

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 36

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As part of the Family to Family Health Care Information and Education Center, Parent to Parent of NYS has established the Links Digest to provide links relevant to the issues of health care. Below is the most recent listing of website links which we have found valuable and hope they will be of benefit to others.

1. Advocacy 101 – items that help strengthen advocacy skills – (Communication skills, parenting skills, letter writing, speaking with professionals, asking questions)

<http://www.tangoresults.com/TangoTimes15.pdf> - mother shares her transition skills

http://www.orthop.washington.edu/uw/livingwith/tabID_3376/ItemID_121/PageID_222/qview_true/Articles/Default.aspx - working with your child's doctor

2. Financing issues – health insurance and other ways to finance the costs of needed services (including Grievances, denials and appeals – i.e. Strategies for Appealing Health Plan Decisions)

http://olrs.ohio.gov/asp/olrs_HealthInsuranceBasics.asp - When dealing with medical insurance claims relating to a person with a disability, navigating the health insurance system is often a time-consuming and aggravating task. This article offers general information about health insurance policies, tips on how to obtain coverage for services, and guidance on how to appeal a denied claim.

3. 504 Accommodation Plans related to Health Conditions (i.e. what are the legal obligations of schools to provide health-related services and therapies? Accommodations needed for equal access)

<http://www.ed.gov/news/pressreleases/2006/08/08032006b.html> - New regulations will help children with disabilities receive the services they need.

<http://specialed.principals.org/discidea/topdocs/peer/accomodationsfs.html> - fact sheet on various accommodations.

4. Who helps with what? Which state agencies are involved in health care and health coverage? What do medical and managed care terms mean? What should families look for in selecting a provider? What questions should families ask?

<http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=500> - federal government's one-stop Web site for information of interest to people with disabilities, their families, employers, service providers and many others.

<http://www.nockonline.org/> - The mission of the National Organization Caring for Kids is to improve the quality of life for special needs children through the use of assistive technology.

5. Parent-to-parent support skill-building (How can parents provide support and assistance to families without substituting their judgment? Understanding and respecting cultural diversity. How can parents be culturally competent in working with diverse families? How can parents emotionally support, inform, and educate parents so that they are strong, knowledgeable, and confident in caring for their child with special health needs?)

<http://www.hcbs.org/moreInfo.php/nb/doc/1658> - . This topic paper highlights innovative strategies developed by individual Family to Family Centers to develop partnerships to expand their reach, to enhance outreach to parents, to serve a culturally diverse clientele, to help youth prepare for transition, and to ensure organizational sustainability.

http://olrs.ohio.gov/asp/olrs_FindingDoctor.asp#having - For families who have children with disabilities, it is sometimes hard to find a primary care doctor who can address their child's unique needs. This section provides information on how to select a primary care doctor for your child with a disability

6. Keeping Records is a learned skill. Parents will learn what kinds of records are important and how to record necessary information. Your child's health care providers rely on your records to help them make sound medical recommendations.

http://www.yourdoctorinthefamily.com/effectivept/doctor_7.htm - Becoming a More Effective Patient - Managing your own health

<http://www.getorganizednow.com/cl-month.html> - creating calendar

7. Parent-professional collaboration strategies. How can families work with their health care provider to secure quality care and coverage for their child? How can health care providers and families communicate more effectively? What are effective health advocacy strategies? What is a “medical home” and how can parents access it for their child with special health needs?

<http://www.cincinnatichildrens.org/about/fcc/mother.htm?view=content> - Reaping the Benefits of Family-Centered Care

http://www.uacc4families.org/resource/mh/EBP_Monograph_UACC.pdf - the role of family organizations in the evidence based practices movement

8. Understanding Medicaid funded Waiver Services (Including the philosophy of individual and family-centered supports)

http://www.health.state.ny.us/health_care/medicaid/ - Answers the question “what is Medicaid”

http://olrs.ohio.gov/asp/olrs_SSA.asp - The Social Security Administration offers programs for people with disabilities, called the Social Security and Supplemental Security Income disability programs. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and who meet specific medical criteria may qualify for benefits under either program.

http://ssa-custhelp.ssa.gov/cgi-bin/ssa.cfg/php/enduser/std_adp.php?p_faqid=326 - question and answers on disability benefits

9. Legal information - what are the rights of children to medical coverage under Medicaid, SCHIP, fee-for-service coverage. How can families use complaint, arbitration, and grievance procedures to resolve disputes? What are the legal obligations of schools to provide health-related services and therapies?

http://www.omr.state.ny.us/hp_healthcare.jsp - The information in this publication is designed to familiarize New Yorkers with health care decision options that are available for individuals who have mental retardation and developmental disabilities and their families when planning for and making choices about their health care in the event that a person is or becomes incapable of making their own health care decisions.

http://olrs.ohio.gov/asp/olrs_ListOfRights.asp - People who are served by public or private agencies have specific rights; some basic rights to keep in mind for your child.

10. **Other links**

http://www.aamr.org/ShapingOurDestiny/consumer_s_guide.html - A Consumer's Guide to Quality Community Services; Shaping Our Destiny For people with developmental disabilities and their families

<http://www.faihtability.org/> - religion and disability resources

***Have you found valuable links that you would like to share?
Please email them to Rosemary Randazzo, Parent to Parent of NYS
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Additionally, we have developed a listserv for families who have children who are medically frail.

<http://www.parenttoparentnys.org/Forms/joinmedfragilegroup.htm>

Fragile Families Network -- The purpose of this group is to disseminate and share information regarding children who have complex medical needs, are considered medically fragile and require skilled nursing care. This e-group is a place where parents can connect and support each other by posting questions, sharing resources, comments and stories. It is interactive, and parents are able to receive feedback from other parents across New York State.