

## **Parent to Parent of NYS**

***New York's Family to Family***

***Health Care Information and Education Center***

***Links Digest - Volume 59***

***August 15, 2007***

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.medicalhomeinfo.org/health/advocacy.html> - being a health advocate for your child with special health care needs

<http://www.medicalhomeinfo.org/training/PI%20downloads/TIPS%20FOR%20EFFECTIVE%20MESSAGE.doc> - tips for crafting an effective message

**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.ncpa.org/sub/dpd/index.php?Article\\_ID=14784](http://www.ncpa.org/sub/dpd/index.php?Article_ID=14784) - A dubious health-care solution

[http://www.ncpa.org/sub/dpd/index.php?Article\\_ID=14868](http://www.ncpa.org/sub/dpd/index.php?Article_ID=14868) - A combination of four measures helped one U.S. hospital's health plan control prescription drug costs and save more than \$6.6 million over three years, according to a study by Wake Forest University Baptist Medical Center published in the American Journal of Managed Care.

The [Medicaid Analytic eXtract \(MAX\) data system](#) 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. The [Medicaid Analytic eXtract \(MAX\) data system](#) 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.

**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.additudemag.com/additude/article/1623.html?j=12330271&e=rosemarylip2p@aol.com&l=752859\\_HTML&u=147273935&mid=26986&jb=](http://www.additudemag.com/additude/article/1623.html?j=12330271&e=rosemarylip2p@aol.com&l=752859_HTML&u=147273935&mid=26986&jb=) - What does your child qualify for? An IEP or 504 Plan?

[http://www.faiusa.org/section\\_home.cfm?section\\_id=4&sub\\_section\\_id=4&article\\_id=35](http://www.faiusa.org/section_home.cfm?section_id=4&sub_section_id=4&article_id=35) - Section 504 Plan outline

**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.thearclink.org/news/article.asp?ID=624> - TheArcLink is the first web site to provide customized, specific information on the various sources of assistance available to individuals with disabilities and their families on a state-by-state basis as well as information on almost 30,000 providers

<http://www.connectforkids.org/> - Information and resources to get the tools needed to make communities work for kids, to get connected to groups that equip adults to act together for kids, to learn how well children are doing in their community, state, or nation.

**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.aap.org/family/frk/aapfrkfull.pdf> - Ways families can prepare for disasters

<http://www.ffcmh.org/Principles%20on%20Family%20Support.pdf> - principals on family support

**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.faiusa.org/uploaded\\_files/authorization.doc](http://www.faiusa.org/uploaded_files/authorization.doc) - authorization form for emergency treatment and when applicable

[http://ocfs.state.ny.us/main/sppd/health\\_services/manual/04\\_chp04\\_healthservice\\_s2\\_12\\_04.pdf](http://ocfs.state.ny.us/main/sppd/health_services/manual/04_chp04_healthservice_s2_12_04.pdf) - maintaining medical records for children in foster care

**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.aap.org/saferhealthcare> - Any medical error is disturbing, especially in Pediatrics. Reports of such errors might leave you wondering what you can do to ensure a safe health care environment for your patients. The American Academy of Pediatrics has just launched a new Safer Health Care for Kids web site - for physicians, allied health professionals, administrators, parents, and caregivers, who are seeking pediatric patient safety information and strategies.

<http://www.suffolkmedicalhome.org/> - website of an established medical home

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

[http://www.commonwealthfund.org/publications/publications\\_show.htm?doc\\_id=470097](http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=470097) - How stable is Medicaid Coverage for children?

<http://www.cms.hhs.gov/apps/media/press/factsheet.asp?Counter=2243&intNumPerPage=10&checkDate=&checkKey=&srchType=1&numDays=3500&srchOpt=0&srcHData=&keywordType=All&chkNewsType=6&intPage=&showAll=&pYear=&year=&esc=&cboOrder=date> - Medicaid citizenship guidelines

**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.nysacra.org/content/view/417/1/> - OMRDD has updated the DRAFT Part 624 Regulation amendments that cover the Access to Records Law (Jonathan's Law). The July 18, 2007, revision has minor changes and is expected to change slightly again before being published as an Emergency Regulation sometime in August. However, it is NYSACRA's recommendation that Agencies follow these DRAFT Regulations until such time they are filed, and we will be sure to disseminate a new copy when that date comes. Of course, every Agency has been subject to

the new law as of May 5, 2007, and with a recent amendment, would now have to provide access to, but not notification of, the ability to retroactively go back to January 1, 2003, to obtain records of Allegations of Abuse. This look-back does not apply to the provision of other records under the law, which is still effective only on or after May 5, 2007.

<http://www.usdoj.gov/crt/ada/cguide.htm> - Guide to Disability Laws

#### **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://usfpeds.hsc.usf.edu/adolescent/pdf/Information\\_Guide.pdf](http://usfpeds.hsc.usf.edu/adolescent/pdf/Information_Guide.pdf) - successful health care transition to adulthood

[http://usfpeds.hsc.usf.edu/adolescent/pdf/Curriculum\\_Students\\_Guide2007.pdf](http://usfpeds.hsc.usf.edu/adolescent/pdf/Curriculum_Students_Guide2007.pdf) - Curriculum for Health Care Transition

#### **11. Other Links and Information**

<http://www.kidsgrowth.com/resources/articledetail.cfm?id=2168> - 10 Back to School Tips

[http://www.nasponline.org/resources/home\\_school/b2shandout.aspx](http://www.nasponline.org/resources/home_school/b2shandout.aspx) - Back-to-School Transitions: Tips for Parents

*Have you found valuable links that you would like to share?  
Please email them to Rosemary Randazzo, Parent to Parent of NYS  
Coordinator for Long Island at [rosemarylip2p@aol.com](mailto:rosemarylip2p@aol.com)*

*Janice Fitzgerald, Executive Director  
Parent to Parent of NYS  
P.O. Box 1296  
Tupper Lake, NY 12986  
[www.parenttoparentnys.org](http://www.parenttoparentnys.org)*