

*The Home of Wisconsin's Family to Family Health Information Center  
in Partnership with the Wisconsin Children and Youth with Special Health Care Needs Program*

## Storytelling with a Purpose



Families are often asked to share their stories because of the powerful impact that these stories carry. Many times, though, as much as families are interested in telling their story, they are unsure if they will be meaningful to others.

They may not know where to begin or how to wrap up their stories. And they might wonder what difference it would really make to share their family stories.

### **The Power of Family Stories**

Stories are the things that people remember. When families share their "lived experience" with others, it makes their involvement with programs and systems real.

Stories paint pictures of family life and deepen the listener's understanding of the issues faced by children and families.

### **How to Share Your Story**

When sharing your story, think about your audience and the impact that you want to make. Choose a "slice of life" to illustrate your point.

The hardest part may be deciding what pieces of your story to focus on and what details can be left out. Being brief and to the point with your story is usually best.

### **Where to Share Your Story**

There are lots of opportunities to share your family story. When you share stories with friends, family and neighbors, you give them an opportunity to better understand your life.

When you share your story and your experiences with the media, policy makers or elected officials, your family story can explain an issue that concerns you and may offer a solution to fix the problem.

Remember, families offer unique and valuable perspectives. We know what works and what doesn't work because we "live the system." We see inconsistencies, and sometimes have ideas to remedy inefficiencies in systems that providers or policymakers may not see.

The newsletter insert provides a guide on how a personal or family story can be used to communicate with legislators or other elected officials. For more resources see the Family Voices website under ["Family Leadership."](#)

### **Why Tell Your Family Story?**

- ◆ Stories are what people remember
- ◆ Makes problems real
- ◆ Deepens listeners understanding of issues for children and families
- ◆ Helps policy makers make decisions that lead to more supportive and responsive policies



## WEB WATCH

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

### National Office of Family Voices

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

### Family Voices of Wisconsin

[familyvoicesofwisconsin.com](http://familyvoicesofwisconsin.com)

### Circles of Life Conference

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

### Children's Community Options Programs

[dhs.wisconsin.gov/ccop/index.htm](http://dhs.wisconsin.gov/ccop/index.htm)

## Well Badger Resource Center 1-800-642-7837

The Well Badger Resource Center is the new home of the Wisconsin MCH Hotlines, Wisconsin First Step, and Wisconsin Informed Consent Help Lines.

Find it online at [wellbadger.org](http://wellbadger.org)

## Did You Know? Now You Know!

### Join a Children's Community Options Program Advisory Committee

The Children's Community Options Program (CCOP) is a long-term support program for children with disabilities. Administered by counties, CCOPs are required to create and maintain CCOP advisory committees.

**Membership on your county's CCOP advisory committee is a good way to use your experiences and your family story to impact change and improve programs for children and families in Wisconsin!**

According to a recently released CCOP Procedures Guide, available at [www.dhs.wisconsin.gov/publications/p01780.p df](http://www.dhs.wisconsin.gov/publications/p01780.p df), *"The purpose of CCOP advisory committees is to assist in developing, reviewing and approving the local CCOP plan and to monitor the program."*

In addition, the local Advisory Committee is, *"encouraged to look at all of the local services and supports that are available to children with disabilities and their families, to identify gaps and needs, and to explore how these needs might be met through the public or private sector and existing community resources or parent-to-parent activities."*

The majority of CCOP Advisory Committee members must be parents of children with disabilities including, but not limited to, parents from families participating in the program.

To find out if there are openings on your county's CCOP Advisory Committee, contact your county CCOP agency. To find county CCOP contact information go to [www.dhs.wisconsin.gov/clts/contact.htm](http://www.dhs.wisconsin.gov/clts/contact.htm)

To learn more about CCOP see the DHS website: [www.dhs.wisconsin.gov/ccop/index.htm](http://www.dhs.wisconsin.gov/ccop/index.htm)

## Circles of Life Family Listening Session

Family Voices will be hosting a listening session on May 3 as part of the Circles of Life Conference. **Join us for a lively discussion!**

**What You Can Share:** Tell us about an experience you had, something that went well or has been hard related to caring for your child with disabilities or special needs. *What would you change to make things better for your family?*

**Why Participate?** Family Voices takes the information we hear from families, as we work with agencies to improve systems of support for children with special needs.

