



# 11

## Out of Searching Comes New Vibrance

Edited by Ren Stone

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My unwavering love affair with words led me down a melodic road more than once in my lifetime. Spending summer vacations reading dictionaries thrilled me as much as swinging from the vines in the woods near my childhood home.

And so it was in 2007 that I found myself staring curiously at my computer screen. I was captivated by a catchy turn of phrase that was foreign to me (“Nothing About Us Without Us”)—and a word (“neurodiversity”) that I had never read in any of the dictionaries I’d spent my formative years teething on. I continued gazing, as my synesthesia (where the stimulation of one sense can automatically lead to the stimulation of a second sense) and ideasthesia (where the activation of a concept can automatically lead to the perception of color) translated the new word and turn of phrase into several vibrant colors and harmonious sounds (“Types of Synesthesia” [1]).

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Earlier that same day, I attended an autism walk in my community. I was attempting to connect with other families and other autistic people. I didn't know much about the host organization other than the information I found on their website.

Later that evening, I went online to share how I had participated in my community's Autism Speaks walk. Within seconds, I received a private message from an acquaintance in the chatroom. With horror, I began reading a chilling account of an autistic girl named Jodie and her mother, Alison Singer, who was then a staff executive at Autism Speaks. Singer was featured in a documentary *Autism Every Day* [2], wherein she brazenly recounted that she had "contemplated putting Jodie in the car and driving off the George Washington Bridge"—all the while Jodie could be seen on camera playing in the background, within earshot of her mother.

Sickened by what I had just read, I immediately threw myself down a search engine rabbit hole. I found the video of Singer's interview and watched for myself *Autism Every Day* [2]. With utter disbelief, I viewed the film clip while struggling to swallow as I wiped the tears from my eyes. I couldn't wrap my mind around this mother's apparent lack of empathy and dismissal of her own disabled child. Singer, with a slight smile on her face, looks directly into the camera as she further admits that the only reason she didn't follow through with killing Jodie was because she had another daughter. I wondered how Singer found herself in an executive position of an autism organization if she was openly discussing thoughts of murdering her autistic daughter.

Nothing made sense.

Nothing.

I felt my fingers sweep across the keyboard as they took on a life of their own. My mouse clicked on link after link after link, and then something caught my eye. I found myself staring at a blue screen with small black font. I had stumbled upon the Autistic Self Advocacy Network (ASAN)'s website ([autisticadvocacy.org](http://autisticadvocacy.org)). I began to relax as I absorbed the affirming, precise, and confident language that emphasized the importance of self-advocacy, activism, and a call to action. ASAN's message was the complete opposite of anything I had ever come across in the autism community to date. Instead of evoking feelings of doom and fear, I had felt a renewed sense of hope and empowerment.

Little did I know that my life was about to change. For the first time since entering online communities, I was reading messages about autism acceptance instead of the drivel of causation and cure. My mind was racing, and I ended up staying awake all night reading everything on ASAN's website as well as their linked articles.

I took several breaks throughout the night as I sat on my back porch piecing together recent conversations I had engaged in with my son which now became clear to me as the starting point on the path toward my understanding of autism acceptance as opposed to a cure. Everything transpiring that night seemed to be the culmination of my deepest desire to accept my son and myself as complete and whole people—perfectly imperfect, as all humans are in this world.

I had so much racing through my mind; how many more words expressed succinctly what I would experience in this flood of feelings? The euphoria was drowning me...and then I was sitting; that catchy turn of phrase and new locution was right there in front of me. Everything I had read that night on the ASAN's website ran circles through my mind while I read kept returning to this newly discovered quote, "Nothing About Us Without Us" and this new word: neurodiversity.

It all rang true; it felt right. Learning about neurodiversity and the importance of autistic people being part of all conversations and every decision involving their lives made absolute perfect sense. So much so that it was hard to grasp that I had never thought of their importance before that night.

Over the next few months, I often struggled to digest the onslaught of information I was taking in. Sometimes the activist bloggers I followed felt loud and I sensed when their energy would trigger my PTSD. All the same, I appreciated the importance of their work and continued to push forward. I knew that no matter how tough it was to hear the experiences of autistic people fighting for their rights, I needed to understand. I would at times get overwhelmed and go offline for up to a week to process what I was learning. Then I'd return to take in as much as I could before I needed another break.

I learned quickly that I had spent my life in ignorance as it pertains to the injustices experienced by people with disabilities. The more I researched,

the more I discovered the importance of social justice activism and its vital place in the world.

## Out of Searching Came Community

Neurodiversity soon became something that I intimately understood as the all-inclusive acceptance of every neurological difference without exception.

I further came to appreciate that neurodiversity didn't leave anyone out. Even the opponents of this concept reaped the benefits of the work by neurodiversity activists. It didn't matter whether they agreed with the concept or not, they personally benefited. Furthermore, their children did as well, as the specific premise of neurodiversity is full and equal inclusion.

It wasn't too long before I reached out to the ASAN, and over the next couple of years I developed friendships with ASAN's founders, Ari Ne'eman and Scott Robertson.

One of the most influential youth activists for disability rights during that time was Savannah Logsdon Breakstone. Savannah and I developed a close friendship which eventually led to the ideas that ultimately influenced the beginning of Autistic Women and Nonbinary Network (AWN) in January 2009.

One of the greatest life lessons that I learned during the early years of my involvement in the autistic community is that we are no different than any other community of people; though we are linked by a familiar neurology, we are still individuals in our own right, with differing opinions, contrasting ideas, and conflicting access needs. When you put all of that together with different personalities, it makes for a brilliantly vibrant and sometimes challenging community.

