



*The Home of Wisconsin's Family to Family Health Information and Education Network
in Partnership with the Wisconsin Children and Youth with Special Health Care Needs Program*

Building a National Agenda for Supporting Families with an Individual with Disabilities

Why Support Families?

Families are the core unit in our society, serving as a source of support for all its members. For people with disabilities the role of family is unique, and often central in the support and care provided across the lifespan. Family members play key roles in identifying and securing opportunities for their family members to participate within their community and ensuring access to self-determined lives.

Parents and other family members of people with disabilities often provide medical, behavioral, financial, and other daily supports beyond what most families provide. Yet, the vital role of families is not fully recognized and supported in disability policy and practice.

In 2011 a group of family support leaders and stakeholders gathered at the Wingspread Conference Center in Racine Wisconsin to develop a national agenda around supporting families who have a member with intellectual or developmental disabilities. The subsequent report provides a definition, a set of strategies and recommendations for federal and state policy for *Building a National Agenda for Supporting Families with an Individual with Developmental or Intellectual Disabilities*. To view the *National Agenda* report go to www.waisman.wisc.edu/cedd/pdfs/products/family/Wingspread.pdf

The overall goal of supporting families, with all of their complexity, strengths and unique abilities, is to support, nurture, and facilitate opportunities for the best possible future for their family member with disabilities. Because of the role that families continue to play in the lives of their family members, future policies and practices must reflect the family as part of the system of support.

What is Family Support?

Family Support is more than a program or service; it is the concept of supporting families who care for a member of their family with a disability. It is a set of strategies directed to the family unit, but ultimately benefit the person with a disability.

Supporting the family strategies is intended to assist family members who have a key role in providing support and guidance of their family member with disabilities to address the emotional, physical and material well-being of the entire family. They should be flexible, comprehensive, coordinated and include the following:

- **Information, education, and training on best practices** within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.
- **Connecting with communities and networking and connecting families with other families**, including parents with disabilities, self-advocates and siblings, grandparents and other guardians for mutual support.
- **Services and goods that are specific to the daily support and care-giving role for the person with disabilities**, such as planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management.

Wisconsin families interested in improving our systems of support can use these strategies as a frameworks for discussion. The Administration on Intellectual and Developmental Disabilities currently funds a 5 year Community of Practice initiative on Supporting Families. The Community of Practice (a learning environment of intensive exploration of a policy) will build capacity in six states to better support families and use the National Agenda's strategies to do this. To learn more go to <http://supportstofamilies.org/cop/>





Did You Know? Now You Know!

Getting Coverage Outside Open Enrollment

WEB WATCH

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

National Office of Family Voices
www.familyvoices.org

Family Voices of Wisconsin
<http://fvofwi.org>

The National Community of Practice / Supporting Families website
<http://supportstofamilies.org/cop/>

Marketplace Website
www.healthcare.gov

Wisconsin Health Care Options
www.dhs.wisconsin.gov/health-care

HealthWatch Wisconsin
www.healthwatchwisconsin.org

Wisconsin PROMISE
<http://promisewi.com/>

While open enrollment in the ACA's new Marketplace is over for 2014, you may still be able to sign up for a new insurance plan through www.healthcare.gov if you experience certain events in your life. These events give you **60 days** from the event date to enroll in a new plan or change plans.

Keep in mind, you can apply for Medicaid or BadgerCare Plus any time and you can enroll right away. This includes applying for Medicaid through the Katie Beckett Program for children with disabilities. To learn more go to the Wisconsin Health Care Options website (see WEB WATCH).

Below are qualifying life events that create a special enrollment period:

- ◆ **Getting married**
- ◆ **Having, adopting, or placement of a child**
- ◆ **Permanently moving to a new area that offers different health plan options**
- ◆ **Losing other health coverage** (for example due to a job loss, divorce, loss of eligibility for Medicaid or

BadgerCare or expiration of COBRA coverage). **Please note:** Voluntarily quitting other health coverage or being terminated for not paying your premiums are not considered loss of coverage.

- ◆ For people already enrolled in Marketplace coverage, **having a change in income or household status that affects eligibility for tax credits or cost-sharing reductions.**

How Can I Learn More? To learn more about the Affordable Care Act and considerations for families who have children with disabilities and special health care need, go to the Family Voices website at fvofwi.org/public-policy/affordable-care-act/.

Also, check out the new **Video Case Tips**, a great new resource from HealthWatch Wisconsin, linked to our webpage or go to www.healthwatchwisconsin.org

The next open enrollment period, if you want to enroll in a new plan or change plans and do not have a qualifying life event, will be from November 15, 2014 through February 15, 2015. To enroll go to www.healthcare.gov or call **1-800-318-2596**.

NEWS FROM FAMILY VOICES OF WISCONSIN

Take the ACA Family Survey!

Family Voices of Wisconsin is interested in finding out what families of children or young adults with special health care needs and/or disabilities know and feel about the Affordable Care Act (ACA), which is sometimes called "Obamacare." **We invite you to participate in the survey!** The purpose of this survey is to help guide education directed to families and individuals in order to increase understanding of and improve access to our changing health care system.

