

**Module 4:  
Facilitating  
the Transition  
From  
Pediatric to  
Adult Care**

## Module 4: Facilitating the Transition From Pediatric to Adult Care

### Learning Objectives

- Describe the role and importance of a medical home in the transition of pediatric patients to adult-oriented systems, including planning this transition during the preteen years.
- Demonstrate successful transition of care to an adult medical and community professional using a transition plan and transition resources.

### Pretest

1. The goal of planned health care transition is to maximize lifelong functioning and well-being for youths who have special health care needs. True or false?
2. The transition planning process should begin when a youth is between 12 and 14 years of age. True or false?
3. When all youths reach the age of majority, parents need to choose an adult primary care physician for their child and arrange for the first adult office visit. True or false?
4. Which of the following documents should be included in the final transition materials sent by a pediatrician to an adult physician?
  - a. Transfer letter, including effective date of transfer of care to adult primary care physician.
  - b. Final transition readiness assessment of the youth and family.
  - c. Care plan, including goals and actions.
  - d. Updated medical summary and emergency care plan.
  - e. All of the above.

### Overview

One role of the patient- and family-centered medical home is to plan a youth's transition from pediatric to adult health care and adult-oriented systems. Another role is to support the youth's readiness to assume responsibility for his own care. The American Academy of Pediatrics clarifies that planned health care transition allows us to "maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the youth moves from adolescence into adulthood."<sup>1</sup>

Transitioning youths to adult care can be quite challenging in today's health care setting. Got Transition ([www.gottransition.org](http://www.gottransition.org)), a program of the National Alliance to Advance Adolescent Health, has created a list of 6 core elements to help health care professionals work through the process.<sup>2</sup> The *Six Core Elements of Healthcare Transition 2.0* are aligned with the *Clinical Report on Transition from Adolescence to Adulthood in the Medical Home* from the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians.

*Core element 1, a transition policy*, describes the process taken by a medical home to transition a youth

to an adult care practice and is critical to the transition process. The policy needs to have input from youths and their families and should include information about privacy and consent. The policy should also be posted for all patients to see and should be shared with youths and their families beginning around ages 12 to 14. It should be included in a new patient packet, posted in a visible area, and informed or reviewed with input from the entire medical home team.

*Core element 2, transition tracking and monitoring*, calls for a medical practice to create criteria that help identify youths who should be transitioned to adult care and involves creation of a process to accomplish such transitions. Data generated during the transition process, such as a transfer letter and final transition readiness assessment, should be managed by flow sheet or a patient registry within the electronic health record.

*Core element 3, transition readiness*, requires the medical home to conduct periodic readiness assessments starting at age 14. The purpose of these assessments is to help identify each youth's self-care needs and goals. These goals should be developed jointly with the youth and her parents and documented in a care plan. Got Transition provides sample tools, including "Transition Readiness Assessment for Youth" ([www.gottransition.org/resourceGet.cfm?id=224](http://www.gottransition.org/resourceGet.cfm?id=224)) and "Transition Readiness Assessment for Parents/Caregivers" ([www.gottransition.org/resourceGet.cfm?id=240](http://www.gottransition.org/resourceGet.cfm?id=240)).

*Core element 4, transition planning*, requires the medical home team to develop and regularly update the care plan ([www.gottransition.org/resourceGet.cfm?id=241](http://www.gottransition.org/resourceGet.cfm?id=241)) and should include findings of the transition readiness assessments, goals of the youth and family, and prioritized actions, as well as a medical summary and details on what to do in emergencies. The transition care plan should also address vocation, specialists, education, guardianship (if applicable), and self-care. As the Got Transition Six Core Elements document explains, this plan should

[p]repare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision- making and privacy and consent, self-advocacy, and access to information, ... obtain consent from youth/guardian for release of medical information... [and] assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.<sup>2</sup>

The transition care plan can be available on an electronic patient portal, and copies can be given to the family, youth, and all involved with caring for him.

*Core element 5, transition of care*, is when the medical home team confirms the date of the youth's first visit with an adult physician and completes a transfer package that includes the most recent transition readiness assessment, care plan, medical summary, and emergency care plan, as well as any letter of medical necessity or nursing orders (if applicable). At this point, the medical home team should also create a letter to send along with all of these documents to the adult physician and make certain that the new practice has received the information. The transition letter, a sample of which is available at [www.gottransition.org/resourceGet.cfm?id=230](http://www.gottransition.org/resourceGet.cfm?id=230), includes the youth's primary condition, date of the transfer, a medical summary, and several other relevant facts about the patient. A transfer package should also include the names and contact information for community supports and partners. The new adult physician should confirm receipt of these documents.

