

Surviving and Thriving During the Holidays

The holiday season should be a time to relax, but in reality, it's often one of the most stressful times of the year. This can be especially true for families who have children with disabilities. We may have family gatherings and holiday meals to attend, and we may spend time with relatives who don't know our children and their unique needs. So, keep in mind that that your holiday celebrations don't have to be picture perfect, and start planning now to make sure your family's holidays are a time to remember fondly!

What is Best for Your Family?

Start by simplifying your holiday traditions. While your extended family might have weekend-long gatherings at Grandma's house, try to be realistic about what your family can handle. Focus on quality time over quantity time. Consider smaller or more intimate gatherings, with some time for immediate family only.

Preparing Your Children

Talk with your kids or show photos from last year to remind them about your holiday visits with family. Explain the schedule of events, who will be there and family traditions and expectations.

Talk about what might be uncomfortable or questions they might be asked. Help prepare them for those situations (*Your aunt might want a hug and kiss, but it's okay to give her a "high 5!"*)

Communicating with Relatives

Talk with your family in advance about your plans. You can let them know what will benefit your child and make the holiday better for your family. Be direct about what your family will be able to handle and explain why so others know what to expect.

If possible, call or email relatives in advance to let them know what's going on with your child and family: what's going well at school; goals they've met; activities they enjoy; and, challenges or triggers. This will help relatives be up to date, so they can better interact with your child. If you will need special food or you anticipate certain behaviors, explain this in advance so that they are ready to support you and your child.

Away from Home at Family Gatherings

If you can, try to keep your routines like meal times and bed and bath times the same, which can help while traveling away from home.

Give your child permission to take a break and a safe space to chill out. Agree on a way he or she can let you know if time away from a large, noisy gathering is needed. And be ready with a backpack filled with toys, a tablet or iPad and drawing supplies so breaktime is fun.

You can help your child by showing and helping with interactions with relatives who might not know them well. For example, your child might not be able to assemble a new toy on their own, but you could suggest to a relative that it would be fun for them to go into another room and help put the toy together.

Caring for YOU

Don't be shy about asking for help from family if you need a short break from direct caregiving for your child so you can have an uninterrupted conversation with family or take a few minutes to get outside for some fresh air. It's your holiday too!

Remember to make your holidays special in the ways that are best for you and your family. Celebrate the little successes, the time together with relatives and time to play and enjoy being with your kids!

What if a Relative Makes an Inappropriate Comment?

As much as possible ignore it, redirect it or turn the conversation to something positive. Try not to be defensive and realize people may have misunderstandings about your child's disabilities. **This is a good time to share family stories, including success stories about your child, to promote better understanding and acceptance.**

Did You Know? Now You Know!

Caregiving Over the Holidays

Many families who have children with disabilities rely on paid direct care workers throughout the year to help their children with daily living needs. This can include respite, personal care services or supportive home care providers. However, over the holidays many of these important people need time off to travel and be with their own families.

Here are a few ideas for finding caregiving help over the holidays:

Ask for Help Now

If you work with a respite or personal care agency, call them now to see if they have providers who might be around over the holidays or other times when your regular workers are away.

Think about Natural Supports

Can grandparents, aunts, uncles or older sibling provide care, even for an hour? This is a great opportunity for them to spend quality time with your child.

College Students

Consider connecting with college students who are home for an extended winter break or high school students who are interested in learning about a career in health care or social services.

Former Caregivers

Can you connect with former caregivers like babysitters, school para-professionals or respite workers who might be temporarily available and already know your child and family?

Find a Buddy

A peer from school or a family friend may not feel comfortable caring for your child alone, but he or she could come over to help with an activity or come along on an outing to lend a hand. Both your child with special needs and their siblings will enjoy the company of someone new.

As you think about 2019, consider the new direct care needs you might have. Will your family need to find new workers?

If so, check out our fact sheets on finding workers, as well as our fact sheets on respite and personal care services, available on the Family Voices of Wisconsin website.

MARK YOUR CALENDAR!

Want to stay informed about Family Voices?

[“Like” us on Facebook!](#)



Learn More

For more information on the articles in this newsletter visit these websites:

Family Voices of Wisconsin
familyvoicesofwisconsin.com

National Family Voices
familyvoices.org

Wisconsin’s Family Caregiver Support Alliance
wisconsin caregiver.org/alliance

Respite Care Association of WI
respitecarewi.org

Advocacy for Change

Our full day advocacy and skills building training will be held in Madison on

Wednesday, March 13

Registration will open in early January 2019

- ◆ Enhance your advocacy skills
- ◆ Connect with other families
- ◆ Practice telling your family story to impact policy change

Scholarships to cover the cost of participating in the event, hotel (if needed) and travel expenses are available for adult family members of children and youth with disabilities and/or special health care needs.

For details visit the Family Voices website:
familyvoicesofwisconsin.com/trainings/afc/

Policy Update

Creating Family Support and Disability Resource Centers

Family Voices, in collaboration with the Children’s Long-Term Support (CLTS) Council, cltscouncil.wisconsin.gov, and other disability advocates, is working to move a budget initiative forward to create a “No Wrong Door” resource called the *Family Support and Disability Resource Centers*. This fall, representatives of the CLTS Council met with Department of Health Services Secretary Linda Seemeyer and will meet soon with Governor-Elect Tony Evers’ transition team to educate them about this important initiative to connect families in a timely, effective way to the resources they need.

