

1. The Secretary of Juvenile Justice
2. A representative of the Department of Children and Family Services
3. A representative of the Department of Education
4. The Executive Director of the Agency for Health Care Administration
5. A representative of the Department of Health
6. The Department of Psychiatry chair of the University of Florida Brain Institute
7. The chairman of the Department of Pediatrics of the University of Miami Medical School
8. The chair of the Florida Partnership for School Readiness
9. The chair of the Florida Interagency Coordinating Council for Infants and Toddlers
10. A professional who has expertise in the needs of children with learning disabilities
11. A professional who has expertise in the needs of children with emotional or mental disorders
12. A professional who has expertise in the needs of children with developmental disabilities
13. A professional who has expertise in the diagnosis and treatment of children with speech and language disorders
14. A professional who has expertise in the early intervention and prevention services rendered to children in Florida
15. A professional with expertise in autism and related disorders
16. The parent of a child with a learning disability or emotional or mental disorder.

The study commission met in seven public meetings across the state, in Tallahassee, Miami, Jacksonville, and Orlando, and provided opportunity for public testimony at those meetings. The commission invited experts in brain research, child development and early intervention to participate in the commission's activities and to make recommendations concerning the state's early intervention programs.

In public testimony, parents of children with disabilities told of their frustration when they sought help for a suspected problem and called one agency after another without finding information or assistance. Parents told of pediatricians who had failed to diagnose serious disorders, saying the problem would disappear as the children grew older. Other testimony indicated that pediatricians and other medical professionals may need special training in order to detect potential learning problems and other developmental delays in their young patients.

The commission formed a scientific advisory workgroup to provide information on the effectiveness of various early intervention and prevention programs. A community advisory workgroup supplied the commission with information about gaps in service and barriers to integrating existing systems. In addition to the work of the advisory groups, several commission members provided summaries of research on learning disabilities (LD) and behavior in very young children that is indicative of future communication problems.

Approximately 15 percent of Florida's public school population, ages 3-21, has an identified disability. Of the 375,716 students with disabilities:

- 45 percent are identified as specific learning disabled
- 24 percent are identified as either speech or language impaired
- 8 percent are identified as educable mentally handicapped

- 8 percent are identified as emotionally handicapped
- 15 percent are identified in other categories

In 2000-01, Florida schools served 30,369 children ages three through five in preschool disability programs, under Part B of the Individuals with Disabilities Education Act (IDEA). Of these:

- 53 percent were speech or language impaired
- 30 percent were developmentally delayed
- 17 percent were in other categories

Under Part C of IDEA, the Developmental Evaluation and Intervention Program in the Department of Health serves 29,053 children from birth through age two who have established disabilities and developmental delays.

The commission found that, “While many of Florida’s children who display early symptoms of developmental delay receive services under the state’s disability criteria, many others with emerging conditions that may result in school failure do not have access to the programs, services, and support necessary to minimize the long-term impact of these conditions.” The commission used the term learning problem to refer to conditions that do not meet the threshold of a learning disability or developmental delay.

In light of new scientific understanding about precursors of learning disabilities and interventions that could prevent or ameliorate them, the study commission focused much of its attention on early risk indicators. The commission also noted that combinations of risks increased the likelihood that a child will experience a learning problem, learning disability, or other disability.

The chart that follows lists risk categories associated with disabilities.

