

Shifting Paradigms: Rethinking Autism Beyond the Medical Model

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INTRODUCTION

In our cosmic narrative, for centuries we believed the Earth held the universe's center, a belief that shifted with evidence and transformed our understanding of our cosmic place. Correspondingly, paradigms surrounding autism have been shaped by medical assumptions that label it a condition, a disorder, or even a tragedy. Just as our understanding of celestial perceptions evolved, that Earth was not at the center of the universe, it is time for a seismic shift in how we perceive and address autism.

ANALYSIS

Venturing into autism research, we see the prevailing medical paradigm that defines Autism Spectrum Disorder (ASD) as a developmental disability caused by neurological differences.¹ Social communication, repetitive behaviors, language, movement skills, cognitive abilities, and emotional reactions—all cast as deficits.¹ This narrative, embraced by researchers, medical professionals, and society, serves as the foundation of our current understanding.

Yet, delving deeper unveils a counter-narrative—one not etched by researchers but articulated by those living with autism. This narrative introduces us to the neurodiversity paradigm, a revolutionary lens that sees autism as a part of the rich tapestry of human neurological development, fostering a stable cognitive landscape.² It posits that there is no singular "healthy" brain; and no definitive way of neurocognitive functioning.² Shockingly, although this perspective is more inclusive, portraying autistic people as crucial contributors to humanity, it remains the more controversial model in society.

Contrasting with the classical medical view that treats autism as a disease to be eradicated, the neurodiversity paradigm challenges the notion of normalizing society and underscores the importance of recognizing autism as an advancement. Without it, we would lose invaluable perspectives, strengths in attention to detail, visual perception, creative and artistic talents, mathematical and technical abilities, and expertise in 'niche' areas.³ Asserting that every form of neurological development holds equal validity, deserving of respect and human rights, the neurodiversity paradigm counters the deficit mindset perpetuated by the traditional medical view.

The repercussions of our medical-centric assumptions extend beyond perception; they infiltrate the very fabric of societal structures. Autism is labeled a disability. But is it autism that disables individuals, or is it the societal environment that excludes and alienates cognitive diversity? The traditional medical model points fingers at individuals, placing the onus on the differently abled person, not the disabling environments.

For example, our societal perspective on disability is largely framed by the medical model, which views disability as an individual problem. According to this model, the disability is located within the person experiencing it—within individuals like me.⁴ For instance, I often find myself becoming excessively overstimulated in places like department stores. The bustling environment—loud, brightly lit, unpredictable, and crowded—is a sensory challenge. Following the medical model attributes my struggle in department stores to a perceived problem with the way my brain processes sensory inputs, attributing it to my autism.

The consequences of the medical model are far-reaching and profound, particularly in shaping our understanding of autism. This perspective places undue blame on those with autism and directs the focus of research toward "curing" autism rather than addressing societal structures that contribute to exclusion and alienation.

One glaring example of this misguided approach is the predominant focus of autism research on finding a cure, as seen in 2020 with a major research theme centered around gene therapies aimed at altering the genetic factors associated with autism-related conditions.⁵ Even influential organizations like Autism Speaks, until 2016, subscribed to the notion of seeking a cure.⁶ Their evolution, acknowledging the need to listen to the lived experiences of autistic individuals, led to a shift in their mission—from searching for a cure to promoting advocacy, support, understanding, and acceptance.⁶

This shift highlights the importance of moving away from the medical model. Instead, we should adopt more inclusive models like the neurodiversity or social model of disability, which are rooted in the idea that neurological differences, including autism, are natural variations of the human brain. Listening to the voices of those with autism and embracing the social model of disability allows us to recognize that disabling factors often reside in societal structures, not within the individuals themselves. This paradigm shift is crucial for fostering an inclusive society that values and accommodates cognitive diversity.

For instance, when we enter the social model of disability—an alternative lens that shifts the blame from the individual to the environment, it views disability not as a characteristic but as an action done to individuals by society⁴. In this model, going to a department store is not a struggle for me because there is something inherently wrong with me, but it is a struggle because the environment around me does not cater to my diverse needs. Imagine if our world, including department stores, were designed with neurodiversity in mind—quiet, dimly lit, predictable, and spacious. Neurodivergent individuals would still be cognitively different, but their surroundings would not disable them.

Adopting the social model of disability would catalyze shifts in research and attitudes toward autism, reflecting the transformative changes observed in the department store examples. Rather than focusing on changing autistic individuals to fit societal norms, the emphasis would shift to enhancing the lives of neurodivergent people by advocating for structural changes in society. This shift aims to foster inclusivity while preserving individuals' authenticity and embracing their unique differences.

