

Self-management and Transition to Adult Health Care in Adolescents and Young Adults: A Team Process

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Education Gap

As health care complexity and outcomes improve, the need for and value of effective health care transition for all youth—but particularly for children with chronic conditions and special health care needs—becomes even more important. While more than 90% of adolescents with chronic medical conditions will survive into adulthood, it is now clear that suboptimal transition generates unfavorable effects on quality of life, access to medical care, disease outcomes, future education, and employment, as well as opportunities for a successful adulthood. Pediatric health care providers and health care systems are underprepared for this important need and can learn from and help implement effective systems that are now being developed to improve the transition of all youth to adult-focused care.

Objectives After completing this article, readers should be able to:

1. Specify how to help families transition their adolescents from a pediatric practice to a provider who cares for adults.
2. Describe the psychological issues of life transition for an adolescent with a chronic illness or disability.
3. Know that for youths with chronic illness and disability, transition to adult health care needs to be planned to avoid any clinically significant disruption of services.
4. Recognize that parents of chronically ill adolescents may have difficulty allowing their children to take control of their own health care management.

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ABBREVIATIONS

AYA	adolescents and young adults
EHR	electronic health record
HCT	health care transition
HCTRC	Healthcare Transition Research Consortium
IEP	Individualized Education Program
QI	quality improvement
SHCN	special health care needs

Abstract

As health care continues to evolve, the need for more effective health care transition (HCT) for all youth, but particularly children with chronic conditions and special health care needs, becomes even more important. With more than 90% of adolescents with chronic medical conditions now surviving into adulthood, suboptimal transition can lead to poorer quality of life and less successful adulthood.

Through a series of clinical vignettes, the challenges of HCT are presented herein and accompanied by comments that underscore how these adolescents can best be helped to transition to successful adulthood. Several methods are presented to assess the readiness of adolescents and young adults (AYA) for transition. The process of transition can be divided into 3 stages: 1) setting the stage: initiation of HCT services and transition readiness assessment, 2) moving forward: ongoing provision of HCT services, and 3) reaching the goal: transfer of care and transition to adulthood.

Several valuable suggestions for incorporating the HCT process into the health care system and improving HCT programs through a quality improvement (QI) approach are outlined. Future challenges in HCT include developing more precise assessments of transition status or transition readiness, better understanding the status and specific needs of AYA with chronic health care needs, continued program evaluation and QI efforts, and more reliance on patients and families to teach us about the challenges and methods in HCT that most effectively work for them.

INTRODUCTION

Health care transition (HCT) is “the purposeful, planned movement of adolescents and young adults (AYA) with chronic physical and medical conditions from child-centered care to the adult-oriented health care system,” as defined by the Society for Adolescent Health and Medicine. (1) During this process, AYA need to gain the skills needed to successfully self-manage their health conditions. (2) It has been estimated that in the United States, parents report that nearly 6 million children live with a developmental or mental health disability and that 10.2 million children aged 0 to 17 years live with a chronic condition (14% of the total 0- to 17-year-old population) and account for 40% of health care costs for all children and adolescents. (3) This translates into more than 500,000 AYA with special health care needs (SHCN) who reach 21 years of age annually in the United States alone. Perspectives on the research efforts in this area are presented in this article, as they are relevant and suitable

for all pediatric health care providers. We also provide a concise blueprint for how effective HCT can be designed and delivered by health care providers in a variety of clinical settings. For the purposes of this review, the term *HCT* refers only to the process of transition from child-centered care to adult-oriented health care and not the other definitions of transition, such as transition of care, or handover, that can be found in the medical literature.

HCT includes 1) the measured transition of responsibility from the parent and health care providers to the adolescent/young adult and 2) deliberate preparation for the actual transfer event. (4) It is estimated that more than 90% of adolescents with chronic medical conditions will survive into adulthood and will thus be undergoing the process of transfer to adult care providers. (5) Suboptimal transition has been shown to generate unfavorable effects on quality of life, access to medical care, disease outcomes, future education, and employment, as well as opportunities for a successful adulthood. (5)(6)(7) Purposeful transition

of adolescents with chronic medical conditions can be a challenging process for all concerned: the family, the health care providers, and the patient above all. It is clear from the work of the past 2 decades that success in transition is not a simple task and requires a concerted effort on the part of the health care team, in concert with the patient and family and in collaboration with interagency partners (ie, rehabilitation counselors or teachers). (2)(4) Effective systems that require clear goals, defined steps, and continuous efforts at improvement based on outcomes must be developed and used. A recent consensus conference report outlines proposed outcomes for transition readiness programs and research to address. (7) Most of all, successful HCT requires dedication and motivation, the necessary attributes of the health care team to be able to support and assist AYA and their families to reach the desired outcomes for a rewarding adult life. It will take no more than that, and no less, for every adolescent and young adult with a chronic medical condition to succeed.

CLINICAL VIGNETTES

Case 1

A 12-year-old boy (Earvin) received diagnoses of sickle cell disease and asthma and has been admitted to the hospital several times for poor treatment adherence. His asthma is treated with fluticasone 220 µg per puff, 2 puffs daily, via a metered-dose inhaler, with intermittent albuterol nebulization treatments as needed (used less than twice a month). He has needed 3 hospital admissions for asthma exacerbations within the past year, one that necessitated ICU admission, and intravenous corticosteroid, magnesium, and terbutaline therapy.

Earvin's sickle cell disease has been better controlled with daily hydroxyurea therapy over the past year. He has had multiple hospital admissions for pain management—mostly bone pain, with 2 episodes of acute chest syndrome in the past 5 years. He has no evidence of renal involvement and has experienced no stroke or other thrombotic episodes.

Earvin attends school but has had many absences for medical issues. While he is in the 7th grade, he is performing at a 6th-grade level on his achievement tests. He is seen monthly in the sickle cell clinic, with his baseline hemoglobin level typically ranging from 9.4 to 10.2 g/dL (94 to 102 g/L).

