Journey to Adulthood
A Transition Travel Guide

Resources for Roadblocks

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Online, find this book and resource list at

www.transitiononestop.org

http://chfs.ky.gov/ccshcn/ccshentransition.htm

This list of resources is a work in progress. If you find resources that should be included, please contact one of authors at

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Tips for Evaluating Internet Sites

The internet helps us improve our knowledge of health issues and become better health care consumers, but the quality of health information on the internet varies tremendously. See www.onguardonline.gov for information on internet safety. Ways to tell if the source can be trusted are:

- Look at the header information and return to the home page to determine the source of the information.
- Is it clear what organization is responsible for the contents of the page?
- How reputable is the source?
- Who is the author, and what are the author’s qualifications for writing on the subject?
- Is the information timely?
- Is factual information clearly separated from opinions or speculation?
- When was the site created and when was it last updated?
- Are the sources for any factual information clearly listed so they can be verified through another source?
- Can you find the same information using other sources? “Hackers” may alter the information—another important reason to verify the information using other sources.

On the web, distinctions between advertising, information, and entertainment can be extremely blurred.
- What are the goals/aims of the web site -- is the web site trying to sell or promote a specific product or service?
- Is the information presented with a minimum of bias?
- Is the information intended for entertainment?
- If there is advertising on the page, can you tell what is information and what is an ad.

Strategies for Searching: One of the goals of this travel guide is to teach youth and their families to become experts in finding useful and credible information on the web. Readers are often encouraged to “google” a topic for more information.

Start with the main topic you are researching. For example if you want to find an independent living center near you, type in “independent living centers.” To narrow the search and find independent living centers in your state, type in “independent living centers + your state”. Scroll down the page and pick the web site that focuses on independent living centers that serve persons with disabilities rather than the elderly or some other group, or you can add “+ disabilities” to your search.

Sometimes you will need to be persistent in finding the right key words and combinations to get to the information you are looking for. Key search terms may include: “youth with disabilities”, “teens with disabilities”, or “transition for youth with disabilities”. Once you find a web site, you often have to “drill down” to find the specific information you are looking for. Major topics are often labeled across the top or in margins. Most web sites have a directory of information. Many have a place to type in a term to search in the site.

Information is POWER and learning to use the web to get useful, accurate information is EMPOWERING! Go for it!
Resources for Roadblocks

General Resources on a Variety of Topics that Apply to Many Chapters


Family Village  http://familyvillage.wisc.edu/index.html  Links to lots of information on variety of topics related to children and youth with special needs

Family Voices, Inc.  www.familyvoices.org  List of the state Family to Family Health Information and Educations Centers and information on family advocacy for children and youth with special health care needs

Find Youth Info  http://www.findyouthinfo.gov/  FindYouthInfo.gov is the U.S. government website that helps you create, maintain, and strengthen effective youth programs. Included are youth facts, funding information, and tools to help you assess community assets, generate maps of local and federal resources, search for evidence-based youth programs, and keep up-to-date on the latest, youth-related news.

Institute for Child Health Policy (ICHP) Transition project: Variety of resources, planning guides for various ages and some streaming videos about talking with your doctor and other topics.  http://hctransitions.ichp.edu/

National Center on Secondary Education and Transition (NCSET)  http://www.ncset.org/  NCSET located at the University of Minnesota provides technical assistance and disseminates information focused on providing students with disabilities with improved access and success in the secondary education curriculum; ensuring that students achieve positive post-school results in accessing postsecondary education, meaningful employment, independent living and participation in all aspects of community life; supporting student and family participation in educational and post-school decision making and planning; and improving collaboration and system linkages.

National Dissemination Center for Children with Disabilities  www.nichcy.org  NICHCY serves the nation as a central source of information on: disabilities in infants, toddlers, children, and youth, IDEA, and research-based information on effective educational practices. NICHY state pages of resources:  www.nichcy.org/Pages/StateSpecificInfo.aspx

PACER Center:  Center in Minnesota that has been promoting transition readiness for decades. For General Transition information:  http://www.pacer.org/publications/transition.asp - look at the list of brochures and handouts for information on a variety of topics including self advocacy, planning in school, higher education, legal issues, transportation, housing. For Person-Centered Planning see  http://www.pacer.org/tatra/resources/personal.asp
United Cerebral Palsy  [www.ucp.org/resources/](http://www.ucp.org/resources/)  Describes issues and resources on a variety of topics to help people with disabilities live full lives. The health and wellness section provides excellent information on wellness and secondary conditions that often accompany disabilities.

