



Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

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Risk and vulnerability encompass many dimensions of the transition from adolescence to adulthood. Transition from pediatric, parent-supervised health care to more independent, patient-centered adult health care is no exception. The tenets and algorithm of the original 2011 clinical report, “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home,” are unchanged. This updated clinical report provides more practice-based quality improvement guidance on key elements of transition planning, transfer, and integration into adult care for all youth and young adults. It also includes new and updated sections on definition and guiding principles, the status of health care transition preparation among youth, barriers, outcome evidence, recommended health care transition processes and implementation strategies using quality improvement methods, special populations, education and training in pediatric onset conditions, and payment options. The clinical report also includes new recommendations pertaining to infrastructure, education and training, payment, and research.

Risk and vulnerability encompass many dimensions of the transition from adolescence to adulthood, and the transition from pediatric, parent-supervised health care to more independent, patient-centered adult health care is no exception. Twenty years of national child health surveys and state and community studies continue to demonstrate that most youth and young adults with special health care needs (SHCN) and families do not receive the support they need in the transition from pediatric to adult health care. In 2011, the American Academy of Pediatrics (AAP), with the endorsement of the American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP), and the authoring group published a clinical report on health care transition (HCT) that included a process for transition preparation, planning, tracking, and follow-through for all youth and young adults beginning in early adolescence and continuing into young adulthood.¹

abstract

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After the release of that original clinical report, new research and several US and international professional societies' statements on the topic have been published.²⁻²⁰ This update of the AAP, AAFP, and ACP clinical report draws on this recent work and presents the latest implementation experience and refinements of the 2011 transition algorithm. It also reviews new transition research, provides more explicit attention to the role of adult medical and behavioral health clinicians in transition, and makes recommendations pertaining to transition infrastructure, training, payment, and research.

HCT has evolved from a focus on pediatric care responsibility to a shared responsibility by pediatric and adult care clinicians (eg, physicians, nurses, social workers, and others who work together to provide patient care). The crucial role of adult care clinicians in accepting and partnering with young adults has emerged as both a delivery system and a professional education and training challenge.²¹⁻²³ Young adults are increasingly recognized as a vulnerable population not only in terms of high rates of behavioral health risks but also susceptibility to emerging or worsening chronic health conditions and traditionally low use of health care.²⁴⁻²⁶ In addition, many young adults regard health care as a low priority compared with other dimensions of their adult transition (education, employment, housing, relationships, and recreation).^{27,28} Successful HCT efforts are needed to raise awareness among youth, young adults, and their families that maintaining health and continuity of care are central to attainment of broader adult goals.

DEFINITION AND GUIDING PRINCIPLES

HCT is the process of moving from a child to an adult model of health care with or without a transfer to a new

clinician. Transition from pediatric to adult health care is part of a larger theoretical framework for transition affecting all youth, young adults, and families, as outlined by Meleis,²⁹ Geary and Schumacher,³⁰ and Schwartz et al.³¹ Transition theory informs the following overarching principles for this HCT clinical report:

1. Importance of youth- and/or young adult-centered, strength-based focus;
2. Emphasis on self-determination, self-management, and family and/or caregiver engagement;
3. Acknowledgment of individual differences and complexities;
4. Recognition of vulnerabilities and need for a distinct population health approach for youth and young adults;
5. Need for early and ongoing preparation, including the integration into an adult model of care;
6. Importance of shared accountability, effective communication, and care coordination between pediatric and adult clinicians and systems of care;
7. Recognition of the influences of cultural beliefs and attitudes as well as socioeconomic status;
8. Emphasis on achieving health equity and elimination of disparities; and
9. Need for parents and caregivers to support youth and young adults in building knowledge regarding their own health and skills in making health decisions and using health care.

The Transitions Clinical Report Authoring Group, cochaired by Drs Patience White and Carl Cooley, included representatives from the AAP, AAFP, and ACP, the medicine and pediatrics (med-peds) and family medicine community, the nursing profession, and family and young

adult transition experts. A draft of this clinical report underwent extensive peer review by committees, councils, sections, and others within the AAP and by the AAFP and ACP.

STATUS OF TRANSITION PREPARATION AND OUTCOME AMONG US YOUTH

The vast majority of US youth are not receiving transition preparation, according to the 2016 National Survey of Children's Health, a nationally representative survey of parents.³² New estimates of transition preparation for youth (ages 12 through 17) with and, for the first time, without SHCN reveal that 83% of youth with SHCN and 86% of youth without special needs do not meet the national HCT performance measure. This composite measure examines the extent to which (1) youth had time alone to speak with the doctor or other health care clinician during his or her last preventive visit; (2) the doctor or other health care clinician worked with youth to gain self-care skills or understand the changes in health care that happen at 18 years of age; and (3) the doctor or other health care clinician talked with youth about eventually seeing doctors who treat adults. These estimates are lower than past national studies of youth with SHCN³³⁻³⁷ because the previous National Survey of Children with Special Needs (in 2009-2010) assessed whether parents perceived a need for discussion of specific transition topics, and many did not. Consequently, those parents were not counted in the overall estimate. Lack of preparation has also been reported in hospitalized adolescents³⁸ and among children's hospitals.³⁹

Published studies continue to reveal the adverse effects associated with lack of structured HCT interventions in terms of medical complications,⁴⁰⁻⁴³ limitations in health and well-being,^{44,45} problems with treatment

TABLE 1 Youth, Young Adult, and Family Transition^{27,28,37,59,63–84}

Fear of a new health care system and/or hospital
Not wanting to leave their pediatric clinician and pediatric institution
Anxiety about how to relinquish control around managing their youth condition
Anxiety of not knowing the adult clinicians, adult health care system, and logistical issues (ie, finding parking, making appointments, finding a physician who is taking new patients, inadequate transferring patient records, and insurance issues)
Changing and/or different therapies recommended in adult health care
Families' fear that adult clinicians will not listen to and value their expertise
Negative beliefs about adult health care
Inadequate planning
Inadequate preparation and support from clinicians on the transition process and adult model of care
Not having seen clinician alone
Youth and young adults less interested in health compared with broader life circumstances
Adolescents' age, sex, and race and/or ethnicity and their parents' socioeconomic status can affect transition preparation
System difficulties
Lack of communication and coordination and transfer of medical records between adult and pediatric clinician or system
Limited availability of adult primary and specialty clinicians
Difficulty in locating adult clinicians who have specialized knowledge about and community resources for youth with pediatric-onset chronic diseases
Loss of insurance coverage among young adults and cost of care barriers

and medication adherence,⁴⁶ discontinuity of care,^{47–51} patient dissatisfaction, higher emergency department and hospital use,^{52,53} and higher costs of care.^{54–57} An additional challenge is that parents often do not appreciate their role in giving youth ways to increase their independence in seeking and managing their health care.⁵⁸ Other barriers to transition for youth with various chronic conditions are unstable living conditions, lack of a high school degree, low parental education, lack of insurance, distance from adult clinicians, low income, poor psychosocial functioning, and age.⁵⁹

PEDIATRIC TO ADULT HCT BARRIERS AND PREFERENCES

To inform the updated clinical report, a literature search was conducted of peer-reviewed articles published between January 2010 and December 2017. Many transition barriers are experienced by youth, young adults, and parents (Table 1). These barriers mainly are measured among youth and young adults with SHCN. The most prominent barrier mentioned by youth with SHCN and parents and/or caregivers is difficulty in leaving their pediatric clinicians with whom they have had a long-standing relationship. Although youth with

SHCN have limited preparation, they appear to have greater transition readiness skills and demonstrate more independence in completing medical tasks than their peers without special needs.⁶⁰ Clinicians also identify many transition barriers (Table 2). The most common obstacles reported by pediatric and adult care clinicians are the lack of communication and coordination and the different practice styles between health professionals. Also, both pediatric and adult clinicians find the transition of youth with medical complexity more difficult.^{61,62}

Studies of pediatric clinicians on barriers to HCT often mention the lack of adult clinicians to care for youth with pediatric-onset conditions. Yet, recent surveys of adult clinicians in 3 large integrated care systems and in a national survey of adult endocrinologists^{85,110} indicate an increased willingness to accept new young adult patients. To care for young adults, especially those with pediatric-onset conditions, adult clinicians request improved infrastructure (care coordination, links to community resources, lists of subspecialists interested in caring for young adults with SHCN, and availability of pediatric consultation support) and education and training about specific disease processes and

the physical and behavioral stages of youth and young adult development.

OUTCOME EVIDENCE FOR PEDIATRIC TO ADULT HCT INTERVENTION

Although the evidence base on HCT outcomes remains limited, there have been several evaluation studies published in the United States and internationally that document beneficial outcomes of a structured transition approach in terms of quality of care and, to a lesser extent, in terms of service use and patient and family experience. A recent systematic literature review of studies published between January 1995 and April 2016 identified 43 (out of 3844 articles) that met rigorous evaluation criteria.¹¹¹ Two-thirds of the included studies revealed statistically significant positive outcomes. The most commonly reported quality of care outcome was improvement in adherence to care followed by improved perceived health status, quality of life, and self-care skills. The most common positive outcomes for service use were increased adult visit attendance and less time between the last pediatric visit and the initial adult visit. Decreased hospitalization rates were also found, although not as often. Unfortunately, in Gabriel et al's¹¹¹ systematic

TABLE 2 Adult and Pediatric Clinician Transition Barriers^{22,82,85–109}

Communication and/or consultation gaps
Lack of communication, coordination, guidelines, and protocols between the pediatric and adult systems
Inadequate communication from pediatric clinicians, often with a lack of medical records and follow-up recommendations
Lack of long-term follow-up guidelines with care information for youth with SHCN
Gap in consultation with pediatric clinicians
Adult clinicians' concerns about not enough adult subspecialty or mental health care clinicians to care for young adults
Training limitations
Lack of knowledge and/or training in pediatric-onset conditions and adolescent development and behavior
Difficulty meeting psychosocial needs of young adults with pediatric-onset conditions
Caring for adult patients reliant on caregivers
Care delivery, care coordination, and/or staff support gaps
Lack of care coordination and follow-up
Lack of mental health and supportive services
Unfamiliarity with local and regional resources for young adults with chronic conditions
Lack of adequate infrastructure and training
Administrative constraints and lack of time and reimbursement
Lack of coverage for young adults
Lack of patient knowledge and engagement
Young adults' lack of knowledge about disease treatments, medications, and medical history
Lack of information about community resources and/or support groups
Dependency on parents or guardians
Lack of self-advocacy, decision-making skills, and self-care skills
Poor adherence to care
Unrealistic expectations of youth or young adult knowledge of adult medical system and lack of readiness for adult care
Lack of comfort with adult care
Unrealistic youth, young adult, and family expectations of time and attention
Concerns regarding loss of strong relationships with previous clinicians (patient, parent, and/or staff)
Pediatric clinician's lack of confidence in adult clinician and in the stylistic differences between pediatric and adult care, particularly for some youth and young adults with intellectual or developmental disabilities or behavioral health conditions
Parents' reluctance to relinquish responsibility
Parents unaware of changes in privacy issues

review, few studies examined costs, and no study revealed significant cost savings. Positive effects on the experience of care most often cited pertained to the general transition or transfer process. Of the 43 studies in this systematic review, all but 5 addressed youth with a single chronic condition; there were no studies that met inclusion criteria that examined youth with mental health conditions or common chronic conditions (eg, asthma) or of youth without chronic conditions. The systematic review concluded that because of the lack of detailed descriptions of transition interventions, it was not possible to link specific transition interventions to outcomes, as was found in earlier reviews on transition.^{112,113} Since the publication of the systematic review by Gabriel et al,¹¹¹ 2 articles reporting transition cost savings have been published.^{114,115}

