



Health Care Reform and Individuals with Disabilities

No doubt, you have been hearing and reading about health care reform. It has been in newspapers, magazines, on television, and even on Facebook and You Tube. And, no doubt, you may be confused about what the various proposals might mean for your child with special health care needs and/or disabilities.

There is widespread agreement that our health care system needs reform. If you have been faced with taking a job just because of the health insurance offered, or lost a job and also lost the accompanying health insurance, you know that the system as it exists doesn't work. But what system of health insurance will work to best serve the needs of your family?

Family Voices would like to offer you some perspectives and resources that will keep you informed as the national proposals are being debated in Washington.

According to the national office of Family Voices, "The pending proposals for national health insurance reform will increase the services available to children with special health care needs and disabilities, in part by eliminating lifetime and annual caps, setting out of pocket spending limits, getting rid of pre-existing condition exclusions, and improving care coordination."

The Catalyst Center, based at the Boston University School of Public Health, provides support to efforts that assure adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families. The Catalyst Center offers the following as essential components of health care reform:

- Universal, continuous coverage
- Adequate coverage
- Affordable coverage

Their publication, "The Essential Components of Health Care Reform for Children and Youth with Special Health Care Needs" can be found at: www.catalystctr.org/

The Consortium for Citizens with Disabilities offers "Principles for Health Care Reform from a Disability Perspective," which can be found at [www.c-c-d.org /task forces /health/CCD-Health-Reform-Principles42209.pdf](http://www.c-c-d.org/task_forces/health/CCD-Health-Reform-Principles42209.pdf). This paper provides principles which you may want to consider as you review of the various health care reform proposals.

In addition, Family Voices of Wisconsin has developed a section on our website (www.wfv.org/fv) on health care financing where you can find additional information.

Family to Family Health Information and Education Network News

As the weather is getting colder, the cases of both seasonal flu and H1N1 flu (aka swine flu) are increasing. CYSHCN and people with disabilities or an underlying health condition are at risk for complications from H1N1. According to a report from the Centers for Disease Control, nearly two-thirds of the 36 children who have died due to the H1N1 flu between April and August experienced a form of developmental disability. As you are waiting for the flu vaccine to become available in your community, you should remember that as your child's primary caregiver, you are a health care provider. Check with your doctor to determine if you could have priority access to the vaccine when it becomes available. Meanwhile, here are some websites that will keep you up to date on the latest flu news: **Centers for Disease Control** www.cdc.gov/h1n1flu/, **Trust for America's Health** <http://healthyamericans.org/>, **US Department of Health and Human Services** www.flu.gov, and **Wisconsin's Pandemic Flu Resource** <http://pandemic.wisconsin.gov/>.



WEB WATCH

For additional resources related to the articles in this newsletter, you can visit the following sites:

Family Voices of Wisconsin

www.wfv.org/fv

National Office of Family Voices

www.familyvoices.org

Disability Rights Wisconsin

www.disabilityrightswi.org

Catalyst Center

www.catalystctr.org

Consortium for Citizens with Disabilities

www.c-c-d.org

Did You Know? Now You Know!

HEALTH IN THE IEP

When a child has medical concerns and goes to school, the school nurse can be a family's best ally. Not only can the school nurse work directly with the student, family and the student's doctor(s), but that nurse can also serve as a member of the student's IEP team.

"Why would I be concerned about health issues in my student's IEP?" you might ask. There are a number of reasons why. They include:

- providing information to all IEP members regarding health concerns;
- identifying if a care plan or emergency care plan is needed for the child and how it will be communicated to all of the child's teachers;

- identifying which school staff may need additional training when dealing with the student's medical concerns including such things as: safe handling and transfers, feeding, personal cares, seizure management and airway management;
- developing strategies for daily communication regarding a child's health status, as necessary; and
- ensuring that all necessary forms and plans are kept in a central location, such as a three-ring binder in the nurse's office.

For more information on health concerns and school the following website may be helpful: Department of Public Instruction School Nursing Program: <http://dpi.wi.gov/sspw/schlnurse.html>

Resources for Families and Providers

If you live in a community where Family Care is now a reality, you should be aware of the Ombudsman Program run by Disability Rights Wisconsin (DRW). It can provide assistance regarding eligibility, services or other Family Care and Family Care Partnership concerns. The *Family Care Ombudsman Program* offers many services, including: investigating complaints, resolving and mediating issues, providing information on consumer rights, assisting in negotiating care plans, appealing denials of services or changes in services, and working with enforcement and regulatory agencies. The *Family Care Ombudsman Program* has staff in DRW's Madison, Milwaukee and Rice Lake offices and is available to advocate for Family Care and Family Care Partnership participants in any Wisconsin Family Care county. For information, contact DRW at: www.disabilityrightswi.org/contact-us/ or call toll free (800)928-8778.

Opportunities Around the State

"Did You Know? Now You Know!"

