

PARTNERS

THE NEWSLETTER FOR WISCONSIN'S ADOPTIVE & FOSTER FAMILIES



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FROM THE CORNER OFFICE

Welcome 2018!!

I hope you have all had a good start to the year and that your families are safe, healthy, and warm. It seems our weather is changing from moment to moment and the flu bug(s) are extra pesky this year. Despite any challenges you may be facing, I hope you are also finding the New Year a time for new possibilities. Here at the Coalition, we are excited for what this new year will bring, and we continue to do our best for and with all of the families, children, and professionals who engage with us.

As always, we hope the articles contained in this issue of *Partners* provide you with information and thoughts for further research and discussion. Please always remember we are only an email or phone call away. If we can't locate you what you need, we will work to connect you with those that can help.

In closing, I leave you with this quote I think applies to the issue of caring for children and youth with special needs:

*A child is like a butterfly in the wind.
Some can fly higher than others,
but each flies the best he/she can.
Why compare one against the other?
Each one is different.
Each one is special.
Each one is beautiful.*

We are grateful to be here for each different, special, and beautiful family!

Warm Regards,

Oriana Carey

Coalition for Children, Youth & Families
6682 W. Greenfield Avenue
Suite 310
Milwaukee, WI 53214-3151

(414) 475-1246
V/TDD (800) 762-8063
Fax (414) 475-7007
info@coalitionforcyf.org
www.coalitionforcyf.org

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Wrapped in the *Unconditional Love* of Family



Adoption wasn't a new road for Danee and her husband Jim. When five biological children left the nest, they added twin boys and Irish-twin girls to their family through adoption from Russia and Guatemala. Shortly thereafter, they also added a 14-month-old and a newborn through foster care.

Even so, Danee had a feeling that her family's adoption journey wasn't done yet. Danee and Jim learned about two boys in an orphanage in Ukraine. The boys' situation was dire. There was a long list of serious medical needs to consider. But their hearts reached out to these two boys and, ultimately, Jim travelled to Ukraine with one of the couple's older daughters to bring home Jais and Mathis.

Surgeries were just the first of the major changes that would take place for this family. Caring for a child who used a wheelchair, making regular trips to specialists in Chicago, multi-day EEG's, and more were now part of everyday family life. Even so, "There has never been a second, not on any day. I have never regretted it for a second," Danee said.

At first, Danee admits, it was hard to know where to turn. "It's tough to ask for help when you don't really realize what help you need," she said. "I liked it when people made suggestions about options or ideas for what things worked for other families with kids with extra needs. I was in survival mode, just getting everything done that needed to be done in a day. I didn't have the time to think about any other way to do it, so, when someone came along and offered ideas or shared something new they saw or used, it helped me a lot."

The boys have been home for five years now, and Danee says she is just now starting to think ahead and plan strategically about what help they will all need. So far, she says that, "We have been fortunate to receive respite care, partner with our great school, utilize physical therapy services, RADD Camp, work with the waiver program to convert our van with a wheelchair lift, worked with Variety Club for a standing wheelchair for Jais, and hear about resources and activities that are available for our kids."

When you have children with significant special needs, the future looks different. As a parent, dreams change. "Our

goal for Jais is to live independently, or with a group of other people," Danee said. "He's amazing. He's a kid who happens to need a wheelchair and who has lived through some extraordinary circumstances."

Danee says that their family journey has taught her and Jim—as well as their children—a lot of life lessons.

"I see how my children stick up for their siblings if someone at school is teasing them or being mean. I see how my kids feel more comfortable interacting with other people of all abilities and appearances. I see my kids do projects at school about their siblings and the journey we've all been on. I hear my adult children talk about possibly adopting children when they are older. I've seen one of my children choose to obtain a special adaptive license with their teaching degree. And I have learned so much about myself. I've grown emotionally and have entered a space of acceptance and openness. I have been humbled by not having all of the answers. I've learned to laugh at myself so much more and to not take any of this life so seriously. I've learned that being paralyzed from the waist down doesn't mean life isn't worth living. I've learned that kids with extra needs are way more typical than atypical. I'm living what I've always known and felt—that all kids deserve to be loved, to be safe, and to feel wrapped in the unconditional love of a family."

