

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: HB 793 Transitional Services for Young Adults with Disabilities

SPONSOR(S): Davis

TIED BILLS: IDEN./SIM. BILLS: SB 988

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR
1) <u>Committee on Health Quality</u>	<u>11 Y, 0 N</u>	<u>Owen</u>	<u>Lowell</u>
2) <u>Healthcare Council</u>	<u>                    </u>	<u>                    </u>	<u>                    </u>
3) <u>Policy &amp; Budget Council</u>	<u>                    </u>	<u>                    </u>	<u>                    </u>
4) <u>                                    </u>	<u>                    </u>	<u>                    </u>	<u>                    </u>
5) <u>                                    </u>	<u>                    </u>	<u>                    </u>	<u>                    </u>

SUMMARY ANALYSIS

HB 793 creates the Health Care Transition Services Task Force for Youth and Young Adults with Disabilities within the Department of Health to address the transition of youth and young adults with disabilities from the pediatric to the adult health care system.

The bill also creates the Don Davis Health and Transition Services Program of Jacksonville in the Children’s Medical Services Network within the Department of Health to assist youth and young adults who have special health care needs or who are developmentally disabled transition from the children’s health care and educational system to the adult health care system and to employment. This program is authorized to serve persons age 14 to 26 who have chronic special health care needs or developmental disabilities and who reside in Baker, Clay, Duval, Nassau, and St. Johns Counties.

The bill appropriates \$650,000 recurring General Revenue to the Children’s Medical Services Network within the Department of Health for operational and expansion costs. However, the cost to implement the provisions of the bill is indeterminate (see fiscal analysis).

The bill takes effect July 1, 2008.

This document does not reflect the intent or official position of the bill sponsor or House of Representatives.

## FULL ANALYSIS

### I. SUBSTANTIVE ANALYSIS

#### A. HOUSE PRINCIPLES ANALYSIS:

Provide limited government - This bill will create the Don Davis Health and Transition Services Program within the Department of Health to assist youth and young adults with chronic special health care needs or developmental disabilities in transitioning from pediatric to adult health care, education, and vocational programs.

#### B. EFFECT OF PROPOSED CHANGES:

##### **Present Situation**

##### Task Force

The definition of a “task force” is found in Section 20.03, Florida Statutes. A task force is defined as an advisory body:

- Created without specific statutory authority for a time not to exceed one year or created by specific statutory authority for a time not to exceed three years
- Appointed to study a specific problem and recommend a solution or policy alternative with respect to that problem
- Terminated upon completion of its assignment

##### Health Care Transitioning

Children with special health care or educational needs face significant obstacles as they age out of child health care and educational service programs. 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.”<sup>1</sup> 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 practicing limitations of practitioners, and the stated mission of particular facilities e.g. children’s hospitals
- 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<sup>2</sup>

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

- 82 percent - specialty medical doctors
- 49 percent - speech therapy
- 48 percent - physical therapy
- 48 percent - occupational therapy
- 29 percent - home health services

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<sup>1</sup> J. Reiss, *Health Care Transition: Destinations Unknown*, Pediatrics 110:6 (December 2002).

<sup>2</sup> *Id.*

- 20 percent - mental health services<sup>3</sup>

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. 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 increasing awareness and promoting cooperative efforts to improve the process of transitioning from child-centered (pediatric) to adult oriented health care.<sup>4</sup>

#### *Children's Medical Services*

Chapter 391, Florida Statutes, governs the Children's Medical Services (CMS) program within the Department of Health. CMS provides children with special health care needs with a managed system of care. CMS serves children under age 21 whose serious or chronic physical, development, behavioral, or emotional conditions require extensive preventive and maintenance care beyond that required by typically healthy children.<sup>5</sup>

#### *The Jacksonville Health and Transition Services (JaxHATS)*

The JaxHATS program was created in 2005 to establish a "medical home" for youths and young adults ages 14-25 with chronic medical or developmental problems in the counties of Duval, Nassau, Baker, Clay, and St. Johns in Florida. JaxHATS has a multi-disciplinary staff that includes a pediatrician, adult internal medicine specialist, nurse care coordinators and a transition specialist who provide primary medical care to address a young person's immediate medical needs. They make referrals to specialty physicians within the region and coordinate medical services while helping the individual develop a care plan to best meet their long term health care needs. Services provided by JaxHATS are covered by Medicaid, Children's Medical Services, and most other private health insurance plans.

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.

The program has been funded by the state for the past three fiscal years, including an appropriation through CMS in the Fiscal Year 2006-2007 General Appropriations Act (GAA) in the amount of \$300,000 in non-recurring tobacco settlement funds,<sup>6</sup> and in the 2007-2008 GAA in the amount of \$300,000 in non-recurring tobacco settlement funds.<sup>7</sup>

#### Educational and Vocational Training

<sup>3</sup> 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, <http://www3.georgetown.edu/research/gucchd/consortium/documents/brief1.pdf> (last visited February 27, 2008).

