

# Transition from Adolescence to Adulthood

## What's It All About?

Transition from adolescence to adulthood is an exciting time. There is much to learn. There are many new experiences. It is common and healthy for teenagers to want to do things on their own. Teens need to be encouraged to grow and try new responsibilities.



Before being able to do things on their own, teens need to learn important lessons. They need to develop skills for independent living. They need friends and time and places to play, relax, and meet with other people. They need to think about education beyond high school and employment. They need to understand about how to get around (transportation). They must determine where to live (housing).

Teens also need to learn about and understand their health care needs. They need to participate in making decisions about their health. They likely will need to make changes in the ways they get medical care. They may need to change doctors. Learning this information, developing these skills, and making these changes is called *health care transition*.

## Family Voices

Family Voices is a national grassroots network of families and friends speaking on behalf of children with special health needs. Special needs children are also part of the wider world of children. Family Voices works to encourage partnerships between families and professionals for children's good health.

Successful *health care transition*, like all transitions from adolescence to adulthood, should be planned, purposeful, and gradual. There are many lessons to learn and skills to develop.

Some of the health care lessons that need to be learned include:

- Information about your health condition and disability
- Personal hygiene and self-care
- Monitoring of your health condition and handling your medicines
- Preventive and responsible health behaviors
- Health insurance and medical record management
- Emergency measures
- Communication about your health care needs with providers and others
- Community resources, accommodations, and transportation

CSHCN will explore these topics in more detail in the next few issues of the *CSHCN Family Newsletter*. Upcoming issues will give you some ideas to help better identify lessons that might be learned. There will be articles that share guidelines to help develop skills. Watch for more information in the January 2006 newsletter.

In the meantime, you can go to the Transition page of the CSHCN website for more information. It is located at [www.dshs.state.tx.us/cshcn](http://www.dshs.state.tx.us/cshcn). Click on the *Transition Information* link in the menu on the left side of the homepage. CSHCN recently revised the Transition Information. There are new weblinks to other resources, including websites primarily for youth. Check it out! ●

*Bright Futures: Family Matters* is a digest of articles and news clips to share with families, family organizations, and our professional partners. Check out the Family Voices websites at: [www.brightfuturesforfamilies.org](http://www.brightfuturesforfamilies.org) and [www.familyvoices.org](http://www.familyvoices.org). ●

# Transition from Adolescence to Adulthood

## Beginning Transition Training

This is the second in a series of four articles about health care transition for children with special health care needs. The first article, "What's It All About?" appeared in the October 2005 issue of the Children with Special Health Care Needs Services Program (CSHCN) Family Newsletter.

Health care transition is the planned movement of teens and young adults with chronic (ongoing) physical and medical conditions from a child-centered health care system to an adult-oriented health care system. The question for many parents and young adults is how to go about getting there. One answer to this question is to teach or train for health care transition.

There are many resources for teaching about health care transition training. One of the best is a series of Health Care Transition Workbooks recently released by the Institute for Child Health Policy at the University of Florida. The workbooks pull together training ideas and relate them to a child's age. There are three workbooks in the series. Each workbook is directed toward a different age range (12-14, 15-17, 18+).<sup>1, 2, 3</sup>

In a review of the workbooks, Bonnie Sayers, parent of a pre-teen child and editor of Autism Spectrum Disorders at *BellaOnline*, says, "I am thankful for the opportunity to prepare for this transition in my child's life. There are questions I never considered and worth discussion at this point in time before he even reaches the age of twelve."<sup>4</sup> More

information about these workbooks and how to get them is at the end of this article.

Much of the information in this series of articles is adapted from these workbooks, but since a child's physical age is not necessarily the same as his/her developmental age, this series of articles takes a slightly different approach and identifies levels of transition training as beginning, intermediate, and advanced. This article is about beginning transition training.

Training for health care transition may be divided into seven main topic areas:

1. Basic knowledge and management of health condition
2. Health care, personal hygiene practices and healthy choices
3. Medications, tests, equipment and supplies
4. Doctor visits, interactions with health professionals
5. Health care transition goal setting
6. Transition and accepting responsibilities away from home
7. Health care systems, records, insurance, emergencies

**See the skills for each of these topics on pages 4 and 5.**

These skills listings are intended to use with a child who is beginning to learn about his/her health care transition. You can use this listing to begin a conversation about transition, to track

transition progress, or to reward transition achievements.

It is important to note that not every child will be able to develop every skill. Some children will develop skills quickly. For others, developing new skills will take more time. Some children may need to adapt some skills to suit their own capabilities. For all, health care transition is a learning process. This means that learning new skills builds upon lessons learned and skills done well. Parents and children both benefit by learning new skills and by transitioning health care responsibilities.

Articles about intermediate and advanced transition training will appear in upcoming issues of the newsletter.

