



FAMILY VOICES IDENTIFIES STRATEGIES TO INCREASE PARTICIPATION BY PARENTS FROM MINORITY GROUPS

Families who have children and youth with disabilities and/or special health care needs and are from particular cultural or ethnic backgrounds, including parents of Native American, African American and Hispanic backgrounds, are under represented in partnership, leadership and decision making activities in Wisconsin. It has been our finding that this under representation is not due to lack of interest from systems to include individuals from these populations, or lack of interest from individuals from these backgrounds to participate in advisory capacities, but rather is a result of inadequate supports and cultural understanding of these ethnic groups.

Several months ago, Family Voices spoke directly with families to learn what supports and understanding would facilitate greater parental participation in decision making roles that affect

children beyond their own. What was found, beyond all else, was a common theme for the need to develop authentic relationships with families. A person trusted by the community, a cultural broker, can assist with connections that develop trust and good will. This person would then pave the way for greater parental involvement.

Family Voices took the responses from the participants in the focus groups and developed a report based upon their suggestions. Their recommendations, along with ideas for effective parental recruitment, training and support, are explored in the report.

Please contact Family Voices if you would like to receive a full copy of the report and it's recommendations. You can download the publication later this fall from our website, www.wfv.org

FAMILY VOICES HOLDS RETREAT FOR PARENT LEADERS

This past summer, Family Voices of Wisconsin held its first parent leadership retreat in Waupaca to strengthen the connection and networking among parent leaders working in different systems of support for children, including health care and education. Nationally renowned parent and speaker, Janice Fialka, joined us and led us through a reflective, renewing and inspiring day. (For more information on Janice, visit her website at www.danceofpartnership.org)

One activity that the group participated in was identifying the top ten things they felt parents of kids with special health care needs absolutely needed to know. Not surprisingly, adequacy, availability and access to health insurance ranked right at the top. Other priorities included: knowing who to call for answers to questions and informational support; learning about possibilities for children as they grow up (sometimes parents need to know what they don't even know they need to know!); and how to document a "life plan" for one's child, that captures the family's values, beliefs and logistics of care, when they are no longer around.

The day provided lots for the parents to take away with them as they continued on their leadership journey, refreshed and rejuvenated!



Did You Know? Now You Know!

WHAT CAN YOU DO WHILE ON A WAITING LIST FOR SERVICES?

For many families who are on waiting lists, it is common to feel frustrated. You know that your child needs more supports, but there aren't funds to support those needs. The reality is that the formal systems of support simply do not have the capacity to serve everyone that needs support in the community. So, perhaps while you are waiting, it would be helpful to look at informal supports.

What are informal supports, you might ask. Essentially, informal supports are those people — family, friends, parents of CYSHCN, neighbors, members of your faith community, service organizations like Elks Clubs, volunteer organizations like RSVP (retired people), co-workers — who you can count on to help you with something you or your child needs. Some families form

child care co-ops with other families in their communities. Other families fabricate therapy equipment for their child out of everyday materials. Creativity is key here! In addition, many communities recycle durable medical and therapy equipment. You might very well find something your child needs from those resources.

Finally, you might want to make sure that you are utilizing your existing formal supports to their maximum benefit. This would be a good time to review your private health insurance policy (if you have one) and to make sure that you are aware of the range of benefits offered by your child's Medicaid card.

The Regional CYSCHN Center staff can help you identify resources in your community and understand your health insurance. They are waiting for your call!

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

MEDICAID HANDBOOK:

<http://dhfs.wisconsin.gov/medicaid2/index.htm>

MEDICAL HOME:

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

NATIONAL KASA:

<http://www.fvkasa.org/resources/health.html>

FAMILY VOICES NATIONAL OFFICE:

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

Around the State

KIDS AS SELF ADVOCATES

KASA (Kids as Self Advocates) is a statewide network for youth with special health care needs. They work to help youth have control over their lives through peer support and training. KASA's goal is for youth to become self-advocates and leaders and to have a voice in issues that affect them. KASA provides opportunities for youth to get involved in their communities, meet other youth with disabilities, and to find out what's going on in Wisconsin for youth with disabilities.