Throughout her journey, Danee has found and continues to find support from other parents who understand that this life isn't typical. Finding others who truly get it is a theme we know well at the Coalition, and one that Danee has first-hand experience with. People who have large families, children with special needs, and challenging diagnoses, need that support. Sometimes a good laugh—without feeling a need to defend your parenting—is a much needed release for parents of children with special needs. If you are parenting a child or children with special needs and are looking to connect with another family that shares similar experiences on this journey of parenting, let the Coalition know. We want to help you build your network of support.

Glass Half-Full:

The Importance of Self-Care when Caring for a Child with Special Needs

Parenting is no easy job. And, when you are parenting a child with special needs, you will often find that you need additional skills, education, advocacy, and patience. Your child will call on you, depend on you, and ask much of you. You may have a child who was born with a disability or developmental delay, or may have special emotional or behavioral needs as a result of abuse or neglect; whatever your family's circumstances might be, your parenting experience may, at times, look and feel very different from what you see around you.

These differences may occasionally stir up feelings of resentment, defensiveness, or frustration. You might feel worn out or pulled too thin. You may at times fall into the game of comparisons or “what if,” measuring your child against other children who do not have special needs. You might feel jealous of other parents or feel sad, grieving the loss of what you had envisioned your child—and your family—to be.

As a parent, you may feel discriminated against because of your child's needs. You might have times when you shy away from public places in order to avoid stares or pointed questions. You may have days when you feel protective to the point of aggression, wanting to guard your child from anything negative or harmful.

For all of these reasons—and many more—it is particularly important for parents of children with special needs to take time for self-care.

First and foremost, please remember that you are not alone. Your friends, family members, circle of support, and us here at the Coalition are here with you and for you. It's okay to feel tired, frustrated, exhausted, or sad—we all do from time to time! You might feel guilty for wanting an hour, an afternoon, or a day to yourself. That's not uncommon, but please also know that everyone needs time to recharge their batteries and “refill their cups.”

When you feel overwhelmed and crazy busy, it can be easy to think, say, or feel that there just isn't time to take care of yourself. However, taking care of yourself is just as essential as taking care of your child. Moreover, finding time to practice self-care does not need to be complicated or time consuming. There are several easy and relatively inexpensive ways to practice self-care; we have listed some suggestions to get you started below:

- **Make parenting “time outs” a priority.** A night out to unwind with a friend or your significant other is not self-indulgence, nor is it selfish. Rather, these kinds of activities are crucial for you and for your relationships with others. Just like you would schedule an appointment for your child to see the doctor, have a play date with friends, or attend an extra-curricular activity, schedule some time for yourself, too. Rely on your circle of support to care for your child or children so you can focus for a few hours on your friendships or your relationship.
- **Spending time alone is equally important.** Try to find time in your day for something you enjoy. This could be something as small as five minutes listening (and maybe dancing!) to your favorite song, stopping while out and about to snap a picture of something in nature, or indulging in your favorite tasty treat. If you are able to carve out a little more time, you might jot down some things you are grateful for in a journal, go for a walk around your neighborhood, or soak in a warm bubble bath.

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THE TRAUMA MASK

As a parent, your first inclination when your child is acting out, showing disruptive behaviors at home or in school, or complaining of chronic physical ailments is to call your family doctor. You start with what may be most obvious: is he sick? Are her behaviors actually symptoms of an illness? And, even if you are given a diagnosis and recommendations for treatment, is that really what's going on? Could trauma be the true cause?

It's thought that every child who has been adopted has experienced some level of trauma. We know that children who have suffered trauma have had stress hormones coursing through their body, perhaps on a regular basis. These children may frequently be in fight-or-flight mode and see the world as a scary, unsafe place. They may feel that, in order to protect their very survival, they have to be constantly on the lookout.

When your child is on constant alert, many behaviors that we would see as healthy or adaptive get put on the back burner. For example, the ability to manage impulsive urges may be lost. If your child is hyper-focused on possible dangers, he may have a tough time sitting quietly at a desk reading. If your child interprets a simple request from you, such as picking up her toys, as a stressful interaction, she may go into fight-or-flight mode. For her, that could mean becoming defiant and disruptive. Many behaviors and emotions that make our adopted (and birth!) kids more challenging to parent have trauma at their roots. Yet that might not be obvious to your child's physician or clinician.

