

Your Voice Matters! Becoming a Family Leader

March 2024



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Family Voices supports families who have children with disabilities and special health care needs. We empower families to navigate health care and community support and services.

As a family-run organization, we guide families on their own leadership and advocacy journeys. We promote family-centered care and family/professional partnerships.

Visit our website to view our fact sheets, newsletters and online learning.

Family Voices of Wisconsin
Connect with Us!
familyvoiceswi.org



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Your Voice Matters – Becoming a Family Leader

Session outline

- Advocacy and leadership
- Moving from advocating for your own family to impacting others
- How advocates (and leaders!) have made impacts
- Growth opportunities
 - Wisconsin Family Leadership Institute (WIFLI)
- Leadership opportunities
- Wrap up / Questions



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Your Voice Matters – Becoming a Family Leader

I am an *Advocate* for my child.

I am a *Leader*, advocating on behalf of *many* children.



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Your Voice Matters – Becoming a Family Leader



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Your Voice Matters

• What is an *advocate*?

An advocate is someone who speaks up on behalf of another person

• When family members advocate, they may do so:

- on behalf of their own child;
- on behalf of another child;
- or on behalf of many children



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Your Voice Matters

Family Members are Natural Advocates for their Children

- Within their own families and social networks
- IEP and school teams
- Doctor’s offices
- Community therapists
- Health Insurance providers
- Service coordinators for long-term supports



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Your Voice Matters

Families Offer a Unique and Valuable Perspective

- We are creative and resourceful and have good ideas;
- We live the system – we know what works and what doesn’t work;
- We can see inconsistencies that professionals may not see;
- Our expertise is critical to improving services and utilizing resources most effectively.



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Your Voice Matters

Your Advocacy Can Make Systems Work Better

“Systems change” happens when there is a change to a policy or a rule which affects many people.

Systems change is long lasting. The changes affect many kids and families, not just one, to be called “systems change.”



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Your Voice Matters

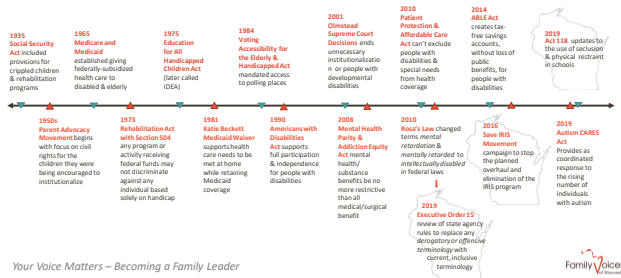
Why is it Important to be Part of Systems Change?

- Our children and family must live with the changes that are being made.
- If we don't give our view, then how can we complain about how it all turns out?
- If we aren't giving our input to the decisions that affect our children, *who is?*
- No one cares more about our child's future than their family members.



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Your Place at The Table: Timeline



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Individual Advocacy → Leadership Advocacy

Greater than your own child

- Focus on working for a meaningful life for *all* children with disabilities and special health care needs, not just your own:
 - Have an impact on improving services and supports
 - Making a community more welcoming
 - Building opportunities for children and youth



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Individual Advocacy → Leadership Advocacy

How to be Effective:

- Speak up – share your opinions – *you are knowledgeable!*
- Don't worry about what you don't know
- Use your experiences and family story to inform your advocacy
- Represent families fairly – consider not just the interests of your own family
- Show up and participate!



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Growth Opportunities/ Skill Building



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Growth Opportunities / Skill Building



Offered by: Board for People with Developmental Disabilities
Topics: History of the disability movement, person-centered planning, disability policy, community engagement, legislative advocacy and the legislative process, and more.
Open to: Parents, siblings and caregivers (to those under age 21), adults with developmental disabilities
Timeline: Applications due late summer for the winter session
More information: <https://wi-bpdd.org/>



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Growth Opportunities / Skill Building

Serving on Groups: WI FACETS

Offered by: Wisconsin FACETS
Topics: Opportunities for involvement, group procedures, tools & tips, using data, skills for serving on groups
Open to: Parents, siblings and caregivers (to those under age 21), adults with developmental disabilities
Timeline: Applications due late summer for the winter session
More information: <https://wifacets.org/>



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Growth Opportunities / Skill Building

Families as Partners WSPEI Wisconsin Statewide Parent Educator Initiative

Offered by: Wisconsin Statewide Parent Educator Initiative
Topics: supporting child's education and learning, school staff connections, skills for collaboration and advocating in IEP settings, and more
Open to: Family members and caregivers
Timeline: Next session planned for Fall 2024
More information: <https://wspei.org/>



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Growth Opportunities / Skill Building

WiFLI Wisconsin Family Leadership Institute

Offered by: Family Voices of Wisconsin
Topics: **WiFLI Foundations:** Telling your story workshops, how boards & committees work, Introduction to Policy, legislative visits, finding leadership opportunities.
WiFLI Advanced: Philosophies of leadership, facilitating through conflict, turning conflict into consensus, development of a leadership project.
Open to: Family members and caregivers to children up to age 21
Timeline: Applications open fall for **Foundations**, spring for **Advanced**
More information: <https://familyvoiceswi.org/wisconsin-family-leadership-institute-wifli/>



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Leadership Opportunities



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Individual Leadership Opportunities

- Start a support group
Plan a community event
Letter to the Editor – local paper
Presentation to faith community
Peer parent mentoring programs
Advocate for rule or policy changes to decision-makers
Legislators
School Board
Hospital / clinic
Create a group around a community need you've identified
Join an existing group



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Things to think about: Joining a group

Expectations

- Length of commitments
Days/ times / frequency of meeting
Compensation?
Virtual or in-person?

Read website carefully about the group

- Values
Mission
Existing members

Attend a meeting before joining



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Your Voice Matters – Becoming a Family Leader Finding group opportunities

- Reach out and connect – email list, social media
- It's okay to be persistent (*and still be nice!*)



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Local Leadership Opportunities

- County Budget Advocacy
- County Human Services Committee
- Children’s Community Options Program Advisory Committee
- School Board Committees
- PTO/PTA
- Civic Organizations/Neighborhood Associations
 - Public Library, Boys & Girls Club
- Transition Advisory Committees
- Hospital Consumer Advisory Committees
- Disability Specific Organizations



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State Leadership Opportunities

- Birth to 3 Interagency Coordinating Council
- IRIS Advisory Committee
- Children’s Long-Term Support (CLTS) Council
- Governor’s Autism Council
- Wisconsin Council on Mental Health
- Wisconsin Council on Special Education



Also see: DHS list of state boards, committees, and councils: <https://www.dhs.wisconsin.gov/aboutdhs/councils.htm>




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Thank You!
 To contact Danielle:
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familyvoiceswi.org
 Find us on Facebook
 and Instagram!



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