Case 2

A 17-year-old girl (Christine) with a history of autism spectrum disorder who is wheelchair dependent owing to spina bifida is seen in the complex care clinic every 3 months for

management of her behavioral and medical issues. She requires intermittent urinary catheterization every 2 to 4 hours, which she is able to perform independently to remain dry, and she undergoes a bowel management program of laxatives and enemas 3 times a week. She has recurrent urinary tract infections (typically twice a year) that respond to antibiotic irrigation of her bladder. Her renal function is normal. Christine performs physical therapy exercises twice a day and cannot stand without the use of assistive devices. She has a well-functioning ventriculoperitoneal shunt.

Christine's autism is mildly incapacitating. She attends a regular community school and participates in special education services each day; she is functioning at an 8th-grade level and is capable of performing her own activities of daily living. Christine is taking escitalopram daily, with good control of her excessive, generalized anxiety. Her parents have many questions about how they can best prepare her and themselves for the challenges they see in her future as an adult.

HCT PLANNING

HCT is a process that starts in adolescence and requires close collaboration between AYA with chronic health conditions, their family members, and their interprofessional team of providers in both the pediatric- and adult-focused settings. Theoretical models to guide preparation and interventions during this process have been proposed to account for socioecological factors. (2)(7) For example, the international and interdisciplinary Healthcare Transition Research Consortium (HCTRC) model (8) (<https://sites.google.com/site/healthcaretransition/>) defines 4 domains that are integral to HCT: individual-level factors, family and social support, environment, and health care system. This model suggests that different factors may be influencing the readiness of AYA to transition and the success of this transition. Several barriers to HCT have been identified. First, it may be difficult for patients and their family members to trust a new provider or adapt to a new practice. Second, in adult-focused care, patients are expected to be more autonomous, so parents may not always be engaged (or welcomed) in the decision-making process. Third, when AYA transfer to adult-focused health care, it is important that they and their family members are adequately prepared. Without adequate preparation, patients experience poor outcomes, including missed medical and mental health services, increased disease activity and complications (ie, increased hemoglobin Arc level, kidney transplant loss, hospitalizations, missed appointments, and increased mortality). (2)(4)(5)(9)

While there is no agreed-upon definition of what constitutes successful HCT, it is accepted that process or transfer outcomes may be regarded as condition specific (ie, adherence to immunosuppression agents) or generic (eg, schedule and attend medical appointment or successful communication with health providers). The US Maternal and Child Health Bureau currently uses the following 2 criteria for defining a successful HCT, as identified in the National Survey of Children with Special Health Care Needs: Providers should 1) encourage adolescents to take more responsibility for their care and 2) provide anticipatory guidance for the transition to adult care. HCT preparation is a continuum that requires coordination between primary care providers and subspecialty services in both the pediatric and adult-focused services, even after AYA have aged out of pediatric service centers. (9) HCT preparation needs to be individualized on the basis of AYA's developmental, cognitive, cultural, literacy, and linguistic needs. Parents are an integral part of HCT preparation, as they must learn how to relinquish the day-to-day management of their child's condition.

PLANNING, DELIVERING, AND MEASURING HCT FOR THE PATIENT AND FAMILY

HCT for the individual begins with baseline measurement of AYA competencies related to management of his or her chronic condition. Measuring transition readiness longitudinally allows the provider to implement HCT on the basis of individualized needs. HCT preparation should start in early adolescence and continue into adulthood at the adult-focused center. Generic (Fig 1) and condition-specific (10) HCT readiness tools have emerged, but validity has not yet been demonstrated. (10)

Early findings have demonstrated that female patients and those with older age and certain health conditions typically display more readiness to transition. (4)(6) Elements important in HCT preparation include having a provider or a group of providers who lead an HCT program (11) and include the AYA as partners in the process. (12) Other outcomes, such as usage of health care resources and quality of life, may be used as proxies for measuring success of HCT for both AYA and an HCT program. Behavioral and medical comorbidities that complicate HCT preparation can limit the AYA's ability to achieve adult milestones; modifying the goals of successful transition (but not the need for efforts toward transition preparation) may very well be warranted. Patient education resources can be useful to facilitate the transition process (such as "Got Transition," the University of North Carolina STARx Program, available

at www.med.unc.edu/transition/for-patients-and-parents/educational-handouts-for-transition-scale.htm). For example, the "Got Transition" website provides resources such as information on finding adult providers, independent living, and mental health. The University of North Carolina STARx Program teaches AYA about kidney disease and encourages them to take responsibility for their medicines, appointments, and health insurance. Unfortunately, patient education resources alone do not appear to be sufficient to accomplish successful preparation and transition for AYA. Effective understanding often requires extensive concept repetition, particularly for those with mild to moderate cognitive impairment. Transition preparation for AYA with severe neurodevelopmental disabilities may need to focus more on preparation of the caregiver.

An important aspect in any clinical practice is to consider the HCT process as a quality improvement (QI) and patient safety activity. Having a dedicated HCT team leader will facilitate this process; this person need not be a health care provider, as long as HCT training is based on best practices. (4) Partnering with AYA and their families is important to facilitate better HCT programs and ultimately leads to improved patient satisfaction (11) and better health outcomes.

PROVIDING TRANSITION

Provision of Services

Provision of HCT is a long-term interprofessional process that should begin in a patient's early adolescence. HCT service models include dedicated transition clinics, integration of HCT into regular clinic visits, and episodic clinics staffed with pediatric and adult care providers. Frameworks to guide the practice, research, and QI of this nascent specialty area include the HTCRC HCT Model and the 6 Core Elements (Table 1) (<http://www.gottransition.org/providers/index.cfm>). HCT service models will be influenced by unique characteristics of the setting (eg, private community pediatrician practice, specialized care center, or major tertiary pediatric medical center), as well as defined needs of AYA and their families. Exploration of our 2 clinical cases will illustrate relevant service components.

