

STEPPING UP

DEVELOPING A HEALTH CARE TRANSITION PROGRAM

TO ADULT CARE

FOR PEDIATRIC SICKLE CELL DISEASE POPULATIONS





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Introduction

THIS GUIDE WILL ASSIST PROGRAMS in developing and establishing a transition program from pediatric to adult care for youth with chronic medical conditions. This manual should be utilized by both pediatric and adult medical providers, hospital systems, and community agencies. The overall purpose of this transition manual is to provide an overview of steps for a successful transition process rather than simply transferring patient care from one setting to another. The hope in producing this manual is to implement a transition process that encourages empowerment, advocacy skills, and communication abilities; thus, leading to decreased morbidity and mortality rates in young adults with chronic illnesses post-transition.

“The Goal of Life is to Grow”

Of course, teens notice how their body and lives are changing. As they continue to grow up, they also must begin taking control over managing their chronic medical condition more on their own. This big change is referred to as the **“TRANSITION TO ADULT CARE.”** It is just as important as high school graduation and also takes years to get ready. Just as teens have a list of things that must be completed to graduate from high school, there is a list of things teens with a chronic medical condition, such as sickle cell disease, must do to get ready for the **TRANSITION INTO ADULTHOOD AND ADULT MEDICAL CARE.**

Adolescents will begin taking the steps to get ready for the **TRANSITION** at the age of 13 and spend the next 6 to 8 years changing, growing, and learning so that they will be ready for the eventual **TRANSFER TO ADULT CARE.**





TRANSITION PROGRAM OVERVIEW

The Adolescent to Adult Sickle Cell Disease Transition Program, located at the Aflac Cancer and Blood Disorders Center – Children’s Healthcare of Atlanta, was modeled after the curriculum described by *Griffin and associates (2013)*, which utilizes a multidisciplinary, developmental, bio-psychosocial and ecological team approach to prepare patients with sickle cell disease for adult care. As children shift from a parental directed care practice to more autonomy, they will need a structured, planned, and guided program to help them develop the skills necessary for successful transition into an adult health system that is uniquely different and more fragmented than what they are used to.

This program involves several components that address transition challenges from the patient, provider and caregivers’ perspective and includes a component that engages the community and various ecological systems in the transition process.

MISSION

To enhance the medical lives and reduce mortality of transitioning young adults with health needs through a purposeful coordinated transition program.

VISION

To be the model for addressing the transition needs of young adults with special health care needs as they transition to adult care by improving specific health outcomes, targeting specific barriers to transition and involving close pediatric and adult provider collaboration to successfully bridge the medical needs of this population.

GOALS & OUTCOMES

The overall goal of this program is to increase successful transition in pediatric chronic disease populations. The expected outcomes of this program are to:

- INCREASE DISEASE KNOWLEDGE
- INCREASE ABILITY TO COMMUNICATE WITH MEDICAL PERSONNEL
- INCREASE AND IMPROVE INDEPENDENT SELF-CARE PRACTICES
- INCREASE KNOWLEDGE ABOUT HEALTHCARE SYSTEMS AND INSURANCE NEEDS
- INCREASE ABILITY TO NAVIGATE COMPLEX ADULTHOOD CARE SYSTEMS
- INCREASE COMPETENCY WITH FUTURE EDUCATIONAL AND CAREER PLANNING
- INCREASE PSYCHOSOCIAL FUNCTIONING WITHIN THE COMMUNITY

TRANSITION PROGRAM OVERVIEW

BACKGROUND & HISTORY

In 2006, the “Sickle Cell Disease – Age Based Curriculum” (Griffin et al., 2013, p.250) was developed as a collaborative between a pediatric hospital system and an adult sickle cell medical program. This program was developed from an initial medical and community needs assessment with vocational rehabilitation services involvement utilizing the format of semi formal focus groups and round table discussions. Based on the article written by Griffin and associates (2013) titled “Applying a Developmental-Ecological Framework to Sickle Cell Disease Transition,” this guide describes the suggested format for a multidisciplinary developmental based transition program described below:

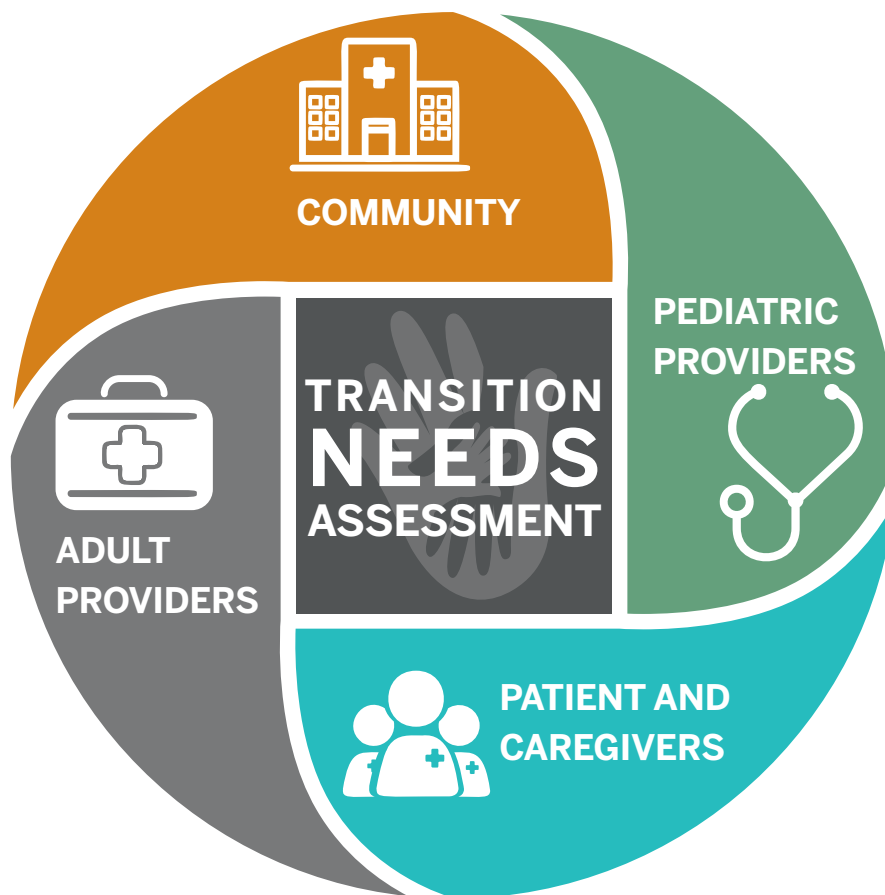
The Sickle Cell Disease – Age Based Curriculum (SCD-ABC) Transition program’s framework begins at birth with the parent/caregiver and spans throughout a child’s development into young adulthood. This program involves a multidisciplinary team approach with collaboration from pediatric and adult medical providers, family and peers, social services, the community, and adult mentors living with SCD. Taking into account the literature and information garnered from semi-structured focus group interviews conducted within the metro Atlanta SCD community, a multi-component, interdisciplinary transition program for adolescents/young adults (AYAs) with SCD was designed. This program focused on developing transition readiness from the time of diagnosis. Several methods were utilized to provide disease specific education, initially targeting the parents/caregivers. Psychoeducation about SCD was repeatedly reinforced with the family, and over time began to include the developing child in an age-appropriate manner. The SCD-ABC Transition program utilized the basic framework of the developmental transition model, as proposed by While et al. (2004), and concurrently incorporated the biosocial ecological transition model, as originally proposed by Bronfenbrenner and recently recommended by Treadwell et al (Bronfenbrenner & Ceci, 1994; Treadwell et al., 2011). The AYA with SCD was encouraged to take on increasing responsibility for their own health and self-care, while parental/caregiver responsibility decreased gradually over time, in order to foster independence within their environment and larger systems.

The program components involved active engagement between adult and pediatric providers, community based organization, representatives from governmental agencies including vocational rehabilitation and social services, public health representatives and partners from both the pediatric and adult hospital systems.



