The Florida Senate BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

	Prepared	By: The Professional	Staff of the Health	n Policy Comm	ittee	
BILL:	CS/SB 988					
INTRODUCER:	Health Policy Committee and Senator Wise					
SUBJECT:	Transitional Se	ervices for Young Ac	lults with Disabi	lities		
DATE:	April 3, 2008	REVISED:				
ANAL	YST	STAFF DIRECTOR	REFERENCE		ACTION	
. Garner		Wilson	HP	Fav/CS		
			CF			
			HA			

Please see Section VIII. for Additional Information:

A. COMMITTEE SUBSTITUTE..... X
B. AMENDMENTS.....

Statement of Substantial Changes Technical amendments were recommended Amendments were recommended Significant amendments were recommended

I. Summary:

The committee substitute establishes the Health Care Transition Services Task Force for Young Adults with Disabilities. The bill directs the Department of Health (DOH) to create this statewide task force. The task force is to be composed of 14 individuals with expertise in youth transitional needs. The director of the DOH's Children's Medical Services Network (CMSN) or his or her designee shall be the chairperson of the task force. The DOH shall provide staff support to the task force.

The task force must convene by August 31, 2008, to obtain input from key stakeholders and youth who have chronic special health care needs and disabilities and to develop a statewide plan to: promote the development of health care transition services; identify common or comparable performance measures for the program; collect and disseminate information concerning best practices in health care transition services; and identify existing and potential funding sources. The task force shall present a final report of its findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives by January 1, 2009.

This bill creates an undesignated section of law.

II. Present Situation:

Health Care Transition

Transitioning into adulthood is a difficult process for all adolescents, but the transition presents additional challenges for young people with special health care needs. The term "health care transition" is defined as the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from [a] child-centered to [an] adult-oriented healthcare system."¹ Among the factors that have a significant impact on the health care transition process are service needs (such as a young adult's desire for developmentally appropriate services that address changing and maturing needs), structural issues (such as insurance policies that preclude reimbursement for certain services over a particular age, the licensing and practice limitations of practitioners, and the stated mission of particular facilities such as children's hospitals) and personal preferences (such as a young person's desire for privacy that may not be available in a pediatric unit, even though pediatric care is required).²

Also contributing to the problem of transition, children and adolescents with special health care needs demonstrate high utilization of medical services relative to other adults. For example, according to a survey by Brandeis University and Family Voices of parents with children with special health care needs, parents reported that in the preceding year, their children needed the following services:

- 82 percent needed specialty medical doctors;
- 49 percent needed speech therapy;
- 48 percent needed physical therapy;
- 48 percent needed occupational therapy;
- 29 percent needed home health services; and
- 20 percent needed mental health services.³

The challenge of transitioning from pediatric to adult health care is to insure that at every age every person receives uninterrupted health care that is developmentally appropriate.⁴ In Florida, some initiatives have been undertaken to conduct research and provide information to patients and their families on how to transition children and adolescents into the non-pediatric health care system. For example:

• The Health Care Transition Initiative at the University of Florida is a multi-disciplinary effort whose activities include research, product development, and networking, with the goal of

¹ J. Reiss. "Health Care Transition: Destinations Unknown." *Pediatrics*. Vol. 110, Iss. 6. December 2002. ² Id.

³ The Consortium for Children and Youth with Disabilities and Special Health Care Needs, *Children with Special Health Care Needs and Access to Health and Rehabilitative Services: A Fact Sheet on Findings*, May 2002. Found at http://www3.georgetown.edu/research/gucchd/consortium/documents/brief1.pdf (last visited on April 2, 2008).

⁴ American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine. "A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs." *Pediatrics.* Supplemental to Vol. 110. December 2002.

increasing awareness and promoting cooperative efforts to improve the process of transitioning from child-centered (pediatric) to adult oriented health care.⁵

• The Jacksonville Health and Transition Services (JaxHATS) program was created in 2005 to establish a "medical home" for youths and young adults with chronic medical illness or a disability in Northeast Florida. The program is based at the University of Florida Shands-Jacksonville campus and has collaborative agreements with other providers such as the Nemours Children's Clinic, the C.B. McIntosh Sickle Cell Center, and the Institute for Health Policy.⁶ For FY 2007-08, the program was funded with \$300,000 through CMSN in the DOH. JaxHATS staff estimates that between 87,000-121,000 adolescents and young adults in Florida have chronic medical or developmental conditions, as well as special needs in education, although few have access to programs such as JaxHATS. As of March 2008, JaxHATS serves 240 individuals in its transition program. The following is a list of the number and kinds of health conditions of the patients enrolled in the JaxHATS program:⁷

Type of Condition	Number of Enrollees
Developmental/Intellectual Disability	45
Cerebral palsy	33
Emotional Disorders	29
Type I & Type II Diabetes	23
Autism, Down Syndrome, Prader-Willi	15
Seizure Disorder	14
Asthma	14
Sickle Cell Anemia	18
Endocrine Disorders/Tumors	12
Recovering From Cancer	8
Spina Bifida	8
Cardiac Disease	7
Pulmonary Conditions/Cystic Fibrosis	3
Transplant	6
Brain/Spinal Cord Injury	5
Total	240

Educational and Vocational Transitioning

Many children with special health care needs also have developmental or mental disabilities, and face significant obstacles as they age out of traditional educational and service arrangements. According to the National Organization on Disability's Harris Survey of Americans with Disabilities:

- Young people with disabilities drop out of high school at twice the rate of their peers.
- As many as 90 percent of young people with disabilities are living at poverty level three years after graduation.
- Eighty percent of people with significant disabilities are not employed.

