

TRANSITION OF CARE REPORT *Final*

I. Introduction

For the patient with a chronic childhood disease or condition, one important outcome measure is a successful transition to adult-centered care. A successfully planned and implemented transition encompasses several objectives. First, it acknowledges that those with chronic conditions are entitled to the same health care as their healthier peers. Second, it assumes a meaningful and productive adult life for individuals whose conditions have historically resulted in early demise. Finally, it helps to preempt some young people with chronic conditions from opting out of health care altogether, if they perceive that their adult health needs will be poorly met.

The pediatric care model is focused on growth and development with education about the patient's condition directed towards the parents or family. In contrast, the adult care model is focused on life-long care with education directed towards the patient. As such, it encourages independence, responsibility and self-reliance for the patient who is entering his/her adult years.

A formal transition program aims to provide uninterrupted health care that is patient centered, age and developmentally appropriate, high quality, coordinated, culturally competent, flexible and comprehensive.¹ The intent is to ensure that patients are capable of personal and medical independence. For those patients who are not capable of achieving this independence (such as those with marked intellectual disabilities), transition to adult care providers is still a desirable goal. It is important that the transfer be a smooth and coordinated process so that the patient has appropriate care and is not "lost" to follow-up. Objectives for the program also include a commitment to educating patients about their medical condition and promoting skills in communication, decision making, self-care and self-advocacy.

The hallmark of a successful transition program includes maximizing the life-long functioning and potential of those with childhood chronic diseases with an objective of developing a secure relationship with a new health care team. To enact this, specific criteria for the transfer must be defined, as must the integration of transition planning with specific milestones. A cooperative effort must be ensured between the pediatric and adult health care teams to develop and maintain a transition program. Finally, a viable economic model must be in place for both the pediatric and adult care providers and institutions to make a smooth transfer possible.

The overarching goal of Transition of Care is to ensure that all pediatric patients transition to an adult care provider. Even when there are special circumstances that limit transition of care for a particular medical condition, the long term plan should be to develop appropriate resources so that transition to an adult care provider can occur.

II. Executive Summary

Successful transitioning for the patient with a chronic childhood-onset disease or condition from the pediatric setting to the adult setting is becoming an increasingly important outcome measure of successful pediatric care. While Transition of Care has been discussed in the literature for the past 20 years and some notable efforts have been made at CCHMC and UC Health to enact successful transitions, with few exceptions, specific guidelines and practices have not been established.

Transition is a process and is one of the long term goals of care for patients with childhood-onset chronic illness. The preparatory process begins no later than early adolescence and an important milestone is achieved when an adult provider assumes care for the former pediatric patient. To facilitate this, a formal transition program needs to be in place to provide uninterrupted health care that is patient centered, age and developmentally appropriate, high quality, coordinated, culturally competent, flexible and comprehensive.¹ The intent is to ensure that patients are capable of personal and medical independence, and that their adult medical needs are appropriately met.

For the past six months, a 19-member task force comprised of physicians, administrators, patients and patient family members from both the CCHMC and from UC Health met semi-monthly with the goal of describing the basic tenants and key elements for a successful transition program. There is a vested interest in transitioning patients from CCHMC to UC Health (the University of Cincinnati, the University of Cincinnati Physicians and the University Hospital) for a variety of reasons. A shared academic vision, an alignment of many programs and a physical proximity are a few of the reasons for this interest. As separate academic centers however, there are numerous perceived and actual institutional barriers to transferring pediatric patients with chronic conditions who have reached the age of majority. The Task Force has identified and made recommendations to address these barriers.

Key Recommendations:

- Identify at least one BCMH provider in each divisional program at UC Health. UC Health to participate in Kentucky and Indiana Medicaid as needed **by 7/1/10**. (*UC Health*)
- Generate an appropriate process for cross-delegation of privileges at UC Health and CCHMC to include a plan to address credentialing costs **by 7/1/10**. (*Medical and Dental Staff Offices of CCHMC and UC Health University Hospital Executive Director*)
- Convene joint meetings between one or more members of the pediatric and adult care teams and the patient, ideally, first at the pediatric facility. When not practical, a member of the pediatric team should accompany the patient to the first visit at the adult care facility. The pediatric and the adult care physicians should familiarize themselves with the alternate facilities. Include a guided tour of the UC Health or other facilities as part of the transition process. A specific guide should meet and greet the patients and families during the first few visits. (*Disease specific Transition of Care Program teams*)
- Identify an efficient and effective process to share medical records including a) creating an appropriate interface between CCHMC and UC Health's medical record systems b) developing an electronic template to systematically produce a hard copy record, c) encouraging all CCHMC users to keep the "Problem List" on Epic up-to-date and complete, and d) providing those without CCHMC privileges with read-only viewing rights **by 10/1/10**. (*CCHMC Information Technology and UC Health IMS Departments*)
- Discuss in sub-group format the differences in scope of practice between the pediatric and adult providers including disease/condition specific expectations and perceptions. Come to consensus as to what is appropriate care for a transitioning patient with that particular disease **by 10/1/10**. (*Disease specific Transition of Care sub-group teams*)

- Educate patients on what to do in case of after hours care needs, including differences between CCHMC and other Emergency Departments. (*Adult provider, Transition of Care Coordinator*)
- Set expectations with the patient and his/her family regarding Transition of Care, commonly beginning at age of 16 with a goal of transition by 21. (*Disease specific Transition of Care Program teams*)
- Identify a disease-specific short or intermediate term solution where no appropriate adult provider exists, i.e., adult congenital heart disease. In these circumstances create a plan for medical care by an appropriate adult primary care provider and other adult consultants, i.e., non-cardiologists, for both outpatient and inpatient care. Consider a long term strategic plan to recruit or train appropriate adult providers **by 10/1/10**. (*Disease specific Transition of Care sub-group teams*)
- Develop a leadership team with representatives from both UC Health and CCHMC for each disease state to create a transition plan and to meet on an ongoing regular basis. Designate a member of the team from CCHMC and from UC Health to serve as the Transition Coordinator **by 7/1/10**. (*Leadership of Disease specific Transition of Care sub-group teams*)
- Create a dedicated Transition Administrator at each institution to oversee all Transition of Care efforts **by 6/1/10**. (*CCHMC Vice President of Clinical Affairs and UCHealth, Department of Internal Medicine, Director, Clinical Operations*)
- Convene a semi-annual meeting of the parallel Transition Coordinators to review patients' readiness for the transition process **by 1/1/11**. (*CCHMC Vice President of Clinical Affairs and UCHealth, Department of Internal Medicine, Director, Clinical Operations*)

The Task Force's vision is that all disease states or conditions will soon have a comprehensive Transition of Care plan for their patients. To this end, the next step will be to convene 9 sub-groups to draft specific disease/condition plans. The Task Force will assist these initial sub-groups in their efforts.

