Office of Families Raising Children
with Special Health Care Needs

Rhode Island Department of Health
3 Capitol Hill
Providence, RI 02908

401-222-5929
www.health.ri.gov

Health Care Transition
Planning for Teens with Special Health Care Needs

PLAN TODAY FOR YOUR TEEN'S ADULT HEALTH

What does health care transition mean?

As teens prepare to enter adulthood, it is important that they understand their health issues and learn to manage their own health care.

The process of changing health care providers (for example, from pediatric health care to adult health care) is called “health care transition.” Most children get their health care from pediatricians who are specially trained in children’s health care needs, such as monitoring growth and treating illnesses that start in childhood. As teens grow into adulthood, their health care needs change, and most will need to leave their pediatricians for adult health care providers. During this transition, most teens will also begin to take more responsibility for their health care.

Adult health care is different from what you and your teen may be used to under pediatric care. It is important to remember that this transition is best for your teen’s adult health. To deal with the transition, ask to be involved in and informed of all decisions made about your teen’s health care. However, in order for transition to occur, it is important that parents eventually allow their teens to take the lead in all areas of their health care.

Why is health care transition planning especially important for teens with special health care needs?

Health care transition planning is important, because all teens should receive quality health care that is appropriate for their age. In addition, teens should not go through a period of time without a primary care provider. Losing access to primary care, even for a short time, can affect the long-term health of a teen with special health care needs.

As teens with special health care needs become adults, receiving proper health care can be a challenge. Advance planning can help address the following challenges before they happen:

- Many pediatricians drop their patients between the ages of 18 and 21.
- Most teens with special health care needs have health insurance through their parents’ plans or through public programs. As teens become adults, their eligibility for these programs may change.
- Teens start needing more adult-oriented health care, including reproductive health care and appropriate screenings for adult risk factors. They may also be at risk of developing secondary disabling conditions that occur in adulthood and require attention from adult health care providers.

Additionally, transitioning to adult health care is part of the process of becoming independent and learning to manage one’s own health. Health care planning and management is an essential component to successful personal, educational, and career planning. Teens may also want the privacy and confidentiality that comes with having adult health care.

When should you and your teen start thinking about health care transition planning?

Planning for health care transition should start early in adolescence (around age 14) for all teens. However, each teen is unique and will be ready to transition to adult health care at a different time in his or her life. That is why it is important to discuss transitioning with your teen early on. As time passes and your teen grows, his or her needs will change. It is important that your teen’s transition plan be flexible to his or her needs and abilities. Start talking to your teen’s pediatrician as soon as possible about what might be appropriate for your teen.

Who should be involved in the transition planning?

Health care transition planning must be a team effort among you, your teen, and your teen's pediatrician, specialists, and adult health care providers. It is important to involve your teen's pediatrician because he or she knows your teen's medical needs best. It is also important to involve teachers, career coaches, and other key people in your teen's life in transition planning.

Consider creative ways to involve your teen in the planning, such as:

- Help your teen understand her health care coverage. Create a chart of your teen's insurance policy. Outline the benefits, co-payments, and visits allowed per provider. Encourage your teen to call her health care insurer whenever something is unclear.
- Go over scenarios for making appointments and create a list of questions to ask the doctor during his visit. Encourage your teen to bring this list to his appointment and talk to his doctor about any concerns he may have.
- Create a list of important contacts like family members, social workers, teachers, health care providers, or other members of the community. Include telephone numbers, addresses, directions, and maps.
- Help your teen create a filing system that is right for her. Encourage her to keep originals or copies of important documents, such as her social security card, birth certificate, insurance card, and driver's license.
- Set wellness goals together by identifying health-related community supports like recreational activities, health clubs, adult education, and other resources that promote a healthy life style.

What should your teen's transition plan include?

