



Health care gap affects 20% of United States population: Transition from pediatric to adult health care

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ABSTRACT

Transition-aged youth and young adults, ages 12 to 26, represent almost 20% of the US population, and an estimated 25%–35% have one or more chronic conditions. The vast majority of youth with and without special health care needs do not receive the necessary and professionally recommended services to transition from pediatric to adult care. Without adequate support during this transition, youth and young adults face an increased risk of adverse outcomes. To accelerate adoption of recommended transition processes in both pediatric and adult systems of care, the authors offer a series of implementation, payment, and research options that are consistent with clinical guidelines from the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians.

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1. Background

The Institute of Medicine in its 2014 report, *Investing in the Health and Well-Being of Young Adults*, called on health care delivery systems and provider organizations to improve the transition process from pediatric to adult medical and behavioral health care [1]. Despite persistent reports documenting the adverse impacts of not having a structured transition process in place for both youth and young adults [2], current national survey data reveal that only 17% of youth with special health care needs and 14% of youth without special health care needs received anticipatory guidance on transition preparation from their health care providers [3]. Unfortunately, no comparable transition data are available for young adults; however, health care utilization data reveal the age-gradient pattern of older adolescents and young adults experiencing incrementally worse access to care compared to both their younger and older peers [4].

Transition-aged youth and young adults, ages 12 to 26, represent almost 20% of the US population [5]. Among the 65 million individuals in this age group, an estimated 25%–35% have one or more chronic conditions [6,7]. Keeping this uniquely vulnerable population group prepared for and

connected to continuous care as part of a planned process for transition from pediatric to adult care is critical for their health and well-being [2].

In 2018, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) articulated a recommended health care transition (HCT) timeline and process for pediatric and adult practices [8]. This process, called the Six Core Elements of HCT, includes a set of patient-centered activities related to transition planning (typically between ages 12 and 21), transfer of care (typically between ages 18 and 22), and integration into adult care (typically between ages 18 and 26) [9].

The *transition planning process* includes informing youth and families about the practice's transition approach; conducting periodic assessments of transition readiness skills with needed self-care education; preparing a medical summary as part of an ongoing plan of care; discussing changes that happen at age 18 with an adult model of care, which includes the changing role of caregivers; assisting in identification of an adult clinician; preparing a transfer package; providing consultation support to adult clinicians, if needed; and obtaining regular feedback from youth and families about their transition experience.

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The *transfer of care process* includes exchange of the transfer package, communication/confirmation between pediatric and adult clinicians, clarification of the residual role responsibility prior to initial visit with adult clinician, the sharing of any supported decision making documents (e.g., power of attorney or guardianship), and communication and education with the transferring young adult.

The *integration into adult care process* includes several activities that are similar to what takes place in pediatric care as part of transition planning. These include informing young adults about the practice's approach to accepting and partnering with them, including clear explanations of privacy and consent protections; welcoming and orienting young adults to the practice and services offered; offering appointment reminders; ensuring that the initial visit allows sufficient time to address concerns young adults may have about the transfer and to clarify key distinctions between adult and pediatric care; updating the medical summary as part of a care plan; continuing to assess self-care skills with needed education, as most young adults still have self-care skill gaps; making referrals to other medical, behavioral, and reproductive health and community resources; and obtaining feedback from young adults on the HCT support received.

Despite Got Transition's extensive experience implementing the Six Core Elements with large systems of care [10], children's hospitals [11–13], academic health centers [14,15], community health centers [10], school-based health centers [16], managed care plans [17], and care coordination programs [18], implementation of these recommended processes largely remains in its early stages. For the most part, pediatric and adult systems of care have not collaborated or established a structured transitional care process, though a growing number are pursuing quality improvement (QI) strategies with pilot populations (e.g., those with type 1 diabetes [19], epilepsy [20], sickle cell disease [21,22], ADHD [23]).

To accelerate adoption of recommended transition processes in both pediatric and adult systems of care, the authors of this commentary offer a series of implementation, payment, and research options that are consistent with the 2018 AAP/AAFP/ACP Clinical Report [8].

