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 Children, Families, and Elder Affairs Committee

BILL: CS/SB 516

INTRODUCER: Children, Families, and Elder Affairs Committee and Senator Garcia

SUBJECT: Autism

DATE: March 15, 2011 REVISED:

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Daniell	Walsh	CF	**Fav/CS**
2.			GO	
3.			BC	
4.				
5.				
6.				

Please see Section VIII. for Additional Information:

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

I. Summary:

Committee Substitute for Senate Bill 516 creates the Autism Spectrum Disorder Study Committee (committee) to examine the effects of autism spectrum disorder (ASD) on families in which English is the second language. The committee, composed of nine members, is to advise the Agency for Persons with Disabilities (APD) on matters relating to the occurrence of ASD in those families. The committee must prepare and present its report by September 1, 2012, when the committee expires.

This bill creates an unnumbered section of the Florida Statutes.

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. More people are being diagnosed with ASD than ever before, and the Centers for Disease Control and Prevention (CDC) considers it a public health crisis.[1]

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.[2]

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),[3] the pervasive developmental disorders, or ASDs, range from a severe form, called autistic disorder, to a milder form, Asperger's syndrome.[4] 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[5] and childhood disintegrative disorder.[6] The NIMH states that all children with an ASD demonstrate deficits in:

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[1] *See, e.g.*, Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, United States, 2006. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm (last visited on March 11, 2011).

[2] Centers for Disease Control and Prevention website, available at http://www.cdc.gov/ncbddd/autism/signs.html (last visited on March 10, 2011).

[3] Department of Health and Human Services, National Institute of Mental Health. Autism Spectrum Disorders: Pervasive Developmental Disorders. Printed 2004 Reprinted 2008. Available at: http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf (last visited on March 10, 2011).

[4] 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.

[5] 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.

[6] 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.

- *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 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 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.

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 (DSM):[7]

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

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]

[7] The 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. 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 scheduled for release in May 2013.

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.[9] This delay in diagnosis may result in lost opportunities for specialized early intervention.

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's symptoms warrant it,[10] or if he or she is at high risk for an ASD.[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.

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 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

[8] Centers for Disease Control and Prevention website. Available at: http://www.cdc.gov/ncbddd/autism/screening.html (last visited on March 10, 2011).
[9] *Id.*
[10] *Id.*
[11] The CDC considers a child with a sibling or parent with an ASD to be at high risk.
[12] Centers for Disease Control and Prevention website. Available at: http://www.cdc.gov/ncbddd/autism/screening.html (last visited on March 10, 2011).
[13] National Institutes of Health, National Institute of Neurological Disorders and Stroke, Autism Information Page. Available at: http://www.ninds.nih.gov/disorders/autism/autism.htm#Is_there_any_treatment (last visited on March 10, 2011).

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]

Florida's Centers for Autism and Related Disabilities (CARD) are established in s. 1004.55, F.S., to provide nonresidential resource and training services for persons of all ages who have autism; a pervasive developmental disorder that is not otherwise specified; who have an autistic-like disability; who have a dual sensory impairment; or who have a sensory impairment with other handicapping conditions. There are seven CARD centers throughout the state,[15] serving clients in their geographic areas.

Each of the centers is involved in academic research, and each provides information and resources to families in order to enable them to assist their loved ones dealing with ASD. In particular, early application of speech-language therapy, occupational therapy, and physical therapy are encouraged 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.

ASD in the Hispanic Community

In 2008, the Hispanic population in Florida exceeded 3.8 million, and 86 percent of Hispanics lived in a household where a language other than English was spoken.[16] The incidence of ASD does not differ across racial or ethnic groups.[17] Dr. Bobbie Vaughn with USF's CARD Center notes:[18]

> The rise in autism spectrum disorders and concomitant rise in the Latino population as the fastest growing minority along with linguistic differences

[14] Commission on Behavioral and Social Sciences and Education, *Educating Children with Autism* 6, 2001. Available at: http://www.nap.edu/openbook.php?record_id=10017&page=66 (last visited on March 10, 2011).