Other systematic literature reviews on transition for youth with SHCN have revealed that transition evaluation studies often fail to incorporate conceptual frameworks,^{111,116} clinical recommendations,^{1,18} and international consensus statements.^{117,118} Studies have identified a variety of transition outcome variables,^{86,117–123} and to date, there is no common agreement on which outcome variables should be measured.¹²⁴ The Agency for Healthcare Research and Quality,¹²⁵ the Institute of Medicine,²⁴ and others^{126–129} have identified the need for more robust and consistent measurement of transition. Using the triple aim approach that includes quality of care, patient and clinician experience, and use/cost measures can offer a framework for evaluating transition outcomes.¹²⁸ Patients who are more activated (eg, willingness to

take independent actions to manage their own health) have better health outcomes and care experiences.¹³⁰ There are several ways to measure patient activation, such as through the Patient Activation Measure¹³¹ or through the assessment of health confidence¹³² and motivation.¹³³ There are readiness and self-care assessment tools modeled after motivational interviewing that include scorable questions on transition and health confidence that lead to improved patient activation.¹³⁴ Care coordination is a common feature associated with increased transition planning activities.¹³⁵

UPDATED HCT PROCESSES AND IMPLEMENTATION

Updated HCT Processes

The tenets of the original AAP, AAFP, and ACP transition clinical report

and algorithm are unchanged and still include transition guidance for all youth and young adults.¹ This update provides more specificity and practical guidance on key elements of transition planning, transfer, and integration into adult care. The 2011 clinical report provided guidance for primary and specialty care clinicians on practice-based transition supports for all youth using an age-based algorithm with a component for youth with SHCN. The algorithm contained action steps (discussion of a transition policy, initiation of a transition plan, and review and/or update of the transition plan) for specific age ranges. It also incorporated an assessment of transition readiness or self-care skills to build a youth's independence and preparation for an adult model of care in anticipation of legally becoming an adult at age 18 years, unless alternative decision-making supports are in place. The algorithm recommended the identification of an adult care clinician, communication between pediatric and adult clinicians, and timely exchange of current medical information. The 2011 clinical report also acknowledged that caring for transitioning young adults can present certain challenges, including a need for adult practices to clarify the following issues for the young adult: (1) medical decision-making responsibilities; (2) continued support for developing self-management skills; (3) adult consent and confidentiality policies; (4) how their practice operates; and (5) how to access routine and after-hours care. Recommendations for clinicians to use an adult model of care for youth in either pediatric or adult clinical settings over 18 years of age was not discussed but now is a key part of transition preparation. An adult model of care places the young adult in the center of their care with primary responsibility for their own health care decisions. They have the option to authorize

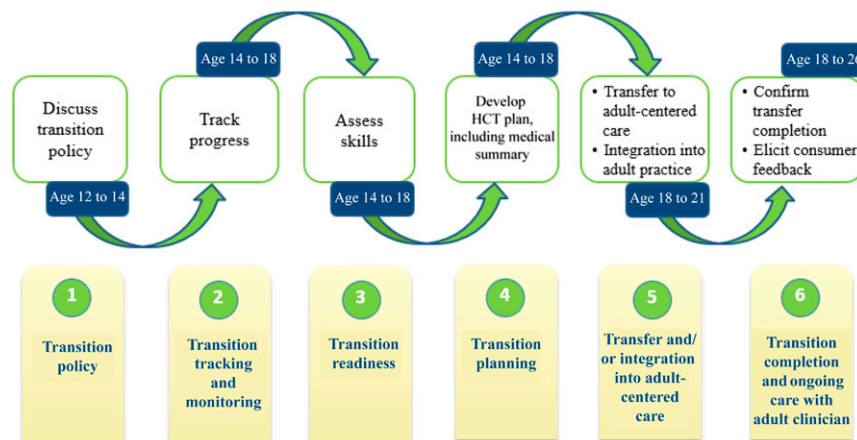


FIGURE 1
Timeline for introducing the Six Core Elements into pediatric practices.

other individuals to be involved in their health care on the basis of Health Insurance Portability and Accountability Act privacy rules and other applicable law. In addition, consistent with Bright Futures,¹³⁶ clinicians should incorporate one-on-one time with youth during the medical visit to better prepare youth for managing their own health and health care. One-on-one time has been shown to increase adherence to care, engagement in care, and the likelihood of sharing health risks with their clinician.^{136–139}

After the publication of the 2011 clinical report, a structured clinical approach with sample tools, called the “Six Core Elements of Health Care Transition,” was developed for all youth. From 2011 to 2013, 5 learning collaboratives with both pediatric and adult care clinicians from rural, suburban, and urban sites across the country tested the Six Core Elements. The collaboratives used quality improvement (QI) methodologies developed by the Institute for Healthcare Improvement¹⁴⁰ to pilot the original Six Core Elements. One of the HCT learning collaboratives was in the District of Columbia and involved teams (pediatric and adult physicians, nurses, social workers, family navigators, young adults, and parents) from both pediatric and adult practices (representing

both family medicine and internal medicine programs) from 3 academic health centers. This work demonstrated the effectiveness of an organized transition process for youth, young adults, and families as well as for primary care pediatric, family medicine, and internal medicine practices.¹⁴¹ In 2014, the Six Core Elements were updated on the basis of the experiences of these multisite QI projects, a literature review, and input from pediatric and adult clinicians and youth, young adult, and family transition experts (Figs 1 and 2).

The Six Core Elements is not a model of care but a structured process that can be customized for use in a busy practice and applied to many different types of transition care models¹⁴² and settings such as transition and young adult clinics and programs. The intensity of the HCT intervention can be guided by several aspects, such as the complexity of the health condition, the social determinants of health,¹⁴³ and adverse childhood experiences¹⁴⁴ of the youth and young adult. For example, if the youth has many comorbidities and/or there is poor adherence to care before the transition, more supports are likely to be needed during and after the transition process.^{145–147} The Six Core Element tools are meant to be

Practice or provider	#1 Transition and/or care policy	#2 Tracking and monitoring	#3 Transition readiness and/or orientation to adult practice	#4 Transition planning and/or integration into adult approach to care or practice	#5 Transfer of care and/or initial visit	#6 Transition completion or ongoing care
Pediatric^a	Create and discuss with youth and/or family	Track progress of youth and/or family transition preparation and transfer	Conduct transition readiness assessments	Develop transition plan, including needed readiness assessment skills and medical summary, prepare youth for adult approach to care, and communicate with new clinician	Transfer of care with information and communication including residual pediatric clinician's responsibility	Obtain feedback on the transition process and confirm young adult has been seen by the new clinician
Adult^a	Create and discuss with young adult and guardian, if needed	Track progress of young adult's integration into adult care	Share and discuss welcome and FAQs with young adult and guardian, if needed	Communicate with previous clinician, ensure receipt of transfer package	Review transfer package, address young adult's needs and concerns at initial visit, update self-care assessment and medical summary	Confirm transfer completion with previous clinician, provide ongoing care with self-care skill building and link to needed specialists

FIGURE 2

Summary of Six Core Elements approach for pediatric and adult practices.

^aProviders that care for youth and/or young adults throughout the life span can use both the pediatric and adult sets of core elements without the transfer process components.

customized for the youth, young adults, and families being served and the transition care model being used by the practice, system, or hospital.¹⁴⁸ They have been shown to facilitate an effective transition process in subspecialty practices,¹⁴⁹ a managed care plan,¹⁵⁰ a children's hospital,¹⁵¹ and a med-peds residency program.¹⁵²

Figure 2 outlines the Six Core Elements. All 3 phases of transition support (preparation, transfer, and integration into adult health care) are included in this approach. The Six Core Elements contain a set of customizable sample tools for use in primary and specialty care practices, 2 process measurement tools¹⁵³ (the Current Assessment of HCT Activities and the HCT Process Measurement Tool)¹⁵⁴ and a feedback measurement tool that can be customized for feedback from youth, young adults, or family on their transition experience (the Transition Feedback Survey for Youth, Young Adults, and Parents and/or Caregivers). In addition, there is a recently validated transition experience tool (Adolescent Assessment of

Preparation for Transition survey) for 16- and 17-year-olds with chronic conditions.¹⁵⁵

The Six Core Elements are packaged into 3 different versions¹⁵⁴:

- For pediatric practices, the Six Core Elements consist of a transition policy, tracking and monitoring, readiness assessment, transition planning (including patient education to fill the gaps in knowledge identified by the readiness assessment), transfer of care, and transfer completion.
- For adult practices, the Six Core Elements include a transition and young adult care policy, tracking and monitoring, orientation to adult practice, initial visit, and ongoing care including a self-management skills assessment and continued self-care education.
- For clinicians who care for youth throughout their life span, such as family medicine physicians, physicians dually trained in internal med-peds, and family nurse practitioners, the Six Core Elements of HCT define ways to transition to an adult approach to care by age 18 years and, if needed,

to transfer to a new adult clinician. This version includes a transition policy, tracking and monitoring, transition readiness, transition planning and/or integration into adult approach to care, transfer to adult approach to care, and transfer completion with ongoing care including continued self-management skills assessment and self-care education.

Figure 3 offers 3 examples of customizable tools available for the first core element (creating a transition policy) for pediatric, family medicine, med-peds, and internal medicine practices.

