The transition from pediatric to adult subspecialists is a significant challenge for adolescents and young adults with special health care needs (YASHCN). More and more children are surviving to adulthood with increasingly complex conditions and are followed by numerous subspecialists. Given this changing dynamic, the transition to an adult-oriented patient-centered medical home (PCMH) becomes less like moving homes and more like moving neighborhoods. General internists who care for these patients need tools to help them facilitate a smooth transition of subspecialty care and to co-manage their patients with multiple subspecialty teams.

With the current system, numerous studies demonstrate increased morbidity during the transition of subspecialty care. Type 1 diabetics experience worsened glycemic control. There is an increased incidence of graft failure in transplant recipients. Patients with congenital heart disease have increased morbidities and need for intervention—particularly when there is a lapse of subspecialty care during the transition process. The transition of subspecialty care is also a source of anxiety for pediatric providers, patients, and families in part due to the long-standing relationships with these subspecialists.

Every year, a growing number of children with special health care needs enters into this potentially hazardous transition process. Roughly half of all patients living with cystic fibrosis are adults, and there are more adults currently living with congenital heart disease than children with these conditions. Similar epidemiologic shifts are seen in patients with sickle cell disease, pediatric transplant recipients, and survivors of pediatric malignancies.

General internists and family physicians now provide care for the vast majority of these patients. Of the nearly 1 million adults with congenital heart disease in the United States, for example, less than 100,000 attend specialized adult congenital heart disease centers. Providing this care is extremely complex and time consuming. The average adult primary care physician in the United States shares patients with numerous adult specialists and subspecialists as well as visiting nurses, physical and occupational therapists, and mental health professionals. The prospect of adding pediatricians and pediatric subspecialists to this list is daunting. Further, many adult providers may not feel as though they have adequate time, reimbursement, or training to coordinate the transition process or to provide ongoing care to adults with special health care needs. This is compounded by a perceived lack of adult subspecialists capable of treating adults with childhood conditions. There is an increasing need for strategies to improve outcomes during the transition process and to optimize co-management between the PCMH and its neighbors—the subspecialists.

Understanding the overall transition process will assist the general internist in facilitating the transition of subspecialty care. Transition planning should begin at age 12, with patient- and family-oriented discussions at each medical home encounter. Beginning by the age 14, a written transition plan should be developed. This portable medical summary should be reviewed and updated through and beyond age 18. For children with special health care needs, the management of their chronic conditions should be included in this plan. Particular attention should be paid to disease-specific information, self-care competencies, and the plan for transitioning subspecialty care. Generic and disease-specific portable medical summaries are available online. The actual transition of care typically takes place between ages 18 and 21. Ideally, this should occur when the patient’s condition is relatively stable. Subspecialty teams should be involved in the process from start to finish and should identify adult subspecialty providers on the receiving end of the transition.

Once the transition occurs from the pediatric to the adult-oriented medical home, the general internist will co-manage the patient initially with the pediatric and adult specialists. In 2010, the Council of Specialty Societies of the American College of Physicians published a position paper titled “The Patient-centered Medical Home Neighbor: The Interface of the Patient-centered Medical Home with Specialty/Subspecialty Practices.” This position paper outlines four forms of interaction between the PCMH and their neighbors (PCMH-N): pre-consultation communication, formal consultation, co-management, and transfer of the patient to the specialty/subspecialty PCMH for comprehensive management. The paper does not specifically address the continued on page 2
complex transition process involving PCMH and one or more PCMH-N for YASHCN. However, the general concepts of co-management are useful in guiding the adult-oriented PCMH provider in managing YASHCN alongside their subspecialty providers.

The ACP suggests three forms of co-management between the PCMH and the PCMH-N. In a “shared management for the disease” model, the subspecialist provides advice but does not actively manage any aspect of the patient’s care. In a “principal care for the disease” model, both teams actively manage the patient with clear and discrete responsibilities. The PCMH remains the primary point of contact. Finally, in a “principal care of the patient for a consuming illness for a limited period” model, the PCMH temporarily assumes primary responsibility of care and is the first contact for the patient. The PCMH is kept up to speed and at times has primary responsibility of defined areas of care. The ideal model of care varies from patient to patient and may change as the patient transitions from a pediatric to an adult-oriented medical home. For example, a child with insulin-dependent diabetes may have his diabetes managed entirely by a pediatric endocrinologist, with his other health care needs managed by his pediatrician—a “principal care for the disease” model. After transitioning to an adult-oriented medical home, the internist may take primary responsibility for the patient’s diabetes management, referring to an adult endocrinologist for specific questions and advice—a “shared management of the disease” model. The critical element is that the PCMH and the PCMH-Ns all understand the co-management model and that the patient is in agreement and understands who his/her point of contact is.

Data-driven guidelines, educational support, and financial incentives are needed to improve outcomes as adolescents and YASHCN transition to the adult-oriented medical home. However, an understanding of the overall transition process and the use of concrete co-management models may serve as a framework for the general internist caring for these patients.

References