A Mother's Journey With Her Autistic Son

By **Melanie MILICEVIC**

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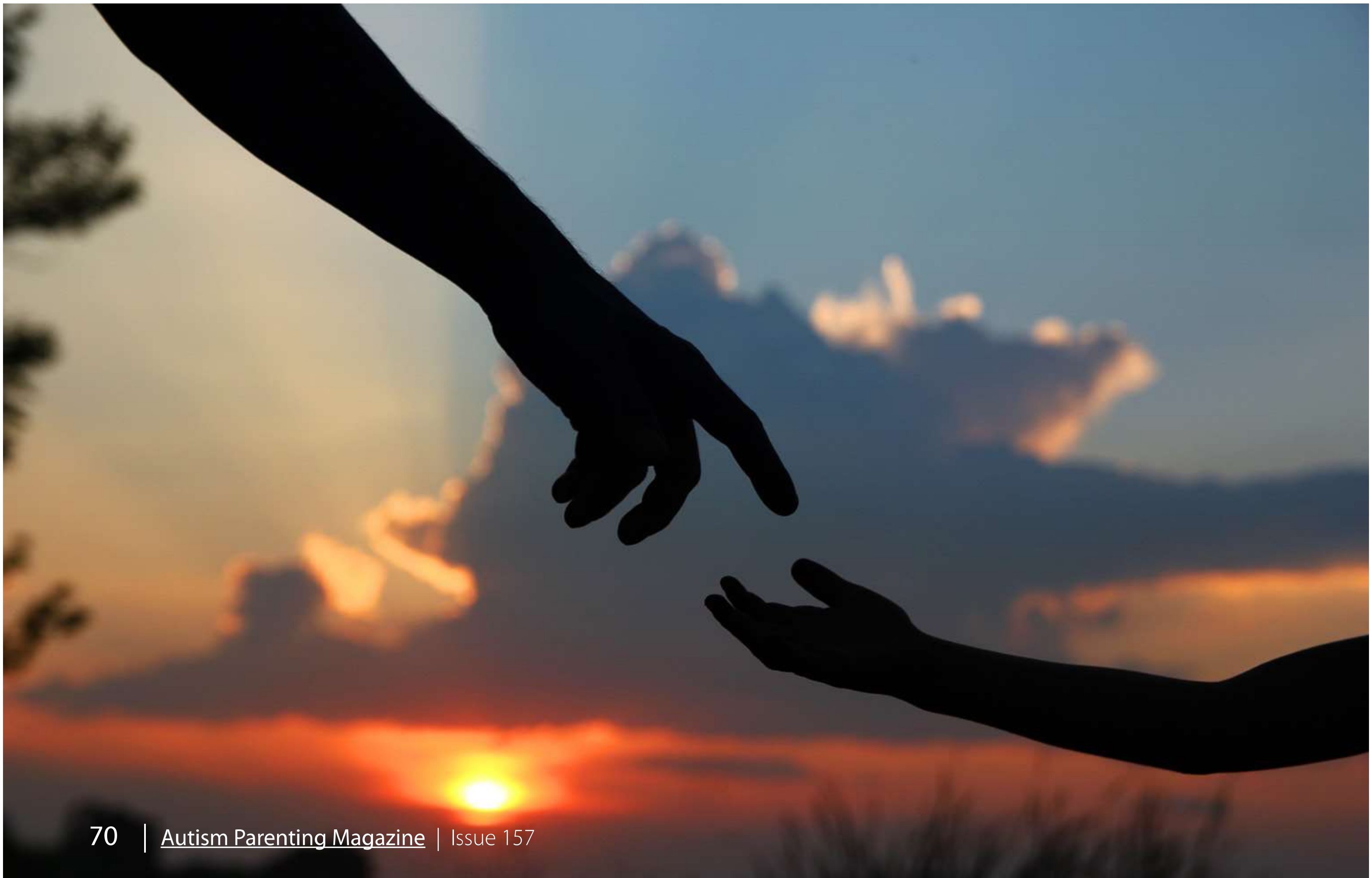
The feeling of being lost and not belonging to a particular group is a theme with which I am extremely familiar. I realize as I age, it's something I've felt on and off my entire life. Maybe all of us endure this from time to time in our lives, and it would be wise to become more comfortable with this experience of feeling lost.

As a child and young girl coming from a divorced home, I went from home to home from the age of five years old. Both homes were extremely loving and cozy, yet there was this tug of war I always felt a part of, and I could never quite make everyone content. I could never heal the wounds I did not create.

This led me to strive for perfection, a goal that was and is always unattainable. The first born in many families feels this, so I don't want to blame my parents entirely. Some of us are just wired in this way, and we want to be pleasers. I take responsibility for my part in this perfectionism. Genetics matters, though, and some of these traits I did inherit.



Additionally, as a child of immigrants, I also lived this experience of belonging neither here nor there. My parents were immigrants from Serbia, and I was the first generation born here. Being a first generation American is a new kind of cultural group. As you develop, you definitely have this feeling of not quite fitting in anywhere. You're not American, exactly. But you're also not really a Serbian. You don't really fit in anywhere except with others who are just like you: Serbian Americans.

This is a constant struggle to fit into both groups, and it requires a great deal of energy. Sometimes you can't even feel at home with those who are Serbian Americans because not all Serbian Americans are alike, just as not all people of certain ethnicities are alike. Finding a pack is not always easy, even within your own tribe.

This presents a problem. Where do you belong? Where do you feel at home? Where are you most comfortable? Who are your people?