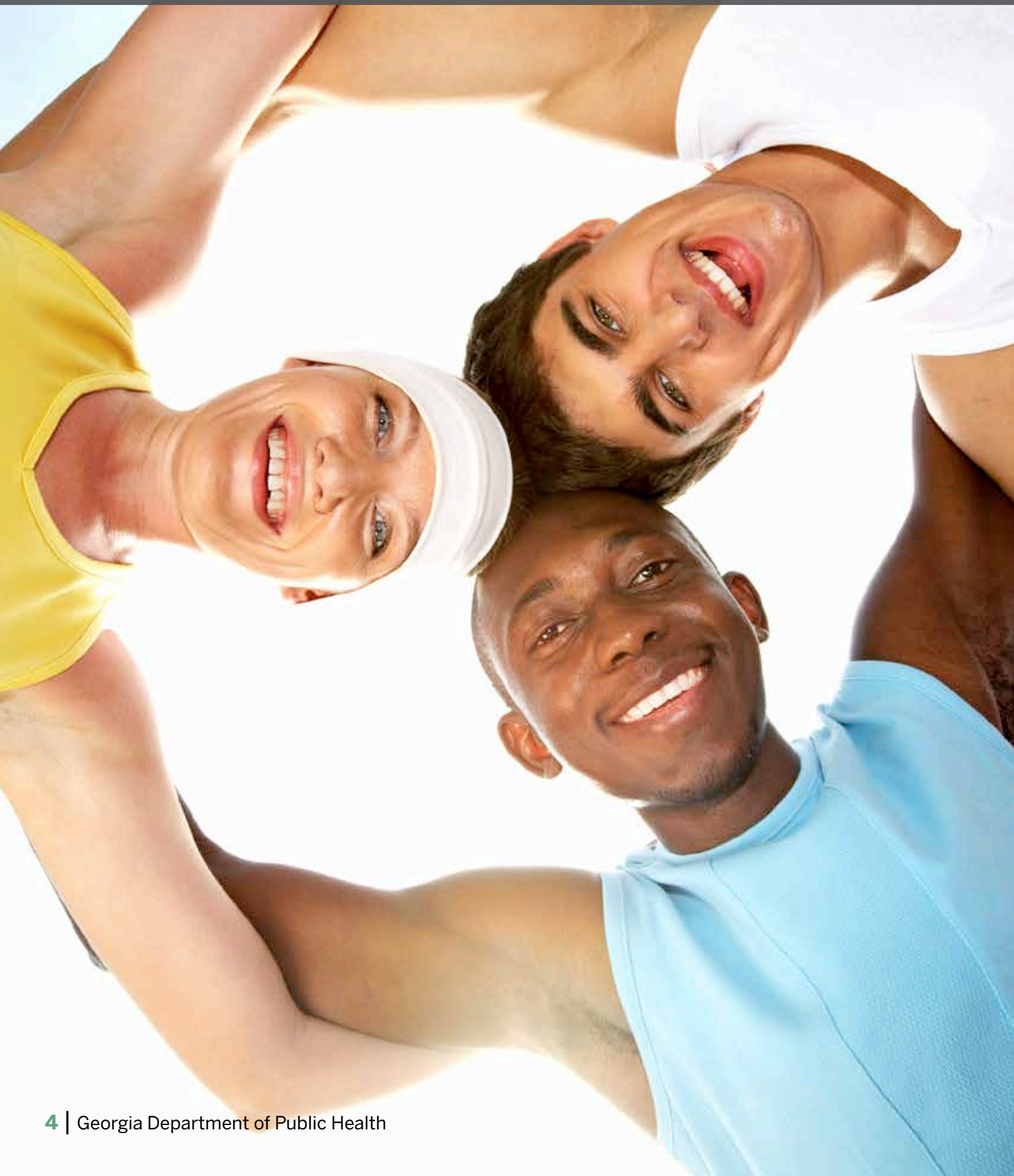
TRANSITION PROGRAM EARLY STAGES: ENGAGING STAKEHOLDERS

Stakeholders must first be identified in the pediatric and adult settings, as well as the community (i.e., patients, parents, agencies, etc.). These stakeholders should then be contacted and invited to meetings for discussions about the barriers to transition of care. Patient (both adolescent and adults) and parental involvement is critical for the pre-planning stages to fully understand the needs of the population. Details of this process have been referenced in Griffin and associates (2013).



Considerations should be made for addressing the following:

- IDENTIFYING PARTNERS AND STAKEHOLDERS
- ESTABLISHING COLLABORATIONS
- DEALING WITH FEELINGS AND ATTITUDES ABOUT TRANSITION
- GAINING SUPPORT FROM ADMINISTRATIVE, GOVERNMENTAL AND ACADEMIC AUTHORITIES





TRANSITION PROGRAM OPERATIONS

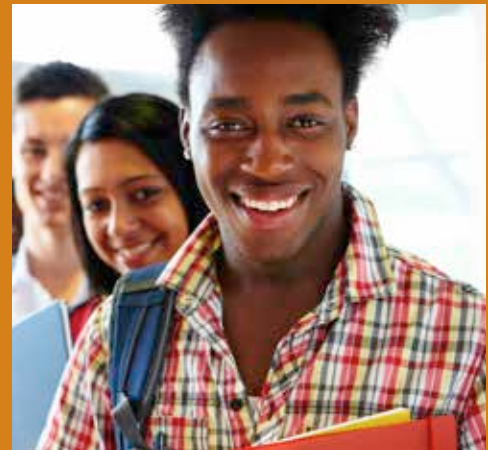
The Adolescent to Adult Sickle Cell Disease Transition Program is comprehensive and offered at all three health campuses of Children's Healthcare of Atlanta (CHOA). The program provides monthly teen clinics and an annual Sickle Cell Education Day for patients' ages 13 to 16 years of age. These clinics provide patients' and their families the opportunity to test their knowledge of sickle cell disease and discuss steps needed to move to adult care. For patients ages 17 to 18, quarterly clinics are offered and information on topics such as finances, health insurance coverage, and college independence are provided. Patients and their families have the opportunity to meet their adult providers and former program participants. Graduates of the sickle cell program are honored at the annual Sickle Cell Education Day. This program model has improved the transition to adult care for many sickle cell patients served by CHOA.

Adolescent Sickle Cell Transition Clinics

PARTICIPANTS: Sickle Cell patients age 13 – 18; their parents, and healthcare providers. Generally, patients attend the transition clinic once per year, but transition goals are reviewed by providers at each regular clinic visit.

CLINIC

START-UP: Triage, Education Group for teenagers (Led by Psychology &/or Child/Life); Support Group for parents (Led by Social Work). Sickle Cell Knowledge Quiz administered to all patients.



STRUCTURED INTERVIEW: 1. Adherence & Medication knowledge (**Nursing**): Number of medications that patient can name; 2. General Healthcare & Discussion of knowledge quiz results (**Pediatric Provider**): What is patient doing to stay healthy; 3. Mental Health and Risk Assessment (**Psychology**): Has patient used recreational drugs in the last 3 months; 4. General Assessment of Social/School Functioning and Health Insurance Knowledge (**Social Work**): Is patient receiving special services at school? All data is entered into an electronic medical record flow sheet by respective provider. 15 to 18 year olds are interviewed alone; 13 & 14 year olds may be interviewed with parents present.

WRAP-UP: Healthcare providers discuss data collected from the structured interview and assign homework from the 18 Steps to 18, which is given to the parent and patient along with discharge instructions from the clinic. Homework assignments are monitored whenever patient returns to clinic.



TRANSITION PROGRAM OPERATIONS

STAFFING MODEL

(See “Welcome” handout in Appendix A)

The staff involved in the transition program includes the entire multidisciplinary team from the pediatric setting, adult providers, and community agencies.