University of Washington Adolescent Health Transition Project  [http://depts.washington.edu/healthtr](http://depts.washington.edu/healthtr)  Extensive resources for teens, families, and professionals to prepare young people for independence to greatest extent possible including health care transition and working with schools.


Transition Timelines for youth with chronic conditions and for youth with developmental disabilities.  [http://depts.washington.edu/healthtr/resources/tools/other.html](http://depts.washington.edu/healthtr/resources/tools/other.html)

Adolescent Autonomy Checklist developed by the AHTP can be downloaded and printed from  [www.medicalhomeportal.org/link/2651](http://www.medicalhomeportal.org/link/2651)

**Websites by and for youth and young adults focusing on youth leadership**

Kids As Self Advocates (KASA)  [http://www.fvkasa.org](http://www.fvkasa.org)  An organization created by youth with disabilities for youth to educate society about issues concerning youth with a wide spectrum of disabilities and special healthcare needs. Affiliated with Family Voices.  Click on Youth Resources.

NAMI Social Networking Site for Young Adults  [www.strengthofus.org](http://www.strengthofus.org)  Developed by young adults, this user-driven social networking community allows young adults to connect with their peers and share personal stories, creativity and helpful resources by writing and responding to blog entries, discussion groups and sharing videos, photos and other news.  Strengthofus.org offers a variety of resources on issues important to young adults, including healthy relationships, family and friends, independent living, campus life, employment, mental health issues and more.


National Youth Leadership Network  [http://www.nyln.org/](http://www.nyln.org/)  NYLN is a youth-led organization working to build power and leadership among people with disabilities between the ages of 16- 28 years old. NYLN has been around since 1997 and is the only youth-led disability rights nonprofit organization in the country.

**Chapter 1: Deciding Where You Want to Go and Mapping the Route**

Cornell University’s Employment and Disability Institute’s Person Centered Planning Education:  [http://www.ilr.cornell.edu/edi/pcp/](http://www.ilr.cornell.edu/edi/pcp/)
ICHP Transition project: Planning guides for various ages, 12-14, 15-17, and 18+ in English and Spanish  http://hctransitions.ichp.ufl.edu/products.php

PACER Center: For Person-Centered Planning see http://www.pacer.org/tatra/resources/personal.asp

YouthHood  http://www.youthhood.org/ A website that helps young people plan for the future. Site has sections called “the job center”, “the high school”, “the community center”, “the hangout”, “the health clinic”, “the government center”, and “the apartment”. Here you can start thinking about what you want to do with the rest of your life.

Chapter 2: Staying Healthy for the Road Trip

Staying Healthy

American Academy of Family Physicians  www.familydoctor.org  Website has lots of downloadable teaching materials and includes a site for teens.

Bandaides and Blackboards  http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/  This is a site about growing up with medical problems. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that.

Centers for Disease Control and Prevention  www.cdc.gov  Offers information on a great variety of health and safety issues. This web site provides resources for people with disabilities to stay well, be active, and be a part of the community. See especially section on healthy living.

Fruits and Vegetables  http://www.fruitsandveggiesmatter.gov/  Learn how many fruits and vegetables you should eat each day.

Girls Health  www.girlshealth.gov  (also known as www.4girls.org)  Website of the Office of Women’s Health of the U.S. Department of Health and Human Services to help girls (ages 10 to 16) learn about health, growing up, and issues they may face. Girlshealth.gov promotes healthy and positive behaviors in girls, giving them reliable and useful health information in a fun, easy-to-understand way. The website also provides information to parents and educators to help them teach girls about healthy living.

Healthfinder  www.healthfinder.gov  Great place to find information on various conditions/diseases and health promotion information


Young Men’s Health [www.youngmenshealthsite.org] Children’s Hospital Boston website

Young Women’s Health [www.youngwomenshealth.org] Children’s Hospital Boston website

**Health and Transition**

**American Academy of Pediatrics**

- **National Center for Medical Home Implementation** [www.medicalhomeinfo.org]
  [Website offers a variety of information for providers including resources on CPT codes to use when caring for children and youth with special health care needs, the Medical Home Training Module, and AAPs Medical Home Policy and description. State pages of resources at http://www.medicalhomeinfo.org/states/index.html]

- **Bright Futures** [http://brightfutures.aap.org]
  [American Academy of Pediatrics website with materials for anticipatory guidance, health promotion, and preventive health services for children birth through 21. Materials for health care providers and for parents. Many downloadable and printable materials. Bright Futures Mental Health and the Tool Kit (Manual 2) offer screening and teaching tools.]