Family Voices of Wisconsin's popular training program has openings for the following dates and locations (each training is held in two parts):

- **Port Washington:** Wednesdays 10/20 and 11/3; 5:00—9:00 pm
- **Salem:** Tuesdays 10/21 and 11/4; 5:00—9:00 pm
- **Neillsville:** Fridays, 10/23 and 11/6; 9:30 am—2:30 pm
- **Park Falls:** Thursdays, 11/9 and 11/16; 5:00 -9:00 pm

For additional information, including registration information, please visit: www.wfv.org/fv and go to "trainings" or call Nancy at 715-355-8458.

Children Come First Conference

The 20th Annual Children Come First Conference will be held on November 16 and 17 at the Kalahari Resorts and Convention Center, in the Wisconsin Dells. This year's theme is "Ready, Set, Relationships." For more information go to www.wifamilyties.org or call 800-422-7145.

Children and Youth with Special Health Care Needs News

Promoting and Developing a Partnership with Your Child's Primary Care Physician

By Christine Breunig, Program Administrator
- NE Regional Center for CYSHCN

One of the goals of the Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) is to promote family/ provider partnerships through a Medical Home approach to primary care.

Part of our effort involves working with primary care physician practices to include parents of children with special health care needs more fully as decision-making partners in providing care for their child(ren). One way we are doing this is by offering training and technical assistance to primary care physicians/practices that includes information on developmental screening, autism specific screening, referral sources, intervention options and care coordination. These trainings will include information on how to partner with parents/families in the process of developmental screening by using a parent report tool, by working with them to create a care notebook or online record of their child's care, medications, and other needs. For more information on the Medical Home concept and how you can establish a medical home for your child/children, refer to this American Academy of Pediatrics website: www.medicalhomeinfo.org and go to "tools/resources."

Are you wondering if your primary care practice is using the concepts of Medical Home? Here are some questions you may ask to get a sense of the answer to that

question:

- Does your child's physician use a standardized developmental screening tool, as recommended by the American Academy of Pediatrics?
- Does your child's physician involved you directly in decision making regarding services and transitions your child may need?
- Does your physician discuss or provide some kind of record keeping option to ensure that care of your child is coordinated and information is available when your child needs emergency services or sees another provider?
- Does your child's physician know of resources such as "First Steps", the Regional Centers for CYSHCN, your local B-3 program or other county services to refer you to?

WE COULD USE YOUR VOICE IN PROMOTING THESE EFFORTS WITH YOUR CHILD'S PRIMARY CARE PROVIDER.

If you think that your primary care practice may be interested in learning more about this, we encourage you to share the following information with your physician or nurse practitioner:

For 2010, the Wisconsin CYSHCN Program, through the five Regional Centers, will be offering two options for primary care practices to improve quality through Medical Home Grants and an Early Identification Initiative. For more information on grants that your Primary Care Provider can apply for, contact your local Regional Center (see sidebar) or call Christine Breunig at 920-969-5330.



Children and Youth with
Special Health Care Needs

CYSHCN CENTERS

Call with your
questions!

Northeastern Region
Children's Hospital of
Wisconsin- Fox Valley
1.877.568.5205

Northern Region
Marathon County Health
Department
Wausau
1.866.640.4106

Southeastern Region
Children's Hospital
Milwaukee
1.800.234.5437

Southern Region
Waisman Center
Madison
1.800.532.3321

Western Region
Chippewa County Dept
of Public Health
Chippewa Falls
1.800.400.3678

**Great Lakes Inter-
Tribal Council
(GLITC)**
Lac du Flambeau
1.800.472.7207

**Website for All
Regional Centers:**
[www.dhs.wisconsin.gov/
health/children/
resourcecenters](http://www.dhs.wisconsin.gov/health/children/resourcecenters)

Policy Update

YOUTH TRANSITIONING TO FAMILY CARE

As of October 1, Family Care is present in 48 of Wisconsin's 72 counties. Each Family Care community has an Aging and Disability Resource Center (ADRC) assigned to it. A list of the ADRCs can be found at: [dhs.wisconsin.gov/
ltcare/Generalinfo/RCs.htm](http://dhs.wisconsin.gov/ltcare/Generalinfo/RCs.htm)

The ADRCs are the first place for you to go with your questions about Family Care and the options it offers for youth transitioning into Family Care. Each ADRC is required to have a lead person to help with youth transitioning from children's long-term services (including Family Support and the CLTS waiver) to adult long-term services. ADRCs can begin working with youth and their families when the youth is 17 years and 9 months old.



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About Family Voices of Wisconsin

Family Voices of Wisconsin is the home of the Wisconsin Family to Family Health Education and Information Network.

Family Voices of Wisconsin is a statewide network of families who have children and youth with special health care needs and/or disabilities and those who work on their behalf. We support families by providing information, training and leadership opportunities so that families can be informed and effective navigators of their child's care. Family Voices of Wisconsin also works to inform and educate health care providers and local, state and national policy makers and administrators about issues that affect children and youth with special health care needs and/or disabilities. We are committed to strong partnerships between families and providers to improve the systems of supports and services for children.

Feedback Welcome

We want to make sure that this newsletter is an effective resource for you. If you have any comments, or wish to provide news and information for us to publish, please contact Barbara at barb@fvofwi.org. We look forward to your ideas and suggestions!