

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 61

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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.bellaonline.com/articles/art51927.asp> -working with bilingual children with special needs

<http://www.ahrq.gov/questionsaretheanswer/> - Clinicians, the Government, and many other groups are working hard to improve health care quality, but improving health care quality is a team effort. You can improve your care and the care of your loved ones by taking an active role in your health care. Ask questions. Understand your condition. Evaluate your options. This site is designed to assist patients improve their health care.

<http://www.eeoc.gov/> -[About Equal Employment Opportunity \(EEO\)](#) with respect to discrimination on a wide array of topics, including disabilities

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://www.npr.org/templates/story/story.php?storyId=12829221> - Coverage for the therapies and treatment associated with autism is limited in most states

http://www.omr.state.ny.us/hp_dentistry_locations.jsp The Dental Directory has been added to the Information for Providers and the Information for Individuals and Families pages for easier access. The Special Needs Dentistry Task Force and NYS

OMRDD assisted in the development of this resource listing of dentists and clinics. It provides information on payment options as well as sedation options.

http://www.tacanow.com/health-insurance/health_ins_reimbursement_tips.htm - health insurance tips for families with children with Autism

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.vesid.nysed.gov/specialed/publications/policy/psgncover.htm> - Revised New York State Procedural Safeguards Notice: Rights for Parents of Children with Disabilities, Ages 3-21

http://www.sbaa.org/site/c.gpILKXOEJqG/b.2021247/k.D685/IEPs_Being_the_Best_Advocate_You_Can_Be.htm - creating a great 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://www.scbn.org/?gclid=CKaOuJLLr44CFQJsPAodHjzNZA> - Select Care Benefits Network (SCBN) is one of America's leading Patient Advocacy Organizations that specializes in free medicine and prescription assistance programs. SCBN gives prescription drug assistance by helping it's member patients locate, qualify for and successfully access hundreds of free prescription programs on an ongoing basis.

<http://www.fema.gov/news/newsrelease.fema?id=38990> - Accommodating People With Disabilities In Disasters: A Reference Guide To Federal Law

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.bellaonline.com/articles/art50678.asp> - mothering babies with special needs

<http://www.omhrc.gov/templates/content.aspx?ID=4375&lvl=2&lvlID=107> - The Office of Minority Health along with The Department of Health and Human Services funded the development of a new tool: A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations. This guide was created to

assist health care organizations in better serving their clients with limited English proficiency and decrease disparities in access to health care.

http://www.tourettesyndrome.net/Files/organizing_concerns.pdf - organizing your concerns to discuss with the teachers

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://ibdcrohns.about.com/library/weekly/aa081601a.htm> - 8 tips for keeping track of your medications

<http://webworkerdaily.com/2007/04/03/6-ways-to-track-your-time/> - ways to track your time

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.sciencedaily.com/releases/2007/09/070911155506.htm> - Pediatricians May Miss Developmental Delays, But Parents Can Help

<http://somepa.org/Guide/files/pdf/ch01.pdf> - creating partnerships

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

<http://www.cms.hhs.gov/eRulemaking> - CMS has proposed regulation changes that would eliminate Medicaid reimbursement for school administration expenditures and costs related to transportation of school-age children, with an IEP or IFSP, between home and school. Comments must be received by November 6, 2007

http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/Downloads/MAX_Chartbook_2007.pdf - contains information about Medicaid enrollees and the health services they use during a calendar year. A new chartbook based on 2002 data presents an overview of enrollee demographic and enrollment characteristics, service utilization, and expenditures at the national and state levels.

<http://www.kff.org/uninsured/upload/7451-021.pdf#page=7> - Medicaid and the uninsured

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.listen-up.org/rights/rights.htm#advocate> - website that discusses your rights as a parent on a multitude of topics and ways to advocate for your child

<http://www.phdsc.org/prism/introduction.htm>. - A Privacy Toolkit for Public Health Professionals is designed to provide direction for government health entities in applying Health Insurance Portability and Accountability Act (HIPAA) privacy regulations to their programs and functions and also in complying with all state and federal requirements.

<http://www.dol.gov/esa/whd/fmla/> - Compliance Assistance — Family and Medical Leave Act (FMLA)

<http://www.nosscr.org/faqind.html> - frequently asked questions regarding SSI

10. Transition from Pediatric to Adult Health Care and Self Determination in Health Care (the important leadership role that individuals with disabilities and their families must play in moving from pediatric to adult health care).

<http://www.bellaonline.com/articles/art50637.asp> -working with the school and your child on transitioning each year.

<http://www.totb.ca/> - New Web Tool Promotes Employment for Persons with Disabilities. Thinking Outside the Box Offers Advice on Accommodations

11. Other Links and Information

<http://www.usdoj.gov/crt/ada/qasrvc.htm> - This document, which was originally created in July 1996 was updated August 20, 2007, represents a fact sheet answering commonly asked questions about the use of service animals by people with disabilities in places of business.

Janice Fitzgerald, Executive Director
Parent to Parent of NYS
P.O. Box 1296
Tupper Lake, NY 12986
www.parenttoparentnys.org