	
5.			WPSC	
6.				

Please see Section VIII. for Additional Information:

A. COMMITTEE SUBSTITUTE.....	☐	Statement of Substantial Changes
B. AMENDMENTS.....	☐	Technical amendments were recommended
	☐	Amendments were recommended
	☒	Significant amendments were recommended

I. Summary:

Senate Bill 242 provides that a physician is required to refer a minor to an appropriate specialist to be screened for autism spectrum disorder under specific circumstances. The bill defines an "appropriate specialist" and "neuropsychologist."

This bill creates one unnumbered section of law.

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 non-verbal communication. The early signs of autism usually appear in the form of developmental delays before a child turns 3 years old.[1]

[1] Centers for Disease Control and Prevention website, available at: <http://www.cdc.gov/ncbddd/autism/symptoms.htm> (Last visited on March 28, 2009).

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 (ASD), 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 ASD, 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 National Institute for Mental Health (NIMH) states that all children with an ASD demonstrate deficits in:

- *Social Interaction* – Most ASD children have difficulty learning to engage in everyday human interaction. Children with an ASD are also slower in understanding subtle social cues (non-verbal communication) and thus struggle to interpret what others are thinking and feeling. This causes them to often find social interaction confusing and frustrating. It is also common for people with 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 ASD remain mute, while others do not develop

[2] Department of Health and Human Services, National Institute of Mental Health. *Autism Spectrum Disorders: Pervasive Developmental Disorders, With Addendum*. January 2007. Found at: <http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf > (Last visited on March 28, 2009).

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

[4] 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 autism spectrum disorder (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 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.

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 ASD often become more aware of their difficulties in communication, which can lead to anxiety or depression.

- *Repetitive behaviors or interests* – Children with 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. ASD children 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 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 ASD often have unusual responses to sensory experiences, such as certain sounds or the way objects look.

In 2008, the Legislature passed the "Steven A. Geller Autism Coverage Act,"[6] which defines 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 act requires certain insurance coverage for diagnostic screening, intervention, and treatment of autism spectrum disorder for eligible individuals. The act defines an eligible individual as:

> . . .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 [emphasis supplied].[7]

Diagnosing Autism Spectrum Disorders

There is no medical test for ASD. 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

[6] Chapter 2008-30, L.O.F.; ss. 627.6686 and 641.31098, F.S.
[7] ss. 627.6686(2)(c) and 641.31098(2)(c), F.S.
[8] Center for Disease Control and Prevention website, available at <http://www.cdc.gov/ncbddd/autism/screening.htm> (Last visited on March 28, 2009).

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 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 ASD or if the symptoms warrant it.[11]

The second stage of diagnosis is a comprehensive evaluation. 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.

According to the Agency for Health Care Administration (AHCA), it is currently at the physician's discretion to determine when a referral for an autism screening is appropriate.[13]

III. Effect of Proposed Changes:

The bill provides that if a parent or legal guardian of a minor who is an eligible individual as defined in s. 627.6686, F.S., reports what he or she believes to be symptoms of autism spectrum disorder to a licensed physician, the physician must immediately refer the minor to an appropriate specialist for screening.

The bill provides that the term "appropriate specialist" includes, but is not limited to a person licensed in this state as a:

- Neuropsychologist;
- Board-certified behavior analyst;
- Psychologist;
- Psychiatrist;
- Neurologist; or
- Developmental or behavioral pediatrician who specializes in child neurology.

The bill provides that a neuropsychologist is a psychologist who is competent in the area of neurological testing and has additional training and experience in understanding brain-behavior relationships. The bill states that a neuropsychologist has an advanced degree in psychology, is

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[9] *Id.*
[10] The CDC considers a child with a sibling or parent with an ASD to be at high risk.
[11] Center for Disease Control and Prevention website, available at <http://www.cdc.gov/ncbddd/autism/screening.htm> (Last visited on March 28, 2009).
[12] *Id.*
[13] Agency for Health Care Administration 2009 Bill Analysis & Economic Impact Statement, Senate Bill 242 (on file with the Senate Committee on Children, Families, and Elder Affairs).

known as a Ph.D. or Psy.D., and usually works with psychiatrists, neurologists, neurosurgeons, physiatrists, and other specialists to coordinate care.

