

# Medical Transition for Your Child With Special Health Care Needs: A Tip Sheet for Parents

When your youth with special health care needs turns 18, their health care transitions from pediatric to adult providers. The planning for health care transition must begin early to allow adequate time for completion of the process by age 18. Clinics and children's hospitals and other pediatric facilities generally have a cutoff age, usually 18-21, after which patients must be seen at an adult facility. Transitioning is a complex process, and early planning, by middle school if not sooner, is critical to a successful health care transition.

*This tip sheet is designed to help you in the planning process, as well as answering questions you may have.*

## **Tip #1: Early planning is key to a successful transition**

Youth with special health care needs should begin the health care transition process at age 12. Part of this process includes determining how much responsibility your youth will be able to manage at age 18. Medical transition is more than transferring care; it is a time when a youth becomes an adult, learns about their medical condition and how to care for themselves, and identifies areas where extra assistance may be needed.

## **Tip #2: Discuss medical transition with all of your youth's health care providers**

It is important to know the age when your doctors stop seeing young adults in their pediatric practices. Some primary physicians are family physicians or combined internal medicine and pediatrics (med-ped) specialists who continue to see youth throughout their adult lives. There are also specialists with med-peds training who can follow patients throughout their lives. Some clinics will have a medical transition process to follow or even a team that will be available to you.

Important questions to learn the answers to include:

- Is there a process available for youth with special health care needs to facilitate the transition to adult medicine?
- Who coordinates that process, and how does your youth become included in it?
- Will the clinic make recommendations as your youth approaches transition age?
- Which specialists provide care that will need to be transitioned to adult care?
- Are some of your child's specialty needs stable so that there is no need for an adult specialist?
- Are there specialties that don't exist in adult medicine, such as developmental behavioral pediatricians or congenital heart disease specialists?
- Should primary or specialty care be transitioned first? Will your youth's insurance be accepted by providers who are recommended?

### **Tip #3: Prepare your youth to manage as much as they are able**

Begin the process of determining how much responsibility for their health care your youth will be able to manage, and the supports they will need as they transition to adult health care. The following questions will help identify those supports and areas that may be incorporated into their IEP (Individualized Education Program). Many of these supports include or require organizational skills that can also be included on an IEP. School-based health care professionals can also be important resources in this process.

- Does your youth know their diagnosis?
- Do they know how their diagnosis impacts their life?
- Do they know the names and doses of their medications?
- Do they know the side effects of their medications?
- Do they understand the importance of medication compliance?
- Are they able to have prescriptions filled on time?
- Do they know how to make an appointment?
- Are they able to advocate for themselves, or can they learn to do this?
- If your youth has a condition that might cause a medical emergency requiring immediate assistance, do they recognize how to avoid this, or get needed help?

When you understand what is involved in transitioning your youth to adult health care, you can avoid last-minute or crisis-based decision making. A smooth, planned process that starts early will ensure your youth access to the best care possible as they move into adulthood.

PACER staff are available to assist you with the process of health care transition. Contact PACER at [PACER@PACER.org](mailto:PACER@PACER.org) or call 952.838.9000 for help.