

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 49

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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.disabilityrights.org/glossary.htm> - glossary for parents on special education terms.

<http://www.familyvoices.org/pub/general/YouAreAnAdvocate.pdf> - Fact Sheet on Advocating for your child with special health care needs

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://thefamilycaregiver.org/caregiving_resources/takecare_newsleter.cfm - Site on various medical deductions. For example, Medical Expenses Deductions –to qualify as a medical expense you must have spent money to alleviate or prevent a physical or mental defect or illness which can include medical insurance premiums (unless pre-tax); prescription medicines; doctors' bills; hospital fees; travel to and from medical appointments at 18 cents/mile. Special Expenses – you can claim oxygen and the equipment; special schools or homes; artificial limbs; false teeth; eyeglasses; wheelchairs and repairs; crutches; guide dogs; etc. Nursing home care – only the medical expenses incurred in a nursing home. Nursing, Therapeutic, and/or aide services

http://nls.org/ssassi/medical_justification.htm - sample medical justification letter

- 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.slc.sevier.org/504meetingsReadersDigestVersion.doc> - Brief overview of Section 504

http://www.parentprojectmd.org/site/PageServer?pagename=edu_developing_iep - developing an IEP

- 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://headaches.about.com/library/docquiz/bldocquiz.htm> - Quiz on whether your Doctor is right for you.

<http://www.nihcm.org/finalweb/HealthDisparitiesFinal.pdf> - The National Institute for Health Care Management (NIHCM) Foundation is pleased to release an issue paper highlighting public and private strategies to reduce disparities, including innovative health plan efforts across the country. NIHCM Foundation's "[Reducing Health Disparities Among Children: Strategies and Programs for Health Plans,](#)"

- 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.childrensdisabilities.info/parenting/snparenting.html> - article on coping with the challenges of parenting a child with special needs

<http://www.ldonline.org/article/12836> - guide to parents on how to help their children succeed titled *Life Success for Students with Learning Disabilities: A Parent's Guide*.

- 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.healthliteracy.com/tips.asp> - ways to maintain your personal health records

http://www.uchsc.edu/misc/diabetes/school_checklist.doc - checklist for parents of children with diabetes.

- 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.familyvoices.org/pub/general/PartneringWithProviders.pdf> - families partnering with providers

<http://www.hhs.gov/news/press/2007pres/20070305.html> - HHS Initiative to Assist Hospitals in Effective Communication

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

<http://www.fullcirclecare.org/caregiverissues/financial/medicaid.htm#difference> - differences between Medicaid and Medicare

http://www.nytimes.com/2007/03/11/nyregion/11health.html?_r=1&oref=slogin - Article in the NY TIMES with respect to escalating public battle over his budget cuts, Gov. [Eliot Spitzer](#) has offered several critiques of the state’s vast health care system, some unquestionably true, and some subtle and complex.

- 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.results.org/website/article.asp?id=347> - Information on the Head Start Reauthorization Bill

<http://nls.org/ssassi/medicaid.htm> - over-view of medicaid buy-in at a glance

- 10. Autism Connection – links regarding autism and accurate information about autism treatments**

<http://manitasporautismo.com/> - Autism website only in Spanish

<http://autism.about.com/od/whatisautism/tp/topmyths.htm> - Autism myths

- 11. Other Links and Information**

<http://ghr.nlm.nih.gov/> - Guide to understanding genetic conditions

<http://www.dgckids.org/Tips.pdf> Tips for Interacting With Children Who are Visually Impaired

***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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