



# Medical Transition— Getting Your Child Ready to Move from Pediatric to Adult Medical Services

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Medical transition is an important piece of the overall move for teens with disabilities to adulthood. Three major issues arise in this process: the legal implications of a person's turning 18, the need for adult medical services, and funding for adult medical services.

## Legal Issues at Age 18

Preparing for your child's 18<sup>th</sup> birthday is often when parents start thinking about medical transition. Eighteen is the age of majority in Texas, when a child assumes the rights and responsibilities of adulthood. At that age, health care professionals may not share information with parents, unless provisions are made to allow parent access.

## How can parents guarantee that they can continue to be part of the medical decision-making process?

In some cases, parents become the legal guardians of their children, guaranteeing that they are the decision makers for all medical issues; they then have the right to sign permission forms for medical procedures, be present at appointments, and have access to medical records. A guardian is authorized to speak for the child. There are several different kinds of guardianship and the process can be lengthy and costly. If you plan to pursue guardianship, begin the process a year before your child will be 18 years old.

In other cases, when parents do not become their child's guardian, the child can invite the parent into medical appointments and to assist with decision making. Also the child can sign a form giving the parent access to medical information. "Children age 18 and older have complete control over their medical care and records, and parents require authorization to access their records. This is true even if the child's care is paid for by the parents' insurance." (Quote from <http://journal.ahima.org/2012/03/01/how-to-request-your-medical-records/>).

Another approach is to prepare your child to assume his or her health care responsibilities. You can actually start this as soon as your child can understand simple medical ideas, but no later than 14. At that age, you can begin to give your child the opportunity to make her own appointments, learn what medications he takes, interact with and ask questions of her health care provider, and be able to state what his medical issues are. You can help your child to compile a written statement to help her present her medical information to others. There is a great Medical Summary form to fill out, available at

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Journey to Adulthood - A Transition Travel Guide, pp.28-30, found at <http://www.gottransition.org/youth-resources>.

Being able to advocate for oneself and participating in medical decision making, even if in small ways, is very empowering for young adults and sets an example for self-advocacy in other areas of life experience. There are several excellent internet tools to help youth develop their expertise in advocating for themselves in the medical arena. For example, <http://www.gottransition.org/youth-resources> has an amazing list of guides for youth transitioning to adulthood, such as a transition toolkit, guide for talking to your doctor, and heading for college with special health care needs. Check it out!

At this same website (Got Transition?), several helpful 1-page checklists are available for both the youth and the family. To access them, go to: [http://www.gottransition.org/UploadedFiles/Files/NHCTC\\_Readiness\\_FamilyTool\\_06Oct2011.pdf](http://www.gottransition.org/UploadedFiles/Files/NHCTC_Readiness_FamilyTool_06Oct2011.pdf) and then go to: **3. Transition Preparation**, *Use the Transition Readiness Assessment (youth, family) to address gaps in preparation, knowledge, and skills.*

This transition time may also be an opportunity for your son or daughter to learn what their disability or chronic illness is called (if they haven't already) and be able to describe its main characteristics, as well as important complications that could occur as they move into adulthood. You and your child might look together at web-based directories that list disabilities and define them, such as <http://www.cdc.gov/ncbddd/disabilityandhealth/types.html>. At this site, you can print out a 1-page fact sheet on a specific disability, something a person could use in other settings. You might pair this activity with a look at the following site, listing famous people with different disabilities:

[http://en.wikipedia.org/wiki/Category:Lists\\_of\\_people\\_with\\_disabilities](http://en.wikipedia.org/wiki/Category:Lists_of_people_with_disabilities)

### **Moving to Adult Services**

Many pediatric professionals will no longer see a youth after age 18, thus pushing families to seek medical providers for adults rather than pediatricians. "Without planning for transition, teens and families may be surprised when they are refused care at a doctor's office or a children's hospital because they have 'aged out.' You don't want to find this out when you are sick and need help really fast. Plan ahead! Start planning at age 16 for your transfer to doctors or nurse practitioners who care for adults. Actual transition is usually between ages 18 and 21." (From Journey to Adulthood - A Transition Travel Guide, p. 26, found at <http://www.gottransition.org/youth-resources>)

**Here are some tips for finding adult health care professionals (from the same source, above, p. 27):**

- Ask your current doctors, nurse practitioners or care coordinators who they recommend.
- Ask adults who have health needs like yours who they see.
- Look at your health insurance company booklet or website for approved providers.
- Call and interview doctors or nurse practitioners. Find out if they have experience with your health condition, how long it takes to get an appointment, and how quickly you can be seen if you are sick.
- Use the internet. Look at websites of the American Academy of Family Physicians, American College

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of Physicians-Internal Medicine, American Academy of Physical Medicine and Rehabilitation, American Academy of Orthopedic Surgeons or other specialists needed for your care.

