

*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*

The School Nurse - An Important Member of the Team



Health is critical to school success! For families who have children with chronic conditions or complex medical needs, that means creating a school team trained to administer medications, use equipment and recognize when urgent medical attention is needed.

The school nurse can be a critical member of your child's team. According to Louise Wilson, WI Department of Public Instruction School Nurse Consultant, "The school nurse can be your child's best advocate! He or she can communicate with teachers, administrators and other staff and advocate for your child."

Partnering with the School Nurse

- ◆ **Meet Face-to-Face and Communicate:** Frequent contact with the nurse to keep him/her updated on your child's medical needs will help all school staff provide better care. Ask the nurse the best way to keep in touch: phone, email or notes in the backpack.

Keep in mind that Wisconsin schools are not required to have full-time nurses, so find out when the nurse is in the building and who is responsible when the nurse is not there. For example, if your child has a seizure or an asthma attack when the nurse is not there, find out who is trained and ready to help.

- ◆ **Sign "Release of Information" Forms:** While families can decide what medical details to share with teachers, it is important that the nurse has a full understanding of the child's condition. Signing release forms will allow him/her to share details and communicate with the doctor.

- ◆ **Make the Nurse Part of Your Team** - The school nurse should be a member of your child's IEP team. "While other staff try to determine how that condition affects learning and have different areas for which they are concerned, the school nurse will likely have a more global approach," stated Ms. Wilson.

The nurse will write and update your child's Individual Health Plan and an Emergency Action Plan (if needed) and will be responsible for either providing direct nursing care or delegating those responsibilities to other school personnel.

Families can work closely with the school nurse to determine who will provide the delegated nursing services. They can share ideas and preferences, and provide input on staff training. Some families find it helpful to participate in the initial training alongside the nurse.

Having a good relationship with the nurse means that families can work together to resolve problems before other actions are needed. See "*Communication Options for Families*" when a dispute occurs at www.familyvoicesofwisconsin.com/school-health/

Know Your Rights!

While a child's IEP team (including parents) can decide what is best for a child, a school district cannot deny attendance based on a child's medical condition or nursing care needs. They cannot require a child to attend another school or attend school for a shortened school day due to lack of staffing or resources.



WEB WATCH

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

[National Office of Family Voices](http://familyvoices.org)

familyvoices.org

[Family Voices of Wisconsin](http://familyvoicesofwisconsin.com)

www.familyvoicesofwisconsin.com/school-health/

[Survival Coalition](http://www.survivalcoalitionwi.org)

www.survivalcoalitionwi.org

[DPI School Nursing and Health Services](http://dpi.wi.gov/sspw/pupil-services/school-nurse)

dpi.wi.gov/sspw/pupil-services/school-nurse

Did You Know? Now You Know! Including Health Outcomes in your Child's IEP

Children and teens with life-long health issues need to learn early how to maintain and sustain their own health and participate in their health care decisions.

One important way children can start to practice taking control of their own needs is to include health outcomes in their IEP.

Health-related IEP goals will encourage a child to take on more independence and provide school supports to help the child meet these goals. This can be especially important for high school students who will be transitioning to adult health care and becoming more independent

Starting the Process: You and your child can talk with the school nurse or other school staff who support your child's health related needs. Are there ways that they can use communication, self-help or other skills to be more active in caring for their own needs?

Record Challenges in the IEP: The IEP team can document health conditions that impact your child's ability to fully participate in school.

Goals can then be developed to help address those concerns or challenges.

Some Examples of Health Outcomes in an IEP:

- ◆ If a teen has asthma that is not well controlled, their *Present Level* section could state, "Jason is not able to recognize the triggers of his asthma which makes it difficult for him to communicate his need for his inhaler." An IEP goal, under the category of "Self Help" could be: "Jason will start to record the triggers of his asthma and will communicate his need for his inhaler to school staff."
- ◆ If child uses a wheelchair and experiences pressure sores, their *Present Level* could state, "Sarah is not able to communicate her need to be repositioned which has caused absences from school due to pressure sores." An IEP goal, under a Communication category, could be "Sarah will use her AAC device to communicate with school staff when she needs to be repositioned to avoid pressure sores."

