

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 Policy and Steering Committee on Ways and Means

BILL: CS/CS/SB 308

INTRODUCER: Banking and Insurance Committee and Health Regulation Committee and Senator Ring

SUBJECT: Autism Spectrum Disorders Health Insurance Screening

DATE: April 17, 2009

REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Bell	Wilson	HR	Fav/CS
2.	Johnson	Burgess	BI	Fav/CS
3.	McVaney	Kelly	WPSC	Pre-Meeting
4.				
5.				
6.				

Please see Section VIII. for Additional Information:

- | | | |
|------------------------------|--|---|
| A. COMMITTEE SUBSTITUTE..... | <input checked="checked" type="checkbox"/> | Statement of Substantial Changes |
| B. AMENDMENTS..... | <input type="checkbox"/> | Technical amendments were recommended |
| | <input type="checkbox"/> | Amendments were recommended |
| | <input type="checkbox"/> | Significant amendments were recommended |

I. Summary:

The bill requires a physician to refer a minor whose parent suspects the minor has autism spectrum disorder (ASD) or other developmental disability to an appropriate specialist immediately for screening, evaluation, or diagnosis. The bill requires insurers and health maintenance organizations (HMOs) to provide direct access to an appropriate specialist for the diagnosis of ASD or other developmental disability.

The bill mandates health insurance policies and HMO contracts to provide at least three visits per policy year for the screening, evaluation of, or diagnosis for ASD and other developmental disorders.

Under current laws governing insurance companies and HMOs, an insured or subscriber is authorized to change providers within a network. An insured and a subscriber are also authorized to obtain a second opinion.

The bill creates the following section of the Florida Statutes: 381.986, and amends the following sections of the Florida Statutes: 627.6686 and 641.31098.

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

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 syndrome⁴ and childhood disintegrative disorder.⁵ The National Institute for Mental Health (NIMH) states that all children with an ASD demonstrate deficits in:

¹ Centers for Disease Control and Prevention website, Found at: <<http://www.cdc.gov/ncbddd/autism/symptoms.htm>> (Last visited on April 7, 2009).

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 April 7, 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.

- *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 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.

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 age 3.⁶ 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.⁷

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 risk⁸ for ASD or if the symptoms warrant it.⁹

⁶ Center for Disease Control and Prevention website, available at <<http://www.cdc.gov/ncbddd/autism/screening.htm>> (Last visited on April 7, 2009).

⁷ *Id.*

⁸ The CDC considers a child with a sibling or parent with an ASD to be at high risk.

⁹ Center for Disease Control and Prevention website, available at <<http://www.cdc.gov/ncbddd/autism/screening.htm>> (Last visited on April 7, 2009).

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 ASD) who evaluate the child in depth and determine if there is a developmental disorder, and if so, render a diagnosis. This may include:¹⁰

- 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.¹¹

Treatment Approaches

Much of the scientific and clinical evidence indicates that early treatment of autism during preschool years (ages 3 to 5) often yields very positive effects in mitigating the effects of autism spectrum disorders. According to the National Institute of Neurological Disorders and Stroke (NINDS), therapies for autism are designed to remedy specific symptoms.¹² 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.”¹³

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

¹⁰ *Id.*

¹¹ 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).

¹² http://www.ninds.nih.gov/disorders/autism/autism.htm#Is_there_any_treatment (Last visited on April 7, 2009).

¹³ 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 April 7, 2009).

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.

Task Force on Autism Spectrum Disorders

On March 7, 2008, Governor Crist created the Task Force on Autism Spectrum Disorders by Executive Order 08-36. The task force is “created to advance public policy for the research, screening, education, and treatment of autism, to assess the availability of insurance coverage for appropriate treatment of autism, and to recommend a unified and coordinated agenda for addressing autism in Florida.”

Health Insurance Coverage for Autism Spectrum Disorders in Florida

In 2008, the Legislature passed legislation that requires certain insurance coverage for diagnostic screening, intervention, and treatment of autism spectrum disorder for eligible individuals.¹⁴ The act 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.

¹⁴ Chapter 2008-30, L.O.F.; ss. 627.6686 and 641.31098, F.S.

The act also, 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].¹⁵

The act also 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 and 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. According to OIR, one regional HMO has signed the compact.

