

Planning for a Healthy Transition

A Family Transition Plan



About this *Guide*

Washington State Department of Health Children with Special Health Care Needs (CSHCN) understands that the transition to adulthood is an exciting time for teens and young adults.

Transition may include changes where your child goes to school, where they work, or where they live. Health care transition usually includes changing from pediatric care and services to adult care and services. Teens and young adults with special health care needs, and their families, need to know that health care transition takes a lot of thought and planning.

This brochure is designed to help parents start thinking about health care transition and helping their child make a health care transition plan so that it will be a successful process. Health care transitions work best when they are discussed and planned. In order to plan, you and your family need to learn about new choices and new ways of getting health care services.



A new Chapter

Growing up with a special health care need presents your child and family with many challenges.

Many people including you, doctors, care coordinators, and therapists have helped to take care of your child and have seen that they got the medical care they needed. However, now that your child is getting older, it is time for them to be more in charge of their health care. This will involve new responsibilities and privileges.

One important change that will happen over the next few years is for them to say good-bye to their pediatrician and to select a doctor who takes care of adults instead. This process of leaving pediatrics and getting ready to go to adult-oriented medical providers is called health care transition.

Health care transition is important because it supports the activities that your child will want to do in life such as living on their own, going to college, and having a job. In practical terms, health care transition means more than getting medical care from health care providers trained to treat adults. It also involves your child becoming knowledgeable about their health condition, being responsible for carrying out their health tasks, and making good health care decisions with less support from you and other caregivers. The purpose of this guide is to help parents to help their children be successful in the transition from pediatric to adult health care.

Tips for Parents

Children Age 12 to 18

Young people with disabilities and chronic health care conditions are often at a disadvantage when it comes to getting a job, despite the fact that these young people want to work.

Early work experiences, particularly part-time work, are very important. These experiences make a young person more attractive to future employers and help get young people to think about themselves as members of the workforce.

A survey of youth 12-18 years old conducted for the Social Security Administration found that these youth, even those with health conditions, reported being very interested in getting a job. Of all the age groups surveyed, young adults ages 13-14 with disabilities were most interested in career readiness programs. Seventh graders with special health needs actually had higher scores for positive attitude, interest, and competency toward work than those without disabilities. However, as they aged, scores decreased. This study tells us that pre-vocational



programs and opportunities for part-time work should be targeted at those 13 and 14 years of age who are most interested in work.

So how do you take advantage of this interest and channel it into focused work at school and ultimately productive employment?

Begin with chores around the house. The successful completion of chores provides an excellent way to demonstrate personal independence and gain early work experience.

Tips for Parents of Children Age 12-18 *(continued)*

Encourage and work with your child to participate in volunteer activities in the community. Your child might start by working for a disability advocacy group such as the Sickle Cell Disease Association, Spina Bifida Association, or the March of Dimes. Other opportunities for volunteering include the public library, animal shelters, church, and recreational programs.

Explore and participate in pre-vocational and vocational support activities. Encourage your child to speak with vocational rehabilitation counselors in your community. Check with the guidance counselor at your child's school for these and other resources.



Encourage part-time work experiences. Use volunteer activities as work experience and as a springboard to paid employment.

Discuss the relationship of good health, educational success, and future employment as a means of achieving personal goals.

Tips for Parents

Children Age 15-18

At this age, it is important for your child to spend some time alone with their doctors and other health care providers.

This means that they are going to have to practice giving the doctors the information they need about how they have been feeling, asking their own questions when more information is needed, and talking about and agreeing to follow treatments. Up to this point, you as parents have probably been asking and answering most of the questions during doctor visits and deciding what treatment you thought was best for your child.

Talk with your child about starting to practice independence during medical visits. Let them know that you would like them to be more involved in their medical appointments, answering the doctor's questions, and helping to make health decisions. You might also ask your child if they would like to practice what to say in advance and develop some questions prior to the doctor visit.

If your child is 16 or 17, now is the time to find out how their legal rights and responsibilities will change when they turn 18. As an adult, they have the right to have most medical and other information about themselves kept private from everybody, including parents.

Health care transition is all about providing your child with a healthy foundation on which to build life goals. Going away to college or vocational training may be part of their plans for the future. If so, there are some things you can do to help make this transition to a new school and to new health care providers easier. Even if they are not going away to school, some of the tips can be helpful.

Tips for Parents of Children Age 15-18

(continued)

Let's begin with some of the basic questions to consider and share with your child:

- What medical care will they need when away from home?
- Will they need physical assistance?
- Will they be using personal assistants to help carry out activities of daily living?