III. Literature Overview

According to the American Academy of Pediatrics, 90% of youth with Special Health Care needs reach their 21st birthday. Discussion of effective Transition of Care from the pediatric to the adult setting began in the literature around 1984 as the long-term survival rate of these children with chronic diseases or conditions improved. For the last 25 years, the value of transition and what connotes success has been extensively discussed.

The Society for Adolescent Medicine first defined Transition of Care in a 1993 in a position paper as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems." While there may be consensus on the definition, transition practices vary greatly across the country and few of these practices have been validated. What is generally agreed upon is that like the maturation process from the dependent child to the independent adult, Transition of Care should be a gradual process taking several years. Such a transition should not be expected to occur as a

single leap, a single phase or a single point in time. Rather, the actual transfer to adult care is one of the many events of transition.

Barriers to Transition

There are multiple barriers to the transition process within our existing healthcare systems which are extensively discussed in the existing literature. They include barriers from the adult providers, pediatric providers, families, patients and hospitals and healthcare facilities.

For the adult provider, the barriers relate to the change from the type of care provided in a pediatric environment to that provided in an adult setting. Adolescents leave behind a nurturing world, where there is active pain management for almost all procedures, time to probe for problems, and tolerance for immaturity. They move into one where autonomy is presumed, punctuality and reliability expected, appointments are brief, and stoicism for discomfort by and large taken for granted.² Research has shown that the adult provider's concerns include the pediatric patient's lack of knowledge about his/her disease and limited self-care skills, the limited patient visit time when compared with the pediatric setting, meeting the patient's psychosocial needs and the perception that only select patients will be transferred, for example, the uninsured patient.

For the pediatric provider, the barriers are fairly paternalistic in that they are reluctant to "let go" of their patients after multiple years of care. They question the level of training and experience of adult providers with childhood-onset chronic conditions. Finally, they have often sheltered their patients from understanding their true prognosis and limitations as well as not equipping them with the tools to address their healthcare needs as an adult.

Parents and families of the patients have previously been key players in the treatment of their children and, in an effective pediatric setting, valued as an integral part of the health care team. Now they are relegated to the sidelines without an active voice or control in decisions. They report feeling excluded and having a sense of loss of control. Parents and families also report that they are reluctant to change for both fear of giving up trusted relationships and being concerned about the quality of care in the adult setting.

Adolescent patients are forced to give up trusted relationships, the transition process challenges them to assume a higher level of independence and they must manage new processes, find their way in new facilities and to forge new relationships. Additionally, financial considerations often become great as the patient is no longer covered under his/her parent's insurance.

In general, barriers to transition emanate from the differences between family-focused pediatric care versus the adult care setting and the lack of training for most pediatric and adult care providers in adolescent care. Key barriers also include the lack of appropriate adult providers and facilities for childhood onset conditions as well as insurance and financial considerations. Finally, transition occurs at a critical and tenuous time in the patient's life during the transformation from adolescence to adulthood.

Key Elements

Several key components of a successful transition are often cited in published studies and reviews on Transition of Care. These components relate to the philosophical basis of transition, the transition team structure, planning and education.

Philosophical elements:

- It is important to lay the foundation early for the transition process. When children and their parents/guardians enter a pediatric service, they should know when they can expect to leave it.
- There should be a flexible policy on the actual timing of the transfer depending on the individual's needs.
- All the multiple principles, people and processes that support transition need to be appreciated, undertaken and completely internalized into the program.
- Affordable continuous health insurance coverage throughout adolescence and adulthood should be ensured.

Team elements:

- A Transition coordinator should be assigned to each patient to guide them through the entire transition process.
- Joint meeting(s) should be conducted with both pediatric and adult care providers with the patient. This key element is cited more often than any other component of successful transition. Family involvement in this part of the process is often helpful but must be tailored to respect the specific medical and developmental needs of the patient as well as HIPAA regulations.
- There should be both primary care as well as preventive care involvement.
- It is paramount that a communication plan exists between not only the pediatric physician and the adult physician, but also between each team member of the pediatric team with their adult system counterparts.
- A network of relevant local agencies and adult services should be developed.

Planning elements:

- A formal, written Transition plan needs to be created with the patient and family. This plan should periodically be reviewed and updated.
- A Transition policy between the pediatric and adult service should be developed.
- A medical summary needs to be developed that is portable, accessible and includes relevant medical data, career and personal interests, family dynamics and support.

Education

- Skills training in communication, decision making, creative problem solving, assertiveness, self care, self determination and self advocacy needs to be provided for the patient.
- Education on the medical, psychosocial and educational/vocational aspects of care needs to be provided for the patient and their family.
- The pediatric and adult team providers need to be educated in the principles of adolescent health and transitional care.
- Patients should be counseled on their condition in general as well as the implications of their condition for other surgery (if applicable), medical care and non-medical procedures. They should also receive counseling about sexual and reproductive health, genetic counseling as indicated, psychosocial support, career, physical activity and travel planning as it relates to their condition. Most commonly, the patient's parents should not be present for this type of counseling facilitating independence whenever possible.

Timing of Transition and Transfer

The issue of when to actually transfer the patient has been considered at length in the literature. While it is stated that there should be a target age, most agree that it must remain flexible. The following key determinants are most often cited to evaluate the timing of transfer: chronologic age, emotional and psychological maturity, current medical status, adherence to therapy, self-

advocacy skills, overall readiness and the availability of an appropriate adult specialist. Many authors cited that it was inadvisable to transfer during any sort of medical crisis.

Models for Transition of Care

Three existing models were discussed to address Transition of Care. Similar to the Medical Home, primary-care-based coordination is one option. In this model, a Primary Care Physician leads a team of individuals who together take responsibility for the ongoing care of the patient. The Primary Care Physician develops a customized plan and utilizes a clear process for the coordination of multiple services and providers.

The second model involves a generic adolescent service, or Transition Clinic, for all specialties with coordination by adolescent health experts. This interdisciplinary approach provides the patient with access to multiple services including social work, nursing, vocational services and training.

