Amplifying Family Voices:
Advocacy, Support & Connection

Melanie L. Kretschmer *she/her*

Advocate • Parent • Partner

Community Engagement Specialist, Family Voices of WI

Family Voices of Wisconsin

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What will we cover today?

Family Voices of Wisconsin

About Me
- My background and what brought me here today

About Family Voices of WI
- Who we are, our mission, and why family voice matters

Resources
- Education and plain language information
- Finding services, resources, and support

Family Leadership and Advocacy
- Building connections and community
- Family leadership and systems change
- Partnerships: Who is the expert?

Your Voice Matters
- The importance of lived experience
- Opportunities to share, connect, and make a difference

Staying Connected
- How to find us and stay involved
- Questions and closing thoughts

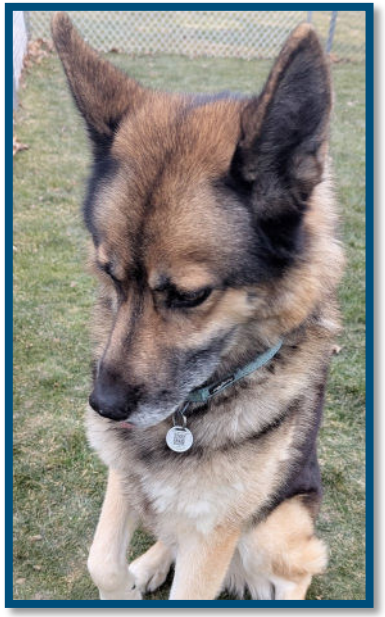


About Me









My background spans across education, health, and human service-related worked, but my children have given me some of my most valuable experience and expertise.

My personal and professional experiences have shaped my passion for supporting families and professionals, particularly in rural communities, where families can face unique barriers to accessing care, services, information, and support.

I live in Marshfield, WI.

My husband Joe and I have two children, Dominic (16) and Naomi (10).

We adopted our senior dog, Pierre in 2024.

I love to read, walk, “glamp,” and travel.

What brought me here today?

A combination of professional experience, lived experience, and a passion for supporting families.

- **Youth & Education:** Working with at-risk youth in school settings
- **Clinical Care and Child Advocacy:** Supporting children and families in the primary care clinical setting and within the Child Advocacy Center working with victims of abuse and neglect
- **Family Experience:** Embracing the unexpected and parenting a child with a disability
- **Kinship Caregiving:** More on the unexpected – serving as a guardian for a youth family member impacted by family substance use and neglect
- **Family Voices of WI**: Combining lived and professional experience. Connecting families with information, resources, and support through plain-language education

A passion for listening, sharing information, building connections, and supporting families navigate complex system a bit more easily.