You may want to encourage your doctor or treatment provider to consider the trauma perspective. We know that many physical symptoms and ailments can have multiple causes. For example, chest pain in adults could have a number of conditions at its root. The same may be true for your child. The diagnoses for ADHD, sensory processing disorder, and OCD, for example, all include behaviors that mimic what some children exhibit when they are suffering from trauma.

You might wonder what's really wrong with that. Won't treatment for these similar-looking conditions help your child just as well? Because trauma affected a specific part of your child's brain during development, treatment needs to take that into account. When it comes to trauma, we know that these children have different needs than children with other diagnoses. If your child has experienced trauma, he may need a more comprehensive kind of assessment and treatment plan than what kids with more traditional diagnoses might need.

As a parent, you are the strongest advocate for your child. By understanding the various symptoms trauma can create, you can help inform the professionals and clinicians who are working with your child and your whole family. Together, you can get to the bottom of what's causing the acting out, sleep problems, eating disorders, or any of the other symptoms your child could be having. In turn, you and your child can get an accurate assessment and get connected with the right professionals. Your child will get the treatment she needs, as well as the most helpful support at home, at school, and in the community.

PREPARING FOR A *Less-than-kind* WORLD



Those not familiar with children who have special needs may not view your child as the unique, remarkable human being that they are. They may only see your child through the lens of their behavior, diagnosis, disability, or delay. There could be stares and whispers from others wondering what is “wrong” with your child.

Because others may view your child as different, you and/or your child might have some bad experiences with other parents, other adults, and other kids. They may do or say unkind things—either unintentionally or just due to ignorance. People may be curious, unaware, or uneducated about your child’s special need. You and your child could experience other people,

- Pointing or staring
- Whispering behind your or your child’s back
- Asking rude or inappropriate questions
- Excluding your child from activities
- Picking on or bullying your child
- Calling your child mean or hurtful names
- Avoiding interacting or engaging with your child

These are certainly not nice things to experience, but ones that many children with special needs do experience at some point in their lives. There are ways to deal with these unpleasant situations with poise and compassion. In order to prepare yourself and your child for this sometimes less-than-kind world, you may want to try,

- Practicing what to say when others ask rude questions. Try to use dispassionate language and speak matter-of-factly.
- Ignoring thoughtless or rude comments or questions. Pretending you didn’t see or hear other’s poor behavior is sometimes okay.
- Building up your circle of support for both you and your child. Have your go-to people who you can lean on to feel understood and accepted.
- Having a plan to involve an adult when a bullying situation occurs, like at school. Talk with your child’s teachers and/or administration and come up with a plan to keep everyone safe.
- Remembering that unhappy people tend to do and say unkind things often stemming from their own insecurities, fear, or unpleasant life circumstances. People who are hurting may tend to hurt other people.
- Educating others when you can. Take the fear out of the unknown for other people. Again, people may just be curious or unfamiliar with your child’s special needs. Taking the time to help them understand those needs can help normalize your child and their individual needs; knowledge is powerful.
- Modeling the responses you want to see from your child. Children are always watching and observing, how you handle yourself will show them how to handle themselves in these situations.
- Trying to keep a sense of humor when possible. Humor can lighten tense situations and redirect negative energy. Sometimes not taking life too seriously can feel good. And, laughter is good medicine!

Having a few different responses you are most comfortable with can help you and your child feel better prepared to handle uncomfortable situations. Practice as a family how to be assertive, yet respectful. Most of all, remember to seek out the joys and “wins” in each day. For as much stress and struggle you and your child may face, there is also joy and accomplishments to look forward to. You have the unique privilege of watching this person grow and achieve successes in their lives. As your child succeeds and stretches his own limits, you, too, will grow—as a person and as a parent. Being the parent of a child with special needs means that there is much your child will need from you; but there is also much your child will teach you: empathy, patience, perseverance, and the ability to meet people where they are. You are on an incredible journey together!