You are invited to sign up to be a part of KASA's Youth Network and receive the latest news and information about KASA's activities. You will receive information about:

- State and local KASA chapters

- Trainings, conferences and events
- Newsletter and listserv

Please contact Kirsten at KASA for more information: kasawisconsin@aol.com

WCDD LOOKING FOR KIDS ON WAITING LISTS

The Wisconsin Council for Developmental Disabilities is looking for children and youth who are waiting to receive services in their community to appear in its new video that will be shown to legislators during this current budget cycle. Called "Heartsick," the video features photographs of children and their families and is set to original music written and produced by The Figureheads, a hip hop group based in Madison. For more information on this opportunity, please contact John Shaw at 1-800-266-7707 or by email at shawj2@dhfs.state.wi.us

Children with Special Health Care Needs News



Children and Youth with
Special Health Care Needs

Bridging the Quality Chasm

Are you still wondering what in the world a medical home is? And why do people keep talking about it? And how can you get one? The "Medical Home Summit: Bridging the Quality Chasm" should answer your questions. Held at the Wintergreen Resort in the Wisconsin Dells on **Thursday, November 9, from 9 am until 4 pm**, the Summit is designed for families, physicians, nurses, care coordinators and other health care and community providers who serve children and youth with special health care needs.

Topics to be covered include:

- improving the care of children and youth by applying the components of medical home in a physician's practice;
- strategies for building and strengthening parent-provider partnerships; and
- creating connections with school and community resources.

For more information on this wonderful opportunity, please contact the Waisman Center, 608-265-8955 or by email: myhre@waisman.wisc.edu

Policy Update

BADGER CARE PLUS

A New Proposed Initiative

Governor Doyle has proposed a new initiative to ensure that all of Wisconsin's children have access to health care with the creation of a single health care initiative called BadgerCare Plus.

BadgerCare Plus is proposing to merge Family Medicaid, BadgerCare and Healthy Start to form a comprehensive health insurance program for low income children and families. Coverage will be expanded to seven new populations:

- All children (birth to age 19) with incomes above 185 percent of the federal poverty level (FPL)
- Pregnant women with incomes between 185 and 300 percent of the FPL (*for a family of four, this would be between \$37,000 and \$60,000 a year*)
- Parents and caretaker relatives with incomes between 185 and 200 percent of the FPL (*for a family of four, this would be between \$37,000 and \$40,000 a year*)
- Caretaker relatives with income between 44 and 200 percent of the FPL

(for a family of four, this would be between \$8,800 and \$40,000 a year)

- Parents with children in foster care with incomes up to 200 percent of the FPL (*for a family of four, this would be \$40,000 a year*)
- Farmers and other self-employed parents up to 200 percent of the FPL, contingent upon depreciation calculations.

In addition, Wisconsin will streamline eligibility; assist employees in purchasing quality, employer-sponsored coverage; and provide incentives for healthy behaviors.

This proposal represents the most sweeping reform of the low-income, family portion of the Medicaid program in Wisconsin since its inception in 1967.

Currently, this proposal is waiting approval from the Centers for Medicare and Medicaid Services in Washington and then will go to the state legislature for debate. The most current information on the BadgerCare Plus initiative can be found on the web at: <http://dhfs.wisconsin.gov/badgercareplus>

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



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

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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 levels.

Family Voices Offers Expanded Training Menu

Family Voices of Wisconsin is pleased to offer a menu of training opportunities for providers and families on health care and community resources for children and youth with special health care needs and can customize trainings to meet specific learning goals. Our "Did You Know? Now You Know!" training, held in communities throughout the state, offers a comprehensive overview of Wisconsin's health and community support systems for children and youth, including youth in transition to adult services. Topics include:

- Using Medicaid for children and youth with disabilities and/or special health care needs
- Family-Physician partnerships
- Family Advisory Committees — nuts and bolts
- Private and public health insurance, including handling prior authorizations, denials and appeals.

For more information, please contact Liz or Barbara at Family Voices. We look forward to designing a training that meets your needs!