



Family Voices Hears From Families and Providers

Family Voices of Wisconsin held its annual Parent Listening Session at the Circles of Life Conference this past spring. This listening session is designed to give parents and providers an opportunity to reflect on services given and received over the past year, comment on challenging situations, and make suggestions for improving the way that services and supports are delivered to children, youth and their families.

Some of the comments included:

- Some families need and want a person who can help them coordinate services and research resources available to the child;
- Families reported feeling unsupported after they transitioned out of services offered through the Birth to 3 program;
- Families with fluctuating income struggle with Medicaid eligibility from month to month and this affects the continuity of care the child receives;
- Children that don't meet the level of care to receive long term support services, but still have high medical needs, don't have access to adequate health insurance coverage;
- There remains a lack of understanding of the lives of children with special health care needs and a continuing need to educate policy makers;
- Families really like working with home health providers and nursing agencies that provide families with the opportunity to choose the worker who comes into their home;
- Families expressed a desire to have more supportive and informative working relationships with partners so that they are well-informed partners; and
- Parents expressed great appreciation for a place to call to get answers to their questions, such as the Regional CYSHCN Centers and Parent to Parent of Wisconsin.

Family Voices uses information gathered from these listening sessions to inform its work with policy makers to improve care for children and youth. Family Voices encourages parents and providers to tell us about their experiences throughout the year by sending an email to Co-Directors Liz Hecht (liz@fvofwi.org) or Barbara Katz (barb@fvofwi.org)

Family to Family Health Information and Education Network

Family Voices of Wisconsin is beginning its work as Wisconsin's Family to Family Health Information and Education Network. This project, funded by the Maternal and Child Health Bureau of the United States Department of Health and Human Services, provides an opportunity for Family Voices to work with families from diverse backgrounds. Family Voices will be adapting its popular "Did You Know? Now You Know!" training program to reflect cultural considerations of Native American families, especially through collaborative work with the Great Lakes Inter-Tribal Council, and linguistic considerations of Spanish speaking families. This adaptation will provide our network of Parent Trainers an opportunity to expand the audiences to which the training is delivered and will provide participants with accessible and culturally relevant information. If you would like to receive more information about any of the Did You Know training formats, please contact Barbara Katz at barb@fvofwi.org



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

Wisconsin Medicaid Handbook

School Based Services

<http://dhfs.wisconsin.gov/Medicaid2/handbooks/sbs/sbs.pdf>

Healthy Wisconsin

<http://www.healthywisconsin.net/>

Medical Home

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

Did You Know? Now You Know!

COORDINATION OF SCHOOL AND COMMUNITY BASED SERVICES

As the school year is beginning, many parents are wondering if their child can receive therapy services in the community while they are receiving therapy services in school through their Individualized Education Plan (IEP). The answer is yes!

The key is coordinating services and treatment plans so that duplicating services is avoided. Families want coordinated services for several reasons:

- Therapies delivered to a child compliment one another. In doing so, families have often reported that a child progresses better when therapy services work together.
- There are different therapy treatments depending if the focus is based on "educational necessity" as written in a child's IEP, or "medical necessity" and is delivered in a community or clinic setting.

- Health insurers, both private insurance and Medicaid, will not pay for duplicated services. Since many school districts bill Medicaid for therapies delivered in schools, this is important to note.

So, how can a family ensure that a child's therapies are well coordinated and non-duplicative? The best answer to this question is to make sure that:

- Parents are involved in goal setting for therapies in the IEP and in community therapy plans. This will help ensure that a child is working on different goals in each setting.
- The therapists should talk with one another to ensure good coordination of services.

There is much more about this topic presented in the "Did You Know" training curriculum. Please see box below for upcoming trainings.

Around the State

"Did You Know? Now You Know!" trainings for the fall are scheduled and you are invited to attend. Registration is free and further information can be found on www.wfv.org/fv Here are some upcoming dates:

Ashland October 3 and October 10 (2 part training) from 9:30 until 3 pm

Rice Lake September 17 and October 15 (2 part training) from 5 until 9 pm

Colfax September 27 and October 11 (2 part training) from 5 until 9 pm

Door County November 3 from 8:30 am until 3 pm

Madison September 20, October 18, November 29, December 20 and January (TBD) (Five part training series).