PROGRAM STAFF INCLUDES:

ADULT PROVIDERS & STAFF			
ROLES	ADULT PHYSICIANS	TRANSITION LIASON FOR ADULT CARE	ADMINISTRATIVE STAFF
Participate in needs assessment and program planning from inception	YES	YES	NO
Coordinate quarterly Transition events	NO	YES	NO
Attend quarterly Transition events	YES	YES	NO
Briefly orient patient to adult care and expectations from adult provider perspective	YES	NO	NO
Attend the transition graduation rights of passage event at the annual Patient Education Day	YES	YES	NO
Provide tour of adult medical facilities	NO	YES	NO
Identify and refer potential adult mentors to pediatric program	NO	YES	NO
Secure location for quarterly Transition Events located at the Adult medical facility	NO	NO	YES

PEDIATRIC PROVIDERS & STAFF

ROLES	PEDIATRICIAN	ADVANCED PRACTICE PROVIDER	PSYCHOLOGIST	SOCIAL WORKER
Participate in needs assessment & program planning from inception	YES	YES	YES	YES
Oversee preparation for all Transition events <ul style="list-style-type: none"> • Order lunch for Transition Events • Coordinate Parking • Coordinate securing venues Provide Transition Event marketing materials Recruit patients to attend Transition Events Coordinate and facilitate agenda for all regular transition team meetings	NO	NO	NO	NO
Contact, invite, and schedule patients for monthly Teen Clinic and quarterly Transition events	NO	NO	NO	NO
Attend monthly Teen Clinics	YES	YES	YES	YES
Attend Quarterly Transition Events	YES	YES	YES	YES
Lead Teen Transition Preparation Groups at monthly Teen Clinics	NO	NO	YES	NO
Co-facilitate Teen Transition Preparation Groups at monthly Teen Clinics	NO	NO	NO	NO
Lead Parents Group during monthly Teen Clinics	NO	NO	NO	YES
Provide medical triage (i.e., BP, blood work, weight, etc.) prior to patients attending monthly Teen Clinics	NO	NO	NO	NO
Assist with triage and physical exam process during Teen Clinics	NO	NO	NO	NO
Provide regular medical billing services for the Physical Examination held during monthly Teen Clinics	NO	NO	NO	NO
Guide patients and parents through the difference in care from pediatric to adult care from pediatric provider perspective	YES	NO	NO	NO
Provide education on the psychological & developmental process of transition of medical care from the parent to the patient	NO	NO	YES	NO
Co-lead parent educational support groups at Transition Events	YES	NO	NO	NO

	CHILD LIFE SPECIALIST	NURSE	TRANSITION COORDINATOR	PATIENT CARE TECHNICIAN	SCHEDULER	MEDICAL BILLING	ADMINISTRATIVE STAFF
	YES	YES	YES	NO	NO	NO	NO
	NO	NO	YES	NO	NO	NO	WNO
	NO	NO	NO	NO	YES	NO	NO
	YES	YES	YES	NO	NO	NO	NO
	NO	NO	YES	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	YES	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	YES	NO	NO	NO
	NO	YES	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	YES	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO

PEDIATRIC PROVIDERS & STAFF, CONTINUED

ROLES	PEDIATRICIAN	ADVANCED PRACTICE PROVIDER	PSYCHOLOGIST	SOCIAL WORKER
Co-lead Gender-Specific groups & address sexual health questions	NO	YES	NO	NO
Facilitate Gender-Specific groups & address needs/barriers related to transition	NO	NO	NO	YES
Facilitate Gender-Specific groups & address psychosocial concerns related to transition	NO	NO	YES	NO
Provide education to patients and parents about the transition process	YES	NO	NO	NO
Coordinate and co-facilitate adolescent program at Education Day event	NO	NO	YES	YES
Coordinate and lead children's program at Education Day event	NO	NO	NO	NO
Attend transition graduation rights of passage event at the annual Patient Education Day	YES	YES	YES	YES
Attend regular Transition team meetings	YES	YES	YES	YES
Provide education related to financial & insurance related needs	NO	NO	NO	YES
Provide assistance with all administrative duties related to Transition Program (i.e. meeting locations, emails, ordering food for transition related events, etc.)	NO	NO	NO	NO
Coordinate with Adult care administrative staff on preparing for Transition Event	NO	NO	NO	NO
Maintain database of all adolescents prior to and after transition for Quality Improvement	NO	NO	NO	NO
Recruit, train, coordinate, and maintain active mentor list	NO	NO	NO	NO

	CHILD LIFE SPECIALIST	NURSE	TRANSITION COORDINATOR	PATIENT CARE TECHNICIAN	SCHEDULER	MEDICAL BILLING	ADMINISTRATIVE STAFF
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	YES	NO	NO	NO	NO	NO	NO
	YES	YES	YES	NO	NO	NO	NO
	YES	YES	YES	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	NO
	NO	NO	NO	NO	NO	NO	YES
	NO	NO	NO	NO	NO	NO	YES
	NO	NO	YES	NO	NO	NO	NO
	NO	NO	YES	NO	NO	NO	NO

TRANSITION PROGRAM OPERATIONS

COMMUNITY PARTNERS			
ROLES	MEDICAL DISEASE SPECIFIC FOUNDATION STAFF	VOCATIONAL REHABILITATION SERVICES REPRESENTATIVES	ADULT MENTORS WITH SAME CHRONIC MEDICAL CONDITIONS
Participate in needs assessment and program planning from inception	YES	YES	YES
Provide information on community resources	YES	YES	NO
Attend Quarterly Transition events	YES	YES	YES
Recruit patients to attend transition events	YES	NO	NO
Attend the transition graduation rights of passage event at the annual Patient Education Day	YES	NO	YES
Provide information on the transition process from their own personal experiences	NO	NO	YES
Participate in the annual Education Day adolescent program for education & support	NO	NO	YES
Provide on-going peer support and mentoring activities throughout the year	NO	NO	YES



TRANSITION PROGRAM OPERATIONS

TRANSITION CLINIC SET-UP

- **AGE SPECIFIC - EACH CLINIC IS BASED ON AGE CRITERIA (I.E., 13-15 YEARS OLD, AND 16-18 YEARS OLD);**
- **GENDER BASED GROUPS - TEEN GROUPS ARE GENDER BASED TO DISCUSS RELEVANT ISSUES THAT PERTAIN TO HEALTH FOR FEMALE AND MALE PATIENTS;**
- **PARENT SUPPORT GROUPS - TO PREPARE PARENTS FOR THE TRANSITION PROCESS. PARENTS GROUPS ARE LED BY A MEMBER OF THE PSYCHOSOCIAL TEAM (I.E., SOCIAL WORK, PSYCHOLOGY, CHILD LIFE SPECIALIST) TO PROVIDE EDUCATION TO PARENTS ABOUT WAYS TO INCREASE AUTONOMY FOR THEIR CHILD;**
- **INDEPENDENT CLINIC VISITS – TEENS ATTEND A CLINIC VISIT WITH PARENTS IN WAITING ROOM AREA TO INCREASE AUTONOMY.**

PATIENT REGISTRY

A program scheduler, along with guidance from the transition coordinator and medical team, will identify appropriate patients for the transition clinics. Once identified, the patients are then invited to attend the appropriate transition clinic based on age. Families are informed that lunch will be provided in advance.

CLINIC FORMS

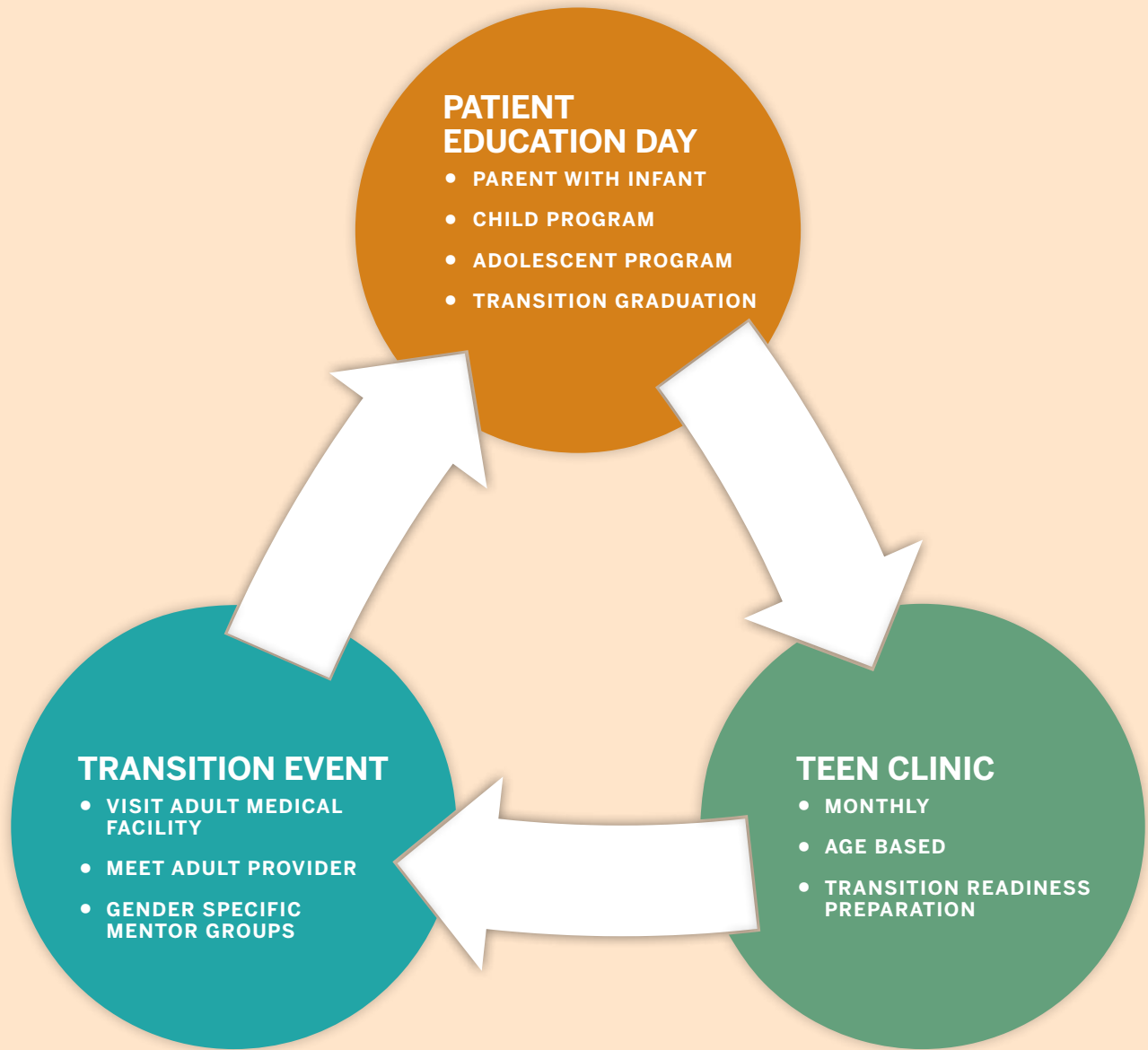
Each Teen Clinic includes a structured interview with the multidisciplinary team. Each provider (physician or advanced practice provider) on the team asks medically related questions. The nursing staff asks questions related to review of systems. The Psychologist asks about psychological functioning. The social worker asks about social functioning and school related needs (See “Structured Interview Questions for Clinic” in Appendix B).

