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SMALL WAYS TO MAKE A HUGE DIFFERENCE FOR PARENTS OF CHILDREN WITH AUTISM

BY DEANNA PICON

"Thanks so much for calling. It was really great talking to you," I said as I finished my telephone call with my neighbor Suzanne. And as I put the phone down, I smiled and thought about our conversation. I realized that kindness shows up in many unexpected ways.

Suzanne lives a few houses down from me on my block, but I wouldn't say we're close friends. She and her husband, John, and their two children, moved into our neighborhood two years ago. Sean is 13 and Amanda is 11.

Before the COVID-19 pandemic, we would usually see each other on weekday mornings. Suzanne always smiled and waved to me from her porch as I waited for my son's bus to take him to school. She drove her two kids to school about the same time in the morning. Sometimes, Suzanne would drive up in front of our house for a minute and say "Good morning" to my son Lorne. Usually, he'd look at her and slightly smile. Occasionally, Lorne would give her a "hi-five", if he was in a really good mood. And Suzanne never took it personally if he ignored her at times.

Lorne was solely focused on looking for his bus to drive down our street. I explained how Lorne loved going to his school and

seeing his classmates, teachers, and therapists. Suzanne laughed when I told her that the only people Lorne wanted to see early in the morning were the bus driver, matron, and the other kids on the bus. By the way, the list of people he was ready to ignore also included me and his dad, Steve. As soon as Lorne sat in his bus seat, he forgot about us as well.

On the weekends, when we had some time between running our errands, Suzanne and I would chit chat in front of her or my house for about 20 minutes. Our talks were usually about community events, national news, weekly sales at our favorite supermarket and department stores, or the latest celebrity scandal. Nothing too deep or personal. Which is why our phone call was so surprising today. We've never had a personal conversation like this before.

For starters, Suzanne told me that she hoped I didn't mind her calling. She didn't want to bother me if I was busy, but I had been on her mind for a few days. Suzanne wanted to "check-in" and see how my family and I were doing, especially Lorne.

Suzanne told me that she missed seeing and speaking to Lorne in the morning, which pleasantly surprised me. She knew Lorne was probably sad or upset that his school was now closed due to the coronavirus pandemic.

"How's Lorne doing? How is handling not being at school?" Suzanne asked.

She confessed that her kids were driving her crazy because they despised remote learning. Suzanne added that she did too. It was too much for her, trying to make sure they were logging in on time, paying attention, and doing their class assignments.



Sean and Amanda kept complaining non-stop about how boring school is now. She's caught them many times playing games on their iPhones when they should be focusing on their school work. Sean and Amanda are also angry that they can't see their friends every day or hang out with them. Deep down, Suzanne knows her kids are not really learning anything substantial anymore because they're tuning out. She's worried about this, but there's not much she can do.

This is part of the reason why she was so concerned about Lorne. Suzanne wondered how Lorne was expressing himself during the pandemic because he's non-verbal. He's the only person with autism she knows. Suzanne admitted that she really doesn't understand much about autism but wanted to learn more.

"I've heard that special needs kids have major meltdowns and become really aggressive or withdrawn when they're upset. Is that true?" she asked. "How does Lorne communicate when he's angry, or frustrated, or sad?"

I told Suzanne that Lorne misses his school, classmates, and staff terribly. But it's definitely not as bad now as it was in the beginning of the pandemic. That's when all the routines, schedules and structures Lorne was accustomed to were suddenly gone, without any notice. His world turned upside down in an instant.

So yes, he had some meltdowns, but Steve and I didn't blame him for his behavior. Lorne doesn't understand there's a global pandemic going on, and we have to stay home and be safe. All Lorne knows is that he can't go to school, ride the bus, and see all the people he knows and likes at school.

I explained that special needs children desperately need the structure and routine of in-person learning at school. Most kids like Lorne also receive physical, occupational, speech and behavioral therapies. And it's extremely difficult for children to learn these kinds of skills remotely. Most parents also don't have access to the much-needed, therapeutic devices and equipment that schools possess to help kids in their therapy sessions.

Suzanne was happy to learn that we've been working with Lorne's school staff through Zoom sessions, emails and phone calls. They've helped us develop new routines and structures for him at home. His speech therapist has been great with helping us learn communication apps for non-verbal kids. We're teaching him some of these apps using his tablet. Lorne's occupational therapist has given us some low-cost and practical exercises that we can do at home to improve his fine motor skills.

Believe me when I say that Lorne isn't the only one who misses the school staff. Steve and I miss them as well. They were a huge part of our support team. We really miss seeing them in person at IEP and PTA meetings, as well as throughout the academic year.

Steve and I are doing the best we can, but we're not trained professionals. We're not educators or therapists who have specialized Bachelors and Masters degrees. So, we worry about Lorne regressing sometimes. Plus, we still have to teach him daily living skills to help him become more independent. Needless to say, this is all very time-consuming, because it may take days,

THANK YOU FOR BEING A FRIEND : THE PARENTS OF INDIVIDUALS WITH AUTISM DESERVE AND NEED YOUR HELP

As the country acknowledges Autism Awareness Month, and hundreds of organizations and people highlight the key issues surrounding autism, it's essential to remember those who rarely receive attention to their unique situation – the parents of individuals with autism. They deserve and need your help. Here are a few, simple ways you can give it.

