

Parent to Parent of NYS

New York's Family to Family

Health Care Information and Education Center

Links Digest- Volume 68 January 1, 2008

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 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)**

From feeling like a victim to being an effective advocate:

<http://www.wrightslaw.com/info/advo.susan.success.htm>

Advocating Through Letter Writing – a guide for parents regarding written communication. Letters....we get stacks and stacks of letters.

<http://parenttoparentnys.org/Family2Family/Advocacy/advocatingletter.htm>

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)**

Future planning for special medical needs:

http://wash.k12.mi.us/perform/Documents/Planning_Medical.pdf

Do you know about "Healthy New York"? It's for individuals and families too! The Healthy NY program is designed to assist small business owners in providing their employees with health insurance, however, uninsured sole proprietors and workers whose employers do not provide health insurance may also purchase comprehensive coverage directly through the Healthy NY program at a lower cost than a direct/private plan.

<http://www.ins.state.ny.us/website2/hny/english/hny.htm>

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)**

My Child with a 504 Plan is Failing, School Won't Help

<http://www.wrightslaw.com/info/sec504.idea.eligibility.htm>

Section 504 Fact Sheet - a quick guide to understanding Section 504 Civil Rights Legislation available in English and Spanish

<http://parenttoparentnys.org/Family2Family/Fact%20Sheets/section504.html>

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?

Access to records in NYS. A Guide for Individuals Receiving Services and Other "Qualified Persons"

<http://www.cgc.state.ny.us/Brochures/Access-to-MH-Records.htm>

Is your child's physician/other provider "family friendly"?

Family friendly is a term that applies to how and to what extent organizations involve, welcome, and value the participation of family members in every aspect of the organization

The checklist for families can be found at:

<http://olrs.ohio.gov/Other/checklistfamily.pdf>

Confused by complex health care terminology? Plain language in health care: philosophy and glossary:

<http://www.plainlanguage.gov/>

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?)

"Group Parent Power"-- see how it can work:

http://wash.k12.mi.us/perform/Documents/Use_Group_Parent_Power.pdf

A comprehensive "how to" publication from NICHCY on accessing parent support groups:

<http://www.nichcy.org/pubs/parent/pa10txt.htm>

Coping strategies for family stress:

<http://www.fcs.msue.msu.edu/ff/pdffiles/familystress3.pdf>

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.

An article giving additional perspective on the significance of record keeping:

http://www.iancommunity.org/cs/articles/the_importance_of_record_keeping

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?

Remember that problem-solving in a collaborative venture will best achieve our common goal - that of becoming a positive driving force toward family-centered, community-based care.

http://wash.k12.mi.us/perform/Documents/PARENT_PROFESSIONAL_COLLABORATION.pdf

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

Did you know that parents and caregivers can take OMRDD trainings to gain an understanding of waiver services and how they should work? The trainings are available throughout NYS at no cost. See the catalogue, here:

<http://www.omr.state.ny.us/wp/index.jsp>

with a link to the next waiver training, here:

http://www.omr.state.ny.us/wp/wp_catalogp1014.jsp

(If this location is not convenient, call for other opportunities.)

What is family-centered care when it comes to pediatric health services? Read a comprehensive discussion here:

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;112/3/691>

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?

What to do when your request to your insurance company for a specific treatment is denied; grievance and more:

http://www.ins.state.ny.us/website1/inshelp/c_denial.htm

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).

Check out this neat "Adolescent Autonomy Checklist" to assess progress for your transitioning child's health care and life skills:

http://www.spannj.org/Family2Family/adolescent_autonomy_checklist.htm

11. Other Links and Information

Understanding the concerns of siblings of children with special needs:

<http://www.archrespice.org/archfs23.htm>

The Family Medical Leave Act: protections for parents of children with medical issues:

<http://www.wrightslaw.com/advoc/articles/fmla.protect.spolter.htm>

*Have you found valuable links that you would like to share?
Please send them to Lisa Terenzio at lisasdesk@verizon.net
Phone: 1-631-434-6196 or 1-800-559-1729*

✓ our website at www.parenttoparentnys.org

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