QUALITY IMPROVEMENT

Patient and parent/caregiver satisfaction surveys are provided at the Transition Events. The transition coordinator is responsible, along with the entire transition team, to maintain a database. This database tallies information about each adolescent. The information included is to assess the success of the transition program and to ensure quality improvements each year. The information in the database includes:

- 1. ACTUAL NUMBER OF PATIENTS WHO TRANSITION TO ADULT SERVICES;**
- 2. TRACKS WHETHER THEY MAKE/ATTEND FIRST APPOINTMENT WITH ADULT PROVIDER;**
- 3. TRACK THAT THEY CONTINUE TO KEEP APPOINTMENTS WITH ADULT PROVIDER FOLLOWING FIRST 6 MONTHS OF TRANSITION.**

TRANSITION PROGRAM ACTIVITIES







TRANSITION PROGRAM REFERRAL AND ENROLLMENT PROCESS

All patients and families are invited to attend an annual sickle cell education day, which informs them about the transition policy and also gives them an opportunity to talk with our transition team.

Our team will review all patients age 12 for enrollment into our Teen Clinics at age 13. All 16 year old patients within the program will be reviewed and referred to our transition event upon turning 17.

● Referral Process

● Pediatric medical team refers patients to the Transition program:

- PATIENT EDUCATION DAY (ANNUALLY)
- TEEN CLINICS (MONTHLY)
- TRANSITION EVENT (QUARTERLY)

● Participation Criteria

- PATIENT EDUCATION DAY (ANNUALLY)
 - PARENTS MAY ATTEND BEGINNING WITH CHILDREN AT BIRTH
 - CHILD PROGRAM
 - AGES 4 TO 7 YEARS
 - AGES 8 TO 12 YEARS
 - ADOLESCENT PROGRAM
 - AGES 13 YEARS AND OLDER
- TEEN CLINICS (MONTHLY ALTERNATIVE AGE-BASED CLINICS)
 - AGES 13 TO 15 YEARS (EVERY OTHER MONTH)
 - AGES 16 YEARS AND OLDER (EVERY OTHER MONTH)
 - PARENT PARTICIPATION IS EXPECTED.
- TRANSITION EVENT (QUARTERLY)
 - AGES 17 YEARS AND OLDER
 - PARENT PARTICIPATION IS EXPECTED.

● Scheduling

- EDUCATION DAY
 - FAMILIES CALL IN TO RSVP FOR THE EVENT ONE MONTH IN ADVANCE
- TEEN CLINIC
 - ALL APPOINTMENTS ARE SCHEDULED AS A REGULAR PHYSICAL EXAM SO THEY WILL NOT BE REQUIRED TO COME IN AGAIN FOR A REGULAR CLINIC VISIT
 - FOLLOW REGULAR CLINIC SCHEDULING PROCEDURES FOR ALL TEEN CLINICS

TRANSITION PROGRAM REFERRAL AND ENROLLMENT PROCESS

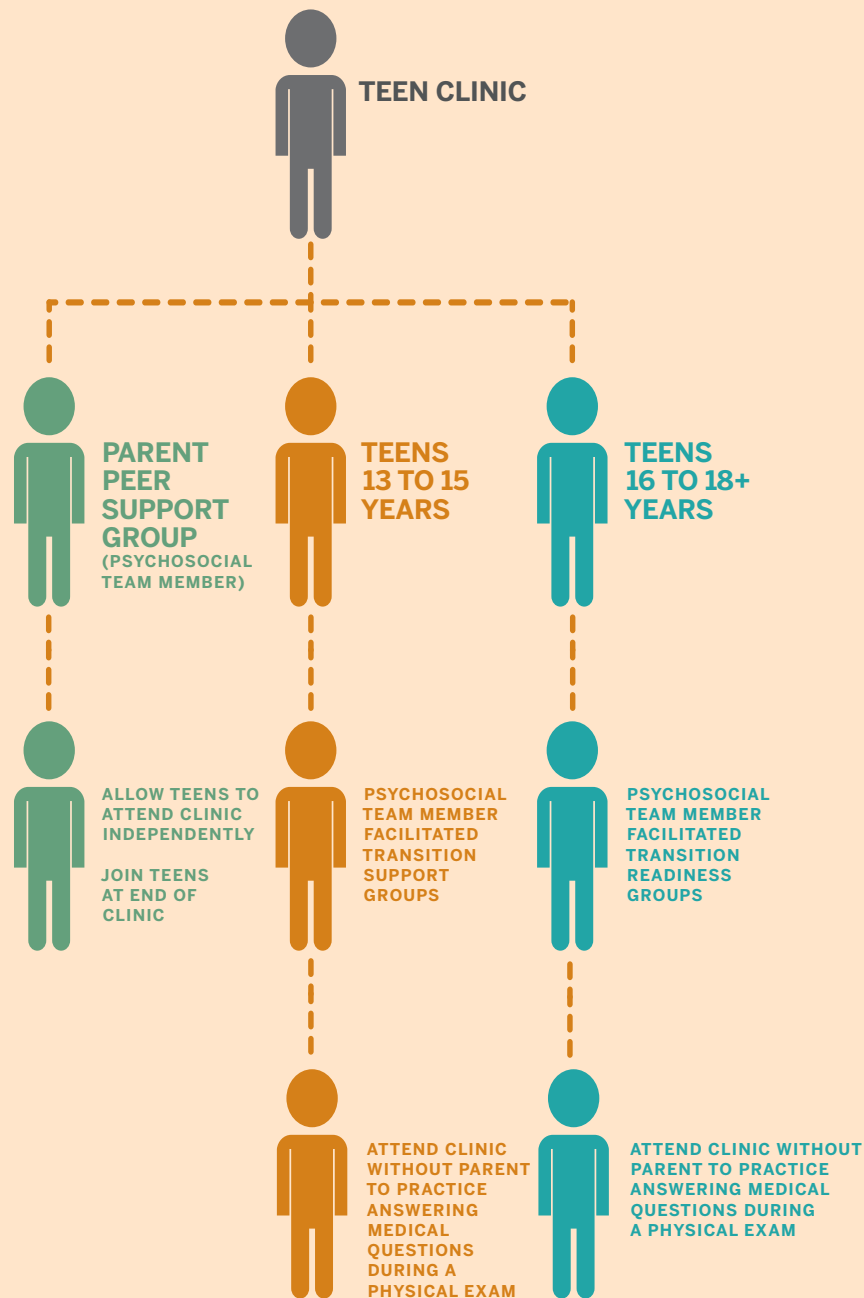
- **TRANSITION EVENT**
 - **PEDIATRIC TEAM SUBMITS NAMES TO TRANSITION COORDINATOR**
 - **FAMILIES ARE CONTACTED BY SOCIAL WORK OR TRANSITION COORDINATOR TO CONFIRM ATTENDANCE AND SET UP TRANSPORTATION OR PARKING**
- **Exclusion Criteria**
 - **INDIVIDUALS WHO HAVE SELF TRANSITIONED OR OLDER THAN 21 YEARS OLD**
 - **18 YEAR OLDS AND ABOVE THAT HAVE NOT BEEN SEEN IN PEDIATRIC CLINIC FOR OVER A YEAR**
 - **18 YEAR OLDS AND OLDER SEEN AT ANOTHER FACILITY**



