

Spring 2009



## ADVOCACY FOR CHANGE: A Parent Leadership Institute

*"Never in a million years did I ever believe that I would be at the state capitol lobbying. So I thank you for opening that door and giving me the tools needed."*

This comment was voiced over and over by the 25 parents who participated in the Advocacy for Change Institute on March 24 and 25. This two-day event was a learning and action forum for parent advocates across Wisconsin to gain new information and skills that enhanced their efforts to improve the lives of children and young adults with disabilities and/or special health care needs. Participants learned about the Survival Coalition state budget priorities affecting families and youth including health care, waiting lists, special education and children's long-term supports. The registration fee, conference materials, lodging and meals were covered by the sponsoring organizations. Participation in the Institute was by application (to ensure that participants were truly interested in this work) and asked for a "commitment to action" following the Institute.

Parents had an opportunity to:

- learn how to become more effective advocates;
- receive issue briefings, as prepared by Family Voices;
- develop, refine and practice their advocacy message;
- meet with their state representatives; and

• process the information they learned, along with the outcomes of their legislative meetings, and determine their next steps for action.

"Advocacy for Change" brought in Nancy Amidei, nationally renowned community organizer and author of "So You Want to Make a Difference: Advocacy is Key!" as keynote speaker. Nancy's involvement throughout the two-day event added a significant dimension to the Institute and was widely praised by participants.

100% of the participants indicated that they felt better prepared to advocate for their concern as a result of participating in the leadership institute. Some of the evaluation comments included:

- It was amazing to be part of a group that has so many empowering stories and wonderful families to support.
- I liked best having the opportunity to network with and meet many of the parent leaders in the state.
- I feel much more confident in my skills and what I have to offer.
- Warm, comfortable setting. I felt extremely comfortable sharing my story.
- It was very powerful. It made me feel important.

Family Voices is grateful to the collaboration of the Survival Coalition, Wisconsin FACETS, Wisconsin Family Ties, the Board for People with Developmental Disabilities and Disability Rights Wisconsin for their partnership on this event.

## Family to Family Health Information and Education Network News

Many parents and extended family members need preparation and additional guidance before they accept new information. Parents are often more likely to connect with people they know and trust, and as a result, are comfortable receiving information from those respected individuals. Family Voices of Wisconsin is delighted to have contracted with Patricia Erving of Milwaukee and Barb Gadbois of Red Cliff to serve as our first Cultural Liaisons. In this roll, Pat and Barb will work with Family Voices to get information on health care and community supports to parents in their communities who have been traditionally underserved by a variety of systems. They will assist us in bringing "Did You Know" trainings to their communities and work with parents to identify leadership opportunities and support them in their activities. Welcome Pat and Barb!



## 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](http://www.wfv.org/fv)

**National Office of Family Voices**

[www.familyvoices.org](http://www.familyvoices.org)

**Disability Rights Wisconsin**

<http://disabilityrightswi.org/>

**Wisconsin Family Ties**

<http://www.wifamilyties.org/>

**Wisconsin FACETS**

<http://www.wifacets.org/>

## Did You Know? Now You Know!

In Wisconsin, county governments are responsible for delivering health and human services to individuals under age 18, including children and youth with special health care needs and/or disabilities. There are 72 counties in Wisconsin which means that there can be 72 ways of determining ways in which services are administered!

So, what services are delivered by counties? They can include the Family Support Program, Medicaid waiver programs, including the Children's Long-Term Support Waiver, and specific county programs, such as respite care and wraparound mental health services. It is important to know that programs serving children and youth may look different from one county to another. For example, one county may have waiting lists for the Family Support program, while other

counties may serve all families every second or third year, on a rotating basis.

What can a family member do to learn what's available in their county or in a county they are considering for a move? Here are some things to do:

- Call the county's human services department and speak to the supervisor of children's services. They will be able to tell you about services available for your child and whether or not there are waiting lists.
- Find out if there are committees which oversee children's services, such as the Family Support advisory committee (each county has to have one!) and consider attending meetings.
- Meet your county supervisor and get to know them. They make decisions on how the county budget is spent; it would be helpful for them to meet you and know your family's story and needs.

## Resources for Families and Providers

As we work to include information dissemination to families as broadly as possible, we may need to translate documents and conversations. Often, we turn to translators in our communities. However, you may have a need for translation services and do not know of a person to turn to. If this is the case, you may want to utilize the services of the Language Line. The Language Line can provide live phone translation services, and can also translate documents in 170 languages. For more information on services, visit their website at: [www.language.com](http://www.language.com)

Do you ever wonder if you are correctly addressing people with disabilities? The United Spinal Association, in New York, recently published a helpful and humorous guide on "Disability Etiquette: Tips on Interacting with People with Disabilities." The free PDF guide can be downloaded at: [www.DisabilityEtiquette.pdf](http://www.DisabilityEtiquette.pdf) Information on the sponsoring organization can be found at [www.unitedspinal.org](http://www.unitedspinal.org)

## Opportunities Around the State

### Communities of Practice

The Community of Practice (CoP) approach has been shown to be an effective way to bring diverse stakeholders together to share information, identify gaps and problem-solve solutions. In Wisconsin, we have two Communities of Practice which are working to advance the knowledge and activity around the areas of Transition and Autism Spectrum Disorders (ASD).

