

*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*

Imagining Possibilities Aiming High for Your Child with Special Needs

"It is never too early (or too late) to start planning for your future" is an idea that is universal for our children, whether they are typically developing or have special needs. Family Voices encourages families who have children and young adults with disabilities to take the time to think broadly and creatively about their child's future.

Starting the visioning process when children are young gives families time to find the tools, resources and the role models to make their child's dreams for their future a reality. While typical children have everyday experiences that prepare them for their future and to advocate for themselves, children with disabilities or special health care needs may have fewer chances to have these kinds of experiences. In addition, families may have no role models for how their adult child will live and work in the community.

A few questions to consider when starting this process include:

- ◆ **If your child was living the best life imaginable, what might that include?**
- ◆ **What makes them smile? What frustrates them?**
- ◆ **What are your child's talents and interests?**

Building Skills - Think about using "teachable moments" and role playing to support your child's independence. Consider breaking down chores around the house into manageable steps for your child. Do the same with self-care. It may take a long time for your child to gain independence with tasks. The important thing is that you keep offering opportunities. Showing your children that you have high expectations will encourage and develop their independence.

Encourage them to participate in activities such as school clubs, team sports or faith groups. Consider community connections that you already have that can provide your child with experiences.

These opportunities strengthen their sense of independence and self-advocacy. As your child gets older consider leadership trainings so that they can learn along with other youth with disabilities about self-advocacy and self determination.



Find Role Models - Talk to other families who have an older child with a similar disability or contact an agency that works with older children or adults with disabilities such as an Independent Living Center. They may be able to connect you to someone who has similar challenges and lives and works in the community. A listing of Independent Living Centers is available at www.dhs.wisconsin.gov/disabilities/physical/ILClist.pdf or call **1-800-362-9877**.

Consider What You May Worry About - As parents or guardians, we have to consider our tolerance for risk and what areas of our child's life we might be willing to let go. While we may feel comfortable letting a typically developing child participate in a team sport, take the bus or stay overnight at a friend's house, we may not feel comfortable letting a child with special needs do the same. Consider small steps you can take to encourage their independence and give them opportunities to be involved in the community.

There are many resources available to help you with thinking about your child's future. Page 3 provides information on Person-Centered Planning tools and techniques, along with resources on self-determination and youth leadership.

In addition, Family Voices has a "Creating a Vision for the Future" presentation that you may find helpful. The PowerPoint and handouts can be found at <http://fvofwi.org/resources/materials-from-our-trainings/#CVF>





Did You Know? Now You Know!

Marketplace Open Enrollment - Reminders for 2015

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>

Family Voices Affordable Care Act webpage

<http://fvofwi.org/public-policy/affordable-care-act/>

Health Transition WI

www.healthtransitionwi.org

Pacer Center - information on Person Centered Planning

www.pacer.org/tatra/planning/personal.asp

ACA's Marketplace

www.healthcare.gov

Enrollment for Health

<http://e4healthwi.org/>

Did you know that close to 140,000 people in Wisconsin enrolled in a health plan through the new ACA Marketplace in 2013 and 2014? And, according to the Department of Health and Human Services, **91%** of people in Wisconsin who purchased their plans through the Marketplace received federal subsidies to decrease their out-of-pocket costs.

Between November 15 and February 15 (called the *Open Enrollment Period*), consumers can again enroll in a Marketplace health plan. Keep in mind if you want coverage to start on January 1 you must enroll by December 15. Go to www.healthcare.gov or call **1- 800-318-2596**. To find in-person help call **211**.

If you already enrolled for 2014, consider that there may be new health plans offered in your area. If your finances changed this year you may be eligible for additional subsidies, including advance premium tax credits or other cost sharing reductions.

As you shop for health plans or consider whether you want to keep the coverage you already have, consider the following:

- *Are you a high user of medical care (e.g., does your child see doctors and specialists often and do you have high medical bills)?*

If so, a health plan that has higher monthly premiums but lower co-payments and deductibles may be a better financial decision.

- *Do you want to continue to see the same providers? Does your child need to go to a specific hospital or medical facility?*

For many families, continuity of care is very important and having to change doctors may be disruptive. Contact your child's clinic and ask if they accept the new insurance plan.

Also, if your child will need surgery during the next year and you want to go to one of the Children's hospitals or to an out-of-state hospital, make sure that your new plan will cover the costs of going to that facility.

