

**Parent to Parent of NYS**

***New York's Family to Family***

***Health Care Information and Education Center***

***Links Digest - Volume 51***

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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.geneticalliance.org/ws\\_display.asp?filter=interactive.guide](http://www.geneticalliance.org/ws_display.asp?filter=interactive.guide) - Through sections and stories, this site will help you understand what you need to do to found and build your advocacy group. In sections, they describe the issues, skills, and elements of advocacy groups and their activities.

<http://www.aginginstride.org/supportcenter/forms/aisform11.pdf> - checklist for choosing a home health agency

**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://familydoctor.org/887.xml?printxml> - Tips on prescription financial assistance

<http://familydoctor.org/887.xml> - Resources for Affordable Prescription Medicine

**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.experiencejournal.com/ibd/family\\_school.shtml#a](http://www.experiencejournal.com/ibd/family_school.shtml#a) - A personal account by a parent of their child's 504 Plan

**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.nphw.org](http://www.nphw.org) – has a wealth of varied information for kids and families, providers and policymakers. Use it as is or add other information you're aware of from your own state or especially for children and youth with special health care needs.

**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.rtc.umn.edu/ildspworkforce/docs/ToolkitforFamilies.pdf> - a toolkit for parents looking for quality, caring and committed direct workers

<http://www.nichcy.org/pubs/newsdig/nd20.pdf> - article written for parents just entering into the world of having a child with special needs

**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.lotsahelpinghands.com/> - free, web-based organizational tool for assigning and coordinating tasks such as rides to appointments, grocery shopping, preparing meals, or helping with childcare when you are going through a tough time and can't manage everything on your own.

<http://www.aginginstride.org/supportcenter/forms/aisform6a.pdf> - home safety checklist record

**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?**

✓ Check out *Parent to Parent of NYS Parent-Professional Collaboration On-line training* at <http://www.parenttoparentnys.org/onlinetrainingcenter.htm> - 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://unlforfamilies.unl.edu/Communication/Family/PosCommLrnHome.htm> - building strong communication skills within the family unit

[http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=472804&#doc472804](http://www.cmwf.org/publications/publications_show.htm?doc_id=472804&#doc472804) - In a [Commonwealth Fund-supported study](#) in the *International Journal for Quality in Health Care*, researchers with the Joint Commission (formerly JCAHO) found that LEP hospital patients are more likely than their English-speaking counterparts to experience adverse events that result in harm--and the severity of that harm is often greater.

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

<http://www.rockinst.org/> According to a report by the Rockefeller Institute of Government, while Medicaid spending-per-capita for many states fell last year, the reason was largely a one-shot: a reduction in prescription drug spending because of the Medicare Part D benefit. The finding comes in a report which goes on to warn that Medicaid enrollment - and, consequently, spending - will likely rise as the economy slows and states move to expand health coverage through the program.

<http://www.cqcapd.state.ny.us/newsletter/issue91/gooddaybadday.htm> - One of the tools used by the Western New York Care Coordination Program (WNYCCP) to assist individuals recovering from mental illness to clarify what is important to them – an important first step in developing a plan that is centered on an individual's strengths, aspirations and needs.

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.ny.gov/governor/press/0401074.html> - Enacted Budget Expands Coverage and Makes Investments in Public Health While Cutting Costs

<http://research.lawyers.com/Lawyers-and-Clients-Responsibilities-to-Each-Other.html> - what is your lawyers professional obligations.

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

[http://www.autism-society.org/site/News2?page=NewsArticle&id=9331&news\\_iv\\_ctrl=-1](http://www.autism-society.org/site/News2?page=NewsArticle&id=9331&news_iv_ctrl=-1) - April is **National Autism Awareness Month (NAAM)**, an awareness initiative established in 1972 which includes hundreds of community-based events around the country.

<http://autism.about.com/> - Beginners Autism Guide

11. **Other Links and Information**

[http://news.yahoo.com/s/hsn/20070403/hl\\_hsn/ushospitalerrorscontinuetorise:\\_ylt=ApUJAcGKnRYeF.a8RN3OM30DW7oF](http://news.yahoo.com/s/hsn/20070403/hl_hsn/ushospitalerrorscontinuetorise:_ylt=ApUJAcGKnRYeF.a8RN3OM30DW7oF) - U.S. Hospitals errors continue to rise

[http://www.omr.state.ny.us/hp\\_dentistry\\_locations.jsp](http://www.omr.state.ny.us/hp_dentistry_locations.jsp) - OMRDD recommended Dentistry locations throughout NYS

*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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