

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. HOUSE PRINCIPLES ANALYSIS:

Provide limited government – The bill requires many private entities to participate in the development and implementation of the pilot program which results in additional responsibilities for those designated groups.

Safeguard individual liberty – If individuals are able to become more self sufficient and productive as a result of participation in the pilot, then they will have an increased ability to conduct their own affairs.

Empower families – If participants of the program are able to become more self sufficient and supporting as adults, then their reliance on assistance from family and other sources should decrease.

B. EFFECT OF PROPOSED CHANGES:

Transitioning from Childhood and Adolescent Services to Adult Services and Employment

Children with special health care or educational needs face significant obstacles as they age out of child health care and educational service programs. Many states, universities, organizations, and health care providers are developing plans to assist youths with special health care and educational needs to successfully transition into multiple aspects of adult life.

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 successful 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 are often poorly prepared for the transition from an entitlement program (such as a free and appropriate education, Children’s Medical Services, 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;
- 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 often 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 \$850, 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 of children with special health care needs, parents reported that in the preceding year, their child needed the following services:¹

- 82 percent needed services from 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.

Currently, in Florida, there are a number of 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 initiative 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.²
- **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. They are also a resource for family members and professionals.³
- **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 ease 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.⁴

Educational and Vocational Transitioning

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>

² See <http://hctransitions.ichp.edu/>

³ See <http://www.thetransitioncenter.org/page.asp?page=content/about.html&pagetype=visitor>

⁴ See <http://depts.washington.edu/healthtr/index.html>

Advocates for persons with disabilities emphasize that education is the key to independence and future success, is critical to obtaining work, and affects how much money an individual 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, 22 percent of Americans with disabilities fail to graduate high school, compared to 9 percent of those without disabilities. According to the National Organization on Disability's Harris Survey of Americans with Disabilities:⁵

- 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; and
- 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, Center for Autism and Related Disabilities at the University of South Florida, 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, the Transition to Independence Process Project, Workforce Florida, Inc., parents, self-advocates, and teachers from throughout the state.⁶

JaxHATS: Jacksonville Health and Transition Services

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

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.

Estimates indicate that as many as 6,000 adolescents and young adults living in North Central Florida have chronic medical or developmental conditions, as well as special needs in education. As of March 2006, JaxHATS served approximately 40 individuals in its pilot program. JaxHATS has several future goals for the pilot program, including:

⁵ The 2004 National Organization on Disability/Harris Survey of Americans with Disabilities. Found at www.nod.org

⁶ Florida Partners in Transition, <http://partnersintransition.org/members.htm>

- The establishment of a Medical Home for all youth/young adults with chronic medical or developmental problems in North Central Florida;
- The development of a reliable referral network of adult medical and surgical specialists;
- The design and implementation of a comprehensive evaluation of the proposed pilot project; and
- The development of 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.

Effects of the Bill

The bill creates the Jacksonville Health and Transition Services Pilot Program, the purpose of which is to assist adolescents and young adults with special health care, educational, or vocational needs in transitioning into the adult health care system and employment. The pilot program is located in the CMS program in DOH for administrative purposes.

The bill requires the Department of Internal Medicine and the Department of Pediatrics at the University of Florida-Jacksonville Campus to develop the pilot program in collaboration with CMS and specified community partners, including, but not limited to, the Area Association for Retarded Citizens (ARC Jacksonville), Hope Haven Clinic, the Spina Bifida Association, and the Down Syndrome Association. The primary care clinic for the pilot program will be located in the Ambulatory Care Center on the Shands-Jacksonville Hospital campus.

The target population for the pilot program includes disabled persons who: are 14 through 25 years of age; reside in the North Central area of CMS; have chronic health-related or developmental conditions; and could benefit from the program. All children in the CMS State Child Health Insurance Program (SCHIP), Medicaid, and Safety Net (CMS), as well as referrals from the Nemours Children's Clinic, the Duval County School District, general pediatricians, and other health care providers, should be assessed for eligibility to enroll in the program.