However, if an insurer or HMO does not sign onto the compact developed by the Developmental Disabilities Compact Workgroup, effective April 1, 2009, all HMOs and group health insurance plans are subject to the requirements of act. The act requires insurers, including the 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.¹⁷ 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 Plan

Section 110.123, F.S., creates the State Group Health Insurance Plan which provides health care coverage to employees and eligible retirees of state agencies and universities. The program is funded by premiums paid by the agencies, the employees and the retirees, and by copayments and deductibles paid by the employees and retirees.

¹⁵ Sections. 627.6686(2)(c) and 641.31098(2)(c), F.S.

¹⁶ Developmental Disabilities Compact. Found at: < <http://www.floir.com/pdf/DDCProposal-A.pdf>> (Last visited April 7, 2009).

¹⁷ Sections. 627.6686 and 641.31098, F.S.

The following is a summary of the financial outlook for the State Employee Group Health Insurance Trust Fund through FY 2012-13.

	FY 2008-09	FY 2009-10	FY 2010-11	FY 2011-12	FY 2012-13
Beginning Cash Balance	237.7	177.7	127.1	0	0
Revenues	1,585.2	1,764.1	1,769.2	1,778.4	1,789.2
Expenses	1,645.2	1,814.7	2,015.1	2,228.0	2,485.6
Operating Gain/(Loss)	(60.0)	(50.6)	(245.9)	(449.6)	(696.4)
Ending Cash Balance	177.7	127.1	(118.8)	(449.6)	(696.4)

An increase of 1% in premiums generates roughly \$13 million per year. Based on the estimated operating losses of \$50.6 million for FY 2009-10 and \$245.9 million for FY 2010-2011, premiums may need to be increased by 5% in FY 2009-10 and another 19% in FY 2010-11 to offset the rising costs for the current benefits offered under the plan.

III. Effect of Proposed Changes:

Section 1 creates s. 381.986, F.S., to provide that if a parent or legal guardian of a minor who is an eligible individual as defined in s. 627.6686 or 641.31098, F.S., reports what he or she believes to be symptoms of ASD or other developmental disorder to a licensed physician, the physician must immediately refer the minor to an *appropriate specialist* for screening, evaluation, or diagnosis. The physician is also required to inform the parent or legal guardian of the right to direct access to the appropriate specialist for such services.

An *appropriate specialist* is defined in the bill as a qualified professional who is experienced in the evaluation of autism spectrum disorder or other developmental disabilities, who has training in validated diagnostic tools and includes, but is not limited to a person licensed in this state as a:

- Psychologist;
- Psychiatrist;
- Neurologist;
- Developmental or behavioral pediatrician who specializes in child neurology;
- Speech language pathologist;
- Occupational therapist;
- Mental health specialist licensed under ch. 491, F.S., 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 ss. 627.6686 and 641.31098, F.S., respectively, relating to mandated health insurance coverage for autism. The bill expands the current coverage requirement by mandating the same coverage for other developmental disabilities. The section also mandates health insurers and HMOs to provide *direct patient access* to an appropriate specialist, as defined in s. 381.986, F.S., for the screening, evaluation of, or diagnosis of ASD and other developmental disorders.

A developmental disability is defined to mean:

a disorder or syndrome attributable to retardation, cerebral palsy, autism, spina bifida, Down Syndrome, or Prader-Willi syndrome which manifests before the age of 18 years of age and constitutes a substantial handicap that can be substantial handicap that can reasonably be expected to continue indefinitely.

Direct patient access is defined as the ability of a subscriber or insured to obtain services from an in-network provider without a referral or other authorization before receiving services.

Finally, this bill provides that all health insurance policies and HMO contracts under ss. 627.6686 and 641.31098, F.S., must provide plan enrollees a minimum of three visits per policy year for the screening, evaluation of, or diagnosis for ASD.

Section 4 provides that 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:

If the overall costs of the State Group Health Insurance plan increases, premiums charged employers, employees and retirees will need to be increased to offset the new costs.

B. Private Sector Impact:

Early identification and treatment for autism spectrum disorders often produces very positive results in mitigating the effects of the disorder.

The provisions in the bill may increase the costs of large group health insurance and large group HMO coverage due to the possible increased utilization of the evaluation services. To the extent that private sector entities provide health insurance to their employees as part of a large group, the bill may cause health insurance costs to rise.

C. Government Sector Impact:

The Department of Health, Children's Medical Services, and Early Steps programs may see an increase in the number of referrals for screening, which could result in an inability for the Early Steps program to meet federally-mandated timelines for evaluation and service provision.