The last model is a specialty or individual disease based approach. In this approach, the sub-specialty pediatrician and sub-specialty adult teams coordinate care together.

Existing Societal Guidelines

Historically, the past decade has created an awareness of the importance of health care transition from child to adult care for children with a chronic disease or condition. In 2001, a consensus statement regarding Transition of Care was issued by the American Academy of Pediatrics, the American Academy of Family Practice and the American College of Physicians-American Society of Internal Medicine with the goals of ensuring “by the year 2010 all physicians who provide primary or sub-specialty care to young people with special health care needs: 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how and when transfer of care is indicated”.

In 2003, the Society for Adolescent Medicine first officially defined Transition of Care in a position paper entitled "Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions" (Journal of Adolescent Health 2003: 33:309-311). This paper also included fundamental principles for a successful transition.

In terms of current efforts regarding health care transition, there are several ongoing efforts. The Council on Children with Disabilities (COCWD) is leading the American Academy of Pediatrics’ transition initiatives. A clinical report and work plan are being developed to help pediatricians ensure that youth continue to receive “high-quality, developmentally appropriate health care services as they transition to adulthood”. The first draft of this report is currently under review with the notion that the American Academy of Family Physicians and the American College of Physicians may jointly endorse this report. In 2008, a summary report entitled "American Academy of Pediatrics: The State of Transition" was written. This report highlights current transition activities and identifies areas where assistance is needed in order for providers to properly address transitioning youth to adult care within their practice. Several other societies including the American College of Cardiology and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition have written disease specific guidelines on Transition of Care. Finally, transition focused projects are being undertaken by the American Academy of Pediatrics including the development of collateral materials, tools, assessments, videos, websites and other resources.

IV. Task Force

A 19-member task force comprised of physicians, administrators, patients and patient family members from both the CCHMC and from the University of Cincinnati met semi-monthly for six months. (See appendix B for member list). The purpose of the group was to describe the basic tenants and key elements for a successful transition from pediatric to adult care for the patient with a childhood-onset disease or condition as well as identify and make recommendations to address perceived and structural barriers in our Academic Medical Center. The diverse nature of the group was to gain perspective from all parties within our Academic Medical Center who are involved in Transition of Care. These parties included representatives from the pediatric provider team, the adult provider team, patients, families, and both the pediatric and adult care hospitals.

The Task Force first performed a literature review to assess best practices and to understand national guidelines. Second, interviews were conducted to understand current Transition of Care practices for many chronic diseases or conditions. Interviewees included representatives of the following Divisions at CCHMC: Adolescent Medicine, Cardiology, Developmental and Behavioral Pediatrics, Gastroenterology, Hepatology and Nutrition, Hematology and Oncology, Neurology, Pulmonary Medicine, and Rheumatology. Interviewers asked questions about the existence of formal practices and the extent to which these practices are considered successful. In addition, questions were asked about current protocols and practices such as the following: (1) to whom do they transfer patients, (2) do they utilize a transition coordinator, (3) have they created a transition plan, and (4) how do they determine when to transfer patients. Additionally, communication methods, joint meetings, summary reports, primary care involvement, skills training for the patient, and patient counseling were discussed during the interviews.

V. Existing Models at CCHMC

A cross-section of Divisional representatives were interviewed as to their experience and practice with Transition of Care. During these interviews, their current practices, past successes or failures, use of transition tools, utilization of a transition coordinator, barriers to transition, and communication methods were all discussed. By and large, very few formal transition processes exist and many adult patients continue to be seen at CCHMC. The following represents an overview of their responses.

A. Inflammatory Bowel Disease, Division of Gastroenterology, Hepatology and Nutrition

In the year 2009, 16% of the active patients in the Inflammatory Bowel Disease (IBD) program were over the age of 18. Substantial efforts have been made to transfer patients as evidenced by the fact that at the end of 2008, 30% of their active patients were over the age of 18. The Division hosts an IBD Education Day which involves a breakout session for families regarding the transition process. While there is no specific target age for transfer, patient communication begins during the patients' junior or senior year of high school. Often, however, patients continue to be seen through college graduation. Efforts are made so that patients are seen without a parent beginning at the age of 17 for a portion of their visit.

The Division is working on a transition clinic with UC Health but locating an appropriate facility as well as an amenable time for the physicians has been difficult. Primary care tends to be involved in transition only if they were already involved in the pediatric patients' IBD care. A written handout is provided which helps to facilitate discussion. The nurse coordinator serves as a

transition coordinator for the program. Acceptance of various insurance at UC Health has been a barrier in the past, but these issues are being resolved.

B. Division of Adolescent Medicine

The Division of Adolescent Medicine is a subspecialty of pediatric and adult medicine addressing the medical needs of the young adult as they transition from childhood to adulthood. In the Division of Adolescent Medicine, typically only those with greater medical are formally transferred. Currently, formal Transition of Care processes such as a transition plan, a transition coordinator or joint meetings are not utilized. For the patients who are transferred, there is an existing mechanism to transfer them to the Medical/Pediatric Division at UC Health. The Division typically provides a phone referral to physicians in the MedPeds and Internal Medicine Divisions at UC Health. For those with greater complex needs, the CCHMC Division sometimes makes the appointment directly. For others, a general recommendation is provided as to an appropriate physician. The Division's policy is to provide prescription refills up to 12 months after a patient is formally transferred, although efforts are made to limit this practice to 6 months. Communication with the patient regarding transition begins close to the age of 18 or as they are about to enter college. However, many are followed until the age of 22. There are some constraints to following adults beyond this age due to issues such as an APN not being credentialed to serve an adult. However, some patients have been followed beyond this age if they continue to be actively followed by a CCHMC subspecialist. The general experience has not been smooth due to traditional differences between the pediatric and adult approach. Additional barriers for transition include adult providers who do not accept public insurance and that the MedPeds Division at UC Health is closed to new patients.

C. Heart Institute, Division of Cardiology

For more than 11 years, there was an adult clinic for congenital heart disease at the Hoxworth Center. Mostly former CCHMC patients attended the clinic. The clinic was moved back to CCHMC in 2005, however, as appropriate care for these patients was not available. A center for adults with Congenital Heart Disease was opened in April 2010. Issues include insurance, surgical coverage and staffing.