Once it has been determined what your child needs, it may be time to see if these services are available at the colleges under consideration. Most colleges have an Office for Students with

Disabilities. Contacting this office is a good place to begin. Some colleges have worked hard to make their campus and educational programs very accessible. These colleges tend to have more comprehensive programs to help you adjust and succeed in college life.



When your Child turns 18

Privacy and Guardianship

Did you know that after your child turns 18 you (parents) no longer have automatic access to your child's personal health information?

Once your child turns 18 years old, health care providers are required by law to respect the right to confidentiality of personal health information. Health care providers cannot provide this information to parents unless they have written permission to do so. This situation presents both opportunities and challenges.

The right to privacy of personal health information can help to prompt you and your child to discuss the changes in responsibility that will occur on their 18th birthday. This discussion can make clear the limitations that parents face and how a young adult at age 18 becomes the responsible person for medical decision-making.



For some young adults whose ability to make informed decisions is diminished, informal supports may be sufficient. This can involve a network of family and friends providing help and guidance. It is important to recognize these informal networks must still operate within privacy laws. Steps for developing and maintaining such an informal network include signing

“release of information” forms so that family members will have access to medical information if the young adult so chooses.

Other young adults whose ability to make informed decisions is more limited, may need the formal supports that are provided through guardianship. Guardianship is a legal process that takes time and money and involves submitting a formal application.

Now that You're Child is Twelve

Youth Transition plan worksheet

| Health | | Things I need to know or do | Will someone else have to do this for me? | I will finish by (date) | Done |
|---|-----|-----------------------------|---|-------------------------|------|
| 1. I understand my healthcare needs. | Y N | | Y N | | |
| 2. I explain my special needs to others. | Y N | | Y N | | |
| 3. I tell the doctor(s) how I am doing and can answer their questions. | Y N | | Y N | | |
| 4. I know the name of my doctor(s). | Y N | | Y N | | |
| 5. I take my medicine with supervision. | Y N | | Y N | | |
| 6. I know the name(s) of the medicine I take and possible side effects. | Y N | | Y N | | |
| 7. I know when I am sick. | Y N | | Y N | | |
| 8. I carry a copy of my insurance card. | Y N | | Y N | | |
| 9. I carry a summary of my medical information with me. | Y N | | Y N | | |
| 10. I am learning to schedule my own appointments. | Y N | | Y N | | |

| Independent Living | | Things I need to know or do | Will someone else have to do this for me? | I will finish by (date) | Done |
|---|-----|-----------------------------|---|-------------------------|------|
| 1. I care for my own personal needs or know how to ask for them | Y N | | Y N | | |
| 2. I know my phone number and address. | Y N | | Y N | | |
| 3. I know how to get help in an emergency, including calling 911. | Y N | | Y N | | |
| 4. I am responsible for doing my homework. | Y N | | Y N | | |
| 5. I think about what I want to do when I grow up. | Y N | | Y N | | |
| 6. I am learning to make choices. | Y N | | Y N | | |
| 7. I spend time with my friends. | Y N | | Y N | | |
| 8. I do chores at home. | Y N | | Y N | | |

Now that Your Child is Fifteen

Youth Transition plan worksheet

| Health | | Things I need to know or do | Will someone else have to do this for me? | I will finish by (date) | Done |
|---|-----|-----------------------------|---|-------------------------|------|
| 1. I understand my healthcare needs. | Y N | | Y N | | |
| 2. I explain my special needs to others. | Y N | | Y N | | |
| 3. I tell the doctor(s) how I am doing and can answer their questions. | Y N | | Y N | | |
| 4. I know the name of my doctor(s). | Y N | | Y N | | |
| 5. I take my medicine with supervision. | Y N | | Y N | | |
| 6. I know the name(s) of the medicine I take and possible side effects. | Y N | | Y N | | |
| 7. I know when I am sick. | Y N | | Y N | | |
| 8. I carry a copy of my insurance card. | Y N | | Y N | | |
| 9. I carry a summary of my medical information with me. | Y N | | Y N | | |
| 10. I am learning to schedule my own appointments. | Y N | | Y N | | |

| Independent Living | | Things I need to know or do | Will someone else have to do this for me? | I will finish by (date) | Done |
|---|-----|-----------------------------|---|-------------------------|------|
| 1. I care for my own personal needs or know how to ask for them | Y N | | Y N | | |
| 2. I know my phone number and address. | Y N | | Y N | | |
| 3. I know how to get help in an emergency, including calling 911. | Y N | | Y N | | |
| 4. I am responsible for doing my homework. | Y N | | Y N | | |
| 5. I think about what I want to do when I grow up. | Y N | | Y N | | |
| 6. I am learning to make choices. | Y N | | Y N | | |
| 7. I spend time with my friends. | Y N | | Y N | | |
| 8. I do chores at home.. | Y N | | Y N | | |

Finding & Using **Adult Health Care**

As young people grow from childhood into adulthood, many will move from care by pediatricians into adult medicine.