You may obtain the Institute for Child Health Policy Health Care Transition Workbooks and other transition resources from the Health Care Transitions Resources page on the Institute for Child Health Policy website at <http://hctransitions.ichp.edu/resources.html>. The April 2006 issue of the CSHCN Services Program Family Newsletter will include an article about skills for intermediate transition training. In the June 2006 issue, the series will conclude with an article about skills for advanced transition training. For more information about transition, the CSHCN Services Program also has a Transition website with links for youth and parents, [www.dshs.state.tx.us/cshcn/transinfo.shtm](http://www.dshs.state.tx.us/cshcn/transinfo.shtm). ●

1 Reiss, John and Robert Gibson. "Health Care Transition Workbook for CMS Enrollees Age 12-14." Institute for Child Health Policy, University of Florida, 2005.

2 Reiss, John and Robert Gibson. "Health Care Transition Workbook for CMS Enrollees Age 15-17." Institute for Child Health Policy, University of Florida, 2005.

3 Reiss, John and Robert Gibson. "Health Care Transition Workbook for CMS Enrollees Age 18 and older." Institute for Child Health Policy, University of Florida, 2005.

4 Sayers, Bonnie. "Health Care Transition for Youth with Disabilities." *BellaOnline, The Voice of Women*, <http://autismspectrumdisorders.bellaonline.com>, 08/30/2005.

# Health Care Transition Topics and Skills

## 1 Basic knowledge and management of health condition

- Child is able to tell someone about his/her diagnosis, disability or health condition and/or carries and can produce this information from wallet or purse
- Child can describe how the condition or its treatment affects his/her body
- Child can describe how the condition or its treatment affects his/her daily life
- Child can describe health problems frequently caused by his/her health condition
- Child can tell a doctor or other medical professional important points about his/her medical history and/or regularly can produce a medical history summary from wallet or purse
- Child knows and can identify when there are unusual changes to his/her condition
- Child knows about his/her allergies and their reactions
- Child asks questions of or expresses concerns to safe resources (parents; medical professionals; school teachers, counselors or school nurse; library; internet; mentors) to learn more about his/her condition

## Health care, personal hygiene practices and healthy choices

- Child is able to toilet, dress, feed, bathe, and care for her/himself
- Child is able to manage daily oral hygiene and routine medical tasks
- Child understands and can tell others about healthy choices concerning diet, smoking, alcohol or illegal drugs, sun exposure, regular exercise
- Child makes healthy personal choices about friends, foods, sun exposure, exercise, smoking and alcohol or illegal drug use
- Child understands and can correctly tell others about changes that take place to his/her body during puberty

- Girls understand about normal and abnormal menstruation (periods) and are able to manage personal care and cleanliness related to it
- Child understands about healthy preventive health care practices, such as the need for and when to get “well-child” and dental check ups, immunizations, or other primary care assessments/screenings
- Child wears Medi-Alert bracelet if needed

## 3 Medications, tests, equipment and supplies

- Child can name and understands dosing for his/her medications or carries this information in a purse or wallet
  - Child knows and can explain why he/she takes each medication
  - Child knows possible side effects for his/her medications and knows what happens if medication is not taken or is not taken as ordered, i.e., under or over dosing
  - Child can take medication correctly with minimal supervision
- Child is able to monitor medication supply and report when to reorder
- Child knows and understands the results of regular medical tests
- Child is capable of some self-testing, such as blood sugar level for a child with diabetes
- Child is able to use and take care of his/her medical equipment or assistive devices
- Child can perform simple maintenance, report problems and request reorder of supplies
- Child requests or makes adjustments to equipment or assistive devices to better meet his/her needs
- Child can instruct others concerning his/her medication, equipment, and use of assistive devices
- Child observes his/her environment and reports needed changes

“ *These skills listings are intended to use with a child who is beginning to learn about his/her health care transition.* ”

## Doctor visits, interactions with health professionals

- Child can name and knows why he/she sees doctors or other health care professionals
- Child knows which is his/her “main” doctor or medical home
- Child participates in scheduling doctor or other health care visits
- Child can describe or demonstrate health care problems he/she is experiencing
- Child answers and/or asks at least one question during a health care visit
- Child spends some time alone with the doctor or other health care professional
- Child expresses his/her needs or wants about medicines or treatments
- Child understands and agrees to take medicines or treatments

## Health care transition goal setting

- Child asks about a change or expresses discomfort going to a “children’s doctor”
- Child talks about or sets personal goals for taking care of his/her own health
- Child learns new skills and assumes more responsibility for self-care
- Child has talked with older youth or young adults about the health professionals they see and how they handle their health care needs
- Child has talked with case manager, social worker, educator or school counselor and asked about help with or planning for changing to adult health care professionals (By age 14, the Individual Education Plan begins to include health care transition goals.)