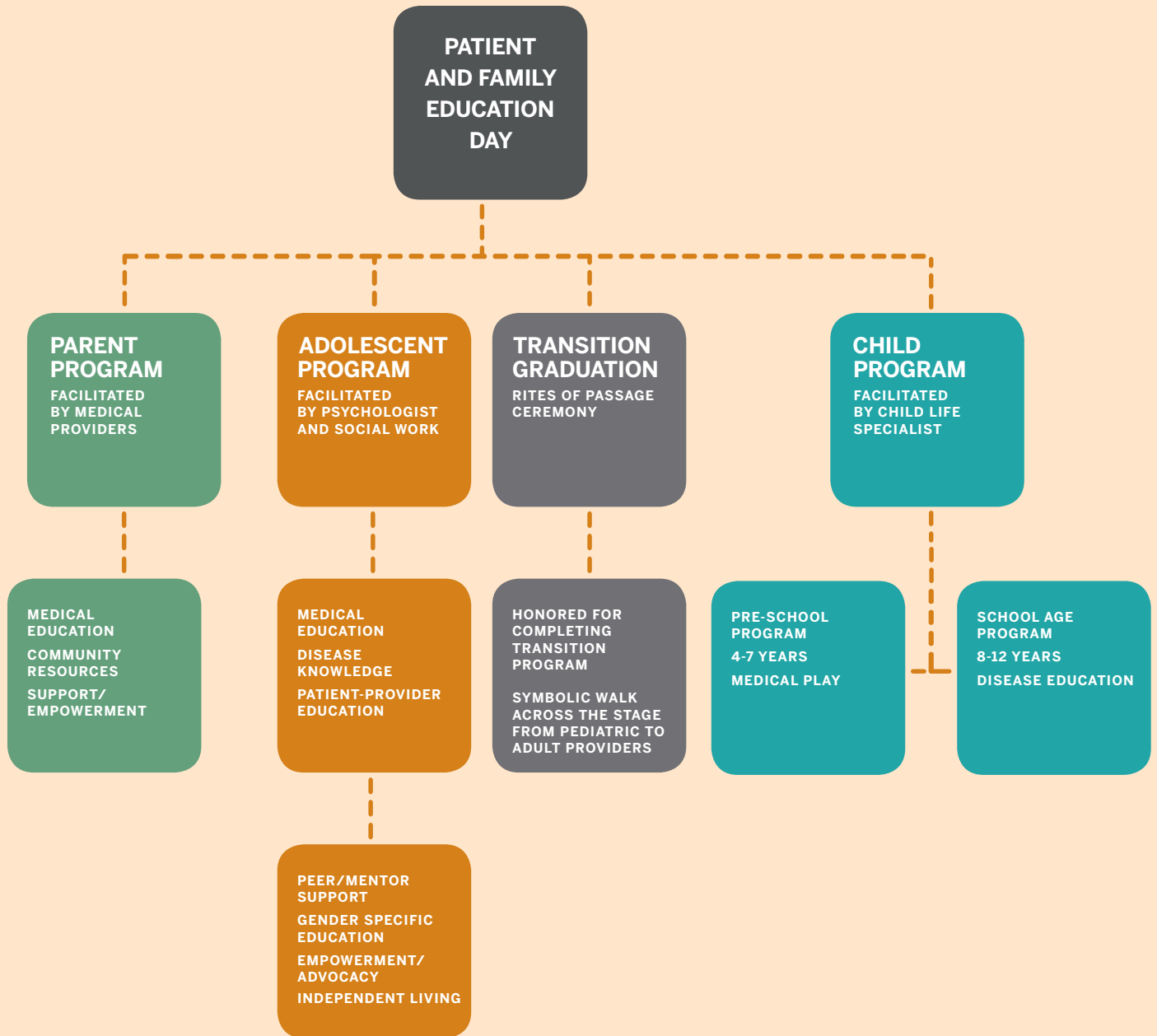


TRANSITION PROGRAM SERVICES

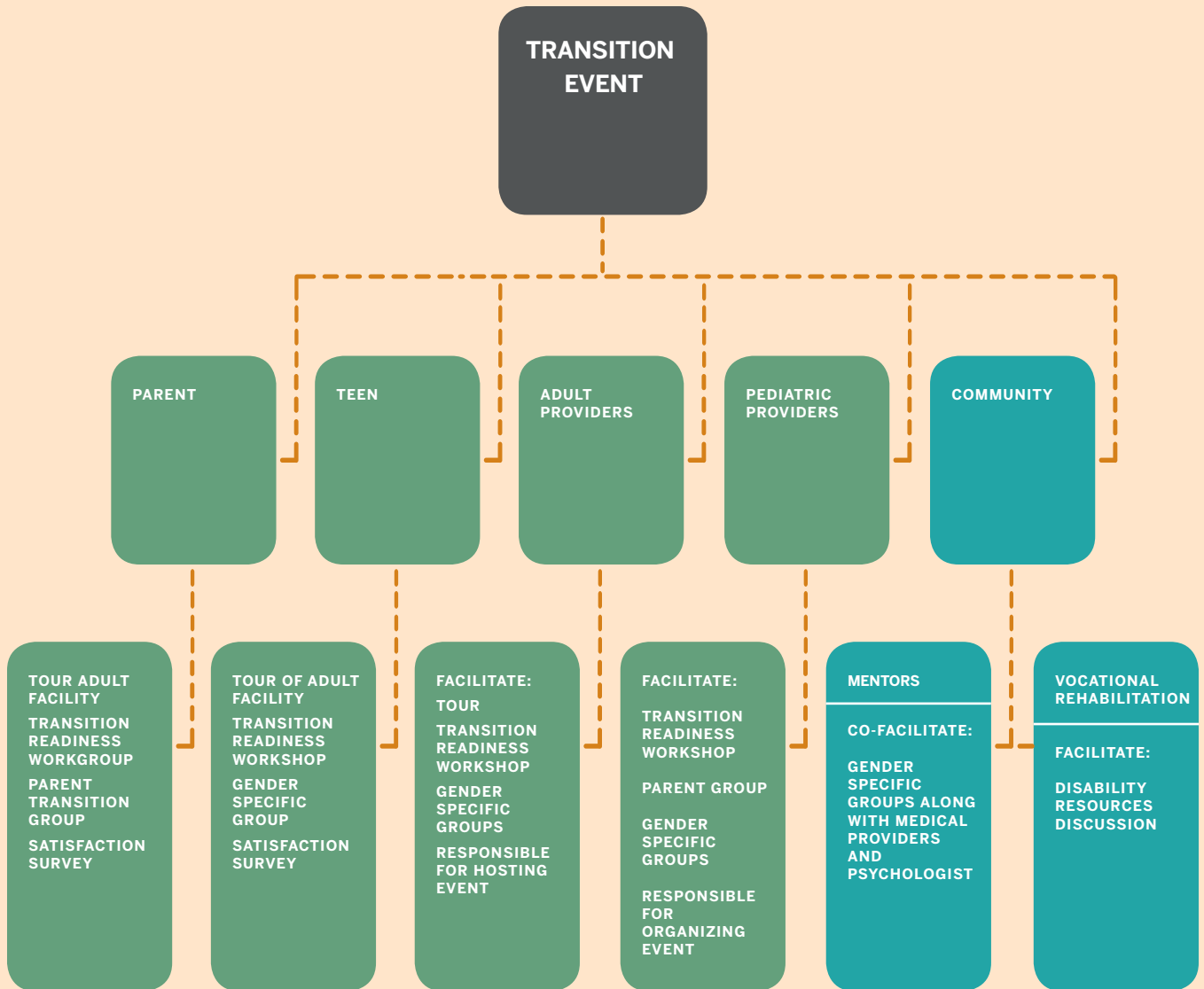
Our team will review all patients age 12 for enrollment into our Teen Clinics at age 13. We offer two aged based clinics for our Teens: one for our younger teens ages 13 to 15 and another for our older teens ages 16 to 18+.