**RISK CATEGORIES ASSOCIATED WITH LEARNING DISABILITIES,
DEVELOPMENTAL DELAYS AND OTHER DISABILITIES**

Established Conditions	Biological Risk	Environmental Risk
<ul style="list-style-type: none"> ■ Congenital or genetic disorders associated with developmental delay (e.g. Down Syndrome, PKU, spina bifida). ■ Neurological abnormalities and insults (e.g. cerebral palsy, hyper/hypotonicity, muscular dystrophy, intraventricular hemorrhage grade 3 and 4, seizures). ■ Congenital and acquired infectious diseases known to be associated with developmental delay (e.g. AIDS, CMV, toxoplasmosis, rubella, syphilis, meningitis, encephalitis). ■ Severe attachment disorder and other atypical developmental disorders (e.g., autism, pervasive developmental disorder). ■ Sensory impairments (e.g., visual or hearing impairments). ■ Birth weight at or less than 1000 grams. 	<ul style="list-style-type: none"> ■ A child with medical complexity or technology dependency (e.g., respirator dependency). ■ A child with an illness or trauma known to be associated with developmental delay (e.g., near drowning, head injury, poisoning, Reye's Syndrome, Sudden Infant Death Syndrome, cardiac or respiratory disease, perinatal trauma or asphyxia). ■ A drug-exposed infant (e.g., an alcohol, cocaine, or a poly-exposed infant). ■ An infant of a mother with a chronic illness known to be associated with developmental delay (e.g., HIV or maternal diabetes). ■ An infant receiving care in or a graduate of a Neonatal Intensive Care Unit complicated by psychosocial and/or chronic health problems. ■ An infant with birth weight between 1000 and 1500 grams. ■ An infant with birth weight between 1501 and 2500 grams complicated by psychosocial and/or chronic health problems. ■ An infant with factors impinging on developmental progress (e.g., unusual behavior patterns in early infancy such as inconsolable crying, sleep disturbance, feeding difficulties; sensory processing deficits such as attention problems, tactile defensiveness, or lack of coordination). ■ Populations known to be at high risk because of exposure to poisons and teratogens ■ Family members with conditions such as learning disability, emotional cognitive disability, autism, or attention deficit disorders. 	<ul style="list-style-type: none"> ■ A child born to a teen mother who has not completed high school. ■ A child whose mother's education is below grade 10. ■ A child who is a victim or a sibling of a victim in an indicated report of abuse or neglect. ■ A child in an institution or for whom no legal residence or guardianship has been established, and/or a child who is in a shelter or in foster care. ■ A child with a parent or guardian who is unable to consistently perform essential parenting functions. ■ Parents who have physical impairment, significant psychological or emotional dysfunction, limited intellectual functioning, dysfunctional child and familial interaction. ■ Parents who are incarcerated; girls in the juvenile justice system who are pregnant or have children under 5; families with children in juvenile justice system, or families in which a sibling of a child under 5 is in the juvenile justice system. ■ Presence of physical, emotional, sexual, or domestic violence among family members. ■ Children of mothers or fathers receiving substance abuse treatment. ■ Parents who are migrant, homeless, or have a home environment that lacks essential physical or financial resources or stability.

Source: Florida Commission on the Study of Children with Developmental Delays, 2000, adapted from NECTAS Notes, Issue No. 5).

The chart that follows lists behavioral risk indicators of learning disabilities and developmental delay.

BEHAVIORAL RISK INDICATORS OF LEARNING DISABILITY AND DEVELOPMENTAL DELAY

Risk of Autism Spectrum Disorder and Other Developmental Delay ¹	Risk of Learning Disability and Other Developmental Delay ²	Risk of Emotional/Behavioral Disorder and Other Developmental Delay ³	Risk of Reading Difficulty and Other Developmental Delay ⁴
<ul style="list-style-type: none"> ■ No babbling by 12 months. ■ No gesturing by 12 months. ■ No single words by 16 months. ■ No two-word spontaneous phrases by 24 months. ■ Any loss of any language skills at any age. 	<ul style="list-style-type: none"> ■ Language – pronunciation problems, slow vocabulary growth, and lack of interest in story telling. ■ Memory—trouble learning numbers, alphabet, days of the week, poor memory for routines. ■ Attention—trouble sitting still, extreme restlessness, impersistence at tasks. ■ Fine Motor Skills—trouble with self-help skills such as tying shoes, clumsiness, reluctance to draw or trace. ■ Other—trouble interacting (weak social skills), trouble learning left from right (possible visual-spatial confusion). 	<p>Infants:</p> <ul style="list-style-type: none"> ■ Poor self-regulation. ■ Abnormal muscle tone and motoric disorganization. ■ Abnormal sensory threshold. ■ Depressed interactive behaviors. <p>Toddlers and Young Children:</p> <ul style="list-style-type: none"> ■ Distracted, less-focused play and daily activities. ■ Difficulties in precision and direction of movement. ■ Learning continuity problems, sporadic mastery of skills. ■ Low stress threshold. ■ Language deficiencies. 	<p>Infants and Prior to Pre-School:</p> <ul style="list-style-type: none"> ■ Significant delays in expressive language, receptive vocabulary or IQ. <p>At Entry to Pre-School:</p> <ul style="list-style-type: none"> ■ Deficient knowledge about letters. ■ Deficient understanding of the functions of print. ■ Deficient verbal memory for stories and sentences. ■ Deficient phonological awareness. ■ Deficient expressive and receptive vocabulary. ■ Deficient overall language development.

