



New York's Family to Family

Health Care Information and Education Center

Fostering Family Leadership and Family Professional Partnerships

NYS Affiliate Organization of Family Voices

Links Digest- Volume 144

November 2016

As part of the Family to Family Health Care Information 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 for others.

“Open Enrollment” is the annual period when individuals and families can enroll in health insurance plans under the Affordable Care Act also known as “Obamacare”. The market is open now through January, 31 2017 to purchase and make changes for 2017 plans. In order for coverage to be effective January 1st, enrollment must be completed by December 15th.

Here are some important dates to note:

- December 15, 2016: Last day to enroll in or change plans for coverage to start January 1, 2017
- January 1, 2017: 2017 coverage starts for those who enroll or change plans by December 15
- January 31, 2017: Last day to enroll in or change a 2017 health plan. After this date, you can enroll or change plans only if you qualify for a Special Enrollment Period.

Shop for available health care plans at New York State of Health at <https://nystateofhealth.ny.gov/>

- ***Families as Partners-*** *Families of children with special healthcare needs will partner in the decision-making at all levels and will be satisfied with the services that they receive.*

Families raising children and youth with special health care needs (CYSHCN) have long been the primary care coordinators for their children, linking home, health care, school and community together in order to achieve best the outcomes. Professionals can relieve some of this stress by partnering with families to coordinate and plan care of the CYSHCN using a tool called a care map. In its most developed form, care mapping is a family-driven, person-centered practice which highlights a family's strengths and communicates both the big picture and the small details of the resources needed to support a child and their family.

<http://www.childrenshospital.org/care-coordination-curriculum/care-mapping>

- ***Adequate Insurance and Financing-*** *Families of children with special healthcare needs will have adequate and/or public insurance to pay for the services that they need.*

Medicaid and Child Health Insurance Program (CHIP) are both programs funded by federal and state governments and provide payment for medical services for children with special needs. This family-friendly guide explains the similarities and the differences between these programs.

<http://cahpp.org/wp-content/uploads/2016/06/medicaid-chip-infographic.pdf>

- ***Medical Home-*** *Children with special healthcare needs will receive coordinated, ongoing, comprehensive care within a medical home*

This learning guide is designed to provide families and professionals basic information on “medical home”. It also suggests specific activities one can use to strengthen their medical home or advocate for stronger primary care services.

https://medicalhomeinfo.aap.org/tools-resources/Documents/Complete-FE-Learning%20Guide_4-29-09.pdf

- ***Early, Continuous Screening-*** *Children will be screened early and continuously for special health care needs*

The Genetic and Rare Diseases (GARD) Information Center is a program of the National Center for Advancing Translational Sciences (NCATS) and is funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides access to

current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish. Using this information, patients and providers can develop evaluation and treatment plans.
<https://rarediseases.info.nih.gov/about-gard/pages/23/about-gard>

- ***Community Based Services-*** *Service systems must be organized so families can use them easily and are satisfied*

The Centers for Medicare & Medicaid Services (CMS) is seeking suggestions to determine what reforms and policy changes are needed in order to grow availability of community-based services. CMS wants feedback from stakeholders on ways to further promote access to community options while continuing to ensure choice for those who prefer institutional care. Suggestions can touch on everything from the way benefits are designed to how they are paid for.

Please register your comments by January 9th at:

<https://www.federalregister.gov/documents/2016/11/09/2016-27040/medicaid-program-request-for-information-rfi-federal-government-interventions-to-ensure-the-provision-of-timely-and-quality-home-and-community-based-services>

- ***Transition to Adulthood-*** *Youth with special health care needs will receive the services necessary to make transitions in all aspects of adult life, including adult healthcare, work, and independence*

Youth and young adults who remain with medical practices from childhood into adulthood (using the family medicine model) require transition support to be ready for an adult approach to care (e.g. managing their own care, understanding privacy and consent).

<http://www.gottransition.org/providers/staying.cfm>

Other Links:

November is National Caregiver Month. Special needs parenting can be incredibly challenging, which is why the topic of parent self-care is so very important. Learn the steps necessary to ensure your own special self-care.

http://www.huffingtonpost.com/marci-lebowitz/please-help---parents-of-special-kids-need-special-care-too_b_9010534.html

The County Health Officials of New York have a comprehensive website for parents and professionals outlining the importance of vaccinations throughout the lifespan. It includes suggestions for vaccination schedules as well as scholarly articles to help people make informed vaccination decisions.

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

- Have you found valuable links and you would like to share? Please sent them to Lin Perry at lperry@ptopnys.org
- If you would like to speak with someone regarding your child with special health care needs, we would be happy to hear from you:
 - Lin Perry at (607) 240-4573 (Upstate NY families).
- ✓ Visit our website at www.ptopnys.org
- ✓  www.facebook.com/ParenttoParentNYS

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