



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 146

January 2017

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.



- ***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.*

A well visit to your pediatrician is important for your child's health at any age, particularly if they have a disability or special healthcare need. Learn how to make the most of these visits so that fewer questions arise outside of the appointment time.

https://www.verywell.com/things-to-tell-your-pediatrician-at-a-well-visit-4078390?utm_content=7521788&utm_medium=email&utm_source=cn_nl&utm_campaign=familysl&utm_term

- ***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.

National Organization for Rare Disorders (NORD) has assistance programs to help patients obtain life-saving or life-sustaining medication that they could otherwise not afford. These programs provide medication, financial assistance with insurance premiums and co-pays, diagnostic testing assistance, and travel assistance for clinical trials or consultation with disease specialists.

<https://rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs/>

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

The medical home is best described as a model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety. It has become a widely accepted model for how primary care should be organized and delivered throughout the health care system, and is a philosophy of health care delivery that encourages providers and care teams to meet patients where they are, from the most simple to the most complex conditions.

<https://www.pcpcc.org/about/medical-home>

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

This chart explores the differences between a clinical diagnosis and a school identified learning or attention issue and how these classifications are addressed differently within the medical and educational settings.

<https://www.understood.org/en/school-learning/special-services/special-education-basics/the-difference-between-a-school-identification-and-a-clinical-diagnosis>

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

Developed for health care professionals and other “first responders”, this tip sheet provides a list of essential resource websites for families concerned about their child’s hearing.

<http://www.infanthearing.org/familysupport/just-in-time-color.pdf>

- ***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

HealthyTransitionsny.org has a transition skills checklist along with supporting tutorial videos that outline the items that need to be discussed and taken care of in order to successfully transition from pediatric to adult healthcare.

<http://healthytransitionsny.org/category/setting-health-goals/>

Other Links:

People with disabilities have the same sexual and reproductive health needs as others yet they often face barriers to information and services. Children and youth with disabilities also require sexuality education so they can develop a positive attitude towards sexuality and help to avoid sexual abuse, sexually transmitted diseases and unplanned pregnancy. This link has resources for both parents and professionals.

<http://ucp.org/resources/health-and-wellness/sexuality/>

One in five American children has a special healthcare need. In December 2016, The Lucille Packard Foundation released a pictorial entitled “Super Parents” highlighting the daily journey of 10 Californian families raising children with special healthcare needs. They would like to hear from other families in an effort to expand the project to a national level.

<http://www.lpfch.org/cshcn/community-engagement/family-stories>

- 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

✓ Visit our website at www.ptopnys.org

✓  www.facebook.com/ParenttoParentNYS

***Michele Juda, Executive Director, Parent to Parent of NYS
500 Balltown Rd, Schenectady, NY 12304***