

## **Parent to Parent of NYS**

*New York's Family to Family*

*Health Care Information and Education Center*

*Links Digest- Volume 95 April 1, 2010*

**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.**

### **Healthy Transitions: Transitioning from Pediatric to Adult Health Care & Services**

Health is the foundation for all that we do. Planning for the transition from pediatric to adult health care and considering the impact health will have on adult services is essential. This workshop provides an introduction to the knowledge, skills and tools necessary to promote a successful transition; allows for the sharing of experience through a panel of parents who have navigated transition planning; and promotes self-advocacy and collaboration between youth, families, service providers, the medical community and school systems. The Healthy Transitions website, a tool for transition planning, will be introduced.

#### **Saturday, April 17, 2010**

9:00 am – 1:30 pm

St. Mary's Hospital for Children  
Bayside, NY

#### **Wednesday, May 5, 2010**

6:00 pm – 8:30 pm

The Resource Center  
Jamestown, NY

#### **Sponsored by:**

Parent to Parent of NYS and the NYS Institute for Health Transition Training

#### **Contact:**

Michele Juda at (800) 305-8817 for more information or to register (mandatory)

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

Parent to Parent of NYS was recently named the State Affiliate Organization for Family Voices. Family Voices offers this guide to being a health advocate for your child with special health care needs:

<http://www.medicalhomeinfo.org/training/materials/April2004Curriculum/Advocacy/Advocacy%20Appendices/App%20B%20-%20families%20as%20advocates.pdf>

Family Voices has recently created a voluntary membership program. Membership in Family Voices is **NOT** necessary to access the services of Parent to Parent of NYS, nor many of the services at Family Voices ([www.familyvoices.org](http://www.familyvoices.org)). If you are interested in an individual or organizational membership in Family Voices, more information regarding the costs and benefits can be found at the link below. A portion of your membership dollar will benefit Parent to Parent of NYS:  
<http://www.familyvoices.org/FVMembershipForm%20FINAL3.4.10.pdf>

## **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)**

The Catalyst Center has released a summary of the strong provisions which will benefit consumers contained within the *Patient Protection and Affordable Care Act*, signed into law on March 23, 2010, and its companion legislation the *Health Care and Education Reconciliation Act of 2010*:

[http://www.communitycatalyst.org/doc\\_store/publications/Health\\_Reform\\_Will\\_Secure\\_Coverage\\_and\\_Improve\\_Quality\\_of\\_Care\\_3.23.10.pdf](http://www.communitycatalyst.org/doc_store/publications/Health_Reform_Will_Secure_Coverage_and_Improve_Quality_of_Care_3.23.10.pdf)

“Consumers Guide to Health Reform” is a user-friendly Question and Answer article from Kaiser Health News regarding both the benefits and taxes included in the recently enacted health care reform law:

<http://www.kaiserhealthnews.org/Stories/2010/March/22/consumers-guide-health-reform.aspx>

## **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)**

This guide offers answers to frequently asked questions about 504 plans for students with disabilities:

<http://specialchildren.about.com/od/504s/qt/504faq.htm>

This guide is more specific providing examples of possible accommodations for 5 specific disabilities (asthma, attention deficit/hyperactivity disorder, bipolar disorder, emotional disturbance, and epilepsy):

<http://specialchildren.about.com/od/504s/a/504accom.htm>

## **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?**

Written with input from families who have sought mental health services for their children, the Family Guide to Systems of Care for Children with Mental Health Needs explains what parents should know, what they should ask, what to expect, and what to do. Available in both English and Spanish:

<http://mentalhealth.samhsa.gov/publications/allpubs/Ca-0029/default.asp>

Complex Child provides this guide to Federal and State assistance programs for children with special needs:

<http://articles.complexchild.com/May2009/00123.html>

**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?)**

South Carolina has published a Resource Guide for Fathers. There are many references to South Carolina-specific programs in the financial section, but pages 4 through 10 are a wonderful primer on the impact of a child's diagnosis on the relationship between couples and within the family at large:

[http://www.familyconnectionsc.org/public/files/docs/Fathers\\_Resource\\_Guide\\_2009\\_6.1\\_Final.pdf](http://www.familyconnectionsc.org/public/files/docs/Fathers_Resource_Guide_2009_6.1_Final.pdf)

When a family is facing a medical crisis or chronic illness, community members often ask "what can I do to help?" Lotsa Helping Hands offers a free, online database for coordinating these volunteer efforts. A Coordinator, usually a close family member or friend, manages the site by adding volunteers as members and posting tasks the family could use assistance with:

<http://www.lotsahelpinghands.com/caregiving/home/>

**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.**

This article provides a good overview of keeping a personal health record, identifying information that should be kept on hand at all times and what should be filed at home:

