

# A Neurodiversity and Gentle Parenting Journey... *in Color*



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# A Neurodiversity and Gentle Parenting Journey...in Color

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Autistic Women & Nonbinary Network (AWN)

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\*With quotes from Jennifer White-Johnson, Lei Wiley-Mydske, A.P., Robert Naseef, Tamika Lecheé Morales, Jules Edwards, Teresita Delgado Rolón, and Kristin Edwards.

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# DEDICATION

Dedicated to my amazing family, whose very existence keeps me going. You are my Crystal Gems, my Z Fighters, and my Wakandans; I'll fight for you and alongside you until my dying breath.

In memory of our various loved ones and/or luminaries from the disability community who now soar among the ancestors, including Lois Curtis, Sandy Kinnamon, Monica Roberts, Judy Heumann, Jae Casper Ross, Melissa Murry, and others. Your legacies are truly the "wind beneath our wings."

With gratitude for everyone at AWN, to RC, and all of my beloved communities - including the many individuals whose existence is often disregarded, the many families who are unfairly rendered invisible by society, and the many allies who labor beside us. Please know that I see you; that we see you, and that you matter and have always mattered.

# INTRODUCTION

*By Natasha Nelson (Supernova Momma)*

Prior to my first pregnancy, Respectfully Connected, a neurodiversity parenting project offering community and support for families, became inactive. By the time I became a mother, it had ceased to operate; I was not aware that it had ever even existed. This information could have been helpful to me because both of my girls are autistic. They have the same mother and father, are 15 months apart, and yet their autism manifests completely differently. I, their mother, am autistic, yet it manifests differently in me too.

I don't have a problem with disability because I don't have a problem with differences. Autism is part of who we are and how we interact with the world and I love us. But in the beginning of my motherhood journey, I struggled not to lose myself. When I looked for similar parents or families to be around me, I couldn't find a community. So I built one. I decided to share our experiences, our parenting, and our lives. That way, in the future, other new parents like me would have that one resource for realistic, relatable motherhood. Respectfully Connected wasn't able to provide that for me, but now this book, *A Neurodiversity and Gentle Parenting Journey...in Color*, along with the community I'm creating with Supernova Momma, can do that so that future families won't feel alone as I did.

The mission of Supernova Momma is to help Black and Neurodiverse people break generational curses from systemic racism and ableism in households, schools, and offices to receive support in a mutually caring, empathetic, and respectful environment. This is accomplished via a method that can be described by the acronym NEED, summarized below.

Network: Building relationships with organizations and advocates of Black and Neurodiverse parents online and in my local community.

Empathize: Learning and listening to the parenting concerns and practices of families of all cultures and backgrounds; respecting and researching different cultural practices, historical data and events, and socialization.

Educate: Providing Positive Discipline classes and workshops, coaching, and public speaking.

Finally, Demonstrate, the final step, involves showcasing Positive Discipline methods and tools for Black and Neurodiverse families in action through videos and words as well as sharing daily re-sources, encouragement and inspiration.

Together, we can share promising practices, including positive parenting and autism acceptance, to help achieve healthy balance in our families. Give yourself grace - mistakes are learning opportunities. (Positive, not perfect; I be messing up, too!)



# HISTORICAL CONTEXT

By Sharon daVanport & Morénike Giwa Onaiwu (AWN)

Respectfully Connected, a volunteer multinational collaborative writing project, was founded in 2014 by Ally Grace with the intent to “celebrate neurodiversity in families and share our stories in hope that they will empower and encourage other parents on their journey with the knowledge that there is a gentler, more compassionate way of raising our children than much of society tells us, and that close attached relationships are very possible.”

As stated in the Introduction to *Respectfully Connected Anthology*, “It all began with an idea.” Leia observes, “When I think of the story of how we got started, I see a visual image of one of those network maps they use with lines moving between people’s names, showing the intersecting connections and relationships. That map is so tangled now, thick in spots where our words and worlds have collided, that I don’t think it’s even possible to say where it started or with whom. I met her and she already knew her. And they knew each other from over there. Then they introduced us to her, who already knew her, etc. It’s a messed up, jumbled ball of thread that’s chaotic and rich and beautiful.”

The anthology editors note that “The common denominator in our connections with each other is neurodiversity. Some of us are autistic and/or other neurodivergent; others are neurotypical. Several Respectfully Connected collaborators have neurodivergent children – most of us have neurodivergent as well as neurotypical children. However, it’s more than that. Individually as well as collectively, we have made a conscious decision that we will parent our children respectfully, not just regardless of neurotype (theirs and/or ours), but in many ways because of it.

One would think that this is likely the goal of any parent. However, when it comes to children who are neurodivergent, sadly it is not. Many aspects of the parenting method we have chosen are derived from a combination of the neurodiversity paradigm paired with the genre widely known as ‘gentle’ or ‘connected’ parenting.”



Today, happily, there are a variety of gentle and positive parenting resources available, including several that are representative of a multitude of family types and sizes including families of color; same gender and/or 2SLGBTQIAP+ parents; multilingual, multiethnic, and/or multiracial households; neurodivergent families; families built via foster care, adoption, blended households, or other methods; individuals from numerous geographic locations; etc. But, as the anthology editors note, when the Respectfully Connected team came together to support one another in 2014, their endeavor was quite a controversial one.

At that time, Michelle recalls, “There was very little gentle parenting material that dealt with neurodiversity or disability at all, much less with a neutral and/or affirming manner. We hoped to demonstrate that families that looked like ours did indeed exist – so that other families embarking on this journey would know that they are not alone. We were considered a ‘radical’ group of disabled individuals on the fringes, parenting in ways our children’s pediatricians, teachers, grandparents, friends, and therapists didn’t understand. But our readers did. They were hungry for the words of neurodivergent families who accept the uniqueness of each member rather than seeking to mold them or mourn them.”

Michelle adds that “Respectfully Connected consisted of many voices telling many stories, all about moving gently through our life journeys, making connections and finding support as we go. We all learned from one another, and our readers learned with us. They related to our stories of living on the edge of community and the power of finding one’s place.”

This particular book, *A Neurodiversity and Gentle Parenting Journey...in Color* is a republication of writing content initially featured on the public Respectfully Connected site founded by Ally Grace as well as its anthology (edited by Leia Solo and Michelle Swan with multiple contributors [listed in the back of this book] from various locations). It is authored by Morénike Giwa Onaiwu, PhD, a global activist and writer who is a twice exceptional autistic parent in

a neurodiverse multicultural family. As one of the original contributors of Respectfully Connected, Morénike (who is also an Equity, Justice, and Representation Co-Chair for Autistic Women & Nonbinary Network [AWN]) has worked closely with the AWN Executive Advisory Board to curate writing from that project (with editing assistance from Catherine Ricotosto) to make this quality content available to the public at no cost.

*A Neurodiversity and Gentle Parenting Journey...in Color* seeks to depict the essence of one neurodivergent BIPoC family's life experiences navigating culturally sensitive and neurodiversity affirming gentle/positive parenting. As part of AWN's commitment to community and empowerment, the entire book is available for unlimited viewing and downloading via DragonBee Press. As an Open Access resource, the book is being provided online free to all readers and shall remain as such. For those who opt to purchase an optional physical copy of the book from AWN's website, any sales proceeds will be used to support AWN's critical work of providing solidarity aid and supporting transformative and restorative justice initiatives for those most impacted (including the Autistic People of Color Fund).

- With sincerity and gratitude from Sharon & Morénike on behalf of the team at AWN.

*Quotes derived from Respectfully Connected: Journeys in Parenting, Autism, and Neurodiversity (edited by Leia Solo and Michelle Swan).*

# FOREWORD

*By Ally Grace (Founder, Respectfully Connected)*

Respectfully Connected was about bringing the right people together. People who were connected by the mindful showing of respect to their autistic or neurodivergent kids. It was also about bringing people together who were good at that, living examples of active gentleness. They listened to autistic and otherwise disabled adults, knew some disability history, and were themselves on many occasions autistic or neurodivergent. They knew or were learning or creating language about the complexity involved. They recognised that their own complicity in harm was unavoidable to some extent. I considered these things to be an important and niche expertise. We didn't just hope to respect our disabled kids. We had ideas about how to enact that and were trying them out. Everyone involved was walking the talk.

At the time this all came about, there was deep and significant ableism and stigma of disability among the wider gentle parenting communities and spaces. There wasn't yet much challenge to that. The spaces were so hostile to these new ideas.

I had come to gentle parenting by reading. A lot! I learned histories and names. I began to grapple with the themes of gentle parenting. I developed what I felt were definitions and values underpinning gentle parenting. Rather than a set of rules, I saw a set of values. Principles and actions were simply serving to carry out these base values. When I applied anti-ableism and love for disabled children to these concepts – people really did not like it! I was met with fierce resistance and aggression. I continued to explore this. If gentle parenting is about countering violence and respecting kids – didn't this necessarily mean anti ableism?

I tried talking to people whom I considered my peers in gentle parenting and Unschooling spaces. This fell flat. I tried next, to find well known people who were working as writers or educators in gentle parenting. I approached many people in a respectful manner

to make my thoughts known to them and attempt to connect. I expressed that I wanted to work with them and support them, to widen their understanding. Several appeared to humour or tolerate me, though most simply argued that I was ignorant. Not a single person who I reached out to during that effort, seemed to recognise that I had anything to offer, or that I was in fact; right.

Was I... dangerous to them? Was anti-ableism too disruptive? Did they like using ableism as a weapon and a marketing technique? Was I, an openly autistic mother, being pathologised by them? The dogmatic beliefs about autistic children being victims of a toxic world, with children seen as burdens and tragedies – was sickeningly prevalent.

I felt crushed. How could I be the only one who saw the sense in this intentional, mindful criticism of how gentle parenting was being carried out? Then, I got mad. Here I was, with so much to offer – and people were not only turning my knowledge away but mocking it, and not seeing knowledge at all.

I felt I had only one real choice next – if I cared about the entity of gentle parenting, I had to work toward its full definition. I couldn't, in good conscience, allow such complicity of what I saw as a total erosion of gentleness within a philosophy defined by that. After feeling that the other avenues had been exhausted I was confronted with, I would have to be the person I was looking for. I had to become what was needed.

I didn't feel ready, my kids were still so young and I felt new and inexperienced. Nevertheless, I didn't feel that complicity was acceptable. If the so-called experts, those being held up on their thrones of knowledge, those who preached gentleness and care for kids, wouldn't do this work – I would do it instead. Through beginning to put my thoughts to paper, I found people who understood and agreed.

Once I began to write, I found a small network growing around me. I found people who, while the numbers were small - wanted this networking for the benefit of their own families. It's important to me to acknowledge that prior to us coming together to collaborate as part of Respectfully Connected, all of the other contributors to the project were doing their own important work regarding gentle parenting and neurodiversity too. I don't want to dismiss that.

Respectfully Connected served as a centre to allow us to combine our efforts, but before we agreed to partner, every single one of the contributors had their own things happening (even if in their homes only and not in published work) in their own cities and/or countries. Everyone was already doing respectful things and enacting love and change in their own ways. Because of that, I felt there were enough people to form a wider project. That project was Respectfully Connected, which for several years served as a helpful lifeline for many families around the globe like ours, letting them know they were not alone.

Because of the violence of the time, with ableism not just existing but disguised and getting through as somehow synonymous with gentle parenting; something like this was desperately needed, and it mattered a lot. It had such potential for supporting autistic children, who deserved love and respect as much as every other child did. It seemed vital to bring the right people together to enact some kind of impact amidst this climate. We, and our kids, could no longer wait for someone to be that for us. We would have to become that for ourselves.

This was how Respectfully Connected was born, and to this day, its spirit lives on in all of us.

# CHAPTER 1

## Our Parenting Journey

How do I write about my parenting style? It has become so intuitive that though I know it's different, I don't really know how to describe it. Yet I know it's important to, and I will hopefully find a way.

I might not have the exact words for it, but I do know that I am capable of recognizing it in others when I encounter it, and it fills me with hope. Though we are all unique, there are many shared beliefs and characteristics among those of us on this journey; those of us who have chosen to take this "unconventional" approach to parenting and are developing a supportive community for ourselves.

So I have asked myself what does it mean to me to be a "connected" parent? What does it mean to respect my children and to be intentionally responsive to their needs?

It doesn't mean that I am a perfect parent, as I am far from that. It doesn't mean that I am not still learning and growing. It doesn't mean that I have all of the answers.

It doesn't mean that I don't have expectations for my children, that I don't offer meaningful support, that I don't challenge them, that I don't encourage their progress.

It does mean that little of what I discover about the latest parenting trends, and/or what I read and hear about the "proper way" to "deal with" children with disabilities seems to make sense to me, or to apply to my family.

It does mean that we do things a little differently.

It means that we choose to be flexible.

It means that we do not allow convention to dictate how we live our lives.

It means that we prioritize the children's needs, share in their interests, value their strengths, and respect their limits.

It means that we go grocery shopping at night, when it's quieter. That we eat certain foods often that the children prefer. That we only attend certain schools (that are accommodating and accepting). It means that we encourage stimming and even join in.

And for us personally, it also means that child-directed play, baby-wearing, natural hair, extended breast-feeding, co-sleeping, and affirming language is how we roll.

Most importantly, it means that there is no place in our home for stigma, for "hating" disability, for stereotypes about cognitive abilities, or for shame.

Sometimes our family life is fun. Sometimes it is challenging. Sometimes it is exciting. And sometimes it's downright boring. But as parents, we always, always strive for it to be respectful. Always.

I hope to share more about our lives in the days to come.



# CHAPTER 2

## Child of Mine

Child of mine, I see you. I see you.  
How you accept your neurodivergent family members –  
without conditions.

How you flap along with your younger siblings even though flapping doesn't come naturally to you, because you want to share in their joy.

How you willingly partake in scripts because you know it brings comfort to him when you do so.

How you avoid entering and exiting a certain door of the vehicle because it causes him stress.

How you count out seven squares when giving her toilet tissue because you know that's how many she needs.

How you've memorized nearly every song by the Laurie Berkner band and on the “Just Dance” games because they get such heavy rotation.

How you pour water to a certain line in their cups because that's what they like.

How you try to make things more comfortable for them when meltdowns occur, and how much it pains you to see him hurting.

How much you love and support them.

How you say with pride, “My mom, brother, and sister are autistic. They don't ‘have autism.’ They are autistic.”



How you jokingly say, “It’s like I’m ‘half’ autistic, because of being raised around it; it’s all I know.” Then you smile – that beautiful, knowing smile.

Child of mine, people like you will change our world. I couldn’t love you more. Not just for that, but for being who you are.



# CHAPTER 3

## Full-Time Jobs for Preschool Children...Because of Autism?

Long before the day we received a formal autism diagnosis, I already knew my daughter was autistic. I hadn't picked it up at first – not because the signs weren't there, because they were, but because I didn't see anything problematic in those signs. She was a lot like the way I was as a child and also in some ways similar to me even in adulthood. For the most part, I understood her, and even the areas that I didn't understand didn't alarm me. I figured she had her reasons, and if she was content, I should be too. (Afterward, I realize my way of thinking might be atypical of others; I am simply sharing my experience.)

It was only when I enrolled her at 2 years old in a part-time Mothers' Day Out program that the differences between my child and others her age were pointed out to me, by the program staff. Not understanding what they were getting at, I decided to come on a few different occasions and observe the class through the window to try to understand. In doing so, for the first time I saw my daughter through their eyes. And I finally understood what everyone else already knew. Watching the way the other children moved, played, and talked in comparison to how she did...it was glaringly obvious at that moment that she was indeed different.

I went home and took to the internet to try to figure things out. It didn't take very long to determine what I saw: autism. I read thoroughly through the DSM-IV as well as a host of other articles. And then I visited several other websites, as well as forums and blogs. For several weeks I spent nearly every spare moment I had online, often awake until 3 or 4 in the morning. Everything I read confirmed her suspected autism diagnosis more and more. On a visit to the pediatrician, I shared my thoughts, and the doctor administered the M-CHAT; the results were no surprise.

Fast forward many assessments and specialists later, and we had our diagnosis.

I was glad to have confirmation of what I already knew. And I was grateful to live in a major city, where I felt my daughter could have proper support and services. Armed with literature, phone numbers, referrals, and URLs to visit, I set about trying to determine if my daughter needed anything and how to get her plugged in. And one thing kept coming up over and over and over.

“Early intervention is key. You will need a minimum of 40 hours per week of behavior therapy in order to obtain the maximum results, and you need to start now, before she’s three.” I read that and was told that more times than I could count. When I questioned this logic, I was told that there was extensive research to support this practice. So I looked that up too. I reviewed numerous studies and sub studies. I examined literature reviews and meta-analyses. I checked out personal accounts and contacted clinics. I reviewed the standards on the BACB (the body that is responsible for the accreditation of ABA programs and personnel). I watched some videos and webinars. I read various articles. I looked at even more research.

And I wasn’t feeling it.

BC (before children) I had taken some undergraduate level psychology courses in college. I took more of them than what was required of my degree because I found the courses interesting, using the extra classes as electives. Aside from the usual intro to psychology survey classes I also took some courses in child psychology, developmental psychology (over the lifespan), social psychology, women’s psychology, etc. While I do not profess that taking a handful of classes makes me any sort of expert in psychology, it seemed to me that this 40 hour a week ABA recommendation was contrary to nearly everything that I’d learned about development and the young child. I mean, 40 hours/week is the equivalent of a full-time job!

There was a plethora of literature about the way children learn. About their need for variety, spontaneity, and learning experiences.

About the need to be nurtured, to move and play, to have supportive relationships, to build trust, to make mistakes, to develop healthy attachments.

Did all of this no longer apply simply because my daughter was disabled?

Before the diagnosis, I had worked part-time in order to spend more time with my kids. I was also blessed to have an employer who allowed me to work from home on some days and bring my daughter to work with me some days. My daughter's Mothers' Day Out program, which she had only recently started attending, was only 10-12 hours per week!

My child was not even in 40 hours per week of childcare for me to go to work, yet now she was supposed to be placed in 40 hours a week of therapy because we now had a name to a condition she'd always had? (I know everyone is not fortunate enough to make the same choices, and for some people such a choice wouldn't be optimal for their families even if they have such an option. I was raised by a wonderful mother who worked full-time outside the home, so this is no indictment of working parents whose children are in day care full-time.)

Moreover, on top of the recommended 40 hours of ABA, we were told that we needed to reinforce the strategies used in the therapies with her at home – so essentially, she would be in therapy all day, every day, even if no therapist was present. Plus, as my daughter had sensory and fine motor differences and speech delay, she needed speech therapy and occupational therapy also. The whole thing was mind boggling. Was my daughter's life going to be nothing but therapy after therapy from morning to night?

When would she have time just to breathe? To play? To be alone and have some down time?

Was she so broken that she didn't deserve a childhood anymore?

I am not anti-therapy. My daughter had already been in therapy a few times per week since the age of six months, for some other health issues. But what was being proposed as a result of her diagnosis seemed far beyond that.

Then there were the costs of these therapies, which were pretty high; it seemed that many families had depleted their savings and refinanced their homes in order to come up with the money to pay for these services. There was huge variation from one provider to the next with regard to having the fees paid for by insurance and out of pocket costs.

Finally, I had to consider the therapy itself. Technically, it “worked,” according to the studies. But the areas measured by most of the studies were not the areas of greatest interest to me, as her mom. I was less concerned about decreasing noticeable stereotypy, increasing eye contact, enrollment in general education, etc. than I was about shaping her into a healthy, whole, decent person.

The therapy seemed repetitive, dry, rigid, impersonal, and domineering. It seemed as if it was designed to “break” my child’s will, obliterating her natural ways of communicating, moving, and engaging so that she could learn how to perform in a more “acceptable” way. All done under the guise of “helping” her, wrapped up with convincing buzz words such as “evidence-based,” “function,” “indistinguishable,” “optimal outcome,” “normalization,” “reversal,” etc.

I wasn’t convinced.

I am the daughter of African immigrants who lived part of their lives under colonial rule and part of their lives under independence. There was a frightening parallel between the government-sanctioned Anglicizing and cultural genocide that my parents observed and described to me and the philosophy that supported such widespread endorsement of 40 hours of traditional ABA as “the” go-to therapy for all Autistic children.

Just like many BCBA's, during the colonial era there were Europeans who sincerely believed that by getting rid of "barbaric" customs and "savage" practices, they were "helping" to make the countries they took over more "civilized." They saw minimal value in the people's way of life and felt an urgent need to teach them the "right" way to be in order to "make their lives better."

No thanks.

We chose a different way for our daughter. A balance that allowed her to retain her autonomy and sense of self while also helping to guide her and teach her new skills. A way to help her begin to learn to navigate a world with people very different from her without having to lose herself in the process. An eclectic, personalized, non-traditional approach that surrounded her with people who were loving and prioritized her needs, but at the same time incorporated healthy, age-appropriate boundaries.

Without subjecting her at two and three years old to the equivalent of a full-time job to change her simply for the "crime" of being Autistic.



# CHAPTER 4

## To the Man in the Barbershop Who Called My Autistic Son a “Sissy”

“Don’t you dare call my autistic son a ‘sissy!’”