## 6 Transition and accepting responsibilities in and away from home

- Child is able to manage health care tasks in school or at other locations away from home
- Child communicates with others about his/her health condition and care needs
- Child participates in Individual Education Plan or 504 meetings at school

- Child participates in after-school or community activities
- Child takes responsibility for and is able to participate in some activities without immediate adult supervision, such as completing home work assignments
- Child uses protective equipment when needed, i.e., seat belts, helmets, mouth guards, knee or elbow pads, etc.
- Child is able to express emotions and feelings and uses constructive ways to cope, such as talking about feelings, asking for help, reading and learning, mental-imagery, watching television, or listening to music
- Child is able to manage his/her own money
- Child accepts responsibility for some chores at home
- Child knows (safety) rules about and understands alternative methods of transportation
- Child has a circle of friends including others with and without special health care needs
- Child has expressed long-term goals for education, work, recreation, social relationships, and family relationships

## Health care systems, records, insurance, emergencies

- Child keeps a diary, log, or other documentation for health care services and needs
- Child understands the basics to transfer health care information (including medical records, test reports, x-rays, and treatment plans) among health care providers
- Child keeps a calendar and can advise others concerning schedules, locations, and reasons for upcoming appointments or treatments
- Child can make or change an appointment with little supervision
- Child knows what kind of insurance he/she has and keeps a copy of the insurance identification card(s) in wallet or purse
- Child understands fundamental information about how insurance works
- Child is able to alert others if an emergency occurs
- Child knows how to contact parent and/or another responsible person in an urgent or emergency situation
- Child participates in planning for emergency situations and in completing an Emergency Care Plan or personal Emergency Information Form ●

# Transition from Adolescence to Adulthood

## Intermediate Transition Training

This is the third article in a series of four about health care transition for children with special health care needs. The first article, “What’s It All About?” appeared in the October 2005 issue of the CSHCN Family Newsletter. The second article, “Transition from Adolescence to Adulthood–Beginning Transition Training,” appeared in the January 2006 issue. The final article about advanced transition training will appear in the July 2006 newsletter.

All four of the articles draw extensively on the Health Care Transition Workbook for CMS Enrollees Age 12-14, Health Care Transition Workbook for CMS Enrollees Age 15-17, and Health Care Transition Workbook for CMS Enrollees Age 18 and older, recently published by the Institute for Child Health Policy (ICHP) at the University of Florida. These workbooks are an invaluable resource for families that want to learn more about health care transition. A complete reference is provided at the end of the article.

Health care transition may be defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems. In keeping with the objective to teach or train parents and providers for health care transition, this article makes suggestions about intermediate skill levels or phases of health care transition training.

Intermediate transition training is targeted toward children 15 to 17 years of age. Remember that a child’s physical age is not necessarily the same as his developmental age. This series of articles targets developmental age. As in the previous article on beginning transition, intermediate training for health care transition covers seven main topic areas:

1. Basic knowledge and management of health conditions
2. Health care, personal hygiene practices and healthy choices
3. Medications, tests, equipment and supplies
4. Doctor visits, interactions with health professionals
5. Health care transition goal setting
6. Transition and accepting responsibilities away from home
7. Health care systems, records, insurance, emergencies

For each topic, a listing of intermediate skills follows. The skills listing is for a child/youth who has mastered most of the beginning level transition skills. Use the skills listing to

learn or teach greater responsibility for transition, to monitor transition progress, or to reward transition achievements.

## Basic knowledge and management of health conditions

The intermediate skill set for basic knowledge and management of a health condition is similar to the beginning skill set. They differ in the amount of assistance needed with the knowledge and detail that a child is able to master. For example, at the beginning level, a child may know the name of her diagnosis and some of its symptoms. The child may need to be prompted to remember. At the intermediate

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*“For all, intermediate health care transition continues to be a learning process. Both parents and children benefit from learning new skills and transitioning health care responsibilities.”*

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level, a child/youth should know more specific information about the disease or disability and require less prompting. In addition to the skills listed in the article about beginning transition training, new skills might include that the youth:

- Is able to keep a personal health notebook or medical journal to track important changes and list questions to ask a medical professional
- Is able to keep, use, update, and tell others about a Medical Summary form (written information about her diagnosis, medications, equipment, doctors, and what to do in an emergency)

## Health care, personal hygiene practices and healthy choices

The intermediate skill set for health care, personal hygiene practices, and healthy choices builds upon the beginning skill set, with the youth continuing to accept increasing levels of responsibility for his own care. For example, after

mastering one or two routine medical tasks, the youth would master three or four new ones, which might include the following:

- Is able to perform routine preventive self-exams, such as testicular or breast self-exams
- Knows about his sexuality, abstinence until marriage, birth control, and how to protect himself against sexually transmitted diseases
- Can tell someone about how his disease or disability may effect sexual development and reproductive health
- Knows when to check his temperature (fever) and is able to take and accurately report it

### **Medications, tests, equipment and supplies**

In addition to beginning skills, the youth's intermediate skills in monitoring medicals, tests, equipment and supplies include the following:

- Understands the difference between brand name and generic medications
- Is able to take medicines at the correct times and in the correct dosage
- Can report when medicine is running low and order refills of routine medications
- Knows if any medications require prior authorization to obtain a refill
- Is able to select over-the-counter medicines for minor complaints, such as a headache, menstrual cramps, or a cold
- Understands and can report if there are medicines that should not be taken because of interactions with other daily medicines
- Knows when routine laboratory or other tests should be done
- Manages her own equipment, requests repairs from vendors, and orders supplies when needed