TRANSITION PROGRAM SERVICES



TRANSITION PROGRAM SERVICES







TRANSITION PROGRAM AND VOLUNTEER INVOLVEMENT

Mentors for these programs help patients acknowledge feelings, explore options, make good decisions, and think with a broader perspective because they have “been there” and have first hand experiences. As a role model they are in the position to demonstrate learned skills such as talking with their health care provider, problem solving, managing their disease, coping skills and information on ways to reduce stress. While the mentor will be glad to share his own experience with the patient, the mentor is there to listen and support.

EDUCATION DAY

- Volunteers are recruited through the Pediatric Hospital’s Volunteer Services to staff the event
- Adult mentors attend this event

TEEN CLINIC

- Psychology and social work trainees assist with the supervision of the Licensed Psychologist and Licensed Clinical Social Worker or Licensed Medical Social Worker
- Adult Mentors attend this event

TRANSITION EVENT

- Adult Mentors attend this event

MENTOR INVOLVEMENT

- (See MENTOR Section in Appendix E)

INTERPRETERS/TRANSLATORS

- Preplanning requires the scheduling of interpreters when necessary prior to any scheduled event once a family is identified as needing these services



Transition Activities Program Sample Tools

1. TEEN CLINICS

A. 'WELCOME' HANDOUT

Welcome to the **Aflac Sickle Cell Adolescent Transition Clinic**. As you start the journey toward adult care, our healthcare team is happy to work with you.

- Our **front desk staff** will gladly check you and your parents into our clinic.
- Next our **medical technicians** will get you ready to meet with our clinic staff.
- You will then meet with our **psychology or child/life team** in a group for teenagers to talk about the ups and downs of being a teenager, but also about how to care for your sickle cell disease. At the same time, your parents will meet in a group with our social work team to learn about how best to help teenagers work on getting ready for the TRANSITION.
- After you and your parents finish group, you will return to a clinic room alone if you are 13 years of age or older. Our **nursing staff** will finish your intake, test your knowledge about taking your medication, and give you our sickle cell knowledge quiz to complete.
- Our **medical providers** will review the results of your knowledge quiz with you and teach you about many of the things you will need to learn to care for your sickle cell disease more on your own over time.
- Our **psychology staff** will check on typical emotional and behavioral concerns that teenagers usually experience.
- Our **social worker team** will explore experiences and interests common to all teenagers (i.e., school, clubs, social groups, etc.)

Clinic ends after your **medical provider reviews** with you and your parent the first steps you will need to complete to move toward the TRANSITION-- Homework on our 18 steps to age 18 form along with your clinic discharge instructions. You will also complete satisfaction surveys to assist us in improving our transition services.

Now that you know a little about us, let's get started!



B. TEEN CLINIC AGENDA (YOUTH AGES 13 - 18+)

1. Triage
2. Teen Group/Parent Group
3. Meet with Providers
 - Nursing
 - Medical Provider/Physician
 - Mental Health Provider(s)
4. Complete Satisfaction/Feedback Surveys
5. Provider to review goals/homework from 18 Steps to age 18
6. Goals to be completed before age 18

Please reference Table 2 “18 Steps to 18” located in the following article:

Griffin, A., Gilleland, J., Cummings, L., Johnson, A., Brailey, T.; New, T.; Eckman, J.; and Osunkwo, I. (2013). Applying a Developmental-Ecological Framework to Sickle Cell Disease Transition. Clinical Practice in Pediatric Psychology, 1 (3) 250-263.



TRANSITION ACTIVITIES PROGRAM SAMPLE TOOLS



C. SICKLE CELL TEEN CLINIC GROUP TREATMENT AGENDA

1. Arrival to Clinic & Triage
2. Parents go to their group
3. Teens Mingle, Introductions, & Pizza
4. Rationale for Group (2 min)
 - A. "Do you know why you are here?" Group leaders state it is for transition preparation
 - B. "Can anyone define transition?" Collaborative definition.
5. Confidentiality (2 min max)
 - A. "Everything discussed in this group will be kept confidential or secret unless someone reveals something dangerous, like if someone were being abused or at risk for hurting themselves or others. If this happens, we will talk privately about that."
6. Pass out (*Novartis 2010*) Be Educated. Be Empowered. Be Prepared. Be Sickle Smart: Get ready to graduate to adult care.
7. Orient to Book and Passport
 - A. There are stories in here about transition for sickle cell. Show the 2 pages of "Gather All your Medical information" page in the center of the Passport, which they should bring in to their providers to complete.
8. Transition/Future Story/Write Your Own Story (p. 7)
 - A. Go through booklet and discuss each answers/response. Have them write out at least a response to the third question about "What my life will look like in 5 years."
9. Be Empowered (pp. 14-15)
 - A. If time, read 1-6. If less time, read 1-3 and 6. Depending on group (e.g., age, discussion) select others.
10. Flex your Knowledge (p. 16)
 - A. Read the story aloud and lead discussion on response to question.
11. SCD, Transitioning, and Me/Write Your Own Story (p. 17)
 - A. Identify 1 specific and measurable transition goal (write on p. 17).
12. Send Teens to Clinic Rooms
 - A. After Clinic Providers have seen teens, reunite with parents
 - B. Team encourages teen to inform parent about their goal(s)



D. PARENT GROUP AGENDA

1. Parents go to their group
2. Parents Mingle, Introductions, & Pizza
3. Rational
 - A. Define goals of parents and their teams to help with the transition
 - B. Share their opinion of their children's readiness for transition to independence
 - C. Parents coping and launching of a child with a chronic illness like sickle cell.
4. Group Work
 - A. Share article "Letting Go So They Can Grow." 2
 - B. Celebrate your parenting thus far by highlighting your successes & struggles.
 - C. Prepare their children for life's mistakes, not prevent them.
 - D. Treat their children as if they are already the person they're capable of becoming.
 - E. Let themselves "off the hook" by giving themselves credit for being good parents.
5. Closing
 - A. Introduction of goal for next session: Giving more responsibility to the teen
 - B. Examining personal goals
6. Follow-up Sessions
 - A. Report on teen goal of greater healthcare independence
 - B. Report on parent goal of setting and achieving personal goals.



2. TRANSITION EVENT

A. 17 YEAR OLDS CLINIC DAY AGENDA

As one of your 18 Steps to Age 18, you are asked at 17 to make arrangements to attend one of our Grady Clinics in order that you may see what an adult program looks like.

Sickle Cell: Transition from Pediatric to Adult Care

For Sickle Cell Patients and Families at the 3-Campuses: Scottish Rite, Egleston, and Hughes Spalding

WHEN: Friday, February 8, 2013 at 9:30am

LOCATION: Woodruff Research Extension Building
Basement Conference Room B-002
46 Armstrong Street SE

The building is adjacent to Grady (emergency ambulance side), between Jesse Hill Jr. Drive and Piedmont Road.

NOTE: The Woodruff Research Extension Building is a secured building. Use the phone located near the front door of the building to call 8-1350. The number is also listed on the wall directory.