Moving to a different town due to school or a change of employment will also create a need to find a new doctor, especially if you happened to grow up with chronic health issues. So, how do you find a doctor who will meet your medical needs, that will be covered by your health plan, and who will give you the care you are looking for?

Before you start looking for a new doctor, think about what you want:

- Is where the office is located important? Will you need help with transportation? Do you need an office that is wheelchair accessible or do you need other special assistance in the doctor's office? Are office hours convenient? How do you contact the doctor at other times? What hospital do you want to use, and is this doctor on the staff there?
- Do you want someone who will take time with you during an office visit or are you comfortable being seen by someone who is "good" in his or her field but perhaps does not have the best bedside manner?
- Is it important that this new doctor is knowledgeable about your special health care needs or do you think you can provide that information or connect the new doctor with those who could provide medical insight?



Ways to look for a new doctor include:

- Ask your current doctor.
- Check out the doctor your parents or other family members see.

Finding and Using Adult Health Care (continued)

- Call a family support group or adult disability agency and check around.
- Ask adults who have health needs similar to yours for recommendations.
- Refer to your health insurance company booklet of approved providers.
- Ask a Vocational Rehabilitation counselor.
- Find a university health center (sometimes there are research studies going on which offer free care).
- Contact your local Medical Society, American Academy of Family Practitioners, or Internal Medicine Society either through the Yellow Pages or on their national websites.



Since your wellness depends on the medical services you receive, it is important that you are comfortable talking with your new doctor and feel that he or she understands your concerns. Consider scheduling a “get-acquainted” interview before you make a final choice of a new doctor. You will have to pay for this visit, as it is NOT covered by insurance benefits.

An ideal interview time is about 15 to 30 minutes and should not waste your time or the doctor’s. The best time to see a new physician is when your health condition is stable so you aren’t asking for crisis care while seeing if you can develop a working relationship.

Think about (and write down) questions that are important to you:

- Is the doctor knowledgeable about your health issues and/or willing to learn from you and from previous doctors?
- Do you like the communication style with the doctor and in the office?
- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if you need them?

Finding and Using Adult Health Care (continued)

Doctors who like to care for children are different from doctors who like to care for adults. For this reason, young adults seeking health care need certain skills:

- Ability and willingness to tell the doctor about your history, current symptoms, lifestyle, and self-care in just a few minutes (including carrying your own records and a summary of your medical history).
- Ability to ask questions about your condition and how it will affect your school, work, recreation, and social life.
- Ability to tell the doctor about your needs for education, technology, and accommodations and how your condition affects or might be affected by these.
- Willingness to follow medical recommendations that have been mutually developed by you and your doctor.
- More independence in following up with referrals and keeping all agencies informed.
- More involvement in keeping yourself well with diet and weight control, limiting risktaking behaviors (such as drinking alcohol, smoking, taking non-prescription drugs, or unsafe sexual practices), and getting help when you feel angry, lonely, or sad for long periods.
- Being more aware of your physical and mental symptoms and health needs before you have a serious medical crisis and know if you cannot (health care surrogate).
- Understanding how the health care benefits/insurance plan you have works for you: when to call for pre-approval, how to get reimbursements, what services are not covered, and how to file an appeal if you do not agree with decisions from the plan.
- Recognizing that as you become more capable in directing your care that you, not your parents, should make medical appointments, be the most knowledgeable about your health needs, know when to seek guidance in solving problems, and demonstrate that you are capable and competent and ready for adulthood!

Medical Home *Key Messages*

What is a Medical Home?

A Medical Home is an approach to delivering primary health care through a 'team partnership' that ensures health care services are provided in a high quality and comprehensive manner.

Who can provide a Medical Home?

A primary care provider (physician or nurse practitioner) leads the medical home with the support and direction of the patient, the patient's family, clinic staff, community agencies, and other specialty care service providers.

What are the core components of a Medical Home?

Accessible & Continuous

- Care is provided in the community.



- Changes in insurance providers or carriers are accommodated by the medical home practice.

Coordinated & Comprehensive

- Preventive, acute care, specialty care, and hospital care needs are addressed.
- When needed, a plan of care is developed with the patient, family, and other involved care providers and agencies.
- Care is accessible 24 hours a day, 7 days a week.
- The patient's medical record is accessible, but confidentiality is maintained.

Family-Centered

- Families and individual clients are involved at all levels of decision-making.