A new resource for what steps to take to help understand your family's insurance options is available at www.childrens-specialized.org/Resources/Health-Insurance-Education/6-Steps-to-Select-Your-Family-s-Health-Plan.aspx

NEWS FROM FAMILY VOICES OF WISCONSIN

Advocacy/Leadership Training for Families

SAVE THE DATE! Family Voices will be hosting our *Advocacy for Change - Family Leadership Institute* on Wednesday, March 4th at the Madison Concourse Hotel. This is a free, intensive advocacy and systems change training for families who have a child (or adult child) with special needs. Participants will learn from policy experts about the latest legislative and policy priorities, including **health care, waiting lists, special education and children's long term supports** and will meet with their Representatives to educate them about issues important to families. To learn more, go to the Family Voices website at <http://fvofwi.org/training-and-events/advocacy-for-change/>

New Medical Home Systems Integration Project

Family Voices is pleased to be partnering with the Department of Health Services (Children and Youth with Special Health Care Needs Program) on a 3-year grant to increase the number of children with special health care needs who are served within a medical home. Family Voices will be providing training and support to families and providers. Stay tuned for more details. To learn about the Wisconsin Statewide Medical Home Initiative go to <http://wismhi.org/>

Children and Youth with Special Health Care Needs News

Family Voices of Wisconsin Trainings

“Did You Know? Now You Know!” provides an overview of health insurance and how to best use your benefits, Medicaid and the impact of the Affordable Care Act, long term supports and services, and resources for children with disabilities and special health care needs from birth through young adulthood. *This training is designed for those who are new to systems and supports for their child or feel their knowledge could be increased.*

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.

- **Green Bay** (training for Spanish speaking families) - Oct. 25, 9:30am - 12:30pm
- **Whitewater** - October 30, 5:00 - 8:00pm
- **Medford** - November 3, 5:00 - 8:00pm
- **Tomahawk** - November 4, 5:00 - 8:00pm
- **Wisconsin Rapids** - November 5, 11:00am - 1:00pm
- **Green Bay** - November 12, 6:00 - 8:00pm

Check our website for more details and registration information. Go to <http://fvofwi.org/training-and-events/training-dates-and-locations/>

Affordable Care Act Update

Auto Enrollment and Staying Covered for 2015

Open enrollment for a new private health plan or to renew your current health plan in the Marketplace starts **November 15** and runs through **February 15, 2015**. If you bought a health insurance plan through the Marketplace in 2013 or 2014 you will be receiving important notices about your coverage before November 15. *We encourage you to watch for this in the mail and review it carefully.*

If your health plan is still available in your area of the state for 2015 you may be able to automatically re-enroll (**Auto Enroll**) which means you do not need to take any action or submit any new paperwork and you will be covered for another year starting January 1st. You will be enrolled with the same premium tax credit or other subsidies. The only consumers who will be able to auto enroll are those who gave the Marketplace permission to check and use their financial information. Those who did not give permission will need to go through a redetermination process and re-enroll in a plan. To learn more go to the [healthcare.gov](http://www.healthcare.gov/keep-or-change-plan/) at www.healthcare.gov/keep-or-change-plan/

BadgerCare May Still Be An Option: Keep in mind that even if the adults in a family are covered by a private health plan, their children may still be eligible for Medicaid or BadgerCare. Having both private insurance and Medicaid may also be something to consider, especially for your child with special needs. In addition, low-income adults without dependent children are now able to enroll in BadgerCare (see the Family Voices fact sheet called “Health Coverage Options for Young Adults with Disabilities”).

To learn more about coverage options go to www.dhs.wisconsin.gov/health-care/



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



Family Voices of Wisconsin

Post Office Box 5070
Madison, Wisconsin
53705

Fall 2014

Volume 9, Issue 3

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 5070
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 (FVW) is a state affiliate organization of the national Family Voices organization and serves as Wisconsin's Family-to-Family Health Information Center. Additionally, FVW is recognized as the Family Leadership Hub for Wisconsin's Children and Youth with Special Health Care Needs (CYSHCN) partnership.

Family Voices focuses its work on health care and community supports in three areas:

- Education and information development and dissemination, including trainings, fact sheets, and newsletters;
- Family leadership activities, including the annual Advocacy for Change institute; and
- Public policy and systems change activities.

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

Imagining Possibilities (continued from page 1)

Person Centered Planning

Having a conversation with the important people in your child's life (care providers, teachers, friends and family members) can be a helpful step in the visioning process. Some families find that using a more formal tool, like the Discovery Process, or developing a PATH or MAP can help move this process forward. These tools provide a process for thinking about your child's interests, gifts and talents as well as their long term goals. These tools help you consider what supports, both formal and informal, could be available to help you and your child reach those goals. And, these tools can be used at any time during a child's life; some find it particularly useful to do at periods of transition.

Information gathered from these tools can be introduced to the IEP process as well.