Autistic individuals are not seeking a cure for autism because our neurodivergent way of thinking is integral to our identity. Yet, the considerable funding directed toward researching autism's causes for prevention or a "cure" underscores a lack of consideration for our voices in deciding how research funds are utilized. The emphasis on normalization, a cornerstone of the medical model's view of autism, prioritizes societal desires over the well-being of autistic individuals already part of our society. It is imperative to recognize this flaw in research that aims to cure autism, as it risks genetic research for eugenic purposes, necessitating regulation by the autistic community.⁷ Redirecting resources from the pursuit of an unwanted cure to research supporting and empowering autistic people to lead fulfilling lives is essential.

This redirection involves investing in communication research, offering tools such as communication boards, picture exchange communication systems, speech-generating devices, or sign language for nonverbal or speech-challenged autistic individuals, giving them a voice in our society.⁸ Community living research, centered on community inclusion programs, not only provides services but also educates and reinforces accommodations for daily activities such as in schools, workplaces, or even in department stores as stated in the example.⁹ Attention to support services for autistic individuals and their families, including residential and day support programs, respite, recreation, and transportation, is crucial.¹⁰ A commitment to promoting lifelong support for autistic individuals necessitates advocating for caregiver support, home and community-based services, financial planning resources, and more.¹⁰ Additionally, research aiming to identify qualitative results of adaptation and modification strategies to support inclusive education for autistic students is paramount at school and classroom levels.¹¹ Research to improve healthcare quality and the healthcare system for autistic individuals is also essential, as they face shorter lifespans and worse health than non-autistics.¹² All these research initiatives align with the principles of the social model of disability.

However, as a society that does not follow the social model; the bulk of our understanding of autism is rooted in research driven by medical assumptions and paradigms. In 2022, the United States allocated \$306 million to autism research¹³. However, a considerable portion of this research approaches autism as a problem to be solved.

An examination of a comprehensive study focused on the allocation of NIH autism research funding from 2008 to 2018 reveals a striking trend. In this distribution, 49.7% of the total funds were allocated to treatment development and evaluation, which represented 53.6% of all projects.¹⁴ This statistic underscores a predominant emphasis on genetic and biological research. However, the goal of such research is not only to understand the underlying reasons for autism so we can cure it. But this research also explores ways of prevention or management of autism through pharmacological treatment or behavioral therapies like intervention or Applied Behavioral Analysis, both of which are intervention models focused on changing the external behaviors of autistic individuals, with the goal of making an autistic person look and act non-autistic.^{14,15}

Contrastingly, only a minimal fraction of NIH funding—9.1%, approximately \$225 million out of nearly \$2.5 billion dedicated to ASD research—was channeled towards services-related research.¹⁴ This includes critical areas such as improving accessibility and quality of services in the community, characterizing understudied groups, policy development, dissemination, and implementation.¹⁴ This glaring discrepancy highlights a diminished emphasis on services research in funding decisions, revealing an imbalanced focus on biological and risk factor research, aiming to eliminate differences rather than seeking ways to integrate accommodations that allow autistic individuals to authentically express themselves within societal structures.

The consequence of this skewed prioritization is evident in distressing statistics. Autism affects about 1 in 100 children worldwide, and yet 85% of college-educated adults on the autism spectrum face unemployment—twice the rate of their non-autistic peers.^{16,17} 7 out of 10 autistic individuals wrestle with mental health conditions, including anxiety, depression, ADHD, or OCD.¹⁸ Alarming, the suicide rate among autistic individuals is three times higher than the general population.¹⁹ Similarly, individuals with autism have an average life expectancy of 54 years, a staggering 16 years less than the average age of mortality for the general population.²⁰ And we deserve better.

These disheartening realities underscore the urgent need for a paradigm shift in our approach to autism within society. It is crucial to recognize that masking autistic traits is not the optimal outcome for individuals with autism. In fact, hiding autistic traits has been linked to worse mental health outcomes and increased suicidality in autistic adults.¹⁵ Services and support systems are required to enable autistic individuals to lead long, happy, and fulfilling lives while respecting their right to be authentically autistic. Embracing neurodiversity is not only a matter of ethical consideration and benefit for autistic individuals but also cultivates progress, acceptance, and overall societal growth for all.

CONCLUSION

The call for change is clear—we need research initiatives led by autistic individuals, addressing the questions that matter most to the community. We need more autistic individuals in the medical profession to advocate for improvements in the medical perspective. Having only 1% of autistic individuals in the medical profession is no longer enough.²¹ Just as the sun is not the center of our universe, individuals with autism are not a tragedy. They deserve a future built on understanding, inclusion, and support.

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