**American Medical Association’s Guidelines for Adolescent Preventive Services (GAPS)**

This website helps families know what preventive services their health care professionals should be offering. [http://www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/adolescent-health/guidelines-adolescent-preventive-services.shtml]

**Got Transition** [http://www.gottransition.org/]

Got Transition is the MCHB National Health Care Transition Center. Through partnerships among youth, families, health professionals, and policy makers, Got Transition focuses on the implementation and dissemination of health care transition best practices in primary care medical homes and specialty settings for youth and young adults. Youth Information section provides websites, videos and other documents to plan for health transition.

**Healthy & Ready to Work National Resource Center** (2003-2010)

[http://www.syntiro.org/hrtw]

Contains information, downloadable files, and numerous links to other resources related to systems and services, youth involvement, health care access and funding, education, employment, recreation, and independence. See especially “Tools and Solutions”.

**National Alliance to Advance Adolescent Health** [www.thenationalalliance.org]

Organization devoted to education, research, policy analysis, and technical assistance in support of improved health outcomes for adolescents. Describes model programs and lists resources.

**Society for Adolescent Medicine**

The Healthy Student: [www.adolescenthealth.org] Click Teen/Family Resources, then Health Information for Teens and Parents. You can download The Healthy Student: Preparing for the College Years and other resources.
Recommendations about clinical preventive services, including screenings, counseling, and preventive services for all ages. These will help you work with your doctor and ask about specific services.

Many state Children with Special Health Care Needs agencies and other organizations have websites with good resources: Some examples are:


  - JaxHATS: Transition Assessment forms: http://www.jaxhats.ufl.edu/
  - ICHP Transition project: Variety of resources and some streaming videos about talking with your doctor and other topics. http://hctransitions.ichp.edu/

Hawaii: Personal health record; workbook from Hilopa’a Project (D70 grant) http://hawaii.gov/health/family-child-health/cshcn/cshcnoutcomes.html

Illinois: Family and provider information http://www.uic.edu/hsc/dscc Click on Transition in the right side column. Resources in English and Spanish.


New York: 4-page health summary, insurance factsheet; H.I.Doc (Health Information Document) http://www.health.state.ny.us/community/special_needs/index.htm


Rhode Island: Rhodes to Independence: http://www.rhodestoindependence.org/youthhome.htm

Utah Medical Home Project transition materials: http://www.medicalhomeportal.org/
  - Becoming Leaders for Tomorrow http://blt.cpd.usu.edu/
  - Youth Leadership Toolkit: http://blt.cpd.usu.edu/Leadership_Toolkit.html

Wisconsin Medical Home project http://wimedicalhometoolkit.aap.org/transitions
  - Wisconsin HRTW project http://www.waisman.wisc.edu/hrtw/
Some Children’s Hospitals have Transition Programs. Some examples are:

Boston Children’s Hospital Transition Toolkit:  

Children’s Hospital of Philadelphia:  
http://www.chop.edu/service/transition-to-adulthood/transition-programs.html

Hospital for Sick Kids, Toronto, Canada:  Good 2 Go Transition Program  
http://www.sickkids.ca/good2go/  Click on Resources.

Shriners Hospitals for Children:  