To learn more, see [Health and the IEP](#) resources from the Waisman Center.

Regional Family Voices Facebook Pages

Our new regional Facebook pages are a great way for families who have kids with special needs to connect and stay informed on a local level.

Want to Join?

Contact Katy at katy@fvofwi.org

By the Numbers: Family Voices of Wisconsin

Family Voices of Wisconsin continues to expand its services and supports to families around Wisconsin!

2016 Summary

FV Website Visits: 31,550

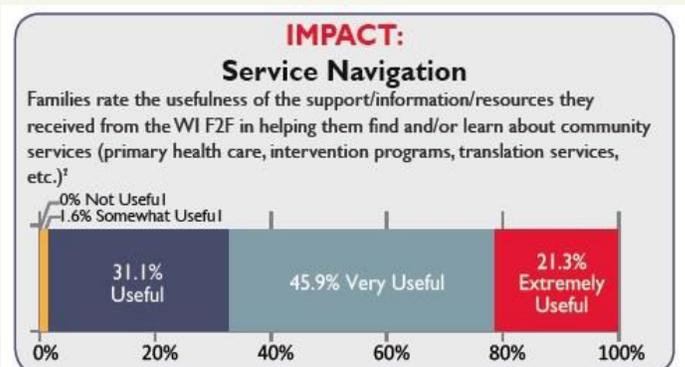
Materials Disseminated: 13,000

Families Served: 13,175

Professionals Served: 8,915

Newsletter Subscribers: 3,500

Training Sessions: 60



*To donate to the important work of Family Voices, go to [DONATE](#) on the FV website! *

Children and Youth with Special Health Care Needs News



Children and Youth with
Special Health Care Needs

Family Voices Training Sessions



Join us for one of our informative training sessions to learn about supports and services for children and youth with special needs. Sessions will be held around the state in partnership with the Regional Centers (see sidebar for contact information). For details go to www.familyvoicesofwisconsin.com/trainings/

[What's After High School?](#) is a broad overview of the transition to adult life for youth with disabilities and special health care needs. Topics include the role of schools, long-term supports, transitioning to adult health care, supported decision making and more.

[Did You Know? Now You Know!](#) explains resources and services for children with disabilities and special health care needs from birth through young adulthood. Topics include Medicaid, private insurance, how to best use your benefits, long-term supports, appealing an insurance denial and more. ****This training is available online! ****

[Coordinating Your Child's Health Care](#) explains coordinated care, a medical home and integrated health care for every child. Tools like the Shared Plan of Care are discussed and ideas for maintaining this plan are given. ****This training is available online! ****

SAVE THE DATE! Advocacy for Change 2018

Join us on Thursday, April 12 in Madison for our annual full-day advocacy skills training event! Advocacy for Change participants learn how to tell their family story in ways that impact policy and systems change and meet with their legislators at the Capitol. Registration will be open in January. To learn more go to "[Advocacy for Change.](#)"



Legislative Update

Funds to End Children's Long-Term Supports Passes in State Budget!

Family Voices has been advocating for over two decades to increase state funding for children's long-term supports (CLTS) so families don't have to wait for essential services. We are thrilled that the final 2017-2019 state budget included funding to end wait lists! The budget adds a total of \$39 million in additional funding to counties who administer the CLTS Waiver Program.

Family Voices applauds Governor Walker's commitment to providing adequate funding to counties so that families have the resources and funds they need to care for their child with special needs. **When you speak with your state legislators, we encourage you to thank them for supporting this funding!!**

Want to learn more about the CLTS program? Check out the new "[Children's Long-Term Support Program](#)" **fact sheet!** All our useful fact sheets are available on FV website.

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



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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 partnership.

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

- Education and information, including trainings, fact sheets, and newsletters;
- Family leadership activities, including the annual *Advocacy for Change* training (April 12, 2018); and
- Public policy and systems change activities.

WE NEED YOUR EMAIL ADDRESS!