[15] Pursuant to s. 1004.55(1), F.S., the following centers are established: The College of Medicine at Florida State University; the College of Medicine at the University of Florida; the University of Florida Health Science Center at Jacksonville; the Louis de la Parte Florida Mental Health Institute at the University of South Florida; the Mailman Center for Child Development and the Department of Psychology at the University of Miami; the College of Health and Public Affairs at the University of Central Florida; and the Department of Exceptional Student Education at Florida Atlantic University.

[16] *Demographic Profile of Hispanics in Florida, 2008*. Pew Hispanic Center. Available at: http://pewhispanic.org/states/?stateid=FL (last visited on March 11, 2011)

[17] See fn. 1.

[18] Project Conectar: Building Capacity in a Community Learn the Signs Act Early. Bobbie J. Vaughn, Ph.D., Associate Professor, University of South Florida, Principal Investigator. (On file with the Committee.) This ongoing research project is investigating the use of natural helpers, or promotoras, in Little Havana, Miami, to overcome the cultural and linguistic disparities that prevent families from seeking early help for their children and preventing early and accurate diagnosis of ASD and other developmental disabilities.

> potentially creates the widening of an already established disparity. …The parents of many of these children also have limited English proficiency. … This presents another challenge for children who might also have communication and social problems related to ASD.
>
> These adult language barriers alone might prevent an immigrant Latino parent from taking their child to a clinic. In addition to language, is documented that racial bias, patient preferences, and poor communication (i.e., relaying of information) present health care access barriers for Latino and other minority families.

These cultural and linguistic issues can lead to late or inaccurate diagnoses, which can be devastating in a disorder like ASD, where early intervention is critical. Further, there exists a general lack of Spanish-speaking health care professionals trained to diagnose individuals with ASD,[19] exacerbating the problems faced by these families.

III. Effect of Proposed Changes:

CS/SB 516 creates the Autism Spectrum Disorder Study Committee to examine the effects of autism spectrum disorder on families in which English is the second language.

The committee is to advise the Agency for Persons with Disabilities (APD) on legislative, programmatic and administrative matters relating to the occurrence of ASD in those families.

Nine members will be appointed to the committee: three by the Governor, three by the President of the Senate, and three by the Speaker of the House of Representatives. The membership must include:

- At least one licensed physician;
- At least one certified behavior analyst specializing in treatment of ASD through speech, occupational or physical therapy or through applied behavior analysis, or a provider licensed under Chapter 491, F.S., *i.e.*, a clinical social worker, marriage and family therapist, or mental health counselor;[20]
- At least one licensed psychologist;
- The State Surgeon General or an employee of the Department of Health whom he or she designates;
- At least one parent of a child with ASD; and
- At least one educator certified in special education.

Initial appointments must be made by July 1, 2011, and subsequent vacancies are to be filled by the original appointing authority for the duration of the term.

The committee must appoint a chair and must meet at least six times, bimonthly, beginning in August 2011. The last meeting may be no later than August 30, 2012.

[19] Conversation with Mary Kay Bunton-Pierce, USF CARD Center, March 10, 2011.

[20] Pursuant to s. 491.003(13), F.S., a licensed clinical social worker, marriage and family therapist, or mental health counselor may also be referred to as a "psychotherapist".

The members will receive no compensation for their service, and no state funds may be expended in support of the committee, except that the Surgeon General may publish the recommendations and public announcements.

The final report must be completed by September 1, 2012, and presented to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The committee expires on September 1, 2012.

The Act is effective upon becoming law.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

D. Other Constitutional Issues:

None.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

The State Surgeon General or an employee of the Department of Health may be required to attend committee meetings, and the Surgeon General has the discretion to spend department funds on the publication of committee recommendations and public meetings. These activities may create a minimal fiscal impact on the agency.

VI. Technical Deficiencies:

The bill does not specify administrative support for the committee, other than publication of its recommendations and public meetings at the discretion of the state Surgeon General.

VII. Related Issues:

None.

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 Children, Families, and Elder Affairs on March 14, 2011:
The Committee adopted an amendment relating to the composition of the committee, which:

- adds that a physician may also be licensed under Chapter 459
- includes at least one licensed psychologist among the required membership
- replaces "psychotherapist" with the more-specific "provider licensed under Chapter 491" among the optional membership.

B. Amendments:

None.

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