

The Florida Senate
PROFESSIONAL STAFF ANALYSIS AND ECONOMIC IMPACT STATEMENT

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

Prepared By: Health Policy Committee

BILL: SB 394

INTRODUCER: Senator Wise

SUBJECT: Transitional Services for Young Adults with Disabilities

DATE: February 19, 2007 REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Garner	Wilson	HP	Favorable
2.			CF	
3.			HA	
4.				
5.				
6.				

I. Summary:

The bill establishes a Health and Transition Services Program for the purpose of assisting adolescents and young adults with special health care, educational, and vocational needs in transitioning into the adult health care system and employment. The program is to serve persons who are 14 through 26 years of age and have chronic health-related or developmental conditions. The program is to be located in the Children’s Medical Services (CMS) program in the Department of Health (DOH) for administrative purposes.

The bill specifies elements which must be in place in order to ensure the success of the program and which services must be provided to enrollees. The bill requires the program to be directed by a medical director with the assistance of a project coordinator and requires an evaluation of the program to determine program process and outcome measures, as well as client outcomes, to determine if the program should be replicated statewide.

This bill creates one undesignated section of law.

II. Present Situation:

Transitioning into adulthood is a difficult process for all adolescents, but the transition presents additional challenges for young people with health care and educational disabilities. “Transition services” is the term used to describe a set of services and supports designed to assist adolescents in adjusting to the change from the home and school environment to independent living and meaningful employment. Students with health or educational disabilities often face this transition unprepared for further vocational training, post secondary education, gainful employment, or the

ability to navigate the non-pediatric health care system. Some of the barriers to a smooth transition include:

- Students leaving school are often placed on a waitlist for adult services and may not be able to keep a job they obtained in school because of a lack of transitional supports as adults. Medicaid waiver rules require students to return to school for services until age 22 if they have a special education diploma;
- Youth with disabilities and their families often are ill-prepared for the transition from an entitlement program (such as a free and appropriate education, CMS, or Medicaid) to an adult service system;
- Priorities and expectations in the systems that serve children and youth with health and educational disabilities are very different than the structure of the service and support system for adults, which is focused on integration into the community rather than separate programs that are only for people with disabilities;
- Commitment to the philosophy of self-determination and choice varies across agencies; in some programs self-determination is the cornerstone of the supports and other agencies provide fewer choices in services and supports;
- Eligibility for services and supports vary by agency and often support staff and families may be unaware of services for which they are eligible because planning processes are often not coordinated;
- Social Security benefits may create a disincentive to work. Individuals on Social Security Disability Income (SSDI) who require supports and health benefits to obtain a job lose eligibility for those services if they make over \$900, thus losing the benefits that enable them to obtain and keep meaningful employment; and
- Agencies may have different criteria for providers of the same service.

Although there are a variety of federal and state programs and agencies with some involvement in meeting the health care, educational and vocational needs of children and adolescents transitioning into adult programs, successfully integrating these efforts has proven difficult.

Health Care Transitioning

Persons with special health care needs or disabilities are more than twice as likely to postpone needed health care because they cannot afford it. Furthermore, people with disabilities are four times more likely to have special needs that are not covered by their health insurance. True independence requires accessible and affordable health care.

However, children and adolescents with special health care needs face significant challenges in transitioning into the adult health care system. Primarily, this is because of the complexity of their health care needs and their 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 child needed the following services:¹

¹ 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 February 17, 2007)

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In Florida, there are several initiatives that conduct research and provide information to patients and their families on how to transition children and adolescents into the non-pediatric health care system. These initiatives include:

- Health Care Transitions - The Promising Practices in Health Care Transition Project is a research and training activity of the Institute for Child Health Policy at the University of Florida. The website includes tools, resources, and links that deal with transition issues and how other youth and families are meeting this goal. It is also the site of a Transition Listserv that provides international communication for youth, families and professionals who would like to communicate and share ideas and resources with each other.³
- The Transition Center - The Transition Center, located at the University of Florida, in Gainesville, aims to enrich the lives of students through self-advocacy, access to contacts, proper resources, and by providing an opportunity for students to interact with one another as they make decisions and discover what they want out of life. The center is also a resource for family members and professionals.⁴
- Adolescent Health Transition Project - this website was created by the University of Washington and is housed at the Center for Human Development and Disability. The Adolescent Health Transition Project is designed to help smooth the transition from pediatric to adult health care for adolescents with special health care needs. This site is a resource for information, materials, and links to other people with an interest in health transition issues. There are a variety of tools and checklists to guide physicians and health care providers, youth, and families through a successful transition.⁵

² 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 February 17, 2007)

³ <http://hctransitions.ichp.edu/> (last visited on February 17, 2007)

⁴ <http://www.thetransitioncenter.org/flash/index.htm> (last visited on February 17, 2007)

⁵ <http://depts.washington.edu/healthtr/index.html> (last visited on February 17, 2007)