### **Doctor visits, interactions with health professionals**

As the youth develops confidence and practice with beginning skills, the intermediate skills for doctor visits and interactions with health professionals might include the following:

- Spends much of the visit alone with the health care professional
- Answers most of the questions about his health
- Asks most of the questions during a visit
- Is able to complete or to tell someone how to complete personal health history forms that are done during a visit

- Can contact and tell someone about unusual changes in his health
- The youth, medical professionals, and parents all participate in decision making about treatments and medicines

### **Health care transition goal setting**

- Understands if and when a "child" health care professional will stop seeing patients of a certain age
- Has identified and expressed interest in visiting one or more "adult" health care professionals
- Has talked about how to select an adult provider, including topics such as the size and type of practice, experience and willingness to take care of people with disabilities, personality, and compatibility
- Continues to talk with a case manager or social worker about health care transition
- Accepts more responsibility for developing and changing a personal health care transition plan

### **Transition and accepting responsibilities in and away from home**

- Can list and manage medical tasks while at school or away from home
- Attends and guides some of the discussion during Individual Education Plan or 504 meetings at school
- Can tell someone about unusual changes in his health
- Is able to manage money and can use a checking account or debit card
- Develops more definite plans about education, work, and what's required to live independently
- Has helped with researching scholarships, financial aid, or job training
- Has participated in submitting an application to the Department of Assistive and Rehabilitative Services (DARS) Vocational Rehabilitation Program or receiving services from them

### **Health care systems, records, insurance, emergencies**

The intermediate skills for health care systems, records, insurance, and emergencies also build on the beginning skill set, increasing the youth's overall knowledge and understanding. Some new intermediate level skills include the following:

- Understands more about insurance and its limitations or restrictions, such as whether prior authorization is needed for medicines and equipment, etc.

- Knows when family health insurance plan may lapse due to age, education status, or other changes in eligibility
- Knows whether she receives benefits from the Supplemental Security Income (SSI), Medicaid, or CSHCN Services Program(s) and if applicable, understands fundamental information about each
- Helps to complete health care, insurance, or other paper work
- Learns about how vocational or educational choices may effect future health insurance options
- Understands the difference between a primary care provider and a specialist
- Understands the differences among the types of specialists seen
- Can tell someone about the new legal rights and responsibilities that come at age 18. For example, the youth knows about signing medical consent and other forms, making medical decisions, what is confidential information, the need to keep insurance and other information current, voting, and for males, registering for the U.S. Selective Service (the military draft)

As with the beginning skills, not every youth will be able to develop every intermediate skill. Some will develop skills quickly, but others may take more time. Some may need to adapt skills to suit their own capabilities. For all, intermediate health care transition continues to be a learning process. Both parents and youths benefit from learning new skills and transitioning health care responsibilities.

The July 2006 issue of the CSHCN Services Program Family Newsletter will conclude this series with an article about

skills for advanced transition training. For more information about transition, visit the CSHCN Services Program Transition website at [www.dshs.state.tx.us/cshcn/transinfo.shtm](http://www.dshs.state.tx.us/cshcn/transinfo.shtm) which has links for both youths and parents.

If the transition training articles are helpful to you, please let us know. Send questions or comments by mail to:

CSHCN Services Program, MC1938  
 Department of State Health Services  
 1100 West 49th Street  
 Austin, TX 78756

Or by email to: [cshcn@dshs.state.tx.us](mailto:cshcn@dshs.state.tx.us)

### Acknowledgement

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Reiss, John and Robert Gibson. Health Care Transition Workbook for CMS Enrollees Age 12-14, Institute for Child Health Policy, University of Florida, 2005.

Reiss, John and Robert Gibson. Health Care Transition Workbook for CMS Enrollees Age 15-17, Institute for Child Health Policy, University of Florida, 2005.

Reiss, John and Robert Gibson. Health Care Transition Workbook for CMS Enrollees Age 18 and older, Institute for Child Health Policy, University of Florida, 2005.

## Remember to Keep Address and Eligibility Information Current

It is very important to keep your address information current. Use the Address Change Form included in this newsletter. If you do not let CSHCN know when your address changes, CSHCN cannot contact you. This is especially important, if you are on the waiting list.

Also remember that you must renew eligibility every 6 months. Do not delay in completing your renewal. Clients who renew eligibility after the 6-month

time period go onto the waiting list. Renewal dates are printed on your CSHCN Eligibility Form. CSHCN also sends a reminder letter 60 days prior to the renewal deadline.

It is important to update your insurance information. If your health insurance changes, contact your case manager immediately. CSHCN needs to know when you have other insurance. CSHCN also needs to know if you lose other insurance coverage for

any reason. Keep all records related to your child's health care. Save receipts for any medical bills you pay, if you pay for services while on the waiting list. If CSHCN has the funds, we may be able to help pay some of these bills.

