

## Making Your Voice Heard without Leaving Home

**W**hile the pandemic continues to impact our lives, it might seem harder to advocate for a cause and make your concerns heard. Until recently, most advocacy efforts meant attending a hearing or a face-to-face meeting with your elected officials.

Today, we're learning to make our voices heard by using our phones and computers. Hearings and other public meetings can be accessed virtually, and elected officials regularly meet with their constituents over the phone or Zoom. By taking part in virtual focus groups, committees or giving your input by completing after-visit surveys you are using the new tools for families to influence change in systems without leaving home.

### Our Next State Budget

Wisconsin's budget writing committee, the Joint Finance Committee (JFC), will be hosting public hearings during April. One of these will be a virtual hearing on April 28. Your comments on how state funds will be used over the next two years can also be submitted by email. To learn more, go to [legis.wisconsin.gov/topics/budgetcomments](https://legis.wisconsin.gov/topics/budgetcomments). Check out our [Budget Priorities for Children and Families](#) and [Suggested Issue Talking Points](#) if you need ideas for your state budget request to improve the lives of families who have children with disabilities.

### Jump Start Your Advocacy Efforts

Visit the [Advocate page](#) on the Family Voices website to find tools and videos to help craft your message for policymakers. Examples of testimony are also available. As families who **live the system**, we are resourceful and creative in finding and paying for our children's needs. This makes the perspective that we offer very valuable to policymakers! So, take a few minutes and use your voice this spring to positively impact change for all families.

## Invest in Families: A Budget Priority for Wisconsin Disability Advocates

**A**s families who have children with disabilities, many of us struggle to navigate systems like health care, long-term supports, education and Medicaid. While each county has an Aging and Disability Resource Center for adults with disabilities, there is no statewide, coordinated effort to connect children with disabilities and their families to information and services.

Family Voices, in partnership with other statewide disability advocates, is urging Wisconsin Legislators to invest in families by adding funding to the budget for a **Disability Resource Center for Children and Families (DRCCF)**. The DRCCF will give families one statewide name, number and staff available throughout the state to offer information, resource navigators, children's advocacy and benefits specialists and a "front door" to eligibility for long-term supports. See the insert in this newsletter and visit the [Policymaking](#) page of our website to learn more. Now is the time to contact your elected representative if you think this is important. Go to [Who Are My Legislators?](#) to find out who represents you.

## Did You Know? Now You Know! Are You Tele-Ready? New Tools for Families

**A**s part of the 2020 CARES Act grant, national Family Voices has developed videos and tools to increase access to and understanding of telehealth for families. While many of us have made the transition to “seeing” our providers virtually over the past year, we can all improve our experiences with remote, or virtual, visits with our children’s providers.

These informative videos are now available on our [Family Voices website](#). Check out the **Fab 4** including:

1. Are You Connected?
2. Do You Have a Device?
3. Can You “See” Your Provider?
4. Your Family’s First Telemedicine Appointment

For Wisconsin’s part, we have a new [Are You Tele-Ready? Fact Sheet](#) and we’re hosting live Are You Tele-Ready? **training sessions** over Zoom. Come learn with us about telehealth and how to make the most of your child’s next visit. Our next Are You Tele-Ready?, in partnership with the Western Regional Center, is [Wednesday, April 14, 11:30 – 12:30](#). You can find more details on our website’s Training Calendar.



# Circles of Life Conference

**May 6, 9:00 – 4:30 and May 7, 9:00 – 1:00**

**The 36th Annual Circles of Life Conference** will be held **virtually** using Zoom. Participants will have **28 breakout sessions** to choose from—Learn about Medicaid, long-term support programs, forgiveness, financial planning, care mapping, shared plans of care and so much more! This year’s **keynote speaker: Matt Glowacki** will inspire us to see our world in a more inclusive and empathetic way.

**BIG NEWS  
BIG NEWS**

This Year **only** the Circles of Life Conference will be **FREE to FAMILIES!!!** Drop in for a few sessions or stay for the whole conference. Take advantage of this great opportunity to learn and share with other families.

Registration [circlesoflifeconference.com](http://circlesoflifeconference.com)

### Family Voices Annual Listening Session\*

**We Want to Hear from You!** Don’t miss the Family Voices Listening Session **May 5, 4:00 – 5:15pm**. Tell us what is working for your child and family and what could make your life better as you care for your child with a disability or special health care needs.

\*You **DO NOT** have to attend the conference to participate in the listening session!

