The Rise of Autistic Voices:

The Time Has Come for Us to Be Heard

By **Siena Castellon**

The voices of the autistic community are rarely heard. At a time when social justice and inequality are at the forefront of humanities' collective consciousness, the rights of autistic people are still being ignored. While most minority and under-represented groups get a seat at the table, we are seldom allowed in the room. To the extent we are heard, others paternalistically speak for us, convinced they know best. Speaking on our behalf denies us agency. It also leads to the rise of ableist agendas that undermine the autistic community, such as focusing on autism cures that do nothing to increase the quality of our lives. However, the autism rights landscape is not all gloom and doom. There are glimmers of hope and signs the winds of change are blowing. As more of us raise our voices and come out of the shadows, our self-advocacy is finally beginning to be heard.

While neurodiversity awareness initiatives are becoming more widespread and mainstream, the movement still has a long way to go. There is still a corrosive stigma and deeply rooted prejudices towards people who are autistic. Just like the Black Lives Matter movement has highlighted the prevalence and pervasiveness of institutional and societal racism, a similar collective movement is needed for autism, learning disabilities, and disability rights more generally. Without a societal awakening to our plight and suffering, our rights will continue to be side-lined and remain on the periphery of society's moral imperative.

The first step towards accepting autistic rights is for society to adopt the social model of disability. This world view acknowledges what makes someone "disabled" is not their medical condition but the prejudicial attitudes and barriers imposed

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on us by our society. The social model separates impairment from disability and, by doing so, opens a world of possibilities. Whereas an impairment is a characteristic or long-term trait resulting from an injury, disease, or condition, disability is the attitudinal or physical barriers that make life harder for disabled people. It is vital to separate the two, so our impairments are not used as a justification to deny us autonomy. The social model aims to remove the attitudinal and physical barriers that prevent disabled people from being independent and having control over how they live, work, and access services.

Unfortunately, the vast majority of society still views disability from a medical perspective. The medical model views impairment as a reason to exclude, ignore, and infantilize disabled people. Since the medical model dominates, most societal, political, and organizational decision-making is influenced by the belief that disabled people lack the ability to advocate or speak for themselves. It is this dominant world view that's holding back autism inclusion and equality.

I am bombarded with the hindering medical view of disability daily. Since many people still believe females can't be autistic, my autism diagnosis is frequently questioned. I'm told I don't "look" autistic or that I don't act like someone who is autistic. My personal favorite is when I am told I must have a very mild form of autism because I appear normal. These prejudicial attitudes based on male stereotypes and ignorance are a reality I have to live with on a daily basis. Just because my crippling social anxiety caused by years of autism-related bullying or my sensory overloads that impair my quality of life aren't on public display for everyone to see does not make my disability any less debilitating or valid.

The medical model reigns even in places where you would expect to have sanctuary, such as an autism and learning disabilities charity's awards dinner. Along with four other candidates, I was shortlisted for an award that highlights the accomplishments of disabled youth. As I read the brochure featuring a short biography of each of the candidates, I couldn't help but notice one of the candidates was not disabled. But what especially stood out was that her biography highlighted her experience of having a disabled brother and how this motivated her to become "the voice" for disabled youth. Call me cynical, but the use of disability savior language and the over glorification of her altruism assured me she had won. You see, society likes to extol disability advocacy by non-disabled individuals over recognizing the advocacy and voices of the actual disabled community. People who support and provide services for us are immediately seen as altruistic and selfless, something to be rewarded and celebrated. Whereas disabled individuals advocating for themselves and their larger community are often overlooked, dismissed, and unseen, even though this advocacy usually takes a huge toll on our physical and mental health.

The fact an award intended to recognize the accomplishments of disabled youth was given to someone who is not disabled but speaks on behalf of the disabled community sent a strong message to the shortlisted candidates who were disabled. It reminded us our voices, contributions, and lived experiences carry less weight and value. It is easy to talk about how hard it must be to be disabled from an imagined perspective. It is much harder to carry out your advocacy while being burdened with the heavy weight of your disability while having to fight through physical discomfort and pain. It is much harder to share your raw lived experiences of abuse, discrimination, and rejection. Instead, the awards ceremony celebrated white knights who are seen as selfless rescuers while relegating us to second class citizens at an event that was supposed to empower and recognize the achievements of disabled individuals.

I recognize the autism community cannot achieve equality on its own. Each and every member of our community has a valuable role to play in bringing about autism acceptance and equality. However, while it is important to have allies and to join forces with non-disabled people, these alliances are not without peril. Historically, organizations created to support the disabled community did not include or listen to disabled people. We were marginalized, silenced, and denied a role in forging our own paths. A new relationship must be forged that rejects the medical and paternal model that infantilizes us. Instead, we must be treated as equals. Our voices must carry weight, and we must be given positions of leadership and power so we can take charge of our destinies.

Until we are heard and until we are seen, very little will change. When I was growing up, there were no prominent autistic role models other than Dr. Temple Grandin. On the contrary, I grew up with the societal message that autism is a tragedy and a burden, something to hide and be ashamed of. I was told it is a disease that needs to be cured. I was told my life was not worth living and I would never accomplish anything. This narrative must change. Some of the greatest contributions and scientific discoveries that have revolutionized the way we live our lives were made by autistic people. If we are given appropriate support and our strengths and talents are nurtured, we have unlimited potential.

I am hopeful change is on the horizon. The United Nations recently selected me out of 7,000 international applicants to be a Young Leader for the Sustainable Development Goals (SDGs). I am collaborating with the United Nations to address the inequalities faced by the neurominority community and to work on projects that amplify our voices and advance our rights. Having a global platform on which to share my lived experience and through which to advocate for autistic rights has given me the ability to continue to change the way society views autistic people and the disabled community. I am using my role to shine a spotlight on the many young autistic advocates around the world who are tirelessly paving the way to equality, so future generations of autistic youth are not held back by their disability.

In 2020, the Centers for Disease Control and Prevention (CDC) reported that one in 54 children in the United States is autistic—a conservative estimate that does not reflect the significant under-diagnosis of autism in girls and women. The time has finally come for us to smash the stigmas, stereotypes, and prejudices that have enchained us. The time has come for our human rights to be recognized and accepted and for us to be treated as equals. Future autistic generations are counting on us to lead the way to a better tomorrow.

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