

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 58

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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.kidsgrowth.com/resources/articledetail.cfm?id=1847> - developing a parenting plan

<http://www.spokaneparentcoalition.org/Publications/7StepstoEffectiveParentAdvocacy.pdf> - Seven tips on being an effective advocate for your child.

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.nytimes.com/2007/07/25/us/25health.html?_r=1&oref=slogin - GOP leaders fight expansion of children's health insurance

<http://www.nichd.nih.gov/funding/foa/> - Funding Opportunity Announcements

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.dol.gov/odep/pubs/fact/faith.htm> Demystifying the Rehabilitation Act. **How Section 504 of the Rehabilitation Act of 1973 applies to your not for profit organization as you serve people with disabilities.**

<http://www.ideapartnership.org/mission.cfm> - The IDEA Partnership is dedicated to improving outcomes for students and youth with disabilities by joining state agencies and stakeholders through shared work and learning.

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.aucd.org/template/index.cfm> = A network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities.

<http://www.nysacra.org/content/view/415/1/> - HEALTH CARE ENHANCEMENT INITIATIVE - OMRDD has been working for several years to improve recruitment and retention of direct care staff through the Employee Health Care Enhancement initiative

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.nasponline.org/resources/culturalcompetence/multicultural.aspx> - series of articles was published in recent editions of the *Communiqué*. The series features culture-focused papers

<http://www.thinkculturalhealth.org/> - With growing concerns about **racial and ethnic disparities in health** and the need for health care systems to accommodate **increasingly diverse patient populations**, cultural competence has become more and more a matter of national concern and attention.

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.kidsgrowth.com/resources/articledetail.cfm?id=1250> - **Health and Safety Precautions: A Back to School "Shopping List" for Parents**

<http://www.kidsgrowth.com/resources/articledetail.cfm?id=2259> -
Immunization Guide for Parents

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.commonwealthfund.org/funddigest/funddigest_show.htm?issue_id=3527&doc_id=507882&#doc50788 - How minorities with a medical home to better

http://www.nasponline.org/resources/home_school/ptconf.aspx - collaboration between home and school

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

<http://www.ncsl.org/programs/health/shn/2007/gs495.htm> - In an effort to restrain climbing Medicaid expenditures, a growing number of states are encouraging individuals to buy private long-term care insurance, according to a new [issue brief](#) from the [Alliance for Health Reform](#). Their tool: the Long-Term Care Partnership program that was initiated by [The Robert Wood Johnson Foundation](#) (RWJF) in 1987.

Using grants and technical assistance from the RWJF, California, Connecticut, Indiana and New York set up Partnership programs based on the RWJF model. That model allows individuals who buy a private policy and use up its benefits to apply for Medicaid and, if approved, to retain assets equal to the amount of money paid out by their long-term care policy.

http://www.health.state.ny.us/health_care/medicaid/program/update/2007/2007-07.htm - Medicaid Update: The official newsletter of the New York Medicaid Program

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?

www.dredf.org - Founded in 1979 by people with disabilities and parents of children with disabilities, the Disability Rights Education and Defense Fund, Inc. (DREDF) is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities

<http://www.elinfont.com/FMLAsum.php> - Family Medical Leave Act

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.pacer.org/tatra/RSA/page1.htm> - Helping Families Transition to the Future

http://www.nsttac.org/?FileName=what_works&type=1 -The *What Works Transition Research Synthesis Project* (Grant # H324W010005) was funded by the Office of Special Education Programs (OSEP) to review and synthesize the past 20 years of research and advancements in the area of transition for youth with disabilities.

11. Other Links and Information

<http://www.patientadvocate.org/pdf/pubs/tooyoung.pdf> - survival guide for parent of children with chronic illness

<http://www.handicappedfraud.org/index.php> - website on handicapped fraud

<http://www.ncptsd.va.gov/ncmain/information/> The PTSD Information Center contains in-depth information on Post Traumatic Stress Disorder and traumatic stress for a general audience, includes fact sheets

***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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