Setting the Stage: Initiation of HCT Services and Transition Readiness Assessment

The age at which HCT is initiated varies from center to center, ranging from early adolescence (ages 10 to 12 years) to midadolescence (ages 14 to 16 years). The recent HCT consensus report issued by the American Academy of

Transition Readiness Questionnaires: TRAQ and University of North Carolina STAR _x Methods	
20-Item Transition Readiness Assessment Questionnaire (TRAQ)	University of North Carolina STAR _x Transition Readiness Method
<p>Managing Medications Do you fill a prescription if you need to?</p> <p>Do you know what to do if you are having a bad reaction to your medications?</p> <p>Do you take medications correctly and on your own?</p> <p>Do you reorder medications before they run out?</p> <p>Appointment Keeping Do you call the doctor's office to make an appointment?</p> <p>Do you follow up on any referral for tests, checkups, or laboratory tests?</p> <p>Do you arrange for your ride to medical appointments?</p> <p>Do you call the doctor about unusual changes in your health (eg, allergic reactions)?</p> <p>Do you apply for health insurance if you lose your current coverage?</p> <p>Do you know what your health insurance covers?</p> <p>Do you manage your money and budget household expenses (eg, use a checking/debit card)?</p> <p>Tracking Health Issues Do you fill out the medical history form, including a list of your allergies?</p> <p>Do you keep a calendar or list of medical and other appointments?</p> <p>Do you make a list of questions before the doctor's visit?</p> <p>Do you get financial help with school or work?</p> <p>Talking with Providers Do you tell the doctor or nurse what you are feeling?</p> <p>Do you answer questions that are asked by the doctor, nurse, or clinic staff?</p> <p>Managing Daily Activities Do you help plan or prepare meals/food?</p> <p>Do you keep your home/room clean or clean up after meals?</p> <p>Do you use neighborhood stores and services (eg, grocery stores and pharmacy stores)?</p>	<p>Section 1: Self-Management Skills 1. How often did you use the Internet, books, or other guides to find out more about your illness?</p> <p>2. How often did you ask your doctor or nurse questions about your illness, medicines, or medical care?</p> <p>3. How often did you work with your doctor to take care of new health problems that came up?</p> <p>4. How often did you make your own appointments?</p> <p>5. How often did you make an effort to understand what your doctor told you?</p> <p>6. How often did you use things like pillboxes, schedules, or alarm clocks to help you take your medicines when you were supposed to?</p> <p>Section 2: Medications/Treatment 7. How often did you forget to take your medicines?</p> <p>8. How often did you need someone to remind you to take your medicines?</p> <p>9. How often did you take your medicines on your own?</p> <p>Section 3: Disease Understanding 10. How much do you know about taking care of your illness?</p> <p>11. How much do you know about your illness?</p> <p>12. How much do you know about what will happen if you don't take your medicines?</p> <p>Section 4: Communication with Physician 13. How easy or hard is it to make a plan with your doctor to care for your health?</p> <p>14. How easy or hard is it to talk to your doctor?</p> <p>15. How easy or hard is it to see your doctor by yourself?</p> <p>Ability to Use Health Resources 16. How easy or hard do you think it will be to move from pediatric to adult care? <i>*If you are already in adult care, how easy or hard do you think it will be to find another doctor?</i></p> <p>17. How easy or hard is it to take care of yourself?</p> <p>18. How easy or hard is it to take your medicines like you are supposed to?</p>

Figure 1. HCT readiness tools. The 20-Item Transition Readiness Assessment Questionnaire, or TRAQ, is available at <http://www.hscj.ufl.edu/JaxHATS/TRAQ/>. The University of North Carolina Self-Management and Transition to Adulthood with R_x therapies program, or STAR_x, transition readiness method is available at <https://www.med.unc.edu/transition/transition-tools/trxtransition-scale>.

Pediatrics, the American Academy of Family Physicians, and the American College of Physicians recommended that HCT begin around 12 years of age; however, HCT initiation is ultimately dependent on the service needs of the teen and the local resources available. (13)

HCT preparation begins with an introductory discussion and an assessment of transition readiness (which can be remeasured annually or semiannually). During the first HCT meeting with the adolescent and family, the purpose, rationale, and importance of HCT is presented, with a timeline of substantial future benchmarks. The comprehensive youth and family-centered HCT service framework of interprofessional efforts directed to the ultimate goal of

support for the adolescent and family is exemplified in the HTCRC HCT Model. (8)

Case 1. Earvin comes to the outpatient clinic for a follow-up visit after a recent hospitalization for asthma. He recently transferred to a new middle school. As the team reviews Earvin's recent medical history and needs for services, they take the opportunity to perform a transition readiness assessment according to the institution's recently implemented HCT policy. The team's HCT coordinator uses the Sickle Cell Disease Intervention Program Skills Checklist to identify current levels of self-management and needs for future instruction that will be identified in Earvin's HCT plan.

TABLE 1. Healthcare Transition Research Consortium Health Care Transition Model and the 6 Core Elements

CORE ELEMENT NO.	CORE DOMAIN
1	Transition policy
2	Transition and tracking and monitoring
3	Transition readiness
4	Transition planning
5	Transfer of care
6	Transfer completion

According to <http://www.gottransition.org/providers/index.cfm>.

Case 2. Christine and her mother are seen by her pediatrician, as she is scheduled for an annual pediatric evaluation. Transition has not been an issue until now but is addressed in today's visit as the introductory presentation of the HCT process that will evolve as Christine ages. Her pediatrician plans to raise a number of issues, which, although not currently relevant to Christine's ongoing management of her care, will become so in the future. The intent is to provide Christine and her mother with a "road map" of planning for the future as Christine ages. Some of the topics that the pediatrician will raise with the mother are the following: 1) based on the initial HCT readiness measurement, facilitate Christine's acquisition of spina bifida self-management skills and clinical knowledge, such as bowel and bladder management and recognition of signs and symptoms of shunt malfunction; 2) incorporate health-related accommodations into her transition Individualized Education Program (IEP); 3) discuss postsecondary vocational training options; 4) promote social activities; 5) initiate the process for obtaining a conservatorship before Christine reaches 18 years of age; and 6) transfer to adult care providers when pediatric eligibility terminates.

Comprehensive assessment of transition readiness is the necessary precursor for the development of an individualized HCT plan. HCT readiness assessment (Fig 1) provides baseline information of the adolescent's current ability to perform self-management skills and demonstrate clinical knowledge needed to independently conduct management of his or her chronic condition. Assessment of transition readiness is an ongoing process that can be performed annually or as needed, such as when learning needs change with cognitive and developmental maturity, the underlying chronic condition changes, or other available learning

resources and individual adolescent and family circumstances are altered.