If you have questions, contact the CSHCN Regional Office nearest you or call the DSHS-CSHCN Austin Central Office at 1-800-252-8023. A listing of the Regional Offices is provided on page 6. ●

# Transition from Adolescence to Adulthood

## Advanced Transition Training

This is the final article in the series about health care transition for children with special health care needs. The first article, “What’s It All About?” appeared in the October 2005 issue of the *CSHCN Newsletter for Families*. The second article, “Transition from Adolescence to Adulthood—Beginning Transition Training,” appeared in the January 2006 issue. “Transition from Adolescence to Adulthood—Intermediate Transition Training” appeared in the April *Newsletter for Families*. Our objective is to teach and train for health care transition. This article offers suggestions on the advanced skill levels of health care transition training.

All four of the articles draw extensively on the *Health Care Transition Workbook for CMS Enrollees Age 12-14*, *Health Care Transition Workbook for CMS Enrollees Age 15-17*, and *Health Care Transition Workbook for CMS Enrollees Age 18 and Older*, recently published by the Institute for Child Health Policy (IHP) at the University of Florida. These workbooks are a very valuable resource for families that want to learn more about health care transition. A complete reference is provided at the end of the article. Advanced training is intended for young adults 18 years of age and older.

## Basic Principles

- Health care transition is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.
- A young person’s physical age is not necessarily the same as his/her developmental age.
- All teens progress through transition at their own pace.
- Some will master all skills, while others will only master a few.
- All teens and young adults should be encouraged to take responsibility for as much of their own health care as possible.

## Main Topics

The topics are the same seven main areas covered in the previous articles:

1. Basic knowledge and management of health conditions
2. Health care, personal hygiene practices, and healthy choices
3. Medications, tests, equipment, and supplies
4. Doctor visits, interactions with health professionals

5. Health care transition goal setting
6. Transition and accepting responsibilities away from home
7. Health care systems, records, insurance, emergencies

For each topic, a listing of advanced skills follows. This skills listing is intended for a young adult who has mastered most of the intermediate level transition skills. Use this listing to teach full responsibility for transition, to show transition success, and to reward transition achievements.

The ultimate goal of this skill set is health care self-sufficiency for the young adult.

## Knowledge and Management of Health Condition

The advanced skill set shows that the young adult knows and understands her condition well enough to talk with health care providers and make her own decisions. Young adults should try to gain as much independence as possible by practicing the following skills:

- Talk about the diagnosis, disability, or health condition and its affects on the body
- Understand and describe how getting older affects the condition
- Describe how the condition affects daily living. For example, the young adult might write a paper or give a talk about these aspects of the condition.
- Discuss medical history and health problems with a doctor, nurse, or other provider
- List allergies, recognize allergic reactions, get help or use antidote to treat a reaction

## Health Care, Personal Hygiene Practices, and Healthy Choices

The young adult should be able either to take care of his own hygiene, nutrition, and exercise, or give directions to an attendant about how to do so. The young adult’s decisions about personal care support independence and a healthy lifestyle. Young adults should try to gain as much independence as possible in doing the following skills:

- Accomplish dressing, feeding, bathing, and personal hygiene without parental assistance
- Complete daily or routine medical tasks independently
- Select a nutritious diet and adopt a regular exercise routine
- Hire, train, supervise, and fire personal attendants

- Recognize onset of illness or unusual changes in condition
- Manage treatment of minor health complaints, such as minor wounds, aches, pains, coughs, and colds
- Complete preventive self-exams, such as testicular or breast self-exams, as recommended
- Behave responsibly about reproductive health, pregnancy prevention, and protection against sexually transmitted diseases
- Obtain routine laboratory or other tests on schedule or as needed
- Manage equipment, request repairs, and order supplies when they are needed

### Doctor Visits, Interactions With Health Professionals

The young adult should interact with health care professionals independently, without immediate parental presence or influence. He should try to gain as much independence as possible in the following skills:

### Medications, Tests, Equipment, and Supplies

The young adult should be able either to manage medications, tests, equipment, and supplies or direct someone else to do so. She should try to gain as much independence as possible in doing the following skills:

- Name and describe routine medications, the amounts taken, and the schedule
- Take medicines at the correct times and in the correct doses
- Order refills of all medications and obtain other routine personal care supplies
- Know when prior authorization may be needed for a refill
- Select over-the-counter medicines to take for minor complaints
- Work with doctors and pharmacists to identify medicines that should not be taken because of allergies or interactions with daily medicines
- Know the names and specialty areas of his doctors or other providers
- Visit his doctors or other providers without a parent present or with a parent present by invitation
- Tell his doctors or other providers what's wrong or unusual about his health status
- Ask and answer questions during an office visit
- Schedule and cancel appointments, complete forms, provide insurance information
- Monitor the need for immunizations and obtain them
- Decide with his doctor and give consent on treatments and medicines
- Seek and obtain new information about health or health care resources

— continued on page 4 —

## TRANSITION CONFERENCE

**November  
2-3, 2006**

The Leadership Education in Adolescent Health (LEAH) Transition Conference, which is held annually in Houston, has been scheduled for November 2, 2006, through November 3, 2006. The conference addresses issues for adolescents who are transitioning into adult medical care.

The target audience for the conference includes children with special health care needs and their family members; physicians who work with children who have chronic illnesses or children with special health care needs, such as pediatricians, psychiatrists, internists, family physicians, and physician assistants; and nurses, social workers, psychologists, case managers, and other health care professionals.