Source: Florida Study Commission of Children with Developmental Delays, 2000.

¹Filipek, P., Accardo, P., Baranek, G., et al. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29, 439-484. Endorsed by the American Academy of Neurology and Child Neurology Society.

²Christopher Lonigan, Ph.D., Florida State University. Endorsed by National Center for Learning Disabilities.

³Marie Kanne Poulsen, Ph.D., Children's Hospital Los Angeles.

⁴Preventing Reading Difficulties in Young Children, 1998, National Research Council.

In January 2001, the commission submitted a report, including proposed legislation, to the President of the Senate and the Speaker of the House of Representatives. The commission examined the research and best practices in the pertinent professional disciplines and recommended pilot programs to determine the organizational arrangement of the delivery system that would assure coordination and integration with existing systems. The commission also recommended a steering committee to oversee the pilot projects and provide technical assistance to them.

The commission stated in its findings:

- Many parents lack an adequate understanding of child development and may not receive the assistance they need from existing systems in identifying problems that require further assessment and interventions.
- There is no visible central point in communities to access information about screening and services to address early learning problems and developmental delays.
- Many of the screening opportunities available in medical settings and early care and education settings are missed.
- Research has advanced medical screening methods to screen for a wider range of medical and biological conditions that lead to learning problems, developmental delays and disabilities.
- Many more children at risk of learning problems, learning disabilities, and mild developmental delays could be identified through a more deliberate screening effort. In addition to screens already in use, more sensitive screening instruments are being developed to identify early indicators of speech, language, and emergent literacy problems.
- Capacity in existing programs and services is limited; services may not be available for young children and their families even after screening is conducted.
- Many proven interventions are not being implemented due to lack of funding, trained personnel and capacity of communities to provide sufficient services.

The commission recommended establishing three pilot programs to create a system for the best use of current resources and to identify gaps in current services in addressing children's learning problems.

The 2001 Legislature passed CS/SB 1018 to create the pilot programs and enact the recommendations of the Study Commission. However, the Governor vetoed the bill, stating in his veto message that the bill was vetoed, in part, because of "the potential for excessive intrusiveness of government in the lives of Florida's families." The bill did not require parental consent for every activity, and the public records bill that would have made Learning Gateway records confidential did not pass. The Governor also cited the expense associated with the Department of Health's purchase of expensive equipment to process tandem mass spectrometry tests in three demonstration counties as a reason for his veto.

During the past year, a significant report, *Rethinking Special Education for a New Century* published in May 2001 by the Thomas B. Fordham Foundation and the Progressive Policy Institute and "The Learning Disabilities Summit: Building a Foundation for the Future," a conference held in Washington, DC on August 27 - 28, 2001, have called for a new approach to learning disabilities.

Rethinking Special Education for a New Century presents discussions of the history, issues, practice and possible future changes in exceptional student education. The report cites estimates that \$35-\$60 billion is spent annually on special education in the United States and notes that approximately 12 percent of American children are touched by the program. In the chapter titled "Rethinking Learning Disabilities," the authors state, "We contend that sound prevention

programs can significantly reduce the number of older children who are identified as LD and who typically require intensive, long-term special education programs. Moreover, prevention programs will prove more effective than remedial programs. Finally, we contend that, given what we now know about LD, it is irresponsible to continue current policies that dictate inadequate identification practices. Instead, we must develop evidence-based alternatives, specific strategies to implement these alternatives, and a research and policy agenda to ensure that these changes are phased into practice as quickly as possible.”