You are receiving this newsletter in the mail because we do not have your email address. Please let us know if you'd like to continue to receive the newsletter in the mail or if we can email it to you.

Call Lynn at 608-828-9959 or email Lynn@fvofwi.org

2017-2019 State Budget Summary

The state budget, signed into law by the governor in late September, has many positive measures that show our state's commitment to supporting and improving the lives of families who have children and youth with disabilities. Below is a summary of issues which Family Voices, in partnership with the Survival Coalition, has been monitoring throughout the budget process. To learn more, see the Family Voices state budget webpage at www.familyvoicesofwisconsin.com/public-policy/state-budget/

- ◆ **Ending CLTS Wait Lists:** Family Voices has advocated for over two decades for increasing the state's financial commitment to children's long term support programs. We are thrilled that the budget includes \$39 million towards the elimination of Children's Long-Term Support wait lists. This will impact close to 2,600 children with developmental, physical or emotional disabilities whose families need funding to keep their child at home and participating in their school and community.
- ◆ **Adult Long-Term Support Programs:** The budget provided funding to continue the state's commitment to expanding Family Care and IRIS across the state. These long-term support programs for adults (those age 18 and older) with disabilities and the elderly will be available statewide by 2018.
- ◆ **Increase in Medicaid Personal Care Reimbursement:** A 2% increase was included in the budget to support the personal care program direct care workforce. However, this is less than the 15% rate increase advocates requested. Many families continue to struggle to find and hire qualified personal care providers and the workforce shortage will likely continue for both adults and children who need in-home personal care services.
- ◆ **Mental Health Funding:** The budget provides increased mental health funding for adults and children, which includes funding for a children's crisis treatment and stabilization facility, a peer run respite center, and the Child Psychiatry Consultation program.
- ◆ **Medicaid/Medical Assistance Purchase Plan:** The budget includes updates to the Medicaid Assistance Purchase Plan (MAPP) work incentives program. The Survival Coalition noted that these changes are a promising start to addressing the limits placed on people who want to work and earn more, but who also need to afford their health insurance.



Public Education:

- ◆ The budget provides increases in general school aids, increases in per-pupil aids, additional funding for mental health programs, and a bullying prevention grant.
- ◆ **Youth in Transition:** The budget includes funding for a Transition Incentive Grant program, which provides payment to school districts based on postsecondary education and employment outcomes for students with disabilities. It establishes a new grant program to support school districts in identifying and creating competitive work opportunities for students with disabilities and successfully placing those students in meaningful work opportunities.
- ◆ **No New Funds for Special Ed:** The budget did not however, provide any increases in special education categorical aid, which has remained flat over the last decade. In addition, disability advocates were very disappointed to see the significant expansion of the special needs scholarship program.

To stay updated on legislation and other policy changes, go to [“Stay Informed”](http://www.familyvoicesofwisconsin.com/leadership/stay-informed/) at www.familyvoicesofwisconsin.com/leadership/stay-informed/

Federal Marketplace Open Enrollment - *Get Ready Now!*

Open enrollment for purchasing insurance through the Marketplace (Healthcare.Gov) starts November 1 and ends December 15. This is a shorter enrollment period than in past years and there is less funding for 1-on-1 assistance to help families sign up. Plan ahead and get your questions answered so you will be ready on November 1!

Use the new [Marketplace Checklist](#) to be learn what you’ll need so you will be ready to sign up. Go to www.healthcare.gov/downloads/application-checklist.pdf

For families who have children with special needs consider the following:

- ◆ If I change plans, will my child’s providers still be in the network?
- ◆ What additional costs will my family be responsible for paying if we need to go to an “out-of-network” hospital or medical provider?
- ◆ Do I anticipate new therapies, surgeries or large medical expenses next year? What will the costs (including premiums, co-pays and deductibles) be in a new plan vs my existing plan?

To find local assistance to answer questions and help with signing up for a Marketplace plan go to www.coveringwi.org/enroll. Covering Wisconsin (www.coveringwi.org) also has great resources, including *How To* Sheets, to learn about insurance and how to use your benefits.