By 2008, I had developed friendships with several other autistic women through online groups. Savannah and I, as well as many of our friends found it difficult to fit into many of these groups, and we found ourselves searching for a community of women with powerful, balanced, and non-hierarchical leadership that shared our core beliefs of autism acceptance and disability rights, as well as an understanding for increased advocacy

and resources as it relates to autistic women and the gender disparities they face.

After several more emails of encouragement from Savannah, I decided to take the plunge. I contacted one of my good friends and web developer, Lori Berkowitz of BeeDragon Web Services ([beedragon.com](http://beedragon.com)) to discuss the possibility of forming an online community and forum for autistic women. Lori and I had gotten to know one another over the past year through our involvement in another group, and we had also worked together briefly on another website project.

Within a few short months, Lori had the website and forum ready to launch. Autistic Women & Nonbinary Network officially went online in January of 2009 ([awnnetwork.org](http://awnnetwork.org)). Those early days were full of nervous energy. Ari Ne’eman of ASAN was a huge help with offering tips and guidance—do’s and don’ts—when creating an online presence.

I reached out to several spectacular autistic women to form Autistic Women & Nonbinary Network’s founding board of directors: Sandy Yim, Tricia Kenney, Lindsey Nebeker, Savannah Logsdon Breakstone, Corina Becker, and Lori Berkowitz were AWN’s founding superstars in the early years. What we originally perceived as an online forum type of community quickly grew larger than we ever imagined.

In 2009, Tricia Kenney and I created and hosted AWN’s BlogTalk Radio Show ([blogtalkradio.com/autism-womens-network](http://blogtalkradio.com/autism-womens-network)), and by 2010, Autistic Women & Nonbinary Network had gained national recognition. In April, I was invited to represent AWN at a White House meeting on World Autism Day, and to participate in discussions with President Barack Obama’s Administration related to their ongoing efforts to better support autistic individuals. In July, I was invited back to Washington, DC for the White House’s 20th Anniversary Celebration of the Americans with Disabilities Act.

There seemed to be no letup with how quickly Autistic Women & Nonbinary Network was growing. Autism research has historically been focused on young school-aged boys, and it was becoming increasingly evident that AWN was fulfilling a great need in our community by keeping the focus on advocacy, resources, and research for autistic women and girls and non-binary people.

AWN steadily became a regular participant in national autistic-centered conversations, and we began seeking opportunities to widen our intersectional activism. I am of the firm belief that a decision-making board or supervisory board's composition should be representative in gender and race. Once a predominantly white cis board of directors, we as a board recognized our need to change and have been intentional about making sure representation is diverse because that is what makes a strong organization. AWN's current board representation is inclusive with intersectional diverse leadership. For the last three years (as of 2019), the board has consisted of mostly people of color and has always been majority LGBTQ+ members. To speak more directly to that intersectional diversity, in 2018, we changed our name from Autism Women's Network to Autistic Women & Nonbinary Network.

From its inception, Autistic Women & Nonbinary Network has strived to provide our board members with personal accommodation requests. This ultimately led to all board meetings being conducted solely online, and since 2012 our meetings have been exclusively held via text-based/real-time communications.

AWN sees itself as part of the wider disability rights movement. Undeterred in our quest to fight for autistic rights, we appreciate our place as being part of the greater civil rights movement for disabled people. In this spirit, we are currently working on leadership development for our committee for our initiative Divergent: when disability and feminism collide ([facebook.com/DivergentFeminism](https://facebook.com/DivergentFeminism)).

Divergent works to change how disabled women are commonly perceived within society while challenging the myths of our inferiority, both as women and as disabled people. We explore the interactions between sexism and ableism within both disabled and nondisabled communities. We seek to offer perspectives on gender and disability by emphasizing non-traditional femininity and non-traditional feminism. [3]

Reflecting on the years gone by, I can't help but feel immense gratitude for all the people and experiences along the way. Time has a magical way of bringing about clarity of purpose. The impact of this clarified praxis

opened conversations around the greater disability community, helping us as an organization to expand our mission. Most recently, we learned in March 2019 that Lori's tireless work to build our online platform had led to recognition by the United States Library of Congress as a culturally significant contribution to society and our content is now archived nationally. The Library of Congress states that AWN's website has been selected "for inclusion in the Library's historic collection of Internet materials related to the Women's and Gender Studies Web Archive" as they consider our website to be an "important part of this collection and the historical record."

Even with all the progress made over the years with respect to disability rights (and specific to autism) we still live in a lopsided world which measures a person's worth based upon false premises. Ableist rhetoric taints the conversations which lead to discrimination. And still, here we are, Advocates and Activists, with even more vigor and determination in the face of all that has dared to silence us. Despite the uneven roads we often travel, we know without a doubt that we will not be erased. It's been an amazing journey so far, and I'm looking forward to the years ahead and experiences yet to come (Fig. 11.1).



Fig. 11.1 Autistic Women and Non-Binary Network tagline

Neurodiversity is for everyone

Nothing About Us Without Us!

## References

1. Synesthesia.com. (n.d.). *Types of synesthesia*. Retrieved from <https://synesthesia.com/blog/types-of-synesthesia>.
2. Watkins, J., Solomon, E., & Thierry, L. (2006). *Autism every day* (Documentary). USA: Milestone Video, The October Group.
3. Liebowitz, C. (2013, December 17). *Divergent: When disability and feminism collide* (Web log post). Retrieved from <https://awnnetwork.org/divergent-when-disability-and-feminism-collide>.

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