

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/ccshcntransition.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

Disability.gov <http://www.disability.gov/> US government website that connects the disability community to information and opportunities. For Example: Supports in community life organizations: http://www.disability.gov/community_life/disability_organizations

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/ 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> 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.

Health Care Skills Checklist:

<http://depts.washington.edu/healthtr/documents/healthcareskills.pdf>

Transition Timelines for youth with chronic conditions and for youth with developmental disabilities. <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

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

Kids As Self Advocates (KASA) <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 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.

NCLD/Youth - National Consortium on Leadership and Disability for Youth <http://www.ncld-youth.info> A youth-led national resource, information, and training center for youth with disabilities.

National Youth Leadership Network <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/>

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>

See *Being Your Own Best Advocate* at <http://www.pacer.org/parent/php/PHP-c116.pdf>

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.

Bandaiders 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

Kid's Health www.KidsHealth.org Website about children's health from the American Academy of Family Physicians. See section for teens. www.kidshealth.org/teen

National Youth Anti-Drug Media Campaign www.abovetheinfluence.com Website of the Office of National Drug Control Policy of the US President.

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.

U.S. Preventive Services Task Force <http://www.ahrq.gov/clinic/USpstfix.htm>

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:

Colorado: Transition Guide, Transition Workbook and Transition Toolkit at:

<http://www.cdphe.state.co.us/ps/hcp/transitioncare.html?col7=open>

Florida: Transition Workbooks and fact sheets at: http://www.doh.state.fl.us/alternatesites/cms-kids/kids_teens/teens/teens.html

- **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.

Kentucky: <http://chfs.ky.gov/ccshcn/ccshcntransition.htm> for fact sheets and Life Map assessment forms. See www.transitiononestop.org for information on many life transitions.

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

North Carolina: Carolina Health and Transition Project (CHAT) Youth Guide

http://www.fpg.unc.edu/~ncodh/pdfs/CHAT_Youth_Guide_2010.pdf

Pennsylvania: Special Kids Network: 44 page transition checklist book, revised 2008:

http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/hc_checklist_final_july2008.pdf

Other resources can be found at <https://www.gotoskn.state.pa.us/>

Rhode Island: Rhodes to Independence:

<http://www.rhodestoindpendence.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/>

- **Wisconsin Community on Transition Health Practice Group**
<http://www.waisman.wisc.edu/wrc/pub.html>
 Health-related training materials that can be used with schools, health providers, families and directly with youth to help youth with disabilities learn to more effectively manage their health care concerns.

Canada: British Columbia Ministry of Children and Family Development “Transition Planning for Youth with Special Needs” www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf

Some Children’s Hospitals have Transition Programs. Some examples are:

Boston Children’s Hospital Transition Toolkit:

<http://newenglandconsortium.org/brochures/Transition-Toolkit-Complete.pdf>

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:

<http://www.shrinershospitalsforchildren.org/en/CareAndTreatment/Orthopaedics/TransitionPrograms.aspx>

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/hcprofessionals/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/livingwithpilepsy/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/
- **Sickle Cell** http://www.dcmsonline.org/jax-medicine/2008journals/transitional_health/Sickle_Cell.pdf
- **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
- Department of Labor- Health Plan: <http://www.dol.gov/dol/topic/health-plans/planinformation.htm>
- Government general health insurance: www.usa.gov/Citizen/Topics/Health/HealthInsurance.shtml
- National Conference of State Legislatures 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 Links to all state offices of insurance
- Health Care Reform: <http://www.healthcare.gov/> to get info on health care reform and coverage for young adults.

Medicaid:

General Medicaid and CHIP information <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/Medicaid-and-CHIP-Program-Information.html>

EPSDT Services

<http://www.cms.hhs.gov/medicaidearlyperiodicscrn/> and <http://mchb.hrsa.gov/epsdt/overview.html>

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
- **The Clearinghouse for Home and Community Based Services** <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

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 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

Federal Emergency Management Agency (FEMA): <http://www.fema.gov/about/odic/> 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.

Get Ready America: <http://www.ready.gov/> 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)

<http://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html> Information on privacy rights for education records and how to file complaints.

GED – Test of General Educational Development www.gedtest.org

Higher Education Opportunities Act <http://www.ed.gov/policy/highered/leg/hea08/index.html> Information on many aspects of high education including funding opportunities

National Assistive Technology Technical Assistance Partnership 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/> 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

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
See booklet Tips for Transition at <http://www.transitioncoalition.org/transition/section.php?pageId=72>

US Department of Education Office of Special Education Programs (OSEP) IDEA Website <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>

Wrightslaw <http://www.wrightslaw.com/> Gives accurate, reliable information about special education law, education law, and advocacy for children with disabilities. Includes Yellow Pages for Kids with Disabilities to find state resources.

