Florida Children's Hospital Health Care Transition Survey Response Summary

During the month of September, I surveyed the Chief Medical Officers of the 12 Children's Hospitals in Florida who are members of the Florida Association of Children's Hospitals (FACH). Only one children's hospital in Florida is not a member of FACH (Nemours Children's Hospital in Orlando) and it was not included in the survey. The survey was conducted on-line with the CMOs being asked to fill out the survey on Survey Monkey. 100% of the CMOs responded. We contacted them via email (4 rounds of emails were sent) and by phone (my research assistant did initial calls asking them to respond to the survey and I did follow up calls if they had not responded within one week).
Below is the list of the hospitals that responded to the survey.

Hospital
All Children's Hospital
Baptist Children's Hospital
CECH
Florida Hospital for Children
Golisano children's hospital of SW Florida
Holtz Children's Hospital
Joe DiMaggio Children's Hospital
Miami Children's Hospital
Sacred Heart Children's Hospital
UF Health Children's Hospital
St Joseph's Children's Hospital.
Wolfson

Responses to the question: **Does your institution have an age limit for services?**

Age Limit				
Age_limit_1	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	3	25.00	3	25.00
Yes	9	75.00	12	100.00
Limit: 18	5	50		
Limit: 21	5	50		

Florida Children's Hospital Health Care Transition Survey Response Summary

Responses to the question: **Does your Children's Hospital have a program to support health care transition?**

HCT Program	Frequency
No	6
Yes	5

For those 5 (five) hospitals that reported they had a transition program below are the individual descriptions of the programs provided by the respondents:

1. Certain specialties are more advanced in developing transition plans, notably cardiology and pulmonology. Specific adult providers have been identified and regularly accept patients >18 with congenital heart disease and cystic fibrosis. The transition is less well developed in endocrinology (mostly type I diabetics) and hematology/oncology. We are trying to coordinate a late effects clinic for childhood survivors of cancer but is in early stages of development

2. Developing Two Programs. One associated with complex care clinic for all patients. The other program is an adult congenital heart program as part of our cardiology program

3. Most of the children are transitioned by their pediatrician. For those children seen frequently by sub-specialists, information about healthcare transition is given to patients and their families around 16 years of age, mostly to those patients with chronic illnesses (CF, sickle cell, ESRD, etc). Depending on the disease process, social worker from that sub-specialty program reaches out to the family and identifies particular issues to be resolved before patient turns 18 years of age. Then, if issues are resolved and an adult specialist is identified and willing to take over the care, transition is made gradually (CF, renal programs and sickle cell disease work quite well). For those who have either unresolved issues or there is no adult service available (endocrinology, gastroenterology, neurology, special care needs, etc), if they present to ER or require admission, nursing staff identifies them (they are flagged in EHR chart) and the adult ER staff accommodates them. Once stabilized, they go home and outpatient providers follow them.

4. The transition program is staffed by an RN Manger, Social Worker and the CMS Nurse,

5. The program is just beginning and is a patient and family education program to provide a structured transition for adolescents with special health care needs from their pediatric medical home to their adult medical home.

Florida Children's Hospital Health Care Transition Survey Response Summary

6. We are starting a program transition program with our congenital heart patients. We have plans to do the same with the rest of our patients as part of a complex care program, but this is only in the planning stage. Wolfson works closely with two institutional partners, Nemours Children's Clinic Jacksonville and University of Florida College of Medicine/Jacksonville for the management of transition services. Nemours and UF physicians provide most of the subspecialty care for patients at Wolfson. As these patients approach adulthood, they are referred to the JaxHATS transition program, staffed by UF. Additionally, Wolfson has a Center for the Medically Complex Child, also staffed by UF physicians, that provides primary care and care coordination for patients with chronic and complex medical conditions. These patients are also transitioned through JaxHATS.

For which clinical or specialty areas/programs/conditions do you provide HCT service? Please list.

1. Primary care (Pediatric to Med-Peds or Family Medicine); Hematology/Oncology - has support group and faculty to faculty transition; HIV has transition program that is not structured.
2. Asthma, cystic fibrosis, metabolic disorders, renal disease, congenital cardiac disease, diabetes, neuromuscular disorders, spina bifida, cancer, sickle cell disease, gastrointestinal disorders, etc.
3. CF, Nephrology, Sickle Cell
4. CPMR, Sickle Cell, CF
5. Cardiology and Pulmonology

What services do you provide in your HCT program? The following services were listed.