D. Division of Rheumatology

The Division has historically experienced challenges with transitioning services for teenagers and young adults with rheumatic diseases. Examples of the challenges centered around availability of providers and appropriate services, shifting of provider-patient relationships, changeover of responsibilities to young adult versus parent, as well as availability of appropriate financial resources. In 2008, the Division of Rheumatology was compelled to address transition challenges when they experienced a dramatic change when three of their pediatric rheumatologists, who were responsible for 75% of the Divisions case load, left CCHMC. To address the patient load, the Division examined supply and demand, adjusted provider templates, and also considered approximately 400 of their patients for transfer based upon medical need as well as psycho-social and family considerations. When appropriate, many patients were transitioned to a different provider within the Division. Ultimately, the Division transferred care for nearly 200 patients to providers external to CCHMC. The 200 patients were sent letters from the Division and respective providers. The letters informed patients and families of their providers upcoming departure, acknowledged their care, commitment and relationship and also identified appropriate adult providers in their community. When possible, final visits occurred with the physician, and when not possible, the patient was seen by a physician or nurse practitioner or reviewed process and resources with one of the rheumatology nurses prior to

release. A referral letter was sent to the adult rheumatologist that the patient chose along with the medical records of the patients initial, penultimate and last visits.

Currently, while there is neither an overarching plan nor individual patient planning, the Division does incorporate several Transition of Care practices and concepts. Developmentally appropriate check lists are available. Materials addressing self-management skills have also been produced. Transition is not formally discussed until the age of 18; however, patients are prepared for transition as they begin to see their clinician alone for a portion of the visit beginning around the age of 13. Patients are also educated about their condition at developmentally appropriate intervals.

Previously in an attempt to slowly transition patients with Lupus to an adult facility, there was a transition clinic at Christ Hospital staffed by a pediatric rheumatologist. Ultimately, the clinic was not successful for a variety of reasons including that the patients continued to rely on the CCHMC staff and were not keen on making a transfer. A special phone line was created for this clinic, but patients quickly realized that it was staffed by CCHMC employees. Additionally, Christ Hospital did not accept Medicaid patients and there was not an opportunity to continue research efforts.

Currently, there are discussions with UC and CCHMC for Lupus patients to be transitioned to UC and followed by an adult rheumatologist. However, numerous challenges have been identified. The Rheumatology Division is in the process of developing a transition plan. They have not yet identified a transition coordinator.

E. Transition of Youth and Young Adults with Intellectual Disabilities (TrYAD) Clinic, Division of Developmental and Behavioral Pediatrics

The Transition of Youth and Young Adults with Intellectual Disabilities (TrYAD) Clinic helps to support the unique Transition of Care needs in this population. They support a patient's transition from school to work/vocation, from home to community, and from pediatric to adult care. They provide education for the patients, their families, and their health care providers, coordination of ancillary services, and liaison with community resources. In terms of Transition of Care, they currently utilize just a few providers because not many providers in the community are comfortable managing these patients. Therefore, many of those providers have reached maximum capacity and are not accepting new patients. When transferring, some of the adult providers are contacted by phone, but most receive a letter with an accompanying medical summary. Transition is a gradual process and most patients are followed until the age of 24 or 25.

The TrYAD staff believes that UC Health is an ideal location to transfer CCHMC's patients. However, UC Health's Medicine/Pediatrics practice, which is an ideal primary care environment for this group of patients, is currently not accepting any new patients. Additionally, it is difficult to find adult providers who feel comfortable and are trained in the medications utilized by this patient population. Communication regarding Transition begins at age 14 when the patient is seen for his/her first visit to the TrYAD Clinic. Per Ohio law, by age 16 a formal Transition plan must be developed and put into place by the school as part of the Individualized Education Program (IEP). Discussions continue at each meeting from age 14 onward as to the patient's progress of transition across the three domains: school to work, home to community, and pediatric to adult care. The most pressing issues for the TrYAD team are the lack of appropriately trained adult providers, patients not having a medical home nor receiving

appropriate primary care, and spreading the word about the need for transition as a process versus an event.

F. Division of Neurology

The Division of Neurology seeks to transfer their patients at a time that is comfortable without setting a specific age criteria. They do not accept any new referrals past the age of 21. For the patients who are transferring, they provide recommendations and contact information, but do not invariably speak to the adult physician directly. Additionally, they provide a copy of the medical record to the adult physician and help establish guardianship for the patient.

Transition planning is documented as part of their medical record. Primary care is always involved and assumes the lead role once the patient is stable. A social worker serves as a key coordinator for transition planning. Conversations with the patient begin in the patient's early 20's. At age 18, visits begin alone without the patient's family, although the family often joins the patient towards the end of the visit. Both nurses and the physicians address self-care issues.

In 1992, the Tuberous Sclerosis program was established at CCHMC with the intention of treating adult patients with this condition. Currently there are more than 240 patients over the age of 21 in the program. There is no plan to transfer them as UC Health adult physicians knowledgeable in TSC have been incorporated into the clinic since its inception to meet this need. There are only two other clinics in the United States that see adults with TSC (Philadelphia and Boston). Even these clinics do not have the expertise available at CCHMC/UC Health in managing renal and pulmonary complications of the disorder, which occur most commonly in adulthood. Patients over the age of 30 are admitted to the University Hospital for, pulmonary, and general medical issues; however, kidney embolization and other diagnostic procedures continue to be performed at CCHMC, when the patient's general medical status does not preclude this.

In 1998, the Tourette Syndrome and Movement Disorders clinical program was established at CCHMC with the intention of optimizing care for children and adults with Tourette Syndrome and children with dystonia, chorea, tremor, ataxia, psychogenic movement disorders, drug induced movement disorders, and stereotypies. This program collaborates regularly in educational, clinical, and research endeavors with the UC Health Neurology Movement Disorders program. The CCHMC Tourette Syndrome and Movement Disorders clinic does accept adult referrals for patients with Tourette Syndrome and continues to provide neurological care into adulthood for chronic, childhood-onset Movement Disorder patients. This clinic also accepts second opinion referrals for adults with rare movement disorders. On a case by case basis, referrals are made of both pediatric and adult Movement Disorder and Tourette patients to the UC Health adult providers either for 1) second opinions regarding diagnosis; 2) second opinions regarding treatment; or 3) expert specialty treatment to be administered at UC Health (for example, vocal cord Botulinum toxin for laryngeal dystonia or deep brain stimulation for dystonia).

