

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 54

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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://add.about.com/od/parentingchildrenwith3/a/sue3.htm> - effective ways to communicate with your child's teacher

<http://www.php.com/> - PHP provides education and skills training, information, guidance, and peer support for families with the unexpected diagnosis of and ongoing impact of childhood disabilities, including but not limited to intellectual, learning or physical disabilities and 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://www.commonwealthfund.org/publications/publications_show.htm?doc_id=482678 - An International Update on the Comparative Performance of American Health Care

<http://www.healthsymphony.com/appealing.htm> - tips on appealing a claim denial

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.k8accesscenter.org/index.php> - Enhancing access to the general education curriculum for students with disabilities

<http://specialchildren.about.com/od/504s/f/504faq3.htm> - how to get a 504 plan for your child

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.kff.org/medicaid/childrenshealth_timeline.cfm?CFID=13207185&CFTOKEN=21587340 - New Interactive Tools from statehealthfacts.org and Kaiser Commission on Medicaid and the Uninsured. As Congress takes up the reauthorization of the State Children's Health Insurance Program (SCHIP), the Kaiser Family Foundation has prepared a diverse set of resources dedicated to children's health coverage including two new online tools.

<http://www.childhealthdata.org/content/Default.aspx> - The Data Resource Center for Child and Adolescent Health allows users to search and display charts and tabular findings from individual survey items as well as derived key child health measures.

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.disabled-world.com/artman/publish/conversation-skills.shtml> - how to improve your communication skills

<http://members.iinet.net.au/~scarffam/cpa.html> - When a child is diagnosed with cerebral palsy, the parents face many new emotional and physical demands. In the initial years they have to learn to cope with the special needs of their child. Parents also have special needs themselves, which require special understanding and support from family and friends.

- 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://specialchildren.about.com/od/specialeducation/a/contactlog.htm> -

One easy way to feel more organized is to set up a system for keeping track of the conversations you've had with case managers, teachers, therapists, specialists and administrators.

<http://personalinsure.about.com/od/health/a/aa122605a.htm> - Keeping a medical log of things such as conversations with your physicians, different procedures and surgeries performed, and prescription drugs prescribed is a way for you to be a pro-active participant in your HMO plan or other health insurance plan you participate in.

- 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.disabilitysolutions.org/newsletters/files/seven/7-1.pdf> -

Newsletter containing an article on page 4 on collaborating with professionals in a school setting to create a successful IEP.

<http://www.fathersnetwork.org/793.html?page=793&SESSION=2328f53fc101468849a3e5897233bf4c&s=0> - The Challenges, Triumphs, Frustrations, and Joys of Collaborating with Health Care Providers

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

http://www.emedny.org/ProviderManuals/NursingServices/PDFS/Private_Duty_Nursing_Policy.pdf - Medicaid Private Duty Nursing Manual – Policy Guidelines

<http://www.medicareconsumerguide.com/medicaid-eligibilitya.html> - Medicaid - What Do You Qualify For?

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.schoolhealthservicesny.com/laws_guidelines.cfm - School Health Services: Guidelines / Memos / Laws from Statewide School Health Services Center

http://pediatrics.about.com/cs/pediatrics101/a/hipaa_guide_2.htm - HIPPA guide for parents and patients

10. **Transitioning to adult health care, work and independence. Resources and self determination in health care**

http://www.ebulletin.us/archive/2007/may/05_07_bridge/05_07_take_control_your_ealth_well.php Taking Control of Your Health and Wellness: Taking Strides Toward A More Fulfilling Life. An article by Kerry Wiley, NYS DDPC and Jason Berner, Personal Trainer.

11. **Other Links and Information**

<http://www.fathersnetwork.org> - website for fathers raising children with special needs

<http://www.birthdefects.org/index.php> - fact sheets on a multitude of disabilities

*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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