These are the words I wish I’d uttered on that particular day. It was a sunny, beautiful Saturday afternoon — made even more beautiful by the fact that it was my youngest child’s birthday. Five years old! We had plans for a fun-filled day that was going to be spent doing things he enjoyed, and I was so excited. Maybe more excited than he was!

My brother-in-law planned to give the birthday boy a haircut, but I ended up having to take him to a barbershop instead. I was disappointed because he does a great job cutting my son’s hair. It wasn’t anyone’s fault; my brother-in-law is a retail manager and had to go in to work earlier than expected because of some scheduling issues with his staff.

I was disappointed because he does a great job cutting my son’s hair. He understands that having an autistic nephew means that haircuts need to be done a certain way in order to not cause discomfort or tears. His approach is gentle, slow, explanatory, and he is willing to let my son take breaks if needed.

It’s difficult to find people who are similarly accommodating, especially on short notice. So I called the barbershop I use for my older boys, explained the situation, made an appointment to arrive within the hour, and hoped for the best.

En route to the barbershop I explained to my son what was happening so he could be prepared, and I asked him what I could do to make him feel more at ease when it was his turn. When we got there, I was ushered over to a barber. I said I was the one the owner told him about, and I introduced him to my son.

I explained I would sit on the chair and my son would sit in my lap for the duration of the haircut because he wasn't comfortable sitting on the chair alone. I also explained the following:

- The apron used to protect clothing from falling hair should not be fastened too tightly around my son's neck.
- My son requested that I sing songs from various Disney Junior shows during the haircut to help keep him calm.
- My son would need to inspect and "test" the electric razor against his hands before allowing the cutting to begin.
- Only I was to hold my son's ears down when we got to the part of the haircut requiring that, not the barber.
- Throughout the haircut, my son needed the barber to explain what was going on and to pre-announce any changes, like the need to pause and switch to a different razor.
- If it got to be too much we might need to stop, even if the haircut wasn't "perfect," just as long as it still looked decent.
- Regardless of all of these precautions, my son would probably still cry.

He listened and told me he was fine with all of that. I said a quick prayer, and then we took our seats and got started.

It's important to me that I always respect my children's privacy, so I won't go into specific detail about how my son reacted during the actual haircut. I don't believe in "live tweeting" or otherwise describing for others the difficult moments my children face and what they might do/say when they're having a hard time and are not at their best. Let's just say it wasn't the best experience of his birthday. Let's just say it totally sucked. And if not for the fact that he was really overdue for a haircut, I would have preferred that he not even have to go through it.

But my son's reaction is far from the worst part of this story. That would instead be a person who was waiting there to get his own haircut. I don't know the name of this male presenting person, and I'd



never seen him before (and I hope to never see him again). Let's just call him Mr. Ableist Sexist Jerk, or Mr. ASJ for short.

Mr. ASJ took it upon himself to bully a little child. A child who was clearly in agony. A child he did not know and had no right to address in such a way. A child many decades younger than he, and a child with a disability who was not in a position to defend himself.

I'll just give you the highlights of some of the "lovely" comments Mr. ASJ felt the need to hurl at my 5-year-old child.

"Hey, you need to stop all that crying. That's too much crying. Nobody wants to hear all that."

"Are you a little boy? I don't think so. Maybe you're a little girl. Because a boy wouldn't be crying like that. I think you must be a girl, huh?"

"Stop acting like a sissy. Only sissies cry for no reason. Haircuts don't hurt."

I had noticed from his loud tone of voice and his exaggerated body language that the man seemed upset about whatever/whoever that he was talking/complaining about. But I hadn't paid close attention to exactly what he was saying. After all, I didn't know him. I didn't realize what he was saying nor that he was addressing my child; not at first. My concentration was primarily on my child and trying to keep him comfortable.

But then, the barber cutting my son's hair stopped what he was doing, stood up tall and said, "Man, you need to quit hollerin' at a child like that. This boy isn't bothering you, so you need to leave him alone. He's a boy with autism, so you don't know if it's hurting him or not. He's my customer, and you need to show my customer some damn respect."

To which Mr. ASJ said, “That boy doesn’t have autism. I heard him talking. He’s just a mama’s boy.”

That’s when it dawned on me that the tirade, which I had ignored, had been directed at my baby boy. And that though I hadn’t been paying attention, the barber had heard it all, gotten upset and was speaking up to defend my son.

I am generally a nice person. I consider myself pretty tolerant and I give people a “long leash.” But when I get mad, I get mad. There is some truth to the phrase, “Hell hath no fury like that of a woman scorned.” And then to add insult to injury you are messing with my child?! Oh heck no. I could feel the anger rising up in me as I prepared a retort in defense of my child. It was about to be ON!

And just then my son’s tears, which had subsided for a short while, resumed. Louder and with more fervor. At that moment, I abandoned my plan to give Mr. ASJ a piece of my mind and turned my attention back to my son. I began singing to him again and slightly rocking him the way he likes, and telling him I was proud of him, I loved him and that he was doing a great job. I told him we could stop the haircut any time he liked. The barber joined in with me to praise him, telling my son, “You’re such a good boy! You look sharp too! Wait till you see your haircut. Almost done now.”

This was NOT a welcome situation on my baby’s birthday. Not at all. But writing helps me cope. I sincerely doubt Mr. ASJ will ever read this, but in case one day he does, this is what I wish to say to him:

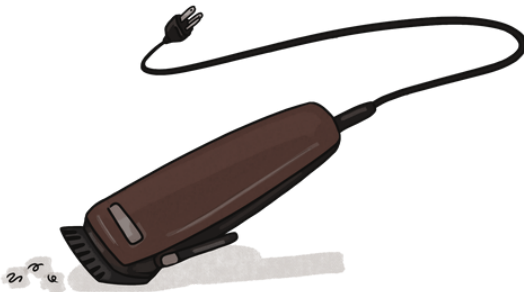
I’m the mother of the autistic little boy you were bullying on Saturday. I want to thank you for being a living example of everything I’m teaching my son not to be. That way he will have no difficulty identifying what behaviors he needs to avoid. Don’t you know it’s rude to chastise little kids? Especially OTHER PEOPLE’S kids?

Like the barber told you, my son is autistic. Just because he can “talk” doesn’t mean he isn’t autistic. He has a disability, and he was crying because haircuts are difficult for him. Instead of you being sensitive to him like every other person in the shop was, you made it worse. I’ll have you know that calling my child a “mama’s boy” isn’t the insult you meant it to be. I am his mama, and I’m proud to have my boy’s back all day every day. I’m raising him to be a strong black man.

A real man wouldn’t yell at a child. He would comfort him. A real man knows there’s nothing wrong with crying. He knows there’s nothing wrong with being a “little girl” and doesn’t think that calling someone a “girl” is some type of slur.

You know what else a real man knows? He knows that to call an autistic boy a sissy is the height of disrespect. It’s rude (and homophobic, for that matter) to call any boy a “sissy.”

There’s nothing shameful or wrong with a child expressing their feelings nor with a mother comforting her child. I’m raising my son to know that when he’s hurt or scared, I’m there for him. I’m not ashamed of being that type of parent, and I won’t let you make my son ashamed of it.



# CHAPTER 5

## Our Neurodivergent Family's Valentine's Day

In the US, Valentine's Day is one of the most successful commercial endeavors of the year. In the weeks leading up to Valentine's Day the pressure gradually increases until the big day arrives. Jewelry, roses, chocolate, and stuffed animals are sold in seemingly endless quantities. Dinner reservations book up quickly as do romantic getaways.

Many a marriage proposal is made on Valentine's Day, and it is also a popular date for weddings and vow renewals. As all of the commercials, movies, and TV programs that air Valentine's Day specials will tell you, love is in the air – and if you're *anybody* then obviously you will be spending the evening in heels and a black dress out at a fancy venue with your significant other.

Uh...nope. Not I.

I have never been “big” on Valentine's Day. I recognize that it is a big day (and a big deal) for many. But it isn't to me, and it hasn't been for a long time. Valentine's often looks very different in neurodivergent families than it does in neurotypical families.

And that's okay. Or at least, it should be okay.

My Valentine's Day is not going to look very different than my other days. Here are some of the reasons why:

- I don't really see the “point” of Valentine's Day. I know its origins and everything, but I don't really “get” its relevance. It basically seems like a duplication of my anniversary. And while I'm more than happy to accept a gift for Valentine's 😊 I still don't understand the fuss, and never have. And I definitely don't like the heavy focus on materialism nor the price gouging that occurs.

- I don't like crowds of people and Valentine's Day tends to draw large crowds. Everyone (it seems) has chosen to go out for a night on the town, which means lines, traffic, waiting, and overstimulation. My favorite ethnic restaurants, ordinarily half-empty during off-peak times, become transformed into hot-spots full of so many people that I feel practically claustrophobic. No thanks.
- Since nearly "everyone" feels the need to celebrate this day of love, securing a suitable babysitter is extremely difficult. I am very protective over my children and very particular about who I allow to watch them. Because of their differences, kids like mine are at risk for being harmed and/or abused, or at the very least misunderstood, and I can't risk just letting a random babysitter or child care provider look after them.
- Traditional/common Valentine's Day activities tend to cater more to those who meet the "status quo" of a "typical" couple: white, middle class, neurotypical, cisgender, heterosexual, etc. And while the activities themselves aren't "bad" things, they aren't what I personally would like to spend a lot of time and money doing.

So how does my family make Valentine's Day work? It varies from year to year:

Sometimes we do a family Valentine's Day thing with all the kids while other times it's a couple only thing. (One year I really needed some "me" time, so I spent my Valentine's Day alone at a day spa while hubby kept up with the kids.) Sometimes we donate the money that would have gone on buying each other a Valentine's gift for a cause of our choosing.

Sometimes we do absolutely nothing!

One year we did a service project for a shelter serving women and children who were survivors of domestic violence. Sometimes we dress up; sometimes we do jeans and t-shirts.

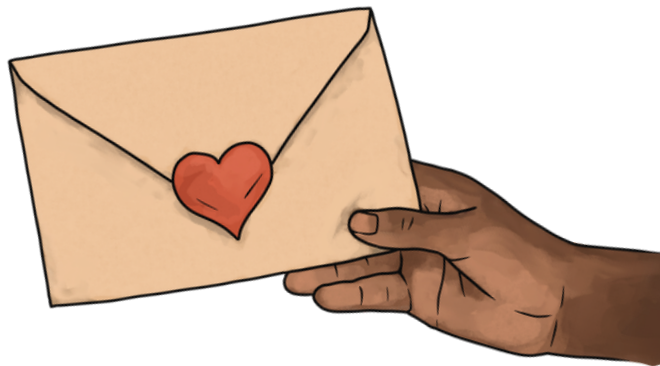
Sometimes we exchange gifts with one another. Sometimes we do go out for Valentine's Day, but do it a few days before or a few days after the actual day to avoid all of the hoopla. Sometimes we cook a Valentine's meal together.

One year we shared different Bible verses about love with one another that resonated with us and then discussed how we wanted to make goals for intentional living and radical loving based upon those Christlike examples. Another year we went to Chuck E. Cheese's on Valentine's Day (as it was practically empty, we had free reign of the place with the kids; that was nice). This year we might be going to a movie with the kids.

Whatever you do or don't do, you are just as valuable as anyone else. Valentine's Day is just a day; nothing more, nothing less. You are not less valuable because you didn't get and/or want a dozen roses, a box of chocolates, a teddy, and gemstones for Valentine's Day.

And your love is no less special either.

Happy Valentine's Day!



# CHAPTER 6

## Face The Truth: What You REALLY Mean When You Say “Low-Functioning”

I’m so freaking tired of people throwing around functioning labels. “High” functioning autism. “Low” functioning autism. “Moderately,” “mildly,” or “severely” affected by autism. Aside from the fact that these labels are arbitrary, divisive, imprecise, and inaccurate, they just don’t make sense. As someone (not me) brilliantly stated, “Low functioning means that your strengths are ignored; high functioning means that your deficits are ignored.”

There are several GREAT written pieces about functioning levels written by adult Autistics and by parent allies that discuss functioning labels far more eloquently than I, and I encourage you to read them. This is merely my small contribution on the subject.

And it’s going to get real up in here. Let’s stop already with the deceptive semantics and just deal with the truth: there IS no “low,” “moderate,” or “high” functioning autism. There just isn’t. Just as there is no Tooth Fairy. Just as parents placing money under their children’s pillows doesn’t magically make those parents transform into the Tooth Fairy, millions of parents and professionals using functioning labels doesn’t make them legitimate/accurate.

Technically, there has never been an actual diagnosis of “low-functioning autism” or “high-functioning autism.” There has never been an ICD code for either or for anything like them. Under the previous DSM-IV TR and ICD-9 there were five Pervasive Developmental Disorders in all: Rhett’s Disorder, Asperger Syndrome, Childhood Disintegrative Disorder, Autistic Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). Three of these once separate diagnoses were merged in 2013 under DSM 5. There is now an ICD code for a singular diagnosis, Autism Spectrum Disorder. There is not – and there has never been – any other autism category. Period.

“But my doctor said Timmy had low-functioning autism!” you cry. Yes, your doctor very well might have said that. That term, and similar ones have been tossed around for many years, but they’re not actual diagnoses. They, along with “severe” autism and “mild” autism, are merely colloquial terms that doctors, parents, and other professionals use for descriptive purposes similar to how some people in the African American community might be described by their complexion. The use of functioning levels is similarly variable, subjective, and often inaccurate. What’s considered “light” or “dark” to one person is not necessarily the same way another person would characterize it. And just as there’s no actual “red,” “high yellow,” or “dark” racial group, there’s no “low-functioning” or “high-functioning” autism.

In discussions about treatment, about services, and about “cure,” the false dichotomy between the “levels” of autism is ever-present. The “high-functioning” people are supposedly taking up all the space and attention. We are also supposedly “draining resources” that are needed for others. People discredit our input and try to limit our involvement. We are disregarded, almost daily, as being too “mild” and/or too “high-functioning” to understand “what it’s REALLY like” to be on the autism spectrum.

“Low-functioning” people are “child-like” and their “suffering” families are apparently desperate for any “help,” be it coercive compliance training; a lifetime of institutionalization; stigmatizing “awareness” campaigns that utilize dehumanizing rhetoric; regressive segregated “programs” that offer minimal autonomy or individualization; invasive interventions; “therapies” with insufficient support or technology for meaningful communication; limited, stifling, and ever-changing living arrangements; subpar services rendered by a revolving motley crew of poorly trained/paid staff; questionable “biomed” pseudoscientific interventions that are ineffective and likely harmful; or the ever-elusive “cure” being peddled by autism’s many snake-oil salesmen.



NO, I don't think everyone on the spectrum is the same.

YES, people present differently. That's why it's considered a "spectrum." There is a phrase that some people use pretty frequently that describes this well: "If you've met one person with autism...you've met one person with autism." Although in recent years that phrase has unfortunately been used unkindly by some autism parents as a dismissive tactic to silence adult Autistics who are "not like my child," I think the phrase's original intent before it was twisted by others was to acknowledge the heterogeneity of the spectrum. And it certainly is heterogeneous.

At any rate, if people are honest with themselves, all "low-functioning" really means is someone who is both autistic AND has a lower score on IQ and/or adaptive living skills assessments. (Additionally, to some it likely also means an autistic person who is primarily non-speaking.) In other words, "low-functioning" is the presence of an autism diagnosis and intellectual disability (and again, to some, also the characteristic of being a non-speaking individual). These are the ONLY substantive differences between those who are "low-functioning" and those who are high-functioning." Nothing else.

I'm writing this because this morning, for the umpteenth time, I had a less than pleasant exchange with someone about autism, disability, neurodiversity, and respectful communication. Among other things, apparently one "shouldn't judge" someone with a "low-functioning" child who is "suffering" for wanting autism to be prevented and eradicated. Evidently, possessing such a viewpoint is understandable and even acceptable, and that such individuals are the "real" voices of autism because they "speak for their children who are unable to speak for themselves." Moreover, anyone who questions or challenges this perspective is "erasing" their reality, "abusing" them, and seeks to peddle a "sugar-coated" and inaccurate view of autism that "ignores families who are suffering under the burden of 'severe autism.'"

Ironically, while complaining of supposedly being “censored” and lacking what they feel is appropriate attention to their needs, this person and their proponents have no qualms disregarding, making inaccurate assumptions, and seeking to silence those who feel differently. They make sweeping generalizations about entire groups of people based upon minimal information and seek to discredit and silence those with perspectives that differ from the narrative they have chosen to embrace. I’m tired of these hostile exchanges. I’m tired of “my side” and “your side.” I’m tired of everything I have ever known being dismissed because someone has decided their opinion is the only one that is valid.

Don’t get me wrong. I don’t, and won’t, for even a moment, disagree that there can be vastly different manifestations of any condition. I won’t disagree that there is a huge scarcity when it comes to options for and access to quality services and care. I know that people’s circumstances differ from one another, and that humans are fallible and need support, especially when faced with things that they did not expect and/or might not feel equipped to address. I know that there are privileges that some have that other people do not, and that the trajectory of one’s life can be difficult in a world that fails to make adequate provision for people who do not have a conventional manner of clearly communicating their thoughts, preferences, feelings, and needs.

I know that it can be unbelievably hard to navigate a system that devalues difference. I know that cognitive ability varies. I know that a household with one or more members who might present with non-suicidal self-injurious behavior, a tendency to elope or wander, minimal or limited ability to speak, incontinence, mobility challenges, etc. is far different from a household with none of those things. I know that co-occurring diagnoses can and often do exist; I have some, as do my autistic kids. I begrudge NO ONE the right to address problematic symptoms with the appropriate treatment. I am not anti-treatment; like most neurodiversity proponents, I am in favor of ethical, helpful treatments.

None of that is the issue. The issue is that the parents need to be honest with themselves and with everyone else. When it comes to “severe” autism, “low-functioning” autism, “profound” autism, or however one chooses to label it, even though on the surface it appears that they are concerned with “autism,” it is not the “autism” part of their child that they want a “cure” for. What they actually want a cure for is how autism presents when there is also low IQ/intellectual disability. And since the so-called “high-functioning” autistics are supposedly “just quirky” and “not really disabled,” then the problem must be with the intellectual disability. So, in other words...

What they really want...is NOT to have a child who has an intellectual disability.

It's just that simple. Autism is a convenient scapegoat, but the manifestation of intellectual disability is what they actually have the greatest problem with. However, no one will EVER say that explicitly (even though it's the truth) because it's not “politically correct” to do so.

They want a “cure” for intellectual disability, but to say as such would be considered discriminatory and disrespectful—as it should. So, even though deep down that is what is MEANT, that is not what is actually said. However, no such “political correctness” exists for autism. With regard to autism, expressing a desire for a cure IS socially acceptable as well as common. It is not at all unusual to hear autism parents, professionals, and even well-known “charitable” organizations frequently and openly lamenting about how difficult “dealing with autism” is; the high “costs” of autism; the need to find a cause and a cure to end the “suffering.” Then to illustrate the point, EVERY single symptom, characteristic, and/or behavior the autistic person has gets lumped under the category of “autism,” even when few of the challenges that the parents are concerned most about fall under autism diagnostic criteria.

According to the DSM 5, autism (clinical name: Autism Spectrum Disorder) is characterized by: “Persistent deficits in social communication and social interaction across multiple contexts...” and “Restricted, repetitive patterns of behavior, interests, or activities, currently or by history...”

That is IT. Period.

It's not seizures or epilepsy. It's not elopement or wandering. It's not pica. It's not gastro-intestinal distress. It's not aggression. It's not urinary and/or fecal intolerance. It's not insomnia or hypersomnia. It's not being overweight or underweight. It's not allergies, or anything else—though it certainly can exist alongside those things. And it can exist along with intellectual disability. It doesn't necessarily have to, but it can, and it does.

With regard to intellectual disability, there are many people with it who have careers, spouses, and families. They have hobbies, interests, goals, talents, and friendships. They add to the diversity of our shared humanity. They may also have challenges. Some might be as a result of everyday life, some might be due to societal discrimination and stigma, and some might be due to their condition. Challenges are not unique to the autism spectrum.

Many of the areas of concern that people have about challenges their autistic loved ones face can also be found in other groups, such as those with intellectual disability. Some people with intellectual disability wander. They might hit themselves and others. They might have communication difficulties that make it hard to express pain or discomfort with speech (though they are likely expressing it in other means that others may be missing). They might have co-occurring health ailments. They might stim and rock frequently, or hum. And you know what? Those people should still exist.

They are all still human.

They all still have value.

One of my children (who is non-autistic) has an intellectual disability.

He should exist.

He is human.

He has value. TONS of it, actually. He is amazing.

I know exactly what you are talking about when you begrudge the existence of individuals who are “low-functioning” and you want to “learn the causes” so you can “prevent” people from being born who are “like that.”

“Like that.” “That” meaning intellectually disabled. Like millions of people around the world...like my son.

You SAY it’s “the autism.”

But then you go on to describe something very much unlike autism, but very much like my child/those who share his diagnosis of intellectual disability. You describe these people almost as if they are subhuman because they are different from you. And that? That I have a huge, huge freaking problem with.

Stop basing the value of people’s lives on minuscule things.

People are more than whether or not they speak, how “social” you think they are, their perceived intellect, or other characteristics.

Start looking at what REALLY matters about a person. Their heart. Their character. Who they truly are in totality. Acknowledge their strengths. Show love. Help build them up.

