

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 52

May 1, 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.serve.org/nche/products_list.php#parent_brochure - This handy foldout booklet assists local homeless education liaisons and enrollment personnel in understanding the legal guidelines for the immediate school enrollment of children and youth experiencing homelessness. It explains the provisions of the McKinney-Vento Homeless Assistance Act related to enrollment and suggests strategies for implementing enrollment procedures that comply with federal law. Its compact size and foldout format make it a great desktop reference.

<http://www.headinjury.com/assertquiz.htm> - an assertiveness quiz, which provides tips on being assertive.

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.ins.state.ny.us/ogco2003/rg030113.htm> - Group Health Insurance, Coverage of Dependent Child and provides Section of the Law applicable.

<http://insurance.lawyers.com/Appealing-Health-Insurance-Denials.html> - tips on filing an appeal with your insurance carrier

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.concordspedpac.org/Section504.html> - explanation and examples of eligibility requirements for a 504 plan

<http://www.education.ky.gov/KDE/Instructional+Resources/Exceptional+Children/Section+504.htm> - frequently asked questions regarding 504 Plans

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.medicalnewstoday.com/medicalnews.php?newsid=64419&nfid=nl> - Uninsured Children Admitted To Hospitals Are Twice As Likely To Die As Insured Children, According To Families USA Study

<http://www.autismlink.com/> - Autism resources by State

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.hhs.gov/ocr/hospitalcommunication.html> - Good medical care depends upon effective communication between patients and providers. Ineffective communication can lead to improper diagnosis and delayed or improper medical treatment. Effective communication with persons who have limited English proficiency - as well as persons who are deaf or hard-of-hearing - often requires interpreters or other services. Many hospitals are actively taking steps to address these needs. However, hospitals face increasing challenges to meet the communication needs of an increasingly diverse population. At the same time, Federal agencies are addressing a significant number of complaints regarding the lack of effective communication in hospital settings.

<http://www.brightfuturesforfamilies.org/pdf/FamilyMattersWinter2007.pdf>-
Newsletter on keeping your home healthy and safe

- 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.clubmom.com/display/205242?fromPage=162269> - checklist to leave out for your babysitter

- 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?**

Parent to Parent offers:

<http://parenttoparentnys.org/onlinetrainingcenter.htm> -Parent-Professional Collaboration - Teaches the elements of family/professional collaboration and how to work as a partner with professionals in order to have your child's needs understood and met.

http://www.lifescrypt.com/channels/healthy_living/Health_Conditions/the_bureaucratic_doctor.asp?utm_campaign=2007-04-15&utm_source=healthy-advantage&utm_medium=email&utm_content=todays-headlines_the-bureaucratic-doctor - Building relationships with new doctors out of medical school.

http://www.lifescrypt.com/channels/healthy_living/Health_Conditions/5_patient_types_which_one_are_you.asp?utm_campaign=2007-04-22&utm_source=healthy-advantage&utm_medium=email&utm_content=todays-headlines_5-patient-types-which-o – The 5 types of patients. By determining which type you are could assist you in finding a doctor best suited to your type.

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

http://www.chcs.org/usr_doc/Physician_P4P_Guide.pdf. - GUIDE FOCUSES ON DESIGN AND DEVELOPMENT OF PAY-FOR-PERFORMANCE STRATEGIES IN STATE MEDICAID PROGRAMS - Physician Pay-for-

Performance in Medicaid: A Guide for States, offers lessons from a variety of pay-for-performance (P4P) programs to help states develop successful Medicaid P4P strategies at the physician level. The guide, published by the Center for Health Care Strategies with support from the Commonwealth Fund and the Robert Wood Johnson Foundation, is based on a 50-state survey to identify innovative practices in the reimbursement of high-quality health care in the public sector; interviews with Medicaid agency officials from across the country, representatives from the Centers for Medicare & Medicaid Services and other experts in health care financing; and a review of recent findings on various P4P initiatives in the public and private sectors. Ten financial models of physician rewards and six non-financial models that states can consider in the design of Medicaid physician P4P programs are presented. A description of selected state activities, a checklist of questions for purchasers, resources, and recommended clinical measures for physician performance are provided as appendices.

http://209.85.165.104/search?q=cache:QkIymSiffNoJ:www.health.state.ny.us/health_care/medicaid/reference/mrg/docs/crhmngts.pdf+nys+care+at+home+handbook&hl=en&ct=clnk&cd=1&gl=us - Medicaid Care at Home Manual

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.cmf.org/surveys/surveys_show.htm?doc_id=479133 - SCHIP is a joint federal–state program enacted in 1997 to cover children in families with too much income to qualify for Medicaid that could still not afford private insurance. The program is scheduled for reauthorization this year, presenting an opportunity to reflect on its successes and challenges. Our survey asked health care opinion leaders to rate the success of SCHIP both overall and with regard to specific objectives, such as improving coverage and health care for low-income children.

<http://www.healthaffairs.org/> - **The March-April 2007 issue of Health Affairs** is dedicated to children's health topics and, specifically, to the design of children's health care. The papers in the opening section of the thematic issue discuss why children count, how they are counted, and what is unique about children's health and well-being that requires accounting for them in new, evidence-based ways. Other contributions include a discussion

of the role of schools in preventing and treating illnesses; the reauthorization of the State Children's Health Insurance Program; and the case of Medicaid's Early and Periodic Screening, Diagnostic, and Treatment benefit.

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

<http://www.nslj.com/body.cfm?id=3732&oTopID=3732&PLinkID=2849> - "Your Next Patient Has Autism ..." is a trifold brochure developed for the many health professionals – nurses, physicians, technicians and others – who provide services for children on the autism spectrum. It is especially designed for those who only occasionally treat this population. Physical assessment, diagnostic imaging, and a variety of other interventions – both invasive and non-invasive – may induce fear and anxiety in people with autism. Their behavioral responses to such experiences often interfere with needed care and increase the risk of physical and/or psychological trauma. "Your Next Patient Has Autism ..." provides caregivers with a brief synopsis of autism together with specific recommendations for managing the special needs of these patients in the context of in-patient or out-patient healthcare.

<http://www.ianproject.org/> - an interactive website for opportunities to participate in research related to autism and organizes resources specific to autism. It looks like a joint effort by those at Autism Speaks and Kennedy Krieger Institute.

11. Other Links and Information

<http://www.cccnewyork.org/publications/SFY08AdoptedHighlights.pdf> - NY State adopted budget highlights!!

In honor of MOTHER'S DAY some sites for the mothers out there....

http://www.clubmom.com/channels/resource_center/archive.jsp?articleType=qtips&tagId=&catId=1403&mid=279370&fromPage=279370 - mothers of children with special needs message board

<http://www.cafemom.com/> - has numerous groups geared only for moms!

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***

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