University of Minnesota:  
http://www.childrensmn.org/web/healthprof/140552.pdf

Managing My Health Condition:  Condition-Specific Transition Information

- Autism  http://www.autismhandbook.org/index.php/Main_Page
- Cystic Fibrosis  http://jaxhats.ufl.edu/docs/resources/hcpprofessionals/CF-clinic-transition-team-perspect.pdf and  
  http://pediatrics.aappublications.org/cgi/content/abstract/125/3/566
- Epilepsy Foundation of America  http://www.epilepsyfoundation.org/
- Epilepsy Foundation Teen site and Teen Forum  www.epilepsyfoundation.org  
  A video for middle and high school students, Seizures and You: Take Charge of the Facts, is part of a multi-year effort to educate teens, dispel myths and reduce the perceived stigma associated with epilepsy.  
  http://www.epilepsyfoundation.org/livingwithepilepsy/youth/youngadults/
- HIV  http://www.thewellproject.org/en_US/Womens_Center/HIV_And_Teens.jsp
- Kidney  http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2849284/
- Mental health: Voices4Hope  www.voices4hope.wikispaces.com  Website created by a group of young adults with mental health challenges that work in the Transitions RTC.  
  The goal of this site is to connect young adults with mental health challenges across the country so they can talk to each other about things that are important to living happy and independent lives.
• Mental Health: NAMI Social Networking Site for Young Adults  
  www.strengthofus.org
• National Diabetes Education Program  www.YourDiabetesInfo.org or  
  www.ndep.nih.gov
• PKU Clinic Adolescent Transition Curriculum plan for responsibility for health care  
  and PKU management  depts.washington.edu/pku/
• Spina Bifida Association of America  www.SBAA.org
• Spinal Cord Injury  http://www.spinalcord.uab.edu/
• Traumatic Brain Injury: Personal Planning book and other resources for youth with TBI are at the Brain Injury Institute at Mt. Sinai Hospital  
  http://www.mssm.edu/research/centers/brain-injury-research-center-of-mount-sinai/publications/futures-planning
• Transition Guidelines for People with Bleeding Disorders  Hemophilia Association  
  www.hemophilia.org/research/masac/masac147.pdf or  
  http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=207
• United Cerebral Palsy  http://www.ucp.org/ Click on Health & Wellness.

Finding an Adult Doctor (Medical Home)

• Contact your local Medical Society through the Yellow Pages or on their website.
• American Academy of Family Physicians  
  http://familydoctor.org/online/famdocen/home.html
• Internal Medicine Society - American College of Physicians,  
  http://www.acponline.org/
• Federally-funded health centers  http://findahealthcenter.hrsa.gov  
  Type in your address and click the 'Find Health Centers' button to find health centers near you. Health centers provide checkups when you're well, treatment when you're sick, complete care when you're pregnant, immunizations and checkups for your children, dental care and prescription drugs for your family, mental health and substance abuse care if you need it.

Finding Adult Medical Specialists – some examples

• American Academy of Orthopaedic Surgeons  http://www.aaos.org/
• American Academy of Physical Medicine and Rehabilitation  
  http://www.aapmr.org/patients/findphysician
• American Urological Association  
  http://www.urologyhealth.org/urology/findurologist.cfm
• American Academy of Neurology  http://patients.aan.com/findaneurologist/  
• American College of Cardiology  http://www.cardiosmart.org/findacardiologist/  
• American Thoracic Society  http://www.thoracic.org/
Health Insurance

- Catalyst Center for Improving Financing of Care for Children and Youth with Special Health Care Needs: [www.catalystctr.org](http://www.catalystctr.org)
- Department of Labor- Health Plan: [http://www.dol.gov/dol/topic/health-plans/planinformation.htm](http://www.dol.gov/dol/topic/health-plans/planinformation.htm)
- Government general health insurance: [www.usa.gov/Citizen/Topics/Health/HealthInsurance.shtml](http://www.usa.gov/Citizen/Topics/Health/HealthInsurance.shtml)
- National Conference of State Legislatures [www.ncsl.org/programs/health/dependentstatus.htm](http://www.ncsl.org/programs/health/dependentstatus.htm) State-by state information about health care coverage for youth through parental health insurance policies
- National Association of Insurance Commissioners [www.naic.org/state_web_map.htm](http://www.naic.org/state_web_map.htm) Links to all state offices of commissioners of insurance

Medicaid:

**General Medicaid and CHIP information** [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/Medicaid-and-CHIP-Program-Information.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/Medicaid-and-CHIP-Program-Information.html)

**EPSDT Services**
The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) service is Medicaid's comprehensive and preventive child health program for individuals under the age of 21 including periodic screening, vision, dental, and hearing services and any medically necessary health care service. These services end at age 22. Preparing for discontinuation of these services or finding adult services is an important aspect of transition for youth with special health care needs.