For their sake. For your own sake.

For the sake of our shared future.

Please.

# CHAPTER 7

## The Joy of Parallel Playdates

This year my kids made a friend.

“What’s the big deal?” some of you might be thinking.

Well, the big deal is that making friends doesn’t come easily to them. And while they don’t seem too bothered by that, I worry about it sometimes (umm...more than sometimes), though I don’t burden them with my concerns.

Lately, however, I’ve been trying not to give it too much of my time and energy.

After all, they are really, really good at entertaining themselves, they enjoy spending time with one another, and they seem content. So I figured in time the whole friends thing would work itself out.

And just like that, they made a friend. Pretty much by accident.

One day shortly after coming home from picking my children up from school, I realized that I had left something outside in the car (as usual; I do that several times a week). I put on my shoes, opened the door, went outside to where the car was parked in the driveway, and opened the car to retrieve the item.

I was closing the car door and about to turn and head back to the house when I heard a little voice shout, “Hey, miss! Hey, miss!”

I looked around and noticed a scrawny preteen boy on a red bike pedaling in my direction. He had an olive complexion, big glasses, and he was barefoot. He stopped, dropped his bike on my lawn, and walked over to me.

He smiled and said, “Miss, my name is Michael. {name changed for privacy}. I have a project for my class that’s due the day after tomorrow and I just barely started it. Will you help me?”

I had never seen this kid in my life – yet here he was, asking me for help. I admired his boldness, and as someone who also struggles with deadlines, I empathized with his procrastination. “What type of help do you need?” I asked.

“I gotta record different people’s responses and make a chart. Then make some observations and type it up in a report and stuff,” he replied.

“Responses to what?” I inquired.

“This,” he said, unzipping a fanny pack he wore across his waist. He pulled out a fistful of plastic snack bags and opened one. Grabbing its contents, he shoved it near my face. “What do you think of how this looks and smells?” he asked.

I stepped back. “Yuck!” I exclaimed. “It smells disgusting. What the heck is it?”

“It’s slime,” he said. “But I added some extra things to it to give it an aroma. You know, to make it more interesting. Too much?”

I laughed. “Yeah, too much.”

“Okay,” he said, “forget the smell. Can you tell me how you would describe how it feels? Use as many descriptive words as you can come up with. But don’t say anything yet. I need to get out my notepad and pen first, so I can write it down.”

I smiled. I liked this kid. He was very straightforward.

Just then, my front door opened slightly. I saw my two youngest kids peeking through the open crack. I assume that since I was gone longer than anticipated, they went looking for me. Michael asked, “Who are they?” at the exact same moment my youngest son exclaimed, “Ooh, slime!”

“Those are two of my kids,” I answered. My son and daughter both came outside and peered at the slime. They love homemade concoctions of all types. “You wanna play with it?” Michael asked them, and they nodded. Next thing I knew, all four of us were in the driveway bouncing and rolling the slime – Michael had made several, all different colors – and we were also throwing it at one another and laughing. We were out there for quite a long time, having fun.

“Oh!” Michael interjected. “I need to get back home. May I stop by tomorrow to get your responses? Since we started playing, I never wrote anything down.”

“Sure,” I answered. We helped him collect all the slime and sent him on his way.

So that was the first time Michael came by. But not the last. After that day, Michael came by all the time, nearly every day for a week and a half. This was something we were unaccustomed to, as my younger children, both of whom are, like me, Autistic, have each only gone on one playdate in their entire lives. Having a friend come by to hang out was something we were not accustomed to.

I wasn't even really sure what to do. I was an '80's baby, and when I was a kid, people played outside until the streetlights came on. But times have changed; kids don't really play outside that much any longer. And although he was playing, in broad daylight, with my children outside in the front yard and not actually entering my home, I wondered if I was supposed to notify Michael's mother of his whereabouts. Since we had only recently met him and to my knowledge his family had no earthly idea who we were, I decided that I would go ahead and make contact as a courtesy, and/or for safety reasons. That day, I asked Michael for his mom's number and sent her a text. I introduced myself and explained the situation, thanking her for allowing Michael to come by so frequently on his way home, and gave her my address so she would feel more reassured knowing exactly where her son was.



She responded very warmly, thanking me as well. She shared that since his first visit, Michael had informed her each time he came by. She also said that she had been meaning to let me know that Michael is allowed to come inside my house if I was comfortable with that. I thanked her with a thumbs-up emoji.

Fast forward to a few days later...we were planning for Michael to come over for a formal playdate. I cleaned the house so nicely you would think we were expecting royalty. I stocked up on snacks. I made the kids find all (well, most) of the pieces to our different board games that they had spread all over the house. I fluffed the pillows and I lit scented candles. I slathered the kids' faces, knees, and elbows with moisturizer so they wouldn't be ashy. And we waited.

Michael's mom came by to drop him off, and mercifully she only hung around for a minimal amount of small talk before departing. (Whew.) Michael and the kids went off to play. I kind of hung around just in case they might need me to help with something, nervously wringing my hands. I shouldn't have worried.

Within minutes the kids were all engrossed in play. Michael was sitting on the couch playing on my daughter's iPad; my son was on the floor next to him playing a video game; my daughter was sitting on the other side of the couch with Michael while she played with some of her toys. They were all doing their own thing. Occasionally one of them might call the other over to look at something cool they were doing, but other than that, they were playing alone.

The experts call it "parallel play" because you are playing NEAR someone else, but not WITH someone else. They say that something is wrong with Autistic kids because they play in this manner, comparing it to the way toddlers play.

Those "experts" don't know a freaking thing.

There is NOTHING wrong with parallel play. Sometimes people want to explore their own activities, their own interests, their own ideas. Everyone is not so socially dependent upon others that they need to be doing the same thing as others with others every second of the day. I think parallel play is a positive sign. It implies, “Hey – I really want to do \_\_\_\_\_, and you might not wish to do that, which is okay. But I care enough about you to still want to be near you even though we might be doing different things.” I don’t think parallel play is a sign of rigidity and closing others off; it’s an individualized way of letting others in while still being cognizant of and responsive to your own personal needs.

I think a playdate with any other kid(s) would have likely been a disaster. My kids wouldn’t have known what to do, and they might have felt forced to “do” things in a particular way to please their guest(s). In other words, they would feel that they had to put on an act and be fake. How can one cultivate a true friendship and a true connection while being fake? In my opinion, you cannot.

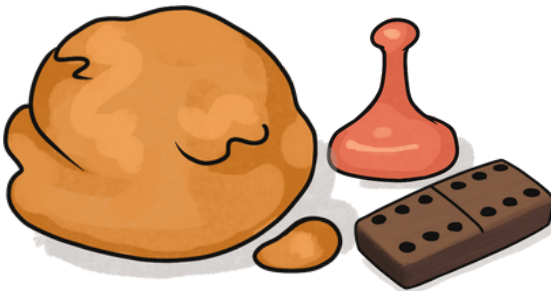
When dealing with those who aren’t neurotypical, such as Michael and my kids, one has to expand the traditional definition and expectation of what “play” is. There is more than one way to bond. There is more than one way to enjoy someone’s company, and there is more than one way to forge a friendship.

There is more than one way to play.

We’ve had a lot of playdates with Michael since then. Sometimes, the three of them DO all play together in somewhat of a “traditional” way for part, maybe even a majority of the playdate. Other times, it has been completely or primarily parallel play. Either way, they have fun with one another. Michael has become such a fixture in our home that my older kids have even joined in to play (though infrequently, as they have their own friends and their own interests).

His mother and I check in via text every time he arrives. I also text her to notify her whenever he hops on his bike to head home. I no longer feel inclined to straighten up the house more than usual when Michael comes over, and he feels completely comfortable walking into my pantry and grabbing himself a snack.

Although the invitation has been extended, we have yet to play over at Michael's house. I don't yet know what to expect, and I like the way things are. Maybe we will "build up" to being able to have a playdate over there one day...or maybe we won't. For now, I am grateful and content with the parallel playdates we have at my house with Michael. This allows my kids to be who they are while also allowing Michael to be who he is, and it allows me to be who I am too. I don't host what would traditionally be viewed as a "perfect" playdate; I don't have a vase full of freshly picked flowers near a tray of fresh baked cookies and glasses of freshly squeezed juice when he visits. However, even though our parallel playdates might not be "perfect," as they happen to be perfect for us, in my opinion it matters little what anyone else thinks.



# CHAPTER 8

## Attachment Parenting While Black and Autistic

As much as I can, I avoid those types of offices when my younger children are with me. You know the type: quiet, sterile, not child friendly. Offices where food, drinks, and/or electronic devices are not allowed and where a security guard is standing watch glaring at people. That type. I'm an adult, and even I don't like being there, much less my young autistic son and daughter.

But this time it was unavoidable – their presence was mandatory. I made an appointment for a time that I assumed would hopefully move pretty quickly, packed some toys, books, paper, and crayons for them, and hoped for the best.

The items I packed amused them for a while. But not long enough. My babies tried hard. But it was a long wait, and it was boring. And they are children – and children aren't designed to sit silent and unmoving for long periods of time. Plus, there were so many interesting things to explore in the lobby. For two autistic toddlers, it was almost like a sensory playground. They weren't being unruly. They were just trying to amuse themselves while waiting.

They walked between the rows of empty seats. The seats were a soft faux leather material. They ran their hands along the seats.

The security guard said no.

The tables were made of particle wood and had decorative metallic pieces at the edges. The shiny, smooth metal felt nice on their hands and made a soothing clinking sound when they tapped their fingernails on it.

The security guard said no.

The floor was cold to the touch and perfect for quietly sliding and for sitting and spinning in place.

The security guard said no.

The area near the entryway was made out of glass and had a mirrored appearance. They were drawn to it. They stood close to it and peered at their reflections as they made funny faces.

The security guard said no.

They sat back down in their seats next to me and amused themselves by reciting scripts of their favorite children's TV shows and excerpts of their favorite songs. They swayed and flapped along to the melody of their voices.

The security guard said no.

And when I say she said no, I don't mean she politely said no. Each time the "no" was accompanied by an exasperated tone of voice, a contorted facial expression, loud sighing, and remarks muttered under her breath about "bad" children with "no home training." Followed by a disparaging "side eye" glance.

Y'all know about that side eye, right? Well, this was no ordinary side eye. It was laden with judgment and hostility. It silently screamed, "You need to control your bratty kids." And it also screamed, "You are an embarrassment to us."

An embarrassment to "us." "Us" being black people – for the security guard, like myself, was black.

We've all heard it. From black comedians to blog posts to casual conversation, there are various places where people remark on what they view is a marked difference between the way white parents and black parents rear their children – especially in the American South. Though a lot of things about child rearing transcend race, there is a sizeable group of people who perceive that black parents often place a stronger emphasis than white parents on the way children

are expected to behave in public – and therefore if a black child was believed to be “acting out” publicly, then such a child didn’t have the right “home training.” The child’s “misbehavior” was perceived as the parents’ fault (for being too lax and/or ascribing to a “white” ideal instead of instilling “proper manners.”)

By this point I was very frustrated with the security guard, and I could see that my kids were growing weary. Every attempt they had made at self-regulation had been shut down. And not even shut down politely, but with a barely veiled attitude. I felt that I needed to say something, so I decided to confront her respectfully but assertively. My purpose was twofold. I wanted to stand up for my kids, but I also wanted to make her understand. This wasn’t about being a “bad” kid or being unruly for the sake of disrupting others. Maybe if she was informed, she would have a different take on things. It was worth a try.

I approached her slowly, stopping at a “neurotypically-appropriate” distance. “Excuse me,” I said. “I heard what you said. About my kids being bad. I needed to let you know you were wrong. My kids aren’t bad; they’re autistic. They’re trying their best to wait here like everyone else, but it’s really hard.”

The security guard was light complexioned, and flushed slightly at my words. “I’m sorry for using the word ‘bad.’ I didn’t really mean that, but it was the first thing that came to my mind. I didn’t mean for anyone to hear,” she stammered.

“My kids aren’t bad,” I insisted.

“You right, girl, they not bad kids,” she conceded, slipping from the way she’d originally been speaking into African American Vernacular English, probably to try to diffuse tension. “They just...spoiled, right? You gonna have to teach them how to act right, though. You know we can’t get away with stuff like *they* can.”

Taken aback at her words, I struggled for a few seconds trying to form my thoughts into a coherent response. Before I could speak again, she continued:

“They always trying to label us with something, right? Your babies sound smart. And they talk real proper too! I bet they not really autistic at all. You gotta be careful; don’t let them put no label your kids! They tried to do that with my son too. But my husband and I stopped all that. We told them they didn’t know what they were talking about ’cause my son does NOT have no ADHD.”

At that moment I heard someone attempting to pronounce my name over the intercom. I hurried away from her and returned to where my kids were seated. I gathered up our belongings and ushered the kids out of their seats so we could walk through the inner set of doors where a woman holding a clipboard was beckoning us with hand movements to come her way.

I didn’t get a chance to tell the security guard all of the things that ere in my mind. Such as her calling my kids “spoiled” was not any better than calling them “bad.” Neither was respectful, and neither was true. My choosing to utilize a responsive way of engaging with my children that promotes attachment and respects their wishes and their limits is NOT “spoiling” them. It’s loving them.

I also wished that I could have told her that my kids DO know “how to act.” They just happen to act differently than neurotypicals do. That even for me, as an autistic adult, the office wasn’t a comfortable place. It had bright fluorescent lights, really cold temperature, and hallways that echoed – on top of the electronics ban and the (unreasonable in my opinion) insistence on silence. Cleary neither inclusion nor universal design was a priority in this place.

Also, I wished that I could have told her that seemingly being “smart” and/or having the ability to communicate by speaking didn’t mean

that someone couldn't be autistic. And that when it's an accurate diagnosis, being autistic isn't a "label" that one should shy away from, but a way to understand and identify oneself. Perhaps it is a form of labeling, but it is a welcome and helpful "label."

I wish I could have told her these things.

But I also wish I could have told her that I knew precisely what she meant by the fact that "we" (meaning people of color, especially black people, and especially those of us with disabilities) don't receive the same consideration or services as our white counterparts. And that her observation about how youth of color are disproportionately placed into special education classes in schools was correct.

And that while my kids' diagnoses were 100% accurate, there is a societal tendency to perceive the behavior of black and brown boys as more problematic than their white peers, and that in many cases these biased and inaccurate assumptions lead to children of color frequently being misdiagnosed. Which increases the risk of dangerous, devastating, and even deadly consequences.

I wish I could have told her that I was offended and annoyed by her ableism and her stereotyping, but I could relate to her feelings of concern about the lack of parity between how people's behavior is perceived from one race to another.

I wish I could have told her how much I both disagreed and agreed with her.

I cannot tell her. But I can tell you. And hope that if more people begin to give a d@mn, and as more people call out these disparities, we can begin to see a noticeable difference in the way things are for ALL autistics, regardless of color.



Until then, I have to brace myself, and my kids, for more instances like this. Undoubtedly, we will encounter many more people who will make similar assumptions. It's bound to happen again – and again – because we are black, because of our relationship-based parenting approach, and because, unfortunately, autism is still so greatly misunderstood by the general public.

She was not the first, and she will not be the last.

We will just have to be ready next time.



# CHAPTER 9

## Time After Time

There's a good-natured running joke in my family about me and my odd relationship between punctuality and lateness. They laugh that since I was born a little bit early, I've been making up for it ever since by running late. It's funny because there's truth in it. As an autistic woman with time agnosia, I do find myself rushing more than I'd like! I often try to compensate for it by building in extra time and/or getting an early start, but that backfires too because sometimes I end up arriving way too early, which can be perceived by some as being just as impolite as being late! (Darned if I do, darned if I don't...) In recent months this dynamic has been complicated by some changes in our family's life, namely a return to "traditional" five day a week brick-and-mortar schooling as well as a return to full-time employment. This has been a huge shift for all of us.

Early mornings. Full days of peopling. Homework. Bedtime routines. Etc. (Sometimes I wonder if it's all worth it.)

I suspect that even if I didn't struggle with timeliness ordinarily, I would in this instance. It's a lot of work to get the six of us ready and out the door. Some of us struggle with falling asleep and therefore drag in the mornings. One of us has arthritic joint pain that is worsened by cold weather, and it's typically colder in the morning here than in the afternoons (so that slows things down also). Some of us need a certain temperature of water to wash up; certain types of lotions or body moisturizers that don't create a sensory nightmare... and/or a particular brand/flavor of toothpaste. Hair brushing must be done starting from a certain side of the head and in a certain order with just the right pressure – not too hard, not too soft.

Getting dressed? The clothes that are selected must feel comfortable...no itchy tags or bunched up seams. No buttons or zippers that pinch against the skin. No shoes that hug the feet too snugly.

“Just wake up earlier then,” you might say, “to make up for all of that.” Sometimes that is a solution, but often it is counterproductive. My kiddos need a certain amount of sleep in order to be able to function. When they have to face the day with less, they have a difficult time making it through the day. And so do I, for that matter. I have my own routines too. I check the light switches as I’m heading out the door to make sure they’re turned off, and I always check in the same order. I grab my keys in the same hand each day. I put on my employee badge and make sure the lanyard is facing the way I want it to face. I start praying aloud with the kids for our day as I reverse the car and finish before we make our second right turn.

One day we were running even more behind than we usually are. Fearing negative consequences at work, I attempted to rush everyone out of the house. Knowing that being rushed can be stressful for some of the children, I tried a little humor to speed things up. I made up a goofy departure jingle and sang it in a silly, off-tune voice. I added a bouncy dance to go with it and deliberately swayed off beat. My plan backfired; the kids were amused by my antics and started laughing loudly. Because they were laughing, now they were moving even more slowly than normal.

Bad idea. Time for plan B.

I decided to go “no-nonsense mom” on them. Using a stern tone of voice, I called each of them by their full name and told them to get going NOW! This earned me whining from the younger kids and loud sighing from the older kids, along with a few “You don’t have to get all mean!” glances.

I groaned inwardly. Time was running out. I was going to need a different approach.

I decided that it was time for some honesty.

AND it was time for some begging.

“Guys,” I said, “I’ve been late to work a lot lately. I really need to get up there on time. If I keep coming late I can get in trouble.

Maybe lots of it. Will you hurry to the car? PLEASE?”

It mostly worked. Four out of five of my brood headed to the car. Only one stayed back; my youngest. I saw no urgency in his expression; no swiftness in his movements. He dawdled happily near the front door in his bare feet, backpack still hanging on the peg. Under his breath he was humming the jingle I had just finished singing. It was clear that he had no intention of rushing.

“Honey,” I cajoled with a faux syrupy sweetness I wasn’t feeling inside, “we need to go. Let’s put on your socks and shoes.”

Still humming, he turned away from the socks and shoes and instead toward some toys. Bending to reach them, he began to line them up in precise order.

Several toys slipped from his hands, knocking against the ones he’d already lined up and disrupting the straightness of the line.

He frowned in distress at the disorder. I felt like frowning too; it did look out of whack...plus I was getting even later.

Without thinking, I walked over and straightened the line.

He stiffened, cried out, and swung his foot across the part of the line that I’d touched. His face contorted and I knew he was hurt and near tears.

I winced, understanding exactly what I’d done wrong. What a jerk move on my part.

“I’m sorry.” This time my tone was genuine. No singsong voice, no yelling, no exaggeratedly sweet pleading. Just real. “I know you can do it yourself...and I know that you need to do it yourself. I’m sorry.”

I am the main one to admonish people to give my kids, especially my son, time. I constantly emphasize to others the importance of showing him the respect of letting him do things on his own. I also highlight how he self-regulates through some of his scripting and patterns.

And why wouldn't he need to try to calm down when his mother had been acting as erratically as I had been that morning?

Was I really SO late that I couldn't afford my child a few much-needed seconds to "right" himself for the day? Was saving a few seconds worth his psyche? Ugh. I know better.

At least I should.

He stood near the mess, not looking at me and not moving. We waited in silence together.

"I was wrong," I admitted. "I'm really worried about being late and not being able to do my job. I wasn't thinking. I shouldn't have done that to you."

"May I hold the ones you're not using so you can fix the line?" I asked. "Then when you're ready for them, you can come get them from me and put them in their place in line. I won't do the line for you. I'll just stand here and hold them until you need them."

He pondered, and gently handed me some of the toys he had clutched in his arms. What a sweet, forgiving child I have. I watched as he tidied the line. Then he came over to me and reached for the toys I was holding. I watched as he added them to the line. Now finished, he smiled at his work. Then he smiled at me. I smiled back.

He sat down and lifted his left foot, which is my cue to help him with his socks and shoes. As I slid a Marvel Avengers sock on one foot, he said, "Mom, you were wrong."

My heart felt like it would break. “I know I was wrong, sweetie,” I said softly. “I said I was sorry.”

“No,” he said forcefully. “I mean you were wrong when you said you were worried about doing your job. You ARE doing your job. You’re being my mom.”

He then reached for the other sock and put it on all by himself, albeit crooked. He smiled broadly at me. I smiled back and lifted him into my arms.

Yes, I was late to work that day. But that day my son gave me a powerful reminder. About what really matters. No responsibility in my life is above my primary responsibility to myself and to my family. Fulfilling work, school, or other important duties are indeed important – but they are secondary at best, and though they are of value, they should never surpass more meaningful things.