*Core element 6, transfer completion*, is the final phase of the transition process, when the medical home

should reach out to the youth and parents 3 to 6 months after he has left the pediatric practice to gain their feedback to determine how well the transition went. The medical home team will also want to offer any consultation to the adult physician and continue to build partnerships with the physician.

The case study that follows illustrates how to put these elements into action.

### **Case Study**

Hannah Johnson has hypothyroidism and has been receiving care from a patient- and family-centered medical home for several years. Now that she has turned 12, her pediatrician initiates a discussion with Hannah and her parents that will empower Hannah to begin thinking about taking greater responsibility for her own care, as well as a discussion about the process of transitioning to adult care. During today's office visit, Mr and Mrs Johnson express surprise that the process is starting before Hannah has even entered adolescence, which gives the pediatrician an opportunity to explain the value of getting the family ready for the move to an adult physician. The pediatrician explains that it usually takes several years for pediatric patients to adjust to taking responsibility for their own care. Initiating the conversation about transition now and consistently over the next few years will help Hannah develop the skills needed to make the transition and allow the pediatrician and Hannah to partner in this journey.

The pediatrician explains that the practice has a transition policy in place to guide them through the process and to ensure a smooth transition to adult care. He points out that the purpose of the policy is to prepare a youth and their family for the change from a pediatric approach to care, in which Mr and Mrs Johnson are making most of the decisions, to an adult approach, in which Hannah will be taking responsibility and making decisions related to her care.

The pediatrician also explains how the transition policy dictates that when Hannah reaches age 18, the practice will recognize her as a legal adult, at which point the medical home team will discuss personal health information with family members only if Hannah gives her consent. Finally, the policy recommends that transition to an adult practice take place before she turns 22. (There are special circumstances, however, in which, if mutually agreeable to the pediatrician, the youth, and, when appropriate, the youth's family, services of the pediatrician may continue past the age of 21, according to American Academy of Pediatrics.<sup>3</sup>)

At this point, the pediatrician also explains to Mr and Mrs Johnson that he needs to spend some time alone with Hannah to help her set her own health goals and support her as she starts thinking about becoming more independent with her health care. Once he receives permission from her parents to talk with Hannah alone, he explores Hannah's understanding of the transition process. During this discussion, he also explores any vocational and educational goals with Hannah. The pediatrician reassures Hannah and her parents that he remains committed to caring for them and that this discussion does not negate their working relationship.

### *The Transition Flow Sheet and Registry*

This practice uses a separate flow sheet for each patient to track his progress as he transitions to adult care. These sheets are used to populate a transition registry that will help the practice monitor the transition process for its entire patient population. Got Transition offers a sample "Individual Transition Flow Sheet" on its Web site ([www.gottransition.org/resourceGet.cfm?id=222](http://www.gottransition.org/resourceGet.cfm?id=222)) for that purpose.<sup>4</sup> A nurse

had downloaded the template and begins working with the Johnson family to fill out the form.

One advantage of using a flow sheet is that it keeps the team on track by reminding them of each step in the transition process. For instance, a section on the chart requires notation of the specific date on which the transition policy was shared with the youth and her parents. It includes space to document each time a transition readiness assessment was conducted. Similarly, the flow sheet asks that the practice document the name, location, and contact information for the adult physician once selected by the youth. There is also a space to list the date of the first completed appointment with the adult physician. As Hannah moves through her adolescent years, the pediatrician and nurse will use this form to monitor her progress.

A medical assistant in the medical home has been assigned the responsibility of maintaining the transition registry ([www.gottransition.org/resourceGet.cfm?id=223](http://www.gottransition.org/resourceGet.cfm?id=223)) mentioned above. It will help keep Hannah, as well as other youths who are transitioning to an adult physician, on track. It lists Hannah's date of birth, her name and age, the primary diagnosis, the transition complexity, the specialist involved in her care, and the date of her next scheduled appointment. Eventually, it will also list the date of her first appointment with her adult physician. Equally important, the registry includes a record that the transition policy has been shared with Hannah's family. The medical assistant also uses the registry to post the dates that the readiness assessments are administered and the dates when her care plan, medical summary, and emergency care plan are updated and shared with Hannah and her family. When Hannah is older, the assistant will also document that the medical home has sent a transfer package to the adult physician and communicated with said physician.