G. Division of Pediatric Physical Medicine and Rehabilitation

The Pediatric Physician Medicine and Rehabilitation Division currently does not have any specific processes or policies related to Transition of Care. The Division currently sees young adults into their 30's, the majority of whom have Cerebral Palsy. In the past, there have been efforts to establish an appropriate adult program at both UC Health and at Drake Center. Neither of these programs was successful as there were not sufficient numbers of appropriate physicians.

Many patients do, however, transition to an adult primary care physician but do not receive sub-specialty care.

The Division does provide assistance with guardianship issues. Of concern for this patient population are the in-patient needs after the age of 30, availability of an appropriate adult physiatrist and appropriate adult subspecialists at UC Health and insurance issues.

H. Cincinnati Sickle Cell Network, Division of Hematology and Oncology

Currently the Pediatric Center for Sickle Cell disease has more than 100 patients who are over 14 years of age. While the Pediatric Team seems to agree that these patients are all of age to be actively working on transition, there is not a clear or well-documented process to affect a smooth transition. Additionally, the lack of a close working relationship with the Adult Center for Sickle Cell disease, a lack of patient interest in transitioning to adult care as well as patient understanding of the need for primary care are also contributing factors. A decade ago, a well-developed and successful process existed to transition patients including an initiative called “First Visit Program” where a CCHMC nurse practitioner would attend the patient’s first Adult Center visit. These programs apparently ended due to a loss of funding support and changes in personnel.

Three years ago, the Cincinnati Sickle Cell Network’s Transition Program was formed with the Pediatric and UC Health Adult Centers as well as three community primary care centers to address Transition of Care issues. A number of plans have been made to revive the former Transition Program and are in various stages of implementation. Efforts have included monthly meetings as a Network, initiation of a Young Adult Clinic at CCHMC where an adult provider attends a once a month clinic, partnering with community-based organizations such as Sickle Cell Affected Families, reviving the First Visit Program, designing transition checklists and transitions plans.

I. Cystic Fibrosis, Division of Pulmonary Medicine

Prior to the 2001 mandate by the National Cystic Fibrosis Foundation to include an adult care provider as part of each Cystic Fibrosis (CF) team, Cincinnati already had an adult center in place. The mandate was, however, a stimulus to formalize the Transition of Care process. This decision was the impetus for the CCHMC Cystic Fibrosis team to create a more formal transition program. The Foundation offers training grants, mentorship programs and courses for the adult providers as well as describing four different models of how an adult provider can be incorporated into a program. The CF adult and pediatric programs in Cincinnati are completely separate entities at separate locations, specifically at CCHMC and at UC, with completely separate staffs and clinics. Currently there are approximately 300 patients in the greater Cincinnati area who have CF, with more than 120 over the age of 21.

The concept of transition is introduced at diagnosis. Beginning at the age of 5, age appropriate education regarding CF is offered to each patient. By the age of 13, there is a push towards independence and participation in the self-management program. Patients are seen alone beginning at the age of 13 and parents are included towards the end of the visit. At age 18 or 19, the initial Transition of Care visit occurs. The adult provider comes to the pediatric program, and meets with the patient which is usually a longer, hour plus meeting. In this case, the adult provider is Med-Peds trained and has an appointment at both institutions. During this meeting, issues such as the patient’s overall knowledge of their disease, reproduction, living with CF as an adult, insurance, and advance directives are discussed. At a minimum, the adult provider sees the patient twice at the pediatric setting. Once the meeting with the adult provider occurs,

however, the patient no longer sees the pediatrician. Next, the nurse coordinator and/or nutritionist provide a tour of the UC facilities. A packet which includes the patient's records is assembled by the nurse coordinator and the information scanned into the UC computer. Once the patient has their first appointment at UC, the patient no longer formally interacts with the CCHMC staff.

The UC team provides primary care services to approximately 40% of their patients. Numerous sub-specialty consultants are part of the extended team including consultants from surgery, ENT, GI, GI-Liver, OBGyn, Endocrinology, Pharm D's, physical therapists, orthopedics and rheumatology.

Part of the program's success was a seminar held at UC several years ago for patients, families, staff, floor nurses, respiratory technicians, and child life representatives. During this seminar, tours of UC were provided, the benefits of transition and the differences between UC and CCHMC were discussed. This seminar was instrumental in eliminating misperceptions regarding the transfer process.

J. Pediatric Cancer, CCHMC Cancer/Blood Diseases Institute

The CCHMC Cancer Survivor Center currently follows approximately 1600 adult survivors of childhood cancers. The population mirrors the incidence of pediatric oncology, and includes disease groups: leukemia/lymphoma, neuro-oncology/brain tumor, neuroblastoma, sarcomas liver/renal tumors, and endocrine and epithelial cancers. Survivors of childhood cancer are at risk for both the consequences of their therapy, which often pose specific health risks, and are also at risk for earlier development of other chronic medical conditions common to adults (e.g. cardiovascular disease, cancer, etc.). Therefore it is imperative for these patients to have survivor-focused regular health care, with an early focus on preventative medicine approaches. Survivor care in adulthood presents one of the biggest opportunities to advance outcomes and quality of life. Transitioning care, however, in this population is very complex.

CCHMC is a national center for laboratory and clinical research for cancer survivors. The Childhood Cancer Survivor Study (CCSS), a national NIH-funded study group representing a dozen national centers for care and research in over 12,000 childhood cancer survivors, has identified a major gap in care for childhood survivors in terms of testing and preventative care. CCHMC is home to the national CCSS biology laboratory, and a center for pharmacogenetic research in these patients.

The CCHMC Survivor Center team is also refining a new paradigm-shifting model for survivor care that does not involve a transition or hand-off. The new CCHMC survivor care model involves a comprehensive team of long term follow-up specialists that coordinate and direct survivor care into adulthood. The patient would move to an adult primary care provider, but direction of care remains integrated to the survivor center which incorporates specialists from multiple disciplines and both pediatric and adult survivor-focused expertise. An ancillary goal is to continue to integrate early adult survivorship efforts at UC into the CCHMC Survivor Center - combining the clinical, educational, training and translational research programs which could lead to a National Center for Adult Survivors. The new strategic plan for the CCHMC Survivor Center is targeted to include six focus areas: survivor health and wellness, new technologies, molecular medicine program, cardio pulmonary health, endocrine health, neuro-cognitive health and muscular skeletal health.

VI. Barriers to Transition

Much of the literature reviewed indicates that there are multiple barriers to the transition process within existing systems. These barriers include those relevant to the adult providers, pediatric providers, the families and patients and in general to the health care systems.

