

Young Adults Transition Plan

Your Future/ Your Life



Adapted From:
Washington State
Department of Health

Planning for A Healthy Transition

A Family Transition Plan

About this Guide

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 guide 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.



FAMILY VOICES

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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.



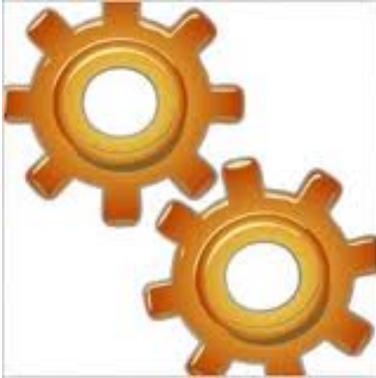
One important change that will happen over the next few years is for them to say goodbye to their pediatrician and to select a doctor who takes care of adults instead. This process of leaving pediatrics and getting ready to go to adult-oriented medical providers is called health care transition.

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.



Shifting Gears

How does my role change during transition?



Moving into a new parenting mode begins with a shift in how you see yourself. Over the years, you've worked hard to do all that you can to insure our child's well-being. In the beginning you're in charge—holding all the responsibility. As your child grows and develops you begin to see ways they can be included in their care and take a more active role. One parent describes how he sees this shift, *"I'm not going away. My role is changing."*

Hear two examples of how parents, Ray and Amy, have shifted gears with their children.

To shift gears:

- **Think back** on the small ways you've already helped your child take on responsibilities in their every day life. Let these experiences expand your view of how both of your roles can shift.
- **Notice** what your child is ready to take on in managing their health care. Think about what natural consequences you're willing to risk to gradually move the transition process forward.
- **Go for it!** Shift your parent gear to one of "watchful waiting"—step back, take note, and step back in when needed and only if needed.
- **Debrief.** Talk with your child about what happened. This will help you both learn from the experience.
 - Listen first
 - Ask open-ended questions such as "How did it go for you?" "What went well?", or "Anything you'd do differently?"
 - Offer feedback in a supportive way. "I noticed. . .", "I like how you. . .", or "From what you said, next time it might make sense to try. . ."
- **Keep in mind** that change doesn't happen over night.

Celebrate small successes. They are the building blocks of transition.

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.

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.

Building Confidence

Parents want their children to feel good about themselves—to be as confident and capable as they can possibly be. This growth happens over time and through experiencing success and accomplishment—usually one small step at a time. Day-to-day life offers countless opportunities for your child or teen to build this sense of mastery on many fronts, including their health.

How to build your child's confidence in managing their health care:

- **Help your child know herself/himself well**--their personal strengths and challenges.
- **Prepare your child with an understanding** of the unique realities of their health condition. This self-knowledge will inform and guide the choices they make.
- **Engage your child in shared decision-making**, at whatever level fits for you and your child.
- **Be responsive to your child's initiative**, suggestions and natural abilities. Each family moves through transition in its own particular ways.
- **Find opportunities for your child to successfully participate in their health care**—Keep in mind this looks different for each child and family.



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.
- 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.
- 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.

Finding and Using Adult Health Care (continued)

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

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 risk taking 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!

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.

Health Coverage Options for Children with Special Health Care Needs

WHAT HAPPENS WHEN THEY AGE OUT OF CHILDREN'S PLANS?

BY LAUREN AGORATUS, M.A.

Parents may not be aware of all the choices available for insurance coverage for their children with special needs as they become young adults. Options can include continuing dependent coverage, as well as public and private insurance.

Dependent Coverage

Due to the Affordable Care Act (ACA), parents can now continue health insurance coverage for their dependents until age 26 (see Marketplace plans.) In some states, dependent coverage is even more generous so state law would apply (for example, in NJ dependent coverage is until age 31.) Another option for parents is the “disabled dependent provision” which covers the dependent indefinitely as long as the parent is employed. Families need to get the forms from their employer before their child turns 18 because once the opportunity is lost, it can't be regained.

Public Health Care: Medicaid & Medicare

Medicaid provides insurance coverage for people who have limited income or disabilities. Before age 18, the income of the parents count, but after age 18 the adult child is seen as a “family of one.” In states where Medicaid coverage was expanded under the ACA, coverage starts at age 19 so it may be possible for the child to

It is important to note that children with special health care needs may be eligible for more than one type of plan. Parents and their young adults with disabilities must examine all options to choose a plan that meets their needs.

move from eligibility for the State Child Health Insurance Program to eligibility for adult Medicaid but this doesn't happen automatically. There is also the possibility that a child with special needs could be eligible for a Medicaid waiver which may allow for eligibility above the usual income limits based on medical status. Families can check with their state's Maternal and Child Health Title V agency that helps children up to age 21 or their Family Voices/Family-to-Family Health Information Center (see Resources.) Usually if a child is eligible for Medicaid, they also get Supplemental Security Income (SSI) which provide additional financial benefits.