<sup>4</sup> <http://hctransitions.ichp.edu/> (last visited February 27, 2008).

<sup>5</sup> Section 391.029, F.S.

<sup>6</sup> 2006 Conference Report on House Bill 5001, Line Item 623.

<sup>7</sup> 2007 Conference Report on Senate Bill 2800, Line Item 629.

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.
- 80 percent of people with significant disabilities are not employed.
- 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.<sup>8</sup>

There are several initiatives in Florida focused on identifying 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. Examples of these programs include:

- *Partners in Transition* - 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. Their mission statement is, "To improve transition services and increase the number of youth with disabilities who achieve their desired post school outcomes." Entities involved in this partnership include the Agency for Persons with Disabilities, the Department of Children and Family Services, the Department of Education, the Department of Health, the Department of Juvenile Justice, the Able Trust, the ADA Working Group, the Florida Developmental Disabilities Council, and the Florida Rehabilitation Council.<sup>9</sup>
- *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. The Transition Center is supported by the Career Development and Transition Project, which is one of the Department of Education's, Bureau of Exceptional Education and Student Services discretionary projects.<sup>10</sup>

## Effect of Proposed Changes

### Health Care Transition Services Task Force for Youth and Young Adults with Disabilities

The bill directs the Department of Health (department) to create a statewide Health Care Transition Services Task Force for Youth and Young Adults with Disabilities. The task force is composed of 15 members that represent at three geographic areas of the state that include rural, suburban, and urban areas. The members shall include:

- The Deputy Secretary for CMS within the department, 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 or 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

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<sup>8</sup> 2004 National Organization on Disability/Harris Survey of Americans with Disabilities, [www.nod.org](http://www.nod.org) (last visited February 28, 2008).

<sup>9</sup> <http://partnersintransition.org> (last visited February 28, 2008).

<sup>10</sup> <http://www.thetransitioncenter.org/home.php> (last visited February 28, 2008).

- The Commissioner of Education, or his or her designee
- The Secretary of Health Care Administration, or his or her designee
- The Director of CMS, or his or her designee
- A representative of a medical school
- A person appointed by the President of the Senate
- A person appointed by the Speaker of the House of Representatives

The Deputy Secretary for CMS, or his or her designee, is directed to chair the task force. The department is directed to provide staff support for the task force. The members of the task force are entitled to reimbursement for per diem and travel expenses incurred while carrying out their duties and those members who are public officers or employees are to be reimbursed through their appropriate budget entity.

The task force is directed to convene by August 31, 2008 and will perform the following functions:

- Assess the need for health care transition services and identify barriers that impede access to comprehensive medical treatment and health care for youth and young adults who have chronic special health care needs or disabilities by obtaining input from key stakeholders.
- Develop a statewide plan to promote the development of health care transition services.
  - The plan should suggest different models that accommodate the diversity of the state and that are adapted to the local needs of communities and to local health services delivery systems. The plan should also promote the integration of health care transition services with transition programs for education, vocational rehabilitation, and independent living.
- Identify common or comparable performance measures for all entities that provide health care transition services for youth and young adults with chronic special health care needs or 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 or disabilities.
- Identify existing and potential funding sources to create healthcare transition services within communities.

A final report of the findings and recommendations of the task force is due to the Governor, the President of the Senate, and the Speaker of the House of Representatives by January 1, 2009.

The Legislature is directed to appropriate up to \$100,000 to offset expenses incurred by the activities of the task force.

#### The Don Davis Health and Transition Services Program of Jacksonville

The bill establishes the Don Davis Health and Transition Services Program of Jacksonville (program) for the purpose of assisting youth and young adults who have special health care, educational, and vocational rehabilitation needs in making a smooth transition from the children's health care and educational system to the adult health care system and to employment. This newly established program will in essence operate as a renamed version of the current Jacksonville Health and Transitional Services Program (JaxHATS). The program is to serve persons who are 14 through 26 years of age residing in Baker, Clay, Duval, Nassau, and St. Johns Counties and who have chronic special health care needs or developmental disabilities. The program is to be located in CMS within the department for administrative purposes.

The bill specifies elements which should 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 health care organization or academic medical setting for the purpose of training and transferring adolescents and young adults to adult health care services;
- A primary care clinic established in a major medical health care organization for the purpose of fostering the partnership between adult and pediatric health care providers;
- Agreements between community-based health care organizations and a major medical health care organization or an academic medical center for the purpose of providing consultation concerning the management of special health care needs; and
- Community-based support organizations that can provide assistance with services, such as supported living and employment, health insurance, and support services to maintain the young adult in the community.