Implementation of HCT Process

Experience implementing a successful transition process underscores the importance of support of key decision makers from both pediatric and adult practices and/or health systems, hospitals and the early and ongoing engagement of parents and/or caregivers and young adults. Along with physicians, other implementation team members to consider are social workers, nurses, clinic administrators, information technology staff, home

A

For Practices Transitioning Youth to Adult Health Care Clinicians

[Practice Name] wants to help our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14 years, and their families to prepare for the change. The change is from a “pediatric” model of care where parents make most health choices to an “adult” model of care where youth make their own health choices. This means that we will spend time during the visit with the teen without the parent present. This will help youth to be more independent with their own health care.

At age 18 years, most youth legally become adults.^a We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that keeps him/her from making health care choices, we ask parents/caregivers to consider options for supported decision making.

We will work with youth and families about the age for moving to an adult provider and suggest that this transfer occur before the age of (insert age^b). We will assist with this transfer process, including helping to identify an adult clinician, sending medical records, and work with the adult clinician about the unique needs of our patients.

As always, if you have any questions, please feel free to contact us.

B

Practices Transitioning Youth to an Adult Model of Care Without Changing Clinicians

[Practice Name] wants to help our pediatric patients become better prepared for an adult model of health care to stay with our practice as young adults. At about age 14 years, we will begin to spend time during the visit without the parent present to help you to answer questions, set health goals, and support more independence with health care choices. At age 18 years, most youth legally become adults.^a We respect that many of our young adult patients choose to continue to involve their families in their health care choices. Yet, we will no longer be able to discuss your health care with parents or share any personal health information without the young adult’s written approval. To allow others to be involved in health care decisions requires that a signed form be completed. We have the form at the clinic. If a youth has a condition that prevents him/her from making decisions, we encourage families to consider options for supported decision-making. Your health is important to us. If you have any questions or concerns, please feel free to contact us.

C

For Practices Integrating Young Adults into Adult Health Care

[Practice Name] welcomes young adults, including those with special health care needs, to our practice. We aim to provide high-quality, complete, and confidential health care to meet young adults’ unique needs.

At age 18, most youth legally become adults.^a The health care clinician is a partner in supporting your health goals. This means that adult clinicians do not discuss any aspects of your care with anyone else unless you ask that we do. We know that some young adults involve family and close friends in their health care decisions and would like their clinician to share information with those close to them. To allow others to be involved in your health care decisions requires that a signed consent form be completed. The form is available at the clinic. For young adults unable to provide consent, we will need legal documentation about decision-making arrangements.

We ask that new patients moving to our practice call their previous clinician(s) to have a medical summary or medical record sent to us before the first visit. We make every effort to coordinate the transfer of care with previous clinicians, including speaking with your pediatric clinician and assisting with transfer of specialty care, as needed. Having your medical information before the visit helps with your continuity of care and a better experience for you.

Your health is important to us, and we look forward to having you as a new patient. If you have any questions or concerns, please feel free to contact us.

care clinicians, and insurers. With the teams identified, defining the HCT QI project’s goals, strategies, outcomes, measures, and timeline at the start and allowing the time needed to test and implement the transition improvements are key. In addition, utilizing a plan-do-study-act rapid cycle improvement approach^{140,157,158} promotes a process that is efficient and well-tested.

Teamwork is key to improving coordination and communication in the HCT process.¹⁵⁹ In the ideal situation, the availability of care coordination support to guide the transition process and team-based care¹⁶⁰ in both the pediatric and adult settings increases chances of success.^{135,161} Clinicians from nursing and social work professions often fill this important role and often drive the HCT QI process.^{162–164} Families also need assistance with their new role in the health care of their young adult.¹⁶⁵ For youth with multiple pediatric clinicians (primary, subspecialty, behavioral) involved in their care, transfers to adult clinicians are best planned sequentially rather than at the same time.

Transferring to adult primary care clinicians^{126,166} could be the initial transfer so the adult care clinicians can assist in locating and/or coordinating adult subspecialty or behavioral care clinicians, as needed. In transitioning youth with certain chronic conditions, the interplay between pediatric subspecialists and the transfer to adult primary care and/or subspecialty clinicians can vary according to the youth’s needs and availability of adult care clinicians with appropriate specialty knowledge. In the absence of a particular adult subspecialty clinician, transitioning the young adult to an adult primary care clinician with consultation to the pediatric subspecialist could occur

FIGURE 3

Examples of customizable tools for Core Element No. 1: creating an HCT policy. ^aAlthough most states have set the age of majority at 18 years, it is greater in some states. For this clinical report, we chose consistently to use the age 18 years out of economy but recommend that readers consult appropriate laws and regulations in their jurisdiction to assist in determining the appropriate age

until adult clinicians are comfortable with the needed subspecialty knowledge or appropriate adult subspecialists are available.¹⁶⁷ In addition, transfer to adult care is best conducted when the youth's health condition is stable.¹⁶⁸ For patients receiving pediatric palliative care or end-of-life care, timing of transition to adult health care depends on the youth's anticipated disease trajectory and overall goals of care.

A growing number of pediatric and adult practices/systems and public health programs in the United States are customizing and implementing the Six Core Elements to establish a structured process for transition to adult care. In 2016, the Council of Subspecialty Societies of the ACP identified pediatric to adult HCT as a priority initiative as part of its High Value Care Initiative.²¹ Several of the adult medical specialty societies created customized transition readiness and self-care assessments and medical summary templates from the Six Core Elements for young adults with selected conditions that include sickle cell disease, type 1 diabetes mellitus, juvenile idiopathic arthritis, systemic lupus erythematosus, epilepsy and other neurologic conditions, and, in conjunction with the Society of Internal Medicine and the Society of Adolescent Health and Medicine, developmental disabilities and physical disabilities.¹⁶⁹

In 2014, the US Maternal and Child Health Bureau articulated HCT as 1 of its top 15 national priorities for state Title V programs.^{170,171} A total of 32 states and the District of Columbia have chosen to focus on transition and are adopting components of the Six Core Elements approach in activities related to practice and

care coordination improvements, health care professional and family and youth education, interagency transition planning, and outreach and communications.¹⁷²

SPECIAL POPULATIONS

Youth and young adults between the ages of 12 and 26 years represent 20% of the population in the United States.¹⁷³ This stage of life is characterized by change as well as growing independence and self-determination.¹⁴⁷ It is also a period when health risk behaviors peak, chronic conditions are often exacerbated, and general health care use, particularly among the male sex, is low, while emergency department use is high.¹⁷⁴ In addition, it is a time when many leave home for college, employment, or military service and begin to use a new system of health care. Although pediatric medical training programs recognize that adolescents are special populations warranting distinct, proactive care and monitoring,¹³⁶ adult medical training programs are just beginning to recognize young adults as a special population.¹⁷⁵ The Institute of Medicine (now the National Academy of Medicine) and the National Research Council acknowledged the young adult population as a particularly vulnerable population and called for improving the transition process with innovative approaches for engaging and communicating with young adults about their own health care and adapting adult care services to better meet their unique needs.^{24,25} Studies have recently suggested a role for digital communication, telemedicine, and shared medical appointments in health communication strategies in HCT with youth and young adults.^{176–181}

Although all youth and young adults need a safe and seamless HCT to adult health care, some youth (those with complex medical conditions, developmental and/or intellectual disabilities, mental and/or behavioral health conditions, and social complexity) may pose additional challenges to the transition process. These individuals often experience multiple transitions in services and supports from pediatric care and special education to much less resource-rich adult systems. For these special populations, refinements in the transition process may be necessary, including flexibility in the age of transfer to adult care,¹⁸² delayed scheduling of specialist transfers, condition-specific protocols, greater care coordination support, pediatric consultation arrangements, use of peer and/or community health workers, and strong linkages to nonhealth support systems such as education, independent living, community, and employment. System supports like care coordination, care planning, and social services found in many pediatric clinical settings may be less available in adult clinical settings.^{87–89}

Youth with developmental and/or intellectual disabilities, including autism spectrum disorders, often face challenges in transitioning to self-directed care because systemic supports for their preparation and training and accommodations in the health care delivery process are not widely available.^{183–187} The presence of intellectual disability or intellectual impairment attributable to brain injury may affect an individual's ability to fully participate in health-related decision-making and to independently navigate the adult health care system. Although these youth and/or young adults aspire to the highest possible level of independence and community inclusion, many will require decision supports, including those formalized

FIGURE 3 Continued

of majority. It is also important to note that there are nuances in the care of adolescents regarding consent and privacy triggered by emancipation, mature minor doctrine, and for specific health services such as reproductive health and substance abuse treatment. These issues are beyond the scope of this report. Consultation with a lawyer in your state may be appropriate. ^bAt the discretion of the practice. Adapted from Got Transition.¹⁵⁶

through a legal process, such as guardianship or custodianship. Planning for decision-making support is best started at least by age 17 years, and the resulting modifications need to be documented in the medical record and communicated to new adult care clinicians.

Youth with mental or behavioral health conditions also face substantial adversity during the transition period for several reasons.^{188–193} Mental health conditions often peak during young adulthood and impair one's ability for self-care and participation in routine medical or mental health care or decision-making. Shortages of mental and/or behavioral health clinicians are pervasive, and many youth and young adults with psychiatric conditions have no access to a regular source of either mental health or medical care. Consequently, they are at higher risk of dropping out of care as well as employment, education, stable housing, and relationships. Transition planning for this special population is most helpful when the clinic incorporates active preparation, outreach, and support for effective self-advocacy as well as partnerships with family members, medical and mental health and/or behavioral clinicians, and community supports to bridge service gaps.¹⁹⁴

Youth with medical complexity represent approximately 1% of all US children and are a subset of youth with SHCN.^{195,196} These youth have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high care need or use, and often use of medical technology.¹⁹⁷ Many youth with SHCN have frequent hospitalizations. Youth and their families have become familiar with the nursing staff, ancillary staff, routines, expectations, and services that are available in children's hospitals or on children's units within hospitals. In addition to their outpatient care sites and

their clinicians, transitioning to adult hospitals represent a unique set of challenges. Youth and families with frequent admissions should have transition planning discussions with both their children's hospital team and the new adult hospital staff about the upcoming hospital, facility, or transition. In both pediatric and adult hospitals, complex care centers and transition clinics and programs have been established to provide both outpatient and inpatient coordination and management for youth and young adults with medical complexity, recognizing their needs for more individualized planning and collaborative care partnerships between pediatric and adult clinicians or practices.¹⁹⁶

Social complexity, either in isolation or in combination with chronic medical conditions, is the source of many disparities in care for ethnic and racial minorities; immigrant and refugee populations; those with linguistic and cultural differences; lesbian, gay, bisexual, transgender, and queer youth and families¹⁹⁸; and youth affected by poverty,^{63,199,200} homelessness, and foster care.^{201,202} Specific resources that may enhance the transition process include engagement of culturally similar peers, use of family navigators and community health workers, and involvement of schools and community centers. Special populations may not represent the majority of youth transitioning to adulthood, but in the aggregate, they include those most vulnerable to poor outcomes and higher health care costs.