At 35 years old, I entered another group; definitely the most influential pack in my lifetime: the special needs parent group. I became part of a club I didn't choose, but the universe chose and had plans for me. This group of families is similar to some of the other groups I've been a part of. You quickly learn that you won't relate to everyone, and not everyone will like each other. Yet you share a very distinctive bond because of the irresistible children who always make your life and the world brighter and more beautiful.

But everyone looks and acts differently in this tribe. You'll meet the widest variety of children and families, and you'd never believe that these people are your people until you realize that you are part of this diverse family. You won't see your tribe often, but when you do meet them, connect with them, and share, it will be at the deepest level of connection. It's not like the kind of intimacy you would share with your spouse but another form of interrelatedness.

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When I entered this special needs' life with my son, I dove into it with all the enthusiasm, energy, and courage I had to offer. I was 38 years old at the time of his diagnosis. I gave 200% just like I have given with everything I've ever committed to. I'm extreme at everything I do: intense and determined about pursuing things I am passionate about doing well. I call this passion “my autism, my OCD, and my ADHD” as well.

I wanted to do my job as a special needs parent well, as I understood that this would be the most important role of my life. My son, my firstborn, was my whole world, and this was the role I had waited a lifetime for. I was going to get this right for him and for my family.

I stumbled clumsily through the first five years of parenting, but then I did find a groove through the turbulent waves of special needs parenting. Don't misread my stoicism; I still get knocked down from time to time. Sometimes I'm sick for a month and can't recover; other times I sink into a dreary kind of state where I'm sleepwalking for a few months. Some months I'm so anxious that everything is just heavy for me. But I've improved at pulling myself up from those waves because I've done it for ten years now, and that means that I'm getting some experience at standing back up when I collapse.

Ironically, it so happens I have a son with special needs who is really not that “special.” If you're in the special needs community, you understand what that means. His needs are not that great. He is easy to work with, responds to almost all of the therapies we've tried, and learns well. As long as he gets the right support, he can do everything. I expect him to live a full life, and I know he will have everything he wants to have in his future. That's an interesting predicament to be in and not one I complain about at all. But here I am AGAIN, neither here nor there.

We're not neurotypical enough, so we don't quite fit in with that crowd, but we're not "special enough" so that most people would really notice that our kid has needs. People will say things like, "Well, he's not that special, so no big deal. Get over it." In general, people just say very insensitive things to special needs parents. Sometimes I do think it's better not to discuss these topics with those who are not cultured about parenting a child with exceptional needs.

This problem of ours, not being special enough and not being typical enough, is a ridiculous problem to have, yet it remains an obstacle. Finding people who relate to this predicament is a challenge.

The special needs' sports and activities are no longer appropriate for my child even though they were very helpful, effective, and needed, especially when he was young. Yet my son wouldn't play on a typical sports team now because that would be too fast paced, too much pressure, and he wouldn't enjoy the physicality of it. Some kids just don't play sports even if they do not have special needs. There are tons of kids in the world who also don't quite fit into typical activities for children and teens.

So where do we go? What do we take part in? How do I squeeze him in somewhere and hope he's getting something meaningful from it so that he's learning and making progress socially, physically, and emotionally? How do I do all this and manage the circus of my life? How do I find parents who understand me and my lack of a community?

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These are questions that I have yet to answer, but I keep looking. Every year I try to find one new thing for my son. I sign him up for a club at school, or I find an activity that I can convince someone to let him join, or I keep looking for other families who seem like us, a little bit special and a little bit typical. I keep saying, "Come hang out with us in our home," "Come for pizza and ice cream," "Come swim," "Come for New Year's, Christmas, Halloween, or a birthday." This is a lot of work. I get tired, and I fall down sometimes for a long while.

I know this group of families is growing exponentially. I meet people all the time now who say their kids have IEPs. They are fully mainstreamed like us, and they too have similar challenges. But some of these families won't use a label or won't embrace the term "special needs." They don't want to be special. They just pretend or ignore facing the things they need to face because it's too hard.

But I love to meet these parents because I can say, "Hey, we are special, and look at us. We are making it. We are part of this or that. We squeeze ourselves into activities that many would have predicted we would never be a part of."

I tell my kids, "Everyone has some sort of special need." According to the numbers and the predictions, there could come a day very soon where 50 percent of people are autistic. I want, not just my children, but for everyone to know and fully comprehend that it's not just ok to have special needs, but it's smart to be honest about what you or your child need so that you can address this.

Why would you ignore something you can help your child with while they are young? Why wouldn't you want them to reach their highest and fullest potential? Does a label mean your child won't make it? Absolutely not. A diagnosis is opening the door to unlock your child's fullest potential. It's smart, it's healthy, AND it's good parenting.

I am always dreaming about things we will try and things we will do. I will teach my kids to dream too. Dream the biggest dreams you can, because if you reach even half or one quarter of those dreams, you will surpass all the things they said you would never surpass when you or your children were diagnosed years ago.

I will never take *No* for an answer, and I will always presume my children and all children with special needs can do everything. I will keep finding a way to squeeze myself and my kids into things that others might not believe we can do. And even though I have often felt like I never quite fit in here or there, I know there are people out there who are exactly like me. They might be reading this now, and to them I say, "Come over for pizza, come swim, and come play some video games with us."

The goal of my life is to teach my kids never to give up, even when you don't fit in anywhere. You have to wake up every day and keep searching for a place that you can call home, or create your own safe space where you can rest your head in between all of the hard work. There is a tribe for everyone. Even us in-betweeners.

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