The survey is available on the Family Voices website at <http://fvofwi.org/aca-survey/>

All of your answers will remain confidential and anonymous. The survey should take no more than 15 minutes and at the end of the survey, you will find a list of resources about the Affordable Care Act and all of the answers to the questions asked in the survey.

Children and Youth with Special Health Care Needs News

TRANSITION ... One Size Does NOT Fit All!

Family Voices will be hosting a conference on transition to adult life for families who have children or grandchildren age 14 - 21 and live in the Milwaukee area on May 5th and 6th at the Country Springs Hotel. Presentations include: **guardianship and other legal issues, employment, special education services, mental health services, and Family Care, IRIS** and other long term support programs for adults with disabilities. To learn more and register go to <http://fvofwi.org/training-and-events/events/> or call Lynn at **608-828-9959**. The conference is free and hotel, meals, and transportation from Milwaukee will be available. Space is limited.

Family Voices of Wisconsin Trainings

Did You Know? Now You Know! provides a comprehensive overview of health care and coverage, including BadgerCare and the Affordable Care Act, community supports and services, and resources for children and youth with disabilities and special health care needs from birth through young adulthood.

What's After High School is a broad overview on transition to adult life for youth with disabilities and/or special health care needs. Topics include: envisioning a youth's future in the community; post-secondary education; long term supports; vocational resources; transitioning to adult health care; guardianship and other legal options; living in the community; and the fundamentals of self-determination.

Training sessions are being planned around the state for Fall 2014! Check our website for dates and locations.

All training material is now available at <http://fvofwi.org/resources/materials-from-our-trainings/> The website also contains materials from our new training, called *Creating a Vision for the Future, It's Never Too Early (or Too Late) to Begin*, which will be presented at the 2014 Circles of Life Conference.



Children and Youth with
Special Health Care Needs

CYSHCN

REGIONAL CENTERS

**Call with your
questions!**

Northeast Region

Children's Hospital of
Wisconsin - Fox Valley

1.877.568.5205

Northern Region

Marathon County Health
Department

Wausau

1.866.640.4106

Southeast 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

WISCONSIN PROMISE -- Opportunity for Youth receiving SSI and their Families

Enrollment is open for the Wisconsin PROMISE Initiative. Wisconsin is one of six sites participating in the U.S. Department of Education's demonstration of a promising path to success for youth receiving Supplemental Security Income (SSI).

Wisconsin Promise will enroll 2,000 youth between the ages of 14 and 16. One half (1,000 youth and their families) will be enrolled in Division of Vocational Rehabilitation (DVR) services, and offered a variety of activities including exploring career and education opportunities, help finding a job that matches their interests and abilities, help achieving education goals, and counseling on benefits and personal finances. Youth and their families in this group (the "program group") will receive a computer tablet and data plan. Supports and services will also be available to family members. The other half will be enrolled in the "usual service group" and will have access to the usual services and supports. All families who participate will receive \$30 in gift cards.

To learn more go to the website at <http://promisewi.com/>

If you have any questions or need assistance completing enrollment materials, call **1-855-480-5618** or send an email to promise-grant@cesa12.org.



Family Voices of Wisconsin

Post Office Box 55029
Madison, Wisconsin
53705

Spring 2014

Volume 9, Issue 1

This newsletter is funded in part by the MCH Title V Services Block Grant, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services through a grant from the Wisconsin CYSHCN Program and with funds from the federal Maternal and Child Health Bureau, MCHB grant # is H84MC21690-01-00.

Contact Us

Family Voices of
Wisconsin
P.O. Box 55029
Madison, WI 53705
www.fvofwi.org
608.220.9598

Co-Directors:

Liz Hecht
liz@fvofwi.org

Barbara Katz
barb@fvofwi.org

Outreach Coordinator:
Lynn Renner
lynn@fvofwi.org

Nonprofit
Organization
U.S. Postage
PAID
Madison, WI
Permit No. 1222

About Family Voices of Wisconsin

Family Voices of Wisconsin is the home of the Wisconsin Family to Family Health Information and Education Network. Family Voices of Wisconsin is part of a national grassroots network of families and advocates who support children with disabilities and/or special health care needs. We provide information, training and support around health care and community supports to families throughout Wisconsin, including the well received "Did You Know? Now You Know!" training program. Family Voices is dedicated to strong collaborative partnerships between families and essential allies to improve the systems of supports and services for children. A core commitment of Family Voices is to involve and support parents in decision making roles that affect program design and policy recommendations on local, regional and statewide levels.

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 Lynn at **Lynn@fvofwi.org**. We look forward to hearing from you!

LIKE US ON FACEBOOK AND JOIN THE FAMILY ACTION NETWORK

LISTSERV (join-fan@lists.wisc.edu)

Would you prefer to have this newsletter emailed to you?

Contact Lynn at Lynn@fvofwi.org