Web Resources for Health, Disability and Adolescent Transition

Evaluating Health Information on the Web

- A User's Guide to Finding and Evaluating Health Information on the Web -Medical Library Association webpage provides guidance on how to find quality health information on the web. Includes how to get started, content evaluation guidelines, additional help, top ten health information websites and recommended websites for cancer, diabetes and heart disease. <u>http://www.mlanet.org/resources/userguide.html</u>
- MedlinePlus Guide to Healthy Web Surfing Clear guidelines for evaluation the quality of health information on websites with links to further resources. <u>http://www.nlm.nih.gov/medlineplus/healthywebsurfing.html</u>

Resources on Health Transition

- Center for Children with Special Needs at Seattle Children's Hospital Page on Teens includes information addressed to teens on self advocacy, moving to adult health care, keeping track of medical information, planning for the future, communication with others. http://cshcn.org/teens
- Health Care Transition Initiative Website at the University of Florida that is devoted to improving the process of transitioning from child-centered (pediatric) health care to adult-oriented health care. Provides training programs, products and resources for professionals and youth. <u>http://hctransitions.ichp.ufl.edu/index.php</u>
- Florida Health and Transition Services (HATS) website for state of Florida that promotes health transition. Many resources are specific to Florida, but the Tool Box has information on health transition topics that are helpful to all. <u>http://www.floridahats.org/</u>
- Healthy Transitions: Moving from Pediatric to Adult Health Care includes detailed modules for learning health care skills. Created by a partnership between Upstate Medical University, GoLisano Children's Hospital and NY State DD Planning Council.

http://healthytransitionsny.org/

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- Transition Resource and Staying Healthy Resources Kentucky Children with Special Health Care Needs Family Assistance Resources page. Lists a number of tools for families and providers. <u>http://chfs.ky.gov/ccshcn/ccshcntransition.htm</u>
- Got Transition? New website of the National HealthCare Transition Center. The plan is for the Center to implement and disseminate health care transition best practices in primary care medical homes and specialty settings for youth and young adults with special health care needs. Learn more at: <u>http://www.gottransition.org/</u>
- **Royal Children's Hospital Melborne** Adolescent Transition website for RCH in Melborne, Australia, includes information, fact sheets, tools for families and professionals.

http://www.rch.org.au/transition/index.cfm?doc_id=8143

 Bloorview Kids Rehabilitation Hospital in Toronto – Web page on Preparing for Adult Life. Includes sections 'For Families & Youth' and 'For Professionals'. The section for families, requires the user to fill out a short registration form before accessing the materials, but there is no charge for downloading or printing materials. Includes attractive color pages with a timeline format. Titles include 'Timetable for Growing Up', 'Getting Started', 'On My Way', 'Almost There' and 'Guidelines for Service Providers'. The section for professionals describes the history of the Bloorview transition framework, which is based on the Shared Management work of Kieckherer and Trahms from CHDD. Includes links to resources and publications.

http://www.hollandbloorview.ca/resourcecentre/transitions/adultservices.php

Resources on General Transition to Adulthood - the focus is mostly school and employment, but some also address health transition.

 Seattle University Center for Change in Transition Services (CCTS) – the goal of this website is to improve post-school outcomes for students with disabilities in Washington State. CCTS is funded by the Office of the Superintendent of Public Instruction's federal resources. CCTS provides training on Secondary Transition to school personnel across the state. Their training materials can be viewed or downloaded from their website and are very helpful in

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- DO-IT The acronym stands for Disabilities, Opportunities, Internetworking, and Technology. DO-IT 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. The website offers a wealth of information, resources and classes. http://www.washington.edu/doit/
- Disability Rights Washington (DRW) A private non-profit organization that protects the rights of people with disabilities statewide. In the Tools To Help You section, you can find Self-Help Information Sheets on a variety of topics related to rights. Topics include guardianship, legal assistance, mental health, voting, and many others.

http://www.disabilityrightswa.org/

- National Secondary Transition Technical Assistance Center (NSTTAC) The purpose of this website is to help states build capacity to support and improve transition planning, services and outcomes for youth with disabilities. The website is focused toward school districts and teachers. Funding for this project ended December 2010, but the site has a wealth of information about the Transition IEP process and is still on the web as of June 2011. <u>http://www.nsttac.org/</u>
- National Center on Secondary Education and Transition (NCSET) coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures. NCSET is headquartered at the <u>Institute on Community Integration</u> in the University of Minnesota's College of Education and Human Development. Good resource on IEP and transition planning, self-determination and other transition topics.