Moving Forward: Ongoing Provision of HCT Services

HCT is not limited to the transfer event but is rather a comprehensive service process that is responsive to the ongoing and changing needs of the AYA. HCT is not a predictable process for AYAs with SHCN. Unanticipated illness episodes may cause regression with self-management skills that require repeat instruction. From early adolescence to emerging adulthood, a number of benchmarks serve as "guideposts" for the delivery of HCT services. These HCT guideposts (Fig 2) are described as follows.

Entry into middle school marks a benchmark by which an inventory of the early adolescent's SHCN technical skills and clinical knowledge are reviewed. Ideally, the early adolescent has become self-reliant or is learning to perform self-management tasks of the daily treatment regimen at both home and school. A meeting between the parents, the early adolescent, and the school officials prior to entry into middle school is useful to discuss formulation of the student's IEP or 504 plan. The health-related accommodations that are needed to support the student's academic achievement needs are identified, reviewed, and included in the IEP or 504 plan. The HCT provider can assist parents with the identification of health-related accommodations that need to be discussed during the IEP team meeting and included in the IEP. Examples of health-related accommodations include school nurse assistance with procedures, adapted physical education, one-to-one school aide assistance, and dietary needs and modifications with classroom assignments. Middle school students should be encouraged to attend their IEP or 504 meetings and should receive preparatory coaching from their parents and/or HCT transition specialist. Each year, the IEP or 504 plan will be automatically reviewed, or—as requested by the parents—the IEP may be revisited to address new academic or health-related needs.

Case 1. Earvin has recently transferred to middle school, and his mother is concerned about his adjustment to this new school setting. His mother shares with the pediatrician that she is hesitant to share diagnostic information about Earvin with his teachers and school nurse, as she does not want him to be "labeled" or identified as "different." Members of Earvin's specialized health care team need to discuss this HCT issue and others, as self-disclosure is a major concern for both adolescents and families. The benefits of condition disclosure are discussed with Earvin and his mother, as it will enable him to access services based on his rights and protections afforded by the Rehabilitation Act,

A. Setting the Stage: Initiation of HCT Services and Transition Readiness Assessment

Initiated beginning in early adolescence (ages 10 to 12) to midadolescence (ages 14 to 16 years)

- Introductory discussion of HCT process
 - o Rationale
 - o Importance
 - o Timeline of substantial benchmarks
- o Comprehensive, youth, and family-centered process, with interprofessional approach
- Baseline assessment of transition readiness
- Development of comprehensive HCT plan

B. Moving Forward: Ongoing Provision of HCT Services

Entry into middle school

- Ongoing monitoring of self-management knowledge and skills acquired
 - o Identify learning needs
 - o Provide self-management instruction
 - o Review and reinforce learning
 - o Assess needs for additional instruction
- Formulation of IEP/504 plan, specifying the following:
 - o Academic supports
 - o Health-related accommodations
 - o Annual review
- Encouraging involvement in recreational activities
- Encouraging participation in peer group activities
- Encouraging development of age-appropriate friendships

Transition to high school

Upon entry to high school: Formulation of IEP/504 plan specifying academic and health-related accommodations

Age 16: Formulation of transition IEP/504 plan specifying the following:

- o Academic supports
- o Health-related accommodations
- o Career development classes/experiences
- o Work-based learning programs
- o Vocational training
- o Driver's training
- o Community living skills training
- o Sex education
- o Social skills training
- Encouraging involvement in recreational activities
- Encouraging participation in peer group activities
- Encouraging development of age-appropriate friendships

Age 17: As appropriate, initiate discussion for obtaining conservatorship

Age 18: Postsecondary plans are implemented

- Preparation for enrollment in college, vocational training
 - o Identify academic and health-related accommodations needed
 - o Identify needs for accessible housing
 - o Refer to campus/program Disabled Student Services office
 - o Locate primary and specialty care providers in community of choice
 - o Enrollment in adult health insurance plan
 - o Obtain disability documentation from pediatric provider
 - o Refer to SSI work/college incentive programs
 - o Refer to state vocational rehabilitation program
 - o Refer to independent living centers
- For adolescents with cognitive limitations
 - o Formulate IEP/504 plan for high school community living skills/vocational training program (up to age 22 years)
 - o Locate primary and specialty care providers in community of choice
 - o Enroll in adult health insurance plan
 - o Obtain disability documentation from pediatric provider
 - o Refer to options of day programs after high school exit
 - o Discuss employment options available: supported employment, job coaches
 - o Refer to Section 8 housing
 - o Refer to independent living centers
 - o Review needs for ongoing attendant care
 - o Refer to SSI work incentive programs
 - o Refer to state vocational rehabilitation program
 - o Discuss issue of special needs trust
 - o Discuss issue of succession planning

C. Reaching the Goal: Transfer of Care and Transition to Adulthood

- Acknowledge termination of care with ceremonial event
- Ensure medical summary is completed prior to service exit

Figure 2. Essential components of HCT services (patient perspective). HCT=health care transition, IEP=Individualized Education Program, SSI=Supplemental Security Income.

the Americans with Disabilities Act, and the Individuals with Disabilities Education Improvement Act. Furthermore, both Earvin and his mother are encouraged to advocate for Earvin's attendance at his IEP meeting. Earvin's mother is counseled on strategies to promote his IEP participation.

Transition to High School

Transition to high school is a significant academic and developmental transition that represents a relevant benchmark for students with SHCN. A discussion prior to enrollment in high school is needed with the high school IEP team to review and plan the forthcoming academic year as it pertains to needed academic and health-related accommodations. As was done during the middle school years, the HCT coordinator provides consultation with the parents and adolescent about these school issues. During the next 4 years, and possibly longer for students with cognitive disabilities who exit high school at age 22, emphasis is directed toward fostering independence with managing primary needs and SHCN.

