

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest - Volume 46

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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.

From shoe boxes and paper bags to organizing and developing a Health Care Notebook

Health care recordkeeping is the focus of the Health Care Notebook developed by Parent to Parent of NYS. With organized records compiled, as years pass, parents will have an accurate compilation of their child's health care records.

A mini-training is available for any parent in NYS who would like to learn about using the Health Care Notebook. The training includes materials to begin organizing records and developing a Health Care Notebook.

For information on the training or the Health Care Notebook, contact Rosemary Randazzo, Family to Family Coordinator at Parent to Parent's Long Island office. 800-559-1729 or 631-434-6196.

Additionally, the Health Care Notebook is downloadable in English and Spanish from Parent to Parent's website

<http://www.parenttoparentnys.org/Family2Family/Record%20Keeping/notebook.htm>

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

<http://www.aboutkidshealth.ca/clinicalAreas.asp?pageContent=EP-nh4-06d> - advocating for your child in the school setting.

<http://ghr.nlm.nih.gov/> - genetics home reference page – parent's guide to understanding genetic conditions

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.truthout.org/docs_2006/printer_012207E.shtml - article on medical debt

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.osepideasthatwork.org/toolkit/index.asp> - tool kit on assessing and teaching students with disabilities.

http://www.tsa-usa.org/educ_advoc/ed_advocacy_q_and_a.htm#whydoes - questions from parents and advocates asking for help with specific school situations on this site

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?**

www.Stateline.org: State of the States 2007 Full of maps, charts and graphics, this annual guide offers an overview of the major developments across the country -- including: families receiving welfare (p. 28-9), how states measure up on student and school performance tests (p. 34), how many states have minimum wages above the federal \$5.15 mark (p.38), health care coverage, a "facebook" of new legislators and Governors, and more

www.osepideasthatwork.org/index.asp
(<http://rs6.net/tn.jsp?t=hwjj48bab.0.6uwea7bab.6g8xrkbab.1108&ts=S0226&p=htp%3A%2F%2Fwww.osepideasthatwork.org%2Findex.asp>), - article on prior authorization with respect to insurance matters

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://specialchildren.about.com/od/behaviorissues/ht/behaviorchart.htm> - how to make behavioral charts work

<http://www.foodallergy.org/questions.html> - frequently asked questions regarding food allergies

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.ed.gov/policy/gen/guid/fpco/ferpa/index.html> - The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records.

<http://www.nclد.org/content/view/1073/> - getting organized and ready for your child's IEP Meeting

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.findarticles.com/p/articles/mi_m0816/is_3_18/ai_53985603 - communicating with your child's doctor.

<http://www.parenttoparentofga.org/Fall0412.htm> - things to remember when you are advocating for your child so that you are effective

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

<http://www.kff.org/medicaid/upload/7491.pdf> - Medicaid and the Uninsured – issues for young adults with disabilities

<http://aspe.hhs.gov/medicaid/122906rpt.pdf> - In May 2005 the Secretary of the Department of Health and Human Services, Michael O. Leavitt, established a Medicaid Commission to advise the Secretary on ways to modernize the Medicaid program so that it can provide high-quality health care to its beneficiaries in a financially sustainable way. On December 29, 2006 the Commission issued its final report.

http://www.cms.hhs.gov/MLNProducts/downloads/Relationship_Brochure.pdf - a brochure on the Medicaid – Medicare relationship

- 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.healthlaw.org/library.cfm?fa=detailItem&fromFa=detail&id=127776&folderID=97576&appView=folder&r=id%7E%7E97576,fa%7E%7Edetail,appview%7E%7Efolder,rootfolder%7E%7E23177> - Medicaid article for new attorneys

<http://www.whitehouse.gov/news/releases/2006/12/20061219-3.html>. - **On December 19, 2006, President Bush signed the Combating Autism Act of 2006 (S. 843).** This Act authorizes expanded activities related to autism research, prevention, and treatment through FY 2011. There are more than 1.5 million cases of autism in the United States. For more about the law is available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d109:SN00843:@@L&summ2=m&>

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

<http://www.autismspeaks.org/howtoCOPE/strategies.php> - how to cope with a diagnosis of autism.

<http://www.projectforum.org/docs/StateApproachestoServingStudentswithAutismSpectrumDisorders.pdf> - **State Approaches to Serving Students with Autism Spectrum Disorders** Source: Project Forum - December 31, 2006 This In-Brief Policy Analysis clarifies terminology and reports findings gathered from a survey of state special education staff. Findings are reported in the following areas: state-level staff time and responsibilities; specific services for Part C eligible children; specific services for students with Asperger Syndrome; types of professional development activities offered; taskforce roles; how states measure outcomes; barriers to providing services to this population; and more. The most mentioned barrier to serving this growing population was the lack of educational professionals with ASD expertise.

- 11. Other Links and Information**

<http://aaid.allenpress.com/aamronline/?request=index-html>. - GET FREE ACCESS TO YEAR 2005 ISSUES OF TWO TOP JOURNALS IN SPECIAL EDUCATION AND REHABILITATION! All issues of the *American Journal on Mental Retardation and Intellectual and Developmental Disabilities* (Formerly *Mental Retardation*) published in the year 2005 are now available for free online at Click on the "Archived Issues" link on

the left to access all the issues published in 2005. The AJMR and IDD are top journals in special education and rehabilitation and are published by the American Association on Intellectual and Developmental Disabilities (formerly AAMR).

<http://www.bazelon.org/publications/movingon/> - Federal Programs to Assist Transition-Age Youth with Serious Mental Health Conditions

***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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