EDUCATION AND TRAINING IN THE CARE OF YOUTH AND/OR YOUNG ADULTS WITH PEDIATRIC-ONSET CONDITIONS

Training of adult clinicians in pediatric-onset diseases and youth and young adult development is a recognized need to improve

transition and improved outcomes for youth and young adults moving to the adult health care system.^{88,90,91,203} Studies of internal medicine residents' exposure and preferences around transition from pediatric to adult health care have shown that internal medicine residents receive little exposure to transition issues or young adult patients in their training⁹¹ and that they want to receive this education mainly through clinical exposure and case discussions.²⁰⁴

HCT is already included in the training of family medicine and med-peds clinicians who care for people throughout the life span. To make transition training more explicit, the Medicine-Pediatrics Program Directors Association developed a special transition curriculum for primary care med-peds residents incorporating training around HCT.²⁰³ Recently, several academic medical centers have started joint pediatric and adult residency training sessions that address transition and caring for young adults with congenital or childhood-onset conditions. Other training approaches include introducing internal medicine residents to young adult patients in continuity clinics and offering electives in college and university health clinics or in transition clinics for youth with SHCN or medical complexity.²⁰⁵

A few pediatric and adult professional societies also have developed HCT training modules for residents in pediatrics and internal medicine, but more training is needed, particularly for adult clinicians during residency and for practicing clinicians through continuing medical education (CME) options and maintenance of certification requirements. Similarly, both pediatric and adult residency training programs could have more training in adolescent and young adult health.^{206,207} The AAP offers a series of case-based, educational

modules designed for pediatric residency program directors and faculty. These modules focus on the patient- and family-centered medical home, care coordination, care planning, transition to adult care, and team-based care.²⁰⁸ In addition, the Association of American Medical Colleges has a transition case scenario, called *But Tommy Likes It Here: Moving to Adult Medicine*, available on its Web site.²⁰⁹

The Society of General Internal Medicine in 2016 published the *Care of Adults With Chronic Childhood Conditions: A Practical Guide*, which provides an overview of HCTs, strategies for primary care clinicians caring for young adults, condition-specific medical information, and sociolegal issues that can assist adult clinicians in caring for young adults.²¹⁰

Two options are available for maintenance of certification Part IV credit for pediatric clinicians from the American Board of Pediatrics: The University of California San Diego and Rady Children's Hospital with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition²¹¹ and the Illinois Transition Care Project.²¹² CME training on transition is becoming more available, especially at national meetings for primary care and subspecialty clinicians.

PAYMENT OPPORTUNITIES FOR HCT

Current payment mechanisms address professional services through traditional fee-for-service reporting or various types of performance-based and alternative models of payment. In recent years, the American Medical Association's Current Procedural Terminology (CPT), along with the Centers for Medicare and Medicaid Services (CMS), have addressed the importance of care management and coordination services through code development for vulnerable care

scenarios such as hospital-to-home transition, chronic care coordination, and behavioral health. These types of codes acknowledge the role that clinical staff play in coordinating the care for vulnerable patients. Although there is currently not a code specifically defined as pediatric-to-adult transition, as called for in the AAP "Principles of Child Health Care Financing,"²¹³ newly developed care management services offer an opportunity to report fee-for-service for many of the elements of transitional care.

Although alternative payment options for transition (eg, using pay-for-performance, capitation, or shared savings) have not yet been incorporated into existing medical home, health home, care coordination, or accountable care payment innovations, collaboration continues to occur among major payers and with CPT to address current voids. CMS recently noted that "...we have sought to recognize significant changes in health care practice, especially innovations in the active management and ongoing care of chronically ill patients. We have been engaged in an ongoing incremental effort to identify gaps in appropriate coding and payment for care management/coordination, cognitive services and primary care within the physician fee schedule."²¹⁴

As billing options for these services continue to evolve, several coding options are currently available to support transition services in both pediatric and adult care settings. For example, in addition to evaluation and management codes for face-to-face visits, CPT includes services that address the following categories: prolonged services with (or without) direct patient contact, medical team conferences, care plan oversight, preventive medicine counseling and behavior change interventions, interprofessional Internet and/or telephone consultations, and

chronic and complex chronic care management.

In addition, CPT includes codes that represent administration of health risk assessment instruments can be used to report transition readiness assessments conducted with youth and parents and self-care assessments conducted with young adults. As a prerequisite for billing, the assessment tools²¹⁵ must be scorable and standardized. Some examples of standardized scorable tools include the Transition Readiness Assessment Questionnaire,²¹⁶ Am I ON TRAC for Adult Care Questionnaire (ON TRAC),²¹⁷ University of North Carolina TR(x) ANSITION Scale,²¹⁸ Self-Management and Transition for Adulthood with Rx = Treatment (STARx Questionnaire),^{219,220} Transition Q,²²¹ an electronic medical record-based transition planning tool,²²² California Healthy and Ready to Work,²²³ Got Transition's Transition Readiness and Self-Care assessment tools,¹³⁴ and the Patient Activation Measure.^{131,224} More information about transition-related codes and case scenarios can be found in the AAP and Got Transition Coding and Reimbursement Tip Sheet²²⁵ as well as a report on value-based payment options.²²⁶

RECOMMENDATIONS

Infrastructure

Since the 2011 clinical report, system infrastructure needs are becoming increasingly apparent as more youth, especially those with pediatric-onset conditions and others included as special populations, enter the transition period. To address these gaps, the following recommendations are called for:

- Clinicians and systems of care (eg, pediatric and adult hospitals including emergency departments, integrated delivery systems, accountable care organizations, community health centers, health plans, public health programs,

behavioral health programs, and school and college health centers) are essential in preparing youth for needed transition preparation, transfer with current medical information, and facilitating integration into adult care. The following actions can support safe and effective transition:

- Integrate HCTs into routine preventive,²²⁷ primary, specialty and subspecialty, and mental and/or behavioral health care.
- Support QI processes within health care systems and pediatric and adult practices to implement the Six Core Element approach with active youth, young adult, and family engagement and feedback. Work directly with their electronic health record support team and/or vendor representative to integrate the Six Core Elements (transition policy, registry, readiness and self-care assessments, transition plan of care, medical summary, transition and/or transfer checklists, and feedback surveys) in a way that supports their own workflow and practice needs.
- Incorporate HCT support as a recommended element in all medical home²²⁸ and health home recognition and certification programs, including standards developed by the National Committee for Quality Assurance, The Joint Commission, and the Utilization Review Accreditation Commission.
- Articulate specific HCT roles and responsibilities among pediatric and adult health care clinicians and systems to facilitate the provision and coordination of recommended transition support.
- Increase the availability and quality of care coordination support, particularly for adult

practices and systems serving young adults with chronic medical, developmental, and behavioral conditions and social complexity.

- Integrate HCT support into other life course systems such as changes in education, guardianship, and power of attorney as needed.^{146,147}
- Expand the availability of pediatric consultation for adult clinicians caring for youth with pediatric-onset conditions.
- Incorporate HCTs into the transition policies and plans of other public program systems (eg, special education, foster care).
- Create up-to-date listings of community resources (eg, adult disability programs) and adult clinicians interested in caring for young adults with pediatric-onset conditions and other special populations.

Education and Training

- In partnership with families and youth, increase education and training opportunities for pediatric and adult health care clinicians in HCTs, youth and young adult development, pediatric-onset diseases, interprofessional practice, and team-based care by adding:
 - CME opportunities²²⁹ (eg, learning modules such as focusing on young adult health and pediatric onset conditions, clinical experiences, curriculum, and interprofessional training opportunities);
 - Enhanced training opportunities during residency and subspecialty training, including joint pediatric and adult training; and
 - HCT processes and support into education systems such as school-based health centers, colleges, and universities.

Payment

To align HCT delivery system innovations with payment incentives, public and private payors and their contracted plans should:

- Compensate clinicians and systems of care for the provision of recommended HCT support related to planning, transfer, and integration into a new adult practice.
- Recognize and pay for CPT and Healthcare Common Procedure Coding System codes important to transition to adult care.
- Develop a CPT Category II code that can be used as a quality measure for tracking the use of transition services by pediatric and adult clinicians.
- Develop innovative payment approaches to encourage collaboration between pediatric and adult care clinicians in the adoption of the HCT process, including the following:
 - Financial incentives for collaboration between pediatric and adult practices around HCT;
 - A per-member, per-month additional payment involved in preparing youth and young adults for transfer out of pediatric care and for outreach and follow-up of young adults coming into a new adult care setting;
 - Performance-based incentives to encourage pediatric practices to transfer their patients at a certain age with a current medical summary, readiness assessment, and evidence of communication with the new practice and to encourage adult practices to accept a certain volume of new young adults with SHCN with pediatric consultation support; and
 - Payment rates for transition as well as future related research and evaluation studies should

stratify for patient risk,²³⁰ taking into consideration not only disease complexity but also social determinants of health, adverse childhood experiences, and availability of family and community supports.

Research

To promote a stronger evidence base for HCTs, funders and researchers should:

- Incorporate all 3 components of HCTs (preparation, transfer, and integration into adult care) in their study design and evaluate HCT processes and outcomes.
- Examine transition outcomes in terms of population health (eg, adherence to care, self-care skill development); experience of youth, young adults, and families; and use (eg, time between last pediatric and first adult visit, adherence to initial and follow-up adult clinician appointments, decreased emergency department use,

and urgent care visits) and cost savings.

- Develop pediatric to adult HCT measures as a part of the CMS Child and Adult Core Measure Set and the National Quality Forum measures.
- Study the impact of HCTs from pediatric to adult health care in terms of long-term outcomes of young adults.
- Encourage national health surveys to include HCT questions for young adults.

