

## From the Editor's Desk

sn't it such a fantastic feeling when you meet someone driven to make change for the better? Their dedication inspires you-it encourages you. As editor-in-chief of Exceptional Needs Today, I have the honor of working with passionate, motivated people every single day. These remarkable individuals comprised of parents, selfadvocates, educators, doctors, and therapists act as catalysts for change. They are the voice of tomorrow.

I want to introduce you to Pam Mines, a passionate champion for families with differently-abled loved ones. Pam, the mother of a young man with autism, introduced JP's Law in Virginia and the District of Columbia years ago to ensure individuals with different abilities are recognized and supported in their communities. The law allows individuals to voluntarily add an innocuous code to their driver's license or identification card noting autism or an intellectual disability to keep them safe. In her exclusive piece, JP is...Just Fine!, Pam shares how her son's autism diagnosis affected their family, including how it fueled her work as an advocate and uplifting voice of support.

Another remarkable person joins us to explore a subject matter too many people tend to shy away from-mental health. Successful novelist and mental health advocate J. Edwards Holt, diagnosed with Tourette's syndrome, anxiety, depression, obsessive-compulsive disorder (OCD), and attention-deficit/hyperactivity disorder (ADHD), has provided us with an excellent article called Top Ways You Can Identify and Manage Obsessive-Compulsive Disorder. His informative piece can help you understand an OCD diagnosis and perhaps guide you in finding new ways to manage it. His approach is both relaxed and supportive.

Disclosing some of your darkest times in an effort to educate and support others can be a most generous gift. Tasnuva Sarwar Tunna, PhD, a neurodivergent autism parent, has courageously shared her journey to becoming a survivor in her piece, Being an Exceptional Parent: Nine Ways to Nurture Your Own Special Needs. Tasnuva's honest and warm-hearted advice will soothe and empower the soul. As she asserts in her piece, "Persevere such that your weakness becomes your strength, and your strength becomes your superpower!"

One of the greatest blessings in life is the role of a parent. It can also be the most challenging—especially when someone you love needs extra care and support. Using her experience as the mother of a non-verbal young man with autism and as an autism coach, Deanna Picon has creatively composed the kind of personal letter every exceptional needs parent would appreciate receiving this Mother's Day or Father's Day. As Deanna so eloquently states in her piece, Celebrating Parenthood: From One Special Needs Parent to Another, parents who stay and accept the challenges of raising a child with a disability deserve a medal for courage. "Even though we didn't know

what was ahead, Dads and Moms like us took a deep breath and walked on. And because of our courage and determination, our children will have a better life," Deanna writes.

We also treasure the loving words of Melissa Dean, a devoted homeschool mom to eight children ranging in age from seven to twenty-five. Melissa's youngest four children have exceptional needs. In her piece, Seeing and Loving Lydia, Melissa has graciously given us a glimpse of her loving journey with Lydia, her delightful daughter with Down syndrome. Melissa's voice is warm and inspirational.

This issue is overflowing with valuable guidance, including an excellent article on how a meltdown differs from a tantrum, how to identify possible triggers, and the importance of allowing the use of individualized stims and other coping methods when overwhelmed. We also have articles focused on why a child may engage in self-injury, ways to improve social skills, and why it's crucial to strengthen executive functioning skills. We provide guidance centered on what to do when a special needs diagnosis is received, facts you need to know about government benefits, and what happens when student services end. There are also several articles centered on the value of authentic friendships when there are different abilities and the importance of parental relationships inside and outside the exceptional needs community. Plus, so much more!

We have been delighted with the tremendous response to Exceptional Needs Today. We want to extend a special thank you to our incredible subscribers, contributors, and advertisers. Let's continue to support and empower one another. Let's make sure every voice is heard!

Amy KD Tobik Editor-in-Chief, Exceptional Needs Today Publisher, Lone Heron Publishing

PLEASE JOIN OUR EXCEPTIONAL COMMUNITY F O in

# Celebrating Parenthood: From One Special Needs Parent to Another

### By Deanna Picon

Hey Jen,

How's it going? Sorry I haven't called or texted you lately. It's been really stressful and crazy trying to work on the PowerPoint presentation for my boss while helping the kids with their virtual learning and the thousand other things on my plate. Sound familiar?

I can't believe it's already May. Boy, this year is going by so fast! I haven't had a chance to get you anything for Mother's Day yet. And Father's Day is right around the corner. Are you still buying the barbeque grill for Steve's present? I think he'll love it. I'm still not sure what I'm getting for Tony.

I went to the store today to buy some Mother's Day cards for my mom, aunt, and sister, but I couldn't find the right one for you. No worries. I did buy you a Lotto card. And if you hit, remember our pact: we split the cash 50/50, buy two oceanfront mansions in the Caribbean, and retire. Sounds like a winning plan to me!

I have to tell you something. An unusual thing happened while I was browsing and reading some cards. I started thinking about what it really means to be a parent and a special needs parent at that. I really couldn't decide if I should buy you a serious or funny card because of all the ups and downs we've been going through. Honestly, I think the last year and a half have been one of the most difficult periods of our journey.

It wasn't easy raising a child with a disability even before the coronavirus pandemic. Between school activities, IEP meetings, doctors' and therapists' appointments, and just taking care of our families (and a million other things!), it was a miracle if we knew our own names. And now, sometimes it feels like a miracle if we can keep our kids focused on the computer for just 15 minutes of their remote school day while making meals and checking voicemails, texts, and emails. Did I mention we still need clean clothes to wear?



We're living through some uncertain times, and so are our kids. The COVID-19 pandemic changed not only our lives but also the routines, schedules, and structures we all depend on. Who knew? We need those routines just as much as our children do.

