

Caring for the Brothers and Sisters of Children with Disabilities

If your child has a disability or complex medical condition you know that this child is not the only member of your family who is affected by this diagnosis. Your entire family will likely feel the effects.

Being a sibling of a child with special needs may lead to positive traits like greater empathy, resilience and a strong sense of responsibility. At the same time, there is a large burden placed on the sibling's shoulders. And, whether your children are 2 or 22, you want to be intentional about supporting their emotional needs.

Feelings Experienced by Siblings

Each family is unique, and each member in the family may have a different journey of living with someone with a disability. Like parents, siblings may go through stages in working toward acceptance and have both positive and negative feelings. Learning about these stages and talking about them will help your children understand their feelings.

Siblings may sometimes feel:

- Neglected or unloved,
- Unable to express feelings in words and might act out instead,
- Frustrated that their own problems get overlooked or seen as less important,
- Isolated because they may not see other children with siblings who have disabilities,
- Determined to be perfect to compensate for the other sibling's challenges, or
- Sad, anxious or out of control in situations.

¹WisconSibs resources include: **Sibsack** (photo) and **Parent Guide**. For more resources go to info@wisconsibs.org or call Harriet Redman at 920.968.1742.

Talking with Your Typically Developing Child about a Sibling's Diagnosis

Harriet Redman, founder and executive director of WisconSibs, states, "The key is to have open and honest communication with your typically developing child. How you talk about your child's disability or medical condition depends on their sibling's age. For younger children keeping things simple is important."¹

As your children grow, you can explain things in more detail and help them be familiar with the terms and language used to explain a sibling's diagnosis or medical condition.

In the meantime, parents can prepare themselves for open communication by talking with other parents and people they trust. They can read books and watch videos with their children that help explain disabilities. This opens opportunities to answer your children's questions as they come up. Regularly spending time alone with each of your children reassures the sibling that they are an important member of the family.



WisconSibs SibSack—Free for Families

Did You Know? Now You Know!

The Importance of Future Planning for Siblings

Planning for your child with a disability's future is important for your own peace of mind. But, as many adult siblings have explained, it's even more important for them because they will most likely outlive their parents. Some families assume that a sibling will take over the caregiving responsibilities and financial support. This may or may not be what your child with a disability or your typically-developing child wants.

Resources to Start the Future Planning Process

According to [The Arc](#) of the US, "There are 600,000-700,000 families in the US in which an adult with an intellectual or developmental disability is living with aging family members and there is **no plan** for the individual's future." With this in mind, the Arc created the [Center for Future Planning](#) to support and encourage adults with disabilities and their families to plan for the future.

The Center for Future Planning webpage provides reliable information and practical assistance to families and individuals, including person-centered planning, decision-making, housing options, financial planning, and making social connections. It also features the stories of individuals and families who have created future plans or are in the planning process.

Future Planning Tools in Wisconsin

As families consider legal options for their adult-child's future, it is important to involve siblings. For example, if guardianship is what a family decides is best for a child with a disability, talk with their sibling, age 21 and older, about whether they want to be added as a **standby** or **successor guardian**. If a family decides a Supported Decision-Making Agreement is best, their sibling may choose to be a **supporter**.

Creating a "Letter of Intent" as a family can be helpful for everyone, including siblings. [WisconSibs](#) offers the **Journey Forward** learning session and a sample [Letter of Intent](#) to get you started.

To Learn More

- See the Board for People with Developmental Disabilities [Supported Decision-Making Toolkit](#).
- For resources on special needs trusts, ABLE accounts, legal considerations and more, see the Family Voices [What's After High School? Resource List](#).

(Continued from p. 1)

SIBLING RESOURCES

For Young Children:

- Sesame Street, [SiblingGuide](#)
- Sibs.org (UK), [Supporting Young Siblings](#)
- Sibling Leadership Network, [Resources for Young Siblings](#)

For Kids of All Ages:

- Sibling Leadership Network, [Resources for Teen Siblings](#)
- Sibling Support Project, [Publications](#)
- Child Mind Institute, [Advice from Siblings of Special-Needs Kids](#)

For Parents:

- "Siblings of Children with Autism: A Guide for Families," Sandra L. Harris, PhD and Beth A. Glasberg, PhD.
- "Views from Our Shoes: A Collection of Stories about Growing Up with a Brother or Sister with Special Needs," Don Meyer.

Policy Update

Summer is a Great Time to Connect with Elected Officials

Wisconsin legislators have finished their session, and many will be spending more time closer to home this summer. Now is a good time to get to know your state senator and assembly representative and let them know what's important to your family. Learn more about your legislators at [Who Represents Me](#) on the Wisconsin State Legislature home page. If you see your legislators in your community, make a point of introducing yourself and your children!

The [Family Leadership](#) page on the Family Voices website is filled with resources on connecting with elected officials including [worksheets](#) and [videos](#) on crafting an effective message for legislators.

Need some ideas for what your state legislator needs to know? See our [2022 Policy Priorities](#) for Children with disabilities and their families. This document has information that you can share and what your legislators can do on the following topics: Disability Resource Center for Children and Families, special education, children's mental health support and family caregiver support.

COVID Vaccine Information

The COVID vaccine booster is now authorized for children ages 5 and over. This means two doses of the Pfizer vaccine and one booster dose even if your child has been exposed to the virus. The American Academy of Pediatrics and other medical experts agree that fully vaccinating all children, **including those with special health care needs**, is the most effective way to avoid getting seriously ill from COVID.

Family Voices has a new [COVID Vaccine Tip Sheet \(en español\)](#) with facts and resources to answer your questions about children and the vaccine.

[#FVvaccineoutreach](#)



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



Early Choices Matter

A Path to Supported Decision-Making

All children need to practice making choices. This is especially important for children with disabilities because it can lead to a more **self-determined life** as an adult.

We're working on an on-demand learning session and a toolkit full of ideas to empower your child with strong choice-making skills!

Coming Soon!

Want to Learn More?



For more information
on our articles visit
these websites:

Family Voices of Wisconsin
familyvoiceswi.org

•
National Family Voices
familyvoices.org

•
WisconSibs
wisconsibs.org

•
Sibling Support Project
siblingsupport.org

Connect With Us!

familyvoiceswi.org

PO Box 5070
Madison, Wisconsin 53705

Co-Directors

Liz Hecht, liz@fvofwi.org

Barbara Katz, barb@fvofwi.org

Information and Outreach Manager

Lynn Renner, lynn@fvofwi.org

Media and Education Manager

Brigit Frank, brigit@fvofwi.org

Spring 2022

Volume 17, Issue 2

The Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H84MC21690-01-00 support this newsletter. The information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Want to stay informed
about Family Voices?

[“Like” us on Facebook!](#)



A Fun Opportunity for the Siblings in Your Family

Sibshop

A Day for Brothers and Sisters of Children with Disabilities to Connect and Learn



This session is for “typical” siblings ages 8 to 12. We will have fun, age-appropriate activities and relaxed discussions about the challenges and joys of having a sibling with disabilities or other special health care needs.

When: Saturday, June 18, 11:00 am – 2:00 pm
(Includes lunch!)

Where: Lussier Community Education Center
55 S Gammon Rd, Madison, WI

Sign Up: [Click Here—Registration is FREE](#)

Questions: Contact Lynn, Lynn@fvofwi.org or 608.556.0375

Presented by:  Family Voices
of Wisconsin

 wisconsibs
Sisters & Brothers of People with Disabilities

This is a registered Sibshop through [WisconSibs](#), and sponsored by [Family Voices of Wisconsin](#) with a grant from [Capital Times Kids Fund](#).

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.