



Providing support and information for families of children with disabilities, chronic illness and other special health care needs

## Top Ten Things to Prepare for (Health Care) Transition

Kathy Griffis-Bailey, DSHS CSHCN

**T**ransition is just another word for change. Everyone experiences change in their lives. For children and youth with special health care needs (CYSHCN) and their families, the term transition most often has come to mean the change from childhood or teen years to adulthood.

ALL young people experience this transition. Some experience transition easily or in shorter periods of time. Others struggle with their changing bodies, conflicting thought processes, and new responsibilities. No two young people experience transition exactly the same way. Every family feels the impact of this transition.

In many ways, CYSHCN really are no different. They also go through transition, some more easily or quickly than others. Each CYSHCN is unique in ability and achievement. Many CYSHCN need more help with transition than other children and youth. This need calls for information, resources, adaptations, and accommodations not usually needed by all.

There are some common transition topics that need instruction or special direction. Some of these topics include self-determination, education, employment, housing, insurance, transportation, and recreation. Also important, but sometimes overlooked, is health care. When physical and mental health and wellness are not well-managed, young adults with disabilities cannot learn, work, or play.

At some point in time, almost all children approaching adulthood must change from seeing doctors and other providers treating mostly children to those that treat adults. This change is known as health care transition. Like other life transitions, success depends upon parental leadership. Below is a list of "top ten" things parents can do to prepare for their children's health care transitions to adulthood. If you have a young child, go ahead and read through the list. None may have to be done today but knowing what they are will help you plan for the future!

1. **LEARN** as much as you can about your child's disability or chronic illness. It's really up to you! Become the expert on the current research and hunt for information from various reliable sources. Some medical conditions change a lot with puberty and maturation. Ask your child's doctor for information about changes that might occur for your child. Ask other parents and share the knowledge you have gained.

2. **SEEK** a clinic or practice that matches your needs for a medical home. A medical home is the place where the doctor(s) and other staff know you and your child. The staff is available and open to you and your child. They work with you in partnership. They seek to locate and collaborate with community resources. They coordinate your child's medical care. They also work with you as a team to prepare and plan for changing your teenaged child to an adult medical home and/or other doctors for adults.

## Texas Parent to Parent

3710 Cedar Street ♠ Box 12 ♠ Austin, TX 78705-1449 ♠ 866-896-6001 ♠ 512-458-8600  
website: [www.txp2p.org](http://www.txp2p.org) ♠ Email: [info@txp2p.org](mailto:info@txp2p.org)

Sometimes it takes several years to complete this change. When your teen enters puberty or no later than about age 14, ask what can be done to begin health care transition planning.

3. **TEACH** your child about his/her chronic disease. **YOU** are your child's parent. You also are your child's **FIRST** and **BEST** teacher. Begin early and share information often. Build on lessons learned and provide more details as your child becomes a teenager. Teach your teen all you know about his/her condition, his/her health care team members, and his/her insurance or payment sources. Paperwork is a challenge for everyone, but as he/she is able, you can teach about that, too.

4. **INVOLVE** your child's school in this teaching process. Learning about his/her condition and health and wellness can be a part of your child's Individual Education Plan (IEP). Identify strengths, needs, and goals related to health care. Ask the school to help with skills development related to knowing about the condition and its treatment(s), likely areas of decision making, and finding other help in your area. Talk about including these skills in transition plans, because health and wellness are important to post-secondary education and employment.

5. **ENCOURAGE** your child to ask questions and talk about his/her condition with doctors, teachers, family, friends, and others. Asking questions and talking about their concerns allows children to begin to "own" their conditions. In the teen years, this skill translates into informed self-confidence and self-determination. Ask for your teen's point of view. Involve your teen in making decisions about treatment alternatives, and encourage others to do so as well. Talk to your teen as you would a respected adult. Give him/her a sense of competence. Even when your teen has little ability to communicate, you often understand his/her wishes and still can offer choices.

6. **ANTICIPATE** age 18. In Texas, children legally become adults at age 18. They are given the legal rights of privacy and confidentiality. Having adult rights to privacy and confidentiality applies for doctors and other members of the health care team. These professionals may not be able or willing to share information about your young adult's health with you. Young adults can give permission to share information, or there are legal alternatives that may be needed. You, your teenaged child, and your family need time to consider which alternatives are best for you.

7. **EXPECT** your teen's doctor to ask you to leave the exam room at some point in time. This may occur even in the early teen years. Most young people will need to learn how to talk with doctors and others. You can prepare for this time by practicing with your teenager and modeling what might happen. Even when you stay in the exam room, encourage your teen to speak directly to the doctor and answer the doctor's questions.

8. **BECOME** familiar with all sources of funding for health care. Learn and teach your teen about using available health insurance plans and benefits. Apply as soon as possible for Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI) and Texas State Medicaid Waiver Programs. Completing and processing applications takes time and can be complex. There are waiting lists for most state programs. Even if you are not sure whether you qualify, submit applications and/or ask to be added to waiting lists. Be sure to keep your address and telephone current with federal and state programs. If your child or young adult is not eligible for these programs, be sure to talk about health insurance benefits and limits, and ways to handle payment responsibilities.

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9. **GIVE** your child responsibility for household chores! In a 1992 study of factors associated with resilience for youth with disabilities, the most important factor was whether the young person was involved with household chores. This factor was more important than self-perception as not disabled, having a network of friends, having disabled and non-disabled friends, family and peer support, and parental support without over-protectiveness.

10. **DON'T FORGET WELLNESS!** Sometimes dealing with the details of disability or illness, it's easy to forget, overlook, or postpone wellness and prevention lessons and practices. Your medical home can help to keep track of routine immunizations, needed screenings, and other prevention practices. It can also help with information on developing diets and healthy eating habits, scheduling exercise, avoiding injuries, getting enough rest, discussing sexuality, preventing pregnancy and sexually-transmitted diseases, and avoiding risk-taking behaviors.

Handling the teen years and early adulthood are challenging for most families. Preparing and planning ahead helps. As your family considers transition issues in education, employment, housing, transportation, recreation, and other areas of life, be sure to consider and prepare for health care transition, too.

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