I find myself running late a lot. And even right now, as I write this, the dishes need washing; laundry needs folding; the oil in my car needs changing; tests need grading; lessons need planning; and I have emails and PMs that need answering.

As an autistic mom to autistic kids and kids with other disabilities, I have a unique set of life circumstances that require a lot from me – and I’m not going to pretend I always have my stuff together. I don’t. I try hard, but I don’t – period. I am far from a perfect employee or a perfect parent. Yet despite my many imperfections, I was somehow fortunate enough to land the “job” of mom to a handful of awesome little people who love me very much even when I screw up.

That day my son did me a great service; he reminded me there’s no greater job on Earth than the one I have as their mom. I don’t always do it right, but I am grateful to have this role, and I will keep striving to be the best at it that I can be, because they deserve that and more. And no matter how late I might be, I will try my best to always make time to learn how to be the mom that they need.

# CHAPTER 10

## Just Another Hashtag

*"Can't sleep. Need to. But too disturbed. Have read the articles. Have not watched the video – can't handle it right now. And won't share it. Just shaken. If there had been no video we all know exactly how this would have went down.*

*This was cold-blooded and deliberate murder along with a fraudulent cover up attempt. Period.*

*My oldest son is now 5'5. And black. Still growing. Voice is starting to change. Has delays in processing and responding, especially when he feels "on the spot."*

*That could be misunderstood as defiance.*

*Insubordination.*

*A threat.*

*He likes cops. Used to want to be one. Sweetest kid alive. I wish I could make him small again until the world begins to make sense. He is starting to look too much like a black man and not enough like a black boy.*

*I am numb. Not able to be mad, or sad, or anything. This keeps happening. Too many times. Too many names. Too many bodies. God help us all."*

I wrote the words above after learning of yet another murder of a black person by a police officer. Which one? you ask. Does it matter? There are so many. Too many. And there will probably be more.

The hurt is the same. The outrage is the same. The fear is the same.

The heartbreaking truth is the same.

The truth is that I cannot protect my children. I cannot.

People who know my kids generally accept and love them. This includes teachers, acquaintances, family, friends, colleagues, church members, etc. These people, who are black, white, Asian, Hispanic, Native, bi/multiracial, etc., understand how my kids are. They give them the benefit of the doubt when they're not at their best and they encourage and rejoice with them when they are. These people don't take the children's atypical words and/or movements out of context.

They know that my oldest son, though "big" and black, is the same teen that lets spiders out of the house alive and is famous for his piggyback rides.

They know that my second oldest son (the same age Tamir Rice was), who is also getting taller and bigger as he approaches adolescence, is the same kid that will willingly play Barbies with his little sister when she doesn't have anyone else to play with.

They know that all of my daughters' natural resting face might appear stern or serious, but that in reality they are kind, compassionate, fun-loving girls.

They know that my youngest might scream or hit when he is dysregulated, but that he means no harm and is a caring, huggable soul with a silly sense of humor.

But what will strangers think? What do strangers see?

What will authority figures, including police, see?

A threat? Noncompliance?

Inherent violence? Danger?

A potential criminal? A "thug?"



I don't know what they will see. And I don't know what they will do.  
And that scares me.

It is no coincidence that a lot of the individuals who have lost their lives have been not only black, but also disabled in some way, typically neurodivergent.

Some of these names you know. Several you don't. They include:

- Freddie Gray.
- Tamir Rice.
- Ezell Ford.
- Tanesha Anderson.
- Tony Robinson.
- Dontre Hamilton.
- Jason Harrison.
- Kaldrick Donald.
- Anthony Hill.
- David Felix.

Who will be next?

As a mom to a neurodiverse black family, I have far more to worry about than IEP meetings. I have to worry about life or death.

I don't want my babies to become just another hashtag.



# CHAPTER 11

## Just the Way You Are (My Nephew P)

I like scripting. A lot. Especially song lyrics – there probably isn't a scenario that exists that I cannot internally conjure up a related songlyric – though I might not state said lyric aloud as it might not be socially appropriate for the setting.

I was originally going to title this post “As he is,” and then changed it to, “Just as he is.” But...because scripting...my mind focused on something and wouldn't let it go. So the title has been changed; many thanks to Bruno Mars for his contribution:

“...When I see your face  
There's not a thing that I would change  
'Cause you're amazing  
Just the way you are.  
And when you smile  
The whole world stops and stares for a while  
'Cause, girl, you're amazing  
Just the way you are...”

Today is one of my little nephews' birthdays. The fact that I can even write that is pretty phenomenal. I suck at remembering dates and times and unfortunately miss/forget a number of significant occasions until after the fact. Other than my children's birthdays, my mother's birthday, my siblings' and spouse's birthdays, my children's “Gotcha Days,” my own birthday, and my anniversary, I can hardly tell you off-head when anyone else was born/got married or whatever. I have a friend who got married on her birthday and I was one of her bridesmaids...yet year after year the day eludes me and I fail to remember to contact her to commemorate the date despite the fact that I was there when it happened!

But P's birthday sticks with me because it reminds me of a math problem. He was born in 2015 on the 8th day of July... in my mind whenever I think of his birthday, I always think of  $7+8=15$ . Thus,

it's very easy for me to remember. His sister's birthday, on the other hand, eludes me. I know it's sometime in August, but I have no idea which day (I'll look it up, though, after I finish writing this).

Birthdays can be a joyous time. I am thankful for the blessing of his life. I am grateful that he continues to develop and grow. But birthdays can also be stressful. There are a lot of "expectations" that society has with regard to children and birthdays that aren't necessarily suitable for our family.

You see, my nephew isn't neurotypical. He has no formal diagnoses at this time, but he has been setting off my inner "Aut-dar" quite loudly for a few years now. P is primarily nonspeaking. Occasionally he has might speak some words (i.e. "Mama"), but generally he does not communicate in that manner. He is, however, very communicative with his body language, and his receptive understanding seems pretty sharp.

P is uncomfortable in many social settings, particularly unfamiliar ones, though he makes efforts to tolerate them. He has strong preferences, especially sensory ones, and for the most part he doesn't respond in a conventional manner to questions or statements. He isn't enamored with eye contact. When he is fond of something or someone, he's all in, and when he dislikes something, he makes that quite apparent.

So his birthday is not necessarily going to be celebrated the way many people would expect – with a party and a bunch of people and commotion.

Because while that might be enjoyable for others, it would not be for him, and since it's HIS birthday, not someone else's, it should be spent in a way that makes HIM happy. Doing things that HE loves with people HE wants to see in places where HE feels safe wearing clothing that HE feels comfortable in.

P grasps a lot more than people give him credit for though he might not display it in a manner that is easily recognizable by most.

Outsiders aren't really certain how to react to an individual like him, so they seem to either underestimate him (i.e. talk to/treat him like a baby, or go overboard trying to make him say or do something a typical child his age would, or ignore him) or misunderstand him (i.e. mistakenly assume that he is spoiled and/or being intentionally "difficult").

P is close to his family, particularly his father; he can almost always be found clinging to Daddy's leg or arm. He is protective over his younger sister, and he adores his "big" cousin – my youngest son. They love being together.

I watch MY baby running around with his little cousins and it moves me to see how much they admire him and enjoy playing with him. When they're around, he's not the "little one" like he is at home, and with them he gets an opportunity to be responsible, lead, and be looked up to by someone else. (It's sometimes bittersweet...as it allows me to observe the big brother way he might have become if I hadn't lost the twins. But that's a story for another day.)

While I love to watch them having fun together, it also stirs up a different emotion. One that isn't very pleasant. And that emotion is apprehension. Or to put it more bluntly, fear. Tremendous fear.

Part of it is a sad, but very familiar fear.

As a mother of children of color (in our case, Black) with various disabilities, I am unfortunately well-versed in the various ways that my children's appearance, mannerism, body movements, etc. increases the likelihood that they will be misperceived by others.

I recognize that due to factors such as racism and ableism, my children are more likely to be viewed as a threat than their White and/or non-disabled peers. My older sons both tower over me;

my youngest child is now close to the height of my shoulder. All are dark-skinned Black boys with fairly athletic builds.

I am aware that no one is immune to being impacted by bigotry. Discrimination comes in all shades, affects multiple genders, is felt by people of various ages, etc. However, because of the reality of the specific place that I dwell in, I am accustomed to having slightly less fear at times for my youngest daughter than I do for my sons...in part because of skin tone. While my boys are of a hue similar to a rich cup of coffee without cream, her complexion is closer to caramel (though she's still unmistakably Black).

My nephew P, though slightly darker than my daughter, is perceived by some to have a slightly racially ambiguous appearance as a result of his Jamaican/Nigerian/South Asian heritage. (He's obviously a person of color, though; there's no doubt about that.) But despite P having a looser hair texture and lighter skin tone than my son has, it's clear to me that my son has privilege in a way that P does not. That, for me, is a less familiar fear, but it is a fear nonetheless. If the world will potentially view my kind, loving Black disabled son poorly, how much worse might they view and try to treat my nephew?

My son might be a dark-skinned Autistic Black boy, but because he frequently communicates by speaking, he is regarded differently than his nonspeaking lighter-skinned Autistic cousin. As more "advanced." As "higher functioning." Even though one's ability to speak or not speak is NOT an accurate measure of how "high" or "low" a person's so-called functioning is, and even though people aren't grades...we're people, and shouldn't be categorized in such a hierarchical manner anyway.

Two precious boys. They share (some of) the same DNA. They share the same last name. They likely share the same neurology (though one has yet to have it as an "official" diagnosis on paper.) So many things are the same about them, but there is a key, unmistakable difference. One that is unfair and yet undeniable.

They will likely both face racism and ableism, but because he is mostly nonspeaking, P has to contend with a different level of ableism than my baby boy does.

Because at the end of the day, we might be in the 21st century, but there are people out there that still have the inaccurate belief/vicious, hateful LIE that non-speaking = nonthinking and maybe even nonhuman.

But they're wrong.

P is a blessing. If he never utters another word aloud, he still communicates every single day. There is more than one way to express oneself; speaking isn't the "be all" and "end all" standard we must all adhere to.

I refuse to let anyone pathologize the way my nephew communicates. Because, P, you're amazing.

Just the way you are.

Happy birthday, sweetie. Auntie loves you.



# CHAPTER 12

## Don't Pray My Autism Away

I am autistic.

I am also rearing children who are autistic — along with non-autistic children who have various disabilities. Our home is swimming in acronyms that stand for all of the different diagnoses in our home. We are quite the “motley crew,” my loud, flapping, spinning, scripting, disabled family and I. And though it’s not always easy (which would be the case with or without disabilities), it’s authentic.

We love each other. We strive to respect one another’s strengths, challenges, boundaries, and needs. We mess up at times. But we make it work.

In addition to being a family with various disabilities, we are also a large family, an adoptive family, a Christian family and a family of color. We stand out when we go places first because of our size and/or demographics, and secondly because sometimes the way some of us present is a little different than the norm. At times we’ve had negative experiences because of this (like being told to leave movies or plays). But generally the people in our lives are welcoming and supportive.

Our church is also a good place of support. Though not perfect, it strives to include people of different backgrounds and experiences and to embrace diversity, including disability. We enjoy attending there and are actively involved in our church. But something happened the other day that I need to address.

Recently there was a special performance at our church one evening, and we attended. My children typically attend classes designed for youth, but this was a family-friendly event, so I had them with me. I was a little worried about one of my kids (my youngest son) because the sanctuary uses lighting effects (dimming, etc.), and there is a lot of noise (praise team, live band, bass pumping out of the speakers) and a lot of people. So I was prepared to leave if we needed to.

Fortunately, this was a “sensory-seeking” day rather than a “sensory-avoiding” day for my son. So not only was he able to tolerate the environment that night, it seemed to energize him.

The music and the movement enraptured him, and he wriggled out of my lap and climbed to his feet. He moved to a space in the aisle near me, but more in front closer to the stage as if to “feel” the music better. He grinned widely and swayed to the beat. He bounced. He clapped. He spun.

My heart burst with joy watching my baby boy become one with the music. I could relate, as there are some things that capture me just as deeply. You see, autistics don’t do anything halfway. We are either all in or we are not in. I can get similarly lost in a book or in my writing or in other things I’m passionate about. When we’re engaged in something, it can be like an all-consuming fire. There is nothing else around us, and nothing else matters at that moment.

Watching my child, I knew he was being propelled to move and to express his joy by something from deep inside of himself.

I didn’t worry about people staring or pointing or whispering because our church is not like that. If anything, I think I saw a few people smiling broadly at him as they noticed his joy and how he was worshiping freely and boldly.

When we left I stopped by the restroom before heading to my car. An elderly lady was inside, washing her hands at the sink. I walked past her en route to one of the restroom stalls. She caught my eye and smiled at me, and I returned her smile.

The woman, who appeared to be about 80 years old or so, was short and had kind, greenish-gray eyes and a sunburst of freckles across her nose. She then spoke.

“Young lady, was that you with that little boy who was jumping around out there?” she asked.



“Yes, ma’am,” I answered with a smile. “That’s my son.”

“He sure is precious,” she said with an even bigger smile. Then she lowered her tone, moved a little closer to me and inquired, “Is he touched?”

“Touched?” I had no idea what she meant. “I don’t understand.”

“I was wondering if your son was touched in the head. You know. Special. He seems different. Is he special?” she clarified.

“Special.” I didn’t understand “touched,” but I understood “different.” And I definitely understood what she meant by “special.” My smile fell.

“Yes, ma’am,” I replied softly. “My son is very special...to me. He is a wonderful child. He is autistic.”

“Artistic?” Her brow furrowed.

“No ma’am. Not artistic. Autistic.” I struggled with how to make her understand, and decided to add, “Some people would say autistic and some would say, ‘He has autism.’ He thinks and acts differently.”

“Oh!” she nodded in understanding. “One of my great nephews has autism too. Can’t talk, but smart as a whip. Well, I’ll pray for you, young lady. And your son, too. I’ll be praying.”

“Thank you, ma’am,” I replied. “We could always use more prayers.”

“I will be sure to pray. Our God is a great Healer. He can heal your son. I’ll pray God continues to give you strength to deal with autism. I know it must be hard. God bless you,” she said.

I was at a loss for words. I didn’t want to be rude, but this was

going completely wrong. “Ma’am,” I choked out, “I don’t need prayers to deal with autism. I understand autism because I am autistic, too. I don’t need you to pray for my son to be healed.”

“Of course not!” she exclaimed. “I am so sorry... You’re right.”

Relieved that she understood the offense, I smiled again. “Thank you, ma’am,” I said, and finally entered the stall.

As I was pulling the toilet seat covers out from their place on the wall of my stall, I heard the woman speak once more:

“Please accept my apology. I will not pray for God to heal your son. I didn’t realize you have the same stronghold as your son. I will instead pray for God to heal *both* of you. By His stripes you are both healed.” I then heard the bathroom door swish open as she left the restroom.

I know the lady meant well. She was trying to be caring. But her words demonstrate a widespread belief and way of thinking that I don’t agree with and think is extremely harmful.

It’s something that needs to stop.

Please don’t try to pray the autism away.

I don’t need to be “healed” of autism. And my children do not need to be either. We are not autistic because of some sin, or some defect or some punishment from God. We are autistic because we just are. This is not an affliction. It’s a way of being.

I believe in prayer. I believe in healing. Feel free to pray for us.

Just not like that.

I believe God made us this way. We are not broken.

We need all types of different people in this world.

We need all types of minds as well. The world would be boring if we were all neurotypical, or if we were all autistic, or if we were all gifted or any number of things.

Just like the world would be boring if we were all white, or all black, or all male or all female, etc. There is beauty in our diversity. There is strength in it. And I believe when God looks upon it, He thinks it is good.

Please don't pray for my or anyone else's autism to go away. It's a part of who I am, how I believe God made me.

I am fearfully and wonderfully made, autism and all.

By all means pray for me, but pray for my health, my family, my finances, my spiritual growth, whatever; don't pray that God takes away part of what makes me "me."



# CHAPTER 13

## Thoughts...On Autistic Pride, Juneteenth, and Freedom

Where I live (Texas), every June 19th is the commemoration of “Juneteenth,” an important day in state and national history. Also known as Juneteenth Independence Day, Emancipation Day, Jubilee, or Freedom Day, it refers to June 19, 1865, the day a Union general and his troops occupied Galveston Island (a small strip of land in the Gulf of Mexico less than an hour away from Houston) and read a declaration from the federal government that announced the total emancipation of all slaves, effective immediately. Although slaves in several other American states were freed from slavery as of January 1, 1863, according to Abraham Lincoln’s Emancipation Proclamation, Texas slaves had toiled an additional two and a half years until that first Juneteenth.

Elated by the news that they were no longer captives, the newly freed slaves rejoiced and celebrated in the streets. Since then, despite the numerous challenges and other forms of marginalization and disenfranchisement the descendants of slaves have had to endure, commemorating Juneteenth has been an annual occurrence that is celebrated beyond Texas. For many, Juneteenth symbolizes the importance of freedom and liberty.

Interestingly, the day that precedes Juneteenth is “Autistic Pride Day.” Since 2005, June 18th has been a day to celebrate Autistic people and culture. Like Autistic Acceptance Day in April, Disability Day of Mourning in March, and Autistics Speaking Day in November, individuals across the globe connect as a community, affirm our existence, and oppose the narrow, negative societal view of Autistic people annually each Autistic Pride Day.

Like Juneteenth, Autistic Pride Day is also a day representative of freedom – the freedom of Autistic people to exist, to be who we truly are, to be able to reside in communities of our choosing; to have a sense of autonomy over our lives; to be accepted and supported as opposed to pitied and patronized.

Sadly, though, when I observe the community, I don't perceive a sense of collective pride. I see established, respected autism groups that have little to no meaningful representation of Autistic people among their leadership. I see the voices of parents and professionals with regard to autism elevated to near-deity status. I see gargantuan efforts to transform Autistic youth, teens, and adults into something we aren't under the guise of "helping."

Although there are many Autistic people who have found ways to accept themselves and maintain pride in who they are, I also encounter many Autistic people who seem to subconsciously despise themselves for not being neurotypical, unable to sufficiently acknowledge nor appreciate their unique strengths and positive attributes.

I also see that segregated educational programs and segregated recreational outings continue to exist. I see that there is excessive promotion of dehumanizing compliance-based "interventions" lauded as "evidence-based" despite growing literature demonstrating minimal sustained positive impact. I see a plethora of targeted, rigid "social skills training" and exploitive research and practice masquerading as seemingly altruistic. I see dubious, unethical, and often unsafe alternative "treatments." I see the proliferation of restrictive diets. I see martyrdom complexes and ableism among some autism parents whose entire identities seem to be derived from their Autistic loved one's diagnosis. I see torture being touted as "treatment" – seclusion, restraints and graduated electric shock "treatments."

I see widespread failure to presume competence or respect privacy.

I see shameless infantilization.

I see so many things that I cannot unsee.

It took over 2,000 Union troops sent to Texas for the slaves residing there to obtain their long-deserved, much anticipated freedom.

Though the newly emancipated slaves faced horrific discrimination and immense challenges after independence, despite their difficulties, they were no longer in bondage. They were no longer property. They would no longer have to be subjected to the abusive mistreatment that they had been forced to endure for hundreds of years. Though life would not automatically become a carefree paradise, it was also no longer what it once was. Juneteenth made certain of that.

Who, I wonder, are the Autistic community's Union soldiers? Because despite the growing size of the "autism community" around the globe, there don't seem to be many outsiders in the trenches with us fighting for our freedom. There are some, yes, and they are greatly valued and appreciated. But when I look around, we seem mostly left to fight for ourselves.

There are others – non-autistic autism "expert" parents and professionals whose opinions and presence are so heavily idolized – that are engaged in fighting too, but they're not here fighting with us and for us, even though they may perceive themselves to be.

In reality, they're fighting for something else entirely, and some of what they are fighting for is in direct contradiction to our fight, as autistic people, for our survival and growth.

They're fighting for multi-million-dollar funding so that they can prevent us from existing. They're fighting for the expansion of "treatment" programs we don't want. They're fighting to modify our natural speech, movement, behavior, and to force us to alter our interactions with others so that we can appear to be "less" Autistic.

They're fighting to limit critical access to a diverse range of technology and communication options that could be transformative, especially for our non-speaking Autistic peers. They're fighting to twist the law to cast aside federal protections such as heightened scrutiny (Olmstead) and vocational choice (ADA) to maintain

exploitative subminimum wage vocational “sheltered workshops” that pay disabled people only pennies per hour.

They’re fighting to strike down protective legislation that sustains our lives, permitting government funding to subsidize the development of sprawling, segregated modern institutions and/or isolated “villages” that have deceitful misnomers such as “specialized services for profound autism” and so-called “intentional living communities” and “peer communities” (such communities do exist, but these are not an example of that).

They’re claiming to be the voices of people who share my neurology, but their DNA. They’re fighting so that people like me will be drowned out or overruled on in policy, research, and other places where we try to offer a stakeholder perspective.

They’re fighting so that people will be subjected to oppressive legal guardianship instead of flexible, person-centered, supported decision-making options and tracking devices instead of innovative means to prioritize safety. They’re fighting for Autistic people to be housed like prisoners in gilded cages rather than being integrated into our communities. They’re fighting to restrict or deny our bodily autonomy, our civil liberties; our activities and living arrangements.

