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 Governmental Oversight and Accountability Committee

BILL: SB 722

INTRODUCER: Senator Garcia

SUBJECT: Autism

DATE: February 17, 2012 REVISED:

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Daniell	Farmer	CF	**Favorable**
2.	Jenkins	Roberts	GO	**Favorable**
3.			BC	
4.				
5.				
6.				

I. Summary:

This bill 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 10 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 a report for the Governor, the President of the Senate, and the Speaker of the House of Representatives by September 1, 2013, which is also 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 autism than ever before, and the Centers for Disease Control and Prevention (CDC) considers it a public health crisis.[1]

[1] *See, e.g.*, Catherine Rice, *Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, United States, 2006* (2006), *available at* http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm (last visited Jan. 13, 2012).

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 as "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), the pervasive developmental disorders, or ASDs, range from a severe form, called autistic disorder, to a milder form, Asperger's syndrome.[3] A child can also be diagnosed with pervasive developmental disorder not otherwise specified (PDD NOS) if the child has symptoms of both disorders, but does not meet the specific criteria for either. Other 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 ASD have difficulty learning to engage in everyday human interaction. Children with 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 ASD to have difficulty controlling their emotions. Examples include episodes of disruptive behavior such as crying or verbal outbursts at inappropriate

[2] Centers for Disease Control and Prevention, *Autism Spectrum Disorders (ASDs), Signs and Symptoms*, http://www.cdc.gov/ncbddd/autism/signs.html (last visited Jan. 13, 2012).

[3] Nat'l Institute of Health, Dep't of Health and Human Servs., *Autism Spectrum Disorders, Pervasive Developmental Disorders*, NIH Publication No. 08-5511, at 2 (2008), *available at* http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf (last visited Dec. 16, 2011). Asperger's syndrome is "a developmental disorder that affects a person's ability to socialize and communicate effectively with others. Children with Asperger's syndrome typically exhibit social awkwardness and an all-absorbing interest in specific topics." The Mayo Clinic, *Asperger's Syndrome, Definition*, http://www.mayoclinic.com/health/aspergers-syndrome/DS00551 (last visited Jan. 13, 2012); *see also* Dr. Tony Attwood, *What is Asperger's Syndrome?*, OASIS @ MAAP, http://aspergersyndrome.org/Articles/What-is-Asperger-Syndrome-.aspx (last visited Jan. 13, 2012).

[4] Rett syndrome is a relatively rare disorder, affecting almost exclusively females. According to NIMH, "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." Nat'l Institute of Health, *supra* note 3, at 4.

[5] Childhood disintegrative disorder (CDD) is a very rare form of ASD, usually found in males. Symptoms may start to appear as early as 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. *Id.*

times or physical aggression. They often can lose self-control when exposed to a strange or overwhelming environment or when angry or frustrated.[6]

- *Verbal and nonverbal communication* – Persons with ASD often 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 a person with ASD can be difficult to understand because it is not always consistent with the words he or she is saying. As they grow older, persons with ASD often become more aware of their difficulties in communication, which can lead to anxiety or depression.[7]
- *Repetitive behaviors or interests* – Persons with ASD often perform 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 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 may become upset. Additionally, autistics often form intense, obsessive preoccupations with certain objects or topics on which they focus much of their energy.[8]

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

Florida law 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 (DSM):[9]

- Autistic disorder.
- Asperger's syndrome.
- Pervasive developmental disorder not otherwise specified.[10]

Diagnosis of Autism Spectrum Disorders

There is no medical test for ASDs. Instead, doctors look at behavioral symptoms to make a diagnosis. Research shows that the diagnosis of autism at age 2 can be reliable, valid, and stable.

[6] *Id*. at 7-8.
[7] *Id*. at 8-9.
[8] *Id*. at 9-10.
[9] 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. *See* Am. Psychiatric Ass'n, DSM-5 Development, *Proposed Draft Revisions to DSM Disorders and Criteria*, http://www.dsm5.org/Pages/Default.aspx (last visited Jan. 13, 2012).
[10] Sections 627.6686(2)(b) and 641.31098(2)(b), F.S.

However, many children do not receive final diagnosis until they are much older.[11] This delay in diagnosis may result in lost opportunities for specialized early intervention.

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's symptoms warrant it or if he or she is at high risk for ASD.[12]

The second stage of diagnosis is a comprehensive evaluation. If the initial screening tests indicate the possibility of 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. This may include:

- 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.[13]

Treatment Approaches for Autism Spectrum Disorders

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.[14] 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."[15]

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[11] Centers for Disease Control and Prevention, *Autism Spectrum Disorders (ASDs), Screening and Diagnosis*, http://www.cdc.gov/ncbddd/autism/screening.html (last visited on Jan. 13, 2012).
[12] The CDC considers a child with a sibling or parent with an ASD to be at high risk. *Id*.
[13] *Id*.
[14] Nat'l Institute of Neurological Disorders and Stroke, Nat'l Institutes of Health, *NINDS Autism Information Page,* http://www.ninds.nih.gov/disorders/autism/autism.htm#Is_there_any_treatment (last visited Jan. 13, 2012).
[15] Comm'n on Behavioral and Social Sciences and Education, *Educating Children with Autism*, at 6 (2001), *available at* http://www.nap.edu/openbook.php?record_id=10017&page=6 (last visited Jan. 13, 2012).