[http://www.health.com/health/library/topic/0,,tstrc\\_tp17627,00.html](http://www.health.com/health/library/topic/0,,tstrc_tp17627,00.html)

Parent to Parent of NYS has developed a Health Care Notebook which serves as the backbone of developing a comprehensive health care record, including day-to-day care routines. The notebook, available in both English and Spanish, can be found here:

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

The Youth Advisory Committee at the NYS Department of Health developed this portable health record which is perfect for carrying the basic health information that would be necessary in an emergency:

<http://www.health.state.ny.us/publications/0972.pdf>

**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 provider 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?**

Confused about what a medical home is? This video from the National Center for Medical Home Implementation features interviews with physicians and families discussing the elements that promote a family-centered medical home:

<http://www.medicalhomeinfo.org/about/ChildHealthDay2009.html#Video>

The Institute on Community Integration and the Research and Training Center on Community Living offers this collection of resources on partnering to achieve quality, inclusive early childhood education:

<http://ici.umn.edu/products/impact/221/221.pdf>

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

The 2005-2006 National Survey of Children with Special Health Care Needs provides information on how NYS compares to the nation in providing family-centered, community-based, coordinated care and facilitating the development of community-based systems of services for such children and their families:

<http://mchb.hrsa.gov/cshcn05/SD/newyork.htm>

The American Academy of Pediatrics released the following articles in December of 2009 in response to the survey results:

[http://pediatrics.aappublications.org/content/vol124/Supplement\\_4/](http://pediatrics.aappublications.org/content/vol124/Supplement_4/)

**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?**

The Family Health Care Decisions Act was signed into law on March 16, 2010. It does not apply to individuals who have developmental disabilities or who reside in mental health facilities if decisions for these individuals can be made under other laws or regulations, such as the Health Care Decision Act for persons with developmental disabilities. An advisory committee will be convened to determine if decision making for these individuals should be incorporated into the Family Health Care Decisions Act:

<http://www.state.ny.us/governor/press/031610FHCD.html>

Information regarding the previously enacted Health Care Decision Act for Persons with Mental Retardation signed in September of 2002:

[http://www.omr.state.ny.us/wt/wt\\_health\\_care.jsp](http://www.omr.state.ny.us/wt/wt_health_care.jsp)

## **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).**

A successful transition to adult health care is a building block for being able to work. Choose Work is a comprehensive website sponsored by the Social Security Administration to explain the Ticket to Work program for those eligible for or receiving cash benefits under the Social Security Disability Insurance (SSDI) program and/or the Supplemental Security Income (SSI) program based on disability or blindness:

<http://www.choosework.net/>

The PACER Center offers this guide to understanding school-based transition planning and provides tips on how to prepare a student for transitioning from school to further education, employment and independent living. Note that in NYS, a transition plan must be in place on the IEP that will be in effect when the student turns 15 years old (not 16 as mentioned in the article):

<http://www.pacer.org/publications/pdfs/ALL14.pdf>

## **11. Fathers – from Jim Swart, Fathers Network Coordinator**

Autism and the Latino Population. How does culture dictate how a family reacts to a child with a disability? Where do underserved populations go to learn about the condition of autism? Here is a story about parents who took matters into their own hands:

<http://www.bridges4kids.org/articles/2002/7-02/LATimes7-7-02.html>

Proyecto Vision (Project Vision), a bilingual website for Latino youth with disabilities, seeks to connect youth to educational and employment opportunities. This link highlights their "Success Stories" page:

<http://www.proyectovision.net/english/success/index.html>

## **12. Other Links:**

The National Institute of Dental and Craniofacial Research offers this guide to helping your family member with a disability have good oral health, including examples of low-tech assistive technology for holding toothbrushes:

<http://www.nidcr.nih.gov/NR/rdonlyres/6BE70179-F1F8-4EB2-A561-175F8D42F927/0/DentalCaregiverGuide.pdf>

To find an oral health provider in NYS who accepts Medicaid or a particular managed public health benefit search this database courtesy of Insure Kids Now: [http://www.insurekidsnow.gov/state/newyork/newyork\\_oral.html](http://www.insurekidsnow.gov/state/newyork/newyork_oral.html)

- *Have you found valuable links that you would like to share? Please send them to Michele Juda at [f2fhealthtools@verizon.net](mailto:f2fhealthtools@verizon.net) 1-800-305-8817*
  - *If you would like to speak to someone regarding your child with special health care needs, contact Michele at the above-referenced number.*
  - *Would you like to speak to Jim Swart, Regional Coordinator supporting our Fathers' Network? Call 1-800-305-8817 or email [jmswart1@verizon.net](mailto:jmswart1@verizon.net)*
- √ our website at [www.parenttoparentnys.org](http://www.parenttoparentnys.org)

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