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ABBREVIATIONS

AAFP: American Academy of Family Physicians
AAP: American Academy of Pediatrics
ACP: American College of Physicians
CME: continuing medical education
CMS: Centers for Medicare and Medicaid Services
CPT: Current Procedural Terminology
HCT: health care transition
med-peds: medicine and pediatrics
QI: quality improvement
SHCN: special health care needs

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REFERENCES

1. Cooley WC, Sagerman PJ; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200
2. Canadian Pediatric Society. Transition to adult care for youth with special health care needs. *Paediatr Child Health*. 2007;12(9):785–793
3. American College of Obstetricians and Gynecologists. The transition from pediatric to adult health care: preventative care for young women aged 18-26 years. 2015. Available at: <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Adolescent-Health-Care/co626.pdf?dmc=1&ts=20170719T1757289470>. Accessed July 21, 2017
4. Andrade DM, Bassett AS, Bercovici E, et al. Epilepsy: transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. *Epilepsia*. 2017;58(9):1502–1517
5. Betz CL. SPN position statement: transition of pediatric patients into adult care. *J Pediatr Nurs*. 2017;35:160–164
6. Brooks AJ, Smith PJ, Cohen R, et al. UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. *Gut*. 2017;66(6):988–1000

7. Brown LW, Camfield P, Capers M, et al. The neurologist's role in supporting transition to adult health care: a consensus statement. *Neurology*. 2016;87(8):835–840
8. Bryant R, Porter JS, Sobota A; Association of Pediatric Hematology/Oncology Nurses; American Society of Pediatric Hematology Oncology. APHON/ASPHO policy statement for the transition of patients with sickle cell disease from pediatric to adult health care. *J Pediatr Oncol Nurs*. 2015;32(6):355–359
9. Committee on Adolescence. Achieving quality health services for adolescents. *Pediatrics*. 2016;138(2):e20161347
10. Committee on Pediatric Aids. Transitioning HIV-infected youth into adult health care. *Pediatrics*. 2013;132(1):192–197
11. Crane S; Autistic Self Advocacy Network (ASAN). The transition to adulthood for youth with ID/DD: a review of research, policy and next steps. 2013. Available at: http://autisticadvocacy.org/wp-content/uploads/2013/12/HealthCareTransition_ASAN_PolicyBrief_r2.pdf. Accessed January 17, 2018
12. Escherich G, Bielack S, Maier S, et al. Building a national framework for adolescent and young adult hematology and oncology and transition from pediatric to adult care: report of the inaugural meeting of the “AJET” working group of the German Society for Pediatric Oncology and Hematology. *J Adolesc Young Adult Oncol*. 2017;6(2):194–199
13. Foster HE, Minden K, Clemente D, et al. EULAR/PRoS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Ann Rheum Dis*. 2017;76(4):639–646
14. Mazur A, Dembinski L, Schrier L, Hadjipanayis A, Michaud PA. European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Paediatr*. 2017;106(8):1354–1357
15. Peters A, Laffel L; American Diabetes Association Transitions Working Group. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society) [published correction appears in *Diabetes Care*. 2012;35(1):191]. *Diabetes Care*. 2011;34(11):2477–2485
16. Royal College of Nursing. Lost in transition: moving young people between child and adult health services. Available at: <https://www.rcn.org.uk/professional-development/publications/pub-003227>. Accessed January 16, 2018
17. Sable C, Foster E, Uzark K, et al; American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011;123(13):1454–1485
18. UK National Institute for Health Care Excellence (NICE). Transition from children's to adults' services for young people using health or social care services. 2016. Available at: <https://www.nice.org.uk/guidance/ng43>. Accessed July 21, 2017
19. Watson AR, Harden P, Ferris M, Kerr PG, Mahan J, Ramzy MF. Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA). *Pediatr Nephrol*. 2011;26(10):1753–1757
20. Young S, Adamou M, Asherson P, et al. Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network. *BMC Psychiatry*. 2016;16:301
21. Greenlee MC, D'Angelo L, Harms SR, et al; American College of Physicians Council of Subspecialty Societies Pediatric to Adult Care Transitions Initiative Steering Committee. Enhancing the role of internists in the transition from pediatric to adult health care. *Ann Intern Med*. 2017;166(4):299–300
22. Tanner AE, Philbin MM, Ma A, et al; Adolescent Trials Network for HIV/AIDS Interventions. Adolescent to adult HIV health care transition from the perspective of adult providers in the United States. *J Adolesc Health*. 2017;61(4):434–439
23. Zuckerman AL. Transition of care to an adult provider. *Curr Opin Obstet Gynecol*. 2017;29(5):295–300
24. Institute of Medicine; National Research Council of the National Academies. *Investing in the Health and Well-Being of Young Adults*. Washington, DC: The National Academies Press; 2015
25. Society for Adolescent Health and Medicine. Young adult health and well-being: a position statement of the Society for Adolescent Health and Medicine. *J Adolesc Health*. 2017;60(6):758–759
26. Spencer DL, McManus M, Call KT, et al. Health care coverage and access among children, adolescents, and young adults, 2010-2016: implications for future health reforms. *J Adolesc Health*. 2018;62(6):667–673
27. Junge N, Migal K, Goldschmidt I, Baumann U. Transition after pediatric liver transplantation - perceptions of adults, adolescents and parents. *World J Gastroenterol*. 2017;23(13):2365–2375
28. Pyatak EA, Sequeira PA, Whitemore R, Vigen CP, Peters AL, Weigensberg MJ. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with type 1 diabetes. *Diabet Med*. 2014;31(12):1615–1624

29. Meleis AI, ed. *Transitions Theory: Middle Range and Situation Specific Theories in Nursing Research and Practice*. New York, NY: Springer Publishing Company; 2010
30. Geary CR, Schumacher KL. Care transitions: integrating transition theory and complexity science concepts. *ANS Adv Nurs Sci*. 2012;35(3):236–248
31. Schwartz LA, Brumley LD, Tuchman LK, et al. Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatr*. 2013;167(10):939–946
32. Lebrun-Harris LA, McManus MA, Ilango SM, et al. Transition Planning Among US Youth With and Without Special Health Care Needs. *Pediatrics*. 2018;142(4):e20180194
33. Downing KF, Oster ME, Farr SL. Preparing adolescents with heart problems for transition to adult care, 2009-2010 national survey of children with special health care needs. *Congenit Heart Dis*. 2017;12(4):497–506
34. Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B, Newacheck P. Planning for health care transitions: results from the 2005-2006 national survey of children with special health care needs. *Pediatrics*. 2009;123(1). Available at: www.pediatrics.org/cgi/content/full/123/1/e145
35. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013;131(6):1090–1097
36. Sawicki GS, Whitworth R, Gunn L, Butterfield R, Lukens-Bull K, Wood D. Receipt of health care transition counseling in the national survey of adult transition and health. *Pediatrics*. 2011;128(3). Available at: www.pediatrics.org/cgi/content/full/128/3/e521
37. Syverson EP, McCarter R, He J, D'Angelo L, Tuchman LK. Adolescents' perceptions of transition importance, readiness, and likelihood of future success: the role of anticipatory guidance. *Clin Pediatr (Phila)*. 2016;55(11):1020–1025
38. Dwyer-Matzky K, Blatt A, Asselin BL, Wood DL. Lack of preparedness for pediatric to adult-oriented health care transition in hospitalized adolescents and young adults. *Acad Pediatr*. 2018;18(1):102–110
39. Collier RJ, Ahrens S, Ehlenbach ML, et al. Transitioning from general pediatric to adult-oriented inpatient care: National Survey of US Children's Hospitals. *J Hosp Med*. 2018;13(1):13–20
40. Foster BJ. Heightened graft failure risk during emerging adulthood and transition to adult care. *Pediatr Nephrol*. 2015;30(4):567–576
41. Majumdar S. The adolescent with sickle cell disease. *Adolesc Med State Art Rev*. 2013;24(1):295–306, xv
42. Wafa S, Nakhla M. Improving the transition from pediatric to adult diabetes healthcare: a literature review. *Can J Diabetes*. 2015;39(6):520–528
43. Yeung E, Kay J, Roosevelt GE, Brandon M, Yetman AT. Lapse of care as a predictor for morbidity in adults with congenital heart disease. *Int J Cardiol*. 2008;125(1):62–65
44. Chaudhry SR, Keaton M, Nasr SZ. Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatr Pulmonol*. 2013;48(7):658–665
45. Maslow G, Adams C, Willis M, et al. An evaluation of a positive youth development program for adolescents with chronic illness. *J Adolesc Health*. 2013;52(2):179–185
46. Annunziato RA, Baisley MC, Arrato N, et al. Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *J Pediatr*. 2013;163(6):1628–1633
47. Bohun CM, Woods P, Winter C, et al. Challenges of intra-institutional transfer of care from paediatric to adult congenital cardiology: the need for retention as well as transition. *Cardiol Young*. 2016;26(2):327–333
48. Luque Ramos A, Hoffmann F, Albrecht K, Klotsche J, Zink A, Minden K. Transition to adult rheumatology care is necessary to maintain DMARD therapy in young people with juvenile idiopathic arthritis. *Semin Arthritis Rheum*. 2017;47(2):269–275
49. Montano CB, Young J. Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. *Postgrad Med*. 2012;124(5):23–32
50. Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. *J Pediatr Urol*. 2017;13(1):40.e1–40.e6
51. Wojciechowski EA, Hurtig A, Dorn L. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: a need for case management services. *J Pediatr Nurs*. 2002;17(1):18–27
52. Shaw KL, Southwood TR, McDonagh JE; British Society of Paediatric and Adolescent Rheumatology. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child Care Health Dev*. 2007;33(4):368–379
53. Shepard CL, Doerge EJ, Eickmeyer AB, Kraft KH, Wan J, Stoffel JT. Ambulatory care use among patients with Spina Bifida: change in care from childhood to adulthood. *J Urol*. 2018;199(4):1050–1055
54. Barr NG, Longo CJ, Embrett MG, Mulvale GM, Nguyen T, Randall GE. The transition from youth to adult mental health services and the economic impact on youth and their families. *Healthc Manage Forum*. 2017;30(6):283–288
55. Cohen E, Gandhi S, Toulany A, et al. Health care use during transfer to adult care among youth with chronic conditions. *Pediatrics*. 2016;137(3):e20152734
56. Lochridge J, Wolff J, Oliva M, O'Sullivan-Oliveira J. Perceptions of solid organ transplant recipients regarding self-care management and transitioning. *Pediatr Nurs*. 2013;39(2):81–89
57. Mosquera RA, Avritscher EB, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial. *JAMA*. 2014;312(24):2640–2648
58. C.S. Mott Children's Hospital. Back off: parents impeding teens' healthcare independence? 2015. Available at:

https://mottpoll.org/sites/default/files/documents/121415_teenhealthcare.pdf. Accessed November 21, 2017