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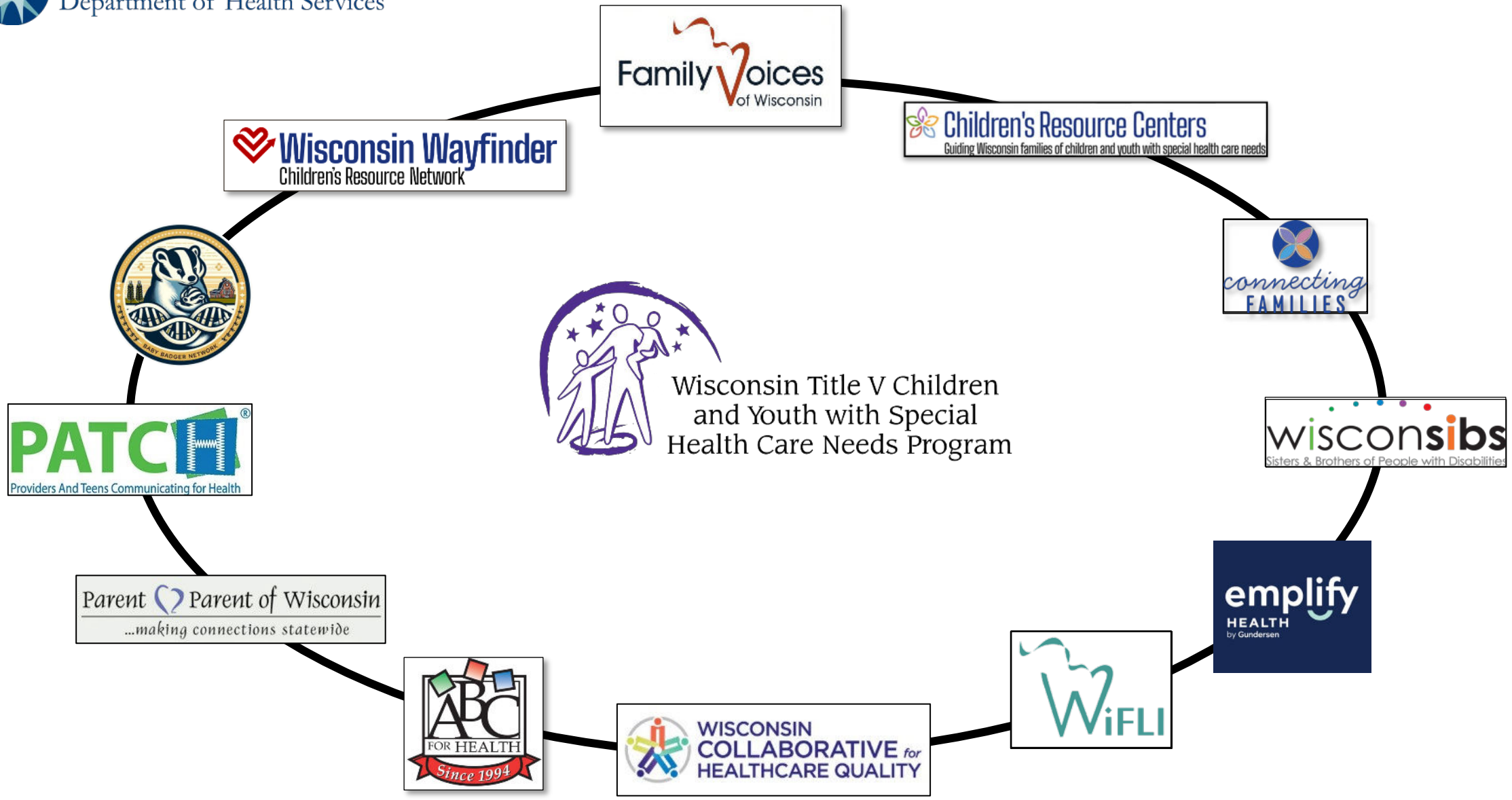
YouTube.com/
familyvoicesofwisconsin

instagram.com/fvofwi

Family Voices supports families of children with disabilities and special health care needs. We empower families to navigate health care, services, and community resources, and build leadership and advocacy skills.

As a family-led organization, we promote family-centered care and strong partnerships between families and professionals.

Wisconsin
Department of Health Services



Family Voices of Wisconsin

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Information Sharing

- **Fact Sheets**
- **Learning Sessions**
  - In-Person
  - Virtual
  - On-Demand
- **Newsletters**
- **Website**
  - Accessible

Family Leadership

- **Advocacy Events**
- **Circles of Life Conference**
- **Coaching**
- **Policy Updates**
- **Skill Building**
- **WiFLI**
  - Leader Reader
  - Office Hours

System Collaboration

- **Community Outreach**
- **Family Engagement**
- **Improvement**
- **Partner Agencies**
- **Support Organizations for Regional Benefit**

