

## **Parent to Parent of NYS**

*New York's Family to Family*

*Health Care Information and Education Center*

*Links Digest- Volume 81      February 1, 2009*

**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)**

The Commonwealth Fund has launched a website that allows professionals, providers, and researchers to compare hospitals on a variety of standard measures and share “Best Practice” experiences. Although the site is geared towards professionals seeking to improve hospital care and outcomes, parents may find it useful as a means to develop informed questions for their providers:

<http://www.whynotthebest.org/>

NY Connects, a joint effort of the New York State Office for the Aging and the Department of Health “provides locally accessible, consumer-centered access points that provide comprehensive information about long term care options and linkages to services for individuals of all ages with long term care needs.” Learn more about it here:

<http://www.nyconnects.org/NYConnectsProgramOverview.shtml>

### **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)**

Information on income tax strategies for parents of child with special needs:

<http://www.tacanow.org/resources/tax-strategies/tax-strategies-for-parents-of-special-needs-children.htm>

The following link provides information on the 3 most important areas of financial planning for a child with special needs:

<http://financialplan.about.com/od/planningforlifestages/a/SpecialNeeds.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)**

This site provides a list of resources for obtaining texts in alternate formats for those with print disabilities:

[http://nimas.cast.org/about/resources/alternate\\_formats](http://nimas.cast.org/about/resources/alternate_formats)

When your child has a chronic health condition the school needs specific information about the care your child will need. The following information describes what should be in a written document for your child during school:

[http://www.aap.org/publiced/BR\\_Chronic\\_School.htm](http://www.aap.org/publiced/BR_Chronic_School.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?**

This article explains when adults age 18-64 would be eligible for Medicare benefits:

<http://www.cahealthadvocates.org/disabilities/overview.html>

Originally published in Exceptional Parent, this article discusses four tips for obtaining Federal Disability Benefits for your child:

[http://findarticles.com/p/articles/mi\\_go2827/is\\_/ai\\_n29345005](http://findarticles.com/p/articles/mi_go2827/is_/ai_n29345005)

**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?)**

The Child Welfare Information Gateway has made a selection of publications available in Spanish. The resources listed under the Supporting & Preserving Families tab may be of particular interest:

<http://www.childwelfare.gov/spanish/>

“What a Difference a Friend Makes” is a brochure from the Substance Abuse & Mental Health Services Administration that describes how to support those who are living with mental illness. View it in English here:

[http://whatadifference.samhsa.gov/docs/NASC\\_English\\_web\\_508.pdf](http://whatadifference.samhsa.gov/docs/NASC_English_web_508.pdf)

and Spanish here:

[http://whatadifference.samhsa.gov/docs/NASC\\_Spanish\\_web.pdf](http://whatadifference.samhsa.gov/docs/NASC_Spanish_web.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.**

In this article from Today's Caregiver, Beth Christiansen tells how a health care notebook literally helped to keep her sane. She offers great tips, including the addition of both "to do" lists and wish lists to the notebook. Her story can be found here:

[http://www.caregiver.com/channels/stories/articles/three\\_ringed\\_binder.htm](http://www.caregiver.com/channels/stories/articles/three_ringed_binder.htm)

A guide to your Medical Record Rights in New York State:

<http://ihcrp.georgetown.edu/privacy/stateguides/ny/nyguide.html>

**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?**

The following link has an information sheet that provides reasons why a doctor's visit can be difficult for a person with an Autism Spectrum Disorder and suggests strategies that can be used to help improve the situation:

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1064&a=11440>

Written by an educator of the deaf and hard of hearing, "Five Reasons Why Professionals Need to Listen to Parents" provides insight for all:

[http://www.handsandvoices.org/articles/parent\\_pro\\_collab/V10-2\\_fivereasons.htm](http://www.handsandvoices.org/articles/parent_pro_collab/V10-2_fivereasons.htm)

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

Center for Disability Rights Position Paper: Make Consumer Directed Models the First Choice for Long-term Care

<http://rochestercdr.org/wordpress/?p=88>

Contact info for all NYS Medicaid Waivers:

[http://www.pascenter.org/state\\_based\\_stats/medicaid\\_waivers\\_info.php?state=newyork](http://www.pascenter.org/state_based_stats/medicaid_waivers_info.php?state=newyork)

**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?**

Are Child Care Centers subject to ADA regulations? Find out here:  
<http://www.ada.gov/childq&a.htm>

The following two links provide information about children with special needs being targeted for bullying including who is likely to be targeted, the effect it has on a child with special needs and consideration of legal issues involved:  
[http://stopbullyingnow.hrsa.gov/HHS\\_PSA/pdfs/SBN\\_Tip\\_24.pdf](http://stopbullyingnow.hrsa.gov/HHS_PSA/pdfs/SBN_Tip_24.pdf)

and

<http://njbullying.org/documents/BULLYINGANDSTUDENTSWITHSPECIALNEEDS.doc>

### **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).**

When is a pediatric patient is no longer a pediatric patient? This article provides answers; a free registration is required:  
<http://medgenmed.medscape.com/viewarticle/578513>

Transition considerations for adolescents and young adults who have diabetes:  
[http://www.ndep.nih.gov/resources/schoolnursenews/SNN\\_January\\_2008.htm](http://www.ndep.nih.gov/resources/schoolnursenews/SNN_January_2008.htm)

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

John C. McGinley, who portrays Dr. Cox on the TV series Scrubs, is the father of Max, an eleven year old with Down syndrome. Exceptional Parent magazine conducted an interview with Mr. McGinley in their December 2008 issue where he spoke about the reaction to learning his son had Down syndrome, advice he would give new parents and his thoughts on the portrayal of individuals with a disability in television and films. Here is the link to the interview; a free registration is required:  
[http://www.eparent.com/main\\_channels\\_family\\_community/His\\_Best\\_Role\\_Yet\\_John\\_C\\_McGinley.asp](http://www.eparent.com/main_channels_family_community/His_Best_Role_Yet_John_C_McGinley.asp)

Fathers often imagine their son being very athletic and exceeding on the field but when a disability is part of the equation what is a father to do? The link below shares the story of an athletic dad and his son who has been diagnosed with catastrophic epilepsy. It is their story of enjoying the sport of running together.  
<http://www.fathersnetwork.org/1079.html>

### **12. Other Links:**

This recent NY Times article discusses the concept of “medical home” and describes a program that is working effectively to meet the needs of Medicaid-eligible children with special health care needs in North Carolina:  
[http://www.nytimes.com/2009/01/23/health/22chen.html?\\_r=2](http://www.nytimes.com/2009/01/23/health/22chen.html?_r=2)

- *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*
  - *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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