Your teen's health care transition team should create a written transition plan. The plan should include answers to the following important questions:

1. WHAT SERVICES WILL YOUR TEEN NEED?

Help your teen make a list of his or her medical history, health care needs, and abilities. Working with your teen's health care transition team, use this list to think about what to expect for your teen's future and what sort of health care needs he or she may have as an adult. Some specific questions that your team could talk about:

- Can your teen manage his own health care? Will he need a case manager or guardian?
- What sort of work, education, or vocational training will she be able to do? What special health care services might she need for these activities?
- Will your teen be able to live independently? What living assistance might he need?

2. WHO WILL PROVIDE THESE SERVICES?

Make a list of the kinds of health care providers that would best address your teen's adult health care needs. It may be appropriate for some teens to stay longer with their pediatricians, while it may make sense for other teens to get an adult health care provider and a team of adult health care professionals and specialists. Talk these issues through with your teen's health care transition team.

Consider the locations of the providers you and your teen choose. This is important if your teen will be using public transportation to get to appointments. Some offices have pick-up and drop-off services; these may be the best option in ensuring your teen keeps his or her appointments.

After determining the kinds of health care providers your teen will need as an adult, ask your pediatrician or other members of your team, your support networks, or your insurance company for referrals. Talk to these providers about the services that your teen will need. Choose a health care team with which you and your teen will be comfortable.

3. HOW WILL THESE SERVICES BE FINANCED?

It is important to figure out in advance how your teen's care will be financed when he or she becomes an adult, so that your teen does not go without health care coverage. Teens have an array of adult health insurance options, but these options require advanced planning in order to understand eligibility requirements and secure a smooth transition.

If your teen receives or is eligible for SSI, the Plans to Achieve Self-Support (PASS) program can help your teen reach his or her work goals. PASS lets your teen set aside part of his or her income (other than your teen's SSI payment) to pay for education or vocational training to meet specific work goals. PASS will help your teen develop a written plan to meet these goals. For more information, contact Boston Regional PASS CADRE at 800-297-4291.

Start with the following resources when researching health care coverage options:

» **SUPPLEMENTAL SECURITY INCOME (SSI):** Some teens with chronic conditions may be eligible for SSI. SSI provides monthly cash benefits to individuals with disabilities and health care coverage through Medicaid. It also offers "work incentives" that provide continued benefits and health care coverage while individuals seek employment. SSI is funded through the United States Social Security Administration. Visit www.socialsecurity.gov for more information.

» **MEDICAID:** Teens with special health care needs may need to apply (if they were not previously eligible) or reapply for Medicaid at age 18. After an application is approved, be sure to find providers who accept Medicaid. Visit www.dhs.state.ri.us for more information.

» **PRIVATE INSURANCE:** Talk to your insurance provider to see how long your teen will be eligible for services. If your teen plans on working as an adult, find out if he or she would be eligible for health insurance through his or her employer. Also, determine how much the health plans would cost and if the providers your teen needs are covered by these plans.

Where can I access resources and support in Rhode Island?

The following resources are available to help guide you as your teen begins the transition process into the adult health care, employment, social and housing world:

» **THE PAUL V. SHERLOCK CENTER ON DISABILITIES:** The Family Support 360 Transition Project at the Sherlock Center is a program for families with students ages 14–21 who have significant developmental disabilities. This project engages and supports families in a comprehensive planning process to develop a smooth transition from high school to adult life. Call 401-456-8072.

» **THE RHODE ISLAND PARENT INFORMATION NETWORK (RIPIN):** RIPIN's Family Voices is a network of families and friends of children and youth with special health care needs. This network promotes the inclusion of families in decision making in the provision of health care services and supports essential partnerships between families and professionals. Call 401-727-4144.

» **RHODE ISLAND DEPARTMENT OF HEALTH:** The Rhode Island Department of Health's Office of Families Raising Children with Special Health Care Needs ensures family-centered, community-based health care transition services for children and youth with special health care needs and youth with disabilities. The Office works in collaboration with families, other state agencies, health plans, and community agencies. Call 401-222-2310.

For additional resources, take a look at RIPIN's new transition guide, "Here's to Your Children's Future! A Parent's Guide to Transition Planning." Visit www.ripin.org or call 401-727-4144.