2. Implementation options

An important driver for influencing the diffusion of HCT innovation in pediatric and adult care practices and systems is the recognition of the benefits of having a structured transition process in place for youth with chronic conditions [2,24]. Another factor that helps to facilitate the adoption of health care innovations is the availability of adaptable clinical support tools, the Six Core Elements, aligned with professional recommendations [9]. Still another important element affecting innovation momentum is consumer demand. In the case of HCT, consumer demand is demonstrated by the 85% of parents/caregivers who report not receiving transition preparation services [3], patient-reported difficulties finding available adult health care clinicians [25], and a substantial number of young adults who remain in pediatric primary and specialty care systems well into their adult years [26].

Pediatric-to-adult transitional care implementation strategies can begin with an examination of current processes in place in pediatric and adult practices as well as in practices that retain youth to ensure that an adult model of care is being practiced. Got Transition's Current Assessment of HCT Activities, available on Got Transition's website at www.gottransition.org, has been widely used to provide a quick baseline snapshot and a roadmap for needed improvements. Health systems often begin introducing transitional care QI as a pilot with youth with selected conditions or with selected specialty clinics [13,17]; others have initiated a broad systems-wide approach [10]. In both instances, this implementation strategy starts with a careful review, selection, and customization of some or all of the Six Core Elements approach and tools, with input from staff and youth and families. Transition clinic processes are then tested using QI methods to determine when, how, and by whom each of the Six Core Elements is provided. Additional practice implementation resources are available on Got Transition's website – e.g., incorporating transition into medical home recognition [27], incorporating transition into preventive care for adolescents and young adults [28], and integrating

young adults with intellectual and developmental disabilities and autism spectrum disorder into adult care [29,30].

Shared accountability between pediatric and adult systems is critical for effective transitional care. Unfortunately, coordination and collaboration between these two distinctive care delivery systems have been very limited. Even in large integrated care systems and accountable care organizations (ACOs), where pediatric and adult care are within the same organizational structure, connectedness for a planned handoff and integration into adult care has not been well-established. Involvement of both pediatric and adult systems at the outset of a QI effort has many short- and long-term benefits, not the least of which is building greater understanding and respect for the unique systems of care and available supports that each offers. Indeed, it is also important for youth and families to understand these distinctions [31,32].

Additional implementation recommendations were made to the authors by a group of 65 key stakeholders from the Centers for Medicare and Medicaid Services, state Medicaid agencies, commercial payers, health plans, employer coalitions, professional organizations, children's hospitals, academic and policy groups, and patient and family advocacy organizations [33]. Informants recommended that transitional care efforts start with youth and young adults with chronic conditions likely to maintain eligibility with the same insurer as they transition to adulthood. In addition, initial transition implementation pilots should focus on the transfer period, as summarized in Table 1, to include the provision of requisite transition services in pediatric care prior to transfer; the actual transfer services involving the exchange of current information and communication between providers; and adult care services following transfer to facilitate a smooth integration of new young adult patients into care, including needed referrals to other medical, behavioral, reproductive, and community-based supports.

3. Payment options

Commercial and Medicaid payers are on a steep uphill climb to implement alternative payment models in place of fee-for-service (FFS) arrangements. To date, there have been no tested examples of a value-based transition payment model for youth with special health care needs. This is not surprising given the current state of pediatric-to-adult transition implementation. Notably, however, with recent funding support from the Working for Inclusive and Transformative Healthcare (WITH) Foundation, The National Alliance to Advance Adolescent Health/Got Transition and the Health Services for Children with Special Needs (HSCSN) Medicaid specialty managed care plan are starting a 3-year project, working with a large academic adolescent primary care site and two adult primary care sites, to initiate a value-based payment (VBP) pilot for young adults ages 18–25 with intellectual and developmental disabilities who are transitioning to adult care.