The Learning Disabilities Summit was a part of a national initiative sponsored by the Office of Special Education Programs (OSEP) of the U.S. Department of Education. This summit is part of an examination of policies regarding learning disabilities that OSEP has pursued for several years. In the 1997 final regulations for the Individuals with Disabilities Education Act (IDEA), OSEP stated, “ the Department plans to carefully review research findings, expert opinion, and practical knowledge over the next several years to determine whether changes should be proposed to the procedures for evaluating children suspected of having a specific learning disability (3/12/99).”

In his introductory remarks at the Learning Disabilities Summit, Secretary of Education Rod Paige said, “President Bush and I will apply the same four principles to IDEA that we did to ESEA. Accountability for results is just as important for all students with disabilities, including children who have learning disabilities. Flexibility and freedom from federal red tape can help school districts tailor their services to the needs of their students-something that has often eluded our special education policy under the current IDEA. Expanded parental options will help the parents of disabled children choose a format for services that fits their child's needs.”

The goals of the Learning Gateway are in keeping with these national reform efforts. Restructuring current services to provide early intervention to lessen, or even prevent, learning disabilities and providing parents access to information, screening and services are the keys to this reform.

III. Effect of Proposed Changes:

The bill establishes pilot programs and a steering committee to design and pilot an integrated, community-based system to lessen the effects of learning problems and learning disabilities for children from birth through age nine. The system is called a Learning Gateway because its key features will be a single point of access for parents and caregivers. In order for the Learning Gateway to lead to a coherent system, the pilot programs must coordinate existing resources and identify gaps in service. The three pilot programs will be established in Orange, Manatee, and St. Lucie Counties. Interagency consortia in each county will develop a proposal for a system that will do the following:

- Give parents who suspect a potential learning problem a single place to call for information on child development and referral to screening and services, if appropriate and if desired.
- Inform and train parents, pediatricians, and teachers of the early warning signs of learning problems, according to the best current research.
- Recommend combining local planning bodies, if that would improve effectiveness of services.

- Develop a model system of care that builds upon and integrates existing services.

The proposals from the pilot sites will be considered and approved by an 18-member Learning Gateway Steering Committee of parents, program providers, and individuals with scientific, medical, and business expertise. The steering committee will support and oversee the pilot programs. The Governor, the President of the Senate, and the Speaker of the House of Representatives will each appoint six members. The Governor will appoint one member from the private sector who has expertise in communications, management or service provision; one member who has expertise in children's vision; one member who has expertise in learning disabilities; one member with expertise in audiology; one member who is a parent of a child eligible for services by the Learning Gateway; and one provider of related diagnostic and intervention services. The President of the Senate will appoint one member from the private sector who has expertise in communications, management or service provision; one member who has expertise in emergent literacy; one member with expertise in pediatrics; one member with expertise in brain development; one member who is a parent of a child eligible for services by the Learning Gateway; and one member who is a provider of related diagnostic and intervention services. The Speaker of the House of Representatives will appoint one member from the private sector who has expertise in communications, management or service provision; one member who has expertise in environmental health and allergies; one member who has expertise in children's nutrition; one member who has expertise in family medicine; one parent of a child eligible for services by the Learning Gateway, and one member who is a school psychologist providing diagnostic and intervention services. Steering committee members will serve 3-year terms. Members will not receive compensation for their services but may receive reimbursement for travel expenses.

Representatives from the Departments of Education, Health, Children and Family Services, Juvenile Justice, and Corrections, and the Agency for Health Care Administration, the Learning Development and Evaluation Center of Florida Agricultural and Mechanical University, and the Florida Partnership for School Readiness will support the work of the steering committee. The Governor will appoint the chair. The Learning Gateway Steering Committee will be assigned to the Department of Education for administrative purposes.