Educational and Vocational Transitioning

Advocates for persons with disabilities point out that education is the key to independence and future success, is critical to obtaining work, and affects how much money one can earn. Before the passage of the Individuals with Disabilities Education Act (IDEA) in 1975, which granted all children with disabilities a free, appropriate public education, many children with disabilities did not attend school because the buildings or class activities were inaccessible. Even now, 21 percent of Americans with disabilities fail to graduate high school, compared to 10 percent of those without disabilities. According to the National Organization on Disability's Harris Survey of Americans with Disabilities:⁶

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

Recently, there have been several statewide initiatives focused on helping to identify challenges faced by young adults with disabilities as they transition from high school to adult life and to develop strategies to create an effective transition system. The state agencies involved in these interagency activities include the Agency for Persons with Disabilities, the Department of Education, the Department of Children and Family Services, the Department of Health, the Agency for Health Care Administration, and the Department of Juvenile Justice.

A variety of private organizations and individuals have also been involved in these activities, including the Able Trust, the Advocacy Center for Persons with Disabilities, Inc., the ADA Working Group, the Family Network on Disabilities of Florida, Inc., the Florida Developmental Disabilities Council, Inc., the Florida Independent Living Council, Inc., the Florida Institute for Family Involvement, the Florida Recreation and Parks Association, the Florida Rehabilitation Council, the Florida Schools Health Association, the Transition Center at the University of Florida, parents, self-advocates, and teachers from throughout the state.⁷

JaxHATS: Jacksonville Health and Transition Services

The Jacksonville Health and Transition Services (JaxHATS) program was created in 2005 to establish a "medical home" for all youths and young adults with chronic medical or developmental problems in Northeast Florida (Duval, Baker, Clay, Nassau and St. Johns Counties). The transition 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. For FY 2005-06 and FY 2006-07, the program was funded through CMS.

⁶ The 2004 National Organization on Disability/Harris Survey of Americans with Disabilities. Found at www.nod.org (last visited on February 17, 2007)

⁷ Florida Partners in Transition, <http://partnersintransition.org/members.htm> (last visited February 17, 2007)

Some of the diagnostic categories covered by the JaxHATS program include: Spina Bifida; Cerebral Palsy; Muscular Dystrophies and other neuromuscular diseases; Sickle Cell Anemia; Cystic Fibrosis and other chronic lung diseases; Down's Syndrome; autism and other developmental disabilities; diabetes and other chronic endocrine disorders; congenital heart disease or heart disease acquired during childhood; chronic gastro-intestinal (GI) disease, such as Crohn's Disease, Ulcerative Collitis, Short Gut Syndrome, etc.; and immunodeficiencies.

JaxHATS staff estimate as many as 134,600 adolescents and young adults in Florida have chronic medical or developmental conditions, as well as special needs in education. As of March 2007, JaxHATS serves approximately 160 individuals in its transition program.

JaxHATS has several goals for the pilot program in the coming years, including:

- Establish a Medical Home for all youth/young adults with chronic medical or developmental problems in North Central Florida.
- Develop a reliable referral network of adult medical and surgical specialists.
- Design and implement a comprehensive evaluation of the proposed pilot project.
- Develop a multidisciplinary research program to formulate and integrate research in the field of medical transition and conduct studies that will establish Standards of Excellence in the field of transition.

III. Effect of Proposed Changes:

The bill establishes a Health and Transition Services Program for the purpose of assisting adolescents and young adults with special health care, educational, and vocational needs in transitioning into the adult health care system and employment. The program is to serve persons who are 14 through 26 years of age and have chronic health-related or developmental conditions. The program is to be located in the Children's Medical Services (CMS) program in the Department of Health (DOH) for administrative purposes.

The bill specifies elements which must be in place in order to ensure the success of the program including: a consultative partnership between adult and pediatric health care providers in a major medical organization or academic medical setting for transitioning children into adult health care services; the establishment of a primary care clinic for fostering this collaboration; agreements among health care organizations to provide community-based health care services for the purpose of providing consultation concerning the management of special health care needs; and community-based support organizations that can provide assistance to maintain the young adult in the community.

The bill requires the program to offer enrolled individuals: an assessment of their health needs, educational and vocational status and needs, and health insurance status; a plan for transitioning into adult health care services and employment; a medical home; and disease self-management programs. The bill also requires the program to be directed by a medical director with the assistance of a project coordinator and requires an evaluation of the program to determine program process and outcome measures, as well as client outcomes, to determine if the program should be replicated statewide.

The effective date of the bill is July 1, 2007.

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. Economic Impact and Fiscal Note:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

There will be a fiscal impact on the Department of Health, however, there is no appropriation provided for the program. CMS will be required to contract with outside entities for development and provision of the required services and evaluation of the program. The language in the bill regarding staffing for the program is vague; therefore, it is not possible to determine the fiscal impact at this time. However, there could be a significant fiscal impact depending on further clarification of the requirements in the bill.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Summary of Amendments:

None.

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