Resources for Visioning, Person Centered Planning, Self-Determination, and Leadership

- ◆ **The Core of a Good Life: Guided Conversations with Parents on Raising Young Children with Disabilities**
www.waisman.wisc.edu/cedd/pdfs/products/early/CORE_Guide.pdf
- ◆ **Fostering Self-Determination among Children and Youth with Disabilities**
www.waisman.wisc.edu/naturalsupports/pdfs/FosteringSelfDetermination.pdf
- ◆ **Pacer Center's Person Centered Planning website** - www.pacer.org/tatra/planning/personal.asp
- ◆ **Department of Public Instruction's Opening Doors to Self Determination**
<http://sped.dpi.wi.gov/files/sped/pdf/tranopndrs-self-determination.pdf>
- ◆ **PATHS and MAPS** (and other future planning tools) - www.inclusion.com/
- ◆ **The Discovery Process: A Path to Employment for All**
http://flfcic.fmhi.usf.edu/docs/FCIC_FactSheets/FCIC_FactSheet_Discovery.pdf
- ◆ **Person-Centered Planning: A Tool for Transition** (a publication from the Pacer Center)
www.pacer.org/publications/parentbriefs/ParentBrief_Feb04.pdf
- ◆ **Family Voices of Wisconsin website - Leadership Opportunities for Youth with Disabilities**, includes information on Youth in Partnership with Parents for Empowerment (YIPPE) and other leadership programs
<http://fvofwi.org/leadership/familyyouth-leadership-opportunities/>
- ◆ **Strategies for Developing Youth Leadership** (a publication from the Waisman Center)
www.waisman.wisc.edu/naturalsupports/pdfs/Strategies_YouthLeadership.pdf
- ◆ **In Control Wisconsin** - an organization that provides information on self-determination and self-directed employment - www.incontrolwisconsin.org/
- ◆ **National Gateway to Self-Determination** (explains self-determination) - www.ngsd.org/everyone/what-self-determination

Family Voices of Wisconsin Fact Sheet

Health Coverage Options for Young Adults with Disabilities or Special Health Care Needs

Families who have a child or teen with special needs know how important good health insurance is for their family. When a child becomes an adult (starting at age 18) his or her health coverage may change and eligibility for certain programs might end. **This fact sheet will give families options and resources to learn more about how their child (age 18 to 26) can get health coverage and continue to get the medical care and prescriptions they need.**

Private Insurance Plans:

- ◆ If parents have private insurance, they can keep their child on their health plan until their child is 26 years old. The Affordable Care Act (ACA) requires that health plans allow parents to add or keep a child on their plan. Adult children can stay on even if they are married, not living at home, enrolled in college or not financially dependent on their parents.
- ◆ College or technical school students may qualify for a student health plan.
- ◆ If a young adult has a job, he/she may be eligible for coverage through an employer.
- ◆ A young adult can purchase private insurance through the Marketplace. As an adult (age 18 and older) a young person with income below 400% FPL may be eligible for help to reduce their out of pocket costs. Those under age 30 can enroll in a “catastrophic” health plan which is a lower cost policy that protects you from very high medical bills.

Wisconsin Medicaid and BadgerCare Plus:

- ◆ A young adult with income below 100% of the federal poverty level (\$11,670 annual income or \$972.50 monthly income) may qualify for BadgerCare Plus – remember this is his or her own income and not the family’s income.
- ◆ A young adult with a disability may qualify for Supplemental Security Income (SSI) and will automatically be eligible for Wisconsin Medicaid. For more information on SSI go to **www.socialsecurity.gov** or call **1-800-772-1213**.
- ◆ Adults with disabilities who work (or want to get a job) may be able to purchase insurance coverage through Wisconsin Medicaid. This program is called the Medical Assistance Purchase Plan (MAPP). The applicant must be at least 18 years old, be determined to have a disability by DHS, be employed in a paid position and have a family income less than 250% of the federal poverty level.

RESOURCES TO LEARN MORE

ACA Resources from Family Voices of Wisconsin: To learn about coverage options for families who have children with special needs, go the Family Voices website - <http://fvofwi.org/public-policy/affordable-care-act/>

ABC for Health, including their *Consumer’s Companion: A 2014 Guide to Health Reform* - www.safetyweb.org/resources.html

ACA facts – Insurance Options for Young Adults from Covering Kids and Families Wisconsin - http://ckfwi.org/documents/Health_Insurance_Options_for_Young_Adult_May-14_000.pdf

SSI and benefits in Wisconsin - www.dhs.wisconsin.gov/ssi/benefits.htm

Medical Assistance Purchase Plan (MAPP) - www.dhs.wisconsin.gov/medicaid/Publications/p-10071.htm

The Marketplace and Young Adults - www.healthcare.gov/young-adults/