The bill specifies that the program must offer enrolled individuals the following:

- An assessment of health needs, educational and vocational status and needs, and health insurance status;
- A plan for transition which includes adult health care services, education, habilitative services, independent living, adult employment, and health insurance;<sup>11</sup>
- A medical home; and
- Disease self-management programs.

The bill also requires the program to be co-directed by two physicians having experience in pediatric and adult health care with the assistance of a project coordinator. A nurse coordinator is also required to provide care coordination services. The bill authorizes other staff to be included to provide a full range of services.

The bill requires the program to conduct an evaluation of its program process, outcome measures, and client outcomes. The results of the evaluation may be used to improve and develop other health and transition programs statewide.

The bill appropriates \$650,000 recurring General Revenue to the Children's Medical Services Network within the department for operational and expansion costs for the program during the 2008-2009 fiscal year.

The bill takes effect July 1, 2008.

#### C. SECTION DIRECTORY:

Section 1: Creates an unnumbered section of Florida Statute which creates the Health Care Transition Services Task Force for Youth and Young Adults with Disabilities within the Department of Health.

Section 2: Creates an unnumbered section of Florida Statute which creates the Don Davis Health and Transition Services Program of Jacksonville.

Section 3: Appropriates \$650,000 recurring General Revenue to the Children's Medical Services Network within the Department of Health.

Section 4: Provides an effective date of July 1, 2008.

## II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

### A. FISCAL IMPACT ON STATE GOVERNMENT:

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<sup>11</sup> This service must be developed in coordination with education and vocational systems and community-based organizations.  
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1. Revenues:  
None.

2. Expenditures:  
See Fiscal Comments.

**B. FISCAL IMPACT ON LOCAL GOVERNMENTS:**

1. Revenues:  
None.
2. Expenditures:  
None.

**C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:**

The bill encourages the participation of community-based organizations in order to ensure a successful Health and Transition Services Program, and thus, may provide potential income for organizations that decide to participate. In addition, the bill will extend health care services to enrolled CMS individuals between 22-26 years of age.

**D. FISCAL COMMENTS:**

The bill also appropriates \$650,000 recurring General Revenue for operational and expansion costs of the program. However, there is not enough information available to determine whether this amount will cover the cost to implement the provisions in the bill. The bill requires that the program shall provide services for persons who reside in Baker, Clay, Duval, Nassau, and St. John's counties, are between 14-26 years, and have chronic health care needs or developmental disabilities. The services to be provided are broadly defined so there is no way to ascertain costs.

The bill also extends health care services to enrolled individuals between 22-26 years. Currently, the Children's Medical Services (CMS) program 'ages out' eligible individuals from coverage for services by 21 years, so there will be additional costs associated with this expansion.

The bill specifies that the Legislature shall allocate \$100,000 of the \$650,000 appropriation to offset expenses incurred by the taskforce. The bill stipulates that all members of the taskforce are eligible for reimbursement for per diem and travel, but the bill does not specify how often the members must meet. However, members of the taskforce who are public employees must have their expenses reimbursed by the budget entity through which they are compensated. The bill further mentions that the department shall provide staff to support the taskforce; it is unclear whether the salary for the department staff is to be paid from this allocation.

### **III. COMMENTS**

**A. CONSTITUTIONAL ISSUES:**

1. Applicability of Municipality/County Mandates Provision:

This bill does not require counties or municipalities to spend funds or take action requiring the expenditure of funds. This bill does not reduce the percentage of a state tax shared with counties or municipalities. This bill does not reduce the authority that municipalities have to raise revenues.

2. Other:  
None.

**B. RULE-MAKING AUTHORITY:**



None.

C. DRAFTING ISSUES OR OTHER COMMENTS:

The Department of Health recommends clarifying that the individual referenced on lines 60-61 to be a member of the task force is actually the "Director of the Children's Medical Services Network".

D. STATEMENT OF THE SPONSOR

This is a great program that helps young adults who are transitioning out of adolescent healthcare and insurance coverage and into the adult version. Oftentimes these young people fall through the cracks at this crucial point in their life, and it is my goal to provide a program that aptly bridges this untimely gap.

**IV. AMENDMENTS/COUNCIL SUBSTITUTE CHANGES**

On March 4, 2008, the Health Quality Committee adopted a strike-all amendment to the bill. The amendment clarifies that one of the members of the Health Care Transition Services Task Force for Youth and Young Adults with Disabilities is the Director of the Children's Medical Services "Network". The amendment also deletes the specific appropriations from the bill.

The bill was reported favorably with one amendment.