59. Gray WN, Schaefer MR, Resmini-Rawlinson A, Wagener ST. Barriers to transition from pediatric to adult care: a systematic review. *J Pediatr Psychol*. 2018;43(5):488–502
60. Eaton CK, Davis MF, Gutierrez-Colina AM, LaMotte J, Blount RL, Suveg C. Different demands, same goal: promoting transition readiness in adolescents and young adults with and without medical conditions. *J Adolesc Health*. 2017;60(6):727–733
61. de Silva PSA, Fishman LN. The transition of the gastrointestinal patient from pediatric to adult care. *Pediatr Clin North Am*. 2017;64(3):707–720
62. Stehouwer N, Edge P, Katie Park B, Piccone C, Little J. Acute pain in adolescents and young adults with sickle cell disease: delayed and increased opioid dosing following transition to adult care. *Am J Hematol*. 2017;92(4):E40–E42
63. Sawicki GS, Garvey KC, Toomey SL, et al. Preparation for transition to adult care among Medicaid-insured adolescents. *Pediatrics*. 2017;140(1):e20162768
64. Betz CL, Nehring WM, Lobo ML. Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *J Fam Nurs*. 2015;21(3):362–412
65. Bindels-de Heus KG, van Staa A, van Vliet I, Ewals FV, Hilberink SR. Transferring young people with profound intellectual and multiple disabilities from pediatric to adult medical care: parents' experiences and recommendations. *Intellect Dev Disabil*. 2013;51(3):176–189
66. Cheak-Zamora NC, Teti M, Maurer-Batjer A, Koegler E. Exploration and comparison of adolescents with autism spectrum disorder and their caregiver's perspectives on transitioning to adult health care and adulthood. *J Pediatr Psychol*. 2017;42(9):1028–1039
67. Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, et al. Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective. *J Pediatr Rehabil Med*. 2014;7(1):43–51
68. Frederick NN, Bober SL, Berwick L, Tower M, Kenney LB. Preparing childhood cancer survivors for transition to adult care: the young adult perspective. *Pediatr Blood Cancer*. 2017;64(10)
69. Garvey KC, Foster NC, Agarwal S, et al. Health care transition preparation and experiences in a U.S. national sample of young adults with type 1 diabetes. *Diabetes Care*. 2017;40(3):317–324
70. Geerlings RP, Aldenkamp AP, de With PH, Zinger S, Gottmer-Welschen LM, de Louw AJ. Transition to adult medical care for adolescents with epilepsy. *Epilepsy Behav*. 2015;44:127–135
71. Gray WN, Resmini AR, Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: perspectives of patients, parents, and health professionals. *Inflamm Bowel Dis*. 2015;21(7):1641–1651
72. Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: a systematic review and thematic synthesis of parents' experiences. *Patient Educ Couns*. 2017;100(1):76–92
73. Kuhlthau KA, Delahaye J, Erickson-Warfield M, Shui A, Crossman M, van der Weerd E. Health care transition services for youth with autism spectrum disorders: perspectives of caregivers. *Pediatrics*. 2016;137(suppl 2):S158–S166
74. Nieboer AP, Cramm JM, Sonneveld HM, Roebroek ME, van Staa A, Strating MM. Reducing bottlenecks: professionals' and adolescents' experiences with transitional care delivery. *BMC Health Serv Res*. 2014;14:47
75. Raina R, Wang J, Sethi SK, Ferris M. Survey on health care transition services in pediatric nephrology. *Clin Exp Nephrol*. 2018;22(1):206–207
76. Rutishauser C, Sawyer SM, Ambresin AE. Transition of young people with chronic conditions: a cross-sectional study of patient perceptions before and after transfer from pediatric to adult health care. *Eur J Pediatr*. 2014;173(8):1067–1074
77. Sheehan AM, While AE, Coyne I. The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: a systematic review. *Diabet Med*. 2015;32(4):440–458
78. Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev*. 2008;34(5):557–563
79. Timmer A, Peplies J, Westphal M, et al. Transition from pediatric to adult medical care - a survey in young persons with inflammatory bowel disease. *PLoS One*. 2017;12(5):e0177757
80. Bregnballe V, Boisen KA, Schjøtz PO, Pressler T, Lomborg K. Flying the nest: a challenge for young adults with cystic fibrosis and their parents. *Patient Prefer Adherence*. 2017;11:229–236
81. Lopez KN, Karlsten M, Bonaduce De Nigris F, et al. Understanding age-based transition needs: perspectives from adolescents and adults with congenital heart disease. *Congenit Heart Dis*. 2015;10(6):561–571
82. Philbin MM, Tanner AE, Chambers BD, et al; The Adolescent Trials Network. Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: using adolescent and adult providers' insights to create multi-level solutions to address transition barriers. *AIDS Care*. 2017;29(10):1227–1234
83. Porter JS, Wesley KM, Zhao MS, Rupff RJ, Hankins JS. Pediatric to adult care transition: perspectives of young adults with sickle cell disease. *J Pediatr Psychol*. 2017;42(9):1016–1027
84. Davidson LF, Doyle M, Silver EJ. Discussing future goals and legal aspects of health care: essential steps in transitioning youth to adult-oriented care. *Clin Pediatr (Phila)*. 2017;56(10):902–908
85. Garvey KC, Telo GH, Needleman JS, Forbes P, Finkelstein JA, Laffel LM. Health care transition in young adults with type 1 diabetes: perspectives of adult endocrinologists in the U.S. *Diabetes Care*. 2016;39(2):190–197

86. Sobota AE, Shah N, Mack JW. Development of quality indicators for transition from pediatric to adult care in sickle cell disease: a modified Delphi survey of adult providers. *Pediatr Blood Cancer*. 2017;64(6)
87. Okumura MJ, Kerr EA, Cabana MD, Davis MM, Demonner S, Heisler M. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*. 2010;125(4). Available at: www.pediatrics.org/cgi/content/full/125/4/e748
88. Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care: internists' perspectives. *Pediatrics*. 2009;123(2):417–423
89. Suh E, Daugherty CK, Wroblewski K, et al. General internists' preferences and knowledge about the care of adult survivors of childhood cancer: a cross-sectional survey. *Ann Intern Med*. 2014;160(1):11–17
90. Hunt S, Sharma N. Pediatric to adult-care transitions in childhood-onset chronic disease: hospitalist perspectives. *J Hosp Med*. 2013;8(11):627–630
91. Patel MS, O'Hare K. Residency training in transition of youth with childhood-onset chronic disease. *Pediatrics*. 2010;126(suppl 3):S190–S193
92. O'Sullivan-Oliveira J, Fernandes SM, Borges LF, Fishman LN. Transition of pediatric patients to adult care: an analysis of provider perceptions across discipline and role. *Pediatr Nurs*. 2014;40(3):113–120, 142
93. Heldman MR, Sohn MW, Gordon EJ, et al. National survey of adult transplant hepatologists on the pediatric-to-adult care transition after liver transplantation. *Liver Transpl*. 2015;21(2):213–223
94. McLaughlin SE, Machan J, Fournier P, Chang T, Even K, Sadof M. Transition of adolescents with chronic health conditions to adult primary care: factors associated with physician acceptance. *J Pediatr Rehabil Med*. 2014;7(1):63–70
95. Nakhla M, Bell LE, Wafa S, Dasgupta K. Improving the transition from pediatric to adult diabetes care: the pediatric care provider's perspective in Quebec, Canada. *BMJ Open Diabetes Res Care*. 2017;5(1):e000390
96. Nathan PG, Daugherty CK, Wroblewski KE, et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. *J Cancer Surviv*. 2013;7(3):275–282
97. Nehring WM, Betz CL, Lobo ML. Uncharted territory: systematic review of providers' roles, understanding, and views pertaining to health care transition. *J Pediatr Nurs*. 2015;30(5):732–747
98. Okumura MJ, Heisler M, Davis MM, Cabana MD, Demonner S, Kerr EA. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med*. 2008;23(10):1621–1627
99. Oskoui M, Wolfson C. Current practice and views of neurologists on the transition from pediatric to adult care. *J Child Neurol*. 2012;27(12):1553–1558
100. Sebastian S, Jenkins H, McCartney S, et al. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists. *J Crohn's Colitis*. 2012;6(8):830–844
101. Sparud-Lundin C, Berghammer M, Moons P, Bratt EL. Health care providers' attitudes towards transfer and transition in young persons with long term illness- a web-based survey. *BMC Health Serv Res*. 2017;17(1):260
102. Szalda DE, Jimenez ME, Long JE, Ni A, Shea JA, Jan S. Healthcare system supports for young adult patients with pediatric onset chronic conditions: a qualitative study. *J Pediatr Nurs*. 2015;30(1):126–132
103. Telfair J, Alexander LR, Loosier PS, Alleman-Velez PL, Simmons J. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*. 2004;15(3):443–461
104. Wright EK, Williams J, Andrews JM, et al. Perspectives of paediatric and adult gastroenterologists on transfer and transition care of adolescents with inflammatory bowel disease. *Intern Med J*. 2014;44(5):490–496
105. Durkin ET, Zurakowski D, Rangel SJ, Lillehei CW, Fishman LN. Passing the baton: the pediatric surgical perspective on transition. *J Pediatr Surg*. 2015;50(7):1196–1200
106. Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving communication in adolescent cancer care: a multiperspective study. *Pediatr Blood Cancer*. 2016;63(8):1423–1430
107. Fishman LN, DiFazio R, Miller P, Shanske S, Waters PM. Pediatric orthopaedic providers' views on transition from pediatric to adult care. *J Pediatr Orthop*. 2016;36(6):e75–e80
108. Rothstein DH, Li V. Transitional care in pediatric neurosurgical patients. *Semin Pediatr Surg*. 2015;24(2):79–82
109. Ekim A, Kolay M, Ocakci AF. Readiness for transition from pediatric to adult care for adolescents with chronic heart disease. *J Spec Pediatr Nurs*. 2018;23(1)
110. White P, Cuomo C, Johnson-Hooper T, Harwood C, McManus M. Adult provider willingness to accept young adults into their practice: results from three integrated delivery systems. In: *Healthcare Transition Research Consortium Meeting*; October 26, 2016; Houston, TX
111. Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: a systematic review. *J Pediatr*. 2017;188:263–269.e15
112. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database Syst Rev*. 2016;4:CD009794
113. Chu PY, Maslow GR, von Isenburg M, Chung RJ. Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *J Pediatr Nurs*. 2015;30(5):e19–e27
114. Burns K, Farrell K, Myszka R, Park K, Holmes-Walker DJ. Access to a youth-specific service for young adults with type 1 diabetes mellitus is associated with decreased hospital length of stay