http://www.ncset.org/

 National Center on Workforce and Disability/Youth (NCWD/Youth) - Website about employment for youth with disabilities. Covers many aspects of transition. Resources for youth, families, employment and educational professionals. <u>http://www.ncwd-youth.info/</u>

- Transition Coalition Website located in the Department of Special Education at the University of Kansas. Provides online information, support, and professional development on topics related to the transition from school to adult life for youth with disabilities. There are resources on assessment for persons with *significant disabilities* in the Publications section under Presentations. <u>http://transitioncoalition.org/transition/index.php</u>
- Wisconsin Statewide Transition Initiative Much of this website is specific to Wisconsin, but the Healthcare Transition page has links to a series of videos on YouTube where young people with disabilities talk about their transition experiences.

http://www.wsti.org/parents.healthcare.php

 Opening Doors for Children and Youth with Disabilities and Special Health Care Needs – A project of the Maternal and Child Health Bureau to promote better futures for youth with SHCNs. Two of the three projects are of interest to teens and young adults and professionals who work with them. Project Adventure is about inclusive recreational opportunities and Opt4College is about making the decision to go to college.

http://www.openingdoorsforyouth.org/index.php

• **Think College!** - Doors to colleges are opening for people with intellectual and other developmental disabilities in many different ways all over the country. This website 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.

http://www.thinkcollege.net/

 PACER Center – parent training and information center for families of children and youth with all disabilities from birth through 21 years old. Many resources, including sections on Transition and Special Health Needs. <u>http://www.pacer.org/</u>

Resources on Health and Disability

 HEAL-WA – Authoritative, current, evidence-based information for health care providers in Washington State. Provides access to many resources not generally available to the public. Access limited to certain categories of health care professionals and funded by licensing fees for the designated professions, including registered nurses. Free, but requires registration for access. Registration instructions are on the home page of the website. <u>http://heal-wa.org/</u>

• UW Health Sciences Library - The Health Sciences Library (HSL) at the University of Washington is the first resource that comes to mind for many of us when we want health information. Explore HealthLinks, the HSL website at http://healthlinks.washington.edu/

Many of the resources of the HSL are restricted to current UW faculty, staff and students. There are other options, however! The HSL website has a page that lists a great number of options for health-related web resources that are *available to the public*: <u>http://healthlinks.washington.edu/howto/life_after_u.html</u>

 Teens Health - Health information website for teens maintained by Nemours Center for Children's Health Media. Information on a wide variety of health topics. Includes a section on Diseases and Conditions. Also has tabs for parents and younger kids.

http://kidshealth.org/teen/

- Washington State Medical Home Offers a wide variety of health and medical information for families, physicians and other providers, arranged by audience and topic. Includes many links to other sources. <u>http://www.medicalhome.org/index.cfm</u>
- MedlinePlus The Website of the National Institutes of Health and National Library of Medicine is organized by Health Topics, Drugs and Supplements, and Videos and Cool Tools. It includes health and wellness information and medical conditions. Not focused on disabilities.

http://www.nlm.nih.gov/medlineplus/

 Office of Rare Diseases Research - National Institutes of Health website designed to answer questions about rare diseases and the activities of the ORDR, including biomedical research, scientific conferences and rare and genetic diseases. Also serves as a portal to information on major topics of interest to the rare diseases community. Search for information on specific rare diseases or find other websites of interest. Includes conditions for which fewer than 200,000 individuals are affected in the US. http://rarediseases.info.nih.gov/Default.aspx

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- National Organization on Rare Disorders NORD is a federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.
 www.rarediseases.org
- Genetic and Rare Diseases Information Center The Center works to help people find useful information about genetic and rare diseases. GARD provides timely access to experienced information specialists who can furnish current and accurate information – in both English and Spanish – about genetic and rare diseases.

http://rarediseases.info.nih.gov/GARD/

Organizational Database for Rare Disorders - Searchable database of 2,000
organizations that help people with rare diseases.
<u>http://www.rarediseases.org/search/orgsearch.html</u>