PARTICIPANTS

James Eckman, M.D.	Pat Waters, RN	Linda J. Williams, M.S.W.
Tonya Brailey, L.C.S.W.	Ify Osunkwo, M.D., M.P.H.	Tamara New, M.D.
Anya Griffin, Ph.D.	Emily Rudd, M.S.W	Eldrida Randall, CRA
Enid Broyard, FNP	Courtney Springman, PNP	

AGENDA

9:30am Arrival in the Lobby of Hughes Spalding Information Desk

10 a.m. – 11 a.m. Welcome/Virtual Tour of Grady

LIFE PLANNING

11 a.m. – 11:40 Financial Planning
Emily Rudd, Tonya Brailey, & Linda Williams

Noon – 1 p.m. “Girl Talk” and “Guy Talk”

OPEN DISCUSSION

1 – 2 p.m. Teens: Sickle Cell’s Top Ten List, Panel
2 – 2:30 p.m. Tour of Grady, Eldrida Randall

TRANSITION ACTIVITIES PROGRAM SAMPLE TOOLS



B. SICKLE CELL COMPREHENSIVE TRANSITION EVENT CHECKLIST

- ✓ Update Sickle Cell Transition Flyer
- ✓ Parent and Teenager Satisfaction Questionnaires
- ✓ Zone Space for Transition Clinic
- ✓ Follow up with Patient Volunteers (Guy, Girl, Parent)
- ✓ Transportation to and from Event
- ✓ Parking on the day of event at venue
- ✓ Catering for event
- ✓ Adult Hematologist for introduction to adult clinic
- ✓ Pediatric Hematologist for commandments of sickle cell



3. PATIENT EDUCATION DAY

A. GRADUATION

Congratulations on your upcoming Transition to Adult Care! We in the Aflac Sickle Cell Adolescent Transition Program are very proud of all you have done over the years to get ready. We are most happy to have had the chance to work with you and your family to get ready for this very important event. We would like to formally recognize your accomplishments at our Annual Sickle Cell Education Graduation Event. As when you finished high school, we would like to celebrate with you and your family as we give you a certificate and a small gift:





Transition Readiness Assessment Tools (Structured Interviews for Clinic)

1. NURSING QUESTIONS
2. MEDICAL PROVIDER QUESTIONS
3. MENTAL HEALTH PROVIDER QUESTIONS
4. NON-MENTAL HEALTH PROVIDER QUESTIONS

In this section, you will find the questions that are asked of the patient by different providers to assist in assessing their transition readiness.



TRANSITION READINESS ASSESSMENT TOOLS



1. NURSING QUESTIONS:

1. Does patient know how to contact patient's primary doctor? Yes No
2. Does patient have the number for the clinic? Yes No
Lab? Yes No
Pharmacy? Yes No
3. Number of medications that patient is taking? _____
4. Number of medications that patient can name? _____
5. Number of medications for which patient knows dose and frequency? _____
6. Number of medication that patient knows indication for? _____
7. Does patient know where to get prescriptions refilled? Yes No
8. Does patient call in own refills? Yes No
9. Does patient call sickle cell center when new prescription refills are needed? Yes No
10. Who takes primary responsibility for making sure meds are taken?
Patient Other (Please list) _____
11. Where does patient keep medications organized? _____
12. Does patient report missing doses of medication in last 7 days? Yes No
If yes, how many doses were missed? * _____
13. Does patient report being late taking medications in the last 7 days? Yes No
If yes, number of hours late? * _____
14. When does patient miss taking your meds? _____

15. What are reasons for missing medications? _____

16. Who reminds patient to take medicines? _____

17. Does patient have trouble taking medicines? Yes No
18. Does the patient understand the importance of staying hydrated? Yes No
19. Eating a balanced diet? Yes No
20. Dressing appropriately for weather conditions? Yes No



2. MEDICAL PROVIDER/PHYSICIAN QUESTIONS

1. Does patient understand what sickle cell disease is? Yes No
2. Is patient having any physical concerns? Yes No
3. What is patient doing to stay healthy? _____

4. Any general health problems Yes No
5. Review of labs, discuss baseline hemoglobin, retic, and importance of compliance.
Can patient explain need for and benefits of regular clinic visits? Yes No
Regular labwork? Yes No
6. Does patient understand why we order specific tests eg neuropsychology eval,
MRI/MRA, CXR, Abdominal U/S, TCD, pelvic XRay, ECHO, Urine test,
Eye exam? Dental exam, Audiogram, Ferritin?..... Yes No
7. What complications can sickle disease cause aside from pain? _____

8. What complications has patient had: ACS, CVA, Asthma, Pulmonary hypertension, etc?
Other (Please list) _____
9. How do you treat your pain? _____

10. How will you cope with pain in college/away from home?

11. Does your school have a student health center, do you know where the closest
ED to campus is located? Yes No



3. MENTAL HEALTH QUESTIONS TO BE ASKED BY A MENTAL HEALTH PROVIDER

1. Is there a stressful situation at home? Yes No
School? Yes No
2. Has patient smoked tobacco products in the last 3 months? Yes No
If yes, number per day? _____ Week? _____ Month? _____
3. Has patient had alcohol in the last 3 months? Yes No
4. If yes, how many drinks per day? _____ Week? _____ Month? _____
5. Has patient used recreational drugs in the last 3 months? Yes No
If yes what drugs and how often? _____
6. How many hours does patient sleep each night? _____
7. Does patient have trouble sleeping? Yes No
8. How many meals does patient eat in a typical day? _____
9. How is patient's appetite? _____
10. How does patient describe mood in general? _____
11. Problem with anxiety? Yes No
12. Problem with depression/sadness? Yes No
13. Problem with hallucinations/delusions Yes No
14. Any suicidal thoughts? Yes No
Plans? Yes No
Attempts? Yes No
15. Any concerns about body image or weight? Yes No
16. Is patient dating? Yes No
If yes, gender or partners? _____
17. Is patient having sexual intercourse? Yes No
18. Is patient using protection against STD and/or pregnancy? Yes No
19. Does patient talk with friends about sex? Yes No
20. When patient has a sexual experience, is this shared
with parents or close friends? Yes No



4. QUESTIONS THAT MAY BE ASKED BY A NONMENTAL HEALTH PROVIDER

1. Is patient attending school? Yes No
2. What grade is patient in? _____
3. Has patient ever been held back a grade? Yes No
4. What are average school grades? _____
5. Is patient receiving special services at school? Yes No
6. Is patient getting homebound services? Yes No
7. If yes, how often during the week? _____
8. Does patient plan to graduate from high school? Yes No
If No, does patient plan on receiving a GED? Yes No
9. Did patient graduate from high school? Yes No
10. If yes, does patient plan to go to college/tech school? Yes No
Is the patient still in college/technical school? Yes No
11. Is patient working? Yes No
12. Does job provide insurance? Yes No
13. Does patient have realistic plans for the future? Yes No
14. How many people live in the home? _____
15. How many close friends does patient have? _____
16. How does patient get along with parents/guardians? _____
17. Does patient have plan to keep insurance? Yes No
18. Does patient know type of insurance plan he/she has? Yes No
19. Does patient know eligibility terms? Yes No
20. What does patient like to do for fun? _____
21. Is patient involved in any clubs, sports, etc at school or in their community?.. Yes No
22. How often does patient hang out with friends? _____
23. Does patient's friends know about patient's sickle cell disease? Yes No
24. Out of all of patient's friends is there one that they can tell their private business to? Yes No
25. How has sickle cell affected patient's social life? _____
26. Is spirituality/religion important to the patient to assist in dealing with sickle cell illness? Yes No
If yes, do the patient feel well supported spiritually? Yes No
27. Does the patient use music as a coping or pain management technique? Yes No
28. Can the patient list sickle cell disease type and triggers for pain? Yes No
29. Does the patient have a method coping when they experience a pain crisis? ... Yes No
30. Is patient comfortable talking about sickle cell disease with family? Yes No
With friends? Yes No
31. Is the patient involved in extracurricular activities to stay healthy/active? Yes No



Transition Program Questionnaires

1. SICKLE CELL KNOWLEDGE QUIZ

TOTAL CORRECT

NAME: _____

DATE: _____

CAMPUS (CHECK ONE): EGGLESTON SCOTTISH RITE HUGHES SPALDING

1. What type of sickle cell disease do you have?
 - A. SC (Hemoglobin SC)
 - B. SS (Hemoglobin SS)
 - C. Sickle Beta + Thalassemia
 - D. Sickle Beta 0 Thalassemia
 - E. AS (Sickle Cell Trait)
 - F. Other (please write your answer): _____
 - G. I am not sure
2. You should call the sickle cell clinic or go to the Emergency Room if you have a fever above _____
 - A. 98.6 F/37 C
 - B. 101F/38.3C
 - C. 99 F/37.2 C
 - D. I am not sure
3. Sickle Cell Disease may cause all of these serious problems EXCEPT? (circle only one that is NOT correct)
 - A. Stroke
 - B. Blindness
 - C. Lung damage
 - D. Obesity
 - E. Leg ulcers
4. I can get all my medical care for sickle cell disease by going to the Emergency room when I am sick or have pain.
(Check true or false) True False
5. If a dad has Sickle Cell Disease (Hemoglobin SS) and the mother only has Sickle Cell trait (AS), then there is no way they will have a baby with Sickle Cell Disease.
(Check true or false) True False