They’re fighting for earlier and earlier detection of Autistic traits so that we can be funneled at younger and younger ages into the system in hopes that we can be “fixed.” They’re fighting for the “right” to openly refer to us using divisive terminology such as burden, abnormal, crisis, disorder, deficits, etc., and to be able to violate our autistic brethren by publicly broadcasting personal, sensitive aspects of our lives in the name of misguided “awareness” and “advocacy” that perpetuates stigma.

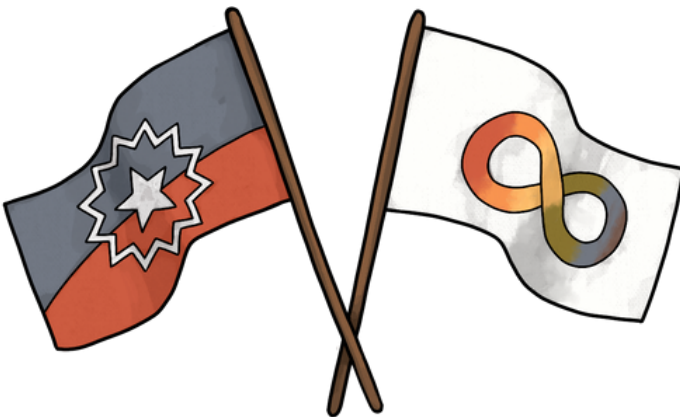
How am I supposed to expect to find a sense of camaraderie and community amongst these people?

How am I supposed to ensure that my Autistic children maintain a sense of pride in who they are and have high self-esteem in the presence of individuals with authority who would be regularly and emphatically sending a completely opposite message?

How does one find a way to effectively impact the worldview that the general public has regarding Autistic people if the people who profess to love us most seem almost impossible to get through to?

instead of breaking the chains that bind us, we should instead line those chains with satin so that they will have a nicer appearance?

When will the equivalent of Juneteenth happen for us, so we can finally celebrate freedom and Autistic Pride not only in name, but in deed as well?





# CHAPTER 14

## Screw Your IQ Test; You Will NOT Limit My Son

I want to introduce you to my son. Five feet seven inches with dark chocolate skin, even darker eyes, and the sweetest smile you've ever seen. He doesn't say a whole lot, but when he has something to say you can tell he has carefully chosen his words. He feels deeply; he's the child who, of his own volition, was baptized in the Gulf of Mexico while on a church youth trip because his soul was so moved. He's the oldest boy in our family and takes his role as "big brother" very seriously.

Is he a perfect kid? Absolutely not. But he is still an amazing kid despite his flaws.

My son is an "old school" Southern gentleman who shows respect for me by opening my doors, carrying my bags, pumping my gas, and (occasionally) cleaning my car. He's the child that gave up his 15th birthday celebration to ride with me during rush hour across town to the humane society in hopes of saving an injured baby bird who'd gotten separated from its mother/nest. He's the child who eats sour rice (a Liberian dessert) on his deceased biological mother's birthday to honor her memory because that was her favorite food.

My son was born for greatness. He possesses a natural ability to solve problems and make sense of his surroundings. Nicknamed the "Human GPS", he is a master at recalling and/or determining routes, detours, shortcuts, and the like. He also loves trivia and interesting facts about a variety of topics, especially history.

Extremely adventurous, he likes to learn new things, visit new places, experiment with various foods and activities. But he is happiest when he has either a ball or some type of technology/electronic device in his hands.

His first name comes from the Bible; his last name comes from a long line of proud, free Liberians who left the shackles of slavery

behind centuries ago. Like his people, he is strong. But he is also extremely gentle and compassionate. He will often overlook or forgive the transgressions of others in order to seek peace. He consents to playing with action figures and/or dolls, watching Disney/PBS Kids/Nick Jr. cartoons, or playing hide and seek/tag/"I Spy" at the request of his youngest siblings...because he likes to make them happy.

My son is so many, many things. He's handsome. He's brave. He's helpful. And he's also a person with an intellectual disability.

The world has never been enamored of disabled individuals, whether one has physical, developmental, psychiatric, sensory, or other forms of disability(ies). It doesn't matter that it's the 21st century; ableism is alive and well. As are other isms. Not only is my son disabled, he's black. And he's a refugee...which in the mind of some misguided political figures means he's a potential terrorist (eye roll). Given these factors, the "odds" for a happy, fulfilling life aren't stacked in his favor according to society's standards.

I know the statistics. I know what people think. I know how my child is portrayed on paper in his IEP documents, neurocognitive evaluations, standardized test scores, etc. Like someone with insurmountable deficiencies. Like someone who is "behind" his peers. Like someone who has "low" cognition and abilities, and therefore needs "lower" standards. Negative, negative, negative, with little to no emphasis on his positive attributes.

To that I say SCREW your effing IQ tests.

My child is a living, thinking, feeling being. A number on a piece of paper is not indicative of his worth as a person. Not to mention there are unavoidable biases in even the most credible and widely used tests anyway; as such it might not be an accurate depiction of his intellect. The issues with properly capturing the IQ of many marginalized groups, including people of color, non-speaking individuals, and non-Westerners, are many.

But even if we put aside that matter and \*assume\* the IQ ascribed to him is correct, that doesn't diminish my son's value.

He doesn't need to have a particular IQ in order to be a good person. In order to have deep thoughts. In order to have the right to be in charge of his own life.

He doesn't need to have a particular IQ to pursue his dreams, to make a living, to get married if he chooses, to have a satisfying sex life if he chooses, to have a family if he chooses.

He doesn't need to have a particular IQ to vote, or to own property, or to start a business, or to help others, or to worship where he chooses, or to become someone others care about, count on, and look up to.

Everyone does not have to be nor want to be a scholar, nerd, ultra-intellectual, "brainiac" in this world. There's more to my son than how he "performs" academically or whatever.

I'm sick of the unspoken disdain and double standards with regard to certain disabilities. I'm tired of feeling like people are (knowingly or unknowingly) creating hierarchies of various diagnoses. That's not right and it's not cool. This isn't some type of competition. I refuse to allow people to "pit" the diagnoses of my gifted autistic youngest daughter against those of my intellectually disabled non-autistic oldest son. I'm disgusted by some people who salivate over her advanced cognitive abilities yet have no comparable compliments for the many positive qualities my son possesses. More than disgusted; I'm pissed.

So her IQ is twice that of his. So freaking what? His kindness is twice that of ANYONE I've ever met in over three decades on this planet.

There is no "grade scale" when it comes to disabilities. Every member of my immediate family – myself, hubby, and kids – is disabled. I won't let you "rank" us. I won't let you divide us. We

are a family whose members are autistic and/or gifted and/or people with ADHD and/or people with psychiatric disabilities and/or HIV and/or speech impairment and/or intellectual disability and/or arthritis, etc. And we are one. Like somebody's quote says, "different, not less."

I do not personally have intellectual disability. But I refuse to let you – or anyone – subtly belittle or disregard people like my son while trying to "sympathize" with another group or disability to gain favor for yourself or to prove a point.

There is no d@mn Switzerland of inclusivity. Intellectually disabled people matter. Period.

They are not some subclass beneath autistics without intellectual disability, or beneath people with physical, sensory, or other disabilities without intellectual disability, or whomever.

If we need ALL kinds of minds, if we need to respect ALL people, if we need to honor the personhood of ALL people, that includes people like my son. Regard and treat him as a whole person, not solely a number on the IQ scale.

Screw IQ tests. And if you can't do that?

Then screw you too, because you're part of the problem.



# CHAPTER 15

## Life Lessons, Aloft

I typically try to sleep or read when on flights. It helps to pass the time and also helps me have to avoid awkward, unwanted small talk with the people seated near me.

On this particular flight, however, I felt inclined to break that rule. The person seated to my right was an older lady, Black like me, and she was soft spoken. So much so that the flight attendants could not hear her when she meekly attempted to communicate with them. She'd been asleep when they passed through earlier to take drink orders. Now, however, she had woken up and was hoping for a drink, and tried to say as such when they came near. But her quiet, plaintive voice went unheard. So I used my louder voice to get their attention on her behalf so that she could order her drink.

This simple act opened the door to a conversation. I would have preferred solitude, but she was a nice, grandmotherly woman whose lilting accented tone reminded me a bit of my own mother. Plus, it would be rude to shut down communication abruptly. So I engaged in dialogue with her for a few minutes, politely answering her questions about who I was, where I was traveling, and why.

"You're going to speak at an event about autism?" she repeated. "My grandson has autism."

"Oh," I said. "How old is he?"

"He's twelve," she answered. "That's a fun age," I replied. "What does he like to do?"

"He really likes computers," she stated, smiling. "He's bashful. He doesn't like people. Or to be around people."

"Maybe he's introverted," I explained. "He might just need alone time to recharge. I'm like that. Not just because I'm Autistic. It

doesn't mean that he doesn't like people. It just might be too much for him sometimes."

"He's the youngest," she said. "My son says that he is like this because of the immunizations. That the immunizations gave him 'the autism.'"

"No, they didn't," I answered. Her brow furrowed. "Immunizations didn't make him Autistic, ma'am. Your son might believe that is the case. And there are definitely children who have had bad reactions to getting immunizations and even some children who are advised to avoid certain immunizations because of allergies or health reasons. But decades of research has not shown a single link to immunizations and autism. Nothing 'gave' him autism. It's just the way he is. The way his brain works. Nothing is wrong with him."

"The immunizations didn't give him 'the autism?'" she repeated blankly. I nodded. She stared at me intensely. I was a little confused. I didn't take her, a kindly, elderly immigrant woman, as an anti-vaxxer. I figured she was just repeating what she had been told. I definitely didn't expect what happened next.

She became emotional.

I didn't know what was going on nor what to do. Nor what to think. I sat in awkward silence for a few moments, looking down at my lap and flapping my hands idly while the woman beside me worked to compose herself.

She laughed softly, and then said in a gentle voice, "Thank you."

I was confused. I glanced over at her. She had wiped her face, but a lone tear still rolled down her face into one of her nostrils. I stared at that tear, which hung from her nostril and threatened to fall. It was easier than staring into her eyes...

“I made him. My son. Made him promise all his kids would get immunizations. They all did. From the oldest to the youngest. I wanted them to be healthy. And protected.”

The tear finally fell, and I lifted my gaze to her eyes. She told me her story. She was originally from a Caribbean island and was one of nine children. She grew up, married and had six children of her own who she also raised on that island. One of whom – the one who later grew up and had the autistic son – had contracted polio as a small child.

She said that she had noticed him walking funny one day when she was preparing a meal. It was during the time that there was an epidemic of polio, and his odd gait concerned her. She stopped in the middle of her cooking, called her son over, and asked him to walk some more so she could observe more carefully. And when he did so, she realized that yes, something was wrong.

Leaving her other kids with her neighbor, she put her son on her back and made the long trek by foot to the hospital. Her son was examined and was diagnosed with polio – but because she brought him in so early, they were optimistic. Her son was hospitalized for a period of time and eventually released. She was instructed how to care for him after discharge, including specialized massages she was to give him every other day and exercises he was to do. Unlike many other individuals who lost their lives to polio, he was spared. Due to medical intervention. She was grateful.

When she and her children relocated years later to the United States, she made sure that she took advantage of the proximity and affordability of medical care (in comparison to what she was accustomed to). She was a firm believer in the medical field as it had saved her son’s life. She instilled in her children an appreciation for preventive medical care, health, and wellness. Including regular checkups, blood draws, and routine screenings. Including immunizations.

I wondered how many years she had harbored undeserved guilt in her heart that the fearful experience she had with her son years ago

had been a contributing factor to her urging her son to have his own children vaccinated, thus, in her mind, “causing” her grandson to be on the autism spectrum.

And now she would no longer have to harbor those feelings of misplaced guilt any longer.

All I did was provide accurate information; clear up a misconception. I did not personally change her life in any way. I was merely a conduit of information.

Information can help. Or it can hurt. How many other people are out there, in the 21st century, like that nice lady on the plane? Believing incorrect, stigmatizing, hurtful information about people who are neurodivergent? Not just about autism, but about other neurological differences?

Whether it’s about false “causes” of autism, eugenic notions that it is better to abort a child with Down Syndrome than to consider carrying to term, misguided beliefs about mental illness and violence/mass shootings that lead to discrimination and disenfranchisement of disabled people, inhumane “treatment” programs such as the Judge Rotenberg Center’s electric shocks that torture the disabled individuals who are unlucky enough to reside in that facility, and/or compliance-based “interventions” or any number of things... what you don’t know CAN hurt you – or at least it can hurt someone, especially if that someone is a person living with a disability. The misinformation that exists demeans people, fuels ableism, and makes the world a less safe and inclusive place for disabled people and our loved ones — and anyone who cares about equality.

People always won’t be grateful to hear what we have to say. To hear our truths. This day, my message evoked tears of joy, but on another day they could instead produce tears of rage. Or indifference. Or disbelief. They could induce a fierce argument, as the other



party might have equally strong opinions that differ sharply from my own. They have done so before. They will likely do so again. There seems to be no shortage of people, especially abled people, willing to “able-splain” to disabled people how we are supposed to feel and think and what we are to believe.

But no matter how others take it, it is our responsibility to still share the truth. It isn’t always well-received nor convenient, nor pleasant. But it is still truth, and it must be told.

I’m hopeful that maybe that woman slept a little bit more soundly, more restfully than she has in many years. Because she now knows that her grandson is exactly who he is supposed to be, and that it isn’t anyone’s fault, but just life as it is meant to be.



# CHAPTER 16

## Breaking the Bough - The Lie They Told Kai

Years ago, on this very day, I first met my friend “Kai.” I have not seen or heard from her in years as we met when we were teenagers. But I tend to think of her this time of year and wonder where she is, and how she’s doing. Wonder what her life is like and wonder if she has peace. And especially since becoming a parent, I wonder how her parents...and sadly, many, many, many parents...can treat their child as shabbily as Kai’s parents treated her.

Although I was a quirky and somewhat socially awkward teenager, I had a few things going for me. One was that I had a small, close-knit group of friends that accepted my “weirdness” and often helped me navigate different scenarios that cause most if not all teenagers angst regardless of neurology (i.e., school dances, crushes, etc.). Another was that my family loved and accepted me (mostly).

Of course, like most adolescents, I had the occasional falling out/argument/spat with my friends over things that seem trivial now but felt really significant then. And of course, though I loved my family, I didn’t always like them. I found plenty of areas to find fault with my family, one of which was how ridiculously strict they were (stereotypical overprotective immigrant parents, except it was no stereotype in my case, it was reality).

However, deep down even when my friends and family got on my nerves, I knew that they cared for me. It was apparent in the way that they treated me, interacted with me, spoke about me, spoke to me. It was evident that even though they didn’t always “get” me, for the most part they allowed me to be myself.

Despite all of the messages that I received from the world that shouted otherwise, my friends and family didn’t make me feel like something was wrong with me. They didn’t try to force me to change or to act like everyone else.

As an undiagnosed Autistic teen, I dwelt in a world that I frequently did not understand and that was often a very cruel place to exist,

my friends and my family were a lifeline that often kept me sane and helped me to keep going.

Unfortunately, as long as I knew Kai, she didn't have anyone in her life like that. She and I were friends, but I don't believe I was capable of filling the parent-sized void in her life. More to come on that...

I met Kai during my winter break from school. Two weeks of holiday to sleep in, to relax, to not have to do much of anything beyond read, and sleep, and watch TV, and sleep, and visit with friends, and sleep some more...it was nice. On this particular day my friends and I decided to go to the mall as we all had holiday money and/or gift certificates to spend. So rather than just "window shopping" we could actually purchase something (yay!) at the mall. An added bonus was that this was a mall where many of our peers frequented, so it was a good place to see cute people – and to be seen.

I had a love/hate relationship with the mall. Hanging out with my friends? Fun. Seeing cuties, even if I felt too shy to talk to them? Fun.

Being in a loud, crowded, overwhelming space? Not fun.

Having to visit store after store even after I had already chosen what I wished to purchase because everyone else was still deciding? Not fun. I went anyway, though.

About 45 minutes into it, I needed a break. I left my friends in a store, letting them know I'd meet them in a while, and I headed to the food court. I was deciding between a smoothie and a soft pretzel when I heard some kind of commotion. I wasn't certain what was happening as there were many people coming and going. But when it grew louder, I realized the source of the noise was a group of teenage boys surrounding one of the food court workers.

During peak times, most food court restaurants positioned one or more of their employees to stand in a busy, open area of the mall with a tray of free samples to offer to people passing by

(in hopes that if some of them liked the sample(s), they would purchase a meal).

One employee apparently worked at a restaurant that did not require uniforms, because instead of the bright polyester shirt and black slacks several other workers had on, she was dressed in her own clothing.

The employee holding the tray, a teen ~my age, was wearing native attire from her culture...and was being harassed for it. A group of older teen boys were making loud, rude, bigoted “jokes” about her, mocking her accent and her appearance publicly for laughs.

Trying to do her job, the girl attempted to ignore them, but a small crowd had gathered to watch, point, and laugh. Having an audience emboldened the boys, who continued their tirade as she stood there holding her tray, visibly fighting tears. Several people who walked by were shaking their heads and frowning. Clearly, many disapproved of what was happening. However, no one was doing anything, and there were no mall security guards who were nearby that could come over to make the boys leave.

I knew what it was like to be bullied for being different. and I couldn't just stand by and watch. I began walking briskly, headed for the group of boys. My heart was pounding because I had no idea what I was going to say, and I felt nervous because I didn't have my friends there with me.

But someone had to do something. If no one else was going to, I would.

I had almost made it to where the group was standing when all of a sudden, I felt a huge splash of cold wetness. I stopped in my tracks and gasped. My entire shirt was now drenched with something sticky.

There was a racially ambiguous girl, tall and pretty, with long curly hair and glasses near me with a smoothie cup in her outstretched hand. Pointing at me, she shouted, “SECURITY!”

Everyone turned around and stared at her. She continued to point at me. I stood in place, cold, drenched, and confused.

“Security!” the girl shouted again. “HELP! Someone bumped into me and made me accidentally spill my drink on my cousin! And she’s allergic! Someone get help, now, please! SECURITY!!!”

I didn’t know who her cousin was or what she was talking about, but I was very unhappy about being soaked. The crowd that had formed around the boys taunting the food court worker immediately dispersed. Some people ran to search for security while others started coming closer to where the girl and I were standing. I had no idea what was going on, but the curly haired girl quickly rushed over to me. Grabbing my arm, she hissed in my ear, “Just play along! No one was doing anything to help that poor girl; I had to do something, okay?”

Finally, I caught on. The whole thing was a ruse; she’d dumped her drink on me, concocted some story, and shouted for help to cause a distraction, hoping to alert the attention of the mall security guards! If security was present, the girl holding the tray would no longer be harassed. Now that I understood, I started moaning loudly and being melodramatic. Someone brought me a chair, and my “cousin” shouted again for security. Not wanting to get in trouble for harassing a mall employee when the security guards arrived, the boys causing the disturbance quickly disappeared from the area, leaving the employee alone.

Seeing that the situation was over, I suddenly “recovered” from my “allergic exposure” and stood up from the chair. After reassuring several well-wishers that I would be fine and NO, I did not need to use their epi pen, I headed to the restroom to try to clean myself off. The tall curly haired girl followed me inside.

“Hey,” she said. “Slow down a sec. I’m really sorry I dumped my drink on you.” “It’s okay,” I said. “That was really cool what you did to help that girl.”

“Nah,” the girl answered, shaking her head. “It’s no big deal. I’m sorry about ruining your shirt, though, it was really cute. Since it’s my fault. I’ll replace it for you. You can’t walk around the mall looking like you’re in a wet t-shirt contest.”

Opening the very large bag on her shoulder, she rummaged around for a bit, and then triumphantly pulled out a shirt. “Most of what I have won’t fit you ‘cause your boobs are pretty big,” she said, “But I think this one will work.” Handing the shirt to me, she gestured toward the restroom stalls. “Go try it on! Don’t worry, it’s clean – it’s brand new, actually. See, it still has the tag on it.”

It did have the tag still on it. I glanced at the tag and gasped at the price. “I can’t take this!” I said. “It’s way too expensive.” I tried to hand it back to her.

She shook her head again. “There’s no such thing as too expensive when you’re giving something to a friend. So “cousin,” let’s be friends! My name’s Kai.” Smiling, she reached out to shake my hand in greeting. Smiling back, I agreed.

So that was the day I met Kai. She joined my friends and I that afternoon. Kai was easy to get along with, and people were drawn to her like a moth is drawn to a flame. She was funny. She was giving. She was brave. She was pretty.

And she was neurodivergent, as well as a transgender teen of color.

I realize exactly how this is going to come off, but in the spirit of transparency I’m going to say it anyway: Kai was the first openly transgender person I personally knew. (I’m deliberately choosing to use the word transgender throughout this as opposed to the outdated and now offensive term that was more commonly used at that time.) As a fifteen-year-old Black girl living in a major US city,

of course I had casually encountered individuals on occasion whom I assumed to be transgender before. I had likely also encountered others unbeknownst to me as well; the transgender community isn't homogeneous. However, as someone who was (undiagnosed) Autistic and not the greatest at socializing, I typically didn't incorporate new people of any background, gender, age, etc. into my life. I had a small, insular group because I struggled to connect with people. The few friends I did have were people whom I'd known since I was younger; they'd already proven themselves to me years prior. Befriending someone new, for me, was rare.