Although there are limited data published, we know that psychological issues can particularly complicate the transition process for adolescents with SHCN. (14)(15) Some of these issues include 1) challenges in accepting and adjusting to change, as a result of their significant dependence on pediatric health care providers; 2) tendency toward denial of transition needs due to priority given to medical issues in their lives; 3) effects of relative isolation on blunting psychosocial development and relationships with peers; 4) pressures to appear normal and the effect this can have on making poor decisions and avoiding SHCN; 5) ineffective health literacy and financial skills related to fewer opportunities to practice and acquire effective management skills; and 6) comorbid mental health disorders and associated psychological dysfunction that have increased incidence in this population.

In this high school period, adolescents are now encouraged to assume greater responsibilities for their health care, such as making their own clinic appointments, reordering medications and supplies, and undertaking care and maintenance of their durable medical equipment. Instruction pertaining to the adolescent's clinical knowledge should be aligned with the teen's developing cognitive maturity and include guidance about high-risk behaviors, sexuality, sexually transmitted infections, and reproductive counseling. Of concern will be questions about how the AYA with SHCN will disclose their condition to peers, friends, and adults in their social network. Of particular importance are the age-related benchmarks that occur during high school that are pertinent to students with SHCN.

At age 16, many students with SHCN meet with the high school educational team to develop the transition IEP. This IEP differs from other IEPs, as the focus of the academic planning expands to address postsecondary education or training, community living, and other lifestyle goals. The transition IEP (depending on the student's interests, needs, and preferences) may include activities for career planning, youth employment, volunteer opportunities, driver's training, and learning of community living skills. By necessity, discussion of health-related accommodations needed for work or volunteer settings, employment disability rights, and protections that include disclosure procedures should be reviewed and included in the transition IEP. Other topics relevant for discussion and referral are driving skills evaluation, adaptive driver's education, automobile modifications, housing modifications, and understanding of disability rights and protections. These are areas for planning and consultation among the HCT coordinator, parents, and adolescent. The importance and benefits of enrollment in work-based programs while in high school for students in special education have been demonstrated. (16) Longitudinal data for students enrolled in special education after their high school exit revealed that those who participated in work-based programs were significantly more likely to be employed as adults than students who had not participated in these programs.

Not all students with SHCN will have a transition IEP, as they may be hesitant to identify themselves as having SHCN. Many students with SHCN are in general education programs and do not require special academic services and supports. However, it is worthwhile to review with students with SHCN and their parents the benefits available with self-identification, such as the provision of health-related accommodations in the high school setting. In addition, there are federal and state-supported Department of Rehabilitation Services programs for high school and college students on the basis of their individual needs for vocational training and college tuition support.

Case 1. When Earvin is in high school, it will be important to include the school counselors, nurse, and teachers in understanding his SHCN. HCT readiness and training will continue to be an important issue. His access to specialized services and protections, including an IEP if needed, will need to be considered.

Postsecondary Plans

At age 17, a discussion can be initiated with parents of adolescents who have cognitive impairment about obtaining a conservatorship. In each state, by law, when an adolescent reaches the "age of majority," the legal right to make legal

decisions is conferred to the adolescent, including the right to be the health care decision maker. In most states, the age of majority is 18 years. Obtaining a conservatorship is a legal responsibility conferred by a judge in a court of law. Parents should be advised to seek legal assistance with low-cost or no-cost legal or advocacy organizations, since these costs can be expensive. If a conservatorship is not obtained in a timely manner, the transfer of care becomes a more complicated process, as other health organizations and providers are likely to decline to provide care for an individual who is unable to provide informed consent.

At age 18, for adolescents with a cognitive disability, a copy of the conservatorship is filed in the patient's chart. This document can be included with the packet of medical records transferred to the adult health services organization.

For many students with SHCN, their postsecondary plans are now being finalized. It is during this time of preparation for college or vocational training that discussion of their present and future health-related needs often occurs, as well. All students with SHCN, regardless of the vocational training or college program they plan to attend, should consider examination of the services provided by the Disabled Student Services office located on every college campus or vocational training program that receives federal funding. Services vary, and some include rapid-response teams for crisis management of students experiencing difficulties in school. Examples of services the Disabled Student Services office provide include priority registration, disabled parking, accessible housing, examination and assignment accommodations, accessibility to student programs, note takers, and sign language interpreters.

If the adolescent or emerging adult with SHCN chooses to move to another community, the HCT coordinator together with the AYA should review health care options available in the new community. Access to primary and specialty care may be problematic and require additional planning. Enrollment in the adult health insurance plan, once the pediatric eligibility terminates, involves review of health plan options to compare and contrast the health benefits most suitable for the individual.

Available community resources and long-term planning, based on the AYA's individual needs, interests, and preferences, are reviewed in terms of their applicability. For AYA with severe cognitive and physical disabilities, long-term planning includes exploration of day programs and the possibility of out-of-home placement, in-home supports, and succession planning as the patient's parents age. At age 18, adolescents who have received Supplemental Security Income will undergo assessment for enrollment in adult Supplemental Security Income programs.

For other groups of adolescents with SHCN, discussion and referrals to community-based programs can be undertaken by the HCT coordinator, some of which are state and federally funded, such as the Workforce Investment Act agencies that provide job training and placement for AYA with SHCN. The Independent Living Centers is a national network of grassroots, consumer-driven, and operated agencies that provide an array of services to adults with disabilities. These services include peer counseling, advocacy, attendant registry, driving modifications, and assistive devices. Affordable housing, known as *Section 8 housing* sponsored by the US Department of Housing and Urban Development, provides housing assistance to eligible individuals. At the local level, there are numerous disability-related advocacy organizations that provide social and lifestyle assistance that the AYA with SHCN can be referred to for additional services.

Case 2. Christine and her mother will need to be asked and encouraged to confront issues such as conservatorship, postsecondary school employment and/or activities, relevant community resources, and potential adult care providers. Seeking capable and motivated adult health care providers for SHCN youth who are entering late teen and adult years can be a challenge but is an important responsibility for the pediatrician.

It will also be important to continue to assess Christine for transition skills and transition readiness during this time. Opportunities for assessment and training continue until the moment of transfer of care.

