CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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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 SHCN[33–37] 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 adolescents[38] 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

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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's[111] systematic

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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 Measure[131] or through the assessment of health confidence[132] 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

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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

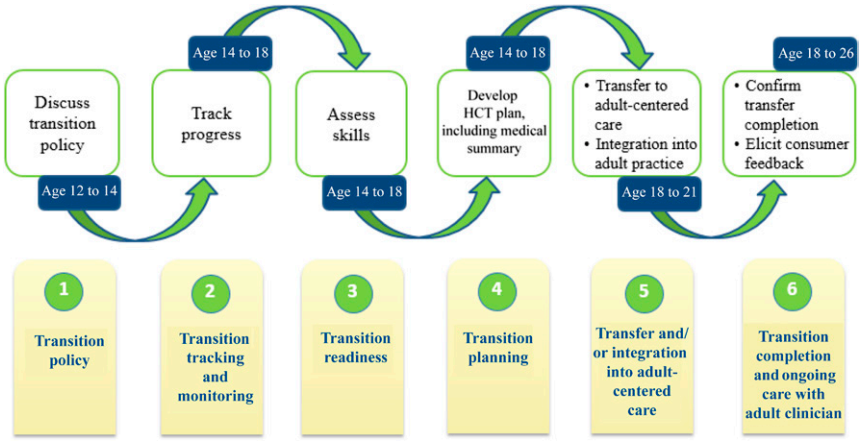

FIGURE 1
Timeline for introducing the Six Core Elements into pediatric practices.

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 Improvement[140] 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 models[142] 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 experiences[144] 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

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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 clincian
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.
[a]Providers 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 tools[153] (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 versions[154]:

- 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

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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 clinicians(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.

FIGURE 3
Examples of customizable tools for Core Element No. 1: creating an HCT policy. [a]Although 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

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 care[160] 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

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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. [b]At the discretion of the practice. Adapted from Got Transition.[156]

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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 families[198]; 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 training[91] 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

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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 Nutrition[211] 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 tools[215] 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 Sheet[225] 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,

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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 home[228] 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 opportunities[229] (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

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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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