Registration information is available by contacting Tamara Greiner, Baylor College of Medicine, Office of Continuing Medical Education.

Telephone: 1-713-798-8237  
Fax: 1-713-798-7955

## Health Care Transition Goal Setting

The young adult should take an active role in this advanced skill set. This includes planning and deciding whether or not to go to new providers who treat adults. The young adult should try to gain as much independence as possible in doing the following skills:

- Determine the need to change doctors or other providers, based on age or changes in condition
- Collaborate with her primary care doctors to identify specialty providers, if they are needed
- Use providers, case managers, or others to plan for health care transition from child to adult providers
- Decide what's most important about doctors or other providers who treat adults
- Participate in the selection of doctors or other providers who treat adults
- Participate in the planning and exchange of information when going to a new provider
- Set and share goals for personal health with each new provider

## Transition and Accepting Responsibilities In and Away From Home

The advanced skill set helps young adults to continue creating individual health care transition goals that match up with educational, rehabilitation, or lifestyle goals. Young adults are preparing to live on their own, even if they continue to live with family members. They should develop and accept responsibility for many aspects of their own care. They should try to gain as much independence as possible by practicing the following skills:

- Manage all health care tasks in and away from home
- Participate in decision making and planning, if moving away from the family home
- Manage household tasks (e.g. cleaning, laundry, shopping, food preparation)
- Manage money (e.g. checking and savings accounts, paying bills, credit and debit cards)
- Manage transportation (e.g. personal automobile, public transportation, vehicle modifications)
- Determine impact of health condition on career objectives
- Determine career options and obtain training when it is necessary
- Participate in the development of an Individual Education Plan (IEP) to achieve goals and objectives

- Get post-secondary education scholarships or grants when it is possible
- Work with human resources at work or with disabled student services at college to identify and secure any necessary accommodations
- Respect safety and avoid risky behaviors, such as experimentation with alcohol or drugs or failure to use protective equipment (e.g. seat belts, helmets)
- Participate in athletic, social, and community service activities
- Use constructive methods to manage emotions, feelings, and anger
- Become a self-advocate

## Health Care Systems, Records, Insurance, Emergencies

Young adults understand the need to document their interactions with the health care service system. They are capable of making their own decisions. They have the written resources that they need. They should try to gain as much independence as possible by practicing the following skills:

- Learn about privacy and confidentiality
- Complete or seek assistance in completing forms
- Keep a diary or notebook of important information and questions to ask about their health condition
- Keep a calendar or schedule of medical and other appointments and deadlines
- Maintain current health records, such as a personal health journal, a medical history summary, and an emergency information form
- Maintain records of insurance coverage and payments
- Identify and practice “what if” situations to avoid or handle emergencies
- Consider alternatives for health insurance coverage, if a change is necessary, such as ineligibility due to changes in age, income, or employment status
- Plan ahead for the impact of aging on their disability or health condition

Young adults with disabilities may be better able to manage their own health care than young adults without disabilities, if they are prepared. Young adults can become experts in their own care. They can adapt skills to suit their own needs and capabilities. At the advanced level of health care transition, previous learning evolves into confident know-how. This confidence and knowledge enable enduring health and success. For more informa-



# Guardianship in Texas

*This article is a follow-up to the “Transition from Adolescence to Adulthood—Advanced Transition Training” article that appeared in the July 2006 CSHCN Newsletter for Families. For more information about transitioning, read the complete series of “Transition from Adolescence to Adulthood” articles in the October 2005 and January, April, and July 2006 issues of the newsletter.*

Mary’s son Alan has cerebral palsy. Alan was about to turn 18 years old. Mary wasn’t sure what that would mean for Alan in legal terms, until she attended an Admission, Review, or Dismissal (ARD) meeting at his school. She found out

He expected that he would be free to make decisions about his personal care, health, and education. He had been practicing his transitioning skills. Alan felt like an adult and looked forward to his independence. He knew he would still need help but felt he was ready for the challenges of being an adult.

The school told Mary the only way she could continue making decisions for Alan was to get guardianship. Guardianship is a legal device used to protect the rights and interests of an incapacitated person. An incapacitated person is an adult who, because of a physical or mental condition,



Alan felt like an adult and looked forward to his independence.



Mary felt that her son Alan wasn’t really ready to make important decisions by himself.

that when Alan turned 18, he would be legally emancipated (a legal adult). She also found out that when a person turns 18, there is a legal presumption of competence. Presumption of competence means that the law assumes a person is able to make his own decisions. Unless and until a judge issues an order that a person is not competent, that person is presumed to be competent to make decisions. That meant Mary would no longer be able to make decisions for Alan.

Mary was concerned about what was best for Alan. What about his health, school, and finances? Where would he live? What would happen if she died or could no longer care for him? Mary had always made most of those decisions for him. Like many parents of 18-year-olds with disabilities, she felt that Alan wasn’t really ready to make important decisions by himself.

