



This edition of the Family Voices newsletter focuses on public policy and state budget issues that affect children and youth with disabilities and special health care needs. Family Voices advocates for cross-disability issues and public policies that improve the lives of children with disabilities and/or special health care needs and their families. Thanks for your support and interest in this important matter!

A LIFE IN THE COMMUNITY FOR CHILDREN WITH DISABILITIES

The Wisconsin Legislature made a commitment to a partnership with families whose children have significant physical, developmental and behavioral/emotional disabilities by passing legislation creating the Family Support Program (1987), and authorizing the Children's Redesign (2001), including the Children's Waivers (2004). This legislation was supposed to create a comprehensive array of supports for children with disabilities. Unfortunately, supports are not available to many families who desperately need them. The financial commitment to services and system improvement for children with disabilities has not kept pace with the need. Currently more than 3500 eligible children are waiting for supports and services that could better connect them to their life in the community. To address this need, the Survival Coalition of Wisconsin Disability Organizations (of which Family Voices is a member) recommends the following:

- **Reduce waiting lists for long term supports by two-thirds (supporting an additional 2000 families).** There are many families who simply cannot wait any longer. Legislators should allocate funding to address waiting lists for children needing access to long-term supports.
- **Improve the current system.** Direct Department of Health and Family Services (DHFS) to seek the needed federal authority to pilot the use of managed care to meet the long-term support needs of children and provide funding to pilot a system that provides information, assistance, advocacy, and access to supports and services that is responsive to the unique needs of children and families.
- **Provide adequate health care coverage.** Many children and youth with special health care needs have inadequate insurance or are at risk of losing private coverage due to policy limits. A solution is to modify the proposed Badger Care Plus expansion to include these children with significant medical costs or disability (meeting SSI criteria), but who do not meet the level of care for Katie Beckett or the Children's Waivers. This group is at risk for poor health outcomes, and eventual high cost to the public sector without expanded coverage. Examples include children with spina bifida, mild cerebral palsy, cancer, organ transplants, and hemophilia.
- **Expand collaborative systems of care (i.e. wraparound) for youth with serious emotional disturbances.** Wraparound systems of care positively impact the functioning of children with serious emotional disorders and their families. By involving the family in all aspects of care planning, decision making and service delivery, parents can start to regain a sense of control over what can be an overwhelming situation.
- **Increase special education categorical aids.** Perpetuating an under-funded system is unacceptable, which is why we urge the legislature to add more funding that the Governor has proposed.

This section is excerpted from a position paper from the Survival Coalition of Wisconsin Disability Groups. To read the entire position paper from the Survival Coalition, please visit the Family Voices of Wisconsin web site at: <http://www.wfv.org/fv/pdf/sb-SurvivalBudget.pdf>



WEB WATCH

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

Family Voices of Wisconsin Policy Issues:

<http://www.wfv.org/fv/statebudget.html>

Disability Advocates of Wisconsin Network (DAWN) — to find out contact information for the Joint Finance Committee members

www.dawninfo.org/advocacy/legislature.cfm

Legislator Look-Up — find your legislators and their contact information

<http://waml.legis.state.wi.us/>

Did You Know?

The state legislature sets priorities and makes decisions about how to spend public dollars. Your legislative representatives want to hear from you about what your priorities and needs are. Representatives will only know what's important to families and children with disabilities if you tell them.

The first page of this newsletter outlines concerns for children with disabilities and special health care needs that have been defined by the Survival Coalition and Family Voices of Wisconsin. You might find that one or more of these issues also concerns you. If this is the case, please take a few minutes to contact your legislator. Members of the State Legislature receive surprisingly few letters from their constituents and they pay a lot of attention to those they do receive.

While letters have the most visual impact other than meeting your legislator face to face, a phone call or e-mail is better than no contact at all! However you decide to communicate, the following suggestions will be helpful in preparing what you want to say.

- **Tell a story.** Stories are what people remember. Use personal examples to make your point. Your story

is what makes the issue real for your representative and deepens their understanding.

- **Know what story to tell.** Tell only the parts of your family story that are relevant to the issue that you want your representative to understand. Be honest, and don't exaggerate. However, do be clear in telling a story that has a great impact. It is tempting to want to talk about many of your family's challenges, but it is best to focus on only one or two issues during your conversation. Remember — you do not have to be an expert on an issue to speak to your legislator.
- **Tips for delivering your message.** Begin by introducing yourself and mentioning that you are a legislator's constituent. Continue by introducing the issue or problem that you want them to understand, and highlight it with your personal story. Conclude with what you think needs to be done and what you would like your legislator to do. Mention how this action will help your child and family. Most of all, be brief, clear and concise.
- **Follow up with a brief thank you note.** This will help the legislator remember you and your concern.