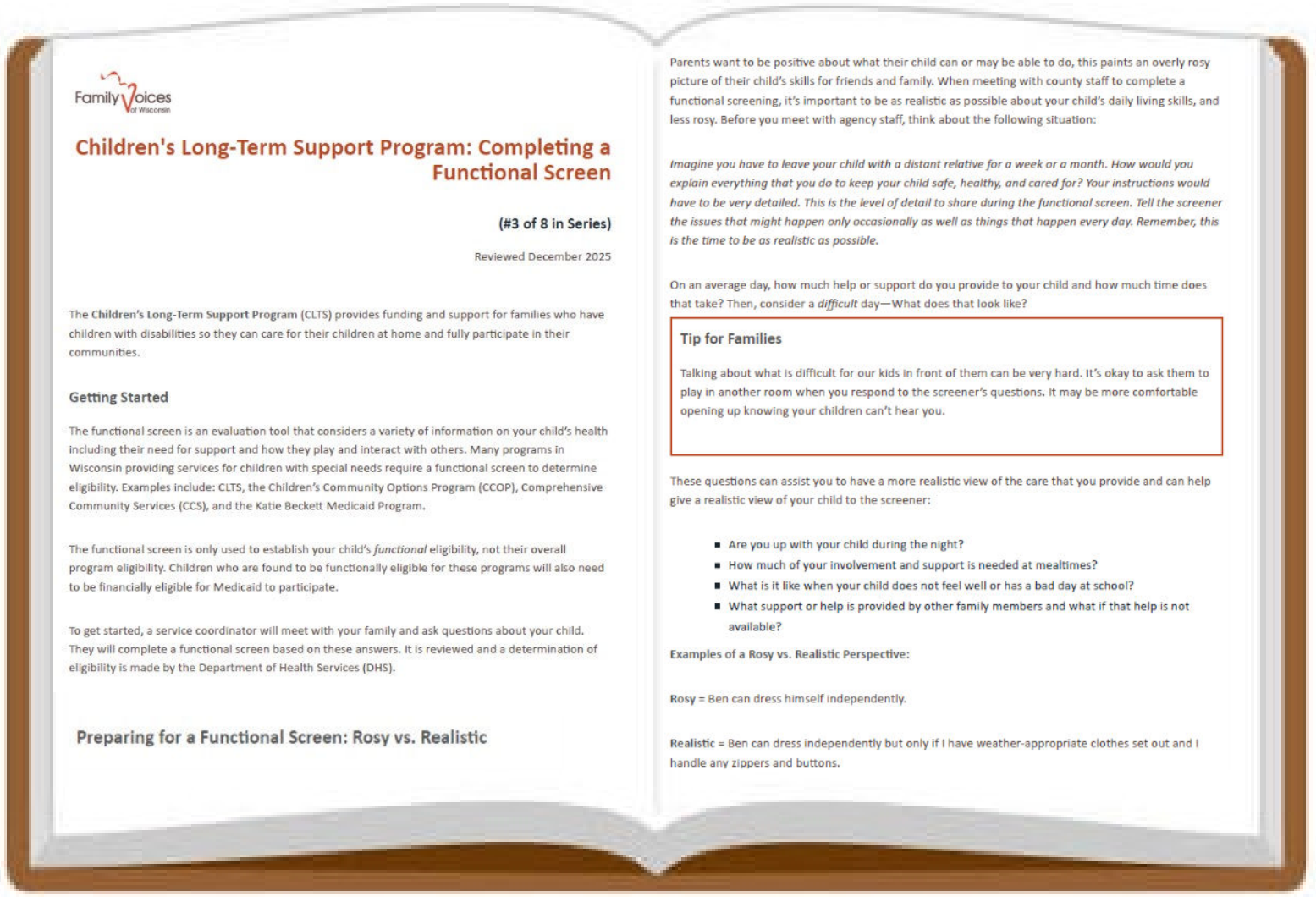
Our Work at Family Voices

- **Information Sharing**
  - Sharing information in plain-language, easy-to-understand formats, including fact sheets, learning sessions, newsletters, and social media.
  - Making complex systems and programs easier to understand for families and professionals
- **Supporting Family Leadership**
  - Supporting public policy and systems-level improvement
- **Partnerships**
  - Building partnerships with professionals and community-based organizations
- **Quality Improvement and Continuous Learning**

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Plain language matters.