All this stuff has given me more insight as well as some different perspectives about parenting.

First of all, parenting is a hard job, period. But for us, it's definitely harder than for the average parent. We've always had to deal with a ton of things parents of typically developing children don't have to. Then, the COVID-19 pandemic came along and added even more overwhelming stress, anxiety, and demands to our lives.

It seemed like overnight, Brianna and other young kids lost access to school and academic programs as well as physical, occupational, speech, and behavioral therapies. Adults with disabilities weren't able to attend day habilitation or vocational and recreational programs. By the way, how did the Zoom session go with Brianna's therapist?

It's like special needs parents were suddenly told we had to become home-based Special Ed teachers and therapists

without proper education or real training, like we didn't have enough on our plates beforehand! Thank goodness for the countless number of YouTube videos and resource materials posted by teachers, therapists, schools, autism organizations, and special needs publications from all over the country. They have been such a tremendous help to both of us.

We stepped up to the best of our ability, and we're still hanging in there. Even with our fears, anxieties, and concerns, we provide a safe haven for our children. I'll be the first to admit it definitely isn't easy. But they're our kids, and we love them. So, we make sacrifices and do what we have to do.

As the country celebrates Mother's Day and Father's Day this year, special needs parents like you and me should be patting themselves on the back for being the dedicated and caring parents we are. And I don't mean in a self-serving or arrogant way.

All those who stay and accept the challenges of raising a child with a disability deserve a medal for courage. We faced up to our responsibilities, even though it meant braving uncharted territory. Even though we didn't know what was ahead, Dads and Moms like us took a deep breath and walked on. And because of our courage and determination, our children will have a better life.

There's a word to describe people who live up and face up to challenges; we call them heroes. Even if the world doesn't recognize it, you will always be a hero to Brianna and to those of us who have walked in your shoes.

Now, I'm not saying we're superhuman. Unless you have a secret identity, superpowers and a cape hidden in your closet I don't know about, neither of us is a superhero. And no parent of a child with a disability is going to make it without help, whether it comes from other people or from within ourselves.

I guess you can tell all of this has got me thinking. I've realized there are a few things I know for sure about parenting. I'm writing them down here so when things get overwhelming, either of us can look back at this letter and remember these words of wisdom.

Okay, okay...stop laughing. I can see your smiley face now and hear your crazy, loud laugh. I know they're rare, but I do have occasional moments of brilliance, if I may say so myself. So, here's what I've come up with...

#### **NOBODY IS PERFECT**

Kicking yourself for not being a perfect parent is easy—it's also not productive or fair. Perfect parents do not exist—only real human beings doing their best. You're allowed to make mistakes, get frustrated, angry, or even become a little sad at times. Please, cut yourself some slack every once in a while.

#### **FOCUS ON YOURSELF WHEN YOU CAN**

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I'm not saying to become selfish—I'm just saying that it's okay to focus on you—the person beneath the "special needs parent" label we all wear. It's not wrong to think about our own needs every so often, and we shouldn't feel guilty for doing so.

With everything that's going on in the world these days, "selfcare" is essential. It'll make you feel better and help the entire family. It can be as easy as going to your bedroom or another room and simply closing the door, tuning everyone out. Take a quick nap. Meditate. Write in a journal. Read a magazine or stream some films on Netflix. Tony grabs a beer and watches his favorite sports teams on TV. I spoke with Julie, and she loves doing her home facials. Next time I go to the pharmacy, I'll pick up some face masks for us to try.

**3 REWARD YOURSELF** Acknowledge you are an amazing parent. Day in and day out, you're caring for your special needs child. It's because of you that your child's needs are being met with consideration and love.

Because of all you do every day, make sure to do something nice for yourself at least once per week, no matter how small. Buy yourself a lovely gift. Have fun shopping online. It comes down to having a healthy respect for your own needs and the circumstances you're handling. Parents have shown great resilience and determination during this pandemic. Give yourself the credit and rewards you deserve.

#### **BE HEALTHY**

I have an idea. We've been talking about getting fit and losing all the pandemic pounds we gained over the winter. It's finally nice and warm, and definitely time to get out of the house. Let's go to the park and walk for 30 minutes two or three times a week and catch up. The fresh air will help clear our minds. It'll be fun and healthy at the same time. Steve and Tony can watch the kids.

Hey, that's it. I just figured out what to get you for Mother's Day. A pair of walking shoes or running sneakers. That way, you'll have no excuse for backing out of exercising with me!

So, what do you think? Call me when you get this, so we can talk about the shoes or sneakers you'd like.

And before I forget, Happy Mother's Day and Father's Day to all!

Deanna



Deanna Picon is the founder of Your Autism Coach, LLC, which provides comprehensive support programs and seminars for parents of special needs children. Her personal mission is to empower parents as they advocate for their children while balancing productive work and family lives. As the parent of a non-verbal young man with autism, Deanna Picon personally understands the impact of autism on a family. She knows first-hand how heartbreaking a diagnosis of autism can be for parents and the personal struggles that often follow. But, through her own journey with autism, Deanna also recognizes the special joys, rewarding experiences, and unique life gifts which can result from raising a child with special needs. Deanna's articles have appeared in Autism Parenting Magazine, Exceptional Parent

Magazine, and Parenting Special Needs Magazine. She is the recipient of both the 2018 "Top Parental Advice Writer Award" and 2015 "Top Life Coach Writer Award" from Autism Parenting Magazine. Her academic credits include a Bachelor of Arts degree in Psychology and a Bachelor of Arts degree in Broadcast Journalism from Syracuse University.

Website: www.yourautismcoach.com Email: info@yourautismcoach.com Book: www.amazon.com/dp/1497581222