It was different with Kai, though.

Even though she was a literal stranger, she seemed to get me. After that one day of hanging out, she almost felt like an old friend. We exchanged numbers and spent the rest of the holiday break communicating with one another every day for hours. Once school resumed, we regularly kept in touch even though we went to different schools. Kai and I became close quickly. She even seemed okay with my info dumping!

Though she spent a lot of time trying to make everyone else laugh and smile, Kai herself was often sad. She often tried to conceal her sadness, but I knew her, and I could feel it.

She shared with me that since she was trans, her parents and her sister thought she was a freak and a weirdo. They didn't understand her. They refused to call her Kai and insisted on deadnaming her despite knowing how much she now hated being called "Kyle."

They continued to purchase masculine clothing even though they knew she didn't want to wear it. Kai was forbidden to wear makeup at home, and she locked herself in her bedroom at night, fearing her mom might sneak in to cut off her long hair while she slept.

In order to get them to leave her alone, Kai always left the house in what she called, "drag" – boy clothes. She would select a masculine

or androgynous looking outfit to put on, rub clear chapstick across her lips, wear minimal, unisex jewelry (or no jewelry), and pull her hair back - no makeup or nail polish.

However, as soon as she was far enough away (i.e., halfway to school, the movies, or the mall), she'd find a place to change into her real clothes and put on her makeup. Later in the day, when it was time to go home, she had to transform her appearance back to that of "Kyle." She would find a place to change back into the clothing her parents found acceptable, remove all of her makeup, nail polish, and jewelry, and pull her hair back into a messy, unisex bun. (That is why Kai had a shirt handy in her purse on the day we met. To avoid fights at home, she always had a few changes of clothes, shoes, and makeup. Hence the ginormous bag she carried.)

Kai lied to her parents so we could hang out without issue. They were delighted that I was "Kyle's girlfriend" and hoped it meant that she was "growing out of that stage" and would start acting more like a boy. They didn't get it at all. Kai couldn't act like something she wasn't - at least not for long. Kai couldn't be a boy because she wasn't a boy. She was not Kyle. She was Kai.

School was difficult for Kai. She struggled with academics, but she seldom raised her hand in class to ask for help because she had more than enough issues at school to deal with. She was called horrible names by transphobic students. There were some classmates who dated/hooked up with her in secret, but ignored her on campus, too cowardly to bring her to school dances or walk down the hall with her. Other than 2-3 students Kai was casually friendly with, most girls at school seemed not to like her. She and I tried, in vain, to figure out why.

Were they shunning her because she had been assigned male at birth? Or was it a race thing, since Kai attended a mostly white school? Was it because being dyslexic, her grades fluctuated? Was it intimidation? Since school was one of the few places where she didn't have to dress and act like "Kyle," Kai, who was already



gorgeous, sometimes overdid it at school. Her flawless makeup, creative hairstyles, and sexy clothing attracted a lot of attention; maybe some girls kept their distance so they wouldn't have to feel like they were competing with her?

Being Black, gifted, and Autistic, I was often stressed out about school also (though my experiences at school paled in comparison to Kai's). Naturally, Kai and I brainstormed devious plans to temporarily shut our schools down for a few days to give ourselves a reprieve. "Let's clog up all the toilets!" she suggested one day.

"Nope," I replied, "I've got a better one. Let's sneak in at night when no one is there and mix all the chemicals in the science labs to blow the place up." We giggled mischievously, somehow not taking the time in any of our silly discussions to devise a plan to escape without harming ourselves. Thank goodness we were only fantasizing!

Kai and I had a lot in common. We were both Black (although our skin, hair, and features differed significantly due to Kai's multiracial Caribbean heritage). We were both neuro-atypical. We were both children of immigrant parents (mine were West African; hers were West Indian). But there was one major difference between us, and that difference caused our lives to be very different. It was a difference that caused Kai a lot of pain.

It's also what ultimately caused us to lose touch and no longer be friends.

I'm not referring to her sex assigned at birth. Kai knew who she was. She told me that even though she didn't confide in her parents nor start trying to live as a girl until high school, she had known since she was very young that she was really a girl. She'd kept it a secret for years because she didn't think her parents could handle it (and sadly, she was correct; her parents were not accepting of it at all).

Kai always maintained that it was other people who had a problem with her being transgender; she was comfortable with who she was.

I was comfortable with her as well, too, but truthfully, it's because of how we "clicked." I won't pretend that 15-year-old me was radically open-minded and progressive about gender diversity; I knew very little about it. My ignorance pretty much rendered me a neutral, blank slate – I didn't have much context – negative or positive – with which to compare Kai. She was okay with that.

The most significant difference between us was the child/parent relationship.

I grew up knowing that while my parents might not agree, approve of, or even understand much of my choices, they were still there for me nonetheless. Don't get me wrong...there was no Utopia in my house. My parents and I disagreed on almost everything, and we "bumped heads" a LOT. Especially in my teen years. But despite that, even though they often frustrated me to no end on many a day, deep down, I knew they loved me. I knew I could rely on them. When it came down to things that mattered deeply, they always had my back.

When I had a difficult day at school, or was bullied, or clashed with a teacher, or was treated unfairly, or had sensory overload, or whatever list of endless things that I encountered, I could count on my family lifting me up.

My older brother would offer to get his friends to "beat up" whomever was bothering me. My dad would start drafting one of his infamous letters to the school administrators. My mother would plan to take off yet another day of work to accompany me to school to right whatever wrong had occurred (and as ableism, racism, and misogyny was then, and still is, pretty rampant in schools, there were plenty of those "ism"-s and more to deal with). My younger brother would tell me some silly story about his day to cheer me up and make me laugh.

My home wasn't perfect, and my family definitely wasn't, but they made my home a haven. I didn't have to hide my stimming (although my mother did let me know that some of my louder vocal stims were

irritating sometimes). It wasn't a big deal that I scripted constantly or liked to eat the same food prepared a certain way or that I liked reading the same books or playing the same songs over and over. They didn't "get" why I was like that, but they allowed me the space to be myself. Whether I had a good day or a bad day, I knew usually when I got home, most of the bad was now over and I could relax.

That wasn't the case for Kai at all.

Kai's parents refused to consent for her to receive educational services for her learning disability at her high school – even though it was available at no cost to them. They argued with diagnosticians that their child was "not stupid" and that they refused to continue to let their child be "labeled" by schools. They didn't seem to believe that dyslexia was a real condition.

Or if they did, they assumed she should have gotten past it/overcome it by now. Kai's parents often told Kai that she was just being lazy. They told Kai that if she "worked harder" her grades would get better, ignoring the fact that she worked damn hard already.

As Kai's grades plummeted, her teachers offered free tutoring after school to help. Her parents repeatedly declined. Instead of attending the tutoring she desperately needed to help her improve academically, she was forced to spend weekday afternoons in "special" meetings with their pastor, whom they had implored to "help Kyle get over this phase of thinking he's a girl."

Kai had attended the same small, evangelical Caribbean American church since she was a toddler, so she knew her pastor well. And while he was an older, staunchly conservative person, she didn't dislike him. She considered him a clueless yet nice person who had good intentions, and although he generally treated her kindly, having to attend the meetings made her feel demoralized. For example, while she was there, she was constantly misgendered as she didn't feel comfortable reminding her pastor that she didn't like being referred to by her deadname "Kyle." Her pastor also ordered

a workbook for her to complete (it contained “manhood” homework assignments on sports and mechanics even though people of any gender can like those things) and assigned her Bible verses.

The following school year, Kai was retained and had to repeat a grade while her peers advanced. She continued to fail tests and quizzes, became demoralized, and then started regularly skipping school rather than attending classes and feeling like she couldn’t understand or keep up.

She began experimenting with different ways to self-soothe, several of which were unhealthy methods. Fearing for her well-being after one of the hotel room hookups she had with a married man she met online went terribly wrong and devolved into assault, Kai sought out her older sister. She shared what happened, hoping for advice about relationships, safer sex, and self-esteem. Her sister, who disapproved, alternatively ignored and shamed her rather than helping. Kai then became acquainted with some individuals who turned out to be toxic and manipulative, which caused her to feel unlovable, hurt, and devalued. Kai continued to self-soothe with people and with substances that weren’t healthy for her. She was spiraling in a lot of ways, but became defensive if I or the few other non-toxic friends she had tried to bring it up.

The double life took its toll on her, and she began to display signs of depression. Tired of always sneaking, hiding, and lying, Kai tried to work out a deal with her parents that she would continue to let them call her Kyle and would dress in boy clothes with no makeup to church and on family outings if they would please allow her to openly be her real self at other times. After angrily refusing, they uncovered her hidden stash of clothing and makeup and burned them in a pile as Kai pleaded and wept. Afterward, they told her she was grounded.

Kai became increasingly distant. She lost weight, slept a lot, and didn’t seem to really want to go anywhere or do anything. She also made some questionable choices. Eventually, her sister, who

had initially been dismissive, became very worried, and in a well-intended but disastrous attempt to get Kai some help, she revealed several things to their parents Kai had shared with her in confidence.

Things didn't go well. Their parents canceled Kai's weekday meetings with her pastor and enrolled her in group and individual therapy. Next, Kai was subjected to "treatments" that she hated. Though they were not formally categorized as conversion therapy, there was a strong similarity. Immersed in this hostile environment on a regular basis, Kai, who was already struggling psychologically, became even more depressed, engaging in self-cutting, binging, and purging. Her parents then checked her into a facility for teens with behavioral problems. They, of course, checked her into the boys' wing of the facility under her deadname "Kyle."

After a few weeks, Kai ran away from the facility and came back home. Her parents were angry with her, and an explosive argument ensued. Kai's sister tried to intervene, but everyone was too upset to communicate calmly.

Kai refused to be forced to live as "Kyle" even one more day. Her parents gave her an ultimatum – either stop this "nonsense" right now or get out of their house.

Kai felt that she had no choice. She left – and went to live with her much older boyfriend. She stopped attending high school altogether. I was worried about her. For a while, she kept in touch with me somewhat, but eventually she stopped. I made efforts to re-establish contact with her, but my efforts were unsuccessful. I didn't hear from her for a long, long time. I had no way of knowing where she might be and how she was doing.

Kai seemed to have just disappeared.

No one seemed to know where she was. I reached out to her older sister online a few times through the years, hoping for news about

my friend. She told me that Kai occasionally made brief contact with her to let her know she was all right. I was glad to know that Kai had remained in touch, however sporadic, with her sister, though I felt a little sad that she didn't reach out to me or any of her other friends. But I tried not to take it personally. Kai had a lot going on.

Maybe she was too stressed out to have to explain her decisions; maybe she was living in survival mode; maybe she just wanted a fresh start; maybe she worried one of us might tell her parents where she was if she shared her location with us.

Wherever she was, I hoped she was happy, as she had lived so much of her life unhappy.

I ran into Kai one time by chance, during my undergraduate years. I'd moved out of state, but I had flown back home for a spring break visit. One day, while out running errands, I stopped to put some gas in the car. As I was preparing to leave, I saw there was someone walking across the gas station parking lot, and felt that there was something vaguely familiar about the person. I looked closer.

I couldn't believe my eyes; it was Kai!

Her appearance was drastically changed, but I still recognized her. I was relieved to see her after so many years. Kai was pale and gaunt; she felt like "skin and bones" as I hugged her. She was subdued and she looked older, almost fragile.

When we were in high school, she had always exuded courage and confidence, even if much of it was bravado. Her clothing had always been immaculate; her nails clean, well-kept, and shiny; her makeup flawlessly applied and glowing. This Kai, in a faded minidress, seemed burdened, and it was evident that she was heavily under the influence of some substance/drug.

We talked for a few minutes. When I told Kai I was in college and what I was majoring in, she smiled broadly, and in that beautiful

smile I caught a glimpse of the old Kai for a minute. When I tried to ask about her and how things were in her life, she waved me off and steered the conversation back to me each time. She dodged all of my questions with, “That’s a LONG story; we’ll get into all that next time we talk.”

I asked for her contact info. She looked away and said that her phone and internet were temporarily disconnected, but that once her boyfriend got some money, she’d get them turned back on. I couldn’t tell if she was being evasive, and decided to give her the benefit of the doubt. She took my info, promising to contact me so we could get together while I was in town. We hugged again and parted ways.

She never called or messaged, and I have never seen her again.

No one should have to experience what Kai did, and her life should be valued as more than simply a cautionary tale. She’s a person; a daughter, sister, friend; she is somebody. Kai cared enough, as a teen, about the pain of an absolute stranger to go out of her way to help. She’s the type of person who will literally give you the shirt off her back...or, more accurately, the shirt out of her purse.

When we first became friends, Kai told me she wanted to be a photojournalist. She said that nothing would make her happier than being able to go to different places around the world, have new experiences, and take pictures of beautiful things that would make people happy.

Kai was creative, caring, and resourceful. Unfortunately, she felt unsafe in school, unsafe out in the world, and eventually, unsafe in her very own home.

Kids grow up. So much of connected parenting focuses on when our kids are young. Making them feel secure and loved and comfortable with who they are. But what benefit is it to your child if you fight with

the world to accept your child's differences at two or five or ten when you, the parent, won't accept their differences at thirteen or sixteen or twenty?

This is a lifelong job; a lifelong commitment. Kids grow up, but your responsibility to them doesn't disappear because they can walk, talk, feed and/or dress themselves, or even drive. You're still supposed to be there.

You don't have to condone everything that they do, but your love for them shouldn't change. Even when you don't fully understand; even when you don't fully agree, whatever – you don't withdraw your love. You don't withdraw your support. Your child may or may not crave your approval, but they'd probably appreciate your acceptance.

I mean, that's the currency of being a parent, isn't it?

That you are going to love and accept them?

They don't owe you anything.

They don't owe you choices you deem acceptable, and they don't owe you a particular gender identity nor a particular religious belief nor a particular sexual orientation nor a particular political affiliation nor a particular career nor any particular type of life.

Kai was lied to. Many of us have been lied to – have been made to believe that we aren't deserving of a parent's love unless we perform, unless we conform. That is bullcrap. It's the biggest lie, and sadly it is a widespread one. Children don't owe us anything – but we, the parents, owe them.

We owe them...we owe them big time. We owe them a sense of safety. We owe them our love. We owe them understanding, or at least a concerted effort to understand even if we don't always understand. We owe them the assurance that we will provide them with the resources they need. And we owe them our support – throughout the lifespan.



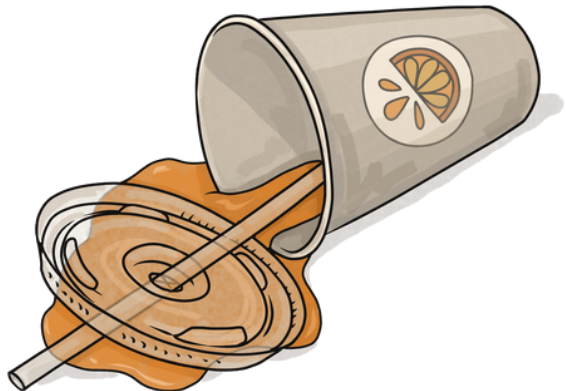
We owe them all this, and probably more.

If you cannot profess to love a child who turns out to be neuro-divergent, who turns out to be transgender, who turns out to be non-binary, who turns out to be disabled, who turns out to be of a different faith tradition than you raised them to be, who turns out to be something other than heterosexual, who turns out to be imperfect, who turns out to be...themselves...then you are not a parent.

You are not family. You have forfeited your right to cast judgment on whomever your child selects as their family of choosing – the family you could have been, but refused to be, for them.

Tonight, all I can do is hope that through the years Kai has been able to find, for herself, that family. A family that loves, nurtures, and values her for the woman that she is.

And that her life will be an endless sea of beautiful images not to make others happy, but to make her happy. For she deserves to be happy.



# CHAPTER 17

## About "Passing Privilege" and Being Autistic

Sometimes I feel like a double agent.

I am Autistic. I'm not ashamed. I think I'm pretty obvious – at least to my own people. Autistics can pretty much peg me as part of the "neurodiverse squad" pretty easily. But it seems many others can't.

Like several (though not all) Autistic people who were assigned female at birth, at times, I guess I "pass" pretty well. At least that is what I have been told anyway. Not that I'm trying to pass per se; I'm pretty "out." But a lot of my "obvious" Autistic characteristics are more internal, and some of the ones that are not internal are traits that are also seen in other groups, such as gifted adults (of which I am one) and introverts (of which I am one also, though it is not always apparent). So they may not necessarily be perceived as being associated with autism as opposed to something else.

It's hard to explain. I feel that the way I advocate, research, and go about doing things is very much on the autistic spectrum, but it is not seen as such, I suppose.

But there are indeed times that I can tell that I am coming off in a way that is more neurotypical. In other words, there are times that I DO perceive that the way that I am being read is as a non-Autistic person.

Basically, in those instances I can "feel" that I am "passing," even though that was not my intention for whatever situation.

It's weird. I don't necessarily plan to act or speak any differently away from home, but it kind of happens instinctively.

Maybe it's a learned survival mechanism; maybe it's just what feels safe. Just like people put on their business attire in order to go to work, I can turn on the neurotypicality as needed. It's not perfect, but it works.

I guess if I think back and ponder the larger issue of how one might learn skills that might make one speak and act in a manner that would result in seeming to “pass,” I suppose I had good role models; my parents are immigrants. They moved from Africa to America many years ago and learned how to balance navigating life in a foreign place...they learned the language, the customs, the etiquette, the nuances, etc.

They are proud of who they are and never hid it. They also raised my siblings and I to be aware and proud of ourselves and our cultural and racial heritage too.

In order to survive in this society they learned how to operate according to its rules. However, they never abandoned their own language, customs, beliefs, etc.

Their true way of communicating, living, thinking, etc never disappeared even as they learned to incorporate the new ways. They simply learned how to “code switch” between the two.

So did I.

I somehow learned how to code switch between my natural Autistic way of being and the neurotypical way. I can do it – apparently well, though it’s tiring.

Consequently, I’m more noticeably “Autistic” in my home than in other places. Not because I’m hiding who I am when in public, because I don’t necessarily suppress my natural way of moving, talking, or speaking. Maybe because home is my haven and I feel more free to just...be.

The desire to flap, spin, engage in scripts, echolalia or perseverative speech, or whatever is much stronger when I am in my comfort zone with my family than when I am out in the world. (Similarly, my desire to have bare feet is stronger at home than in public – to let my toes

“breathe” and not feel confined inside shoes. I guess home just evokes a sense of being truly free.)

Back to feeling like a “double agent.” Since I am not immediately pegged as being Autistic, I am afforded the ability to speak about autism in circles where self-advocates aren’t always able to do so.

I don’t hide who I am, but to many my role(s) as a parent of Autistic children and/or an individual with a graduate degree in autism and as someone with doctoral fellowship training in autism are more evident (and seemingly perceived to be of more value) than my own identity as an Autistic woman.

It seems, sadly, rather than having interest in my neurology, people are more drawn to those other things...

The piece of paper and letters after my name.

The research I’ve done on autism.

The “big name” professionals I’ve worked with.

Or the fact that Autistic children came out of my vagina (or, more accurately, out of my uterus).

All of that apparently carries more weight and is of more value than living over three decades in my own Autistic skin.

I don’t understand it. I truly don’t.

But if it gets me in the door, then I don’t have to understand it, I guess.

If it gets me a seat at the table and a platform to share my people’s views, then maybe my ability to “pass” is useful. Because I’m no token; this stuff is important to me. So once I’m allowed “on the inside” I don’t waste much time before I begin to share important concepts that are central to the Autistic community (as well as

principles that are important to other marginalized groups, including people with other disabilities, people of color, women, queer, gender diverse individuals, etc., when I can).

The way that I might introduce these principles might vary depending upon the audience and their ability to comprehend what I am sharing. Some people are more receptive when a gradual approach is employed; others prefer being given a lot of information that they can think through and ponder.

It might mean that I have to wade through a lot of “muck” to make my point and it might mean that I have to give people some latitude to make mistakes and even unintentionally offend me (“choosing my battles”) while they figure things out.

Such is life as a double agent...

If I think about this for too long, though, I have to admit it bothers me that if I was understood to be “just” an Autistic adult I would likely be relegated to the outside and not taken seriously.

That’s not cool. I, and others, should be respected and sought after for our perspective and lived expertise as persons on the autism spectrum. But more often than not that doesn’t seem to be the case. Instead of “Nothing About Us Without Us” it seems more like “Nothing About Us With Us.”

But all marginalized communities throughout time have needed different types of people to get the job done. Abolitionists were slave and non-slave, black and white. Suffragists, desegregation activists, disability rights pioneers, gender and racial equality advocates...all of these groups are composed of “affected” stakeholders from within the community as well as others who align with them who might not be personally affected in the same manner but still care.

And it also includes people who can “pass” but choose to use their passing privilege not for their own gain but for a larger purpose, the

collective benefit. Rather than disappearing into the “majority” group and blending in, they opt instead to serve as a bridge between the group they look like and the group they are actually a part of.

To improve understanding, communication, interaction, and relations between the groups. To help increase acceptance of the marginalized group. To use their role to make things better.

