

## ***Youth and Young Adult Transition-Children's Medical Service***

Location: Florida

Date Submitted: 2006, updated 5/2011

Category: **Emerging Practice**

### **BACKGROUND**

Over 90% of youth and young adults with special health care needs are living into adulthood, and systems of care have historically not been in place to assist these individuals with a successful transition to adult life. Nationwide, over 80% of young adults with disabilities are unemployed and have limited opportunities for competitive employment, which leads to a lack of healthcare benefits. These individuals are not able to participate in the fulfillment of their goals for self-determination and independent living.

In 2008, the Florida legislature funded the creation of the Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities. The task force submitted a report, [Ensuring Successful Transition from Pediatrics to Adult Health Care](#), with recommendations to the legislature in January 2009.

Children's Medical Services (CMS) currently contracts with the University of South Florida to support the Florida Health and Transition Services (FloridaHATS) program. FloridaHATS uses the 2009 report to provide technical assistance and support for the development of local health transition coalitions in three areas of Florida, implements educational and training activities for both consumers and providers; and examines potential strategies to improve health care transition financing and policies.

One of the goals of CMS transitions program is to help youth and young adults with special health care needs learn self-determination and develop strategies for a successful transition into adulthood. Each of the 22 CMS area offices in Florida has designated a care coordinator (either a nurse or social worker—some offices have teams) as a point of contact for communications about youth and young adult transition. The care coordinator identifies national, state, and community resources for the successful transition of youth

TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED
#11: Percent of children with and without special health care needs having a medical home
#12: Percent of children with and without special health care needs who received services necessary to make transitions to adult health care

and young adults with special health care needs to all aspects of adult life; including health, work, and integration within their community.

### **PROGRAM OBJECTIVES**

The key objective of this program is that each of the 22 CMS area offices in Florida will meet the transition goal performance measures at or above 90%. The goal states that:

"Beginning at age 12, all teens and young adults with special health care needs who are enrolled in the CMS Network and their families will receive the services needed to make transitions to all aspects of adult life, including adult health care, work, and independence."

### **TARGET POPULATION SERVED**

This program is targeted to CMS enrollees 12-21 years old CSHCN who need help with transition into adulthood.

### **PROGRAM ACTIVITIES**

Local CMS care coordinators and family health partners provide transition education and assistance for CMS enrollees 12-21 years old. CMS also provides funding for Jacksonville Health and Transition Services (JaxHATS). The JaxHATS program provides a medical home and transition services for adolescents and young adults, ages 16 to 26 years, in northeast Florida. There are currently 331 patients enrolled in the program. The main goal of JaxHATS is to develop, test, and evaluate a model system of care for youth and young adults with chronic health or developmental conditions to show how the system facilitates continuity of

care as young adults transition from pediatric-based to adult-based health care. JaxHATS staff collects patient data regarding the number of emergency room (ER) visits and hospitalizations during the year prior to enrolling in JaxHATS, compared to the following two years after enrollment in the JaxHATS program. Data shows a significant reduction in avoidable ER visits. JaxHATS also uses tools assess transition readiness in youth with special health care needs.

### PROGRAM OUTCOMES/EVALUATION DATA

The two outcome measures for which data are collected on all CMS enrollees between the ages of 12 to 21 years are:

- Measure 1: Teens and young adults will participate in the development and periodic review of their care coordination and transition plans.

Indicator: The percent of youth, 12 and older, who have received transition education increased to 74.04% during the state 2009-2010 fiscal year compared to 51.5% in 2008 and 40.7% in 2007.

- Measure 2: Teens and young adults will receive transition services that are age appropriate.

Indicator: The percentage of youth, age 16 and older, whose regular source of primary medical care facilitates the transition from pediatric to adult providers increased to 51.06% in the state fiscal year 2009-2010 compared to 44.4% in 2008 and 33.7% in 2007.

The University of Florida Institute for Child Health Policy completed a 2009-2010 family satisfaction report based on surveys of CMS families. According to this survey, an average of 38% of CMS families reported that their primary care provider discussed transition and adult health care with them. Responses varied according to geographic location within the state and ranged from 29% to 47%.

### PROGRAM COST

Transition education and assistance is included in other services, therefore the program does not assess the cost of the transition portion as a separate service.

### ASSETS & CHALLENGES

#### Assets

- Due to exceptional student education and vocational rehabilitation there was recognition of the important role of healthcare in assuring a successful transition process.

#### Challenges

- Youth and their families have difficulty leaving trusted pediatricians.
- There is a lack of primary and specialty care adult providers willing to take children and youth with special health care needs due to low Medicaid reimbursement.
- Many youth with special health care needs (YSHCN) lose important benefits such as health insurance coverage and supplemental security income when they reach ages 18-21.
- Many adult health care providers are unfamiliar with childhood onset conditions and how to support transitioning YSHCN.

#### Overcoming Challenges

- Transition liaisons in the CMS area offices start working on transition issues when children reach age 12, and continue support as the adolescents become young adults.
- CMS is working on strategies developed from the Transition Task Force including using CMS regional offices to support the development of local transition coalitions. CMS also supports interagency collaboration and service coordination.
- CMS and the Transition Task Force are also working on issues regarding health care provider training and continuing education about transition issues.

### LESSONS LEARNED

- Individuals who do not work in a health field often state that they understand the importance of healthcare for successful youth transition; however, health is not typically included in their interagency activities or planning. It took persistence and education to make a "place at the table" for healthcare issues.
- Transition-related materials for youth and young adults with special health care needs must be available for individuals with varying cognitive abilities.

### FUTURE STEPS

CMS continues to contract with the University of Florida, Institute for Child Health Policy to create and up-date transition educational materials for CMS staff and enrollees. CMS is also committed to meet with interagency and organizational groups working on successful youth transition.



## COLLABORATIONS

On both a state and local level, partners for transition collaboration is occurring between Department of Health/Children's Medical Services and the Department of Education, Vocational Rehabilitation, Agency for Persons with Disabilities, Department of Children and Families, Division of Blind Services, the Florida Developmental Disabilities Council, the Florida Resource Coalition Inc., the USF University Center on Developmental Disabilities, and a number of other organizations.

## PEER REVIEW & REPLICATION

The Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities' report: [Ensuring Successful Transition from Pediatrics to Adult Health Care: January 2009](#); has received broad support and has been distributed to the state Title V Directors for children with special health care needs.

## RESOURCES PROVIDED

The CMS transition information and workbooks, both English and Spanish, are available at <http://www.cms-kids.com>. These materials help CMS enrollees, and their families learn about transition and develop independence and self-determination in reaching their transition goals.

For more research on the subject--refer to the American Academy of Pediatrics, December 2002, Vol. 110, #6 Supplement entitled "*Improving Transition for Adolescents with Special Health Care Needs from Pediatric to Adult-Centered Health Care*".

**Key words:** CSHCN, Program/Service Integration, Transition, Children Medical Service

***\*\*For more information about programs included in AMCHP's Innovation Station database, contact [bp@amchp.org](mailto:bp@amchp.org). Please be sure to include the title of the program in the subject heading of your email\*\****

