Transcending Neurotribalism: Rescuing Autism Advocacy from Identity Politics

by Sarah Dillingham (August 2019)

Pailleron Children, John Singer Sargent, 1880

Autism Spectrum Disorder, or ASD, is a complex array of developmental disabilities varying in severity, characterized by impairments to communication and interaction, executive functioning, motor skills, and sensory processing. First identified as a distinct psychiatric disorder in 1943 by Leo Kanner, autism has skyrocketed in recent decades from the sole

11 cases initially identified to a rate of about 2 to 4 cases per 10,000 throughout the mid-20th century, to the CDC's most recent estimate of 1 in 59 counted among 8-year-olds and the NCHS's reported rate of 1 in 36 among children aged 3 to 17 years—or 1.7-2.8% of the U.S. population, with prevalence four times higher among boys (1 in 28 boys aged 3 to 17). There is no longer a single extended family, school district, or community in America so remote as to be untouched by this pervasive and ubiquitous condition: everyone knows someone diagnosed with ASD in this new era which authors Mark Blaxill and Dan Olmsted have christened "The Age of Autism."

Indeed, moving into the 21st century, autism prevalence—or at least the prevalence of ASD diagnoses—increased by 290%, as the incidence of all developmental disabilities increased by 17% between 1997 and 2008. By 2008, one in six American children was diagnosed with a developmental disability. While autism prevalence remained fairly constant throughout the early to mid-20th century, autism rates sharply curved upward in the 1990s and increased 21-fold over the next decade—reaching 7 cases per 1,000 by the year 2000, when the CDC first began tracking rates of ASD. Since that time, reported prevalence has increased 11% per year on average in the U.S.

As rates of autism diagnosis began exploding in the 1990s, so did competing theories of causation and interpretations of the disorder itself. Autism was first defined and treated within the context of Freudian psychoanalytic theory which prevailed in the early 20th century; Kanner and his contemporaries defined autism as a strictly psychological condition resulting from aloof and deficient parenting, or "refrigerator mother syndrome." Most children diagnosed with autism during that period were institutionalized and their parents blamed for their condition, resulting in misery and tragic outcomes for many patients and their families. In 1964, Bernard Rimland, a developmental psychologist and parent of an autistic child, published an alternative biological theory of causation which sparked a pivot in the perception and treatment of autism. Applied Behavioral Analysis (ABA) emerged in the 1960's as the preferred treatment protocol for autism, and in 1980 autism was added to the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM). Subsequent editions further honed the diagnostic criteria, and the DSM IV, released in 1994, expanded the criteria to include Asperger's Syndrome within the broad umbrella of what are now defined as autism spectrum disorders.

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The steep rise in reported prevalence beginning in the 1990s seemed to correlate neatly with the expansion and refinement of diagnostic criteria, which begged the question: do the ever-improving diagnostic criteria and treatment protocols *cause* increasingly accurate measurement of a constant background rate of autism in the population? Or are they the natural *result* of a burgeoning environmental epidemic, developed in *response* to the emerging reality of new cases? Are autism rates really rising, or have better diagnostic tools and increasing awareness driven the double-digit year-over-year increase in prevalence, for four decades following the inclusion of initial diagnostic criteria in the DSM? The answer to this question informs a more fundamental one: if "refrigerator parenting" doesn't cause the symptoms of ASD, what does? Is it environmental or innate and inherited, or some combination of both?

Two interconnected, parallel communities began to take shape amid these developments, aided by nascent internet technology which facilitated the development of grassroots organizations. The rapidly growing community of autistic children’s parents began to form networks and organizations, from which they shared and publicized their common experiences of regressive autism among their children: at some point usually before their third birthday, often following routine vaccinations, a formerly healthy, socially typical child would suddenly regress and lose language, social and motor skills while their physical health deteriorated on multiple fronts. Parents publicly expressed alarm at their growing ranks, denial of their experiences among healthcare providers, and dwindling access to finite resources and services earmarked for children with special needs. Through tireless and dogged advocacy, Dr. Rimland and a community of pioneering autism parents worked to dispel the stigma imposed on autistic patients and their families in the heyday of Freudian psychology. Their efforts, along with those of the larger community of special-needs parents and activists, led to passage in 1975 of the law which ultimately became the Individuals with Disabilities Act (IDEA), establishing the right to a public education for all children with disabilities. However, as demand for limited slots in these special needs public programs grew suddenly and exponentially in the years leading up to the 21st century, parents had to fight and often sue their school districts in order to access these services.

Meanwhile, as the community of adults diagnosed with developmental disabilities grew along with increased awareness about their conditions, the most intellectually functional and verbally communicative among them—those on the “mild” end of the autism spectrum, many with Asperger's syndrome—also began to form international networks and organizations promoting self-advocacy in the autism community. Autism Network International was formed and organized the first conference for autistic people, or "Autreat," in 1996. It was within this climate that an alternate, novel explanation of expanding autism diagnoses emerged: the *neurodiversity* movement.

The concept of neurodiversity, first introduced by autistic sociologist Judy Singer in the late 1990s, seeks to reframe ASD and other neurological conditions such as Attention Deficit Disorder and Dyslexia not as impairments or deficits, but rather traits which fall within the range of normal variation on a vast, diverse continuum of human cognitive experiences and personality types. A key tenet of the neurodiversity movement is the idea that autism and other neurological conditions are inherently genetic and have always been part of the human landscape; thus there has been no autism epidemic in recent decades, but rather contemporary advances in psychiatry and neurobiology which facilitated greater understanding and acceptance, and more accurate diagnoses.