- for diabetic ketoacidosis. *Intern Med J*. 2018;48(4):396–402
115. Maeng DD, Snyder SR, Davis TW, Tomcavage JF. Impact of a complex care management model on cost and utilization among adolescents and young adults with special care and health needs. *Popul Health Manag*. 2017;20(6):435–441
 116. Betz CL, Ferris ME, Woodward JF, Okumura MJ, Jan S, Wood DL. The health care transition research consortium health care transition model: a framework for research and practice. *J Pediatr Rehabil Med*. 2014;7(1):3–15
 117. Fair C, Cuttance J, Sharma N, et al; International and Interdisciplinary Health Care Transition Research Consortium. International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatr*. 2016;170(3):205–211
 118. Suris JC, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. *J Adolesc Health*. 2015;56(6):612–618
 119. Coyne B, Hallowell SC, Thompson M. Measurable outcomes after transfer from pediatric to adult providers in youth with chronic illness. *J Adolesc Health*. 2017;60(1):3–16
 120. Philbin MM, Tanner AE, Ma A, et al. Adolescent and adult HIV providers' definitions of HIV-infected youths' successful transition to adult care in the United States. *AIDS Patient Care STDS*. 2017;31(10):421–427
 121. Pierce JS, Aroian K, Schifano E, et al. Health care transition for young adults with type 1 diabetes: stakeholder engagement for defining optimal outcomes. *J Pediatr Psychol*. 2017;42(9):970–982
 122. Rachas A, Lefeuvre D, Meyer L, et al. Evaluating continuity during transfer to adult care: a systematic review. *Pediatrics*. 2016;138(1):e20160256
 123. Sattoe JNT, Hilberink SR, van Staa A. How to define successful transition? An exploration of consensus indicators and outcomes in young adults with chronic conditions. *Child Care Health Dev*. 2017;43(5):768–773
 124. Sharma N, O'Hare K, Antonelli RC, Sawicki GS. Transition care: future directions in education, health policy, and outcomes research. *Acad Pediatr*. 2014;14(2):120–127
 125. Davis AM, Brown RF, Taylor JL, Epstein RA, McPheeters M. Transition Care for Children With Special Health Needs. *Pediatrics*. 2014;134(5):900–908
 126. Bhawra J, Toulany A, Cohen E, Moore Hepburn C, Guttman A. Primary care interventions to improve transition of youth with chronic health conditions from paediatric to adult healthcare: a systematic review. *BMJ Open*. 2016;6(5):e011871
 127. Le Roux E, Mellerio H, Guilmin-Crépon S, et al. Methodology used in comparative studies assessing programmes of transition from paediatrics to adult care programmes: a systematic review. *BMJ Open*. 2017;7(1):e012338
 128. Prior M, McManus M, White P, Davidson L. Measuring the “triple aim” in transition care: a systematic review. *Pediatrics*. 2014;134(6). Available at: www.pediatrics.org/cgi/content/full/134/6/e1648
 129. Vaks Y, Bensen R, Steidtmann D, et al. Better health, less spending: redesigning the transition from pediatric to adult healthcare for youth with chronic illness. *Healthc (Amst)*. 2016;4(1):57–68
 130. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207–214
 131. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005; 40(6 pt 1):1918–1930
 132. Wasson J, Coleman EA. Health confidence: an essential measure for patient engagement and better practice. *Fam Pract Manag*. 2014;21(5):8–12
 133. Wigfield A, Eccles JS. Expectancy-value theory of achievement motivation. *Contemp Educ Psychol*. 2000;25(1):68–81
 134. Got Transition. Transition readiness. Available at: www.gottransition.org/providers/staying-3.cfm. Accessed July 21, 2017
 135. Sharma N, O'Hare K, O'Connor KG, Nehal U, Okumura MJ. Care coordination and comprehensive electronic health records are associated with increased transition planning activities. *Acad Pediatr*. 2018;18(1):111–118
 136. Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*. 4th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2017
 137. American Academy of Family Physicians. Adolescent and young adult health. Available at: <https://www.aafp.org/patient-care/public-health/adolescent-young-adult.html>. Accessed March 23, 2018
 138. Edman JC, Adams SH, Park MJ, Irwin CE Jr. Who gets confidential care? Disparities in a national sample of adolescents. *J Adolesc Health*. 2010;46(4):393–395
 139. Ford CA. Which adolescents have opportunities to talk to doctors alone? *J Adolesc Health*. 2010;46(4):307–308
 140. Institute for Healthcare Improvement. *The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement*. Boston, MA: Institute for Healthcare Improvement; 2003
 141. McManus M, White P, Barbour A, et al. Pediatric to adult transition: a quality improvement model for primary care. *J Adolesc Health*. 2015;56(1):73–78
 142. Wright C, Steinway C, Jan S. The genesis of systems of care for transition to adulthood services: emerging models in primary and subspecialty care. *Curr Opin Pediatr*. 2018;30(2):303–310
 143. Byhoff E, Freund KM, Garg A. Accelerating the implementation of social determinants of health interventions in internal medicine. *J Gen Intern Med*. 2018;33(2):223–225
 144. Chartier MJ, Walker JR, Naimark B. Separate and cumulative effects of adverse childhood experiences in predicting adult health and health care utilization. *Child Abuse Negl*. 2010;34(6):454–464

145. Alassaf A, Gharaibeh L, Grant C, Punthakee Z. Predictors of type 1 diabetes mellitus outcomes in young adults after transition from pediatric care. *J Diabetes*. 2017;9(12):1058–1064
146. Nguyen T, Stewart D, Gorter JW. Looking back to move forward: reflections and lessons learned about transitions to adulthood for youth with disabilities. *Child Care Health Dev*. 2018;44(1):83–88
147. Wood D, Crapnell T, Lau L, et al. In: Halfon N, Forrest CB, Lerner RM, Faustman EM, eds. *Handbook of Life Course Health Development*. Basel, Switzerland: Springer International Publishing; 2018:123–144
148. Farre A, McDonagh JE. Helping health services to meet the needs of young people with chronic conditions: towards a developmental model for transition. *Healthcare (Basel)*. 2017;5(4):E77
149. Jones MR, Robbins BW, Augustine M, et al. Transfer from pediatric to adult endocrinology. *Endocr Pract*. 2017;23(7):822–830
150. McManus M, White P, Pirtle R, Hancock C, Ablan M, Corona-Parra R. Incorporating the six core elements of health care transition into a Medicaid managed care plan: lessons learned from a pilot project. *J Pediatr Nurs*. 2015;30(5):700–713
151. Hickam T, White PH, Modrcin A, McManus M, Cox K. Implementing a nationally recognized pediatric-to-adult transitional care approach in a major children's hospital. *Health Soc Work*. 2018;43(1):3–6
152. Volertas SD, Rossi-Foulkes R. Using quality improvement in resident education to improve transition care. *Pediatr Ann*. 2017;46(5):e203–e206
153. Bilimoria KY. Facilitating quality improvement: pushing the pendulum back toward process measures. *JAMA*. 2015;314(13):1333–1334
154. Got Transition. Six core elements of health care transition. 2014. Available at: www.gottransition.org/resources/index.cfm. Accessed June 29, 2017
155. Sawicki GS, Garvey KC, Toomey SL, et al. Development and validation of the adolescent assessment of preparation for transition: a novel patient experience measure. *J Adolesc Health*. 2015;57(3):282–287
156. Got Transition. Home page. Available at: www.gottransition.org/. Accessed July 25, 2017
157. Fredericks EM, Magee JC, Eder SJ, et al. Quality improvement targeting adherence during the transition from a pediatric to adult liver transplant clinic. *J Clin Psychol Med Settings*. 2015;22(2–3):150–159
158. Langley GL, Moen R, Nolan KM, Nolan TW, Norman CL, Provost LP. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. 2nd ed. San Francisco, CA: Jossey-Bass; 2009
159. Mahan JD, Betz CL, Okumura MJ, Ferris ME. Self-management and transition to adult health care in adolescents and young adults: a team process. *Pediatr Rev*. 2017;38(7):305–319
160. Bolen SD, Stange KC. Investing in relationships and teams to support managing complexity. *J Gen Intern Med*. 2017;32(3):241–242
161. Katkin JP, Kressly SJ, Edwards AR, et al; Task Force on Pediatric Practice Change. Guiding principles for team-based pediatric care. *Pediatrics*. 2017:e20171489
162. Davidson LF, Chhabra R, Cohen HW, Lechuga C, Diaz P, Racine A. Pediatricians transitioning practices, youth with special health care needs in New York State. *Clin Pediatr (Phila)*. 2015;54(11):1051–1058
163. Gold JI, Boudos R, Shah P, Rossi-Foulkes R. Transition consultation models in two academic medical centers. *Pediatr Ann*. 2017;46(6):e235–e241
164. Zoni S, Verga ME, Hauschild M, et al. Patient perspectives on nurse-led consultations within a pilot structured transition program for young adults moving from an academic tertiary setting to community-based type 1 diabetes care. *J Pediatr Nurs*. 2018;38:99–105
165. Suris JC, Larbre JP, Hofer M, et al. Transition from paediatric to adult care: what makes it easier for parents? *Child Care Health Dev*. 2017;43(1):152–155
166. Kerr H, Price J, Nicholl H, O'Halloran P. Transition from children's to adult services for young adults with life-limiting conditions: a realist review of the literature. *Int J Nurs Stud*. 2017;76:1–27
167. Shah P, Boudos R. Transitions from adolescent to adult care. *Pediatr Ann*. 2012;41(2):73–78
168. Klostermann NR, McAlpine L, Wine E, Goodman KJ, Kroeker KI. Assessing the transition intervention needs of young adults with inflammatory bowel diseases. *J Pediatr Gastroenterol Nutr*. 2018;66(2):281–285
169. American College of Physicians. Homepage. Available at: <https://www.acponline.org/>. Accessed July 21, 2017
170. Association of Maternal & Child Health Programs, National Academy for State Health Policy, Lucile Packard Foundation for Children's Health. *Standards for Systems of Care for Children and Youth With Special Health Care Needs, Version 2.0*. Washington, DC: Association of Maternal & Child Health Programs; 2017
171. Lu MC, Lauver CB, Dykton C, et al. Transformation of the title V maternal and child health services block grant. *Matern Child Health J*. 2015;19(5):927–931
172. McManus M, Beck D. *Transition to Adult Health Care and State Title V Program Directions: A Review of 2017 Block Grant Applications*. Washington, DC: The National Alliance to Advance Adolescent Health; 2017
173. US Census Bureau. Annual estimates of the resident population: April 1, 2010 to July 1, 2016. 2016. Available at: <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>. Accessed September 20, 2018
174. Hemker BG, Brousseau DC, Yan K, Hoffmann RG, Panepinto JA. When children with sickle-cell disease become adults: lack of outpatient care leads to increased use of the emergency department. *Am J Hematol*. 2011;86(10):863–865
175. Ozer EM, Urquhart JT, Brindis CD, Park MJ, Irwin CE Jr. Young adult preventive health care guidelines: there but can't be found. *Arch Pediatr Adolesc Med*. 2012;166(3):240–247