The next CoP on ASD will be held on May 20 in Madison at the Sheraton hotel. For more information on this, and to register, please contact Amy Whitehead via email at [amy.whitehead@wisconsin.gov](mailto:amy.whitehead@wisconsin.gov) or by telephone at 608-267-3861.

The next CoP on Transition will be held on June 18 from 9:30-12:30 on the Truax Campus of Madison Area Technical College, room 142A and B. The topic will be post-secondary education. For more information, and to RSVP, please contact Cathy Hare by email at [chare@matcmadison.edu](mailto:chare@matcmadison.edu) or by telephone at 608-246-6716.

A repository of work by these two Communities of Practice can be found on the Shared Work website, <http://sharedwork.org/> Begin by clicking on "National Community of Practice on Transition", then click on the Wisconsin link on the left side. If this is your first visit to the site, you will need to register.

# Children and Youth with Special Health Care Needs News

Resources to help with the transition of youth to adult health care is a common question received by the Regional Centers and Family Voices. Fortunately, Wisconsin offers some excellent resources that can be of great assistance to both families and providers.

One resource is a newly published "Transition to Health Care: A Training Guide in Three Parts" from the Waisman Center and is on-line: <http://www.waisman.wisc.edu/wrc/pub.html> This resource compliments other work produced by the Waisman Center around transition issues.

Another resource is also web-based, and is from Children's Hospital

of Wisconsin. They have added a section to their internet page with information about transitioning to adult care. Several transition topics are addressed as well as a Family Resource section with links to several helpful tools and resources. The link to this page can be found at: <http://www.chw.org/display/PPF/DocID/43541/router.asp>

Finally, the Southeast Regional Center for Children and Youth with Special Health Care Needs has developed useful Family Fact Sheets. Transition is just one of several topics that are featured on these fact sheets, which are at:

<http://www.southeastregionalcenter.org/factsforfamilies.htm>

## Policy Update

### Seclusion and Restraint

Disability Rights Wisconsin, in partnership with Wisconsin Family Ties and Wisconsin FACETS, recently released "Out of Darkness, Into the Light," a report which exposes the tragedy of secluding and restraining Wisconsin children in schools and treatment settings throughout the state. It describes the ways in which Wisconsin children have been both emotionally and physically injured by such practices, including one child who died in restraints. It further describes actions taken by many other states to reduce the use of seclusion and restraint of children, and calls for legislative and administrative agency action to protect Wisconsin children from these dangerous practices. The report can be found at: <http://www.disabilityrightswi.org/archives/296>

Representative Sandy Pasch announced that she is drafting a bill which calls for reducing the use of seclusion and restraint in Wisconsin schools, making it safer when it is used, and which encourages the use of Positive Behavioral Interventions and Supports (PBIS) as a tool to prevent the use of seclusion and restraint in Wisconsin schools and teach appropriate behavior.

### BadgerCare Plus Core Plan

Beginning in July 2009, single childless adults ages 18-64 will be able to access Medicaid benefits through a new plan called BadgerCare Plus Core Plan. This plan will provide access to basic health care services, including primary and preventative care and some generic drugs to low-income adults. For more information on this, please contact your county human services department or review the fact sheet on line at: <http://www.badgercareplus.org/core/gampfs.htm>

### State Budget Update

The state budget for the 2009-2011 biennium is currently being debated by the Legislature. Information can be found at the Family Voices website, <http://www.wfv.org/fv/statebudget.html>

Family Voices has drafted a number of budget issue papers on topics that affect children with disabilities and/or special health care needs. These papers are available to be used by advocates as talking points when they speak with policy makers. The Waiting List issue paper is an insert in this newsletter.

Up to date alerts and legislative activity can be found the DAWN website at: <http://dawninfo.org> and additional information can be found on the Arc Wisconsin website at: <http://www.arc-wisconsin.org/>



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



c/o The Arc Wisconsin  
2800 Royall Avenue #209  
Madison, WI  
53713

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Madison, WI  
Permit No. 1108**

**Spring 2009**

## **Volume 4, 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, grant #H84MC07995-02-00

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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 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 Barbara at [barb@fvofwi.org](mailto:barb@fvofwi.org)