So while it might be annoying to constantly hear things like, “You?!?! YOU’RE Autistic? Are you sure? I NEVER would have known; you seem so ‘normal.’ You must be ‘really high functioning’ or really mild on the spectrum,” I can endure it if it means that the way that I present affords me the opportunity to use my voice for the greater good and my position to help make things better for my people.



# CHAPTER 18

Who Really Cares About All This? I Do.

She didn't mean any harm, this "nice" woman who is the parent of one of my children's classmates. I'd recently contacted her to respond to (yet another) query asking several parents to consider volunteering at a particular time of day. I gently explained that while I was happy to help out as needed in other ways and at other times, I couldn't commit to this particular task due to other obligations. She seemed satisfied by my answer at the time, but proceeded to bring it up on other occasions when we both happened to be standing around outside waiting for our children to be dismissed from school.

Today, I'd gotten to school early (a rarity for me, lol), so I had a few minutes to spare before the bell rang. She was waiting there, along with another parent. I greeted both of them, exchanged some polite pleasantries/used my small talk script. She brought up the volunteering thing again and I politely declined, citing the same reasons that I'd already given her.

Then, since I had some unexpected time, I whipped out my phone. I logged on to Twitter, and I started signal boosting some tweets about the current anti-filicide project as well as the upcoming Day of Action to End Violence Against Women with HIV.

After a few minutes, I glanced up and noticed that the parent I'd mentioned earlier had come back over near me. She was peering (nosily) over my shoulder, looking at my screen and literally reading my tweets! A bit startled, I gave a half-hearted smile, put my phone in my lap, and searched my brain frantically for the appropriate script to use when someone is reading your tweets/posts without your permission. I didn't come up with one, and was trying to figure out what to say when she asked, "So what is this thing you're writing about, exactly?"

O-kay.

Although that wasn't what I was expecting her to say, I thought it was as perfect an opportunity as any to share. I asked her if she was

familiar with autism, and informed her that I was autistic. We then spent some time talking about autism, and progressed to a discussion of filicide, the Stapleton tragedy, and the Dr. Phil show episodes. She was familiar with the topics, and we had a relatively decent conversation.

I then segued into how important it was for the public to have an accurate, non-stigmatizing portrayal of autistics and their families – as well as people with disabilities in general. I talked about how harmful it can be when people equate autism to violent behavior, using media speculation over the neurology of people involved in recent school shootings as an example. I shared how many in our community were hoping that we could re-center the conversation about autism to make it more balanced and more inclusive.

She listened attentively. Then, with a dismissive wave of her hand and a little laugh, she remarked that she “couldn’t be me” because she thought the idea of being involved in activities outside of our children’s school was “draining.”

“Is all that really a big deal?” she asked. “I mean, isn’t there time to worry about all that autism stuff later? It seems like you’re making a big deal out of stuff that’s not necessary right now. I mean, when they grow up and graduate, maybe you should do something then,” she said. “I don’t think you should be doing all this stuff about people you don’t even know. What’s the point? To me, it seems like overkill to worry about that right now; who really cares about all this?”

Fortunately, that was the end of the conversation, because the bell rang and kids started pouring out. As I walked away, I replayed the conversation in my head, wondering if she feels sorry for me because I think there’s a world outside the PTO, class mom duties, and class parties? She says she “couldn’t be me?”

I find that ironic, because I “couldn’t be” like her.

Who really cares about all this?” she asked.



Well, I do, d@mn it. I do.

I'm not knocking the very important role of parental involvement in schools. Research shows that it is extremely important for parents to play an active part in their children's education. I have no "beef" with the PTO; I'm a proud dues-paying PTO member of all four of the schools my kids attend. I've chaperoned many field trips and baked treats for many class parties.

Heck, I drive over four hours a day to three different sides of town to ensure my kids can attend schools that best meet their needs as opposed to just settling with the school that's five minutes away. I help with homework, revise rough drafts, make "flash cards" for quizzes, cut and glue items aplenty for science fair projects. I agree that it's important to be involved in my kids' school affairs.

However, I reject the idea that there's something wrong with caring about things outside of that. I can't fathom what it means to think it's acceptable to ignore the world around me until my kids get out of school. My youngest child just barely turned four; he has a minimum of 14 more years until he is out of school. And as he, like his siblings, is disabled, it may not be in his best interest to finish school in 14 years; he might need to retain extended public school transition services and be a student for a total of 16-18 years. Am I supposed to refrain from any meaningful involvement in life activities until then?

People are being viewed as "less than" NOW. People are having their constitutional rights denied NOW. People are being bullied NOW. People are being abused NOW. People are being discriminated against NOW. People are being hurt NOW. People are being killed NOW.

I cannot wait, and I will not wait.

My strong love for my children and the desire to fight to make this world a better place for them will not permit me to ignore the world around me for years on end until the timing is "more convenient" for

me. By the time my kids grow up, many opportunities to try to effect change will have been lost. The time to DO something is now, not later. Not only so that I can try to make things better for their future, but also so that I can lead by example. They will not always be children; they will one day be adults, and when that time comes, they and their peers will be the leaders, the thinkers, the decision-makers. They will need to know how to speak up – and out – for themselves. But if I – their parent – don't do that, how will they learn?

Until they can speak for themselves, I believe it is MY job, my duty, my responsibility, and my privilege, as their mother, to do it for them. To assert their personhood. To make sure that they are viewed properly and not tokenized and/or stereotyped. To demand that they are given the rights and dignity they deserve as human beings, regardless of their skin color, the country they were born in, their serostatus, their faith, their gender, their disability status, their neurology, or any other factor.

They need me to do that just as much as they need me to look over their homework, bring fruit for the class party, or check their reading logs.

In fact, they probably need it even more than any of that.



# CHAPTER 19

## Fast Forward to 2021

So much has happened since 2019! Not just in my life, but truly, for everyone. None of us could have predicted how the months to come were going to unfold, and I don't know if anyone could have believed such a prediction even if we'd been privy to it!

In recent years, the world has changed in extraordinary ways. We've survived an immensely difficult year (2020) whose notable aspects include a deadly global pandemic that to date has been contracted by ~130 million people across the globe and has taken nearly 3 million lives on top of essentially shutting down traditional face to face work, school, commerce, medical, and social operations for over 13 months and counting.

That would be enough to contend with on its own, but since 2019 we've also experienced the #MeToo Time's Up movement, a huge implosion with regard to people speaking out against sexual harassment and assault that had for too long been ignored and/or condoned.

There has been the courageous stance of indigenous leaders pushing against the continued exploitation and genocide of their people, most recently in the blatant encroachment of their sacred lands for the purposes of profit for privileged outsiders.

There have been protests, curriculum change, removal of public monuments that celebrate colonialism, slavery, and other community-led demonstrations of global outrage over the insidious, systemic, and inexcusable racial inequities endured by BIPOC around the world, in particular anti-Blackness that manifests in many forms but particularly in police and institutional violence perpetuated against unarmed people.

There has been a public denunciation of the lethal combination of centuries of anti-Asian racism and widespread, despicable misogyny against Asian women.

There have been a series of movements, many led by marginalized communities such as women, youth, and disabled people, demanding that the world provide real solutions as opposed to platitudes for major issues including climate change and global warming; growing number of mass school shootings; widespread ableism; antisemitism; underrepresentation and inaccurate media portrayals of various groups; anti-immigrant policies and practices; widespread voter suppression; Islamophobia; gender and sexuality violence and discrimination; wage gaps; terrorism; inadequate healthcare; economic and technological disparities; bigoted and divisive political “leaders” and so, so much more.

It’s almost like the world is starting to awaken from years of slumber. There’s so very much broken and though we’ve made progress, there’s so very much still to be done in spite of the small changes and hard-earned victories that have occurred in the last few years.

And here we are...at the beginning of 2021.

Much has changed for us since Respectfully Connected, the global collaborative writing project I have contributed to was launched years ago.

We’re now older and our kids are older.

Some of our family compositions have changed; some of our names have changed.

Some of our locations and/or affiliations have changed.

Some of us have finally recognized and embraced our neurology and/or gender and/or other aspects of ourselves that we might not have initially been fully cognizant of. We have grown, learned, lost, and gained, in a number of ways.

One thing that remains the same now as it was the first day for all of us is our continued belief in the importance of not only neurodiversity and other essential elements of human rights, but also to personally striving to cultivate a strong sense of acceptance and connection in our own lives and that of our loved ones. The manner in which we relate to our kids, partners, families of origin and/or choosing, and society in general might evolve, but the basic principles of our inherent humanity and value does not change.

Whether they are age two or twenty-two, we believe in and honor our children's personhood and we live our lives, as neurodiverse families, without shame.

The project, a volunteer labor of love that is no longer active, received no external funding. The cost and effort to maintain this project came directly out of the pockets of its founding members/leaders, none of whom are wealthy individuals. Their generosity allowed us to make collaborative writing content on neurodiversity-influenced connected parenting accessible for free on a public website and a free ebook to anyone in the world for several years. Its founders have also elected to render support efforts for it to be made available in archived form as a helpful resource for others. Mechanisms for making this happen are being explored and will be shared.

Thanks for taking this voyage with me. - MGO

\*This article, written for Respectfully Connected, but not published online, concluded the project.

# CHAPTER 20

## *Respectfully Connected Interview*

As AWN is dedicated to building an inclusive community that can support one another and share experiences, we are excited to feature a 10 question interview from 2015 with several contributors from the innovative neurodiversity gentle writing project Respectfully Connected. We hope you will enjoy learning more about this initiative and some of the great people behind it!

**Date:** February 2015

**Interviewer:** Morénike Giwa Onaiwu (**MGO**)

**Participants:**

Four of the Respectfully Connected contributors: Cat Walker (**C**), Michelle Swan (**M**), Naomi Callaghan (**N**), Jaime Franco (**J**)

**MGO:** *Thank you all so much for agreeing to participate in this AWN interview! Question 1...Are you neurodivergent (ND), or just your child? If you are ND, are you #ActuallyAutistic? Are any other members of your family also ND?*

**C:** I am Autistic. Two of my family members are Neurodivergent.

**M:** We are a family of eight. I have one Autistic daughter, who also has significant sensory processing challenges. I also have one Autistic son, two bipolar family members, and one who experiences very high levels of anxiety. I myself am neurodivergent; I experience depression as a normal part of life and relate to a lot of the same sensory challenges as my daughter but on a much lesser level.

**N:** Yes, I am autistic, and my youngest daughter is autistic. So far we are the only neurodivergent family members.

**J:** I think that both my daughter and I are autistic. Neither of us have diagnoses, but that may be something we look into in the future. My husband is diagnosed as autistic and some (or all!) of our other children may be neurodivergent also.

**MGO:** *Question 2...What five words would you say best describe your family?*

**C:** Different, accepting, joyful, tenacious, determined.

**M:** Only five words? That's not even one per family member!! Hmm... Diverse. Divergent. Eclectic. Resilient. Learning. When I asked my daughter what five words to describe our family we should consider, she said, "Didn't you used to say we are your own personal tornado?" Hubby replied, "That's four, not five words!"

**N:** Awesome, LOUD, bouncy, funny, curious.

**J:** Neurodiverse, numerous, passionate, joyful, chaotic.

**MGO:** *Question 3...Each of the various contributors involved in Respectfully Connected has a parenting style that differs from the "status quo" in some way, such as attachment or gentle parenting, homeschooling, unschooling, virtual schooling, etc. What are some of the differences that apply to your household?*

**C:** We try our best first and foremost to treat our children as individual human beings deserving of respect and compassion. We try to model the type of behavior we hope to see in our children including forgiveness, honesty and owning up to our own mistakes. It is a tremendous joy to be able to parent these children and I found once we were able to follow our own instincts more closely, there was a deeper connection to our children. Understanding and accepting that behavior is communication in children has also made for a deeper connection to our children. We homeschool and I take great joy in learning along with them.

**M:** We do a lot of things part time; it works best for us in meeting the needs of individual family members, sharing income, and home management duties. We have two kids attending school and two schooling at home (one by Distance Education, one homeschooled).

We bed share with our youngest, (and we did the same with all the other kids when they were little as well). We are not big on punishments, preferring a natural consequences approach to learning over a fear based one (although this is one area I am still learning to be flexible in as mess is a major sensory trigger for a few in our family and I struggle to let go of the desire to control the physical environment in our home). We are flexible in our expectations around meal time routines, contributions to household chores and participation in family activities. We believe everyone will contribute what they can when they are able and don't manipulate or attempt to force involvement (unless there is a safety concern).

**N:** We homebirth, co-sleep, homeschool/unschool, attachment parent. My partner and I believe that children deserve respectful communication, and we don't use corporal punishment. We've done most of this (my eldest goes to school) with all our children from birth.

**J:** We're radical unschoolers at heart (though school has a place for some of our children due to factors outside our control), so every day is filled with learning through life. We wear our children - all four of them, ranging from three months old to nearly eight years old. Our home is one of food, sleep and learning freedom.

**MGO:** *Question 4...What are some ways that the gentle, neuro-diversity affirming parenting style you have implemented supports your family's needs?*

**C:** We don't take a one size fits all approach to parenting our children. They are very different people and accordingly, have very different needs at times. At the heart of our parenting is respect. To me, that's what it all boils down to; if children feel respected as people, I've found everyone to be much happier.

**M:** I have always taken a "make it up as you go" approach to parenting. I give myself permission to let go of expectations, to



ignore the “shoulds” and do what’s best for the kids. As a result, I often feel underprepared and a bit overwhelmed, but at the same time, my kids have a mother who is not trying to force conformity and compliance for the sake of blending with society. I listen to the kids and trust they know what they need, and do my best to support them in that.

I try to be a partner with them as they explore the world, and to offer my experiences to them as wisdom if they want to draw on it, recognising that mostly they just need to do their thing and learn their own way with me as backup when things don’t go quite how they planned. And I apologise when I mess stuff up.

**N:** Because one of the basic foundations of attachment parenting is to respond to your child’s needs, it kind of just flows. Attachment parenting talks about how young babies and children express their emotions as ways of communicating – so they cry when they are sad or frustrated, they yell when they are mad or upset, they get bouncy and shriek when they are happy, etc.

Since NinjaGirl is nonspeaking, we need to rely on her nonverbal communication skills to understand her. That concept can be hard for parents to wrap their brains around, but we’re a bit more familiar because we were already doing it.

Another way that our parenting style helps support NinjaGirl is with its flexibility. We aren’t bound by strict routines or bedtimes or ways of doing things, so when any of us need to change things around we can. I feel that due to our emphasis on neurodiversity and attachment parenting, there is a lot of freedom for NinjaGirl to make her own rhythms, to try new things and to be supported when she wants to explore because we always use the concepts of bodily autonomy and respectful communication with our children. She is a very flexible thinker, a good problem solver, and I think it is in part because we allow her the time and the space to try these things out at her own pace.

Attachment parenting also talks a lot about not restricting comforting your child – whether that be via breastfeeding, babywearing, cosleeping. NinjaGirl is a very snuggly child, she loves cuddles and body contact. It soothes her (and me), and has promoted a strong bond between her and us as parents. My partner did a lot of babywearing when she was little, and they have a very close, trusting relationship.

**J:** Wearing our children in wraps and carriers helps them to be on our level, it eases their anxiety in social situations or crowds, gives them a new vantage point to learn from and provides deep pressure when necessary. Food freedom, bedtime freedom and unschooling help them listen to their instincts and support them to ask for help when they need it. They also are understanding, each at their own levels, how to respect their siblings needs- and ours too.

**MGO:** *Question 5...How did you first come to learn about the concept of neurodiversity and the neurodiversity movement? Did that discovery impact you and/or how you interact with your family, such as your parenting style?*

**C:** I read a lot and have come across it on a lot of the autism material online. I think it's had the biggest impact by helping me identify my own autism and realizing that everything I am and believe in isn't bad or wrong. It's just my own uniqueness. By uncovering my own neurodivergence, I've really been able to notice and understand it better within my own family.

**M:** I learned about neurodiversity as I met new friends online within the community of Autistic Activists and Advocates. The five greatest influences on my thinking in the early days of my exposure to these new ideas were Kassiane (Sibley) Asasumasu, Ibby Grace, Nick Walker, Amy Sequenzia and Maxfield Sparrow. I found their writing at a time when I was really struggling with the difference between how I felt about my kids' autism diagnoses and what I could see society expected me to feel. I couldn't see my kids as disordered or broken; they just needed some more support.

Finding others saying the opposite of what the main discourse about autism was a welcome relief to me. It gave me confidence to do things I suspected were right even though professionals advised differently. It also gave me the gift of community and the knowledge there is a community waiting for my kids whenever they are ready to venture into the world of the internet.

**N:** I've been a feminist for a long time, so things like equal rights, disability rights and intersectionality were already rumbling around in my head when we started to wonder if NinjaGirl was autistic. It just made sense that the best voices to listen to when learning about autism would be those of autistic people.

And after reading some of the conventional information about autism, and what it was and wasn't, it just didn't seem to fit well at all with my understanding of intersectionality or disability, or equal rights. I found several things on social media written by parents who parented in similar ways, and through them quickly found the autistic voices I was looking for.

I wasn't aware of the term neurodiversity until then, but once I found it, it slipped seamlessly into the rest of our parenting/living style. It makes a lot of sense to us – if you are a supporter of equal rights for women, a disability rights supporter, if you see children as people in their own right, if you support same sex marriage and the non-het community, well the idea that neurodiverse people deserve the same love and respect as the rest of us is just part of that.

Learning about neurodiversity was both a moment of, “Of course!” and also a feeling of coming home. It hasn't really changed how I interact with my family, because we were already working from a place of respect, but it has impacted how we explain things to other people, and has helped me understand our autistic minds better.

**J:** I've known for a while that my husband and I are both Autistic. We both had separate experiences being introduced to autism, but each

came to the conclusion that if this was us, it must not be a bad thing because we're awesome! When we met and later became a family unit, we knew that meant that our children might be Autistic also.

I started doing research about Autistic children and found a lot of horrible stuff, not only from the point of view of an Autistic person who was once a child, but also from the point of view of the attachment parent I was already becoming.

Once my daughter was born, I knew that I could never go along with those suggested therapies. We found the answers in radical unschooling; what could be more perfect for her than absolute acceptance of who she is? From there I've learned more about the theory of neurodiversity and also the neurodiversity paradigm (vs. the pathological paradigm).

**MGO:** *Question 6...Many "expert" disability resources concentrate on deficits. What would you say are your child(ren)'s greatest strengths? In what ways do you try to encourage those strengths and help your child to build upon them?*

**C:** My children have some of the biggest hearts I have ever encountered. I try very hard to regularly affirm to them how wonderful and loved they are just the way they are. They are unique individuals who think for themselves and sometimes question everything.

I do my best to explain things to them that they question or may feel unsure about. I've always found that the more I explain why things happen a certain way, or why we need to do something a certain way, they are much more receptive.

**M:** I'll answer this one specifically about my Autistic daughter, Miss G. Miss G is amazing at drawing, creating, designing, crafting and constructing. As she is homeschooled, I use this ability and interest as a way to help her learn pretty much everything! As she learns math and science and other things, she is also developing her skills in creativity at the same time as engaging in activities she finds soothing and/or stimulating.

Contrary to what some think, autistic people have plenty of empathy. Miss G is also very good at compassion. She gets very attached to the chicks we breed and raise and loves to spend time holding and loving them. She is great at knowing when her younger brother is upset and she does not hesitate to offer comfort even if it means letting him use something special of hers that she was already using. She feels so strongly that sometimes it overwhelms her, and I suspect this is part of the reason why she doesn't make it through a whole movie and finds being around other people for more than short periods really draining.

**N:** NinjaGirl's greatest strengths would have to be her curiosity and her sense of humour. She has an incredibly dry and sharp sense of humour for a four year old. She has a great love of slapstick style humour, which is pretty common in little kids. One of her favourite things is to watch something she finds funny and then to rewatch, again and again. She will grab one of us and bring us over to sit with her, watching and laughing, and then looking at us to see if we are laughing too.

Her curiosity is a source of joy and mess here. NinjaGirl loves to explore different sensory experiences. We make sure we have a variety of different options for her – an outside bathtub for lots of waterplay, several swings and a hammock, playdough, pencils, dirt, sand. Messy play is something all our kids love. It's good for them, good for their bodies and minds.

NinjaGirl also loves books. It is pretty common to find her tucked up somewhere with a book in front of her or on her lap. She is more partial to non fiction picture books than storybooks at this point, and has only just started to come over and listen when I'm reading to her brother, but I think I would say books rate in her top four things to play with (#1 being eggs, if she can get her hands on them, lol).

**J:** Our oldest two children love learning all about how things work; car rides are a free-for-all with my husband and I answering whatever questions are thrown at us as best we can. Our toddler is an avid explorer, both of her physical space and also of her limitations. Due to this, we have done what we can to make our house a comfortable space she can always safely explore.

**MGO:** *Question 7...How did you end up becoming involved with the Respectfully Connected collaborative project? What has the experience of sharing so publicly about gentle, neurodiversity parenting been like for you?*

**C:** I am thrilled to be one of the Respectfully Connected contributors. It has been such a joyful experience to both write and connect with others who share the same parenting philosophy.

