Transition of Care

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Transition from Adolescence to Adulthood

As adolescents reach adulthood, inevitably they must transition from pediatric to adult-oriented health care. Far too often, this passive process occurs when an adolescent ages out of his or her pediatrician's practice. During this period, a fifth of adolescents and young adults lose access to health insurance, and a quarter of them have gaps in their medical care. This transition is particularly challenging for the 20 % of youth with special health care needs, defined as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require more than routine health and related services. Medical progress in the last several decades has improved the survival rates for children with chronic illnesses such that 90 % of such youth now survive and thrive into adulthood.

Transition medicine, as defined by the Society for Adolescent Health and Medicine, refers to the purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems. The goal of health care transitions (HCT), according to a 2002 consensus statement by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP), is to "maximize lifelong functioning and potential through the

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provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood." In addition to preparing for medical transitions and transfer of care, providers should prepare and empower adolescents for transitions throughout all other aspects of their lives, including psychosocial, work, school, and independent living. While the timing of the actual "transfer" of medical care will vary between pediatricians, adolescent specialists, and med-peds or family medicine (where the health care provider may follow them longitudinally), all providers of health care services to adolescents should incorporate transition planning into their practice.

Best Practices: *Six Core Elements of Health Care Transition*

With the publication in June 2011 of "Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home," the AAP, AAFP, and ACP provided detailed practice-level guidance for supporting this health care transition. Out of this consensus, the National Health Care Transition Center (called "Got Transition") developed the Six Core Elements of Health Care Transition (see www.gottransition.org). They adapt these core elements for each type of provider, outlining concrete steps in the transition process for providers practicing pediatrics, adult internal medicine, or both (see Table 29.1 for Provider Transition Checklist and Timeline).

1. **Transition Policy**

   Create a transition policy to establish a consistent practice-wide approach and describe how transition planning is a part of lifelong preparation for a successful adult life. The policy should explicitly state the age and process by which youth shift from a pediatric to an adult model of care. It should be included in practice introductory materials and be reintroduced to youth and families around age 12 years.

Table 29.1 Provider transition checklist and timeline

Transition step	Ages 11–13	Ages 14–16	Ages 17–19	Ages 20–22
Transition readiness				
• Encourage the adolescent to assume increasing responsibility for his/her health care management	❑	❑	❑`	❑
• Meet privately with the adolescent for part of the visit	❑	❑	❑	❑
• Assure the adolescent understands his/her health condition and medications	❑	❑	❑	❑
• Assess the adolescent's and the family's readiness for transfer to an adult care provider		❑	❑	❑
• Address gaps in preparation, knowledge, and skills		❑	❑	❑
Transition planning				
• Address health care transition needs		❑	❑	❑
• Assess the need for guardianship/conservatorship; assess the adolescent's ability to make independent decisions		❑	❑	❑
• Create health care transition action plans, portable medical summary		❑	❑	❑
• Identify possible adult care providers			❑	❑
• Initiate communication with the adult provider			❑	❑
Transfer of care and transition completion				
• Send "Transition Package" and transfer letter			❑	❑
• Discuss nuances of care with the adult provider via direct communication			❑	❑
• Follow-up after the transfer			❑	❑

The timeline provided here can be modified as developmentally appropriate for your adolescent patient. Use your clinical judgment as to which items apply to your patient

(continued)

Table 29.1 (continued)

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2. **Transition Tracking and Monitoring**

   Identify transitioning youth and create a transition registry or database for the practice to track the preparation and progress of these patients. Some electronic health records can be used to identify and tag these patients.

3. **Transition Readiness**

   Assess an adolescent's strengths and weaknesses in order to guide the process of transition to adult health care. This involves identifying an adolescent's specific needs and goals in self-sufficiency and management. A number of tools are available to assess this transition readiness (see Table 29.2 for Provider Resources). One such validated form is the Transition Readiness Assessment Questionnaire (TRAQ), which has been shortened to a 20-item scale, organized into five main categories: managing your own medications; appointment keeping (accessing medical care and health insurance); tracking health issues (keeping a medical history); communicating with providers (talking with your doctor or nurse); and managing other transition activities (job or school, activities of daily living, personal safety).

4. **Transition Planning**

   Address the HCT needs and gaps in knowledge and readiness identified in step three. This involves creating a HCT action plan with the youth and family, as well as a portable medical summary and emergency care-plan if needed (see Table 29.3 for web sites that allow families and youth to create portable medical summaries and develop self-care skills). These forms should be given to the family, patient, and eventually to the adult provider. Families should be given information regarding

Table 29.2 Resources for providers

Resource	Web site
American Academy of Pediatrics Medical Home Modules: offers an education module for residents on Facilitating the Transition from Pediatric to Adult Care	www.aap.org/en-us/professional-resources/practice-support/medicalhome/Pages/Modules.aspx
Florida Health and Transitions Services (HATS) (Supported by the Florida Dept of Health, Children's Medical Services Network, Florida Developmental Disabilities Counsel, University of Florida): offers training modules and continuing education credits on Health Care Transitions, tools for transition, resources for youth and families	www.floridahats.org/
Got Transition? National Health Care Transition Center (supported by the US Maternal and Child Health Bureau/HRSA and the Center for Medical Home Improvement): broad source of information for providers, youth, families—including training materials and a comprehensive list of resources for transition planning and preparation	www.gottransition.org
National Alliance to Advance Adolescent Health: adolescent advocacy organization	www.thenationalalliance.org
Adolescent Health Transition Project (Supported by the University of Washington): resources for youth, families, providers	depts.washington.edu/healthtr