RESOURCES

Tip Sheets

- **The Balance Beam: Caring for Yourself While Caring for Your Kids**
<http://postadoptccyf.org/Resources/Tip-Sheets/Taking-Care-of-Yourself/The-Balance-Beam-of-Life-Caring-for-Yourself-While-Caring-for-Your-Kids>

Additional Information

- **4 Life Lessons from Parents of Kids with Special Needs**
<https://www.parents.com/health/special-needs/4-life-lessons-from-parents-of-kids-with-special-needs/>
- **9 Ways You Can Help a Special Needs Parent**
https://www.huffingtonpost.com/m-lin/special-needs-parents_b_1338169.html
- **Confessions of a Special Needs Parent: The Hard Things**
<https://www.ellenstumbo.com/confessions-of-a-special-needs-parent-the-hard-things/>
- **20 Things Every Parent of Kids with Special Needs Should Hear**
<https://www.abilities.com/community/parents-20things.html>
- **15 Truths of Parenting Special Needs Kids**
<http://www.scarymommy.com/parenting-special-needs-kids/>
- **7 Things You Don't Know about a Special Needs Parent**
https://www.huffingtonpost.com/maria-lin/special-needs-parenting_b_1314348.html?ref=parents
- **Preparing to Parent a Child with Special Needs**
<https://adoptionnetwork.com/adoptive-parents/preparing-to-parent-a-child-with-special-needs>
- **WI FACETS: Wisconsin Family Assistance Center for Education, Training and Support**
<http://www.wifacets.org/>
- **Taking Care of Yourself when Your Child has Special Needs**
<https://www.greenchildmagazine.com/self-care-when-child-has-special-needs/>

Library

- *Married with Special Needs Children: A Couple's Guide to Keeping Connected*, by Laura Marshak and Fran Pollock Prezant
- *Leah's Voice*, by Lori DeMonia (children's book)
- *Adopting the Hurt Child, Hope for Families with Special Needs Kids*, by Gregory C. Keck, PhD and Regina M. Kupecky, LSW
- *Finally a Family: Help for Prospective Parents of Special Needs Children*, by Barbara Braumann and Shirley McCain
- *Kids Explore the Gifts of Children with Special Needs*, by Westridge Young Writers Workshop

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- **Celebrate and cherish your child.** Spend quality time playing, cuddling, and observing developmental milestones (even if these milestones are more unique than for other children). Share your happiness with those you love.
- **Be gentle with yourself.** Show yourself the same love, respect, kindness, and empathy that you would give to others.
- **Do one nice thing for yourself each day.** It doesn't have to be anything big, just something that will provide you with a little more happiness. Treat yourself to a special cup of coffee or lunch at a favorite spot. Take a walk over your lunch break or after work. When you give yourself kind gestures, you are really re-energizing your state of mind and reminding yourself of what is important.
- **Put yourself on the calendar.** Before you leave your hair or massage appointment, schedule the next one right away. You might also create your own routines. For example, sticking to a targeted bedtime will help you feel better physically and emotionally.
- **Don't hesitate to ask for—or accept—help.** When someone offers to help you, we encourage you to answer with a firm yes! If you have the opportunity, explain exactly what might help make your life a little bit easier and accept the other person's assistance. You might even take advantage of support offered by groups of other parents caring for children with special needs. Joining a support group can provide you with information, a sense of community, and a perspective that few other parents have.
- **Call in a lifeline.** Your friends and other members of your circle of support can be a lifeline—especially during more challenging days. Your spouse, partner, or co-parent is a wonderful source of support. But sometimes being able to talk about issues, discuss options, and even share good news with someone other than that one person can provide you with a fresh perspective that we all need. If you're not one to talk on the phone, you might text, SnapChat, or use Facebook Messenger to keep in contact, hear about what's happening with your friends, and share news or updates.

Taking care of yourself is a very important part of the job of being a parent. Remember that we can all use a little help now and again. We hope one or more of the ideas included above can help you find ways to focus on yourself as you care for your children and family.



Coalition for Children, Youth & Families

6682 West Greenfield Avenue
Suite 310
Milwaukee WI 53214

T/TTY 414.475.1246
FAX 414.475.7007
TOLL FREE 1.800.762.8063
info@coalitionforccyf.org

Family of websites:
coalitionforccyf.org
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An umbrella of services over
foster care and adoption;
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Coalition for Children, Youth & Families
6682 West Greenfield Avenue
Suite 310
Milwaukee WI 53214