### Auction

Don’t miss this year’s **online auction** to benefit the parent scholarship fund. Bidding ends April 30 and winners will be announced during the conference. Go to the [Elsie Shaw Scholarship Fund Auction](#)



**Children and Youth with  
Special Health Care Needs**

**Northeast Region**  
Children’s Hospital  
of Wisconsin  
Fox Valley  
877.568.5205

**Northern Region**  
Marathon County  
Health Dept.  
Wausau  
866.640.4106

**Southeast Region**  
Children’s Hospital  
Milwaukee  
800.234.5437

**Southern Region**  
Waisman Center  
Madison  
800.532.3321

**Western Region**  
Chippewa County  
Dept of Public Health  
Chippewa Falls  
800.400.3678

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[familyvoiceswi.org](http://familyvoiceswi.org)

# Policy/Budget Update

## A Call to Action!

Now is the time to let state legislators know what is important for your family and your community! Family Voices is closely monitoring the 2021-2023 state budget and we are urging families to stay informed and get involved in advocating for what is best for Wisconsin families. Visit the [Advocate](#) page of our website to find our **Budget Asks**, including the **Disability Resource Center for Children and Families**, increases in funding for special education, and increases in school-based mental health services and pupil-services staff including social workers, psychologists and school nurses. These additional staff are desperately needed now more than ever as children and teens return to in-person school life.

### Joint Finance Committee Hearing Dates and Locations



April 9 Whitewater

April 21 Rhinelander

April 22 Menomonie

April 28 virtual

If you plan to be part of the virtual session—**highly recommended**—please note that pre-registration is required, and space is limited!

For registration information visit

[legis.wisconsin.gov/topics/budgetcomments](https://legis.wisconsin.gov/topics/budgetcomments)



### COVID Vaccine Update

Starting April 5, all adults ages 16 and older are now eligible to receive a free COVID vaccine, however, the supply is still limited so getting your shot may take time. The best way to find out where vaccines are available near you is to go to your local health department's website and/or contact your child's health care providers. Many pharmacies across the state now have vaccines available with an appointment.

The new state **COVID hotline** can answer your questions about the vaccine. Call **844.684.1064**

### Want to Learn More?



For more information on these articles visit these websites:

Family Voices of Wisconsin  
[familyvoiceswi.org](https://familyvoiceswi.org)

National Family Voices  
[familyvoices.org](https://familyvoices.org)

Joint Finance Committee  
Public Comments  
[legis.wisconsin.gov/topics/budgetcomments](https://legis.wisconsin.gov/topics/budgetcomments)

Family Voices Telehealth  
Training Webinars  
[familyvoices.org/telehealth/curriculum/](https://familyvoices.org/telehealth/curriculum/)

### Family Voices Trainings

Family Voices and the Regional Centers for Children and Youth with Special Health Care Needs are hosting **virtual trainings this spring**. Learn about programs and services for your child without leaving home! See our website for times and registration details [familyvoiceswi.org/events/month](https://familyvoiceswi.org/events/month). Or, watch them online, any time at [familyvoiceswi.org/learn](https://familyvoiceswi.org/learn).



#### [What's After High School?](#)

Learn about the transition to adult life for youth with disabilities and special health care needs.



#### [Did You Know? Now You Know!](#)

Explains all the resources and services for children with disabilities and special health care needs from birth through young adulthood.



#### [Coordinating Your Child's Health Care](#)

This training was created to help you partner with your child's care team.



#### [Medicaid Made Easy](#)

Gives you a solid understanding of Wisconsin's Medicaid programs. Most importantly, it's focused on how these programs work to cover what your child needs!

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### Connect With Us!

[familyvoiceswi.org](http://familyvoiceswi.org)

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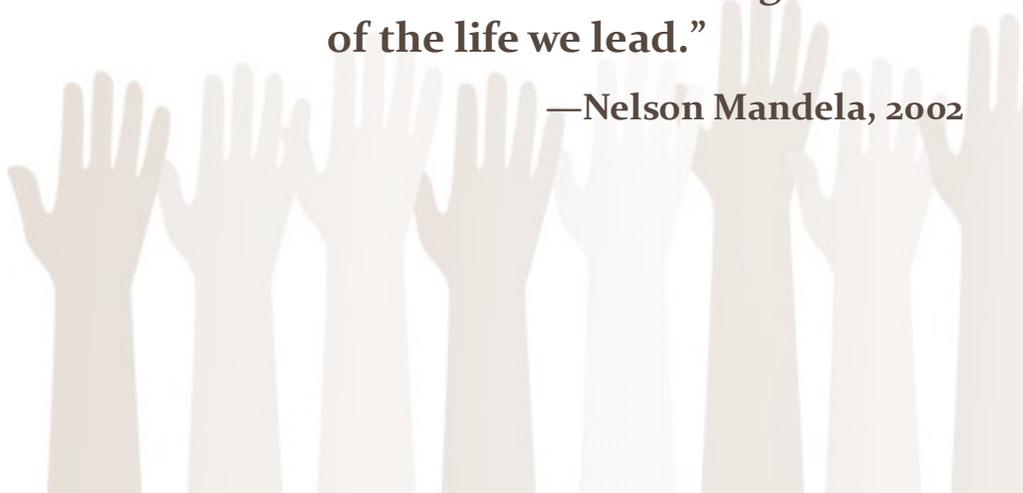
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Madison, WI

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“What counts in life is not the mere fact that we lived. It is the difference we have made to the lives of others that will determine the significance of the life we lead.”