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Table 29.3 Resources for youth and families

Resource	Web site
Being a Healthy Adult: How to Advocate for Your Health and Health Care (Supported by Boggs Center on Developmental Disabilities at Robert Wood Johnson Medical School): guide to transition for youth with disabilities in English and Spanish	http://rwjms.rutgers.edu/boggscenter/products/documents/transitiontoadulthealthcare-en-complete.pdf
Center for Children with Special Needs (Supported by Seattle Children's Hospital): information on communication, planning future, keeping track of medical information	http://cshcn.org/teens
Florida Health and Transitions Services (HATS) For Youth and Families: skill building curricula and videos, care plans, medical summary forms	www.floridahats.org/?page_id=616
Got Transition? National Health Care Transition Center: FAQs, educational materials, tools	www.gottransition.org/youthfamilies/index.cfm
Healthy Children (from the American Academy of Pediatrics): parenting web site with information for specific age groups, including teens and young adults	https://healthychildren.org
Kids as Self-Advocates (KASA): leadership and advocacy organization run by youth with disabilities	www.fvkasa.org
National Center for Medical Home Implementation (supported by the American Academy of Pediatrics and the US Maternal and Child Health Bureau): guide to building a care notebook and medical history summary	https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx
Sick Kids Good 2 Go Transition Program (from the Hospital for Sick Kids, University of Toronto): transition tools including health passport, health apps, educational materials	www.sickkids.ca/Good2Go/For-Youth-and-Families/Index.html
Teens Health (Supported by Nemours Center for Children's Health Media): information on general teen health, chronic disease and conditions	www.kidshealth.org/teens

insurance planning, self-care management, and community resources. And for families whose youth have intellectual disabilities, it is important to plan early to address guardianship issues (see below).

5. **Transfer of Care**

   Ensure an appointment is set up with an adult provider. In advance of this appointment, there should be direct communication between the pediatric and adult providers (e-mail, phone, or in-person) regarding the patient's medical history, unique needs, and anticipatory guidance on potential complications that may arise in the transition period. The pediatric provider should send a transition package, not merely a copy of the patient's whole medical record, but rather this includes a transfer letter, portable medical summary, and supplemental documents as needed (i.e., guardianship or legal documents, condition fact sheets). For adolescents continuing with the same provider, at this point an adult approach-to-care should be implemented. Adolescents should be counseled on shared decision-making, privacy and consent, adherence to care, and preferred methods of communication.

6. **Transition Completion**

   Finally, the pediatric team remains a resource for the transferred patient and the adult team following care transfer. The pediatric team should make contact with the adult team 3–6 months post transfer to answer any unforeseen questions and ensure successful continuity of care.

Addressing Guardianship

The legal age of majority in most states is 18 years. Health Insurance Portability and Accountability Act (HIPAA) privacy rules apply—meaning that a clinician cannot release information about a patient over 18 without the patient's consent, regardless of the intellectual level or communication abilities of the patient. Therefore, parents should be informed that they cannot be given health information about their adult child without consent or legal guardianship. There are less restrictive forms of guardianship that

can support specific decision-making, while still allowing the youth to share in the process and participate as much as possible in the assent and consent of their care. But, like most aspects of the transition process, families and providers must plan ahead, as successful implementation of these important changes cannot happen overnight.

Barriers and Solutions

There are many barriers to successful transitions. Patients and families are often reluctant to leave their trusted pediatrician of many years. Additionally, they may feel uneasy about moving away from the comfortable pediatric model into an adult-centered model in which the youth takes on more autonomy. Accordingly, pediatricians should introduce the concept of transition planning at an early age and emphasize that it will be a long-term collaborative journey. Listening to and communicating carefully with the patient and family remain key parts of transition planning and have been found to be predictive of successful transitions. Transition practices must be flexible, and adapt to the unique needs of each individual, as some adolescents and their families may need more guidance in acquiring self-sufficiency and management skills.

Providers cite time constraints and the lack of reimbursement for transition services and care coordination as additional barriers to adequate transition planning. These issues can be mitigated by using coding strategies to increase reimbursement. Transition planning often happens within regularly scheduled office visits (checkups, chronic disease management), and thus providers can bill for their time using existing Current Procedural Terminology (CPT) codes for health maintenance visits (CPT 99394, 99395) or prolonged encounter with an established patient involving counseling for more than 50 % of the visit (99214, 99215). Even work such as phone calls, emails, and other coordination activities outside of discrete office visits can be billed using care plan oversight CPT codes (99374, 99375). In addition, training modules and resources have been developed to guide providers through the transition process (see Table 29.2).

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