Despite the movement away from FFS arrangements, it is important to note that many VBP arrangements are built on a FFS foundation. However, when it comes to pediatric-to-adult transitional care, there is no ambulatory transition CPT code that captures the set of face-to-face and non-face-to-face codes that are like the CPT codes 99495 and 99496 for hospital-to-home transitional services. Thus, clinicians seeking payment for recommended transition services are challenged to identify a set of CPT codes that are reimbursed by payers – for example, for the important preparation and updating of a medical summary/emergency care plan/plan of care. Phone or internet consultation between sending and receiving doctors – a key element of seamless, continuity of care – is seldom reimbursed. Consequently, this gap in payment and care often leaves youth, young adults, and their families to navigate the transition process without these critical services. These and other examples underscore the value of recognizing transition-related codes [34] as an important step in moving forward to VBP.

At a recent leadership roundtable, payers, plans, clinical leaders, and advocates prioritized a set of VBP options with several examples of how each option could be structured [33]. The top three options selected were enhanced FFS payments, infrastructure payments, and pay-for-performance (P4P) payments.

Table 1
Actions for implementing a structured pediatric-to-adult HCT process

Transition planning during pediatric care	Transfer	Integration into adult care
<ul style="list-style-type: none"> • Development of the practice's transition policy to share with youth/family • Transition readiness skill assessment and education • Preparation/update of medical summary and emergency care plan • Preparation of plan of care with HCT goals for youth with special health care needs • Referral, if needed, for supported decision-making • Discussion and practice of an adult model of care at age 18 • Assistance with identifying an adult clinician • Preparation of transfer package • Outreach for pediatric appointment adherence • Sequenced transfers (if seeing multiple clinicians) • Consultation support to adult clinicians, if needed • Youth/family feedback 	<ul style="list-style-type: none"> • Transfer package exchange • Communication/confirmation between pediatric/adult clinicians • Clarification of residual role responsibility prior to initial visit with adult clinician • Communication and education with transferring young adult 	<ul style="list-style-type: none"> • Development of a transition policy for accepting young adult (YA) patients into the practice, and sharing of the policy with YA/family. • Identification of adult clinicians in practice to care for YAs • Preparation of FAQs and orientation information for YAs • Pre-visit outreach and appointment reminders • Review of new patient records • Initial face-to-face visit with YA • Update of medical summary • Medication reconciliation • Update of plan of care (especially for those with special health care needs) • Self-care skill assessment and education • Assistance in establishing referrals for medical specialists/behavioral health/reproductive care/community supports
Ages 12–21	Ages 18–22	Ages 18–26

Resources and tools to implement a structured transition process are included in Got Transition's Six Core Elements of Health Care Transition. Six Core Elements packages are available for different clinical settings (pediatrics, family medicine, med-peds, and internal medicine). The customizable packages as well as implementation guides can be downloaded for free on Got Transition's website at www.GotTransition.org.

Enhanced FFS payments are built on a traditional FFS structure, and payment amounts for certain CPT codes are positively adjusted. For example, an enhanced fee for evaluation and management services could incentivize adult practices to accept a certain volume of young adults with chronic conditions. Another example is to pay a higher fee for care plan oversight services on the pediatric side to ensure the preparation of a current medical summary, plan of care with HCT information, and communication between the pediatric and adult clinicians. An enhanced FFS could act to compensate for the extra time required for clinicians to provide HCT services.

Infrastructure payments are investments that support fundamental changes at the practice and system levels. For example, an infrastructure payment could support a practice or system as they upgrade their electronic medical records (EMRs) to incorporate recommended HCT clinical processes. Another example of an infrastructure payment is to build care coordination supports for adult practices accepting young adults with chronic conditions. Similarly, on the pediatric side, an infrastructure payment for care coordination supports could be carried out by parent partners or community health workers representative of the community being served. Since most systems and practices do not currently have a structured HCT process in place, an upfront infrastructure payment is important to stimulate a planned and sustainable HCT process.

