

Ten Steps to Health Care Transition

How families can help their child with special health care needs plan the move from child-centered to adult-centered health care systems.



- 1. Start Early!** There are some things you can do to get ready for transition even when your child is very young, like starting to keep a medical summary and teaching your child about his or her health care needs. It is important to plan for the future so you have everything ready when it is time for your child to make the move to the adult health care system.
- 2. Create a medical summary.** Put all of the important information about your child's health care in one place, including plans for an emergency. Ask your child's doctors for help and keep the information up-to-date. Give any new health care providers a copy of the summary so they will know all of the important details about your child's medical history.
- 3. Create a health care transition plan.** Work on a written health care transition plan with your child's primary care doctor. Include your child's future goals, what services he or she will need, who will provide them, and how they will be paid for. Start this plan by the time your child is 14 years old. Review and update the plan at least once a year.
- 4. Focus on responsibility for health care.** Help your child understand and take responsibility for his or her health care based on age and abilities. Find out what your child knows about his or her health care needs and fill in the gaps. Teach your child the skills that are needed to manage his or her health care. Encourage your child to participate in decisions about health. Your child's doctors can help you with this.
- 5. Consider the need for additional supports.** Some young people will be unable to make informed decisions about their health care in adulthood due to illness, mental illness, or a developmental disability. In Maryland, the Health Care Decisions Act allows a family member or close friend to act as a surrogate to make most medical decisions for someone in this situation. Only in special circumstances is legal guardianship needed to make health care decisions. You should also consider whether your child might need other types of support with health care as an adult, like a home health aid or personal care attendant.
- 6. Maintain wellness.** Encourage a healthy lifestyle. Help your child start good habits that will continue into adulthood. This means emphasizing good nutrition and exercise, and teaching your child to make healthy choices. Talk with your adolescent about risky behaviors such as alcohol use and smoking. Discuss sexuality and relationships. These topics in some form are important for all adolescents. Ask your child's primary care doctor to address these issues as well.
- 7. Know your child's health insurance options.** It is important to find out what types of private or public insurance your child will be eligible for as an adult. The possible options will depend upon things like your child's age, health conditions, income, and ability to work. It is also important to make sure that any new health insurance plan will meet the young person's needs. Look closely at the health plan costs and the benefits package. If you have already chosen health care providers who work with adults, check to see if these providers are in the plan.

8. **Find new providers.** Pick a primary care doctor (and specialist if needed) who works with adults. You can ask your child's current providers for a referral. Ask local support groups or other families that you know to recommend a doctor. You can also get a list of physicians from your child's insurance company. You and your child should interview possible doctors, and pick one that you think will meet your child's needs. Ask your child's current providers to speak with the doctor you have selected.
9. **Include health in other areas of transition.** Find out how your child's special health care needs may impact his or her future and other areas of life such as independent living, work, and relationships. Consider whether accommodations will be needed in the home, workplace, etc. Ask your child's primary care physician to provide documentation of his or her medical conditions and special health care needs for other programs or agencies as needed.
10. **Celebrate moving on.** Transition can be an emotional process. Sometimes it may be hard to let your child take responsibility for his or her health care when you have done it for so long. You may not want to say goodbye to a doctor who has taken good care of your child and family for many years. Remember that transition is a part of growing up, and all young people deserve the right to take on adult roles to the best of their abilities. Celebrate transition as an important milestone in your child's life!

Have questions, or need more information about transition? Here are some resources that can help:

Maryland Transition Resources:

Office for Genetics and CSHCN
<http://www.fha.state.md.us/genetics>
 Contact: Mary Anne Kane-Breschi
 Phone: 410-767-6743

Maryland Interagency Transition Council
<http://www.mdtransition.org>

Developmental Disabilities Administration
<http://www.ddamaryland.org>

Maryland Division of Rehabilitation Services
<http://www.dors.state.md.us>

Family NETworks
<http://www.family-networks.org/teens.cfm>

Other Health Care Transition Resources:

Healthy and Ready to Work National Center
<http://www.hrtw.org>

National Center for Medical Home Initiatives
<http://www.medicalhomeinfo.org/health/trans.html>

Health Care Transition Initiative
<http://hctransitions.ichp.edu>

Adolescent Health Transition Project
<http://depts.washington.edu/healthtr/index.html>

KY Commission on CSHCN Transition Resources
<http://www.chfs.ky.gov/ccshcn/ccshcntransition.htm>

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