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 the become 16.
- 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, but many programs have waiting lists.
- Plans for transition need to be written into the child's IEP each year, starting at age 14.
- Kentucky has a parent groups that give families free help in learning about special education rights and getting ready for transition. These are:
  - KY-SPIN (Kentucky Special Parent Information Network – the PTI – Parent Training and Information Center): 1-800-525-7746; **www.kyspin.com**

Resources

- Contact your public school to request transition planning as provided for by federal law IDEA or contact the Kentucky Department of Education at 1-800-533-5372. Some schools have School-to-Work programs.
- Community and technical colleges and universities have Disability Coordinators. Explore **www.kctcs.net** for information on Kentucky community colleges and technical schools. Explore **www.kheaa.com** or call 1-800-928-8926 for information about scholarships, loans, grants and work-study at KY colleges.
- Vocational Rehabilitation can assist with vocational assessment, referral, training, and work placement, fund college tuition and expenses, and help with van modification. 1-800-372-7172
- KATS (Kentucky Assistive Technology Services Network) can help with assistive technology and equipment. 1-800-327-5287 or **www.katsnet.org**
- Centers for Independent Living offer information and referral for housing, transportation, work, personal assistance, education, recreation, and legal issues. KY has 5 Centers for Independent Living: *Lexington:* Independence Place (859) 266-2807; *Louisville*: Center for Accessible Living (502) 589-6620; *Harlan*: Pathfinders for Independent Living (606) 573-5777; *Bowling Green*: BEST (270) 796-5992; *Covington*: Disabilities Coalition of N. KY (859) 431-7668.

Medical Issues

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

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

Paying for Medical Care

- If the teen 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.
- If the teen 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 apply for SSI benefits/Medicaid when they turn 18. Then the Social Security Administration will count only the young person's income. Parents' income is NOT counted once the young person turns 18.
- If a person receives Medicaid and gets a job, it is very important to find out how much someone is allowed to earn and still stay on Medicaid. The Ticket to Work and Work Force Improvement Act (TWIIA) helps people with disabilities who want to work but cannot get health insurance from their employers. In Kentucky in 2004, a person can earn about $20,000 and still keep their Medicaid benefits. Contact the Social Security Administration for more information on Work Incentives and the Benefits Plus Program at 1-800-772-1213 or explore **www.socialsecurity.gov**.

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 how long 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 the disability needs of your teen.
- Ask adults with disabilities where they go for medical care.
- Ask care coordinators, insurance plan coordinators, and Vocational Rehabilitation counselors about doctors who care for adults with disabilities.
- 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 the names of doctors and clinics that 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 teen so you can meet each other, talk about 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 KY Protection and Advocacy at 1-800-372-2988

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 with your teen.
- Call the Department of Vocational Rehabilitation (1-800-372-7172) and ask for a Counselor in your area.
- Talk with your service/care 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, and find out what they are doing about transition and what ideas they have to help you.
- Young adults with severe disabilities may be eligible for SSI (Supplemental Security Income). SSI eligibility changes at age 18. If the young person has been receiving SSI under 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 re-determined. Other young adults with severe disabilities who were previously were not eligible for SSI due to their parents' income should apply for SSI within 30 days of their 18th birthday. Once a young person reaches age 18, the Social Security Administration counts only their income and assets (not their parents'). For more information call the SSA at 1-800-772-1213.

Adapted from: Preparing for the Future: Transition to Adulthood, Illinois Chapter of the American Academy of Pediatrics - April 2004

Commission for Children with Special Health Care Needs

Preparing for the Future for Families of Teenagers with Special Needs

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

http://chfs.ky.gov/ccshcn
http://www.UnbridledSpirit.com