

## **Parent to Parent of NYS**

*New York's Family to Family*

*Health Care Information and Education Center*

*Links Digest - Volume 55*

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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.

### **Happy Father's Day**

*Being a parent brings out a person's humanity and fathers play an immense role in who we are. They shape our values, our perception of the world and of who we are. Most of us can also identify other father figures who played a role in forming our character. It's never too late to say "Thank You" to those special people in our lives...pick up the phone, stop by for a visit, or send a note. Thank you and Happy Father's Day to all fathers and especially to those who are positive role models and advocates for individuals with special needs.*

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

<http://www.familycenteredcare.org/advance/sharingyourstory.pdf> - tips on sharing personal stories as a tool to promote changes in service systems

<http://members.iinet.net.au/~scarffam/cpa.html> - informational booklet for families and friends of a child with special needs (i.e. Cerebral Palsy)

**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://incenterstrategies.org/jan07/factsheet4.pdf> - public health insurance for older adolescents

[http://www.accessproject.org/adobe/the\\_illusion\\_of\\_coverage.pdf](http://www.accessproject.org/adobe/the_illusion_of_coverage.pdf) - A new report, *The Illusion of Coverage: How Health Insurance Fails People When They Get Sick*, recounts the personal, emotional, and physical hardships of the millions of hard-working, insured Americans who are struggling with 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.ed.gov/about/offices/list/ocr/complaintintro.html> - electronic complaint form for violation of civil rights (which 504 Plan falls under)

<http://www.ode.state.or.us/groups/supportstaff/hklb/schoolnurses/diabetes.pdf> - sample 504 plan for child with diabetes and needs that school has to meet

**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.medicarerights.org/maincontentthebasicstoc.html> - Medicare and HMO's

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

**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://child.uscuedd.org/ProductsResources/KeepingOurChildrenSafe/tabid/652/Default.aspx> - This 5-part parent information sheet series provides essential information on identification, reporting, and prevention of abuse and neglect. Developing skills to keep you guide safe from abuse

<http://www.guideline.gov/resources/glossary.aspx> - glossary of medical terms

**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://medicalhomeinfo.org/tools/youthguides.html> - guide to keeping a portable medical summary

<http://internet.dscu.uic.edu/forms/psu/4202.pdf> - health care checklist

**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.newsday.com/news/health/ny-hscov5242352jun05\\_0\\_2784855\\_print.story?coll=ny-health-print](http://www.newsday.com/news/health/ny-hscov5242352jun05_0_2784855_print.story?coll=ny-health-print) - teaching residents “empathy”

[http://www.familycenteredcare.org/advance/IFFCC\\_checklist.pdf](http://www.familycenteredcare.org/advance/IFFCC_checklist.pdf)- patients and families as advisors: a checklist

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

[http://www.aarp.org/research/housing-mobility/homecare/fs128\\_cons\\_dir.html](http://www.aarp.org/research/housing-mobility/homecare/fs128_cons_dir.html) - Consumer-Directed Home and Community-Based Services

<http://www.partoparvt.org/Fcc.html> - definition and principles of family centered care

**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://capwiz.com/familyvoices/issues/alert/?alertid=9368421&PROCESS=Take+Action> - SCHIP reauthorization

<http://www.cnn.com/2007/LAW/05/21/scotus.specialed/index.html> - Court: Parents don't need lawyer to sue school

**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://sickle.bwh.harvard.edu/transition.HTML> - transitioning shown with children with Sickle Cell Disease

<http://www.ncset.org/publications/mfmp.asp> - A Transition Planning Resource for Life After High School

## **11. Other Links and Information**

[http://www.newsday.com/news/health/ny-hscov5242352jun05\\_0\\_2784855\\_print.story?coll=ny-health-print](http://www.newsday.com/news/health/ny-hscov5242352jun05_0_2784855_print.story?coll=ny-health-print) - breaking the silence on mental illness

[http://www.fns.usda.gov/cnd/Guidance/Special\\_Dietary\\_Needs.pdf](http://www.fns.usda.gov/cnd/Guidance/Special_Dietary_Needs.pdf) - guidance for accommodating children with special needs in the school nutritional program

<http://www.op.nysed.gov/opsearches.htm> -NYS Professions: Online Verifications. This link is a place where you can go to check a doctor, nurse, accountant, dentist, social worker, veterinarian, etc., license and if there are any past issues with them. It does not have any of the "pending" claims as they will not have been proven as of yet, but past ones that were proven are listed.

***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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