Around the State

"Did You Know? Now You Know!" trainings will be held at least two times in each CYSCHN region during this year. The first two trainings, scheduled in May, are listed below. For a training in your community, please check the Family Voices website for the most up to date information.

The following trainings are free and provide lots of useful information. Registration is necessary.

- **Saturday, May 5** 9 am—4 pm
Heritage Room C, Third Floor
St Vincent Hospital, Green Bay
To register, please contact:
Wanda Sperry, Northeastern Regional CYSCHN Center
1-800-236-3030 ext 8296
wanda.sperry@stvgb.org

- **Tuesday, May 8** 9:30 am—4:30 pm
Community Room, Ceder Creek Mall
Rothschild

To register, please contact:
Jill Nelson, Northern Regional CYSCHN Center
1-866-640-4106
jnelson@mail.co.marathon.wi.us

Disability Awareness Rallies

Rallies will be held in Racine, Eau Claire and Milwaukee during the next several weeks...April 30 at 8:30 am at the Racine Marriott...May 11 at 10:30 am at the Eau Claire Expo Center...May 18 at the State Fairgrounds in Milwaukee. For further information, please contact John Shaw at the Wisconsin Council on Developmental Disabilities at 1-888-332-1677

Children and Youth with Special Health Care Needs News



Children and Youth with
Special Health Care Needs

Input Sought for the Maternal and Child Health Block Grant

Parents are encouraged to provide input into the annual Maternal and Child Health Block grant proposal. This Block Grant supports programs and organizations that your family may use, including Wisconsin's Regional Children and Youth with Special Health Care Needs (CYSHCN) Centers, First Step, Parent to Parent and Family Voices. Your comments are important to Department of Health and Family Services staff as they continue to work to strengthen their programs so that they are more responsive to families like yours. Your comments will be anonymous, so you will not receive a personalized response. You can offer your comments at the following website: http://dhfs.wisconsin.gov/DPH_BFCH/PublicInput.htm

Policy Update

What Can I Do To Make a Difference?

Oftentimes, parents are interested in communicating their concerns to policy makers and to the general community, but are unsure where to begin. Here are a few suggestions about how you might take action to impact an issue of concern.

- Join the Family Voices of Wisconsin email network. Visit www.wfv.org/fv to join our email listserv and get the most up to date information on issues.
- Find out who your legislators are and contact them. Currently, the legislature is deciding how to allocate state funds for the 2007–2009 state budget. This budget process takes place every two years.
- If possible, testify at a Joint Finance Committee hearing. In addition, you can write letters to the Joint Finance Committee members. See "Web Watch" for contact information.
- Meet with a legislator in person. You can visit them in Madison or in their local office (many legislators hold office hours in their district); you can invite them to your home; or you can invite them to a meeting with families in your community. A meeting makes it easier for you to develop a relationship with a legislator.
- A face-to-face meeting has more impact than a letter. However, if a meeting is not possible or comfortable for you, an individualized letter is next best. An advantage of a letter over a phone call or a visit is that you can take the time to think over what you want to say and how to say it.
- A phone call is preferable to a non-personalized letter or email. An advantage of a meeting or a phone call is that if the legislator or their aide doesn't understand something you've said, you can explain it immediately.
- Use the DAWN "Take Action" tool to easily send a letter to your legislator. Visit www.dawninfo.org to access this tool.
- Remember to vote! There are many, many close elections and your vote truly can make a difference! When you speak with legislators, they will often check voting records to see if you are a regular voter; this matters to them.

Sometimes, legislators simply cannot meet with all their constituents. If this is the case, and a meeting with an aide is offered, take that opportunity. Staff that work with legislators are often assigned specific areas of interest, and their job is to communicate your concern to the legislator.

Finally, whether you meet in person, write or call, keep it brief. If you can make your point quickly, clearly, and simply, it will be absorbed and remembered.

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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Contact Us

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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 Receives Funding From the Maternal and Child Health Bureau!

We are pleased to announce that Family Voices of Wisconsin recently received notice of funding for its Family to Family Health Education and Information Network (FVF2F). This three year grant, received through a competitive process, will enable Family Voices to broaden and deepen its network of families and advocates across Wisconsin. This project further establishes Wisconsin's attention to the needs of families of children and youth with special health care needs to access quality and timely health information, training and services by building on the current Family Voices efforts, in collaboration with the Regional Centers for Children with Special Health Care Needs and its partner organizations. Families throughout Wisconsin will benefit from the FVF2F network because it will strengthen their ability to access health information and resources, navigate the complex service system, and develop leadership skills to assure that all parents of CYSHCN are partners in decision making. Watch for updates of this exciting project in the next newsletter!

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!