The steering committee must be appointed and must hold its first meeting within 90 days after the bill becomes law. Within 90 days after its initial meeting, the steering committee will accept proposals from interagency consortia in Orange, Manatee, and St. Lucie Counties to serve as demonstration sites for design and development of the Learning Gateway. If there is no proposal from one of the designated counties, the steering committee may select another county by majority vote.

The steering committee must approve, deny, or conditionally approve a Learning Gateway proposal within 60 days of receipt of the proposal. If a proposal is conditionally approved, the steering committee must assist the Learning Gateway applicant to correct deficiencies in the proposal by December 1, 2002. Funds must be available to a pilot program 15 days after final approval of its proposal and no later than January 1, 2003.

The Learning Gateway pilot programs (or, demonstration programs) will provide information and referral but will not provide direct services to children or parents.

The steering committee will:

- Establish guidelines for screening children from birth to age 9.
- Cooperate with the Florida Pediatric Society in developing a child health care checklist.
- By January 2005, make recommendations to the Governor, Legislature, and Commissioner regarding the merits of expanding the pilot projects.

The demonstration projects will:

- Work to increase early identification of precursors to learning problems by providing parents the option of improved screening and referral in public and private early education and care settings and in public and private school settings in grades K-3.
- Work to reduce the duplication of cross-agency screenings.
- Develop public awareness strategies to provide information regarding developmental milestones and precursors of learning problems to parents of children from birth to age 9, and to health care providers and care givers for children of those ages.
- Collaborate with the Health Start program or similar local resources, to develop strategies for offering hospital or home visits to new mothers.
- Engage local physicians and other medical professionals in enhancing the screening opportunities presented by immunization visits and well-child appointments.
- Conduct a needs assessment of existing services and programs and determine where targeted screening should be offered to parents of children who are served, or whose parents are served in, state intervention programs.
- Provide families whose children were found ineligible for services under Part B or Part C of the IDEA information about available services.

As a measure to reduce duplication of screenings, agencies participating in the Learning Gateway are authorized to provide the Learning Gateway confidential information regarding a developmental screening on any child participating in the Learning Gateway who is or has been the subject of a developmental screening in that agency. Such information would remain confidential in the possession of the Learning Gateway.

By January 1, 2005, the steering committee, in conjunction with the demonstration projects, will develop a model county-level strategic plan to formalize the goals, objectives and strategies developed by the pilot projects. There is no anticipation for statewide implementation of this plan; rather it will be a model plan a county could adopt.

The bill provides an appropriation of an indeterminate amount to fund the demonstration programs. The selected communities may blend funding from existing programs consistent with federal requirements to the extent that blending is advantageous to the community.

The bill will take effect upon becoming a law.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

V. Economic Impact and Fiscal Note:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

The private sector impact is indeterminate.

C. Government Sector Impact:

The Study Commission estimated a cost of \$6 million for the 3 pilot sites with oversight by the steering committee. The revisions in the proposed committee substitute lower the cost to \$2.4 million.

Expenditures – Statewide Support and Coordination

Meetings/Staff/Support

10 meetings 2 days for 18 members (\$350/meeting) =	\$ 64,000
National experts to advise steering committee	\$ 60,000
Staff costs or contracted services for Committee support	\$125,000
Dissemination of materials on successful practices/programs	\$ 50,000
1 conference for pilot participants	\$ 75,000

Assistance to Demonstration Sites

Provision of experts for 3 local demonstration sites	\$225,000
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Statewide Products/Services

Comprehensive Health Care Checklist	\$100,000
Screening Guidelines	\$ 50,000
Subtotal	\$749,000

Expenditures—3 Local Demonstration Sites

Centralized telephone number for parents	\$300,000
Community awareness campaign	\$150,000
System for Screening and Tracking	\$600,000
General operating costs	\$ 90,000
Staff support for coordination**	\$450,000
Evaluation planning activities	<u>\$ 75,000</u>
Subtotal	\$1,665,000

Total \$2,414,000

These amounts are provided in the proposed Senate Budget.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Amendments:

None.

This Senate staff analysis does not reflect the intent or official position of the bill's sponsor or the Florida Senate.