Some families and pediatricians may question the need for such an extensive transition process and worry that it will consume too much time. A recent case report in the May 2015 issue of *WebM&M*, a publication of the Agency for Healthcare Research and Quality, which is outlined in the box at the end of this module, illustrates the danger of not fully preparing youths for the transition to adult care.

### *Hannah Reaches the Age of Majority*

Hannah is a patient in a practice that sees the value of an expansive care transition process. In the years between the first transition visit at age 12 and Hannah's pediatric visit at age 21, she has matured physically and emotionally. During that time, the pediatrician has been conducting periodic assessments to evaluate her readiness to take on her new role as an adult and now Hannah is eager to accept additional responsibilities for her own health care. At today's visit, she is almost ready to transition to an adult physician, so the pediatrician reviews the basics she will need to manage on her own. Some of the many issues they discuss are

- Has she chosen an adult physician, and does she have all the necessary contact information?
- Has she made arrangements with the health center at the college in which she is about to enroll to coordinate care and manage emergencies?
- Can she recognize the signs and symptoms of an overdose of her levothyroxine?
- Does she know the symptoms that suggest she needs a higher dose of medication?
- Does she know what pharmacy her family is currently using to fill her Levothyroxine prescription, and if she chooses another pharmacy, does she know how to renew her prescription?
- Does she see the importance of having thyroid-stimulating hormone and thyroxine levels checked periodically to monitor her condition and adjust her dosage?
- Does Hannah understand the long-term prognosis for patients with hypothyroidism? Is she

aware that she may have to remain on thyroid medication for the rest of her life? Has she considered the effect of the condition on any future pregnancy?

In the past, Hannah did not give much thought to these issues because her parents had always handled them. But she is at the stage of her life in which she wants to be considered an adult and appreciates that her pediatrician wants to help her transition into that role.

Now that Hannah is almost ready to take on the role of an adult patient, the nurse provides her with all necessary links to insurance resources and self-care management materials, including fact sheets on hypothyroidism, proper nutrition, physical exercise, and other basic health education materials as they pertain to her condition.

The nurse also discusses the importance of the practice's online patient portal with Hannah, ensuring she is aware of how to access her medical records through the portal and demonstrates accessing the portal in the office. She also asks Hannah if she wants to provide her new adult physician and college health center access to this information. Sharing Hannah's records with the college health center does not mean her care is being transferred there.

Many youths receive care in a college health center during the school year, but when out of school, they continue to receive care through their pediatrician or adult physician. An online patient portal can serve as a valuable asset for youths transitioning to adult care, as long as the practice takes time to explain its features and encourage its use.<sup>5</sup> Many electronic health record systems have a patient portal component that allows patient access to prescription refills, laboratory results, medication history, and patient education materials.

Practices that rely on paper medical records can still use hard copies and faxes to facilitate the care transition process.

## **Summary**

At Hannah's final pediatric visit at age 21, her pediatrician "closes the loop" with the adult physician, making sure that all correct documents have been received by the new adult practice team. The nurse also confirms that Hannah has made an appointment with her new adult physician.

At this last visit, the pediatrician confirms that all necessary information has been incorporated into her transition package. Necessary information includes the

- Transfer letter, including effective date of transfer of care to an adult physician
- Final transition readiness assessment completed by Hannah with her pediatrician at her last visit
- Transition care plan, including goals and actions
- Updated medical summary and an emergency care plan
- Community resources supporting the transition process
- Educational and vocational supports

For many patients, the transition package will include additional legal documents and medical records, depending on complexity of their care.

Three months after Hannah’s last pediatric visit, the nurse from the pediatric medical home reaches out by phone to see how Hannah’s health is, sends her a feedback form, and confirms that she is seeing her new adult physician. The nurse also reaches out to the new adult physician to elicit feedback and foster an ongoing collaborative relationship.

The feedback form that Hannah completes—also available from Got Transition ([www.gottransition.org/resourceGet.cfm?id=243](http://www.gottransition.org/resourceGet.cfm?id=243))—confirms that she is adjusting well to her new role as an informed health care consumer and her hypothyroidism remains under control.<sup>6</sup>

### Posttest

1. The goal of planned health care transition is to maximize lifelong functioning and well-being for youths who have special health care needs. True or false?

Explanation:

The American Academy of Pediatrics sums up the goal of planned health care transition by stating that its purpose is to “maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.”