176. Badawy SM, Kuhns LM. Economic evaluation of text-messaging and smartphone-based interventions to improve medication adherence in adolescents with chronic health conditions: a systematic review. *JMIR Mhealth Uhealth*. 2016;4(4):e121
177. Coyne I, Prizeman G, Sheehan A, Malone H, While AE. An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: design and early use. *Patient Educ Couns*. 2016;99(9):1496–1504
178. Griffiths F, Bryce C, Cave J, et al. Timely digital patient-clinician communication in specialist clinical services for young people: a mixed-methods study (the LYNC study). *J Med Internet Res*. 2017;19(4):e102
179. Hausmann JS, Touloumtzis C, White MT, Colbert JA, Gooding HC. Adolescent and young adult use of social media for health and its implications. *J Adolesc Health*. 2017;60(6):714–719
180. Los E, Ulrich J, Guttman-Bauman I. Technology use in transition-age patients with type 1 diabetes: reality and promises. *J Diabetes Sci Technol*. 2016;10(3):662–668
181. Raymond JK. Models of care for adolescents and young adults with type 1 diabetes in transition: shared medical appointments and telemedicine. *Pediatr Ann*. 2017;46(5):e193–e197
182. Hardin AP, Hackell JM; Committee on Practice and Ambulatory Medicine. Age limit of pediatrics. *Pediatrics*. 2017;140(3):e20172151
183. US Government Accountability Office. *Youth With Autism: Roundtable Views of Services Needed During the Transition Into Adulthood*. Washington, DC: US Government Accountability Office; 2016
184. Anderson KA, Sosnowy C, Kuo AA, Shattuck PT. Transition of individuals with autism to adulthood: a review of qualitative studies. *Pediatrics*. 2018;141(suppl 4):S318–S327
185. Nathenson RA, Zablotsky B. The transition to the adult health care system among youths with autism spectrum disorder. *Psychiatr Serv*. 2017;68(7):735–738
186. van Schalkwyk GI, Volkmar FR. Autism spectrum disorders: challenges and opportunities for transition to adulthood. In: Martel A, Fuchs DC, eds. *Transitional Age Youth and Mental Illness: Influences on Young Adult Outcomes*. Philadelphia, PA: Elsevier; 2017:329–340
187. Walsh C, Jones B, Schonwald A. Health care transition planning among adolescents with autism spectrum disorder. *J Autism Dev Disord*. 2017;47(4):980–991
188. Abidi S. Paving the way to change for youth at the gap between child and adolescent and adult mental health services. *Can J Psychiatry*. 2017;62(6):388–392
189. McConachie H, Hoole S, Le Couteur AS. Improving mental health transitions for young people with autism spectrum disorder. *Child Care Health Dev*. 2011;37(6):764–766
190. Nguyen T, Embrett MG, Barr NG, et al. Preventing youth from falling through the cracks between child/adolescent and adult mental health services: a systematic review of models of care. *Community Ment Health J*. 2017;53(4):375–382
191. Paul M, Street C, Wheeler N, Singh SP. Transition to adult services for young people with mental health needs: a systematic review. *Clin Child Psychol Psychiatry*. 2015;20(3):436–457
192. Signorini G, Singh SP, Marsanic VB, et al; MILESTONE Consortium. The interface between child/adolescent and adult mental health services: results from a European 28-country survey. *Eur Child Adolesc Psychiatry*. 2018;27(4):501–511
193. Singh SP, Tuomainen H. Transition from child to adult mental health services: needs, barriers, experiences and new models of care. *World Psychiatry*. 2015;14(3):358–361
194. McManus M, White P. Transition to adult health care services for young adults with chronic medical illness and psychiatric comorbidity. In: Martel A, Fuchs DC, eds. *Transitional Age Youth and Mental Illness: Influences on Young Adult Outcomes*. Philadelphia, PA: Elsevier; 2017:367–380
195. Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status complexicus? The emergence of pediatric complex care. *Pediatrics*. 2018;141(suppl 3):S202–S211
196. Kuo DZ, Houtrow AJ; Council on Children With Disabilities. Recognition and management of medical complexity. *Pediatrics*. 2016;138(6):e20163021
197. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–538
198. Rogers SM. Transitional age lesbian, gay, bisexual, transgender, and questioning youth: issues of diversity, integrated identities, and mental health. In: Martel A, Fuchs DC, eds. *Transitional Age Youth and Mental Illness: Influences on Young Adult Outcomes*. Philadelphia, PA: Elsevier; 2017:297–310
199. Bisgaier J, Rhodes KV. Auditing access to specialty care for children with public insurance. *N Engl J Med*. 2011;364(24):2324–2333
200. DeBaun MR, Telfair J. Transition and sickle cell disease. *Pediatrics*. 2012;130(5):926–935
201. Kang-Yi CD, Adams DR. Youth with behavioral health disorders aging out of foster care: a systematic review and implications for policy, research, and practice. *J Behav Health Serv Res*. 2017;44(1):25–51
202. Lee T, Morgan W. Transitioning to adulthood from foster care. In: Martel A, Fuchs DC, eds. *Transitional Age Youth and Mental Illness: Influences on Young Adult Outcomes*. Philadelphia, PA: Elsevier; 2017:283–296
203. Kuo AA, Ciccarelli MR, Sharma N, Lotstein DS. A health care transition curriculum for primary care residents: identifying goals and objectives. *Pediatrics*. 2018;141(suppl 4):S346–S354
204. Mennito S. Resident preferences for a curriculum in healthcare transitions for young adults. *South Med J*. 2012;105(9):462–466
205. Chung RJ, Jasien J, Maslow GR. Resident dyads providing transition care to adolescents and young

- adults with chronic illnesses and neurodevelopmental disabilities. *J Grad Med Educ.* 2017;9(2):222–227
206. Coles MS, Greenberg KB. The time is here: a comprehensive curriculum for adolescent health teaching and learning from the Society for Adolescent Health and Medicine. *J Adolesc Health.* 2017;61(2):129–130
207. Michaud PA, Schrier L, Ross-Russel R, et al. Paediatric departments need to improve residents' training in adolescent medicine and health: a position paper of the European Academy of Paediatrics. *Eur J Pediatr.* 2018;177(4):479–487
208. American Academy of Pediatrics. Homepage. Available at: <https://www.aap.org/>. Accessed July 21, 2017
209. Fishman L. But Tommy likes it here: moving to adult medicine. 2012. Available at: www.mededportal.org/publication/9190. Accessed July 21, 2017
210. Pilapil M, DeLaet DE, Kuo AA, Peacock C, Sharma N, eds. *Care of Adults With Chronic Childhood Conditions: A Practical Guide*. Basel, Switzerland: Springer International Publishing; 2016
211. North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN). Home page. Available at: www.naspghan.org. Accessed July 21, 2017
212. American Academy of Pediatrics. Illinois chapter. Welcome to ICAAP online. Available at: <https://icaap.remote-learner.net/>. Accessed July 27, 2017
213. Hudak ML, Helm ME, White PH; Committee on Child Health Financing. Principles of child health care financing. *Pediatrics.* 2017;140(3):e20172098
214. Centers for Medicare & Medicaid Services; US Department of Health and Human Services. Medicare program; revisions to payment policies under the physician fee schedule and other revisions to part B for CY 2018; Medicare shared savings program requirements; and Medicare diabetes prevention program. Final rule. *Fed Regist.* 2017;82(219):52976–53371
215. Stinson J, Kohut SA, Spiegel L, et al. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *Int J Adolesc Health Med.* 2014;26;159–174
216. Wood DL, Sawicki GS, Miller DM, et al. Factor structure, reliability and validity of the Transition Readiness Assessment Questionnaire (TRAQ). *Acad Pediatr.* 2014;14:415–422
217. Moynihan M, Saewyc E, Whitehouse S, Paone M, McPherson G. Assessing readiness for transition from paediatric to adult health care: revision and psychometric evaluation of the Am I ON TRAC for Adult Care questionnaire. *J Adv Nurs.* 2015;71(6):1324–1335
218. Ferris ME, Harward DH, Bickford K, et al. A clinical tool to measure the components of health-care transition from pediatric care to adult care: the UNC TR(x)ANSITION scale. *Ren Fail.* 2012;34(6):744–753
219. Cohen SE, Hooper SR, Javalkar K, et al. Self-management and transition readiness assessment: concurrent, predictive and discriminant validation of the STARx questionnaire. *J Pediatr Nurs.* 2015;30(5):668–676
220. Nazareth M, Hart L, Ferris M, Rak E, Hooper S, van Tilburg MAL. A parental report of youth transition readiness: the parent STARx questionnaire (STARx-P) and re-evaluation of the STARx child report. *J Pediatr Nurs.* 2018;38:122–126
221. Klassen AF, Grant C, Barr R, et al. Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: the TRANSITION-Q. *Child Care Health Dev.* 2015;41(4):547–558
222. Wiemann CM, Hergenroeder AC, Bartley KA, et al. Integrating an EMR-based transition planning tool for CYSHCN at a children's hospital: a quality improvement project to increase provider use and satisfaction. *J Pediatr Nurs.* 2015;30(5):776–787
223. Betz CL. California healthy and ready to work transition health care guide: developmental guidelines for teaching health care self-care skills to children. *Issues Compr Pediatr Nurs.* 2000;23(4):203–244
224. Bomba F, Markwart H, Muhlan H, et al. Adaptation and validation of the German Patient Activation Measure for adolescents with chronic conditions in transitional care: PAM® 13 for adolescents. *Res Nurs Health.* 2018;41(1):78–87
225. McManus M, White P, Harwood C, Molteni R, Kanter D, Salus T. 2018 coding and reimbursement tip sheet for transition from pediatric to adult health care. 2018. Available at: www.gottransition.org/resourceGet.cfm?id=353. Accessed October 1, 2018
226. McManus M, White P, Schmidt A. *Recommendations for Value-Based Transition Payment for Pediatric and Adult Health Care Systems: A Leadership Roundtable Report*. Washington, DC: The National Alliance to Advance Adolescent Health; 2018
227. White P, Schmidt A, McManus M, Irwin CE Jr. *Incorporating Health Care Transition Services Into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians*. Washington, DC: Got Transition; 2018
228. Harwood C, McManus M, White P. *Incorporating Pediatric-to-Adult Transition Into NCQA Patient-Centered Medical Home Recognition*. Washington, DC: Got Transition; 2017
229. Stevenson R, Moore DE Jr. Ascent to the summit of the CME pyramid. *JAMA.* 2018;319(6):543–544
230. Stille CJ, Antonelli RC, Spencer K, et al. *Aligning Services With Needs: Characterizing the Pyramid of Complexity Tiering for Children With Chronic and Complex Conditions*. Palo Alto, CA: Lucile Packard Foundation for Children's Health; 2018

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