These statewide centers will be able to provide:

- ◆ accurate and complete information and assistance;
- ◆ family navigators to help with accessing health, community and school systems, and transition;
- ◆ family-to-family connections;
- ◆ education and skills training for families; and
- ◆ seamless access to eligibility determination for long-term supports and services for children.

The CLTS Council believes that the right amount of support at the right time is the most effective way to support families, prevent crisis and the need for more costly services, and maximize the use of existing “generic” community, health and school-based supports while reducing and even eliminating reliance on formal disability services.

To learn more about this important budget initiative, go to the Policy page of the Family Voices of Wisconsin website familyvoicesofwisconsin.com/public-policy/wisconsin/. To stay informed and know when your voice is needed as the 2019—2021 state budget is being debated, join the Family Action Network (FAN) at waisman.wisc.edu/cedd/fan.php and like our Facebook page, facebook.com/FVofWI/.



Northeast Region
Children’s Hospital of WI
Fox Valley
877.568.5205

Northern Region
Marathon Cty. 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 Cty. Dept.
of Public Health
Chippewa Falls
800.400.3678

Family Voices Winter and Spring Training Schedule

Family Voices and the CYSHCN Regional Centers will be hosting training sessions for families and providers. These sessions are free! A light meal and a resource binder will be provided to each registered participant.

Sessions will be held in the following communities this winter and spring: Appleton, Cudahy, Fennimore, Fort Atkinson, Madison, Wausau. Check our website for dates and locations at familyvoicesofwisconsin.com/2019-training-schedule/.

[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 the importance of coordinated care and a medical home for every child.



Your Support Makes a Difference!



Family Voices needs your help to keep making a difference in the lives of families. Please donate to Family Voices of Wisconsin! Your tax deductible contributions can be mailed to:

Family Voices of Wisconsin, PO Box 5070, Madison WI 53705
or go to [DONATE](#) on the Family Voices website.



PO Box 5070
Madison, Wisconsin 53705

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About Family Voices of Wisconsin

Family Voices of Wisconsin is a state affiliate of national Family Voices and serves as Wisconsin's Family-to-Family Health Information Center.

Family Voices 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 13, 2019); and
- ◆ Public policy and systems change activities.

Children with special needs and their families can benefit from having help at home. This can include hiring someone outside of immediate family members to give parents much needed “time off” from direct caregiving.

However, even if your family has funding through Medicaid or a Children’s Long-Term Support Program to pay for these workers, finding workers may be a challenge. *(To learn more about Medicaid personal care and respite services see the [Family Voices fact sheets on our website](#).)*

Before starting the recruitment process, think about your needs, such as what time of day your family needs help most and what type of caregiving or activities are needed. Being as specific as possible will help you find the right workers.

Where Do I Find a Worker?

- **Word of Mouth:** Let friends, neighbors and people you work with know that you are looking for a direct care worker. If you are part of a faith community, neighborhood group or parent support group, let those members know as well.
- **Your Child’s School:** Let teachers, therapists, and paraprofessionals at your child’s current and former schools know that you are looking for workers.

- **Colleges and Technical Schools:** Connect with local colleges or programs for students interested in health care, education, nursing, social work or related fields. Schools often have “job boards” where notices can be posted electronically.

- **Other Job Boards:** There are both online and physical job boards available where a position description can be posted. Libraries, grocery stores and community centers may have job boards. Respite programs or personal care agencies can also help you locate job boards.

- **Community Programs:** Contact local programs that serve children, like the YMCA, summer camps, after-school programs or babysitter services to let them know you are looking for workers.

- **Ads in local newspapers:** Place an ad in local or neighborhood newspapers, or on a local Facebook page.

Hiring Family Members:

If your child is under age 18, you may be able to hire a relative to provide personal care covered by Wisconsin Medicaid. For youth over age 18, a parent can be hired to provide personal care services. Respite programs may also be willing to hire relatives, including an older sibling.

Interviewing Potential Direct Care Workers

Once you have successfully found a potential worker for your child, it is important to invite him or her to your home and make sure he or she will be a good match for your family.

Consider using the following guidelines as you interview potential candidates:

Start by:

- Explaining your child's health, medical and/or behavioral conditions.
- Let them know what days and times of day you need help.
- Describe what you are looking for in a worker and what their time with your child will look like.
- Discuss any special rules or expectations you have for any worker. For example, you may want the worker to always call when he/she is running late or ask that he/she call you and not come over when they are not feeling well.

Questions You Could Ask:

- Do they have experience working with children with special needs? If not, have they been a babysitter or a caregiver for a sibling?
- How much time do they want to work? Do they have flexibility to work with your family more often or on short notice? Will their availability change each semester (if they are a student)?
- Do they have reliable transportation? Will they need a car or are you on a bus line or close enough to walk or bike?
- Are they comfortable with all the duties of the position? For example, are they willing and able to use equipment, change diapers, prepare a meal or appropriately react to behaviors?

If you will be hiring the worker to provide respite or personal care services, contact the agency. The worker will likely have to complete an application, participate in training, and have a background check which could take several weeks.

If you have additional questions, or need help finding services, contact the following organizations:

- **Regional Centers for Children and Youth with Special Health Care Needs** - www.dhs.wisconsin.gov/cyshcn/index
- **Well Badger Resource Center** - wellbadger.org or 1-800-642-7837