There is a vested interest in transitioning patients from CCHMC to UC Health for a variety of reasons. A shared academic vision, an alignment of many programs and a physical proximity are a few of the reasons for this interest. As separate academic centers however, there are numerous perceived and actual institutional barriers to transferring pediatric patients with chronic conditions who have reached the age of majority to an adult care provider. The following details the perceived barriers specific to UC Health, examples of ways in which these barriers have been resolved and various recommendations to help minimize these barriers. Similar barriers may exist when transitioning patients to other local, regional and national institutions.

Insurance

Insurance issues are frequently cited as both a perceived and an actual barrier to transitioning patients. At CCHMC, a great number of patients are either insured by Medicaid and/or are enrolled in the Bureau for Children with Medical Handicaps (BCMh) program. A perceived barrier is that UC Health does not have any BCMh providers, when in fact UC Health has 110 providers who do accept BCMh. Similarly, it is believed that UC Health does not accept Indiana or Kentucky Medicaid. However, UC Health does accept Kentucky and Indiana Medicaid for medical and surgical care, although not all University of Cincinnati Physicians are enrolled. Additionally, UC Health needs to reach an agreement with “Buckeye” managed care. Psychological and behavioral mental health services remain a challenge, but currently are a challenge as well at CCHMC.

Recommendation: In each divisional program, at least one BCMh provider should be identified. UC Health should become enrolled for Kentucky and Indiana Medicaid as needed.

Privileging and Credentialing

The perception is that it is difficult or impossible to obtain appropriate privileges at the alternate institution from where one is currently privileged due to Joint Commission regulations. CCHMC’s Medical and Dental Staff Office confirmed that this is not correct, rather that each institution can cross-delegate the other institution to be in charge of privileges, i.e., if one is privileged at one institution, the other will accept that appointment. The tax payor ID would remain the same. CCHMC quality assurance data can be used as proof of performance based privileging.

Recommendation: The Medical and Dental Staff Offices of each institution should generate an appropriate process for this cross-delegation including a plan to address credentialing costs. Further, dual appointments for all physicians should be considered as it may help make the physicians feel more welcome and comfortable at the alternate facility.

Facility Issues

Several barriers exist for Transition of Care regarding facility and treatment locations. First, there is no facility for both the pediatric and the adult provider to simultaneously see the patient. The Task Force considered at length whether to recommend such a joint Transition of Care location. While intriguing to have a separate and neutral location at which to see these adolescent patients, it was deemed that this would not be a cost effective nor prudent solution for

most transition plans. It would in essence necessitate an additional transition step to enter and then leave this temporary location. In lieu of creating such a physical space, a joint meeting, or several, between one or more members of the pediatric and adult teams are suggested. It is suggested that joint meetings are held with the patient first at the pediatric facility. When this is not practical, having a member of the pediatric team accompany the patient to the first adult visit may be a reasonable alternative.

Second, there is a level of discomfort for the physicians, patients and families with facilities that are unknown to them. Physicians are not familiar with the processes and physical space at the alternate facility. Families are uncomfortable finding their way in new facilities as they transition to UC Health. Lastly, UC Health does not have one point of access for care which can prove to be unwieldy when compared to CCHMC's system.

Recommendation: Joint meetings with one or more members of the pediatric and adult care teams should be convened with the patient first at the pediatric facility if practical. Where this is not practical, a member of the pediatric team should accompany the patient to the first adult visit. Efforts should be made by both the pediatric and the adult care physicians to familiarize themselves with the alternate facilities. A guided tour of the UC Health or other facilities should be part of the transition process. Additionally, a specific guide should meet and greet the patients and families during the first few visits.

Medical Records

A medical summary needs to be shared as part of the transfer process. At present this needs to be a hard copy but opportunities exist for transfer of information or joint access to an electronic medical record.

Recommendation: CCHMC and UC Health's IT departments should identify an appropriate interface between each institution's systems. Additionally, an electronic template needs to be developed to systematically produce a hard copy record for the transitioning patient with relevant information for the adult care provider.

Expectations and Differences in Care

The concern of the pediatric provider is that there are differences in scope of practice between the pediatric and adult providers, resulting in care which is not comparable. Alternatively, the concern of the adult provider is that the transferring pediatric provider has an expectation for the adult provider to treat a patient in excess of the patient's needs by performing outside of standard adult provider care. Additionally, the adult care setting at UC Health has traditionally had less support services than their counterparts at CCHMC. This is a problem especially for individuals with marked intellectual disabilities. Clearly, there needs to be a common ground on the expectations between the pediatric and adult providers, however how to achieve this is complicated.

Recommendation: Each disease/condition specific sub-group should discuss these expectations and perceptions. They should come to consensus as to what is appropriate care for a transitioning patient with that particular disease.

Patients view each facility (CCHMC and UC Health) as a provider of an integrated continuum of care. Unevenness in the system is disruptive to patient care. For example, a negative perception of the Emergency Room may be transferred to an out-patient clinic. A number of concerns were discussed about the patient experience in the UC Health Emergency Room. At the same time,

the appropriateness of treating adults at the CCHMC Emergency Room was also considered. The Task Force understands that a number of process improvements are being made to the UC Health Emergency Room to not only affect issues such as flow, but also enhancements such as segregating potentially disruptive patients and to offer a faculty/staff physician referral phone line to expedite care.

Recommendation: Both the adult and pediatric provider teams should be aware of this perception when educating patients on the available opportunities at UC Health. The UC Health adult provider should educate patients specifically on what to do in case of after hours care needs, including differences between CCHMC and other Emergency Departments.

Lack of parallel adult provider

For a number of disease states or conditions, there is not an appropriate adult care provider. This may result from a gap specific to the Cincinnati area, or alternatively the absence of such providers on a national level.

One of the tenants of a successful transition program is the involvement of a Primary Care Physician. Currently, UC Health's Med/Peds Division is closed to new patients; thereby appropriate transition using the Med/Peds program cannot be offered.

Recommendation: Where no appropriate adult provider exists, a disease-specific short or intermediate term solution should be identified for transitioning patients and a long term strategic plan to recruit or train appropriate adult providers should be considered.

Ownership of transition process

There are numerous misconceptions from providers at each institution regarding the alternate institution. These misconceptions have not been specifically identified, rather, it is perceived that there is not a high level of trust between the two organizations.