Understanding information builds confidence and helps families navigate systems and supports.



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Children's Long-Term Support Program: Completing a Functional Screen

(#3 of 8 in Series)

Reviewed December 2025

The **Children's Long-Term Support Program** (CLTS) provides funding and support for families who have children with disabilities so they can care for their children at home and fully participate in their communities.

Getting Started

The functional screen is an evaluation tool that considers a variety of information on your child's health including their need for support and how they play and interact with others. Many programs in Wisconsin providing services for children with special needs require a functional screen to determine eligibility. Examples include: CLTS, the Children's Community Options Program (CCOP), Comprehensive Community Services (CCS), and the Katie Beckett Medicaid Program.

The functional screen is only used to establish your child's *functional* eligibility, not their overall program eligibility. Children who are found to be functionally eligible for these programs will also need to be financially eligible for Medicaid to participate.

To get started, a service coordinator will meet with your family and ask questions about your child. They will complete a functional screen based on these answers. It is reviewed and a determination of eligibility is made by the Department of Health Services (DHS).

Preparing for a Functional Screen: Rosy vs. Realistic

Parents want to be positive about what their child can or may be able to do, this paints an overly rosy picture of their child's skills for friends and family. When meeting with county staff to complete a functional screening, it's important to be as realistic as possible about your child's daily living skills, and less rosy. Before you meet with agency staff, think about the following situation:

Imagine you have to leave your child with a distant relative for a week or a month. How would you explain everything that you do to keep your child safe, healthy, and cared for? Your instructions would have to be very detailed. This is the level of detail to share during the functional screen. Tell the screener the issues that might happen only occasionally as well as things that happen every day. Remember, this is the time to be as realistic as possible.

On an average day, how much help or support do you provide to your child and how much time does that take? Then, consider a *difficult* day—What does that look like?

Tip for Families

Talking about what is difficult for our kids in front of them can be very hard. It's okay to ask them to play in another room when you respond to the screener's questions. It may be more comfortable opening up knowing your children can't hear you.

These questions can assist you to have a more realistic view of the care that you provide and can help give a realistic view of your child to the screener:

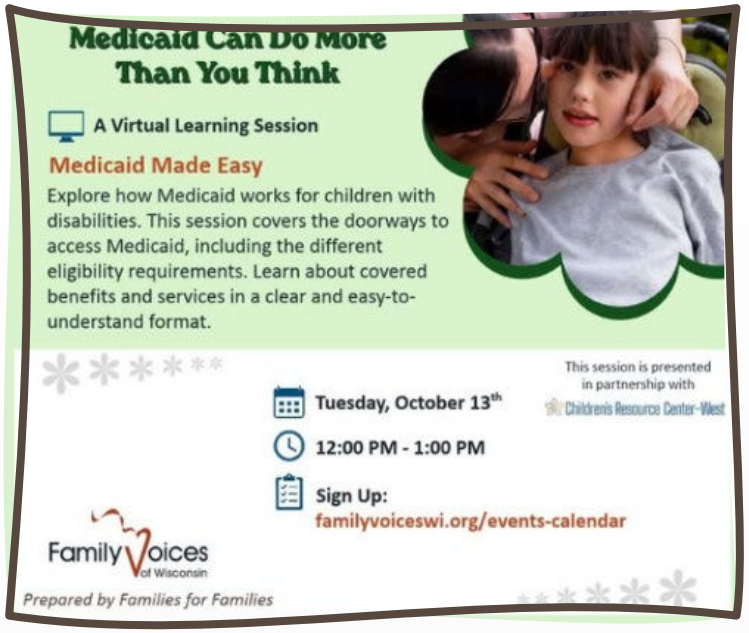
- Are you up with your child during the night?
- How much of your involvement and support is needed at mealtimes?
- What is it like when your child does not feel well or has a bad day at school?
- What support or help is provided by other family members and what if that help is not available?

