



## ATTENTION - FAMILIES OF TEENAGERS WITH SPECIAL NEEDS



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## PLANNING FOR YOUR TEENAGER'S FUTURE INCLUDES MANY ISSUES THIS IS CALLED TRANSITION PLANNING

### School Issues

- Students who get special education services (means they have an IEP) can stay in school until they earn enough credits to graduate from high school, or until they turn 21 years of age.
- If you want your teenager to stay in school until age 21, you must decide this ahead of time and write this into their IEP when they become 16 years old.
- Students with special needs who DO NOT have an IEP (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 diploma.
- 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 four "Parent Training and Information Centers" (PTIs) that give families free help in learning about special education rights and getting ready for transition. The four PTIs are:
  - 1) Designs for Change: 312-857-9292
  - 2) Family Resource Center on Disabilities: 312-939-3513
  - 3) Family Ties Network: 217-544-5809
  - 4) National Center for Latinos with Disabilities: 800-532-3393

### Medical Issues

Families need to make two kinds of decisions about medical care for their teenager 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 is covered by the parents' insurance from work, the parents need to find out until what age the child can stay on the family policy. This depends on where the parent works, the child's age, whether or not the child is in school, and whether or not the employer allows a "dependent child" with a disability to stay on the health plan after age 18 or 21. There are no laws about this in Illinois.
- If the teenager goes to work, he/she needs to find out if the job offers health insurance. If insurance is offered, then you need to find out how much it will cost each month and if the doctors and hospitals you want are covered by the insurance.
- Young adults with special needs can sign up for Medicaid when they turn 18, and the Department of Public Aid will count only the teen's income, if any. PARENTS' INCOME IS NOT COUNTED ONCE THE CHILD TURNS 18.
- If a teen receives Medicaid and also gets a job, it is very important to find out how much someone is allowed to earn and still stay on Medicaid. A new law, the Workincentives Improvement Act (WIIA), finalized in 12/99, will help people with disabilities who want to work but cannot get health insurance from their employer. Under the WIIA, working people with disabilities will be able to pay a certain amount each month to the state in order to keep their Medicaid benefits, if they cannot get health insurance from their job. This law is not yet in effect. For more information, call the SSI Coalition at 312-223-9600.

- Many programs for adults with disabilities require the participants to be on Medicaid.

## 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.
- You will need to ask each doctor and therapist until what age they will continue to see your child, and tell your child about this.
- Ask the doctors who care for your child now for the names and telephone numbers of "adult doctors" who know about the kind of special needs your child has.
- Ask other families for names of "adult doctors" who understand about the disability needs of your teenager.
- If your child will go on Medicaid at age 18, ask the doctors you see now if they accept Medicaid or not (they do not have to do so). If not, ask them for names of doctors and clinics who accept Medicaid.
- If you need to change doctors/clinics/hospitals, call them ahead of time and ask for an appointment to come in with your teenager so you can meet each other, talk about the medical needs, and your teen's special needs.

## Guardianship

- If your teen will not be able to make decisions about medical care independently, you will need to go to court to obtain guardianship once your child reaches age 18. If you do not do this, only your child will be asked to give consent for medical care, hospitalizations, surgery and treatments.

You will NOT be asked for your permission and will NOT have the right to decide about your child's medical care, money or living arrangements any longer.

- You can get more information about guardianship from the Illinois Guardianship and Advocacy Commission, 312-793-5900.
- Guardianship is handled by the Circuit Court in the county where you live, and families must pay a fee in order to get guardianship. You can find out what the cost will be by contacting your county's courthouse. Families can file for guardianship on their own; a lawyer is not required.

## Getting Help with Transition

- Start with your 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), 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.
- 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 their 18th birthday. If a young adult has been receiving SSI under the eligibility guidelines for children, his/her "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, should be sure to apply for

SSI within 30 days before their 18th birthday. Once a young adult reaches age 18, the Social Security Administration counts only their own income and assets. Parents' income and assets are no longer counted. For more information, contact the Chicagoland SSI Coalition at 312-223-9600.

## Federal, State, and Local Resources

- Contact your public school to request transition planning as provided for by the Federal IDEA Amendment of 1990 (Public Law 101-496).
- Illinois DHS Office of Rehabilitation Services (ORS) (800-275-3677)
- Illinois Vocational Curriculum Center (800-252-4822)
- Division of Specialized Care for Children (DSCC) (800-322-3722)
- Illinois DHS, Disability Services (800-843-6154)

### 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.**