We partner with other disability organizations to advocate for funding in the state budget, for new state laws and we meet with Medicaid and other department officials to promote programs and services that help families care for their children with disabilities and special health care needs.

**Can't attend the Family Listening Session?** We still want to hear from YOU! Share your stories and experiences with Katy, Family Network Coordinator, at [Katy@fvofwi.org](mailto:Katy@fvofwi.org)

# 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. Spring trainings are planned for Cedarburg, Hudson, Adams and Middleton.

*Not able to attend a live training?* All our helpful trainings are also online! View the presentation at your own pace and watch the parts that are most important to your child again and find links to all our informative resources.

- ◆ [What's After High School?](#) is a broad overview of the transition to adult life for youth with disabilities and special health care needs.
- ◆ [Did You Know? Now You Know!](#) explains resources and services for children with disabilities from birth through young adulthood.
- ◆ [Coordinating Your Child's Health Care](#) explains coordinated care, a medical home and integrated health care for every child.



## Legislative Update

In early April, Governor Walker signed legislation that adds Supported Decision Making into state statute. Family Voices and many other disability advocates applaud the passage of this important option for adults with disabilities!

The statute creates a less restrictive alternative to guardianship that allows individuals to retain their decision-making authority with the help of trusted supporters.

**What is Supported Decision Making?** A supported decision-making agreement is another legal tool for people with disabilities and older adults to use besides guardianship. It will allow people with disabilities and older adults to formally designate others they want supporting them and gives the supporter a seat at the table when decisions are being made, allowing the individual to consult with their supporter when they need it.

Wisconsin is only the fourth state in the nation to create such a statute, making Wisconsin a leader in this area and a model for other states and territories. To learn more, see the [Family Voices fact sheet on Supported Decision Making](#) (go to "fact sheets" on our website).



Children and Youth with  
Special Health Care Needs

## 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



## Family Voices of Wisconsin

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## About Family Voices of Wisconsin

Family Voices of Wisconsin (FVofWI) is a state affiliate organization of the national Family Voices organization and serves as Wisconsin's Family-to-Family Health Information Center. Additionally, FVofWI 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 (March 2019); and
- Public policy and systems change activities.

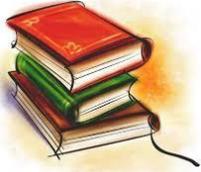
Please donate to Family Voices of Wisconsin so we can continue to help families navigate health care and community supports, and be the voice for improving systems for children with disabilities and special health care needs!

Go to [DONATE](#) on our website!

# Telling Your Story

## A Guide for Families Who Want to Impact Policy Change

This guide will help families who have children and youth with special needs use their personal experiences to create messages for policymakers that impact changes in services and systems of support.



### Identify Your Issue

**What's Your Issue?** Almost everyone has encountered a situation that made them say, "This is wrong. Someone has to do something! Enough is enough!" These situations are issues in disguise.

It's important to narrow your issue to something that is manageable and realistic. Remember, you can't accomplish everything. You will lose credibility fast if you approach a policymaker asking for too much or for something he/she can't do anything about. Focusing on a specific area will help you determine exactly what needs to be changed or improved.



### Develop Your Story

**What's Your Story?** When you're pushing to change public policy, your family story is your most important tool. From an advocate's point of view, a good story:

- Introduces you and your family.
- Focuses on one thing.
- Explains your situation.
- Has enough details to make it interesting.
- Includes only information that relates to the situation or your goal.
- Reminds the policymaker that you are a constituent.
- Captures your emotion and passion for an issue.
- Asks for a specific action to correct the situation.



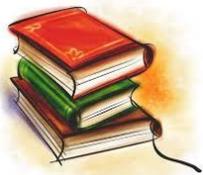
This guide was modified with permission from "Telling Your Story: A Parent Guide and Workbook" created by the Statewide Parent Advocacy Network ([www.spanadvocacy.org](http://www.spanadvocacy.org)). The guide was part of a "virtual train-the-trainer" hosted by the National Center for Family-Professional Partnerships ([www.fv-ncfpp.org](http://www.fv-ncfpp.org)) and facilitated by Mercedes Rosa, Director of the NJ F2F at the SPAN Parent Advocacy Network and Diverse Family Leadership Coach on the NCFPP.