**M:** My involvement with Respectfully Connected was pretty much a ‘right place right time’ thing I think. I’d become acquainted with the founder, Ally Grace, and a couple of the other people involved through other projects and from various circles the past couple of years. I was keen to get involved because I could see there was currently no other project around doing exactly what Respectfully Connected is trying to do.

I love that it involves so many contributors. I believe one of Respectfully Connected’s greatest strengths is the diversity of voices and experiences represented by its contributors. Though many of us do have lots in common, the individual experiences and variety of storytelling styles serves to make the writing capable of reaching such a wide audience.

It has been an incredibly positive experience getting to know all the wonderful people involved and seeing how well received it has been and how quickly the community around it is growing.

**N:** I crossed paths with a few of the other contributors in various online groups, and was invited to one particular group where we were all hanging out together, talking about and supporting each other with parenting our kids gently, when Ally Grace raised the idea for Respectfully Connected. I've always loved writing, and I especially love writing about things I have a strong passion for.

Having the opportunity to write about something so close to my heart, and which seems to be missing from much of the discussion around parenting autistic children – as well as hearing from autistic parents – was something I couldn't pass up. I'm on a constant learning curve. There is such a wide variety of experiences and skills within the group, and the support is so fantastic.

I know that when I have a moment of doubt about what I've written, I can share that with the group and get the feedback I need to either be more confident with my writing, or to try a different approach. It feels very much like a team, where we enjoy and respect each other's writing styles and experiences, while at the same time encouraging each other to branch out in ways we might not have thought of ourselves.

**J:** I became involved in the project after taking part in a conversation discussing the idea. I've loved being a part of it so far. I've enjoyed being able to write whenever inspiration strikes, knowing that with so many of us contributing we have plenty of content with a wide range of experience and points of view but also a basis in common ground.

**MGO:** *Question 8...What are some things you'd like to share with us that make you happy - any intense interests? Also, what makes your child/ren happy?*

**C:** I am a voracious reader of fiction and would probably let the house fall apart around me if it allowed me to finish a good book! I love to travel with my family and am a novice knitter. My children are happiest exploring as a family and playing video games and Legos.

**M:** Things that make me happy? When my kids are smiling and laughing; hanging out with loved ones; gardening; tending to my chickens; writing; seeing the kitchen benches clean; washing drying on the line; time spent with friends sharing stories; taking photos of pretty things in my garden and also around my local community.

I see happiness as different from contentment. Happiness is intense and can be fleeting. Contentment is more about a deep seated sense that things are as they should be. Things that give me a feeling of being content are the knowledge that each of my kids' needs are being met, acknowledging that I am satisfied with my life even though it isn't what I thought I wanted when I was younger, and having a community around me that values my family just as we are.

Things that make my kids happy? That would be a long list and I'd likely miss stuff....but I can definitely say they are most content when I treat them with respect and when I demonstrate that I trust them to know themselves well enough to be their own best advocates.

**N:** My kids make me happy, and so does my partner. I like being in my home, and in my gardens. It sounds very domestic, I guess. I like creating things, whether that is with words or with my hands. I do a lot of crocheting, and I like to sew and stitch, although I haven't had much opportunity to do that lately. I love gardening (I'm a horticulturalist by trade). I love getting my hands in the dirt!

My kids like getting their hands in the dirt too, although sometimes the "help" in the garden is not as helpful as they think lol. NinjaGirl loves to dance, and to sing along to her favourite songs. She might not use words, but she holds a decent tune! Climbing is also a big hit here, and my kids love drawing and bouncing.

**J:** My main area of interest is craft. I sew, knit and crochet. It makes me happy to make things for my family and to see them loving it. It is one of my areas of hyper-focus, though I cycle through the different forms in time.



Our oldest child loves understanding physical things. He builds with lego to try and replicate the forms of objects, reads books and always asks questions to learn more. Our second is a real artist. She makes drawings, books and paper sculptures. Our third child loves music; she was so auditory in the womb and also as a baby. Now, at age two, she sings along to her favourite songs and has taught herself to whistle so that she can replicate the theme music that goes along with the logos appearing at the beginning of her favourite shows and movies. Our youngest child is only three months old at the moment, so it seems that nothing makes him happier than milk, lol!

**MGO:** *Question 9...What can others gain from reading about your family life?*

**C:** My hope is that by learning about my family experiences, it will help others to grow. Our neurodiversity isn't something to be feared. By embracing and accepting our differences, we have found great joy in one another.

**M:** Sharing our journeys helps us know we aren't traveling alone, and gives us access to more wisdom and experience than we have on our own. I've learned so much and received life changing support online about autism and neurodiversity. I hope that my story will encourage others and contribute to positive dialogue.

**N:** I guess I hope that people will see that you don't have to follow the rules. That you can build a life with your family, with your children that suits what your needs are. I hope they see the biggest rules worth discarding are the ones about how parenting an autistic child "should" go. The best person to guide parents on what their child needs is their child - not professionals, not therapists, not other parents. I hope that other autistic parents read what I write and feel less alone.

**J:** Just that having a child with autism is having a child. They may have different neurology, but they are still deserving of being respected and loved.



**MGO:** *Question 10...Is there anything else that you would like to share?*

**C:** It's very exciting for me to be involved in the Respectfully Connected project. Having only recently identified my own neurodivergence, it makes me happy to be a part of such a knowledgeable and supportive group.

**M:** Can I encourage any parents of newly diagnosed kids to actively seek out the writings of Autistic adults? There is no better thing you can do in the few months after diagnosis. Continue to educate yourself in the years after diagnosis as well.

**N:** Not right now; I feel pretty "shared out," lol.

**J:** No thanks.

*End of AWN Respectfully Connected Interview, February 2015*

# AFTERWORD

*By Kayla Rodriguez (AWN)*

My name is Kayla Maria Rodriguez, and I co-chair AWN's Executive Advisory Board on Equity, Justice, and Representation. I am a disabled Latine autistic lesbian young woman living in the US South, diagnosed with ADHD, Type 1 Diabetes, PCOS, and other diagnoses including psychiatric disability and an eating disorder. AWN has been a crucial community to me, and I've been proud to contribute to their work as an advocate and regular contributor to their blog. AWN is committed to neurodiversity, disability justice, racial equity, and 2SLGBTQIAP+ liberation with a focus on transformative and restorative justice—all values I strongly believe in. I am heavily involved in several initiatives to help further disability justice and other human rights causes, including various outreach, education, and empowerment activities with collaborative partners. As an active part of the community, I am especially grateful for the important work of many leaders in my generation who are now offering important perspectives about the intersection of parenting and neurodiversity, carrying the torch originally lit by the Respectfully Connected contributors and others years ago.

As a proud Puerto Rican autistic, I love being in community with other autistic, disabled, and Black Indigenous, and People of Color (BIPOC) people. However, these communities aren't perfect. Sadly, I have witnessed racism and lack of representation within the autistic and disability communities. I also have witnessed lack of understanding and acceptance of autistic people like me within communities of color. That's why I'm so glad this book exists. It can help to provide visibility for families that look like my own and to share the stories of neurodiversity family life "in color," because we're not less than anyone else.

To close this book, I am proud to share some important quotes I have collected from members of our community related to neurodiversity and positive parenting. I hope they are of benefit to you!

## CLOSING QUOTES

“My definition of ‘Mothering as an act of Resistance’ means to redesign ableist visual culture. The sole intention is to empower and activate change encouraging communities to engage in conversations about acceptance, rooted in how Black Neurodivergent children are valued and seen.”

-Jennifer White-Johnson

[JenWhiteJohnson.com](http://JenWhiteJohnson.com)

“It’s important to champion your child, especially in a world that tells them they’re broken. I want people to recognize my child’s humanity. I wish that for everyone. Because every kid deserves that. That’s every child’s right.”

-Lei Wiley-Mydske

[NeurodiversityLibrary.org](http://NeurodiversityLibrary.org)

“My experience, along with my children, has given me a more layered look at how people are accessing their world. We face incredible pressures, challenges, and setbacks, and it’s not always just because of our disabilities. It’s because the world is not designed for us, and so, we’re constantly having to educate and advocate.”

-A.P.

[www.pcori.org](http://www.pcori.org)

“On the path to acceptance, I have learned many things that have helped me. I learned the developmental approach of celebrating what my son could do. This made a huge difference for our relationship. My son taught me the meaning of unconditional love —to honor his sacred right to be loved for who he is, not what he has achieved lately, how he looks or how much money he will earn.”

-Robert Naseef

[DrRobertNaseef.wordpress.com](http://DrRobertNaseef.wordpress.com)

“Our world has to prepare itself. What are we going to do when these children become adults? We have to create a world that is empathetic, kind and inclusive.”

-Tamika Lecheé Morales

[Linktr.ee/TheNuyorican](https://linktr.ee/TheNuyorican) | [Linktr.ee/AutismHeroProject](https://linktr.ee/AutismHeroProject)

“I’m the parent of Afro-Indigenous Autistic children living full and authentic lives on their own terms. My children will succeed at exactly what they choose to – with my wholehearted encouragement, love, and support.”

-Jules Edwards

[AutisticTyping.com](https://AutisticTyping.com)

“Find support through school or look for groups that have autistic children in it. It would be helpful to find other parents of autistic children as well. Try to get as many services as you can, like occupational therapy, physical therapy, Medicaid waivers, etc. Lastly, be patient with your child.”

-Teresita Delgado Rolón

Mother of AWN Executive Advisory Board Co-Chair Kayla Rodriguez

"Parents, your children are whole already. Autism is a part of who they are, their core being. They are not broken. Your child is a gift. Our job is to help them navigate a world that often doesn't accept them so they can share their talents with the world.

I underestimate my child. She is capable of so much. Be your children’s protectors and advocates, but also give them the freedom and independence to be their best selves - whatever that looks like to them. So be strong, for them and for yourselves. You have a challenging but rewarding ride ahead of you - all fueled by the tremendous love for your child.”

-Kristin Edwards

[WICT.org](https://WICT.org); sister of AWN Executive Advisory Board Co-Chair Kayla Rodriguez

## ABOUT AWN

Autistic Women & Nonbinary Network (AWN) is a 501(c)(3) tax exempt non-profit committed to disability justice, gender and racial equity, neurodiversity, and trans liberation with a focus on transformative and restorative justice in disability spaces. The mission of AWN is to provide community support, and resources for Autistic women, girls, transfeminine and transmasculine nonbinary people, trans people of all genders, Two Spirit people, and all people of marginalized genders or of no gender. AWN is committed to recognizing and celebrating diversity and the many intersectional experiences in our community. AWN recognizes and affirms all people's gender identities and expressions, as well as choices about disclosure, transition, and keeping your identity private. AWN's goal is to dispel stereotypes and misinformation which cause unnecessary fears surrounding autism. AWN is committed to sharing information which works to build acceptance and understanding of disability.

Learn more by visiting <https://AWNnetwork.org>

## ABOUT DRAGONBEE PRESS

DragonBee Press is an imprint of Autistic Women & Nonbinary Network (AWN) focused on amplifying intersectionality in neurodiversity publications. Founded in 2013, DragonBee Press has published three anthologies to date. These are *What Every Autistic Girl Wishes Her Parents Knew* (which earned an Autism Society of America national award), which has been republished by Beacon Press as the acclaimed *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity*; the groundbreaking *All the Weight of Our Dreams: On Living Racialized Autism*; and this edited collection, *A Neurodiversity and Gentle Parenting Journey... in Color*.

## ABOUT THE AUTHOR

Morénike Giwa Onaiwu, PhD is a global advocate, educator, disabled person of color, non-binary woman, and parent of children with various disabilities in a neurodiverse, multicultural, twice-exceptional serodifferent family. A prolific writer and social scientist- activist whose work focuses on intersectional justice, meaningful community involvement, equity, and inclusion, Morénike, raised in the U.S. by immigrant parents and diagnosed with ADHD, autism, and alopecia in adulthood, is a recognized leader in human rights endeavors.

Morénike is a content expert and highly sought after public speaker, trainer, and consultant. As founder and principal operator of Advocacy Without Borders, a grassroots community initiative, Morénike has presented at the White House, the United Nations, and numerous peer-reviewed international conferences. Morénike works collaboratively with various entities, to address the needs of underrepresented and marginalized individuals. Morénike has also written for and/or been featured in the NY Times, Psychology Today, the Atlantic, the Today Show, NPR, BBC, Salon, HuffPo, Spectrum, POZ, and Autism in Adulthood, etc. Books include *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity* and *All the Weight of Our Dreams: On Living Racialized Autism*.

Morénike was the first Black woman to Chair the NIH-funded Global Community Advisory Board for HIV clinical research and the first Black Executive Board of Directors member of the Autistic Self-Advocacy Network and Autistic Women and Nonbinary Network. Morénike is the first public appointee of the Interagency Autism Coordinating Center (the US federal advisory committee on autism) who is a Black autistic self-advocate, parent, and professional.

Morénike has also previously served in a leadership capacity in roles funded by the National Institutes of Health and Health Resources and Services Administration.

Morénike earned a Bachelor of Arts in International Relations, a Master of Arts in Special Education with a concentration on autism and developmental disabilities, and an interdisciplinary Doctor of Philosophy. Morénike, who has years of writing, K-16 teaching, research, and nonprofit experience, resides in the US Gulf Coast with a spouse and six beautiful biological and internationally adopted “tween” to young-adult-aged children as well as “bonus” children and nibblings.





# ABOUT THE CONTRIBUTORS

## INTRODUCTION

### **Tash Nelson**

Every day Natasha (Tash) Nelson, more widely known as “Supernova Momma,” seeks to “Showcase real, honest, and accessible motherhood.” Diagnosed with autism in adulthood, Tash is a Certified Positive Discipline Educator (CPDE), veteran, military spouse, and stay at home mother to two autistic Black girls. She served over seven years in the United States Army as an active duty Staff Sergeant (including two tours to Afghanistan) demonstrating exemplary leadership.

Tash’s work focuses on traditional child-rearing, motherhood balance, positive parenting, and autism acceptance. When not developing culturally inclusive neurodiversity-affirming content creation, homeschooling her daughters, or educating others online, Tash offers customized one-on-one virtual consultations and hosts a six week “Parenting the Positive Discipline Way” as well as Positive Discipline workshops. These interactive sessions are focused on supporting Black and Neurodiverse parents to transform their homes and their lives by gaining and implementing skills to change their mindset, manage stress in healthier ways, identify triggers, and address trauma.

Follow Tash’s work <https://supernovamomma.com/>

# HISTORICAL CONTEXT

## Sharon daVanport

Sharon daVanport is the founder and executive director of the Autistic Women and Nonbinary Network (AWN). Sharon's work encompasses several aspects of the wider and cross-disability justice movement, including a focus on restorative and transformative justice, and strengthening leadership and partnerships through collective capacity and horizontal organizing practices. Sharon is the lead researcher for a multiyear national autism protocol, a steering committee member of the National Disability Leadership Alliance, a member of Consortium for Citizens with Disabilities, serves as board treasurer for Crushing Colonialism, and an advisory board member at Felicity House. Sharon is co-editor of *Sincerely, Your Autistic Child* published by Beacon Press and the author of various chapters and international peer-reviewed publications. They have spoken before the United Nations and the White House, and they were inducted into the Susan M. Daniels Disability Mentoring Hall of Fame.

Over the past decade, Sharon has advocated for autistic women, girls, and nonbinary people through forging critical research collaborations and providing consultations to White House and U.S. Government Accountability Office staff. In connection to their role as Felicity House advisory board member, Sharon was interviewed on the Today Show during the morning program's Sisterhood Series in 2020. Outside of Sharon's work in disability advocacy, they have nearly a decade of experience as a social worker, and they are a parent of four diversely neurodivergent adults.

Sharon's educational pursuits include women and gender studies, as well as entrepreneurship and business administration. Sharon is also a certified peer support and wellness specialist. In Sharon's spare time, they enjoy traveling, research, reading, music, and spending time with family and close friends.

## FOREWORD

### Ally Grace

Ally, the founder of the international *Respectfully Connected* writing project, is a parent in a neurodiverse family in Australia. They are an unschooling, no punishment family, with dreams to travel around the country. Ally strongly believes in challenging the pathology paradigm of autism. Ally's primary topics include rejecting conventional autism assumptions, anti-ableism family, challenging social norms around raising children, unschooling tips, autistic identity, and promoting intersectionality. Some archives of Ally's writing about her family's experiences can be found at:

<http://suburbanautistics.blogspot.com/>

## AFTERWORD

### Kayla Rodriguez

Kayla Rodriguez is a Puerto Rican autistic adult in Georgia by way of her native New York. She has spoken on several panels and she has been honored with a Golden Goal Goldie Young Community Advocate Award as well as the BDI Empowers Luminaries Award. Kayla, who identifies as a woman of color and a lesbian, completed Bobby Dodd Institute and Georgia LEND training as well as a policy internship at the Georgia Council on Developmental Disabilities. She served as Vice President and Chief Ambassador of Autistic Self-Advocacy Atlanta, and is an author of a chapter in the award-winning edited collection *Sincerely, Your Autistic Child*. In addition to serving as Co-Chair of AWN's Executive Advisory Committee on Equity, Justice, and Representation, Kayla is a founding member of the WEI North American Gender Disability Alliance and works as the social media coordinator for the Foundation for Divergent Minds, a national nonprofit that seeks to ensure equity, access, and fulfilled lives through inclusive, practical, and affirming neurodiversity-based programming and education.

## EDITING

### Catherine Joy Ricotoso

Catherine “Cathy” Joy Magalona-Ricotoso is a parent, content creator, and multilingual professional who enjoys helping others, spending time with family, music, literature, and learning new things. Cathy has a diverse entrepreneurial background that includes writing, management, operations, and various other skills. She was an instrumental part of this edited collection. Cathy resides in the Oceania region with her family and is an advocate for women and children.

## ILLUSTRATION & BOOK DESIGN

### Erin Casey

Erin Casey, AWN’s Art Director, is a neurodivergent artist, writer, and mother of two. Erin grew up in New England and attended Rhode Island School of Design before graduating with a BA in Art and Writing from Marlboro College in Vermont. Erin is passionate about disability rights and social justice, writing and cartooning, being courageous and finding ways to laugh amidst the battles we fight. You can see more of her work at [eisforerin.com](http://eisforerin.com).

## RESPECTFULLY CONNECTED CONTRIBUTORS

Ally Grace (*Respectfully Connected* founder)

Amy Bean

Briannon Lee

Cas Faulds

Cat Walker

Court Alice Thatcher

Jaime Franco

Leia Solo (*Respectfully Connected* anthology editor)

Meg Murry

Michelle Swan (*Respectfully Connected* anthology editor)

Morénike Giwa Onaiwu

Naomi Callaghan

Sophie’s Trains

Zita Dube-Lockhart

## ADDITIONAL (FREE) RESOURCES

**Autism and Neurodiversity Book Lists**, from *Not An Autism Mom* (Meghan Ashburn):  
<https://notanautismmom.com/bookclub/>

**Autism Moon, Written for Parents of Newly Diagnosed Kids**, from AWN Board Member Jules Edwards of *Autistic, Typing*:  
<https://autistictyping.com/2021/05/10/today-your-child-was-diagnosed-with-autism/>

**Autism Resources**, compiled by *Thinking Person's Guide to Autism*:  
<https://thinkingautismguide.com/resources>

**Autistic BIPOC/Pass the Mic**, a resource from AWN Board Member Jules Edwards of *Autistic, Typing*:  
<https://autistictyping.com/pass-the-mic-2/>

**Autistic Community & the Neurodiversity Movement**, Open Access book:  
<https://link.springer.com/book/10.1007/978-981-13-8437-0> (Dr. S.K. Kapp)

**Autistic POC Resource List**, from Autistic Black, Brown, Indigenous, Asian, & Mixed-Race People of Color Fund; *Fighting, Building, & Sustaining for Justice, Healing, & Liberation*:  
<https://autismandrace.com/resources/>

**AWN Welcome Packets**, for newly diagnosed adults & parents of newly diagnosed children:  
English: <https://awnnetwork.org/awn-welcome-packets-english/>  
Plain Language: <https://awnnetwork.org/awn-welcome-packets-plain-language/>  
Español: <https://awnnetwork.org/awn-paquetes-de-bienvenida-espanol/>

**Black Disability Politics**, Open Access book from Dr. Sami Schalk:  
<https://read.dukeupress.edu/books/book/3091/Black-Disability-Politics>

**A Climate of Justice**, Open Access book from Dr. Marvin Brown:  
<https://library.oapen.org/handle/20.500.12657/52426>

**Start Here: A Guide for Parents of Autistic Kids**, a collaborative booklet with AWN, Thinking Person's Guide to Autism, Autistic Self Advocacy Network, and Little Lobbyists:  
<https://autisticadvocacy.org/book/start-here/>

**SuperNova Momma**, best practices for traditional child-rearing, motherhood balance, positive parenting, and autism acceptance for Black and Neurodiverse families:  
<https://supernovamomma.com/>

## NOTE ON FAIR USAGE

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This material is being made available in this manner via a collaborative effort with AWN to ensure continual free access to the author’s content as part of AWN’s mission to provide community support, and resources and commitment to recognizing and celebrating diversity and the many intersectional experiences. Similar material might still appear in other formats as part of archival efforts to preserve the original project. The author is supportive of such efforts.

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