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 who have autism, a pervasive developmental disorder that is not otherwise specified, an autistic-like disability, a dual sensory impairment, or a sensory impairment with other handicapping conditions. There are seven CARD centers throughout the state, serving clients in their geographic areas.[16]

Each of the centers is involved in academic research, and each provides information and resources to families 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.

Autism Spectrum Disorder in the Hispanic Community

In 2009, the Hispanic population in Florida was nearly 4 million, and 86 percent of Hispanics lived in a household where a language other than English was spoken.[17] The incidence of ASD does not differ across racial or ethnic groups.[18] Dr. Bobbie Vaughn with the University of South Florida's CARD Center notes:

> The rise in autism spectrum disorders and concomitant rise in the Latino population as the fastest growing minority along with linguistic differences 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, [it] 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.[19]

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

[16] The seven centers are located at 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. Section 1004.55(1), F.S.

[17] PEW Hispanic Ctr., PEW Research Ctr., *Demographic Profile of Hispanics in Florida, 2009*, http://pewhispanic.org/states/?stateid=FL (last visited Jan. 13, 2012).

[18] Catherine Rice, *supra* note 1.

[19] Bobbie J. Vaughn, Ph.D., Associate Professor, University of South Florida, *Project Conectar: Building Capacity in a Community Learn the Signs Act Early* (on file with the Committee on Children, Families, and Elder Affairs). 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.

general lack of Spanish-speaking health care professionals trained to diagnose individuals with ASD, exacerbating the problems faced by these families.[20]

III. Effect of Proposed Changes:

This bill 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 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.

The committee shall consist of 10 members, four of whom are appointed by the Governor, three are appointed by the President of the Senate, and three by the Speaker of the House of Representatives. The membership must include:

- At least one physician licensed under chs. 458 or 459, F.S.;
- At least one psychiatrist licensed under chs. 458 or 459, F.S.;
- At least one psychologist licensed under ch. 490, F.S.;
- At least one certified behavior analyst specializing in treatment of autism through speech, occupational, or physical therapy or through applied behavior analysis, or a provider licensed under ch. 491, F.S. (*i.e.*, a clinical social worker, marriage and family therapist, or mental health counselor);[21]
- The State Surgeon General or an employee of the Department of Health appointed by the State Surgeon General;
- At least one parent of a child with autism;
- At least one educator certified in special education;
- At least one doctor from UM-NSU CARD, Center for Autism & Related Disabilities; and
- At least one person who has autism.

Initial appointments must be made by July 1, 2012, and subsequent vacancies are to be filled by the original appointing authority for the duration of the term.

The committee must appoint a chair by majority vote at its first meeting. The committee must meet at least six times bimonthly beginning in August 2012. The last meeting may be no later than August 30, 2013.

The members do not receive compensation for their service, and state funds may not be expended for the management and operation of the committee; however, the State Surgeon General may expend money to publish the recommendations and public announcements.

A final report must be completed by September 1, 2013, and presented to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The committee expires on September 1, 2013.

[20] Conversation with Mary Kay Bunton-Pierce, USF CARD Center (Mar. 10, 2011).
[21] 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 bill 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.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

The bill requires specified physicians and members of the public to participate in the bimonthly meetings of the committee. The bill does not provide compensation to these people for participating on the committee. Therefore, there may be a slight fiscal impact to these committee members.

C. Government Sector Impact:

The bill requires the State Surgeon General or a Department of Health designee to participate in the bimonthly meetings of the committee. Additionally, the bill authorizes the State Surgeon General to spend state funds on publishing the committee's recommendations as well as any public announcements. However, the exact fiscal impact of the bill cannot be determined at this time.[22]

VI. Technical Deficiencies:

The bill does not specify which agency is to provide administrative support to the committee.[23] The bill does provide that the State Surgeon General (within the Department of Health) is authorized to publish the committee's recommendations and public announcements; however, it is not specifically clear if the Department of Health is to provide other administrative support, if needed, to the committee.

[22] Fla. Dep't of Health, *Bill Analysis, Economic Statement and Fiscal Note, SB 722* (Nov. 21, 2011) (on file with the Senate Committee on Children, Families, and Elder Affairs).
[23] *Id*.

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.)

None.

B. Amendments:

None.