

UF-Wolfson Children's Hospital Center of Excellence in Health and Transition Services (UF/WolfsonHATS)

Vision. We envision the UF-Wolfson JaxHATS (Health and Transition Services) program as a national model for the provision of transition services to ensure that youth with special health care needs in NE Florida achieve optimal health and development as adults.

Mission. To establish and continuously evaluate a continuum of comprehensive, accessible and high quality health and habilitative services during transition from adolescence to adulthood for youth and young adults with special health care needs living in Northeast 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 NE Florida there are an estimated 7,000 youth and young adults 14-24 who need support to successfully transition to adulthood. The experience of children's hospitals and child health providers in the U.S. has been well documented—after leaving pediatric services, many young adults experience substantial problems, including difficulty finding adult providers, loss of insurance and supports, decreased adherence to medical regimens, difficulties with living independence, increased morbidity and premature death. In response to these compelling needs, most free standing children's hospitals in the US have initiated transition program. These programs vary in structure but all have core staff, including physicians, nurses and social workers, which support families and youth, especially those with complex medical conditions, in their transition to independence and adulthood. All of the top rated children's hospitals have transition programs that 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, just to name a few.

In NE Florida the JaxHATS program has gained national prominence as a model Medical Home program in health care transition (HCT). A coalition of youth, parents, organizations and providers has developed a strategic plan for implementing a regional health care transition program. However, despite these advances, the JaxHATS program is meeting only a fraction of the need for HCT services in NE Florida: we provide care for only 500 of the estimated 7000 youth that need some level of support during transition.

The purpose of this proposal is to build on the foundation accrued by JaxHATS over the past 5 years to implement a comprehensive system of transitional care that engages all community stakeholders. This proposed continuum of care includes inpatient care at Wolfson Children's Hospital; outpatient care at 2 JaxHATS clinics; health care transition education and training by primary care and specialty care pediatric providers; recruitment, training and referral to adult primary care and specialists; mental health care coordination; developmental disability services; vocational assessments and counseling; counseling on independent living for the child and family; and care coordination for health, educational and habilitative services. Ultimately, the proposed program will ensure all youth with special health care needs in NE Florida receive the support they require during their transition to adult care and adulthood to achieve their optimal health and well-being. The proposed program will engage and enhance our community's existing network of pediatric primary and specialty programs in NE Florida, Wolfson Children's Hospital, and the adult health care system to ensure youth with special needs transition from child to adult health and social services.

UF-Wolfson Children's Hospital Center of Excellence in Health and Transition Services (UF/WolfsonHATS)

Current program. Currently, the JaxHATS group consists of 2 Board certified attending physicians (Drs. Wood and Edwards, both 0.3 FTE), a Physician Assistant (1 FTE), a patient advocate/social worker (1 FTE) and clerical support (2 FTE). Approximately 500 youth and young adults are provided a comprehensive Medical Home by JaxHATS. The JaxHATS program conducts clinics 5 days per week at two sites—on the 19th floor of the Aetna Building in the UF Pediatric Multi-Specialty clinic and on the first floor of the Ambulatory Care Center on the 8th Street campus of UF&Shands.

Overview of Development Plans. In order to establish a national model, we propose to build on the foundation of JaxHATS to:

- Add clinic days at the Aetna Building UF Multispecialty Clinic;
- Increase the number of patients enrolled in JaxHATS;
- Establish an inpatient consultation service at Wolfson, Baptist and UF&Shands;
- Train primary care and specialty pediatric and adult providers in transition health;
- Enhance the quantity and sophistication of care coordination in transition health;
- Expand our evaluation and research endeavors; and
- Train medical students, residents and other health professional students in transition health.

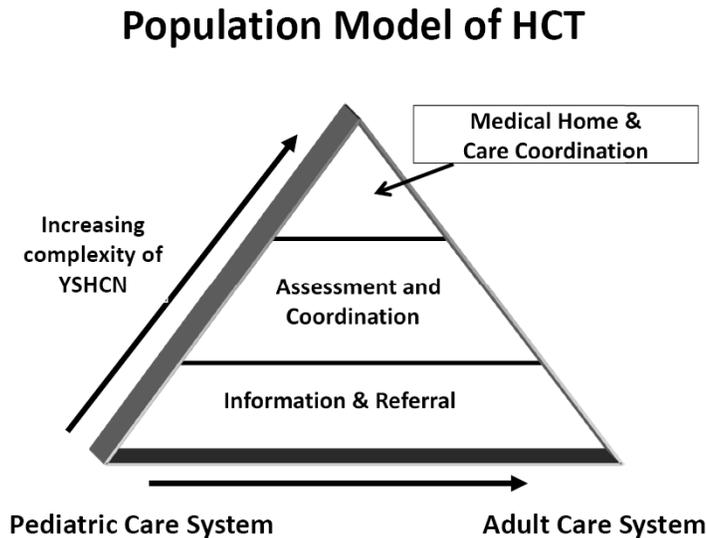
In order to accomplish these initial objectives, we will:

- Train all pediatric providers, both primary care and specialty care providers, in NE Florida on how to prepare youth and families for transition using resources and tools prepared by the AAP and by JaxHATS and FloridaHATS.
- Provide leadership and technical assistance to UF and Nemours specialty services, as well as to private practice primary care pediatricians, to incorporate HCT planning and education into their office processes, procedures and electronic medical record systems.
- Recruit and train care coordinators dedicated to the Program.
- Educate key stakeholders about HCT, including youth and their families, schools and advocacy organizations (ARC, Down Syndrome Association, Spina Bifida Association, etc.) to inform them of the need for HCT and the supports and services that are available through UF-Wolfson JaxHATS program.
- Expand JaxHATS to provide information and referral to all youth and families needing guidance during HCT.
- Engage all adult providers in NE Florida to ensure that youth and young adults can access adult services.