TRANSITION PROGRAM QUESTIONNAIRES

6. What things might cause a sickle cell pain crisis? (circle only one)
 - A. Cold temperatures
 - B. Stress
 - C. Too much physical activity
 - D. Not drinking enough water
 - E. All of the above
7. What is true about sickle cell disease? (circle only one)
 - A. It is a blood disorder that you can catch or give to someone else (contagious).
 - B. It is a blood disorder that you can out-grow as an adult.
 - C. It is a blood disorder that you are born with (inherited).
 - D. It is a blood disorder where you bleed too much.
8. When is the best time to get refills on your medications? (circle only one)
 - A. When I notice that I have about a week or more left of my medicine supply
 - B. When my medicine runs out and I have no supply left
 - C. It is okay to let my medicine run out as long as I have a clinic visit scheduled to get my refills
 - D. When I go to the emergency department
9. Why is it important to go to your regular doctor appointments? (circle only one)
 - A. To know my baseline Hemoglobin (red blood cell count) level
 - B. To get my medications refilled
 - C. To get my blood counts checked and make sure they are stable
 - D. To ask my doctor questions and to get educated about sickle cell disease
 - E. To check for complications since my last visit
 - F. All of the above
10. Sickle Cell Disease (circle only one)
 - A. Affects only the blood
 - B. Affects only the heart and lungs
 - C. Affects the blood and many parts of the body including heart, lungs, and brain
 - D. Does not affect any organs in the body
 - E. Affects only chemicals in the body (like hormones)

ANSWER KEY

- | | |
|---|-------|
| 1. Hgb Type (Staff to check for correct answer) | 6. E |
| 2. B | 7. C |
| 3. D | 8. A |
| 4. False | 9. F |
| 5. False | 10. C |

TRANSITION PROGRAM QUESTIONNAIRES



2. SICKLE CELL TEEN TRANSITION PROGRAM SATISFACTION QUESTIONNAIRE (PARENT VERSION):

I am aware that there is a Sickle Cell Disease (SCD) Teen Transition Clinic.

- YES I am aware NO I am not aware

1. The SCD Teen Transition Clinic helps improve the quality of care provided to patient's aged 13-18years with SCD.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
2. The information given during the SCD Teen Transition Clinic was easy for me to understand.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
3. The information given to me during the SCD Teen Transition Clinic was specific and important to me.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
4. My experience with the SCD Teen Transition Clinic has made me feel better able to take care of my teenager.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
5. During the SCD Teen Transition Clinic my questions about my teenager's health and well-being were well answered.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
6. The places used for the SCD Teen Transition Clinic were very appropriate.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
7. I learned more about how SCD affects my teenager during the SCD Teen Transition Clinic.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
8. The staff listened to me and was helpful to me during the SCD Teen Transition Program.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
9. I feel that I was given enough time for each session during the SCD Teen Transition Clinic.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
10. Meeting with the different SCD team members was very helpful:
 Psychologist * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Nurse Practitioner * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Social Worker * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Nurse * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Physician * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Child Life Specialist * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Nurse * Strongly Disagree Disagree Neutral Agree Strongly Agree
 Chaplain * Strongly Disagree Disagree Neutral Agree Strongly Agree

• Please circle the asterisk (*) after the name if you did NOT see this team member.

TRANSITION PROGRAM QUESTIONNAIRES

11. We want to hear from you. Please let us know what we can do to make our Teen Clinic more helpful.
Thank you for your participation:

TRANSITION PROGRAM QUESTIONNAIRES



3. SICKLE CELL TEEN TRANSITION PROGRAM SATISFACTION QUESTIONNAIRE (TEENAGER VERSION):

I am aware that there is a Sickle Cell Disease (SCD) Teen Transition Clinic.

- YES I am aware NO I am not aware

1. The SCD Teen Transition Clinic helps improve the quality of care provided to patients aged 13-18 years with SCD.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
2. The information provided during the SCD Teen Transition Clinic was easy for me to understand.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
3. The information provided to me during the SCD Teen Transition Clinic was specific and important to me.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
4. My experience with the SCD Teen Transition Clinic had made me feel better able to take care of myself with SCD.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
5. During the SCD Teen Transition Clinic my questions about my health and well-being were well answered.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
6. The places used for the SCD Teen Transition Clinic were very appropriate.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
7. I learned more about how SCD affects me during the SCD Teen Transition Clinic.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
8. The staff was listened to me and was helpful to me during the SCD Teen Transition Program.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
9. In my opinion I feel that I was given enough time for each session during the SCD Teen Transition Clinic.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
10. The food provided in the SCD Teen Transition Clinic was very appropriate.
 Strongly Disagree Disagree Neutral Agree Strongly Agree
11. Meeting with the different SCD team representatives was very helpful:

Psychologist *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Nurse Practitioner *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Social Worker *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Nurse *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Physician *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Child Life Specialist *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Nurse *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree
Chaplain *	<input type="radio"/> Strongly Disagree	<input type="radio"/> Disagree	<input type="radio"/> Neutral	<input type="radio"/> Agree	<input type="radio"/> Strongly Agree

 - Please circle the asterisk (*) after the name if you did NOT see this team member.

TRANSITION PROGRAM QUESTIONNAIRES

12. We want to hear from you. Please let us know what we can do to make our Teen Clinic more helpful.
Thank you for your participation:

TRANSITION PROGRAM SAMPLE BUDGET

APPENDIX

D



Transition Program Sample Budget

ANNUAL TOTAL BUDGET = \$2,500

ADULT PROVIDER CLINICS

1. Food for events = \$400/event
2. Donated Professional Services
 - 8 hours of Psychology
 - 8 hours of Pediatric Hematology
 - 4 hours of Adult Hematology
 - 8 hours of Social Worker
 - 2 hours of Vocational Rehabilitation
 - 12 TO 24 hours of Adult Mentor time

GRADUATION EVENT

1. Certificates (\$150 for 500)
2. Honor Cords (\$100 for 150)
3. Gift Cards (\$20/Graduate)
4. Donated Professional Services
 - 2 hours of Psychology
 - 2 hours of Social Worker
 - 2 hours of Medical Providers
 - 1 hour of Nursing Provider

TEEN CLINICS

1. Professional fees charged for provider time (1 hour/participant).
2. Social Work and Child –Life (Donor funded for 4 and 1 hours respectively)
3. Food (\$100 Monthly)

Transition Coordinator (Grant funded position for 1.5 hours per week FTE)



Mentors/Volunteers

ADULT PROVIDER CLINICS

Our volunteers, who serve as mentors for our adolescents, have met the following criteria:

- Have been diagnosed with sickle cell disease
- Currently are managing their healthcare well
- Are pre-screened by our Transition Coordinator and/or Transition Team Member (i.e., medical provider or mental health provider)
- Agree to participate in gender specific groups to discuss sickle cell/life management issues.

Topics discussed in gender specific groups

- Adherence
- Adolescent Risk Behaviors
- Genetics
- Sexual Health
- Stress and the impact it has on the disease

Additional information about our volunteers

- Range in age from 21 – 74



References

1. Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: a bioecological model. *Psychol Rev*, 101(4), 568-586.
2. Griffin, A., Gilleland, J., Cummings, L., Johnson, A., Brailey, T.; New, T.; Eckman, J.; and Osunkwo, I. (2013). Applying a Developmental-Ecological Framework to Sickle Cell Disease Transition. *Clinical Practice in Pediatric Psychology*, 1 (3) 250-263.
3. Novartis (2010) Be Educated. Be Empowered. Be Prepared. Be Sickle Cell Smart: Get ready to transition to adult care.
4. Martin, J. (2005) "Letting Go So They Grow" SelfGrowth.com: The online self improvement encyclopedia.
5. Treadwell, M., Telfair, J., Gibson, R. W., Johnson, S., & Osunkwo, I. (2011). Transition from pediatric to adult care in sickle cell disease: establishing evidence-based practice and directions for research. *Am J Hematol*, 86(1), 116-120.
6. While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2004). Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child Care Health Dev*, 30(5), 439-452.



STEPPING UP DEVELOPING A HEALTH CARE TRANSITION PROGRAM TO ADULT CARE FOR PEDIATRIC SICKLE CELL DISEASE POPULATIONS



Georgia Department of Public Health
Maternal and Child Health Section
www.dph.ga.gov

Children's Healthcare of Atlanta
Sickle Cell Disease Program
www.choa.org