SPECTRUM OF LOVE: MY JOURNEY THROUGH AUTISM

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This book is a work of nonfiction. Events and experiences are recounted to the best of the author's memory. Some names and identifying details have been changed to protect privacy. *Disclaimer*: The information in this book is for educational purposes only and should not be considered medical or legal advice.

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DEDICATION

First and foremost, I dedicate this memoir to my exceptional children, Messiah, Marjaani, Micah, and Malakai, whose courage, resilience, and unique brilliance inspire me daily. You have taught me to see the world in colors I never knew existed. This memoir is a testament to the love and lessons you have given me. This is for you, always!

To my kid's father, Maurice Payne, who taught me the meaning of unconditional love and has supported me through every trial I have experienced.

To every parent on this autism journey, may this memoir be your guide, companion, and source of hope.

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To my family and friends, thank you for believing in this mission and supporting me every step of the way. Your encouragement and understanding gave me the strength to bring this project to life.

To the incredible professionals, educators, and advocates who are tirelessly working to create a more inclusive world, thank you for your guidance and expertise. Your insights shaped the content of this book and will empower countless families.

To the community served by Horizon Over the Spectrum, Inc., you are the reason we do this work. Your courage, determination, and love for your children inspire us daily.

Finally, this book is for everyone who has ever felt unseen or unheard in their journey with autism. I hope these pages bring you comfort, knowledge, and the reassurance that you are never alone.

With gratitude,

Dr. Simbi Animashaun

Co-Founder & Advocate, Horizon Over the Spectrum, Inc.

INTRODUCTION

Since I was a little girl, I always dreamed of being a mother. I would play "house" with my dolls and pretend to care for them like I thought a mother should. I named them Simeon (son) and Simone (daughter). They were my imaginary children. Parenting included bathing, feeding them breakfast, lunch, and dinner, reading books, combing their hair, and then tucking them tightly into bed at night. As I got older, my perspective on parenthood changed, and I eventually discovered that parenthood included a plethora of roles and responsibilities.

Eventually, my dream would become a reality in January 2014 when I discovered I was pregnant. I was 29 and a six-year middle school English teacher in the Metro Atlanta. I was excited about this new journey. I had been working with children to fulfill my desire for parenthood. I took my job very seriously. Unfortunately, my dreams were shattered when I experienced a miscarriage a few weeks after my first OB/GYN visit. If you've never experienced a miscarriage, let me share that it is one of the most painful and traumatic experiences. I had to deliver a dead fetus. A lack of support from the hospital staff, family, and friends drove me into depression that I eventually managed to overcome. I wrote about my experiences with recurrent miscarriages in my first published novel, *The Power of Healing: A Memoir of Loss & Victory*.

Two years later, I finally became a mother, unprepared for my life's new challenges. I would not only become a mother, but I would explore the parenthood of children on the autism spectrum. I must admit this journey has been a challenging yet rewarding

experience. I have learned that love grows in every shade. Today, I am a mother of four beautiful blessings. My oldest children were both medically diagnosed with autism. In this parent guidebook, I offer hope, my personal experience parenting a child on the autism spectrum, and lessons learned for parents navigating similar journeys.

PART 1

THE DIAGNOSIS – A NEW CHAPTER BEGINS

CHAPTER 1

SEEING THE SIGNS

My first son, Messiah, was born on January 18, 2018. After suffering multiple miscarriages, it was such a refreshing experience to give birth to him despite having a challenging pregnancy. At the beginning of my pregnancy, I worried every single day that I would lose him, but the anxiety decreased as I approached my delivery date. During my second trimester, I began to bleed heavily for days, but my OB/GYN assured me that everything was fine.

To comfort me, I had an ultrasound completed every 2-4 weeks. Hearing my son's heartbeat each time helped relieve the stress tremendously. In my third trimester, I began to show signs of preeclampsia. After a visit to the doctor's office, my blood pressure was 180/95, and they were unable to stabilize it that day. Thus, the surgeons moved my scheduled c-section surgery date up to the next day. I should have known something was wrong days before my doctor's visit because my feet were swollen, and I didn't have an appetite. Thankfully, I had no complications with surgery, and Messiah was a healthy 5 lb. and 12 oz. baby boy.

As a first-time mother, I would learn so much about a child's developmental stages even though I studied education in college and was a teacher. The first 4 months of his life were difficult. In addition to experiencing postpartum depression, I had a colicky new baby. He would cry from sun up to sun down for no apparent reason, and nothing seemed to work. These intensive crying episodes typically last three hours to three days, most weeks. His father, Daddy, and I tried everything! First, we changed his formula

at least three times and hoped to find a sensitive brand to alleviate the gas and bloating. We also played white noise, rubbed his belly throughout the day, and gave him colic drops as needed. Despite being colicky, he met his developmental milestones each time we visited his pediatrician.