Examples of a Rosy vs. Realistic Perspective:

Rosy = Ben can dress himself independently.

Realistic = Ben can dress independently but only if I have weather-appropriate clothes set out and I handle any zippers and buttons.

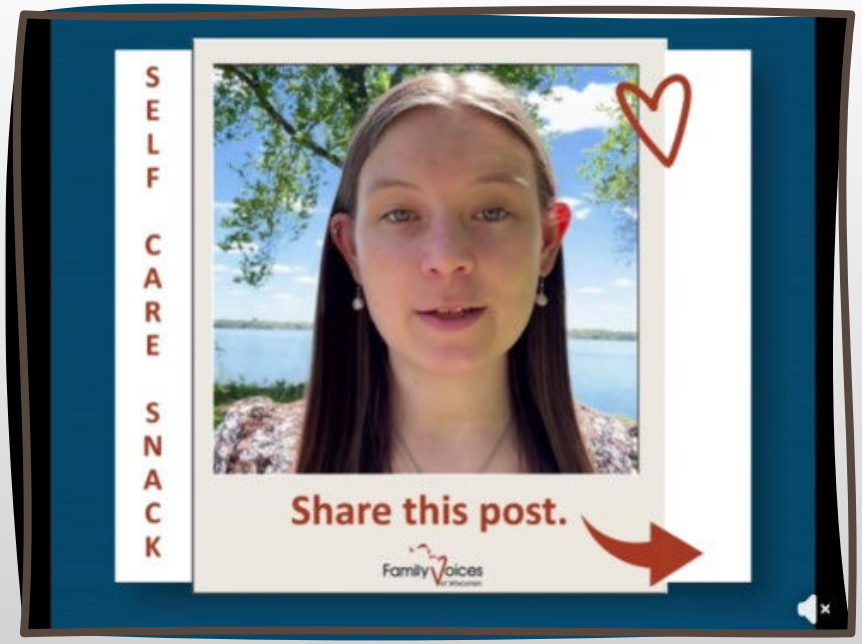

TWO MINUTE TIP
2 MIN
Rosy vs. Realistic
Family Voices of Wisconsin
0:01 / 1:49


Medicaid Can Do More Than You Think
A Virtual Learning Session
Medicaid Made Easy
Explore how Medicaid works for children with disabilities. This session covers the doorways to access Medicaid, including the different eligibility requirements. Learn about covered benefits and services in a clear and easy-to-understand format.
This session is presented in partnership with
Children's Resource Center-West
Tuesday, October 13th
12:00 PM - 1:00 PM
Sign Up:
familyvoiceswi.org/events-calendar
Family Voices of Wisconsin
Prepared by Families for Families


FAST FACT FRIDAY!
Family Voices of Wisconsin
When a child has a disability or special health care needs, a care map can help families visually organize the people, services, and supports involved in their child's life.
It can help:
• See how different people and supports connect.
• Recognize the support already in place.
• Identify gaps or additional support needs.
• Share a clear picture of the support network with others.
WATCH VIDEO


A New Issue of Our Newsletter Is Here!
Looking Ahead: What Families Need to Know
From adult guardianship and CLTS to caregiver breaks, family leadership, and navigating new fall routines – this issue brings together resources, opportunities, and information allowing families to feel informed and connected.
STAY UP TO DATE
READ THE LATEST ISSUE
JOIN OUR EMAIL LIST
Family Voices