Accomplishing the above activities will result in a coordinated system of care during transition and will assure that all youth in NE Florida have access to education, coordination and physician care that supports their transition to adult care and adulthood.

UF-Wolfson Children's Hospital Center of Excellence in Health and Transition Services (UF/WolfsonHATS)

Program Goal. The goal of this initiative is to have a comprehensive system of HCT, as described in the Florida State Plan and portrayed schematically in the following figure.



The mature UF-Wolfson JaxHATS program will provide a single source of information for youth, parents and providers via phone, internet and/or in-person consultation. The Program will ensure youth and families access information, resources and information and referrals to support transition from pediatric care to adult care and adult life. A comprehensive HCT system provides the level of supports needed by youth and families to successfully transition. Families and youth will be triaged into one of 3 levels of support. The first level of support will include information and referral (bottom of the pyramid). The second level of support will include some degree of care coordination and planning for youth and families with more complex conditions and less social support. This level of support will be offered by nurses and social workers working directly with families and providers. The most intensive level of support will be for those needing ongoing management and education to promote self-management by emerging adults with chronic complex conditions and limited social supports. This highest level of support will be offered by enrollment in the JaxHATS primary care medical home program.

Objectives for 2013-to mid 2014. The following objectives provide a blueprint for the development of an expanded and enhanced system of care for transitional health services in NE Florida.

- Form an HCT medical advisory group composed of representatives from Wolfson, UF Pediatrics, Nemours, Children's Medical Services, UF Adult Services and Baptist Adult Services
- Expand JaxHATS services to the Baptist/Wolfson system
 - Expand the JaxHATS Aetna clinic incrementally to offer services 5 days per week

UF-Wolfson Children's Hospital Center of Excellence in Health and Transition Services (UF/WolfsonHATS)

- Initiate an inpatient HCT consultation service for all youth and young adults (16-26) admitted to Wolfson, Baptist Downtown or UF&Shands
- Empower pediatric providers to offer transition education and preparation
 - Develop and implement a HCT training program that trains providers to offer HCT education and preparation for their families and patients.
 - Offer this program to all primary care providers in NE Florida using an on-line, learning collaborative working with the CMS, NEFPS, Partnership for Child Health, the UF Pediatric Research Network and the JaxHERO practice network.
 - Promote the adoption of tools developed by the AAP, Got Transition and FloridaHATS to standardize transition preparation and transfer to adult care
 - Develop and implement a training program for specialty care pediatric providers using a QI/Collaborative model working with specialty divisions at UF and Nemours.
 - Establish an EMR working group to adapt and integrate transition prompts, educational materials and other tools into EPIC, Cerner and other EMRs used by the NE Florida provider community.
- Assess the effectiveness of the learning collaborative through a formal evaluation.
- Hire staff to accomplish the above activities.

Objectives for mid-2014 and beyond. After focusing primarily on pediatric primary care and subspecialty providers, the focus will expand to the community and adult providers.

- Adult provider outreach. Reach out to adult specialty and primary care to participate in transition planning collaborative
 - Engage adult providers in the leadership of the UF/WolfsonHATS program
 - Adopt transition tools promoted by Got Transition, the ACP and AAFP
 - Provide medical homes for young adults with special needs
- Community outreach. Establish a comprehensive information and referral program for the NE Florida community, in collaboration with the JacksonvilleHATS Coalition, which has representation from CMS, Wolfson, UF and Nemours, the Duval County School District, advocacy organizations, youth and families.

UF-Wolfson Children's Hospital Center of Excellence in Health and Transition Services (UF/WolfsonHATS)

Budget for 2013-2014

Personnel	Positions/Cost Estimate	
Program Administrator (Green)	1	FTE
Medical Director (Wood)	0.25	FTE
Nurse Practitioner (TBN)	1	FTE
Nurse Coordinator (TBN)	1	FTE
Outreach coordinator/educator (TBN)	1	FTE
 Personnel Subtotal	 \$296,000	
Benefits @30%	<u>\$ 88,800</u>	
Personnel Total	\$384,800	

Other expenses

- Office space/phones
- Office supplies
- Local travel

Timeline and Budget Justification.

The task timeline is outlined below. We will hire the additional clinical staff as the program grows. We anticipate that 50% of clinical costs can be offset through billing.

	April - July, 2013	August-November 2013	Nov 2013-March 2014	April 2014-July 2014
Form an HCT medical advisory group				
Expand JaxHATS clinics from 1 to 5 half days per week				
Initiate an inpatient HCT consultation service at Wolfson, Baptist and Shands				
Train pediatric providers to offer transition education and preparation services				
Offer this program to all primary care providers in NE Florida on-line				
Adopt HCT tools in pediatric practices				
Offer this program to all specialty providers				
Establish a EMR working group to adapt and integrate transition prompts and resources				
Adult provider outreach, participation in HCT network				
Develop Community outreach				
Establish Information and referral center				
Assess the effectiveness of the learning collaborative through a formal evaluation				