Public health institutions and the psychiatric community, for the most part, have enthusiastically embraced the "better diagnosis" theory even as numbers continued to soar for decades and many parents and caregivers expressed growing alarm about scarcity of needed resources and the lack of a definitive scientific explanation for what they perceive as an autism epidemic. A simmering polarity developed between the biodiversity movement, whose adherents embraced their diagnosed conditions as permanent, innate, and fundamental to their identities, versus the growing network of parents and advocates who understood autism to be an environmentally triggered industrial-era epidemic, and pursued a variety of emerging biomedical interventions to alleviate or reverse the most debilitating symptoms of ASD.

Against this backdrop, a culture of identity politics began to permeate public and private institutions in the U.S. and elsewhere. As Mark Lilla observed in a 2016 op-ed which he later expanded into a popular book: “At a very young age our children are being encouraged to talk about their individual identities, even before they have them…they are encouraged to keep this focus on themselves…and heighten the significance of ‘diversity issues.’” As it gained momentum, the neurodiversity movement incorporated the language and strategies of other identity groups which historically sought civil rights protections, with all the associated positive and negative implications.

The neurodiversity movement initially provided a sense of community and shared identity for kids and adults who may have struggled to forge human connections and feel at home in the world with others. At its best, the movement empowers autistic people to discover and celebrate their strengths, while counterbalancing the fallacies and enduring harms of Freudian interpretations of autism. At its worst, framing developmental disabilities as a protected innate identity provides this platform for highly functional autistic people at the expense of more profoundly affected autistics who have limited or no means of self-advocacy. As with other frontiers of identity politics, the celebration and balkanization of the subgroup potentially undermines its connection with the larger community, and thus ultimately dissipates its power. While it may be uplifting to see out one’s “tribe,” our increasingly isolating and polarized cultural and political environment has given rise to a public discussion about the pitfalls of identitarian “tribalism.”

And in contrast to other identity groups seeking a sense of community and guaranteed civil rights, the neurodiversity movement provides an alluring and dangerous opportunity for public health institutions and society at large to defer reckoning with the disquieting, ominous implications of a potential catastrophe we may prefer not to face. It’s certainly tempting to embrace the idea that human progress is linear and ever-expanding, that technology has unbound the neurodiverse and their neurotypical brethren from the shackles of ignorance and unleashed a bottomless pool of human potential, and that there’s absolutely nothing to worry about in ballooning autism statistics. And there has been a steady stream of books and articles reinforcing this concept in recent years, culminating in the 2015 release of Steve Silberman’s exhaustively optimistic and widely acclaimed *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. Silberman’s feel-good chronicle showcases all of the hallmarks of identity narratives in general and neurodiversity theory in particular: interwoven with the compelling, detailed accounts of the pioneers in autism research and treatment are glaring omissions, retrospective lay diagnoses, and wildly speculative historical interpretations which bolster the preferred, least discomfiting explanation of our current landscape. Silberman presents a saccharide case study of once biomedically-inclined parents who came to embrace their son’s autism diagnosis after dabbling in various alternative medicine “cures.” He then reaches energetically into the past in search of pre-Kanner members of the long-forgotten Neurotribes, and showcases two in particular: 18th-century physicist and philosopher Henry Cavendish and early 20th-century inventor Hugo Gernsbach. Their eccentricities are detailed at length, but conspicuously lacking are accounts of epilepsy or seizures, self-injury, gastrointestinal disease, horribly distressed outbursts, or other inflammatory conditions.

Silberman goes on to speculate that the work of Austrian doctor Hans Asperger, after whom Asperger's syndrome is named, had his work and deserved notoriety stolen by Kanner—in opposition to the hypothesis that Kanner and Asperger observed novel, related conditions of disparate severity at approximately the same time because both conditions *emerged* within the same historical time frame, triggered by the same environmental factors. Silberman continually conflates traits and historical examples of Asperger's with the more severe and debilitating autism disorder first defined by Kanner. Though rigorous in his presentation of 20th century autism history, he is clumsy in his presentation of Rimland and the biomedical community. He predictably assigns credit to actress and author Jenny McCarthy and "discredited gastroenterologist Andrew Wakefield," apparently without a close examination Wakefield's now-infinitely controversial 1998 paper (a case series which drew no definitive conclusions about a vaccine-autism connection) or the Justice Mitting's 2012 high court decision which fully exonerated Wakefield's lead co-author on the paper, Dr. John Walker-Smith—widely regarded as the "father of pediatric gastroenterology"—of all charges associated with study, and reinstated his medical license. (Wakefield faced the same charges, but his insurance carrier refused to fund his defense, while Walker-Smith's insurance covered his appeal expenses.) And while Silberman gives reasonably fair historical treatment to Rimland, he glosses over many of the most influential and rigorous proponents of the environmental causation theories of autism, or doctors who developed the most effective biomedical interventions to address them.

Though a thorough discussion of autism causation theories and biomedical interventions is beyond the scope of this piece, it’s important to note that McCarthy, whose personal account is certainly compelling and influential, is not and has never claimed to be the primary architect of contemporary causation theories of autism, including, but not limited to, adverse reactions from vaccines. Suffice to say here that encephalitis, seizures, and brain injury resulting from adverse vaccine reactions are documented by both vaccine manufacturers in their package inserts, and the National Vaccine Injury Compensation Program table of vaccine injuries (to date, over $4 billion has been paid out to petitioners who won their cases in court). And it is an uncontroversial fact that mercury in all its forms is a potential neurotoxin, as is aluminum