**Medicaid Waivers:** Centers for Medicare and Medicaid Services (CMS)
- Home and Community based waivers general information and State Medicaid waiver information can be found at: [http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/08_WavMap.asp](http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/08_WavMap.asp)
- The Clearinghouse for Home and Community Based Services [http://www.hcbs.org/](http://www.hcbs.org/) HCBS.org promotes the development and expansion of home and community-based services by gathering resources and tools for research, policy making and program development into this one-stop website. By facilitating the sharing of information, HCBS empowers professionals to be more effective in supporting real choice and independence for older Americans and people with disabilities
- For information in your state on Medicaid Waivers and other resources for youth in transition, contact your state’s Family to Family Health Information Center. To find that Center in your state, go to the Family Voices website at [http://www.familyvoices.org/admin/miscdocs/files/F2FBrochure_10-14-2010.pdf](http://www.familyvoices.org/admin/miscdocs/files/F2FBrochure_10-14-2010.pdf)
Children’s Health Insurance Program

CHIP:  https://www.cms.gov/LowCostHealthInsFamChild/ or http://insurekidsnow.gov/ or call 1-877-Kids-Now (1-877-543-7669) to find the program in your state.

Children with Special Health Care Needs programs

You can find your State’s Title V/CSHCN Program

- at http://mchb.hrsa.gov/ or
- by clicking on the map at http://www.medicalhomeinfo.org/state_pages/
- or contact your state’s Family Voices Network member through the website, www.familyvoices.org or call Family Voices toll free: 1/888-835-5669.

Other Health Care Resources

NeedyMeds Drug Discount Card  www.needymeds.org  With the NeedyMeds Drug Discount Card you can save up to 80% off the price of your prescription medications. The card may be used by those without insurance and by those who decide not to use their insurance - for example if the drug is not covered under their plan, the co-pay or deductible is high, or the cap has been reached,

Partnership for Prescription Assistance  www.pparx.org  The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need through the program that is right for them. Many will get their medications free or nearly free.

RX Assist  www.rxassist.org  Patient assistance programs are run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need.

St. Jude Children’s Research Hospital  www.stjude.org  The hospital in Memphis, TN, works to find cures for the catastrophic diseases of childhood and cares for children regardless of race, religion or ability to pay.

Shriners Hospitals for Children  http://www.shrinershospitalsforchildren.org/  The 22 hospitals in the North America care for children and youth with orthopaedic conditions, spinal cord injuries, cleft lip and palate, and burns regardless of ability to pay.
**Disaster Preparedness**

American Public Health Association (APHA)  
[http://www.getreadyforflu.org/new_pg_facts.htm](http://www.getreadyforflu.org/new_pg_facts.htm) Use these free materials from APHA to help Americans prepare themselves, their families and their communities for all public health hazards they may face, including disasters, pandemic flu or other emerging infectious diseases

Office of Disability Integration and Coordination (ODIC) integrates and coordinates emergency preparedness, response and recovery for children and adults with disabilities and others with access and functional needs before, during and after a disaster.

Information for families, businesses, and people with disabilities about planning for disasters.

**See General Resources for more information on health transition**

**Chapter 3: Getting Ready for the Trip: Staying in High School**

Family Educational Rights and Privacy Act (FERPA)  

GED – Test of General Educational Development  [www.gedtest.org](http://www.gedtest.org)


National Assistive Technology Technical Assistance Partnership  [www.resnaprojects.org](http://www.resnaprojects.org)  
Describes demonstration, reutilization, loan, and financing programs available in states.

National Center on Secondary Education and Transition (NCSET)  [http://www.ncset.org/](http://www.ncset.org/)  
NCSET located at the University of Minnesota provides technical assistance and disseminates information focused on providing students with disabilities with improved access and success in the secondary education curriculum; ensuring that students achieve positive post-school results in accessing postsecondary education, meaningful employment, independent living and participation in all aspects of community life; supporting student and family participation in educational and post-school decision making and planning; and improving collaboration and system linkages.

National Dissemination Center for Children with Disabilities  [www.nichcy.org](http://www.nichcy.org)  
NICHCY serves the nation as a central source of information on: disabilities in infants, toddlers, children, and youth, IDEA, and research-based information on effective educational practices. NICHY state pages of resources:  [www.nichcy.org/Pages/StateSpecificInfo.aspx](http://www.nichcy.org/Pages/StateSpecificInfo.aspx)
National Secondary Transition Technical Assistance Center [http://www.nsttac.org/]
NSTTAC located at University of North Carolina-Charlotte helps states build capacity to support and improve transition planning, services, and outcomes for youth with disabilities and disseminate information and provide technical assistance on scientifically-based research practices with an emphasis on building and sustaining state-level infrastructures of support and district-level demonstrations of effective transition methods for youth with disabilities. Website materials can assist teachers, parents, and students regarding effective transition education and services. See the Transition Assessment Toolkit.

