



Perspective / Opinion

The Miracle is You...All of You

By Allison DeVan, PhD, MA

April is World Autism Month. In recognition of World Autism Awareness Day on April 2, 2022, Dr. DeVan shares a bit of the struggles and joys that she and her daughter, Caroline, share as they journey through the world ...

I'd been waiting to hear my beloved daughter say my name for years. "Mama," she said, smiling up at me. "Mama," she said for the first time. She was four years old.

At nineteen months old, my first child, my daughter Caroline, was diagnosed with severe autism and other developmental delays. She barely spoke. Her food intake was poor. She avoided eye contact, rocked, hummed, and flapped her hands. But she also smiled, enjoyed social contact, and was a huge fan of classical musicals like *Mary Poppins*, *Sound of Music*, *Singin' in the Rain* and, of course, all Disney films. My husband and I began suspecting something was unusual about Caroline when she was about three months old but were still shocked when the diagnosis was formally made.

My husband and I experienced many of the same thoughts and feelings that K. Jane Lee, MD, MA mentioned during January's Kern Grand Rounds, "Changing Perspectives on Disability." Dr. Lee read from her book, [*Catastrophic Rupture: A Memoir of Healing*](#), and spoke about her journey with her daughter who was born with challenging health conditions. How did this happen? What will we do now? Will our little Caroline have a joyful fulfilling life with numerous opportunities? Will she be able to contribute to society?

We immediately enrolled Caroline in Applied Behavior Analysis (ABA) therapy at nineteen months old. I delayed rejoining the workforce while we established this full-time therapy. Fortunately, with my husband being a physical therapist and I having a doctorate in physiology, we both understood the importance of early intervention and the general principles of treatment. Caroline was immersed in therapy, receiving swallow therapy, speech therapy, feeding therapy, physical therapy, and occupational therapy. For over thirty hours a week, ABA therapists worked with Caroline inside our home. It felt like "autism" was swallowing us whole; there was no space for friends, balance, or wellness. Just this.

But more than the stress of the therapy were the nagging thoughts I couldn't shake: Will Caroline be able to read? Will she ever have a job? Will she be a "burden to society" or the flipside, will she be able to contribute to society? As Dr. Lee noted during an early stage of her journey with her daughter, I was falling into the trap of "able-ism," believing that one's worth is based upon what one can do. This belief was magnified for me especially from years of graduate school and postdoctoral training, being entrenched in academia where one's degrees, titles, publications, and grant funding are the metrics of success typically used to judge reputation and promotion. Now, every family gathering, every interaction with a similarly-aged cousin, every rare venture out of our therapized-home to a playground, store, or restaurant was a brash reminder of what our daughter *couldn't* do or just how far our family life was veering off the "normal" path.

Last November, Walt Disney Studios Motion Pictures released a new film called *Encanto* about a multi-generational Columbian family. Part of the story focuses on three sisters. Two boast well-recognized gifts for which they are well-known within their small town: Luisa who is exceptionally strong, and Isabela who makes flowers and plants grow. But the third sister, Mirabel, has no apparent gifts and is "waiting for her miracle." Despite their wonderful gifts, Luisa and Isabela struggle with the weight of expectations and maintaining perfection. In songs written by Lin-Manuel Miranda we learn that Luisa is struggling with her gift of physical strength, "*...under the surface, I'm pretty sure I'm worthless if I can't be of service.*" She wishes to "*shake the crushing weight of expectations...free some room up for joy or relaxation or simple pleasures.*" Likewise, Isabela also struggles with perfection; "*What could I do if I just knew it didn't need to be perfect?*" Isabela and Luisa's struggles are certainly applicable to the art and science of academic medicine: the need to maintain balance and wellness and the importance of being kind to ourselves while we provide compassionate patient care and serve the community, perform research to gain new knowledge for the prevention, diagnosis, and treatment of diseases, and train the next generation of physicians and scientists.

And then there is Mirabel, the sister who supposedly has no gifts or “miracles.” Early in the film, Mirabel longs to have the gifts that her family members have. She believes if she had these gifts, she could heal her family’s struggles. She wishes her family would just give her a chance and open their eyes. Mirabel sees what others can do and is fully aware of what she can’t do. Is this how my Caroline, now eight years old, feels at home and in school with her neurotypical peers? Does she wish she could speak in sentences without her augmentative and alternative communication (AAC) device? Does she wish she didn’t hum, flap her arms, and rock when she becomes excited? How must she feel when her neurotypical sister, who is three years younger, surpasses her in academics and other activities of daily living? Like Mirabel, what does Caroline see that we don’t? I feel as Dr. Lee mentioned during Kern’s Grand Rounds, wishing for my daughter “to feel deeply loved, fulfilled, valued, and at peace with who she is.”



As the storyline of *Encanto* progresses, we gradually realize that Mirabel does have gifts. She is perceptive, curious, and empathetic. She encourages her sisters to be kind to themselves and practice self-care. She facilitates the healing of relationships. She helps bring out the best in others and promotes harmony. By the end of the film, her whole family realizes that Mirabel, just by being who she is, is her gift. *“The miracle is not some magic that you’ve got, the miracle is you, all of you.”*

How true this is, and what a wonderful message for my daughter! She is intrinsically valuable as a person. Caroline makes her therapists, teachers, and peers laugh with her purposeful, silly antics. Even though she can’t easily say “I love you,” she will walk up to me, hug me, and then proclaim in a sweet tone, accentuating every syllable saying, “mmmooommm-eeee.” She and I both know this is her way of telling me that she loves me. She adores her father and sister.

She may not accomplish what the world considers as “success,” but she is making gains on her own timeline. Her life enriches others around her by just being who she is. This April, during World Autism Month, may we all strive to see the intrinsic value of people, not measuring their worth solely by what they do. May we help others to grow, be kind to ourselves and others, and live in harmony.

It was indeed a very long wait to hear Caroline say my name. At times, I was unsure if it would ever happen. But then it did. And the joy of hearing “Mama” after those four years of effort and struggle was absolutely worth it.

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