

Making the Change: From Children through Adolescence to Young Adults with Special Health Care Needs

As youth or adolescents with special health care needs get older, their needs will change but they still require high-quality, coordinated, developmentally appropriate health care services that continue without interruption. Healthy People 2010 established the goal that all young people with special health care needs will receive the services needed to make necessary transitions to all aspects of adult life including health care (see <http://www.healthypeople.gov/document/HTML/Volume2/16MICH.htm>). This may mean choosing another primary care provider. Primary care provider (PCP) refers to a range of professionals including physicians, nurse practitioners, or physician assistants. Depending on the young adult's gender, the PCP may be an OB/GYN, internal medicine or family medicine practitioner, or nurse practitioner or physician assistant working with one of these specialists. It may also mean staying with the same PCP with changes in the clinical interactions that show your child's increasing maturity and emerging adulthood.

What steps can you take to help make the transition a success?

- Make sure to find a PCP to partner with you and your child in coordinating current care and planning for the future. Don't be afraid to ask if the PCP has received training that included the knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs.
- Prepare and maintain an up-to-date medical summary that is easy to move around and read/understand. This is also called a Health Notebook or a medical journal.
- Create a written health care transition plan with your child's PCP by the time your youth is 14 years old. To the greatest extent possible, make sure to include your child in creating this plan. The plan should at least include what services need to be provided, who will provide them and how they will be paid.
- Make sure that your youth receives standard primary and preventive health care that is appropriate for her age. Examples of guidelines for such care include the American Medical Association's *Guidelines for Adolescent Preventive Services* (<http://www.ama-assn.org/ama/pub/category/1980.html>) and the U.S. Public Health Service's *Guidelines to Clinical Preventive Services* (<http://www.ahrq.gov/ppip/childguide>).
- Begin exploring health care financing options for young adults by the time your child is 17 years old. You may be able to get help with this from your child's PCP, a clinical social worker, parent-to-parent support networks, family-to-family health information centers or other advocacy groups. If you have insurance through your job, talk with your human resources department—your employer may have a policy to keep individuals with disabilities on their parents' policies beyond the usual age limits for all children.
- Evaluate your child's ability to perform skills necessary to assume more responsibility for her own health care. You can find a helpful checklist to do this and other useful information developed by the Adolescent Health Transition Project at http://depts.washington.edu/healthtr/Checklists/health_care.htm.

See Related Articles:

<http://gucchd.georgetown.edu/nccc/transition.html>

Is Your Youth With Special Health Care Needs Prepared to Partner With the Medical Home?

Additional Resources:

<http://gucchd.georgetown.edu/nccc/nccc4.html>

<http://gucchdgeorgetown.net/ucedd/links.html#transitions>

<http://www.hrtw.org>

Healthy and Ready to Work is a federally funded project that provides information and connections to national expertise on youth transition and

health. Information on the site centers on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes useful tools and resources for youth, their families and providers, needed to make more informed choices.

<http://www.familyvoices.org/projects/f2f.php>

Family-to-Family Health Information Centers (F2F HICs) are family-run centers established by the federal government to provide information and support to families with children and/or youth with special health care needs and the professionals that serve and support them.