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/doi/> 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/doi/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

The Arc for People with Intellectual and Developmental Disabilities <http://www.thearc.org/> National and state resources.

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
Nonprofit organization providing information on special needs trusts and other legal issues in planning for persons with special needs.

PACER Center <http://www.pacer.org/publications/transition.asp> See especially their booklet called *Possibilities: A Financial Resource for Parents of Children with Disabilities*.

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/ and www.studentjobs.gov Websites with information on work and preparing for work.

Disability.gov <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 A comprehensive source on federal government benefits

Institute for Community Inclusion (ICI) <http://www.communityinclusion.org/>
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)

Job Accommodation Network <http://janweb.icdi.wvu.edu/> U.S. Department of Labor's Office of Disability Employment Policy (ODEP) service. Answers questions on accommodations and employment for workers with disabilities.

National Collaborative on Workforce and Disability - NCWD/Youth
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>
- The 411 on Disability Disclosure: A Workbook for Youth with Disabilities
<http://www.ncwd-youth.info/topic/disability-disclosure>

- 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.

Vocational Rehabilitation <http://rsa.ed.gov/> For state information on contacts and statistics about education and vocational rehabilitation. Many states have Consumer Guides www.ed.gov/about/contacts/state/index.html?src=gu for your state program. See <http://www.ovr.ky.gov/programservices/> for a sample consumer guide (see right side of page).

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*

Florida Children’s Medical Services http://www.doh.state.fl.us/AlternateSites/CMS-Kids/kids_teens/teens/transitions.html “Envisioning My Future” and other materials in English 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.

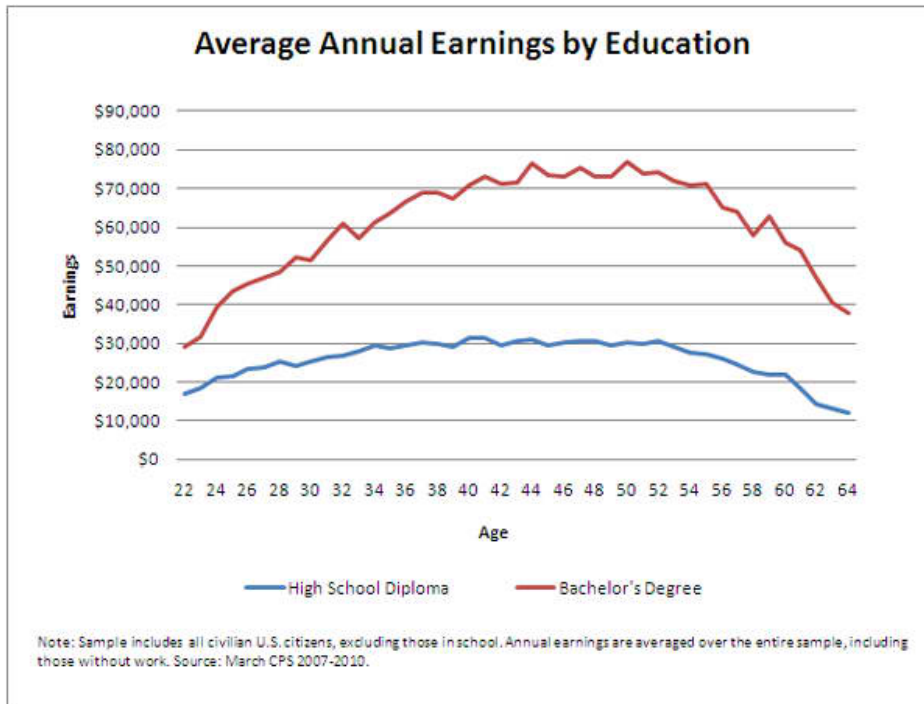
Health Resource Center at the National Youth Transitions Center www.health.gwu.edu
Online clearinghouse on postsecondary education for individuals with disabilities.

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.

Waisman Center, University Center for Excellence in Developmental Disabilities,
University of Wisconsin – Madison <http://www.waisman.wisc.edu/wrc/pub.html> Materials
Supporting Youth with Special Health Care Needs in Technical College and University Life.

*Information from the Brookings Institution Hamilton Project – A study on average earnings
by education* http://brookings.edu/papers/2011/0625_education_greenstone_looney.aspx?p=1



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 http://www.disability.gov/community_life/independent_living/home_&_community-based_services

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
<http://whatsmyscore.org/downloads/pdf/StudentWorkbook.pdf> Excellent student workbook.

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.

National Sports Center for the Disabled <http://www.nscd.org/> The National Sports Center for the Disabled provides therapeutic sports and recreational programs for people of any age and any ability.

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.

Planned Parenthood <http://www.plannedparenthood.org/> See section for teens.
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