2. The transition planning process should begin when a youth is between 12 and 14 years of age. True or false?

Explanation:

A transition policy describes the process taken by a medical home to transition a youth to an adult care practice and is important in helping a medical practice manage this responsibility. The policy needs to have input from the patient and his family and should include information about privacy and consent. Said policy should also be posted for all patients to see and should be shared with youths and their families beginning around ages 12 to 14, allowing for ample time to plan the transition journey or process.

3. When all youths reach the age of majority, parents need to choose an adult primary care physician for their child and arrange for the first adult office visit. True or false?

Explanation:

During early childhood, parents manage all important medical decisions for their children, but by the time youths reach age 18, they are at the stage of their life when they should be encouraged to take on the responsibility of caring for themselves. That includes deciding who will act as their adult physician.

4. Which of the following documents should be included in the final transition materials sent by a pediatrician to an adult physician?
  - a. Transfer letter, including effective date of transfer of care to adult primary care physician.
  - b. Final transition readiness assessment of the youth and family.
  - c. Care plan, including goals and actions.
  - d. Updated medical summary and emergency care plan.
  - e. All of the above.

### Explanation:

To ensure that an adult physician is fully prepared to accept a youth from a pediatric practice, it is important to make certain that all necessary documents have been received by the new practice. If the youth has a relatively rare disorder that the adult physician may not be familiar with, the pediatrician can also send a fact sheet with details on the condition. It is recommended that the transition process be finished before the youth turns 22.

### Reflections to Consider

The following questions are meant to prompt thought and discussion either individually or in a small group. There are no right or wrong answers.

- What aspects of transition to adult oriented systems do you feel are most critical?
- What aspects of transition to adult oriented systems do you anticipate will be the most challenging for the patients and families in your practice?
- Think about some of the youth in your practice. How might you approach the transition process?
- How might you engage adult health care providers in caring for your patients as they transition to adult care?

### References

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3. American Academy of Pediatrics Council on Child and Adolescent Health. Age limits of pediatrics. *Pediatrics*. 1988;8(5):736
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6. Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *J Am Med Inform Assoc*. 2011;18:i8–i12
7. Got Transition. *Sample Healthcare Transition Feedback Survey for Youth/Young Adults*. <http://www.gottransition.org/resourceGet.cfm?id=243>. Published January 2014. Accessed July 22, 2015

### Resources

American Academy of Pediatrics Transitions “Clinical Guidance and Resources” Web page

([www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Policy-Resources.aspx](http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Policy-Resources.aspx))

Florida Health and Transition Services Web site ([www.floridahats.org](http://www.floridahats.org)) GotTransition.org

- “Youth & Families: Healthcare Transition FAQs” Web page ([www.gottransition.org/youthfamilies/index.cfm](http://www.gottransition.org/youthfamilies/index.cfm))
- “Health Care Transition Resources: Six Core Elements of Healthcare Transition” Web page ([www.gottransition.org/resources/index.cfm](http://www.gottransition.org/resources/index.cfm))

Illinois Healthcare Transition Project *Finding Adult Providers* handout (<http://illinoisAAP.org/wp-content/uploads/FindingAdultProviders.pdf>)

National Center for Medical Home Implementation “Transitions Videos” Web page ([www.medicalhomeinfo.org/how/care\\_delivery/transitions.aspx](http://www.medicalhomeinfo.org/how/care_delivery/transitions.aspx))

### **Transition of Care Process Requires More Than Referral to an Adult Care Doctor**

A case study from the May 2015 issue of *WebM&M* involved a pregnant 21-year-old woman with Marfan syndrome and aortic root dilation who found herself in the emergency department with abdominal pain. She required urgent surgery to repair the vascular damage and avert a life-threatening aortic rupture. It turns out, 4 years earlier, her pediatrician and pediatric cardiologist advised her to have aortic surgery during a previous pregnancy because they recognized the risk of a rupture. They referred her to an adult physician and cardiologist when she turned 18, but the referral was not followed up upon. Fortunately, her visit to the emergency department at age 21 resulted in reparative surgery without complications.

In a commentary about the case presented by Megumi Okumara, MD, assistant professor of pediatrics at the University of California, San Francisco, and her colleague, they point out that the emergency surgery could have been averted if her pediatrician had a more formal health care transition process in place long before the youth turned 18. They summarize by stating

The transfer from pediatric to adult care is, indeed, a point in the transition process, but it takes years of preparation for young adult patients to become fully independent in their medical care. In this vignette, there were failures of two processes: the process of transitioning the patient to prepare her for the future as an adult with congenital heart disease, and the process of transfer to ensure that the woman's care would be monitored to minimize poor outcomes.<sup>5</sup>