On the other hand, Alan was excited about turning 18.

is unable to provide food, clothing, or shelter for himself, to care for his own physical health, or to manage his financial affairs. Mary would be able to make decisions for Alan as his guardian. But guardianship has its drawbacks:

- It is a public declaration of incompetence. Parents work hard to help their child be accepted by others. They teach their child not to let a disability limit goals. With guardianship, parents are faced with telling the child that he is unable to make decisions for himself.
- It takes away freedom and choice. Other people involved in making decisions will deal with the guardian instead of the adult child.
- It is expensive to setup. It is also difficult and expensive to modify or end it.

Still, guardianship seemed like a good idea to Mary, because Alan could not get by without help from her and others. She loved him very much and wanted the best for him. So, she decided to file the papers to become his guardian.

The guardianship process is not very complicated, but it does require a lawyer in Texas.

1. An application is filed in the appropriate court in the county of residence. The person who wants to be the guardian files the application. The adult this person wants to be the guardian for is called the “proposed ward.” The court appoints a lawyer to represent the proposed ward. This lawyer is called the Attorney Ad Litem. The application must contain the following:
  - a. Information about the proposed ward
  - b. The kind of guardianship wanted (in this case, guardianship of the person)
  - c. The nature and degree of the incapacity
  - d. The value and description of any property owned by the proposed ward
  - e. Why the guardianship is needed
2. If the proposed ward has mental retardation, he or she must be examined by a physician or psychologist within the six months before the guardianship hearing. If the person has a disability other than mental retardation, the court must receive a written letter from a licensed physician stating that the person is incapacitated.
3. Once the application is filed, notice is delivered to the proposed ward, the parents, and any person having control of the care of the proposed ward. It is also mailed to the spouse, siblings, and children, if any, of the proposed ward.
4. A hearing is held so that the judge can decide whether the person is incapacitated. The proposed ward has a right to be present at the hearing and has a right to jury trial, if requested. The court must find, by clear and convincing evidence, that the person with a disability is incapacitated.
5. If the court finds that the person is incapacitated, the guardian must take an oath and file a bond in the amount

ordered by the court. After that, the court issues letters of guardianship. That is when the guardianship is effective.

6. The court requires annual review of each guardianship.

Alan didn't think he needed a guardian. He knew his mother had good intentions, but he wanted to make his own decisions. At the hearing, Alan asked the judge to rule that he was able to make his own decisions, even though he needs help. The judge looked at all of the information and decided not to appoint Mary as Alan's guardian.

Instead, the judge told Mary about other ways she could give Alan independence and still look out for him. Alan could sign (or make a mark, with witnesses signing) a power of attorney. A power of attorney would let someone that Alan chose to make medical, financial, legal, and educational decisions when he could not. The judge told Mary about programs that could help Alan make financial decisions, such as representative payee programs, limited bank accounts, special needs trust accounts, and budget skills education. A person called a “surrogate decision-maker” (a substitute decision-maker) could be appointed to make decisions for Alan if he was in a hospital, nursing facility, or Intermediate Care Facility for the mentally retarded (ICF-MR). Alan now makes decisions for himself. He still relies on advice from his mother and friends for the big decisions.

There are situations in which guardianships are necessary, but in many cases it can be avoided. Finding other solutions lets people with disabilities make their own decisions, be treated as adults, and live with dignity and independence.

### About the author

Jacque Brennan is an attorney who practices disability law in Houston, Texas. She is the parent of nine children. The youngest five are adopted and have different kinds of disabilities. She works with the Disability Law Resource Project (DLRP), which is part of Independent Living Research Utilization at The Institute for Rehabilitation and Research (TIIR). DLRP provides education, training, and materials about the *Americans with Disabilities Act* and disability law topics. For more information, call 1-800-949-4232 or visit [www.dlrp.org](http://www.dlrp.org). ■

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## Snacks

Snacks and drinks that contain a lot of sugar make it easier for a child to develop cavities. Therefore, it is important to choose snacks that are tasty, but will not hurt teeth. Always remember to follow any special diets prescribed by your health care provider.

- Use fruits and vegetables instead of sweet snacks, whenever possible.
- Choose foods without a lot of sugar or fat.
- If your child eats sweets, offer the sweets as a dessert after a main meal, rather than in between meals.
- Brush your child's teeth after he or she eats sweets.
- Do not let your child go to bed with a bottle that contains anything but plain water.

## Signs of a Dental Problem

Children can develop a problem with their teeth or gums at any time. Look for signs that your child might have a dental problem, such as if your child:

- Grinds his or her teeth
- Refuses to eat certain foods, or prefers soft foods
- Is sensitive to hot or cold foods
- Has bad breath
- Has discolored teeth
- Gets sick more often than usual
- Has pain or starts touching his or her mouth, teeth, jaws, or cheeks.

If you suspect that your child has a dental problem, take your child to a dentist immediately.

Because oral health care problems affect children with special needs more often than other children, it is especially

important for people who care for children with special needs to teach them good oral hygiene habits and to perform daily and thorough oral health care. It is also important for older children to learn the skills they will need to be responsible for their own oral health as adults.