Reaching the Goal: Transfer of Care and Transition to Adulthood

Active planning for the termination of services will begin at least a year prior to the transfer of care. This period of time is needed to ensure that preparatory transfer paper processing has been completed, introductory visits with the adult providers have occurred, durable medical equipment has been ordered and received, new medical suppliers have been located, and enrollment in an adult health insurance plan has been initiated.

In some circumstances, electronic or hard-copy transfer of medical records to the receiving adult medical practice may be the operative procedure. If so, then written consent is obtained from the AYA or the parent or guardian who serves as the conservator. Otherwise, hard copies or a compact disk of the medical records can be given directly to the AYA or the parent or guardian. The medical summary—a concise written version of past medical history, listing of medical diagnoses, recent hospitalizations and surgeries, medications,

and treatment plan—are provided to the AYA or the parent or guardian for their personal use.

The termination of pediatric services and transfer to the adult health care system is a major developmental transition and adjustment for not only the AYA and the parents but for the interprofessional team of pediatric providers, as well. Over the years, trusting relationships have developed, and bonds of attachment for the relationships that have developed as a result now must end. Studies have demonstrated the emotional distress experienced by AYA and families as a result of this transfer of care. This experience is similar for the members of the interprofessional team, as well. It is therefore fitting, as has been suggested, to have a ceremonial event to acknowledge the termination of care and the ending of these relationships. Saying goodbye to the AYA and the AYA's parents, and likewise to team members, formalizes the experience of having “grown up” and accepting a new stage in the life journey.

INTEGRATING HCT INTO THE HEALTH CARE SYSTEM

Health care systems vary widely in their resources and ability to implement transition-focused activities. Large, integrated health systems that care for the continuum of pediatric and adult patients, such as Kaiser Permanente, have electronic health records (EHRs) and multiple subspecialists that can communicate easily in a single system and are able to build transition tools into their system EHR. Several institutions have initiated such efforts recently. Meanwhile, private pediatric clinics and freestanding children's hospitals that provide services to children and adolescents enrolled in the Title V children with SHCN program are required to develop special programs to reach out and collaborate with adult colleagues or assist families to find appropriate providers to receive transfer of care for these AYA patients. To assist providers, insurance companies and Title V agencies have case management services that can aid families directly and help families manage transitions of care (see Title V Roles in Coordinating Care for Children with Special Health Care Needs, available at <http://www.jhsph.edu/research/centers-and-institutes/womens-and-childrens-health-policy-center/publications/cshcn-final.pdf>).

Each of the authors has been involved in initiating transition programs at their own institution. In each case, these programs required seed money and/or other dedicated resources from their respective hospitals, funding through grants, and/or donations from local foundations to develop initial infrastructure and personnel to launch the programs. Efficiencies from collaborative groups such as the HTCRC (<https://sites.google.com/site/healthcaretransition/>),

composed of a group of practitioners and HCT researchers devoted to developing effective transition processes and programs, and collaborative EHR efforts, such as HCT template sharing between Epic Systems and Cerner users, have substantially improved the quality and rate of progress in this field. Other valuable national resources are available on the US National Health Care Transition Center “Got Transition” site (<http://www.gottransition.org/about/index.cfm>).

In any transition program, substantial clinical time will be required to assist families through the process. Time spent on transition activities can be billed as care coordination and management (Table 2). For the child without SHCN, transition planning and education can be incorporated into regularly scheduled health maintenance visits and billed accordingly (*Current Procedural Terminology* codes 99394 and 99395). For youth with SHCN, transition services can be documented as involving counseling for more than 50% of the visit and billed as an established patient (code 99214 or 99215). If transition consultation performed as part of the visit results in a longer visit, prolonged services codes can be used (code 99354 or 99355). These service codes can be used if the physician spends more than 30 minutes beyond the time identified for the highest evaluation and management code in that category (codes 99205, 99215, and 99245).

For transition services, it is important to document the specific counseling delivered and the exact time in the note. Other billing codes that can be used include care plan development and oversight (codes 99339 and 99340), team conference (codes 99366 and 99368), group counseling visits (codes 99411 and 99412), and prevention and education counseling (codes 99401 through 99404). Documentation should include transition topic and outcome and time spent in direct contact with the patient/family and in preparation/wrap-up of the visit. Some Title V agencies also pay for transition counseling and care coordination by health care providers. Preplanning on what an insurance program covers for a particular adolescent or young adult is a critical component to ensure that the patient has continuous access to health care. Since 2014, AYA who are covered under Medicaid or private insurance can now be covered until age 26, owing to provisions in the US Affordable Care Act. For those who are covered under Title V, unfortunately, the benefits stop at age 21, and AYA have to find other means for coverage if they are not covered by a private plan or do not qualify for Medicaid. In some states, AYA can continue coverage from Title V through adulthood (eg, for cystic fibrosis, hemophilia, or sickle cell disease, see <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/schip-enrolled-children-with-special-health-care-needs.pdf> for

TABLE 2. Billing Options for Transition of Care Activities (in the United States)

ACTIVITY TYPE	CPT OPTIONS
Visit with a child without SHCN	
As part of regular health maintenance visit	Codes 9934, 9935
Visit with a child with SHCN	
Established patient visit (with counseling >50% of visit time), usual visit time length	Codes 99214, 99215
If transition counseling as part of the visit results in a prolonged visit, bill prolonged service time (if physician spends more than 30 minutes beyond the usual length of a visit in that category, use code 99205, 99215, or 99245)	Codes 99354, 99355
Care plan development and oversight	Codes 99339, 99340
Team conference	Codes 99366, 99368
Group counseling visits	Codes 99411, 99412
Prevention and education counseling	Codes 99401–99404

CPT=Current Procedural Terminology, SHCN=special health care needs.

details). For most youth covered under Title V programs, planning for alternative forms of coverage is critical prior to aging out of services. Multiple health care program options exist and are variable from city to city and county to county, which also include the new health care exchanges through the Affordable Care Act. Partnering with nursing, social work, case management, and/or local public health department staff is important for the physician or other health care provider who cares for the patient with SHCN, and providing appropriate information to these patients and families is a key component of effective and thoughtful care.