Recommendation: Each disease state needs to develop a leadership team with representatives from both UC Health and CCHMC to increase the level of confidence in the available services and system. The leadership team should develop an initial transition plan and meet on an ongoing regular basis. A member of the team from CCHMC and from UC Health should be identified as the Transition Coordinator who will be accountable to the team for this process. This may be a physician, nurse practitioner, nurse coordinator, or social worker.

VII. Timing of Transition and Transfer

The appropriate age at which to transfer a patient with a chronic disease or condition can vary greatly depending on multiple factors. As discussed in the literature, chronologic age, maturity, current medical status, adherence to therapy, self-advocacy skills, readiness of the young person and availability of an appropriate adult specialty should all be considered. Additionally, it is important to recognize that transition is a process, as opposed to the actual transfer which is one point in time. Transition must be addressed in multiple ways at multiple points in time to adequately prepare the young person for the milestone in which care is transferred.

While individual needs will vary, the following are the basic principles regarding the appropriate time for Transition of Care:

- Setting expectations with the patient and his/her family should begin by the age of 16 with a goal of transition by 21.
- Consideration should be made for the college-bound patient so as to not transfer care multiple times. It may be advisable for those who are eventually returning to the greater Cincinnati area to transfer prior to college or to remain in pediatric care through college.
- It is unadvisable to transfer a patient when in medical crisis.

VIII. Models for Transition

There are four key principles to create a smooth transition between the pediatric to adult setting. First, it is imperative that both the pediatric provider and the adult provider convey a positive attitude when addressing the transition plan and details regarding options for the future. Setting realistic expectations for the transition process from the start will help reduce the patient and their family's anxiety and concerns by giving them the necessary information and tools. These discussions will ensure a higher level of comfort with both the process and their future care provider. Securing familiarity between the pediatric and adult care providers as well the new facility will also increase their level of comfort. Providing a positive endorsement for the adult provider when transferring the medical record will also help. Finally, there should be a person dedicated to the entire transition process, such as a transition coordinator, who has complete responsibility for the transition needs of the patient.

Several options exist to foster a sense of familiarity and comfort with an adult provider team as well as facility. The adult provider could see a transitioning patient once at CCHMC along with the pediatric provider, then the next visit could be with the adult transition coordinator, and progress to being seen alone in adult setting. The pediatric transition coordinator could escort the patient to UC Health for a tour and a visit with the adult provider. Finally, a clinical space could exist where the patient is seen several times jointly by the adult provider, pediatric provider and transition coordinator(s).

When considering transition from the pediatric setting to the adult care model, three possibilities for models exist. The first is when there is an appropriate adult provider. Adolescents with diseases or conditions with parallel adult providers such as diabetes would completely transfer to an adult provider and leave the pediatric setting. A parallel adult provider is one that has complete knowledge and training in the disease or condition.

For diseases or conditions without parallel adult providers such as Congenital Heart Disease, alternative models are required. These could include continued care by a pediatric led specialist team. Planning for medical care by an appropriate adult primary care provider and other adult subspecialists, for both outpatient and inpatient care, is imperative.

Adolescents with diseases or conditions with multi-disciplinary needs such as Spina Bifida have several options. These options include being seen in a joint multidisciplinary clinic, transitioning to a comparable adult multidisciplinary clinic or utilizing a Primary Care Physician as a Medical Home. In the latter case, the Primary Care Physician would facilitate visits with all necessary individual sub-specialists and coordinate all medical needs.

IX. Transition Team

The Transition Team would ideally encompass staff to support the medical, sociological, psychological, and financial well-being of the patient from both a pediatric and adult care perspective. The Team would be comprised of an appropriate pediatric subspecialty provider(s), adult subspecialty provider(s), pediatric primary care provider, adult primary care provider, pediatric social worker, adult social worker, pediatric transition coordinator, adult transition coordinator as well as other nursing, mental health and financial advocates. To what extent involvement is required by each team member will be determined on an individual basis.

Identifying a Primary Care Physician is encouraged for all transitioning patients. The adult Primary Care Physician can serve to coordinate and organize all subspecialty care and primary care needs.

The Task Force recommends the creation of a dedicated Transition Administrator at each institution to oversee all transition of care efforts. In addition, each disease/Division should have a Transition Coordinator for the specific disease/condition. The number needed for each disease/Division depends on both volume of patients and the complexity of their medical condition(s). The Transition Coordinator would facilitate contact with the adult provider(s), support the development of the medical summary, and orient the patient to the adult care team and facility. A semi-annual meeting of the parallel transition coordinators is recommended to review patients' readiness for the transition process.

X. Transition policy between CCHMC and UC Health

Since both UC Health and CCHMC are part of larger Academic Medical Center, have a number of overlapping tertiary care programs, are physically proximate and are dedicated to improving patient care through best practices, education and research, there are excellent reasons to establish strong transition programs between CCHMC and UC Health. However, for reasons of geography, individual preference, as well as expertise of available adult providers, patients will undoubtedly be transferred to non-UC Health physicians as well. The transition efforts set up as a result of this Task Force can be used as a conceptual framework for transition of patients to other adult providers.

XI. Education recommendations

As part of the overall transition process, ongoing education needs to be provided for patients and their families to emphasize the value of a developmentally appropriate and thoughtful transition.

At a developmentally appropriate level, patients need to be thoroughly educated on their disease including the basic patho-physiology, early signs of crisis, and implications of high-risk activities. Adolescents need to be empowered with the skills and information necessary to make responsible choices for their future. Training opportunities need to be available in skills such as communication, decision making, creative problem solving, assertiveness, self care, self determination and self advocacy. Patients need assistance and practice with learning to take responsibility for their care, including keeping appointments and with adherence to medical regimens. Additionally, an orientation to the adult provider, facility and clinic needs to be carefully orchestrated. Finally, providing a peer-to-peer mentoring opportunity is often advisable.

The patient's family needs the tools and resources to support their adolescents' burgeoning independence. Education needs to be provided in how adult care will differ and how to provide their child the necessary skills to function within the adult healthcare system. Families also need help in assisting the adolescent to develop their own support systems outside of the family. Finally, the family needs reassurance that the adult provider and adult facilities are appropriate for their child's well-being and future. For patients who are unable to assume independence in medical decision-making, such as those with intellectual disabilities, adult providers and programs must be able to work with guardians to provide ongoing education and support in their role.

