Proposal to Establish Health and Transition Services (HATS) Programs in All Children's Hospitals in Florida

Vision. Every children's hospital in Florida will provide transitional care services, ensuring that all young Floridians, including those with special health care needs, experience a smooth transition from pediatric to adult health care.

Mission. To provide a high quality system of health care that supports transition from adolescence to adulthood for all youth and young adults in Florida.

Need. Over the past 30 years, we have witnessed a significant increase in life expectancy for children and youth with special health care needs, even those with serious life threatening and debilitating chronic conditions. In Florida, there are an estimated 130,000 youth and young adults ages 14-24 with physical and mental health conditions who need support to successfully transition to adulthood.[1] After leaving pediatric services, many young people experience difficulty entering the adult system: they may have trouble finding adult providers, lose insurance and supports, become less adherent to medical regimens, and experience preventable morbidity or even premature death. In order to promote a smooth transition to adult care, most children's hospitals in the U.S. have initiated "transition programs" to better prepare youth in the pediatric system for the transition to adult care and to engage the adult system to accept these patients. These programs vary in structure but all have a core staff of one or more physicians, nurses and social workers that support families and youth - especially those with complex medical conditions - as they move out of the child-serving health care system and into the adult-serving health care system. All of the top-rated children's hospitals now have transition programs, including Boston Children's Hospital, LA Children's Hospital, CHOP, Nationwide and Cincinnati Children's Hospital, Nemours Children's Hospital, Delaware and Riley Hospital for Children, to name a few.

In Florida, the JaxHATS and the FloridaHATS programs have gained national prominence as models for providing transition care at the local level and for providing information and supports for health care transition at the state level. The purpose of this proposal is to build on that foundation to implement a comprehensive system of transitional care based in every children's hospital in the state of Florida. These Health and Transition Services (HATS) programs will help establish a system of care as described in the State Plan for Health Care Transition "Ensuring Successful Transition from Pediatric to Adult Health Care." (see www.floridahats.org/wp-content/uploads/2010/03/2009-FL-HCT-Task-Force-Report-CMS.pdf). The system of care will engage primary care providers, pediatric specialty care providers, the children's hospital, adult hospitals and adult primary care and specialty providers. The proposed model of care is portrayed in the diagram below. The basic components of this health care system are:

- Outpatient care at a dedicated health care transition clinic for youth with complex social, emotional or physical health issues
- Education and training for primary care and specialty care pediatric providers to implement health care transition preparation for youth and families
- Recruitment and training of adult primary care and specialty providers
- Care coordination by nurse and lay care coordinators

[1] In the Florida 2010 census, 2.686, 000 persons were between the ages of 14-24. An estimate 5% of the child and young adult population has physical and mental health conditions that need support during transition to adulthood.

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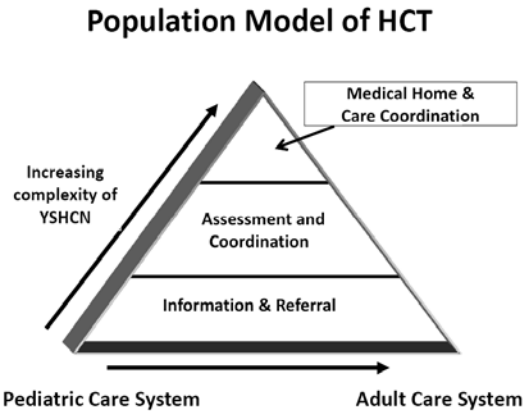

The proposed program will ensure that youth receiving care from the children's hospital will receive the support they need during transition to achieve optimal health and well-being in adulthood. It will engage and enhance the local community's existing network of pediatric primary and specialty programs and connect them to the adult health care system.

Key steps to develop a Health and Transition Services (HATS) program:

- Establish a HATS clinic staffed by primary care provider and care coordinator(s).
- Establish an inpatient HATS consultation service.
- Train primary care and specialty pediatric and adult providers in how to educate youth about independent disease self-management and accessing the adult health care system.
- Provide care coordination for all youth and families needing support.
- Establish quality monitoring, outcomes measurement and quality improvement programs.
- Educate key stakeholders about health care transition, including youth and their families, schools, disability and social service programs, and advocacy organizations (e.g., ARC, Down Syndrome Association, Spina Bifida Association)
- Provide information and referral to all youth, families, providers and other agencies needing information about health care transition.
- Engage adult primary care providers to provide a medical home to young adults with special health care needs and engage adult specialists to provide specialty care to young adults.

The mature HATS program will provide a single source of information for youth, parents and providers via phone, internet and/or in-person consultation for the hospital's population that is "aging out." It will ensure that youth and families have access information, resources and information and referrals to support transition from pediatric care to adult care and adult life.

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