⁵ <u>http://hctransitions.ichp.edu/</u> (last visited on April 2, 2008).

⁶ <u>http://jaxhats.ufl.edu/about.php</u> (last visited on April 2, 2008).

⁷ Senate professional staff communications on March 28, 2008, with Dr. David Wood, Associate Professor of Pediatrics, University of Florida, JaxHATS program administrator.

• Only one out of ten persons with a developmental disability will achieve integrated, competitive employment, and most will earn less than \$2.40 an hour in a sheltered workshop.⁸

There are some initiatives in Florida focused on identifying the challenges faced by young adults with disabilities as they transition from high school to adult life and developing strategies to create an effective transition system:

- Partners in Transition is a broad-based partnership working to identify issues and barriers faced by Florida's youth as they make the transition from high school to adulthood. Entities involved in this partnership include the Agency for Persons with Disabilities, the Department of Children and Families, the Department of Education, the Department of Health, and the Department of Juvenile Justice, the Able Trust, the ADA Working Group, the Florida Developmental Disabilities Council and the Florida Rehabilitation Council.⁹
- The Transition Center, located at the University of Florida in Gainesville, serves as a catalyst for coordination of research, education, and services relating to adolescents and adults, especially those with disabilities, as they make and act upon transition choices. The center is also a resource for family members and professionals.¹⁰

III. Effect of Proposed Changes:

Section 1. Creates an undesignated section of law to establish the Health Care Transition Services Task Force for Young Adults with Disabilities. The bill directs the DOH to create this statewide task force and specifies legislative intent for the task force. The task force is to be composed of 14 individuals, including:

- The director of the CMSN within the DOH or his or her designee;
- A representative from the children's health care medical community;
- A representative from the adult health care medical community;
- The director of the Agency for Persons with Disabilities or his or her designee;
- Two representatives of associations that advocate for persons who have chronic medical conditions or disabilities, such as the American Diabetes Association, the Sickle Cell Foundation, the Cystic Fibrosis Foundation, United Cerebral Palsy, the Spina Bifida Association, or the Down Syndrome Association;
- Two young adults who have chronic health problems or developmental disabilities or a family member;
- The deputy commissioner of the Division of Vocational Rehabilitation within the Department of Education or his or her designee;
- The Commissioner of Education or his or her designee;
- The Secretary of Health Care Administration or his or her designee;
- The Secretary of Children and Family Services or his or her designee;

⁸ 2004 National Organization on Disability/Harris Survey of Americans with Disabilities. Found at: <u>http://www.nod.org/Resources/harris2004/harris2004_data.pdf</u> (last visited on April 2, 2008).
⁹ http://partnersintransition.fmhi.usf.edu/index.html (last visited April 2, 2008).

¹⁰ http://www.thetransitioncenter.org (last visited on April 2, 2008).

• A person appointed by the Speaker of the House of Representatives.

The director of the CMSN or his or her designee will be the chairperson of the task force. The DOH will provide staff support to the task force. Task force members shall serve without compensation, but are entitled to reimbursement for per diem and travel expenses incurred as provided in s. 112.061, F.S., in carrying out their duties. Members who are public officers or employees shall be reimbursed through the budget entity through which they are compensated.

The task force must convene by August 31, 2008, to:

- Obtain input from key stakeholders, community stakeholders, public agencies, the medical practice community, and youth who have chronic special health care needs and disabilities and their families to assess the need for health care transition services and to identify barriers that impede access to comprehensive medical treatment and health care for youth and young adults who have chronic special health care needs and disabilities.
- Develop a statewide plan to promote the development of health care transition services. The plan should put forth different models that accommodate the geographic and cultural diversity in the state and that are adapted to the local needs of communities and to local health services delivery systems. Furthermore, the plan should promote the integration of health care transition services with transition programs for education, vocation, and independent living.
- Identify common or comparable performance measures for all entities that serve the needs for health care transition services of youth and young adults who have chronic special health care needs and disabilities.
- Collect and disseminate information concerning best practices in health care transition services for youth and young adults who have chronic special health care needs and disabilities.
- Identify existing and potential funding sources to create health care transition services within communities.

The task force must present a final report of its findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives by January 1, 2009, at which time the task force will expire.

Section 2. Provides that the bill takes effect July 1, 2008.

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.

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The provisions of this bill have no impact on public records or open meetings issues under the requirements of Article I, Section 24(a) and (b) of the Florida Constitution.

C. Trust Funds Restrictions:

The provisions of this bill have no impact on the trust fund restrictions under the requirements of Article III, Subsection 19(f) of the Florida Constitution.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

Department of Health

During the 2007 legislative session, a non-recurring appropriation of \$300,000 was provided to develop a transition for adolescents and young adults with disabilities pilot project in Jacksonville covering Duval, Baker, Clay, Nassau and St. Johns counties. These funds were contracted to the JaxHATS program via the CMSN in the DOH.

This bill requires the CMSN to chair and staff a task force. The bill requires reimbursement for travel expenses and per diem for task force members who are not public officers or employees. Public officers or employees are to be reimbursed through the budget entity through which they are compensated. The DOH will incur travel expenses for task force participants.

VI. Technical Deficiencies:

None.

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 Health Policy on April 1, 2008:

The committee substitute adds the Secretary of Children and Family Services or his or her designee to the task force; eliminates the establishment of the transitional program for youths in the original bill; and removes appropriations.

B. Amendments:

None.

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