Other conferences coming up...

Second Annual Respite Conference in Janesville on October 3 from 8:30 to 2:15 pm. Contact Family Respite Care Services at 608-758-0956 or email at family.respite@sbcglobal.net

18th Annual Children Come First Conference October 18 and 19 in the Wisconsin Dells. Register online at: www.wccf.org/event_ccf2007.php

The first annual Wisconsin Self-Determination Conference, "Organizing for Self-Directed Supports" on November 5 -7 in the Wisconsin Dells. For more information, contact Steve Stanek at 608-266-8337 or email at stanesj@dhfs.state.wi.us

Children with Special Health Care Needs News

Medical Home Summit: Small Steps, Big Changes

The second annual Medical Home Summit will be held on November 15 at the Country Springs Hotel in Waukesha from 9 am until 4 pm. Registration is free and can be completed by contacting Sharon Myhre at the Waisman Center at myhre@waisman.wisc.edu or at 1-800-532-3321. Continuing Education (CEU) credits are available. In addition, Family Voices is offering a limited number of stipends for family members to participate. Please contact Barbara Katz at barb@fvofwi.org for more information on the stipends.

This year's summit will feature

keynote addresses by Dr. Carl Cooley, a pediatrician and co-director at the Center for Medical Home Improvement, and parent Brenda Sulok and physician, Lisa Zetley, both affiliated with the Downtown Health Center in Milwaukee. Other highlights of the day include sessions on Developmental Screening, Outcomes and Financing, Transitions, Partnership Building and Links to Community Care.

Medical Home is an approach to providing comprehensive primary care for children, youth and adults. Children and their families who have a medical home work in partnership to identify and access medical and non-medical services need to achieve their maximum potential.



Children and Youth with
Special Health Care Needs

CYSHCN CENTERS

Call with your
questions!

Northeastern Region

St Vincent Hospital
Green Bay
1.800.236.3030 ext.
8296

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

Policy Update

Update on the State Budget

As of this newsletter printing, Wisconsin is the only state in the country that has not passed its current budget. In February, the Governor presented his budget to the Legislature. During the summer, the Senate and the Assembly each passed their own versions of the state budget. These budgets differed significantly in both dollars and philosophy, so a conference committee, comprised of key legislators from both the Senate and the Assembly, is working to draft a budget that resolves the differences between the Senate and the Assembly versions of the budget.

Here is a brief update on the status of two proposals which will impact all children with long term support needs and are included in the current legislative budget discussions: 1) The request for funding for piloting concepts of managed care with children, as recommended by the Council for Children with Long Term Support Needs, was included in the Governor

and Senate versions of the budget, but was eliminated from the Assembly version. (See Spring 2007 Family Voices newsletter.) The current conference committee could include this proposal in its version of the budget. However, to date, they have heard from few people about the importance of this initiative. (For more information on this proposal, please see the minutes from the Council for Children's Long Term Support Needs, at: <http://dhfs.wisconsin.gov/bdds/clts/council/Minutes20070320.pdf>)

2) Although not in the Governor's budget, the Joint Finance Committee passed a proposal providing \$4.4 million over two years (with an additional federal match of about \$10 million) to address waiting lists. (The Spring 2007 issue of the Family Voices newsletter also had information about waiting lists.) This proposal remained in the Senate and the Assembly versions of the budget, so this will be in the budget that goes to the Governor for approval.

The next issue of this newsletter will have a summary of the new budget that affects CYSHCN.



c/o The Arc Wisconsin
600 Williamson St.
Madison, WI
53703

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Fall 2007

Volume 2, Issue 2

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 by funds from the Centers for Medicare and Medicaid Services.

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About Family Voices of Wisconsin

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. 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 level.

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!