When he turned 6 months old, the colicky episodes drastically disappeared; I felt like I finally had a "normal" baby. Let me add I intensively despise the word "normal" because it is used to ostracize those individuals who are uniquely different. Messiah crawled, responded to his name, laughed, and danced when Daddy played his favorite songs, ate fruits and veggies, etc. Luther Vandross was Daddy's favorite music artist to play at 3 a.m. He was such a delightful baby. Always smiling and always laughing. He enjoyed playtime with his father, which consisted of Daddy chasing him around the house.

As time passed, he was still making adequate developmental progress at each visit to the pediatrician. By 10 months, he had learned to walk and had said "mama" and "dada." I also started teaching him his ABCs and 123s, and I was happy to hear him mimic words and sounds that he would hear me say. On the other hand, I failed to recognize some critical signs due to my demanding job, and at the time, his father and I were experiencing some challenges in our relationship. We would eventually separate and move into different households, but we learned to co-parent effectively for the sake of our children.

By this time, I had enrolled him in a new daycare closer to my job. Things were falling into place in our new home and daycare. Then, life drastically changed for us. I started receiving daily reports that often stated that Messiah had a difficult day, including biting the teachers and other children in the classroom, not responding when his name was called or "ignoring his teachers," not following simple directions, struggling to hold a fork, spoon,

drink out of an open cup, and he often got hurt while there. I remember receiving a phone call that he had fallen into the bookshelf because he was running in the classroom and not listening to directions. This situation was shocking, but I blamed it on him undergoing "toddler blues."

On January 18, 2019, we celebrated his 1st birthday with a "Boss Baby" themed party at Catch Air. We had a blast with family and friends, and it was a joy to know I had survived my first year as a mother. I was very proud of myself. At his 12-month doctor's visit, he passed all of his developmental milestones. I shared his teacher's behavior concerns at that appointment, but Dr. B ignored me. Months later, I found out that I was pregnant with my daughter, and it seemed like my maternal instincts elevated. I began to notice that Messiah's development was regressing at 15 months. He stopped responding to his name and making eye contact when spoken to, saying "mama" and "dada," and his behavior worsened at his daycare. Unfortunately, most of my time was spent ensuring that I had a healthy pregnancy and delivery with my daughter.

Due to my age and medical history, I was deemed "high risk," and I was seeing different doctors, including a fetal and maternal specialist, every 2 weeks. This situation put an emotional and mental strain on me, especially since his father and I were still separated. By Christmas that year, we had moved into a newly purchased townhome, he was attending a new daycare, and his sister was born on November 1. I was now a single mother trying to balance two young children, a home, and a full-time job.

At the new daycare, Messiah's behavior worsened. He started eloping, running out of the classroom, laughing when being redirected by his teacher, being disruptive during learning time, etc. One day, the daycare's Director called and asked if I could pick him up. She shared that he had a tantrum and ran under her desk, and

she could not control him. I immediately shared the news with my Assistant Principal, and on the way to pick him up, I cried because I knew something was wrong with him. I felt like it was my fault.

I had neglected him and not advocated for his needs. While waiting in the Director's office, the daycare's Head Cook stopped me and blatantly asked if he had gotten his autism diagnosis yet. I almost cursed her out. I was utterly shocked that she would say that to me, but instead of being rude, I asked her to explain her reason for saying that. She then went into detail about her eldest son and how she experienced similar situations when he was younger, later discovering that he was on the spectrum. I did not know much about autism other than my experiences with teaching children on the autism spectrum in my classroom, but this was very different.

When the Director entered the office, she shared behavior observations that the teacher had noticed about Messiah since joining her class. He often engaged in repetitive behaviors, such as fixating on spinning a toy car's wheels in the classroom. Messiah also had difficulty sitting in his chair during lessons and, as I mentioned before, would elope out of the classroom. Finally, she shared that he would not play with the other children and had difficulty with transitions. This instance was the primary reason for his meltdown. They were transitioning from one activity to another. When he joined us in the office, he acted as if nothing had happened. He ran and gave me a big hug.

That night, I cried again! The conversation with the Director and Head Cook played in my head repeatedly. I opened my laptop and began to research early signs of autism. My mouth dropped as I read several online articles. This research article described my son perfectly, from the lack of eye contact to delayed speech. How did

I miss this? The next day at work, I shared my concerns with a few coworkers, and they offered their advice. Attempting to balance my intuition and external advice as a parent was difficult. To be honest, I did not want to have a son on the autism spectrum or special needs. Motherhood instantly changed, and I was about to prepare for a new testament in my life.

Here are some common early signs of autism to look out for in children, typically noticeable by the age of 2–3 years:

Social Communication Signs:

- Limited Eye Contact
- Avoids or makes little eye contact during interactions

Delayed or Limited Speech:

- Do not babble or use single words by expected milestones
- Speech develops later or not at all in some cases

Difficulty Responding to Name:

 They may not respond when their name is called, even if they have normal hearing

Challenges with Social Interaction:

- Prefers to play alone rather than engage with peers or siblings
- Limited interest in social games like peek-a-boo

Unusual Tone of Voice:

 Speaks in a monotone or singsong voice or may repeat phrases without understanding (echolalia)

Behavioral Signs:

- Repetitive Behaviors
- Engages in repetitive actions like hand-flapping, rocking, spinning, or lining up toys