

STEPPING STONES

Helping You Find Your Way Forward

It may seem like every time you walk into a doctor's office or go to an IEP meeting, every other word is "transition." Although you know that it is important and has to do with "becoming an adult", there's a good chance that you don't know much how it will affect you or why it really matters. Transitions happen to everyone, throughout life. However, for young adults with disabilities these transitions can have a greater effect on that person's ability to do what they want (such as college, job, independent living, relationships, etc.). Since transition is all about you and your future, you should be the one guiding it.

Healthcare Transition

For a young adult, transition means moving from pediatrics to adult medicine and can involve many changes including; getting a new doctor, going to a new hospital or medical facility, and legally becoming an adult. Each of these changes requires learning new rules and responsibilities.

Healthcare transition is a lengthy process that takes many years and for both parents and children/young adults, it is important to start this process early.

One of the key elements in a successful healthcare transition is self-determination. Self-determination is a concept reflecting the belief that all individuals have the right to direct their own lives. It "encompasses concepts such as free will, civil and human rights, freedom of choice, independence, personal agency, self-direction, and individual responsibility" (University of Illinois at Chicago National Research & Training Center, 2002). With a good sense of self-determination, health care transition milestones are more likely to be met.

Health Care Transition Stages

There are three main stages through which children and youth will move during the transition from pediatric to adult health care.

Stage One: Preparation

Begin preparing for the transition to adult health care while still in pediatric medicine. Be sure to begin preparing no later than age 14. Some helpful tips to be aware of while in the preparation stage include:

- Become aware of yourself and your needs. It is important to know basic information about yourself (date of birth, social security number, and address), information about your disability, allergies etc.
- Start talking to your parents and doctors about your needs regarding your healthcare.
- Advocate: Start talking to your doctor about what you want to achieve and ask for support
- Carry your own health insurance card. It is important to make copies so you can keep the original in a safe place.
- Utilize the "Incase of Emergency" (ICE) function on your phone. This function allows you to store important phone numbers like parents, doctors etc. There is also space available for medications, allergies, went setting and any other important medical information. If you do not have this function available on your phone, create a paper copy that you can keep in your wallet or purse.

Parents!

It is essential to start this process early. Transition is not something that happens over night. It takes many years and a lot of preparation, so start early!

FYI: The Managed Care Ops-Memo allows you to see your primary care pediatric physician while you are finding an adult healthcare provider. For more information on the Ops-Memo visit http://www.pealcenter.org/help-special_needs.

Stage Two: Becoming an Adult (age 18)

Once you turn 18, you are legally an adult. With this new adulthood come many new rules and responsibilities. Some things to remain aware of after your 18th birthday are:

- You now get to decide whether you share healthcare information with your parents.
- During this time you will have new decisions to make such as: Who can receive information about your healthcare? Who helps you in making those decisions?
- At this point doctors will begin looking to you to make decisions about your healthcare. This is when all of that preparation preparation you did while in the pediatric healthcare system will come in handy!
- Parents, you have just spent the last 18 years overseeing your child's healthcare. However, and at age 18, unless your child gives you permission, you will not have access to their healthcare information. It is important to discuss this with your child prior to their 18th birthday. Families may want to take a look at the David Gates webinar "Changes at 18 and 21" for more information about this topic.

Stage Three: Transfer to Adult Healthcare

By this point you should be ready to start transitioning over to adult healthcare. Some recommendations to make this transition smooth are:

- Ask your current pediatrician for a recommendation for a good adult physician
- Ask others in your community where they have found good, and not so good, service.
- It is important to find a doctor that has accommodations that allow you to fully access the office and someone who has experience and knowledge of your condition
- Find a doctor who speaks directly to you during your visit. And make sure that they are willing to learn from you! After all, you are the expert on your own disability.
- It is not only the doctors who are important, it is the entire office staff. It is ok to interview multiple different doctors and their staff, you don't have to go with the first one you meet.
- During the initial visit it is important to bring a few essential items: your insurance card, identification, any questions you have for the doctor, and something to take notes on.
- If you are uncomfortable or unable to take notes, use a recording device (be sure to ask for the Dr.'s permission to record him/her prior to recording)
- Once you have selected a physician it is important to keep all of the information (bills, test results, medical history etc.) in one place. Some hospitals offer to store this information for you electronically, be sure to ask!

For more information on healthcare transition contact the PEAL Center at 1-866-950-4408 or 412-281-4404. Also, be sure to check out the Health Care Transition page under "Help Topics" on our website

