

# The Never-ending Power of Special Needs Parenting

By **Melanie K. Milicevic**

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**BEING A SPECIAL NEEDS MOM IS A LITTLE LIKE BEING AN FBI AGENT. YOU HAVE TO BECOME THE SMARTEST, MOST DETERMINED PERSON IN THE WORLD TO SOLVE A MYSTERY NO ONE CAN SOLVE, AND YOU CAN NEVER GIVE UP ON SEARCHING FOR ANSWERS.**

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You become your child's doctor, nurse, speech therapist, occupational therapist, physical therapist, best friend, and every other kind of specialist out there. When I meet special needs mothers, I know I am meeting the strongest people alive. Screw Iron Man. Try raising a child with special needs. Then we can talk about marathons. There are very few jobs that are as demanding as caring for someone who has exceptional physical, neurological, or emotional needs.

I don't have a particularly difficult child to care for, yet their care demands I be very consistent, persistent, and always ahead of the game. There is no "Let's see how it goes" or spontaneity. It takes meticulous planning and careful construction to pave a road for your child in the world.

People don't always understand why I have to plan so carefully. Yes, it's partially my obsessive-compulsive disorder (OCD), but really, it's because I have to have a plan so I can make things happen for my family. I can't just stop by somewhere for fun. I have to think about my child's mood, his ability to handle more, and my abilities as well. I am not Iron Man or Superwoman. I'm just a weak, sensitive old



soul trying my damndest to give my child a chance to make it in this broken and flawed world.

Many times, doctors or specialists don't know what to tell you about how to help your child. They don't know why your child has a rash, or a stomachache, or can't go to the bathroom. They don't know why your child is crying or looks off, is flushed in the face, can't sleep, or can't sit still. You become the investigator because you need quiet; you need rest, and you need to find a solution so you can function and be what your child needs day after day. It's a marathon, to say the least, but as you keep running, the wear and tear on your body never ends. It keeps eating away at your muscles, your bones, and your mental and spiritual self. It is the hardest journey I have endured so far in my lifetime.

Yet, there is nothing I would rather be doing than helping my child progress. I keep going no matter what, and I will

always be working to improve my abilities to advocate for my child. I have to be sharp always—to think and plan, think and plan, think and plan. Every day this takes energy. I can't have the kind of body I would like or make the kind of meals I would like, or even be the kind of wife I would like because I am thinking, planning, and finding a way to carve a space for my child in this world.

My focus is advocacy, support, skill-building, and trying to create a community for my son. This is not easy because other parents look at you like the helicopter parent from hell. Believe me, if I could just sit back, drink coffee or wine, and relax while my kids run wild and free, I would. But I can't for a number of reasons, and so I have to be more active and involved so I can help make things happen for my wonderful boy.

Special needs parenting and mothering, in particular, is a very challenging job. It's one that takes incredible inner strength and incredible persistence. You can never give up even if you're ready to do so every day. You have to find a way to wake up. You have to find a way to stay positive and keep smiling at everyone even when you want to pull the covers over your head and never come out. You have to be indestructible and fight hard like a cage fighter even though they've been counting a long time, and everyone knows the match is over. Somehow you have to keep getting up, even after the worst blows to your head. Get up, keep trying, find another way, plan your next move. Though it seems impossible, you can make it even though some will look at you with pity and make you feel like you are crazy even for trying.

I write about this because even though some of us might make all of this look easy; it isn't easy. It is incredibly hard. It forces you into dark corners all alone, screaming internally but not making a sound. You want to throw punches at people who are insensitive to your pain and struggle, but instead, you have to smile and listen to them lovingly speak about their children and their successes. You are happy for everyone always, but your internal struggle and your fight for your child take you to places no one ever wants to visit. It's a dark journey often. You are alone, and you just have to learn to live with it.

Even so, I find comfort in small encounters everywhere. This is why getting out of your house is so important. You have to interact with lots of different people because when you do, someone somewhere will say something incredibly kind and lovely and make you feel better even for a short moment. This weekend a woman complimented my children and how beautiful they are together. She told me

how well they performed dancing folklore on stage and how sweet they were playing together. This simple compliment was all I needed to keep myself above water. When I told her my son had autism, she made a funny face because she couldn't believe it and her reaction demonstrated that she had never met an autistic child like mine. The way she complimented how well he behaved was, again, a small stroke that gave me the courage to keep breathing. I know when people don't believe your child has autism, that means he looks more typical. I'm not trying to make him more typical, but I do want him to be able to survive in this place we all live in, so looking somewhat more typical can be helpful. But more than anything, I tell people about his autism because I am educating them about



what autism looks like. Here, it looks like him. Take a look and be in awe of my extraordinary child. I believe in educating everyone about autism because one day I will be gone, but there will be many more autistic children and adults around, and I want each and every one of them to be embraced, loved, and cared for. When I am gone, I want my community to love and support my child so he feels successful in the world. I am thankful I had that short but special chat with a woman I barely know because her kindness helped me make it through some personally difficult moments.

When you see someone with a child with special needs, no matter how challenged they are, give their parent a compliment about their child. Give them something to feed their soul a tiny bit. Ask about their child. Show interest in their needs and challenges. Ask what you can do if you are close to them. Talk directly to that child if they are close to you, even if they are nonverbal. Make eye contact and smile. Those are priceless gifts to our families.

Your loving gestures might be the reason a parent keeps fighting another day. There are angels everywhere, and I'm thankful to keep meeting them.



*Melanie K. Milicevic is a graduate of UCLA and a former fifth-grade teacher for the Los Angeles Unified School District. She worked mostly with second language learners and collaborated with special needs families to meet the unique needs of her students. She now advocates for her own special needs children and continues to work with schools to help educate them about ways to include children of all abilities in the classroom. Melanie is a passionate writer and hopes to be a voice for special needs families in her community. She lives in San Diego with her husband and two children.*

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