Participants in the pilot program must be offered an assessment of their developmental, educational, and vocational achievement. The pilot program must work with participants and their families to plan for transition to college or to programs for adult educational and vocational rehabilitation. The pilot program must work with local educational and vocational entities to provide vocational counseling and training. The pilot program should develop partnerships with the community agencies listed above to support comprehensive transition planning and educational and vocational counseling services.

The pilot program shall include:

- A primary-care clinic in the University of Florida-Jacksonville Adult Ambulatory Care Center, which shall be staffed by a multidisciplinary team that includes a pediatrician and an internist, a nurse care coordinator, a transition specialist, and an insurance specialists;
- A network of adult medical and surgical specialists in the community and from the University of Florida-Jacksonville System who agree to treat the special needs of the program's participants;
- Comprehensive intake-evaluation and transition-planning services for participants which cover health care planning, assessment of educational needs, vocational preparation, referral to habilitative support services, assistance in securing insurance, and coordination of services across these areas;
- Coordination and collaboration with other agencies that are involved in providing services to adolescents and young adults who have special health care needs, including the ARC of Jacksonville, Hope Haven Clinic, Nemours Children's Clinic, the Duval County School District, the juvenile justice system, family support services, the foster care program of the Department of Children and Families Services, faith-based community programs, and the Duval County Health Department;

- Ongoing evaluation of patient satisfaction, disease self-management, and success in taking steps toward employment and health-related quality of life and other health-related outcomes; and
- Services that support the intellectual development and educational and vocational preparation of program participants.

Specified health services, educational and vocational services, and administrative services must be provided to participants by the Department of Internal Medicine at the University of Florida-Jacksonville, the Department of Pediatrics at the University of Florida-Jacksonville, the Nemours Children's Clinic, the Institute for Health, Policy and Evaluation Research within the Duval County Health Department, and other state and local entities.

C. SECTION DIRECTORY:

Section 1. Creates an unnumbered section of Florida Statute relating to the creation of the Jacksonville Health and Transition Services Pilot Program.

Section 2. Provides for a \$350,000 appropriation from General Revenue to Children's Medical Services to implement the provisions of the bill.

Section 3. Provides for an effective date of July 1, 2006

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

The bill contains a \$350,000 appropriation from the General Revenue Fund to CMS for the purpose of paying startup and operation costs of the pilot program during the 2006-07 fiscal year. However, there are no estimates for the cost of services that must be provided under the pilot program by school districts, university medical schools, local county health departments, community colleges, technical and vocational schools, the Department of Juvenile Justice, the Department of Children and Families Services, and the Vocational Rehabilitation Agency.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

The pilot program creates a number of administrative and service requirements for nonprofit agencies and health care providers who choose to participate. While CMS is provided an appropriation for initial startup costs to administer the pilot program, there is no specific appropriation for the activities required in the bill for private and non-profit entities. Although the exact amount is indeterminate at this time, it is estimated that substantial resources would be necessary to implement the provisions of the bill in the private sector.

D. FISCAL COMMENTS:

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

This bill does not appear to require counties or municipalities to take an action requiring the expenditure of funds, reduce the authority that counties or municipalities have to raise revenue in the aggregate, nor reduce the percentage of state tax shared with counties or municipalities.

2. Other:

None.

B. RULE-MAKING AUTHORITY:

None.

C. DRAFTING ISSUES OR OTHER COMMENTS:

The bill appears to require a number of private entities to participate in the development and implementation of the pilot program. It is unclear if the intent is to mandate these specific activities or if the pilot program should strive to develop collaborative agreements with the private entities to implement the program. If the intent is to mandate these activities, it is unclear how the bill can require these entities to perform these activities with no state funding.

IV. AMENDMENTS/COMMITTEE SUBSTITUTE & COMBINED BILL CHANGES