TREATING THE HCT PROCESS AS A CONTINUOUS QI ACTIVITY

Quality of care is defined as ensuring that health care is effective, efficient, accessible, acceptable and patient-centered, equitable, and safe. The emphasis on delivering on the “Triple Aim” (Fig 3) for all patients in the United States has been a key driver in efforts to examine and improve the

Figure 3. The “Triple Aim” (from the Institute for Healthcare Improvement). Available at <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>

The “Triple Aim”
Improving the patient experience of care (including quality and satisfaction)
Improving the health of populations
Reducing the per capita cost of health care

quality and value of health care for all individuals. The challenges for youth with SHCN are especially complex, but the potential gains in value for health care expenditures can be substantial for this population. HCT is ultimately about developing and maintaining high-quality care for affected individuals. (5) Most AYA struggle with HCT; efforts to improve HCT systems can be profitably addressed through the framework of improvement of quality of care. (17)

Transition QI inevitably starts with acknowledging that the transition process for (most) AYA can be improved. This is typically achieved through completing the “plan, do, study, act” cycle of QI (17) (Fig 4).

Improvement QI activities need not involve radical changes within the practice or clinic. For example, if insurance planning is a key feature or gap in the delivery of quality transition services, the practice can plan on improving insurance education and making sure AYA receive an insurance handout (“plan”) via a handout given by the physician during the clinic visit (“do”), with this activity documented in the chart. The practice can then measure delivery of the handout (“study”). After baseline measurement (chart review), the practice may note that only 50% of AYA received the handout; the next improvement step may be to change the way the handouts are given (perhaps by front staff to all youth over the age of 17 during check-in, rather than by physicians) and then install this practice (“act”). If this outcome is satisfactory, the practice could then move to working on other gaps identified, such as assistance in finding an adult provider.

Some health systems have the capacity to undertake large transition projects, such as developing EHR tools or hiring transition coordinators to provide a range of services in the clinic (transition readiness assessments, care coordination, transition-related case management). As noted in the previous example, implementing transition and transition QI does not necessarily require large effort and funds. A number of free resources are available to families, patients, and providers to help guide the practice transition process. Practices can approach this in different ways, depending on local resources, practice characteristics, and philosophy. Practices early in the course of HCT work may start with generating a basic transition process and implementing that approach. Some practices may undertake more formal QI strategies that involve systematically assessing AYA in the

<p>Identify a Specific Aim based on an area of patient/provider need; a Specific Aim should be a measurable outcome.</p> <p>Plan—the intervention in the HCT process generated by the medical group or practice (QI team) to address the gap between what is needed and what presently exists in the HCT process</p> <p>Do—implementing the change in the HCT process and collecting data</p> <p>Study—analysis and interpretation of the results, conducted by the QI team</p> <p>Act—defining next steps in improving the HCT process based on results of the earlier intervention</p> <p>Repeat the “plan, do, study, act” cycle as needed to improve process and outcomes</p>
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Figure 4. HCT QI plan (“plan, do, study, act” cycle). HCT=health care transition, QI=quality improvement.

practice and addressing deficits in transition readiness or actual transition milestones, in some cases in subgroups of high risk or high complexity.

There are many free tools available to assist practices and patients in the transition process. The US National Health Care Transition Center “Got Transition” site (<http://www.gottransition.org/>) has generated “transition steps” and toolkits that may be used by practices to help develop specific transition processes.

Regardless of the improvements a specific practice chooses to undertake to improve the transition process, important elements include 1) getting HCT buy-in from patients and staff, 2) developing clearly defined goals, and 3) defining outcomes and/or metrics of interest to the group. These elements are foundational to ensure that the QI strategy and approach can be used to reach the goals defined by the practice.

CLINICAL VIGNETTES: WRAP-UP

Case 1

For Earvin, the boy with sickle cell disease and asthma, support will be required throughout the remainder of his adolescence and young adulthood. It will be important that his health care providers remain aware of the opportunities to teach Earvin and his parents the skills required for Earvin to be a successful self-managing adult and for his parents to support him in these efforts. For some patients like Earvin, this means regular repetition and reviews to reinforce and assess the necessary knowledge and skills. As he makes his way through middle school and high school into a job or university, he will likely benefit from regular formal transition readiness assessment to define areas to focus training. The use of the team’s Sickle Cell Disease Intervention Program Skills Checklist will continue to shape the efforts of the health care team to assist Earvin.

Case 2

Christine and her mother have successfully confronted the important issues—conservatorship, postsecondary school employment and activities, relevant community resources,

and potential adult care providers—through a series of visits to the health care provider. They have been helped by the efforts of the HCT coordinator in the clinic. They have identified a capable adult health care provider who will assume Christine’s care in the next year.

FUTURE CHALLENGES, DIRECTIONS, AND INTERNATIONAL PERSPECTIVES

Regardless of provider transition skills and specific transition practices in an institution, the transition process best serves AYA by promoting development of their self-management skills and successful transition to adult care providers. The self-effectiveness and satisfaction of the AYA and the satisfaction of the receiving adult care teams should be measured systematically over time. More precise assessment of “transition” status or “transition readiness” of AYA can assist care providers in addressing the needs of AYA with SHCN. Continued program evaluation and QI efforts will be necessary to develop the programs that our patients deserve. Patients and families also have much to teach us about the challenges and methods that most effectively work for them. As health care systems continue to integrate and become responsible for the quality and costs of care, more emphasis on the benefits of successful transition for AYA with chronic medical problems will emerge. Best practices that are cost-effective will move beyond “desirable” or “preferred” to most logical and wise. Systems will inevitably seek these best solutions for their patients.

Future challenges will include the following methods to leverage:

1. Engagement of AYA and their families in driving the HCT process;
2. True interprofessional efforts, since multiple perspectives will best serve complex patients;
3. Focus on building transition knowledge and transition competencies in these patients (Fig 5);
4. Use of systems that value successful transition as a quality care or patient safety proposal and an economic imperative; and

1. I understand my condition and can describe it to others
2. I know my medications and what they are for
3. I can make decisions about my treatment for myself
4. I know what the adult clinic arrangements are and who will be reviewing me in clinic
5. I know how to make my appointments
6. I can make my own transport arrangements to get to the hospital for appointments
7. I know whom to call in a medical emergency
8. I am able to talk about my worries concerning blood tests and other treatments
9. I know the dietary advice that I have to follow and the importance of activity
10. I have appropriate knowledge about sexual health matters
11. I have discussed alcohol, smoking, and drug issues

Figure 5. The 11 competencies expected in an older teen or young adult who will be successful in the transition to adult care providers. Adapted from reference 9.