Upcoming EVENTS
Family Voices of Wisconsin
OCT 13
MEDICAID MADE EASY
VIRTUAL LEARNING SESSION
12:00 PM - 1:00 PM
OCT 15
INTRODUCTION TO CHILDREN'S LONG-TERM SUPPORT (CLTS) PROGRAM
VIRTUAL LEARNING SESSION
12:00 PM - 1:00 PM
OCT 20-21
2026 WISCONSIN SELF-DETERMINATION CONFERENCE (EXHIBITOR)
KALAHARI RESORT, WISCONSIN DELLS
APPROXIMATELY 7:30 AM - 3:30 PM DAILY
OCT 21
TRANSITION LEARNING SESSION: FOCUS ON GUARDIANSHIP AND SUPPORTED DECISION-MAKING
VIRTUAL LEARNING SESSION
12:00 PM - 1:00 PM
OCT 21
GET STARTED: NAVIGATING SYSTEMS OF SUPPORT
VIRTUAL LEARNING SESSION
6:30 PM - 7:30 PM
REGISTER NOW
FAMILYVOICESWI.ORG/EVENTS-CALENDAR


SELF CARE SNACK
Share this post.
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Our Approach to Advocacy

- Focus on education and information sharing
- Empowering families to have a seat at the table
- Individual mentorship and support
- Being a partner in systems improvement
  - *Practical and reasonable*
  - *Solution-focused*
  - *Grounded in partnership*
  - *Making space for individual experiences*
  - *Building bridges*

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Wisconsin Family Leadership Institute (WiFLI)

- Intended for parents, caregivers, and family members new to, or interested in, leadership roles
- Supports early skill-building
- Content focus:
  - *Why families belong at the decision-making table*
  - *An introduction to policy*
  - *Identifying allies and influencers*
  - *Active listening, brainstorming, consensus building*
- Offers advocacy specific content including advocacy days

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WiFLI

Partnerships with Professional Organizations

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Family Voices is at the Table

We ensure there is a **family voice** when statewide decisions are made – and in national groups, by actively participating and partnering.

- Wisconsin DHS Children's Long-Term Support Council Member
- National American Academy of Pediatrics Care Coordination Materials Expert
- AMCHP Family Engagement Community of Practice
- National Family Voices Projects
- DHS Transportation Advisory Council Member
- WI Children with Medical Complexity Collaborative
- American Family Children's Hospital Research Projects Family Advisor
- Epilepsy Foundation of WI



What comes to mind when you think about navigating systems and finding support for a child?

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The Expert in the Room

Professionals bring expertise in their areas of practice.

Clinical Care • Systems • Programs • Services • Processes • Options • Requirements

The family is the expert in their experience.

Baseline • Patterns • Changes • Things that Matter

Good care and effective systems make room for both.

For most families, the goal isn't for one form of expertise to replace the other. It's for us to bring them together — and use both to advocate for the child.

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What Happens Next?



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Confusion → Hesitation → Missed Support → Larger Challenges

OR

Listening → Collaboration → Plan → Better Support and Care

Real Resources, Real Support

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Fact Sheets

- Practical, plain language information on long-term supports, transition, Medicaid, and more.
- Over 70 different fact sheets available.
- Free, printable, and translated into English and Hmong.

Learning Sessions

- Breaking down complex systems and programs live regularly with recorded versions on the website.
- Medicaid Made Easy, Introduction to Children's Long-Term Support, What's After High School – and more!
- Learning from people with real-life experience navigating the programs and systems we share.

Newsletter

- Timely topics and information relevant to families.

Social Media

- Plain-language updates, resources, and reminders.

Partnerships

- Connecting families with people and organizations who can help.
- If we don't have the answer, we will help find someone who does.
- Insurance, school questions, transportation, we hear it all – and we are grateful for the strong partnerships that allow us to support families so well!

Workshops and Annual Conference

- Annual Circles of Life Conference in May providing a space for community, connection, and learning.
- Future Ready – planning for transition workshop offers a dual track for young adults and their family to learn together and develop a plan for adulthood.

familyvoiceswi.org/connect

Sign up for newsletters, policy alerts and more



Facebook: FVofWI

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Website: https://familyvoiceswi.org/

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