The effective date of the bill is July 1, 2009.

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 this 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 provisions in the bill may increase the number of claims for specialist's evaluations in the Medicaid program and private insurers because more minors may be referred for screening. The private insurers and the AHCA would be responsible for paying any additional claims.

C. Government Sector Impact:

According to the AHCA, the Department of Health, the Children's Medical Services programs, and Early Steps programs may see an increase in the number of referrals for screening.

VI. Technical Deficiencies:

Lines 11 and 12 of the bill refer to a minor who is an "eligible individual" as defined in s. 627.6686, F.S. Use of this definition of the term "eligible individual" creates an internal inconsistency, as the minor, whose parent or guardian ". . .believes that the minor exhibits symptoms of autism spectrum disorder," must have already been diagnosed with a developmental disability. This comment applies to the bill and the amendment.

According to the Agency for Persons with Disabilities, the diagnosis of specific disorders is outside the scope of the certification of a board-certified behavior analyst. This comment applies to the bill and the amendment.

Health care practitioners are generally not licensed by specialty in Florida. The bill and the amendment refer to "appropriate specialist" as a person who is licensed in this state as a neuropsychologist, board-certified behavior analyst, psychologist, psychiatrist, neurologist, or developmental or behavioral pediatrician and who specializes in child neurology.

Sections 2 and 3 of amendment barcode 868330 adopted by the Children, Families, and Elder Affairs Committee use the term "an appropriate specialist," but do not define the term or cross reference the term as defined in s. 381.986, F.S., as created in the bill. The amendment also defines the term "direct patient access" in sections 2 and 3 of the bill to mean the ability of a subscriber or insured to obtain services without a referral; however, section 1 of the bill requires a physician to refer the minor to an appropriate specialist.

VII. Related Issues:

This bill and the amendment may cause a physician's professional judgment to be superseded by a parent or guardian's belief that his or her minor child exhibits symptoms of autism spectrum disorder.

VIII. Additional Information:

A. Committee Substitute – Statement of Substantial Changes:
(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

B. Amendments:

Barcode 868330 by Children, Families, and Elder Affairs on March 11, 2009:
(WITH TITLE AMENDMENT)
The amendment creates a section of law relating to screening, evaluation of, or diagnosis for autism spectrum disorder within chapter 381, F.S., relating to general provisions of public health.

The amendment also amends ss. 627.6686 and 641.31098, F.S., (the Steven V. Geller Autism Coverage Act) to provide that notwithstanding any provision within the act, an insurer shall provide direct access by a patient for screening, evaluation or diagnosis for autism spectrum disorder from an appropriate specialist. The amendment defines "direct patient access."

Barcode 209710 by Health Regulation on April 1, 2009:
(WITH TITLE AMENDMENT)
The amendment requires a licensed health care provider to obtain written consent for vaccination from the child's parent or legal guardian, or other authorized person and to give the parent, guardian or other authorized person a copy of the current vaccine information statement published about the vaccine by the U.S. Centers for Disease

Control and Prevention along with other specified information prior to giving a vaccination to a child.

The amendment grants parents, legal guardians, or other authorized persons, in consultation with a child's pediatrician, the right to choose an alternative immunization schedule to the immunization schedule recommended by the U.S. Centers for Disease Control and Prevention, as long as the child is vaccinated before beginning school.

The amendment prohibits the sale, purchase, manufacture, delivery, importation, administration, or distribution of any vaccine that contains any organic or inorganic mercury compound in excess of 0.1 microgram per milliliter.