

Family 2 Family Health Information Center

Family 2 Family Health Information Center (F2FHIC) is uniquely able to help families because we are staffed with family members that have first hand experience in navigating the maze of health care services and programs for children with special health care needs.

How does the F2F HIC assist families?

- They provide assistance to families and professionals in navigating the health care system
- o They provide information, education, support and community referral services
- o They offer support to families that feel "lost" in the everyday struggle of providing for children with special health care needs.

Quick Links

GENERAL:

Family Voices

Family Voices of Ohio

Topics!

Affordable Care Act

Social Security Changes

Contact your Health Information Specialist

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Affordable Care Act (ACA):

Helping families of children with special healthcare needs access prevention and wellness care

The Affordable Care Act (ACA) covers many aspects of wellness and prevention at no cost to families. For families of children with disabilities who may see multiple doctors, often the focus is on the condition. However, health promotion and prevention is also important for children with special needs. Wellness and preventive care are important to overall health, and making these services available without cost-sharing to families means that more children will receive these services.

The ACA requires that the following sets of services be provided to children without cost-sharing:

- Immunizations for routine use that are recommended by the Advisory Committee on Immunization Practices (ACIP) of the Centers for Disease Control and Prevention; and
- 2. Evidence-informed preventive care and screenings provided for in the comprehensive guidelines supported by the Health Resources and Services Administration (HRSA), which is a reference to the "Bright Futures" guidelines (see below).



Immunizations

Being vaccinated for preventable disease is essential to wellness. Immunization schedules are available from the

Centers for Disease Control and Prevention (CDC) at http://www.cdc.gov/vaccines/schedules/ index.html. Flu prevention is especially important for children at high risk of complications, such as those with developmental disabilities or neurological disorders (see http://www.cdc.gov/flu/protect/neurologic-pediatric.htm.)

Screening

Most often, it is the parents who have concerns that something is "off" with their child and who bring their concerns to the attention of their child's pediatrician or family doctor. Good information on screening is available from the American Academy of Pediatrics at http://www.healthychildren.org/English/ages-stages/Pages/default.aspx. The "Act Early" campaign of the CDC has checklists for families at http://www.cdc.gov/ncbddd/actearly/concerned.html. Good information regarding concerns about a child's development is available from First Signs at http://www.firstsigns.org/concerns/index.htm. Screenings can also include hearing, vision, lead, and psychosocial/behavioral assessment. The ACA covers the "Bright Futures" recommended screenings for a variety of developmental areas and at periodic times throughout a child's life.

Hearing

When hearing loss is detected earlier, children have better outcomes. Information is available for families from the CDC at http://www.cdc.gov/ncbddd/hearingloss/families.html. In each state, there is an Early Hearing Detection and Intervention Program which can be found at http://www.infanthearing.org/states/index.html. "Opening Doors: Technology and Communication Options for Children with Hearing Loss" from the U.S, Department of Education is found at http://www2.ed.gov/about/offices/list/osers/products/opening_doors/espanol.html. Medicaid also covers hearing services for children.

Vision Care

Vision care for children is one of the 10 Essential Health Benefits under the ACA. In each state, there is also a Commission for the Blind or Visually Impaired (usually found under the Department of Human Services) which is a good resource and collaborates with schools. Medicaid also covers pediatric vision services. For parents who do not have insurance for their child, there are vision resources such as

- New Eyes for the Needy at <u>www.new-eyes.org</u>,
- One Sight at http://www.onesight.org, and
- Vision USA at http://www.aoafoundation.org/vision-usa/how-to-apply/.

Behavioral Health

Behavioral health screenings are covered under the ACA. Medicaid also covers mental health services. The National Alliance on Mental Illness (NAMI) Child & Adolescent Action Center offers information at http://www.nami.org/Template.cfm?

<u>Section=Child_and_Adolescent_Action_Center&template=/</u>
ContentManagement/ContentDisplay.cfm&ContentID=21090.

NAMI also has workshops and support for parents of children with challenging behaviors at http://www.nami.org/Template.cfm?
Section=Your_Local

NAMI&Template=/CustomSource/AffiliateFinder.cfm.

A "Family Guide to Systems of Care for Children with Mental Health Needs is available from the U.S. Department of Health at http://store.samhsa.gov/product/Family-Guide-to-Systems-of-Care-for-Children-With-Mental-Health-Needs-bilingual-English-Spanish-/



<u>SMA05-4054</u>. Most states have a chapter and/or state organization of the National Federation of Families for Children's Mental Health, which can be found at <u>www.ffcmh.org</u>.

General Wellness

- The Family Voices publication "Family Matters: Promoting Health & Wellness for Children with Special Health Care Needs Family Booklet" has general information on wellness available in English and Spanish at http://www.familyvoices.org/page?id=0005.
- "People with Disabilities: Living Healthy" is available from the CDC and found at http://www.cdc.gov/features/disabilities/.
- Bright Futures even has an activity book for children found at http://brightfutures.aap.org/pdfs/BFActivityBook_L%200626.pdf?
 Site=nf.aap.org&WebKey=68530b27-2adb-43ae-9c87-2fa20cb86cae&url_keyword=Bright+Futures+Activity+Book.

A discussion of prevention and wellness wouldn't be complete without mentioning nutrition and exercise. There are many good resources available on these topics. These include:

Nutrition

- CDC http://www.cdc.gov/bam/nutrition/index.html or similar information in Spanish at http://www.cdc.gov/spanish/especialesCDC/ObesidadNinos/
- AAP/Bright Futures http://www.brightfutures.org/nutrition/index.html
- AAP information for families http://www.healthychildren.org/english/healthy-living/nutrition/Pages/default.aspx; in Spanish http://www.healthychildren.org/spanish/healthy-living/nutrition/paginas/default.aspx.

Physical Activity

- AAP Bright Futures at http://www.brightfutures.org/physicalactivity/about.htm
- AAP Fitness Guide at http://www.healthychildren.org/english/healthy-living/fitness/Pages/default.aspx or Spanish http://www.healthychildren.org/spanish/healthy-living/fitness/paginas/default.aspx.
- The U.S. Department of Health and Human Services (for girls only) http://www.girlshealth.gov/fitness/index.html or in Spanish at http://www.girlshealth.gov/padres/forma_fisica/index.html
- "Body & Mind: Physical Activity "at http://www.cdc.gov/bam/activity/index.html or in Spanish at http://www.cdc.gov/spanish/hojas/actividad_fisica.html.
- "14 Weeks to a Healthier You" from the National Center on Health, Physical Activity, and Disability at http://www.ncpad.org/14weeks/.

A listing of accessible playgrounds can be found at http://www.accessibleplayground.net/united-states/new-jersey/. Other organizations have peer buddies for physical activities, such as Miracle League, Little League Challenger Division, and Special Olympics Project Unify.

Special Note on Dental Care

Pediatric oral health is also one of the ACA's 10 Essential Health Benefits. For information on how to access dental care, why it is so important for children with special health care needs, and how it affects overall health, see last month's blog at http://www.fv-ncfpp.org/blog/why-oral-health-important-children-special-needs-how-access-it/.

Families of children with special health care needs want the best care for their children, and this includes prevention and wellness care. The ACA helps parents by covering prevention and wellness at no cost.

This tip sheet was authored by Lauren Agoratus, M.A. Lauren is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and as the southern coordinator in the New Jersey Family-to-Family Health Information Center, both housed at the Statewide Parent Advocacy Network (SPAN) at www.spanadvocacy.org.

More of Lauren's tips about the ACA can be found on the website of the Family Voices National Center for Family/Professional Partnerships: http://www.fv-ncfpp.org/.