PACER Center [www.pacer.org] Center offers resources on a variety of topics for families with children and youth with disabilities.

Transition Coalition [www.transitioncoalition.org] Provides online information, support, and professional development on topics related to the transition from school to adult life for youth with disabilities. *My Future, My Way: First Steps Toward College — A Workbook for Students in Middle and Junior High Schools* provides information for middle and junior high school students about how to go to college and how to pay for education beyond high school. This publication also includes charts, checklists, and other activities to help students answer important questions, such as "Why think about college now?" "What can a college education do for me?" and "How will I pay for college?" Also available at [http://studentaid.ed.gov/students/publications/my_future_my_way/index.html](http://studentaid.ed.gov/students/publications/my_future_my_way/index.html)

US Department of Education Office of Special Education Programs (OSEP) IDEA Website [http://idea.ed.gov/explore/home](http://idea.ed.gov/explore/home)

US Department of Education Office of Special Education Programs (OSEP) Frequently Asked Questions about Section 504 and the Education of Students with Disabilities. [http://www.ed.gov/about/offices/list/ocr/504faq.html](http://www.ed.gov/about/offices/list/ocr/504faq.html)


**Accommodations and Assistive Technology**

Able Data [www.abledata.com] Assistive technology of all kinds for all sorts of conditions. from the National Institute on Disability and Rehabilitation Research (NIDRR), US Department of Education. Lists state resources for assistive technology and funding.

Disability.gov [www.disability.gov/technology] Information on assistive technology and funding sources.
Family Center on Technology and Disability (FCTD)
http://www.fctd.info/show/fig_summary  A resource designed to support organizations and programs that work with families of children and youth with disabilities. Offers a range of information and services on the subject of assistive and instructional technologies. From Academy for Educational Development and PACER Center. See Family Guide to Assistive Technology and Transition Planning.

National Assistive Technology Technical Assistance Partnership  www.resnaprojects.org
Describes demonstration, reutilization, loan, and financing programs available in states.

University of Washington, DO-IT Disabilities, Opportunities, Internetworking, and Technology
https://www.washington.edu/doit/  DO-IT Center promotes the success of individuals with disabilities and the use of computer and networking technologies to increase their independence, productivity, and participation in education and careers. National Resources for Parents of Children and Youth with Disabilities, part of DO-IT, is at
https://www.washington.edu/doit/Brochures/Parents/naparent.html

Service Animals

Delta Society  http://www.deltasociety.org  Delta Society help lead the world in advancing human health and well-being through positive interactions with animals. We help people throughout the world become healthier and happier by incorporating therapy, service and companion animals into their lives. National Service Dog Resource Center at http://www.deltasociety.org/Page.aspx?pid=302

Paws with a Cause  http://www.pawswithacause.org/

See General Resources for more information on school

Chapter 4: Abiding by the Laws: Becoming an Adult at Age 18


Bazelon Center's Mental Health Law  http://www.bazelon.org/  The Bazelon Center for Mental Health Law is a nonprofit organization devoted to improving the lives of people with mental illnesses through changes in policy and law.

Family Village  http://www.familyvillage.wisc.edu/general/estate.htm  Resources for estate planning and other legal issues.

National Disability Rights Network  http://www.ndrn.org  NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in
the United States. To find the services provided and your state’s Protection & Advocacy contact information, click on the map.

**National Foundation for Special Needs Integrity, Inc.**  [www.specialneedsintegrity.org](http://www.specialneedsintegrity.org)
Nonprofit organization providing information on special needs trusts and other legal issues in planning for persons with special needs.


See **General Resources for more information on legal adulthood**

**Chapter 5: Hitting the Highway: Working**

**Department of Labor’s Employment and Training Administration**  [www.doleta.gov/youth_services/](http://www.doleta.gov/youth_services/) and [www.studentjobs.gov](http://www.studentjobs.gov)  Websites with information on work and preparing for work.

**Disability.gov**  [http://www.disability.gov/employment](http://www.disability.gov/employment) Offers job seekers, employers, and employees practical information about finding a job, recruiting and hiring people with disabilities, and job accommodations. It also offers resources on starting a small business and laws and regulations that protect the employment rights of people with disabilities. Family members and teenagers with disabilities can find information on mentoring programs and job training services.

