

- Parents should ask the child's doctors for the names and telephone numbers of "adult doctors" who know about the kind of special needs of the child.
- Parents should ask other families for names of "adult doctors" who understand about the disability needs of the teenager.
- If the child will go on Medicaid at age 18, parents should ask the doctors their child sees now if they accept Medicaid or not (they do not have to do so). If not, ask them for names of doctors and clinics that accept Medicaid.
- If patients need to change doctors/clinics/hospitals, parents should call them ahead of time and ask for an appointment to come in with the teenager to meet each other and talk about medical and special needs.

### Guardianship

- If the teen will not be able to make decisions about medical care independently, parents will need to go to court to obtain guardianship once the child reaches age 18. If parents do not do this, only the child will be asked to give consent for medical care, hospitalizations, surgery and treatments. Parents will NOT be asked for their permission and will NOT have the right to decide about the child's medical care, money or living arrangements.
- Guardianship is handled by the Circuit Court in the county of residence, and families must pay a fee in order to get guardianship. Parents can find out what the cost will be by contacting their county's courthouse. Families can file for guardianship on their own; a lawyer is not required.

Parents and caregivers can get more information about guardianship from the Illinois Guardianship and Advocacy Commission at 312-793-5900 or 866-274-8023 or [gac.state.il.us](http://gac.state.il.us).

### **Getting Help with Transition**

If you need help with transition you should:

- Start with the teen's school, and find out the

name and number of the vocational or transition coordinator. Talk with them before the IEP meeting and work on transition plans together.

- Call the Illinois Department of Human Services, Office of Rehabilitation Services (ORS) at 800-275-3677, and ask for the ORS counselor assigned to help people in the area where you live.
- Talk to your service coordinator or case manager in any programs that are already helping your child, and ask for help with transition.
- Talk with other parents of young adults with special needs, find out what they are doing about transition, and ask for their ideas.

### **State and Local Resources**

- Public schools provide transition planning under the Federal Individuals with Disabilities Act (IDEA) Amendment of 1990 (Public Law 101-496).
- Illinois Department of Human Services (DHS) Office of Rehabilitation Services (800-275-3677)
- Illinois Vocational Curriculum Center (800-252-4822)
- Division of Specialized Care for Children (DSCC) (800-322-3722)
- Benefits Planning, Assistance and Outreach Projects: Mayor's Office for People with Disabilities (312-746-5743 for Chicago residents); the DHS Department of Mental Health (866-390-6771) or Office of Rehabilitation Services (800-807-6962 voice, 866-44-8018 TTY)

#### **What makes a difference?**

- **having high expectations**
- **having clear, caring and consistent rules**
- **believing disability is a natural part of life and not a handicap**

#### **What makes the biggest difference?**

- **planning ahead**
- **being assertive**
- **stressing self-determination**

# ATTENTION

## FAMILIES OF TEENAGERS WITH SPECIAL NEEDS

### Transition Issues for Adolescents with Special Needs



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DEDICATED TO THE HEALTH OF ALL CHILDREN™



Illinois Chapter

# PLANNING FOR YOUR TEENAGER'S FUTURE INCLUDES MANY ISSUES

## THIS IS CALLED TRANSITION PLANNING

### School Issues

- Students who receive special education services (they have an Individualized Education Plan, or IEP) can stay in school until they earn enough credits to graduate from high school, or until they turn 21 years of age.
- If parents want their teenager to stay in school until age 21, they must decide this ahead of time and write this into the IEP when he becomes 16 years old.
- Students with special needs who DO NOT have IEPs (mostly students with long-lasting illnesses) cannot stay in school until age 21. They graduate when they earn enough credits to get their high school diplomas.
- Children with special needs ages 3-21 years have the right to special education services in school. (This means that any child who needs special education services can get them free of charge from the public schools.)
- AFTER AGE 21, ADULTS HAVE NO RIGHT TO EDUCATION OR ANY OTHER SERVICES FOR PEOPLE WITH DISABILITIES. Families who plan ahead can often get these services, since many programs have waiting lists.
- Plans for transition need to be written into the child's IEP each year, starting at age 14 years, 6 months.
- Illinois has three "Parent Training and Information Centers" (PTIs) that give families free help in learning about special education rights and getting ready for transition. The three PTIs are:

1) Designs for Change: 312-236-7252 (voice),

312-857-1013 (TTY) or [www.dfcl.org](http://www.dfcl.org)

- 2) Family Matters: 866-436-7842 (voice) or [www.fmptic.org](http://www.fmptic.org) (statewide except Chicago)
- 3) Family Resource Center on Disabilities: 800-952-4199 (voice), 312-939-3519 (TTY) or [www.frcd.org](http://www.frcd.org)

### Medical Issues

Families need to make two kinds of decisions about medical care for their teenagers with special needs:

- 1) How will the medical care be paid for?
- 2) Where will the teenager go in the future to get care?

### Paying for Medical Care

- If the teenager prior to age 18 is covered by the parents' insurance from work, she may remain covered under the parents' fully insured (not self insured) group health plan after she reaches the age at which dependent coverage is usually terminated. The dependent adult will not be issued a separate policy but can remain on the parents' policy, provided that it remains in force.
- If the teenager goes to work, she needs to find out if the job offers health insurance. If insurance is offered, then parents need to find out how much it will cost each month and if the desired doctors and hospitals are covered by the insurance.
- Young adults with special needs can sign up for Medicaid when they turn 18, and the Illinois Department of Public Aid will count only the teen's income, if any, with a resource/asset limit of \$2,000. PARENTS' INCOME AND RESOURCES ARE NOT COUNTED ONCE THE CHILD TURNS 18.
- Many programs for adults with disabilities require the participants to be on Medicaid.
- If a teen receives Medicaid and also gets a job, it is very important to report all income and have an

understanding of the Social Security and Medicaid work incentives. A law, the Ticket to Work-Work Incentives Improvement Act (WIIA), finalized in December 1999, has allowed for new and improved work incentives that assist people with disabilities who want to work while maintaining access to health care. Under this law, working people with disabilities, who may not be eligible for Social Security cash programs, can still apply for Medicaid through the Health Benefits for Workers with Disabilities program by calling 800-226-0768.

- Young adults with severe disabilities may be eligible for SSI (Supplemental Security Income) from the Federal Government. SSI eligibility changes when a young adult reaches his 18<sup>th</sup> birthday. If a young adult has been receiving SSI under the eligibility guidelines for children, the "case" will be transferred to the SSI program for adults, and eligibility to continue to receive SSI will be redetermined. Other young adults with severe disabilities who previously were not eligible for SSI due to their parents' income must apply for SSI within 30 days before their 18<sup>th</sup> birthdays. Once a young adult reaches age 18, the Social Security Administration counts only his own income and assets. Parents' income and assets are no longer counted.

For more information on the Ticket to Work-WIIA or SSI, contact Health and Disability Advocates at 312-223-9600 (voice), 800-427-0766 (TTY) or [www.hdadvocates.org](http://www.hdadvocates.org).

### Where to go for Medical Care

- Many doctors and therapists who take care of children and teens with special needs only see patients up to age 18 or 21.
- Parents will need to ask each doctor and therapist until what age they will continue to see the child, and tell the child about this.