—Nelson Mandela, 2002



### About Family Voices

If you have a child with a disability or special health care need, you’ve come to the right place! We’re here to help you **navigate** the services available to your family. It’s a complicated system and our goal is to provide you and your family with some tools. **Connect** with other families, learn how to **advocate** for your child, and discover how you can be a voice for all children with special needs.

Each family has a voice • Together, our voices will be heard

[familyvoiceswi.org](http://familyvoiceswi.org)

- Have you ever had trouble finding the information you need to support your child?
- Have you made multiple phone calls to get the answer to a question?
- Are you wondering if there is a service that might help your child and family?
- Do you have Medicaid, but don't know what it pays for?
- Has your insurance denied a service for your child?

If you answered YES to any of these questions, now is the time to talk with [your legislator](#) about creating a **statewide Disability Resource Center for Children and Families** (DRCCF).

## EDUCATE YOUR LEGISLATOR

**\$2.9 million in state funding is needed to develop and implement a statewide Disability Resource Center for Children and Families so families know where to get the help they need. [Here](#) is information you can share with your legislator.**

## WHAT DO FAMILIES NEED?

Families want a reliable and trustworthy source of accurate information. Families benefit from one statewide name and one number to call. Create a statewide DRCCF to coordinate outreach, regional staff, referrals to county services, and a person who families can talk with to get help navigating complex systems including:

- Information, assistance, and resources to help families find available community resources, programs and services,
- Family navigators with lived experience to provide culturally competent assistance,
- Advocacy services and benefits counseling,
- Seamless access to eligibility determination for long-term supports, services, mental health supports and Medicaid.

## SOME FACTS

Families struggle daily to navigate complex systems such as health care, long-term supports, education, community resources and Medicaid. Lack of information and support can lead to family crisis, lost jobs, lost opportunities for child development and lost economic stability. Wisconsin has no statewide, coordinated effort to connect children with disabilities and families to information, assistance and services.

- 56,000 children in Wisconsin have a disability requiring long-term supports.
- Only 25% of these are connected to a long-term support program.
- Current information and assistance resources serve about 5% of these families.
- The Wisconsin legislature made this commitment to adults and elders by funding Aging and Disability Resource Centers (ADRCs) in every county.
- ADRCs don't serve children.
- Without these services and supports the only option for a family who has critical needs is to place their child **out of home** either in an institution or specialized foster care.
- Supporting families prevents crisis and maximizes the use of existing community, health and school-based supports.

# BACKGROUND

It is estimated that approximately 56,000 (DHS 2018) children in Wisconsin have a disability such as cerebral palsy, autism, Down Syndrome, or mental illness that could result in a need for long-term supports such as special equipment, respite, living skills training or family education. One or more of our long-term support programs currently serves approximately 14,400 of these children (e.g., Medicaid, Children’s Long-Term Support Waivers, Katie Beckett Program, Comprehensive Community Services or the Children’s Community Options Program).

In addition to the children’s long-term support program, a handful of disability specific information resources currently exist in Wisconsin. While some have a focus on supporting families of children with disabilities few have the capacity to provide comprehensive, cross program information and assistance services statewide. Most are grant funded with limited capacity. Recent data shows these organizations and state programs were able to serve less than 5% of the 41,600 who might need help. A 2019 study of 2,600 Wisconsin families and youth provided with navigation assistance showed a reduction in the need for public benefits and an increase in expectations around employment, connection to services and supports, and help achieving education, employment and financial self-sufficiency goals. Another study of 400 Wisconsin families with access to information and assistance showed over 80% of families felt more able to cope, navigate systems, knew where to turn to for help and better advocate for their child.

- 1 in 4 families of children with disabilities live below the FPL compared to 1 in 6 without children with disabilities.
- Over half report financial hardship.
- 1 in 4 have had to cut back or stop working to care for their child.
- 1 in 4 report high levels of stress compared to 1 in 20 of families without children with disabilities.

*“I didn’t take a promotion at work because I thought if our income went up my daughter would lose Medicaid. Why didn’t anyone ever tell us about Katie Beckett Medicaid?”*

The role of family is unique and essential in the support and care for children with disabilities. By providing medical, behavioral, financial and daily supports, families facilitate opportunities for their child to develop, be healthy, included and meaningfully connected within their community. But to do this well families need accurate information from a trusted

source that can help them support and advocate for their child. Unlike typical children, children and youth with significant disabilities may need unique supports to fully participate and benefit from school, work and community experiences that benefit all children. The programs that pay for these supports and services, like Medicaid and Medicaid waivers, are essential to family health and wellness.

Providing information is frequently more than a simple phone number. It requires a deep understanding of the supports, services, family experience and the interaction between different systems. It is critical families receive accurate, timely and comprehensive information that is based on a family’s identified need (family-centered) and is actionable based on the family’s skills and values.

*“We’ve been living paycheck to paycheck. I didn’t know we could get help paying for my 6-year old’s diapers!”*

## WHO DEVELOPED THIS PROPOSAL?

Wisconsin County Human Service Association  
Family Voices of Wisconsin  
Disability Rights Wisconsin

DHS Children’s Long-Term Supports Council  
Survival Coalition of Wisconsin Disability Organizations