**Government Benefits: Online**  [www.govbenefits.gov](http://www.govbenefits.gov)  A comprehensive source on federal government benefits

ICI offers training, clinical, and employment services, conducts research, and provides assistance to organizations to promote inclusion of people with disabilities in school, work, and community activities. Website offers a variety of publications related to supports for people with disabilities including *Going To Work: A Guide to Social Security Benefits and Employment for Young People with Disabilities* (2011 Edition)


**National Collaborative on Workforce and Disability - NCWD/Youth**  [www.ncwd-youth.info](http://www.ncwd-youth.info)  NCWD/Youth is source for information about employment and youth with disabilities. Experts in disability, education, employment, and workforce development strive to ensure the highest quality, most relevant information available.
- Guideposts for Success:  [http://www.ncwd-youth.info/guideposts](http://www.ncwd-youth.info/guideposts)
• Publications by Topic: http://www.ncwd-youth.info/topic
• NCWD/Youth Blog for youth, families and professionals: http://www.ncwd-youth.info/blog/
• Publications on Transition Supports: http://www.ncwd-youth.info/topic/transition-supports includes information on Benefits Planning, Breaking down Technological Barriers, Building Infrastructure, Financial Literacy, Personal Assistance Services, Mental Health, and Disability Disclosure

Social Security Administration  www.socialsecurity.gov
The Red Book is a general reference source about the employment-related provisions of Social Security Disability Insurance and the Supplemental Security Income Programs for educators, advocates, rehabilitation professionals, and counselors who serve people with disabilities. Describes a number of programs which help people with disabilities get higher education, training, accommodations, work experience without losing SSI and Medicaid benefits including PASS, 1619a and b, IWRP, IPE, Student Earned Income Exclusion; IWRE and Ticket to Work.

Social Security Administration’s Work Site http://www.socialsecurity.gov/work
Youth Demonstration Projects: http://www.socialsecurity.gov/disabilityresearch/youth.htm
About Children: http://www.ssa.gov/kids/

SSA: The Benefit Eligibility Screening Tool (BEST)  http://www.ssa.gov/ssi/
Supplemental Security Income (SSI) is a Federal income supplement program designed to help aged, blind, and disabled people, who have little or no income by providing cash to meet basic needs for food, clothing, and shelter. In 2011 the maximum monthly payment is $674 ($8,088 per year).

SSA: State by State  https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate  State by state listing of resources such as VR, WIPA, Ticket to Work, Protection and Advocacy, Benefits Counselors.

Ticket to Work: www.yourtickettowork.com/ and http://www.choosework.net/ The Ticket offers people with disabilities a shot at achieving financial independence by enabling more choice in employment-related support services and access to meaningful work.


Workforce Development Department of Labor: Office of Disability Employment Policy (ODEP)  www.dol.gov/odep/ Programs and statistics on employment of people with disabilities. See section on Youth in Transition.

See General Resources for more information on work
Chapter 6: Moving Toward Your Destination: Continuing in School

AHEAD – Association on Higher Education And Disability [http://www.ahead.org/]
AHEAD is a professional association committed to full participation of persons with disabilities
in postsecondary education. AHEAD addresses current and emerging issues with respect to
disability, education, and accessibility to achieve universal access.
Transition Resources A-Z: [http://www.ahead.org/students-parents/transitions]

AAP’s Health Care for College Students
[http://www.rowan.edu/open/studentaffairs2/healthcenter/documents/AAPhealthcollegeSHC.pdf]

College Entrance Examinations
- SAT [www.collegeboard.com].
- ACT [www.act.org].
- *The Forgotten Middle* notes that 8th grade is a critical time for students to begin preparing
  for college. See [www.act.org/research/policymakers/pdf/ForgottenMiddle.pdf]
- The federal department of education has a book entitled “Students with Disabilities
  Preparing for Postsecondary Education: Know Your Rights and Responsibilities” at
  [www.ed.gov/about/offices/list/ocr/transition.html]

College Readiness: College of the Desert, Disabled Students Programs and Services
[http://www.collegeofthedesert.edu/students/sp/dsps/Documents/dspsreachforyour.pdf] *Reach for your Dream*

and Spanish.

Free Application For Student Aid (FAFSA) [www.fafsa.ed.gov] This site gives information
about different kinds of federal education loans.

Going to College: A Resource for Teens with Disabilities [www.going-to-college.org] Learn
about planning for college. View video interviews with successful college students with
disabilities. Learn what to expect in college and what professors will expect from you. Tips for
good grades, accommodations and using technology.