1. KEEP IN TOUCH

The COVID-19 pandemic has made a majority of people feel more isolated and anxious than ever. Not being able to be with family and friends has taken an emotional toll and resulted in loneliness, stress, and depression for so many. Special needs parents have often felt alone and isolated, but at no time more so than now.



It would be wonderful if you let them know you care and are there for them, if needed. Using social media platforms is quick and easy. Sending a thoughtful "Thinking of You" text or "How's it going?" email can mean so much. Calling for a quick chat or heartfelt conversation can make them feel good and lift their spirits. Ask them how they're doing. Allow them to laugh, cry, vent, and blow off some steam. Your words of encouragement and support may be all they need to get through the day.

2. LEND A HAND

Because of the pandemic, special needs parents assumed more tasks and duties with full time caregiving, home schooling and managing the challenging behavioral issues of their children. With these increased responsibilities, there isn't suffi-



cient time to take care of all household tasks and simple errands. Little things like picking up a few items from the drug store for them as you shop or dropping off some clothes at the dry cleaner can be a real time-saver. It will allow them some extra time to spend on activities with their kids.

weeks or even months for Lorne to learn a new skill or behavior.

Honestly, it's been difficult trying to incorporate all of Lorne's school stuff into our own work schedules. And we still need to cook meals, clean the house and do laundry. But as parents, you make sacrifices because you love your children.

Suzanne said she had no idea how much work and time went into raising a child with special needs. She never realized how overwhelming and demanding it was. And I gave her the condensed version of "life of a special needs parent," and not the detailed, "day-to-day" stuff. If I did, we would have been on the phone for hours and hours.

Suzanne admitted that she felt a little guilty for complaining about her own kids to me. She hoped that I didn't think she was an insensitive person for not understanding or being aware of the things our family is going through.

"Of course not," I assured her. "I really appreciate your concern. And, more important, how are you supposed to know? You're not a mind reader. This pandemic has turned everyone's life upside down. We just have to do the best we can as we deal with it."

Suzanne felt so much better. She asked if there was anything she could do for me or my family. She really wanted to help in any way she could.

REACH OUT

Perhaps, like Suzanne, you have a neighbor, friend, family member or co-worker who is a parent of a special needs child. And, like her, you may think everything's fine with them. But

don't be misled. Their lives are not perfect and they're probably struggling in some areas. They could really use your assistance and compassion.

A NEW FRIENDSHIP

It's amazing how one telephone call can make such a big difference. It really can. I told Suzanne that it meant the world to me that she reached out. I was genuinely touched by her kind words and thoughtfulness. And it felt so good to talk to someone who really cared.

Best of all, I think we're on the path to becoming good friends and not just neighbors. Suzanne feels the same way. I'm sure we'll be having many more, meaningful conversations in the days to come. •

ABOUT THE AUTHOR:



Deanna Picon is the founder of Your Autism Coach, LLC, which provides personalized guidance, 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. She received her BA in psychology and BA in broadcast journalism from Syracuse University. Deanna is a parent of a non-verbal, young man with autism. She is an award-winning writer and author of *The Autism Parents' Guide to Reclaiming*

Your Life. This life-affirming guide provides parents with proven techniques and a clear-cut action plan to build a good life for themselves and their family. It is available from Amazon, www.amazon.com/dp/1497581222 and through her website, www.yourautismcoach.com. Email her at info@yourautismcoach.com.

3. ENCOURAGE HEALTHY HABITS

With everything that's going on in these parents' lives, taking care of their physical and emotional health is usually placed on the back burner. So, it's important to remind parents that their well-being should be a priority,

along with their children's health.

Getting at least six hours of sleep, eating properly, and exercising should be part of their family routine. Meditation and other relaxation techniques can also help them unwind.

The spring and summer months are perfect times to start an exercise program, especially after being stuck indoors during the winter. A 30-minute walk, three times a week, is not only excellent for your heart, but regular fresh air and exercise can benefit your mental health by reducing stress. If you've been thinking about taking regular walks yourself, why not encourage a special needs parent to join you?



4. SEND A SURPRISE MEAL OR SNACK

A box of chicken, a pizza pie, or any take-out meal from neighborhood restaurants would also be deeply appreciated by parents. Not worrying about what to cook for dinner will allow everyone to have a stress free and enjoyable meal.

A little basket of popcorn, potato chips, cheese curls, and some chocolate bars. A bowl of fruit, crackers or nuts. Snacks are definitely guaranteed to put a huge smile on the weary faces of special needs parents and delight their kids. With many theatrical movies currently being released to streaming services, any night can be a movie night. The family can have a good time, right at home, and wind down from a busy day.

