

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 50

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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.

A special thanks to Rosemary Randazzo for preparing this 50th Links Digest as well the previous 49!

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

✓ Check out Parent to Parent of NYS' Advocacy Skills & Techniques On-Line Training at <http://www.parenttoparentnys.org/onlinetrainingcenter.htm>

Learn how to be an effective advocate for your child in the health care system, learn the steps necessary to advocate in person, on the phone, and in writing.

<http://www.psoriasis.org/advocacy/assistance/insurance/doctor.php> - advocating for yourself: working with your doctor

http://www.nfcacares.org/improving_caregiving/advocating_for_your_family.cfm - advocating for yourself and others

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://209.85.165.104/search?q=cache:HMhVmg97Br4J:www.healthinsuranceinfo.net/ny.pdf+continuation+of+health+insurance+for+disabled+dependents,+New+York+State&hl=en&ct=clnk&cd=12&gl=us> - Consumers guide to getting and keeping health insurance in New York State

<http://www.healthsymphony.com/> - a comprehensive health insurance web site.

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/about/offices/list/ocr/transition.html> - Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities

<http://www.altaread-austin.org/504.htm> - 504 Information for Parents

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.kaisernetwork.org/healthcast/alliance/26feb07> - **Reaching Out: Enrolling and Keeping Kids in the SCHIP Program**-Alliance For Health Reform and Robert Wood Johnson Foundation During this briefing on the State Children's Health Insurance Program (SCHIP), panelists discussed what is keeping about three-fourths of America's nine million uninsured children from enrolling and answer these questions and others: how successful have state outreach, enrollment and retention efforts proved to be? Is there evidence that SCHIP outreach, enrollment and retention initiatives have affected Medicaid?

<http://www.ins.state.ny.us/ogco2006/rg060401.htm> - Disabled Dependent's Entitlement to Conversion Benefits after Exhaustion of Continuation Rights When Dependent is Covered by Medicare

http://www.usatoday.com/news/nation/2007-03-08-kids-health-coverage_N.htm - kids face cutbacks in health insurance

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.nclد.org/images/stories/downloads/parent_center/rti_final.pdf - parents advocacy guide to response-to-intervention ("RTI")

<http://www.familycenteredcare.org/advance/sharingyourstory.pdf> - sharing your personal experiences in a group can be a powerful tool. This article offers tips on how to present your personal story so that it achieves the best and desired impact.

- 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://familydoctor.org/838.xml?printxml> - creating a family health journal

http://www.microsoft.com/mac/products/excel2004/using.aspx?pid=usingexcel2004&type=howto&article=/mac/LIBRARY/how_to_articles/officex/xl_athome.xml - keeping track of medical information 6 different ways in excel

- 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.lifescrypt.com/channels/healthy_living/Health_Conditions/doctor-patient_personality_types.asp?utm_campaign=2007-03-25&utm_source=healthy-advantage&utm_medium=email&utm_content=todays-headlines_are-you-and-your-doctor - Article on if you are compatible with your Doctor.

<http://www.cwla.org/voice/0603exceptional.htm> - article on how effective communication is the best medicine

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

<http://www.kff.org/medicaid/upload/Medicaid-A-Primer-pdf.pdf> - March, 2007 Medicaid Primer

http://www.nectac.org/~pdfs/idea/smithltr_medicaid_01-23-07.pdf - OSEP Policy Letter - Parental Consent Requirements Related to Accessing Medicaid, Other Public Benefits, or Insurance-Source: Office of Special Education Programs - January 23, 2007 One question raised since the IDEA 2004 regulations were released was about the parental consent requirements related to accessing public benefits or insurance. Specifically, the question was whether separate consent must be obtained from a parent each time access to Medicaid or other public benefits is sought to pay for required special or related services. An initial letter that addresses this issue was recently sent out by Alexa Posny, Director of the Office of Special Education Programs, US Department of Education.

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.healthinsurance.info/health-insurance-and-you/Your-Legal-Rights.HTM>
- your legal rights with respect to health insurance.

<http://www.hhs.gov/news/facts/privacy.html> - fact sheet on protecting the privacy of patient's health information

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

<http://ici.umn.edu/products/impact/193/> - Impact: Feature Issue on Supporting Success in School and Beyond for Students with Autism Spectrum Disorders

<http://projectforum.org/docs/StateApproachestoServingStudentswithAutismSpectrumDisorders.pdf> - State approaches to serving students with autism

11. **Other Links and Information**

http://www.associatedcontent.com/article/158458/how_to_effectively_communicate_with.html - How to effectively communicate with people who are hard of hearing

http://www.lifescrypt.com/channels/healthy_living/Health_Conditions/doctor-patient_personality_types.asp?utm_campaign=2007-03-25&utm_source=healthy-advantage&utm_medium=email&utm_content=todays-headlines_are-you-and-your-doctor - tips on getting children to swallow medicine

http://www.nphw.org/2007/pg_howprepared.htm National Public Health Week is 4/2-8/07 Take the first step – preparedness and public health threats.

*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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