## Special Note About Adolescents

**As part of their transition to adulthood, adolescents need to learn certain skills to help them become as independent as possible. Some of those skills are related to oral hygiene. Adolescents need to learn how to:**

- **Choose oral health care products like toothpaste and floss that are appropriate for them.**
- **Perform their own daily oral hygiene (brushing and flossing).**
- **Choose foods that promote good oral health (foods and drinks without a lot of added sugar).**
- **Plan and schedule visits to the dentist for routine cleanings and treatment.**
- **Take as much control over their own oral hygiene as they are able.**

## For more information about oral health care, visit the following websites:

- [www.first5oralhealth.org/downloads/0/1596/oralhealth%20for%20children%20with%20special%20needs%20042105.pdf](http://www.first5oralhealth.org/downloads/0/1596/oralhealth%20for%20children%20with%20special%20needs%20042105.pdf)
- [www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Healthy\\_Athletes/Special\\_Smiles/Oral\\_Health/default.htm](http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Healthy_Athletes/Special_Smiles/Oral_Health/default.htm)
- [www.aapd.org/publications/brochures/specialcare.asp](http://www.aapd.org/publications/brochures/specialcare.asp)
- [www.nidcr.nih.gov/HealthInformation/DiseasesAndConditions/ChildrensOralHealth/SnackSmart](http://www.nidcr.nih.gov/HealthInformation/DiseasesAndConditions/ChildrensOralHealth/SnackSmart)
- [www.nidcr.nih.gov/HealthInformation/DiseasesAndConditions/DevelopmentalDisabilitiesAndOralHealth/DentalCareEveryDay.htm](http://www.nidcr.nih.gov/HealthInformation/DiseasesAndConditions/DevelopmentalDisabilitiesAndOralHealth/DentalCareEveryDay.htm)

# newsletter

April 2010

# for families



La versión en español del boletín empieza en la página 9.

## inside

## Attention clients aged 17-20 years!

If you are a client who is at least 17 years old, you are in the time of life we call “transition.” That means you need to start getting ready for your life as an adult now. The CSHCN Services Program has a lot of materials about transition on its website at [www.dshs.state.tx.us/cshcn/transinfo.shtm](http://www.dshs.state.tx.us/cshcn/transinfo.shtm). At the bottom of that page, you can link to a brochure that lists the Texas resources for youth who are making the transition to life as an adult. The phone numbers and services listed in it were current at the end of 2009. If you do not have access to the Internet, please call us at **1-800-252-8023** and ask for one. We are happy to send it to you for free.

Clients your age also need to know that the CSHCN Services Program will only cover your health care and other services until the day you turn 21 (unless you have cystic fibrosis). That means you need to start looking now for a doctor who can help you with your special needs after you turn 21. Also, if you have any special

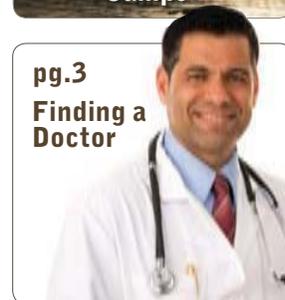


The CSHCN Services Program will only cover your health care and other services until the day you turn 21.

equipment that might need to be replaced or repaired, talk about it with your social worker now. Sometimes it takes a long while to get special equipment or find the right help. If you don't start the process at least 10 months before your 21st birthday, you may not be able to get the service at all. Call your social worker to start finding the help you need right away or if you have any questions. If you don't know who your social worker is, call the central office at **1-800-252-8023** and we can tell you. Don't wait until it's too late! ■



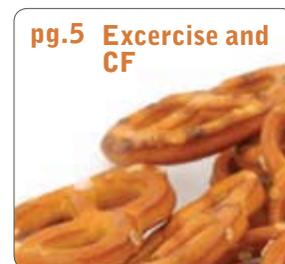
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pg.5 Exercise and CF



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## Got Transition Radio

### Looking for information and conversation about health care transition?

Hear experts and real people talk about health care transition issues for youth with or without special needs.

This radio program is for youth, families, and professionals who want to know more about youth transition to adult health care. Hosts Mallory Cyr, Eileen Forlenza, and special guests shine a light on health care transition hot topics! Hear real stories from people with experience and expertise. Get your questions answered. Join the conversation with your comments. Learn more about Got Transition's online information and resources.

### How to Participate:

Simply go to [www.GotTransition.org](http://www.GotTransition.org) and register for the next episode!

Radio show topics include:

- ▶ How to make the most of a doctor's visit
- ▶ Small steps to health care independence
- ▶ Go to the doctor without a parent
- ▶ Understand health insurance

- ▶ Health Care Transition - Why this, why now, and what does it have to do with me?
- ▶ Healthcare Transition & College - It Doesn't Have to be Learned the Hard Way!
- ▶ Grasp the importance of health and health care
- ▶ Health policy and the impact it has on health care transition
- ▶ Family's role in health care transition
- ▶ Speak up for your health needs ...just to name a few!

Sign up to get e-news at <http://www.gottransition.org/get-e-news> and you will get a reminder notice to register for the next episode. ■



▶ See the vehicle modification and repair resources information from Easter Seals!

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