Health Resource Center at the National Youth Transitions Center [www.heath.gwu.edu]
Online clearinghouse on postsecondary education for individuals with disabilities.

Scholarships for students with disabilities [www.disaboom.com/scholarships]

Think College [www.thinkcollege.net] Think College is designed to share what is currently
going on, provide resources and strategies, let you know about training events, and give you
ways to talk to others. The information is for transition-aged students as well as adults attending
or planning for college. It provides resources and tools for students, families, and professionals.

![Average Annual Earnings by Education](image)

See General Resources for more information on higher education

Chapter 7: Cars, Buses, Trains, Planes, Boats: Transportation

Department of Transportation [http://www.fhwa.dot.gov/webstate.htm] State information
Freedom to Travel Independently across Town or Across the Country: information about accessible transportation systems

Disability.gov - Transportation [www.disability.gov/transportation]

Easter Seals Project Action [www.projectaction.easterseals.com] Mission is to promote universal access to transportation for people with disabilities under federal law and beyond by partnering with transportation providers, the disability community and others through the provision of training, technical assistance, applied research, outreach and communication.

See General Resources for more information on transportation
Chapter 8: Lodging Along the Way: Housing

Centers for Independent Living  [www.ilru.org/html/publications/directory/index.html] Map offering information on state CILs. From Section 702 of the Rehabilitation Act of 1973, as amended: The term “center for independent living” means a consumer controlled, community based, cross disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services.

Disability.gov – Housing  [www.disability.gov/housing] General and state information on housing for people with disabilities; also

Housing and Urban Development (HUD)  [www.hud.gov/]
Find your local Public Housing Agency:
[http://www.hud.gov/offices/pih/pha/contacts/index.cfm]

Housing for people with disabilities  [http://www.hud.gov/offices/pih/programs/hcv/pwd/]

Learn more about renting and HUD rental assistance programs.
[http://portal.hud.gov/portal/page/portal/HUD/topics/rental_assistance]

See General Resources for more information on housing

Chapter 9: Paying for the Trip: Money Management

Money management course from U of Illinois extension (in English and Spanish)
[http://web.extension.illinois.edu/money/]

VISA’s website on money management  [http://www.practicalmoneyskills.com/calculators/]
Practical Money Skills for Life - Financial Literacy for Everyone

Winona Bank ABA budget sheet – (adapted in the text)
[http://www.winonanationalbank.com/Personal/YoungAdults.aspx]

See General Resources for more information on money management
Chapter 10: Friends and Fun: Having Adventures

NAMI Social Networking Site for Young Adults  www.strengthofus.org

National Center for Physical Activity and Disability  www.ncpad.org  The mission of the National Center on Physical Activity and Disability (NCPAD) is to promote substantial health benefits that can be gained from participating in regular physical activity. The slogan of NCPAD is Exercise is for EVERY body, and every person can gain some health benefit from being more physically active. This site provides information and resources that can enable people with disabilities to become as physically active as they choose to be.


New Mobility: The Magazine for Active Wheelchair Users  www.newmobility.com

Special Olympics  http://www.specialolympics.org  Special Olympics transforms lives through the joy of sport, every day, everywhere, especially for people with intellectual disabilities. Special Olympics is world’s largest sports organization and global social movement.

Relationships and Sexuality

Advocates for Youth  http://www.advocatesforyouth.org/topics-and-issues  provides resources on various topics to help young people make informed and responsible decisions about their reproductive and sexual health. Advocates for Youth believes it can best serve the field by boldly advocating for a more positive and realistic approach to adolescent sexual health. Also includes some great information about policy!

I Wanna Know  http://www.iwannaknow.org/  Iwannaknow.org is a trusted source of information on sexual health and sexually transmitted infections (STIs). Here is where you can learn about relationships, sexual health, reducing your risks for STIs and unplanned pregnancies, myths and facts about sexual health and more.

www.noplacelikehome.org/ helps parents talk with their children and teens about sex.

Spina Bifida Association of America  www.SBAA.org  and  http://www.sbtween2teen.org/

Spinal Cord Injury  http://www.spinalcord.uab.edu/

United Cerebral Palsy  http://www.ucp.org/resources/health-and-wellness/sexuality  Resources help parents talk with their children.

See General Resources for more information on friends and fun