5. Use of defined HCT protocols effective for both primary care and subspecialty patients.

There is ample evidence that the transition challenges for AYA in other countries share many similarities to AYA HCT in the United States. International collaborations may inform health care providers throughout the world to help AYA meet the necessary challenges of growing up and succeeding in life.

Organizations such as the international and interdisciplinary HTCRC (<https://sites.google.com/site/healthcaretransition/>) will help lead the process of developing and identifying best practices for AYA and those with SHCN. A strength of this organization of practitioners and researchers is that it is guided by youth with chronic conditions and their caregivers.

A big challenge for HCT is the paucity of evidence for effective measures and outcomes. The lack of good evidence does not alter the compelling need to help these patients now make their way to successful adulthood. Only a commitment to continue to gather evidence of effectiveness can build the best future for these patients and those to come.

Summary

- On the basis of expert opinion (level D), health care transition (HCT) preparation is a process that should start around 10 to 12 years of age for adolescents and young adults (AYA) with chronic conditions.
- On the basis of limited research evidence (level C), successful HCT processes require interprofessional collaboration from both the pediatric and adult-focused providers and settings that promote AYA to continue to gain skills even into their mid-20s.
- On the basis of expert opinion (level D), effective HCT needs to be delivered in a congruent cultural, literacy, and linguistic fashion, based on the unique needs of the AYA.
- On the basis of limited research evidence (level C), measuring HCT competencies by using readiness assessments can guide interventions that ultimately result in improved outcomes and better quality of life for AYA.

References and Suggested Readings for this article are at <http://pedsinreview.aappublications.org/content/38/7/305>.

Additional Resources for Pediatricians

AAP Textbook of Pediatric Care, 2nd Edition

- Chapter 9: Partnering With Families in Hospital and Community Settings - <https://pediatriccare.solutions.aap.org/chapter.aspx?sectionid=140000175&bookid=1626>
- Chapter 66: Transitions to Adulthood - <https://pediatriccare.solutions.aap.org/chapter.aspx?sectionid=139996217&bookid=1626>

Parent Resources from the AAP at [HealthyChildren.org](http://www.healthychildren.org)

- How to Help Your Teen Transition to Adult Health Care – Video: <https://www.healthychildren.org/English/family-life/health-management/Pages/How-to-Help-Your-Teen-Transition-to-Adult-Health-Care-Video.aspx>
- Encouraging Teens to Take Responsibility for Their Own Health: <https://www.healthychildren.org/English/family-life/health-management/Pages/Encouraging-Teens-to-Take-Responsibility-for-Their-Own-Health.aspx>

For a comprehensive library of AAP parent handouts, please go to the *Pediatric Patient Education* site at <http://patiented.aap.org>.

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1. You are speaking with a group of residents about planning for the transfer of the care of adolescents and young adults (AYA) from pediatricians to adult health care providers.

Which of the following statements best describes the most important rationale for focusing on completing that transition?

- A. Adolescent care is poorly compensated.
 - B. Adult health care providers are better prepared than pediatricians to deal with chronic illness.
 - C. Insurance companies now require it.
 - D. Pediatricians need to make more room in their offices for younger children.
 - E. Transition should be completed to avoid suboptimal transition, which will undermine the quality of adult life.
2. A 17-year-old highly functional girl with Down syndrome, obesity, and type 2 diabetes is followed up in the primary care clinic. A few years ago, her pediatrician initiated the process of preparing her for health care transition. While all of the following factors are important in readiness assessment, which one should receive the most attention when setting the stage for this adolescent with special health care needs to transition to adult health care services?
 - A. Cognitive ability.
 - B. Gender.
 - C. Insurance coverage.
 - D. Physical health status.
 - E. Sexual orientation.
 3. A 17-year-old girl who has above-average intellectual ability and a demonstrated capacity to provide self-care but who requires a wheelchair to facilitate efficient movement because of her midlumbar spina bifida hopes to attend a 2-year college in a nearby community after graduation. Because the patient's cognitive ability is not in question, which of the following is of least concern in the transition process?
 - A. Considering vocational training opportunities.
 - B. Developing a transition Individualized Education Program.
 - C. Discussing conservatorship.
 - D. Enrolling in appropriate work-based programs before graduation.
 - E. Reviewing disabled student services available on the college campus.
 4. A 17-year-old boy with severe hemiparesis from a stroke is doing well academically in high school. He is receiving Supplemental Security Income. To reach his life goals, he wants to continue his education in a nearby state after graduation. In ensuring that his care successfully transfers from his long-established pediatric office to a new adult care provider in that state, which of the following steps will be the most detrimental to a smooth transition for this patient?
 - A. Advising him to explore enrollment in the adult Supplemental Security Income program.
 - B. Arranging a ceremonial event that formally acknowledges transfer of care.
 - C. Delaying any consideration of transfer of care until his parents agree to it.
 - D. Preparing for his transfer at least a year ahead of time.
 - E. Putting together a clear and concise summary of previous care for the new provider.

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5. You are preparing your practice to safely and seamlessly transition your AYA patients into adult care. You realize that the integration of the transition between pediatric and adult health care providers for chronically ill AYA into the health care system is one of the many challenges our health care system faces.

Which of the following circumstances is contributing most usefully to that necessary integration?

- A. Declining numbers of AYA with chronic medical conditions are reducing the demand for such integration.
- B. For chronic illness, the transition of insurance coverage from children to adults is now practically seamless.
- C. In this era of precision medicine, patients and families no longer cherish relationships with their pediatric provider teams.
- D. Much more attention is now being paid to transition and case management by both private organizations and public policy makers.
- E. The transfer of well-organized electronic medical records from one provider to another now occurs automatically.

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