And I would add, ask other parents for advice about adult providers through the Texas Parent to Parent listserv for your area. Parents are often a great resource for other parents! Request to get on a listserv at by emailing Susan Prior at TxP2P at [Susan.Prior@txp2p.org](mailto:Susan.Prior@txp2p.org).

Remember, to the extent that your child is able to do so, include him or her in the process. For most young people with special needs, this is the beginning of an important and long-term relationship.

### **Finding Medical Insurance for your adult child**

Youth and families often need to find new sources of funding for adult health care services. Health care insurance can be obtained through any of the following:

1. Employer-based coverage through a family member's work. Children may now stay on their parent's insurance through age 26. Even after age 26, a parent may petition to keep a child on his or her plan through many company plans if your child is: "(1) incapable of self-sustaining employment because of intellectual or physical disability; and (2) chiefly dependent on the insured or group member for support and maintenance." (Texas Insurance Code, Section 1201.059). Be sure to check well before the 26<sup>th</sup> birthday, as sometimes there is a limited time during which you can make this request and it may have to be renewed each year. You may also be able to extend coverage through COBRA for up to 36 months for your child through your employer-based insurance.

2. A government-sponsored health plan:

a. **Medicaid:** a government program which pays for an array of health care services for individuals with disabilities with low incomes. You child may become eligible for Medicaid through: getting SSI (Supplemental Security Income - Medicaid is automatically granted after your child becomes eligible for SSI at age 18, when family income is no longer counted toward eligibility) or getting on a Medicaid Waiver program. See [http://www.hhsc.state.tx.us/medicaid/med\\_info.html](http://www.hhsc.state.tx.us/medicaid/med_info.html) and <http://www.ssa.gov/disability/>

If your child has Medicaid, he or she may be eligible for:

- PCS (Personal Care Services for Children)-up to age 21
- PHC (Personal Home Care for Adults)--over 21
- See [Dads.state.tx.us/services/list\\_of\\_services.html](http://Dads.state.tx.us/services/list_of_services.html) for a list of Medicaid-based services in Texas.

**Important:** Even if right now you don't think you will need or want eligibility for Medicaid Waiver services, go ahead and place your child's name on the interest lists. Most Waiver programs have many years' waiting time, and you will want to have all possible options available.

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b. **Medicaid Buy-In:** a program available for working people with disabilities aged 16-65 who are not on SSI and earn income less than 250% of poverty level; for more information, go to <http://www.hhsc.state.tx.us/mbi.html>

c. **Medicare:** young people may qualify for Medicare through Social Security Disability Income (SSDI) because:

- they are “adult disabled children” of adult workers who have become disabled, retired, or deceased; Medicare starts 24 months after getting SSDI; see <http://www.ssa.gov/disability/>
- they have worked and paid into Social Security for two or more years and then become disabled. After receiving disability benefits for 24 months, they are eligible for Medicare.

**Insurance for people who can't get coverage because of a pre-existing condition:**

**Texas High Risk Pool:** provides health insurance to Texans who cannot obtain coverage because of a medical condition; go to <http://www.txhealthpool.org/> for more information.

**Pre-Existing Condition Insurance Plan (PCIP):** created in 2010 under the Affordable Care Act and offers uninsured people with pre-existing conditions coverage; the person must have been without coverage for at least 6 months. See [www.pcip.gov](http://www.pcip.gov)

**HIPP (Health Insurance Premium Payment):** for families in which one member has Medicaid and another family member gets work-place health insurance; Medicaid may pay your family's private health insurance costs. Go to <http://www.gethipptexas.org/>

You can fit together the 2 kinds of medical insurance, private and public. Usually Medicaid is the payer of last resort, or the “secondary” payer, which means that Medicare and work-place health insurance are “primary,” and they will pay first. Most medical providers will be able to sort out who to bill first and then second.

**Two final considerations:**

1. Write down your child's medical history, major issues and care - a how-to guide for your child's care, so that others in your child's life can be prepared to provide care when you can't. Keep the summary short, if possible, identifying the most important points and limiting it to one or two pages.
2. Create an emergency plan for your child's care. See <http://cshcn.org/planning-record-keeping/emergency-preparedness-children-special-needs/emergency-preparedness-referen> for complete instructions and a checklist. Another emergency-preparedness form to fill out is at <http://www.acep.org/content.aspx?id=26276>.

Good luck with this process, an important step for your child's growing up. If you have questions on this topic or other transition topics, please get in touch with us at TxP2P and our new Pathways to Adulthood program ([www.txp2p.org/parents/pathway.html](http://www.txp2p.org/parents/pathway.html)).

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