## Think about the issue you've decided to tackle:

- What experiences made you choose this issue?
- What situations made you say "Enough"?
- What do you think should have happened but didn't?
- What do you want to happen in the future?
- What really happens?
- How it's different from what policymakers think happens?

Successful advocates have one key story that they know inside and out. It's important to narrow many personal stories to one that represents many experiences. When deciding which situation to focus on:

- **Think about emotions.** We remember stories that make us feel something—anger, joy, frustration or sadness. That's because emotion generally stays with us longer than cold facts.
- **Decide what you need a policymaker to know.** For example, if you need more support, think about how family support will help you live more productively. What difficulties and challenges do you face?



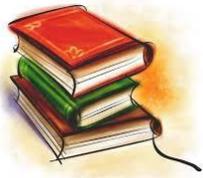
## Define Your Request

**What's Your Action Request?** Now that you know your issue and have developed your family story, it's time to figure out exactly what you want the policymaker to do. Your request for action should describe specifically what you think should be done:

- Are you offering to help the policymaker understand firsthand how something does or doesn't work?
- Are you asking the policymaker to continue his or her work in an area important to your family?
- Are you asking the policymaker to sponsor, approve, amend or repeal a specific policy?

## Your Request for Action should be:

- **Timely.** Is the legislature or other governmental body preparing to vote? If so, when is the vote scheduled to take place? Is the legislature between sessions so the policymaker may have more time to learn about your situation?
- **Realistic.** In many cases, your goal will be achieved through small, incremental steps that build momentum over time and lay the groundwork for the future. If this is the case, what do you want or need to happen now? What other changes need to occur before your future vision can be implemented?
- **Specific.** Your demand should be specific and clear. For example: I am asking you to support additional special education funding for transition services in the state budget.
- **Concise.** Boil down your request to as few words as possible. This will make it easier for you and policymakers to remember it.



## Write Your Story and Request for Action

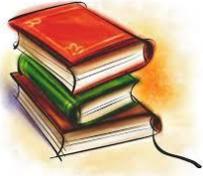
**My Personal Story:** Think about the following questions in light of your personal situation and the details that you want to share. Then, write your family story. You should be able to tell your story in five minutes or less.

- Describe who you are and where you are from. Include your name.
- Do you have a picture of yourself and your family that you are willing to share?
- Describe the situation that you want changed. What is happening? What is working? What needs to change?
- What could be done to improve the situation?
- What makes this situation memorable for a policymaker?

**My Request for Action:** Describe in 30 words or less what you would like the policymaker to do.

### Next Steps:

Contact your elected officials in Madison, Washington, DC, or at the local or county level and share your story and your request for action! If you want help, contact Katy, the Family Voices of Wisconsin's Family Network Coordinator, at [katy@fvofwi.org](mailto:katy@fvofwi.org) or go to the Family Voices website for more resources on telling your family story.



## What Makes a Good Story?

**It's the one you love to tell.** Think about the stories you've told your family and friends when describing the situation you're trying to change. What examples do you use? What facts or incidents draw an emotional response from them?

**Captures a central idea.** Don't try to cover too many incidents in one story. Focus on one issue and use real-life details to make it come alive.

**Has a main character that people want to help.** The more your audience knows about you or your child as individuals, the stronger the emotional connection and the more likely you are to make your story memorable.

**Presents a struggle, conflict or challenge.** Conflict is a struggle between two different needs, wants or situations. Your story might illustrate a conflict between your right to equal education and the school board's refusal to pay for a specific curriculum.

**Has a high point.** Your story should build up to an example that makes your listener say, "That's wrong" or "That's too ridiculous to be true."

**Contains vivid images.** Use words to draw mental pictures that help listeners connect to your story. Don't be afraid of strong words like *cold*, *dark*, *terrified*, *cringed* or *panic*. Positive words can cause emotional reactions just as easily. Think about how you feel when you hear words like *giggle*, *beautiful*, *artistic* and *loving*.

**Includes details.** The more details you can provide, the better the policymaker will understand and support your position. A note of caution: Make sure the details and images you include are relevant to the story you're telling.

**Addresses the five W's (and an H): who, what, when, where, why and how.** Policymakers need the basic facts.

**Has a beginning, middle and end.** Think about an ongoing television series. You might not be a regular viewer but within a few minutes of watching, you know the characters and what's happened.

**It's short and to the point.** Policymakers are very busy. You need to be able to tell your story in five minutes or less so stay focused!