1. Counseling on HCT by specialty programs by 2 hospitals
2. In-patient consultation/education for HCT by 3 hospitals
3. Care coordination services by 3 hospitals
4. An outpatient clinic dedicated to the care of youth with complex social, emotional or physical health issues including HCT by 2 hospitals
5. Outreach education and training on HCT for primary care and specialty care pediatric providers by 3 hospitals
6. Outreach education and training on HCT for youth and families by 3 hospitals
7. Recruitment and training of adult primary care and specialty providers by 4 hospitals

Florida Children's Hospital Health Care Transition Survey Response Summary

Is the hospital leading or participating in any on-going planning process related to health care transition? Seven (7) hospitals indicated that they have on-going planning process. The 7 hospitals described their planning process in the following manner:

1. Focusing first on the establishment of medical homes for chronic and complex adult patients. Pediatric component will follow.
2. On-going coordination with JaxHATS and development/expansion of the Center for the Medically Complex Child.
3. Outpatient department for primary care, specifically addressing the transition of children with special needs
4. Specialty clinics are under the physicians employed by Nemours Children's Clinic-Pensacola. The leadership of the Children's Hospital does recognize the importance of building an HCT process but has not formally developed one yet.
5. The focus of our project is to provide structured and care coordinated transition for adolescent CSHCN identified by MCH, HCH and CMS from Pediatric Medical Homes to Adult Medical Homes. Families with adolescent CSHCN will be offered group education and preparation for transition to adult care. Program physicians and CMS staff will identify adult care provider(s) for each family. Care coordination will be provided for patients through CMS until age 21. Adult and Pediatric Providers will be offered education through available on-line transitional care modules provided by AHEC (Area Health Education Center) as well as education regarding the tools available on the FloridaHATS website. As part of this project, a network of primary care and subspecialty providers will be developed who are educated and knowledgeable about transition of care.
6. We have a small steering committee forming with Nursing, physician, Case Management and Social Work (initially). We are looking at forming a program that begins at age 14 driven by case management for medically complex children. This is limited due to availability of adult physicians willing to assume care for patients who are on Medicaid.

We asked them who the physician leaders were of their HCT planning projects or services. Below are the responses of 8 hospitals that responded to this question.

1. Director of the medical home project, Director of Primary Care Clinic.
2. Dr. Arwa Saidi, Dr. Schuler.
3. Dr. Constantine Mavroudis-Adult Congenital Heart; Dr. Stacy McConkeyand Dr. Ben Guedes-all other patients.
4. Dr. David, Wood
5. Hospitalists.
6. Rosha McCoy, MD Alex Constantinescu, MD.
7. Stefanie Brown, Nidhip Patel, Lawrence Friedman, Stephanie White, Audrey Ofir, Judy Schaecter.
8. William Blanchard-Cardiology, Okan Elidimir-Pulmonology, CF Clinic Director

Florida Children's Hospital Health Care Transition Survey Response Summary

We asked those hospitals that DID NOT have a transition program if they would be interested in stating one (n=6). All hospitals indicated they would be interested in starting one.

We asked if the Children's hospitals had had any discussions with adult hospitals or physicians about establishing a referral program for children from the children's hospital to the adult system. Nine (9) hospitals indicated that they had had some discussions with their adult system but that these were in very preliminary stages and no formal programs existed linking the children's hospital patients to the adult health care system.

We asked what aspects of a Health Care Transition system would be attractive to or be perceived as providing benefit to the adult care system and then offered them the following options (number of hospitals agreeing with that option are in parentheses:

- As a cost saving program (3 hospitals)
- As a revenue generating program (3 hospitals)
- As a quality of care program (3 hospitals)
- As volume builder (1 hospital)

Conclusion

The results of this survey demonstrate that there is a significant opportunity for CMS to partner with the Florida Children's hospitals to further the practice and policy agenda in health care transition. Some hospitals are starting transition programs, but they are just getting started. Those who haven't started transition programs want to. Virtually all children followed by CMS are patients of the children's hospitals, especially those most in need of support during health care transition, those with complex conditions. By partnering with FACH, CMS can substantially enhance its access to children with transition services.