Compassionate & Culturally Effective

- The patient's and family's cultural needs are recognized, valued, respected, and incorporated into the care provided.
- Efforts are made to understand and empathize with the patient's and family's feelings and perspectives.

Medical home Key Messages (Continued)

What are the benefits of a Medical Home?

Promotes Health through Prevention

- Preventive services such as annual physical exams, developmental screening, health education, immunizations, well-child care, and other medical and community-based services help maintain optimal health.
- Women who have a regular source of health care are more likely to access prenatal care.¹
- Regardless of age, sex, race, or socioeconomic status—all people can receive an array of acute, chronic, and preventive medical care services through a medical home.²

Healthier Children and Families

- Among children with special health care needs (CSHCN), children with a medical home have less delayed care, less problems getting care, fewer unmet health needs, and fewer unmet needs for family support services.³
- In a study of medical home among CSHCN, parents reported improved care delivery, a decrease in the number of missed work days, and a decrease in hospitalizations.⁴

Reduce Health Care Costs

- Children who receive care in a medical home are half as likely to visit an emergency room or be hospitalized.⁴
- Having health care access through health insurance is not enough to avoid acute care and treatment costs – other issues such as quality of care and the relationship with a primary care provider also influence the use and cost of health care services.⁵

1 Braveman, P., Marchi K., Egerter S, Pearl M, Neuhaus J, Barriers to timely prenatal care among women with insurance: the importance of prepregnancy factors. *Obstetrics and Gynecology*. 2000; 95:874-880

2 Kahn, Norman (2004). *The Future of Family Medicine: A Collaborative Project of the Family Medicine Community*.

3 Strickland, B., et al. (2004). *Access to the Medical Home: Results of the National Survey of Children With Special Health Care Needs*. *Pediatrics* 113:5 (1485-1992).

4 Palfrey, J., et al (2004). *The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model*. *Pediatrics*. 113:5 (1507-1516).

5 Starfield, B & Shi, L (2004) *The Medical Home, Access to Care and Insurance. A Review of Evidence*. *Pediatrics*. 113: 1493-1498 Revised: July 2007

Transition Resource List

| Type | Title or Description |
|----------|--|
| Magazine | Exceptional Parent, vol. 38, Issue 11, "What To Do When Your Child Turns 18," Harry S. Margolis and Eric Prichard, pp. 24–26 |
| Magazine | Exceptional Parent, vol. 38, Issue 10, "Transition Planning, Special Education Law and Its Impact On Your Child," Terry Schmitz, pp. 37 – 39 |
| Magazine | Exceptional Parent, vol. 39, Issue 01, 2009 Annual Resource Guide. |
| Website | http://depts.washington.edu/healthtr |
| Website | http://hctransitions.ichp.ufl.edu |

Suggested timelines for **Teens** with Disabilities

Before Age 14

1. Develop your transition plan for school to post-school for your IEP.
2. Receive invitation to participate in your IEP.

Before Age 17

1. Learn about healthcare funding options available for you after you turn 18.
2. Contact the Division of Vocational Rehabilitation by the Fall of the year before graduation.
3. If full or limited guardianship is being considered, begin procedures two months before turning 18.
4. Discuss your legal rights and responsibilities upon turning 18 (legal adulthood).

Before Age 18

1. During the month you turn 18, find out if you are eligible for SSI.
2. If you are eligible for SSI, learn about their work incentive programs.
3. If you will be living away from home (such as college), request any accommodations you will need.

More stuff about Transition

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CSHCN Transition Plan Worksheets. These worksheets will help you and your child to think about future goals and to identify the things that they are doing now to be more in charge of their health. These worksheets will also help you to figure out what else you and your family need to do now and over the next few years so that, when your child is a young adult, you are prepared for the transition from pediatric to adult-oriented health care; and that they are ready for work and living more independently.

On the Web

Children’s Special Health Program Web Site

<http://www.doh.wa.gov/cfh/mch/cshcnhome2.htm>. This web site has information about Children’s Special Health Program.

Health Care Transition Training Web Site

hctransitions.ichp.ufl.edu
This web site was developed by the University of Florida for teens, parents and professionals. It has lots of information about transition and some videos about teens who have taken charge of their health.

Jim’s Story

video.ichp.ufl.edu/JimStory2.htm
This 10-minute on-line video is about a young man with Cystic Fibrosis.

College and Beyond

video.ichp.ufl.edu/collegeandbeyond.htm
This 20-minute on-line video is about Jeff, a young man who has a severe physical disability. As he grew up, Jeff learned how to be in charge of his health and make medical decisions with his doctors. This helped him be able to be independent and successful at college. Now he is about to graduate and get a job!

Health and Ready To Work Web Site

www.hrtw.org
This web site has lots of information about being healthy and getting ready for the future!