XII. Transition communication vehicles

Effective communication is the foundation for a successful transition process to provide continuity and coordination of care. The nature of the communication required will depend upon the complexity and needs of the patient. An overview or synopsis, i.e., a medical passport will facilitate the transition. For most with a chronic condition, communication will need to be extensive and involved but easy to navigate. However, no matter the format of communication, it is imperative that the adult care provider be well versed on the patient's history and current status prior to seeing the patient. Having a high level of familiarity will help to foster a greater level of emotional comfort and trust for the patient and family.

An up-to-date medical summary that is portable and accessible is recommended for most transitioning patients. This summary should provide the pertinent information on the patient's current status, full diagnosis, current course of treatment, recent test results, and significant historical issues. For more medically complicated cases, a full medical notebook may be required. This could be the shared responsibility of the transferring physician and the transition coordinator as well as the patient and family.

A shared electronic medical record would be optimal. Currently, there are no electronic options for record sharing with physicians outside of the CCHMC system. Epic, CCHMC's electronic medical record system, includes a function called "Problem List" that may prove useful for Transition of Care purposes.

Recommendation: It is the Task Force's recommendation that all users be encouraged to keep the "Problem List" up-to-date and complete. Those without CCHMC privileges need to be provided with read-only viewing rights to the electronic patient record. Finally, efforts should be made to permit electronic record sharing with physicians outside of the CCHMC system.

In addition, an in-person meeting or phone consultation between the pediatric provider and the adult provider is highly recommended to convey the finer details of the patient's history and disease.

XIII. Template for Sub-Groups

The Task Force's goal is that all disease states or conditions will soon have a comprehensive Transition of Care plan for their patients. An appropriate leadership team with representatives from both the pediatric and adult care provider teams should be assembled to draft these plans. The following is a template to aid in the creation of those individualized plans.

NEEDS ASSESSMENT

Evaluate the current practices for transitioning care from the pediatric setting to the adult setting for the specific disease/condition.

- How many patients do you follow over the age of 18?
 - Is there an existing tracking mechanism to identify those approaching independence for medical care?
- If you don't transfer (all) patients to an adult care provider,
 - What happens to these patients after the age of 21?
 - What are the reasons you do not?
 - What are the barriers to transition?
- For patients that transfer,
 - To whom do you transfer?
 - What are the reasons for this selection(s)?
 - How do they transition?
 - Is there a well-documented process?
 - How many of these transfers are successful?
- Identify the adult providers and programs available to accept patients
- Consider your success(s) with transition of care
- Consider any failure(s) with transition of care
- Discuss concerns raised by the adult provider
- Discuss concerns raised by the pediatric provider
- Discuss concerns raised by the patient and family
- Discuss any potential collaborative research needs
- What is the projected need for the future, i.e. how many patients will be 18 years or older in the next year, next 5 years, next 10 years?

DEVELOP PHILOSOPHY

Considering the specific disease/condition, discuss the best way to transition patients.

- What does a successful transition process look like?
- Who owns the process?
- Is there a maximum age to accept new patients into the pediatric setting?
- What connotes maturity and ability to be transferred?
- If considering a shared or joint clinic, how long would patients remain in the transition clinic before transitioning to adult care?

TEAM

Consider who will create, direct, and coordinate plans for transitioning patients.

- Develop a leadership team to create a transition plan as well as to be the long-term oversight team.
- Decide how often and how the team will meet.
- Identify a list of appropriate sub-specialty adult providers, when available.
- Identify a list of appropriate primary care physicians.
- Define roles and responsibilities for a clinical coordinator for both the pediatric and adult settings.
- Identify transition coordinator(s) for both the pediatric and adult settings.
- Determine whether a provider needs to obtain privileges at another institution, e.g, UC Health or CCHMC.

TRANSITION PROCESSES

Develop a step-by-step process for transitioning patients.

- Create an appropriate plan to introduce and to foster a solid relationship with the adult care team.
- If obstacles were identified during needs assessment, what resources are required to address them?
- Create an appropriate model(s) for establishing familiarity with the adult facility, flow of care and processes.
- Create a communication plan to exchange patient information between each team member of the adult and pediatric care team including a template for a written (electronic) summary report.
- Develop a referral process for both the adult sub-specialty physician and the primary care physician.
- Identify a primary care physician for the transitioning patient.
- Develop appropriate support systems such as a peer-mentoring program for transitioning care.
- Create tools and plans to address financial aspects of care.
- Develop, if appropriate, a collaborative research plan.
- Develop a post-transfer follow-up and communication plan to ensure continued success and that patient is not “lost in transfer”.
- Identify appropriate outcome measurements and a system by which to track appropriate data.

EDUCATIONAL TOOLS AND COLLATERAL MATERIAL DEVELOPMENT

Create the support tools for transitioning patients. (Resources and sample tools to be provided.)

- Develop a template for individualized planning for the pediatric care team including
 - Age appropriate milestones and checklists
 - Form to assess patient readiness to assume self-care
 - Age appropriate counsel for patients on their disease/condition
- Develop a template for issues to be addressed by the adult care team including
 - What to do in case of after hours care needs, including differences between CCHMC and other Emergency Departments
 - Partnership expectations between the adult provider and patient
- Develop a Transition Package for patients/families including
 - Step-by-step transition plan
 - Checklist of age appropriate goals
 - Expectations of adult-centered care
 - Name and contact information for transition coordinator
 - Appropriate adult sub-specialty providers
 - Appropriate primary care physicians
 - Training opportunities or materials in skills such as communication, decision making, creative problem solving, assertiveness, self care, self determination and self advocacy
- Develop a Website including
 - List of support groups
 - Other transition resources

XIV. Selection of Sub-Groups

The Task Force's hope is that all disease states or conditions will soon have a specific Transition of Care plan for their patients. As an initial step, the Task Force's mission is to assist the content and program experts of 9 teams to develop a formal transition plan over the next 6 months. Based upon the following criteria, the Task Force discussed at length the best options for the initial sub-groups:

- Current Transition of Care practices including whether a program exists or not
- Size of patient population as derived from CCHMC's Decision Support Outpatient list of patients over the age of 21
- Assessment of need for a Transition of Care program
- Appropriate physician counterparts at UC Health
- Relative ease in which to create a plan

Based upon these criteria, the following diseases/conditions were selected as the initial groups to create a Transition of Care plan:

Adult Congenital Heart Disease
Cystic Fibrosis
Diabetes
Down's Syndrome and other Intellectual Disabilities
Inflammatory Bowel Disease
Kidney Transplant and Dialysis
Lupus
Sickle-Cell Disease
Spina Bifida

XV.Appendix

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