In 2008, the Legislature expanded the benefits under the State Group Insurance Plan to include therapies for autism with a \$36,000 annual limit and a \$200,000 lifetime limit. The estimated costs of this expansion of benefits are \$3.7 million in FY 2009-10, \$8.0 million in FY 2010-11, and \$8.7 million in FY 2011-12.

The bill expands benefit coverage for retardation, cerebral palsy, spina bifida, Down syndrome, and "Prader-Willi syndrome. It is unclear to what extent this expansion of benefits will increase claims to the State Group Insurance Plan.

To the extent the State Employee Group Health Insurance Trust Fund incurs additional claims for covered benefits, its operating deficit will increase. As a result, premiums (revenues to the trust fund) must be increased or other cost-sharing mechanisms (co-payments or deductibles) must be adjusted to offset the increased costs to the trust fund.

VI. Technical Deficiencies:

Line 26 of the bill refers to a minor who is an "eligible individual" as defined in s. 627.6686 or s. 641.31098, 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.

It is unclear whether section 1 of the bill would have binding authority over physicians practicing medicine in Florida and licensed under chapter 458 or 459, F.S. If so, the Board of Medicine would have the authority to discipline a physician that did not comply with the mandatory referral provision in section 1. It is unclear how many business days would satisfy the requirement for an immediate referral by the physician.

Since sections 2 and 3 mandate insurers and HMOs to provide direct access to specialists, it is unclear why the referral provision would be necessary in the bill.

The "Children's Medical Services Early Steps Program," referenced in lines 46-48 of the bill, does not exist as one entity in law. The Children's Medical Services Network is a collection of programs for special needs children and the many Early Steps Programs make up the statewide comprehensive, coordinated, multi-disciplinary, interagency system to provide early intervention services and supports to infants and toddlers with disabilities and their families in accordance with the Individuals with Disabilities Education Act (IDEA), Part C, the CMS Developmental Evaluation and Intervention Program, codified in ss. 391.301 - 391.308, F.S., and the Developmental Disabilities Program, under Chapter 393, F.S. Children who exhibit symptoms of

ASD may be enrolled and receiving services through the Children's Medical Services Network and the Early Steps Program.

The bill defines an "appropriate specialist" as a qualified professional who is experienced in the evaluation of autism spectrum disorder, which has training in *validated diagnostic tools*, and includes, *but is not limited to* a list of health care providers licensed in Florida. Health care practitioners are not licensed by specialty in Florida. Since the list of appropriate specialists is not all inclusive, other persons that do not meet education, licensure, or experience criteria may provide such services. However, if the other unspecified persons provided such services and were not network providers, the insured or subscriber would be responsible for the payment of the claim. It is unclear what the undefined term, "validated diagnostic tools," means.

VII. Related Issues:

Currently, an insured or subscriber has the right to change physicians within the network of providers. An insured may obtain a second opinion within the network. Section 641.51, F.S., allows a subscriber the right to a second opinion in any instance in which the subscriber disputes the HMO's or the physician's opinion of the reasonableness or necessity of surgical procedures or is subject to a serious injury or illness.

The bill 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.

Proposal for Health Insurance Mandate

Section 624.215, F.S., requires every person or organization seeking consideration of a legislative proposal mandating health coverage to submit to the AHCA and the appropriate legislative committees having jurisdiction a report assessing the social and financial impacts of the proposed coverage. The statute contains twelve assessments that the report is to include, if information is available. The Senate Committee on Health Regulation and the Committee on Banking Insurance have not received a report analyzing the insurance mandate created in 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.)

CS by Health Regulation Committee on April 6, 2009:

The committee substitute substantially revises the bill in the following ways:

- Removes the requirement for health care providers who vaccinate minors in Florida to provide consultation and disclose information to parents or legal guardians of the minor before administering vaccines;
- Removes the requirement for the Department of Health to develop a standardized form and provide each Florida-licensed health care provider with the form to indicate the provider has completed the vaccine and disclosure requirement;
- Removes the requirement for a health care provider who serves pregnant women to inform each woman about childhood vaccines during the patient's 30th week of pregnancy; and

- Removes the requirement for the Department of Health to create and maintain a website that contains information about each childhood vaccination.
- Defines an “appropriate specialist” qualified to diagnose ASD;
- Defines “direct patient access” as it relates to the health insurance coverage of screening for and diagnosis of ASD; and
- Requires health insurers and HMOs to provide at least three visits per policy year for the screening, evaluation of, or diagnosis for ASD.

B. Amendments:

None.