A P4P payment rewards clinicians based on their performance on selected quality measures. For example, pediatric and adult clinicians or practices could be rewarded for the transfer of patients who have accessed adult primary care or demonstrated improved outcomes (such as improved preventive or primary care visit rates or reduced rates of preventable emergency room visits and hospitalizations). Pediatric and adult clinicians or practices could also be rewarded if they achieve specific transition quality performance targets. Roundtable participants noted that it is important for a P4P payment to be time-limited and clearly linked to measurable outcomes that can be captured in claims data or EMR systems [33]. They also noted that the selection of VBP options in this early stage of innovation may be very different than what it looks like following more widespread adoption.

4. Research options

Building on lessons learned from research on patient-centered medical homes [35], implementation research/QI studies are needed to examine how the Six Core Elements are being customized, utilized, and replicated in integrated care systems/ACOs, primary care, specialty care, behavioral health care, care coordination, hospital and surgical care, and managed care. Understanding how programs effectively implement pediatric-to-adult transitional care in different settings, using different clinical

processes, with different patient populations, and having different types of pediatric and adult collaborative arrangements is critically important, especially because of the complexity of this transitional intervention.

Previous systematic literature reviews on HCT have noted that descriptions of interventions are often limited, making it difficult to distinguish specific individual or combined characteristics associated with positive outcomes [2]. To the extent that future research projects can use frameworks, such as the Six Core Elements [9] or the AAP/AAFP/ACP Clinical Report [8], to describe their transition components in pediatric and adult care, there will be a better understanding of what is in the “black box” constituting HCT interventions. To support the spread of effective pediatric-to-adult HCT programs, it will also be important to clearly describe the specific HCT interventions and QI approach that influenced both positive and negative outcomes.

When considering quality performance measures for pediatric-to-adult HCT, as called for by the previously described leadership roundtable, process measures are initially important to ensure that a structured transition approach has been implemented, and several outcome measures can be considered as well. An example of an existing HCT process measure is Got Transition's Current Assessment of HCT Activities, which is available for free on Got Transition's website. With respect to triple aim measures of population health, utilization/costs, and consumer experience, early adopters are most likely to want to improve appropriate utilization of health care among their transition-aged population, such as an increase in annual primary care visits, decrease in emergency room use, and/or decreased time between the last pediatric visit and initial adult visit. Measuring population health improvements can be more challenging as few disease-specific measures are available. Alternatively, one can examine medication reconciliation and related meaningful use requirements around exchange of medical information as population health and transition process measures. Measuring consumer experience with the transitional process is very important, and Got Transition has multiple transition feedback surveys for possible use, including one following transfer out of pediatric care (to assess the transition planning supports) and one following integration into adult care. Both are available for free on Got Transition's website.

In each of the research options, it is important to be attentive to the role of culture in the implementation and measurement of HCT processes. Many youth and young adults with special health care needs are members of cultures plagued by health disparities. The study of the intersectionality of disability, race, ethnicity, socioeconomic status, geographic location, and/or gender, and its role in achieving a successful HCT to adult health care is necessary in order to reduce the risk of increased health inequalities as young adults with special health care needs move through the life course. In addition, it will help to ensure that the Six Core Elements are culturally sensitive to diverse populations.

5. Conclusion

In summary, numerous implementation, payment, and research options are available that on their own or together can help to ensure that youth with chronic conditions and their caregivers have available a structured HCT process to facilitate transition planning, transfer, and integration into adult care.

CRedit authorship contribution statement

Margaret McManus: Conceptualization, Writing - original draft. **Patience White:** Conceptualization, Writing - original draft. **Annie Schmidt:** Conceptualization, Writing - original draft. **Michael Barr:** Conceptualization, Writing - review & editing. **Carolyn Langer:** Conceptualization, Writing - review & editing. **Kevin Barger:** Conceptualization, Writing - review & editing. **Allysa Ware:** Conceptualization, Writing - review & editing.

Declaration of competing interest

The authors have no conflicts of interest relevant to this article to disclose. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by the Lucile Packard Foundation for Children's Health. The authors have not presented study data as an abstract or poster.

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