Medicare covers people over age 65 or people with certain disabilities. Medicare will cover children who have end stage renal disease, for example, who need dialysis or a kidney transplant. Or if a child becomes disabled before age 22, they will be eligible for Medicare if their parent is disabled, retired, or deceased. They are then considered a Disabled Adult Child (DAC.)

Healthcare.gov: Marketplace Plans

As mentioned above, parents can continue dependent coverage until age 26 under the ACA. After that, the dependent can apply for their own plan in the health exchange marketplace. Dependents can stay on their parent's plan even if they are:

- married
- not living with their parents
- attending school
- not financially dependent on their parents
- eligible to enroll in their employer's plan

Please note that Marketplace will only allow families to pick one type of plan (for example, Qualified Health Plan or Medicaid.) Families can apply for coverage during open enrollment or special enrollment under circumstances such as losing employer health coverage (see Resources.)

Other Types of Health Care Plans

College Plans: Students may be eligible for insurance coverage available by their college. However, families must check "with your student health plan to see if it qualifies as coverage under the health law." Some of these plans may not have as many benefits as Qualified Health Plans in the Marketplace. Also, students can check if they would be eligible for tax credits to pay for Marketplace plans. There is no student exemption from the requirement to have coverage or pay a penalty.

Catastrophic Plans: Individuals under age 30 are eligible for catastrophic health plans. These plans are affordable and help protect against high cost medical care. However, they only allow for three

primary care visits and limited prevention/wellness services, so they don't provide as much coverage as Qualified Health Plans. Since they have minimal benefits, these plans may not provide the best coverage for students with disabilities.

Coordinating Benefits When There Is More Than One Plan

As mentioned above, a child may be eligible for a private employer plan as well as Medicaid and/or Medicare. It is important to have as much coverage as possible if a child has disabilities. If a child has more than one plan, it is essential that benefits are coordinated so that all plans are billed by hospitals, doctors, and pharmacies. Even if a doctor doesn't take Medicare, they can send their Medicare opt-out letter with the bill to the private insurance company or families can file claims (see Resources.) Even if a doctor doesn't take Medicaid, if the child has a private plan as primary, the doctor's office can call the plan to find out how to bill "out of network" as secondary. Parents can ask the billing department to bill both private and public insurance. This will maximize reimbursement to the provider and also lessen expenses for parents.

Parents have many choices available to them as their children get older. Families can check resources to find out about the best coverage choices for their child with disabilities. •

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Resources

Medicaid

www.healthcare.gov/what-if-my-state-is-not-expanding-medicaid/

Medicare

Eligibility

www.ssa.gov/pubs/EN-05-10026.pdf
or Spanish

www.ssa.gov/pubs/ES-05-10926.pdf

Claim form

(even if doctor doesn't participate)

www.cms.gov/Medicare/CMS-Forms/CMS-Forms/Downloads/CMS1490S-ENGLISH.pdf
or Spanish

www.cms.gov/Medicare/CMS-Forms/CMS-Forms/Downloads/CMS1490S-Spanish.pdf

Healthcare.gov

(also click on Spanish)

Dependent Coverage

www.healthcare.gov/can-i-keep-my-child-on-my-insurance-until-age-26/

Coverage for College Students

(including catastrophic plans)

www.healthcare.gov/if-i-m-a-college-student-what-do-i-need-to-know-about-the-marketplace/

Catastrophic Health Plans

(under age 30)

<https://www.healthcare.gov/can-i-buy-a-catastrophic-plan/>

Comparing Costs - Qualified Health Plans

www.healthcare.gov/how-much-will-marketplace-insurance-cost/

Special Enrollment

www.healthcare.gov/how-can-i-get-coverage-outside-of-open-enrollment/#part=1

Helpful Contacts

Title V

Title V (under 21)

<https://mchdata.hrsa.gov/tvisreports/StateMchApps/StateHotline.aspx>



Family Voices/Family-to-Family Health Information Centers

www.familyvoices.org/states

HealthCare.gov

Marketplace/Healthcare.gov questions

www.healthcare.gov/how-do-i-get-help-enrolling-in-the-marketplace/



Medicare-State Health Insurance Assistance Program counselors

<https://shipnpr.shiptalk.org/shipprofile.aspx>