

Catherine Tan, *Challenging Autism* proposal

## **Challenging Autism: The Making of Controversial Bodies and Identities**

### **BRIEF DESCRIPTION**

How are controversial beliefs empowered? How do they persist? *Challenging Autism: The Making of Controversial Bodies and Identities* investigates two movements that resist experts, taking issue with conventional understandings of Autism Spectrum Disorder, a developmental disability. I argue that social movements are important spaces for the cultivation and preservation of unorthodox ideas because they organize the resources necessary to transform contested ideas into practice. This study draws from over three years of ethnographic fieldwork and interviews with members of the alternative biomedical and autistic rights movements. These two movements reimagine autism in different and conflicting ways. The alternative biomedical movement is dominated by parents and practitioners who believe in a disproven idea: that vaccines “trigger” autism. Believing in “vaccine injury,” they argue that autism can be “reversed” with alternative and experimental treatments. The autistic rights movement, in contrast, is composed primarily of autistic adults who contend that autism is a natural human variation, as opposed to a *disorder*; thus, they demand social and cultural acceptance. Focusing on structural barriers, autistic rights activists advocate for policy changes that would expand the rights and protection of autistic people. Both movements encounter opposition from researchers, professionals, and other parents outside their communities who support a mainstream model. In this study, I examine their separate struggles to gain legitimacy and their efforts to transform their beliefs into lived realities.

### **DESCRIPTION**

At a time when there is vocal public distrust in the epistemic authority of experts—exemplified by vaccine hesitancy, COVID-19 conspiracy theories, climate change denial, and other forms of “post-truth politics”—it is critical to understand the persistence of controversial ideas. *Challenging Autism: The Making of Controversial Bodies and Identities* is an ethnography that explores the tenacity of what I term *contentious knowledge*—knowledge that is subversive, that challenges expert authority and orthodoxy. I argue that contentious knowledge is animated into lived realities within social movements. I take the case of Autism Spectrum Disorder as a site in which to examine collective resistances against dominant experts and expertise. Autism is a lifelong developmental disability that is presently estimated to impact 1 in 54 children in the United States (Maenner et al. 2020). Despite global research efforts, there remains much uncertainty about autism’s causation, prevention, and treatment (Singh 2016). Although there are many unknowns, two groups confidently—and *defiantly*—claim to have the answers.

*Challenging Autism* investigates two movements—alternative biomedicine and autistic rights—and shows how they separately reject the way mainstream researchers, medical professionals, and therapists understand autism. Both groups criticize the prioritization of genetic research and behavioral therapy. However, they have radically different designs for how autism should be reimaged. Alternative biomedical members are mainly parents and practitioners who insist that autism is caused by toxic exposures—notably, vaccines—and that autistic children can be “recovered” with specialized diets, supplements, and experimental treatments (e.g., stem cell therapy, parasitic worms, hormone therapy). Meanwhile, autistic rights members are mostly autistic adults who argue that there is nothing inherently wrong with being autistic; they shift the focus from “fixing” individuals to addressing social and institutional failures. Comparing these two movements brings into stark relief the importance of embodiment for reimagining autistic bodies and identities. The actors’ experiences with and relationships to autism (as parents or practitioners or as autistic people) define their interests, which direct knowledge production and shape cultures of resistance. Moreover, because the alternative biomedical movement experiences more public vilification than the autistic rights movement does, this comparison highlights how the intensity of outside criticism informs strategies.

Movements that question the jurisdictional boundaries of experts and their authority are not easily neutralized with reason or negotiation, as illustrated by today's anti-vaccination groups and political conspiracy theorists. Thus, it is imperative to understand not only the motivation of such movements, but also how they operate and fortify themselves against attacks. *Challenging Autism* merges the theoretical orientations of the sociology of scientific knowledge, medical sociology, and social movements scholarship to examine the internal workings of movements that resist dominant knowledge and ways of knowing. Sociological research on contentious knowledge (e.g., controversies, pseudoscience, forbidden knowledge) tends to analyze activities that are concentrated within intellectual and academic institutions (Collins and Pinch 1979, Frickel and Gross 2005, Gieryn 1999, Kempner, Merz and Bosk 2011, Sweet and Giffort 2020); less is known about how lay actors engage with controversies (Reich 2016). Moreover, research that examines lay challenges typically investigates collaborations between activists and experts (Epstein 1996, Frickel et al. 2010, Zavestoski et al. 2004), as opposed to antagonistic relationships that preclude opportunities for lay-expert partnerships. Yet today, worries about public faith in expert authority concern movements that cannot be easily coopted or mitigated with collaboration. Addressing such movements, *Challenging Autism* examines the structures and mechanisms that drive more subversive resistances. The implications of this study extend beyond issues of science and medicine to advance the understanding of challenges to experts more broadly.

Following parents into the offices of alternative doctors and autistic adults to woodland retreats, *Challenging Autism* offers a rare and close look at what it means to resist experts. Between 2013 and 2016, this study followed movement members across nine states, where I conducted observations in both formal (e.g., conferences, retreats, special events) and informal settings (e.g., dinners, parties). In addition to these ethnographic observations, I interviewed 71 unique participants, including autistic adults, non-autistic advocates, parents of autistic children, and practitioners. This research intimately details the processes by which controversial bodies and identities are formed, a collective endeavor across three distinct processes: (1) movement entry, (2) resource innovation, and (3) boundary work.

First, a sense of injustice motivates entry into the alternative biomedical and autistic rights movements. Being autistic or parenting an autistic child could mean a lifetime of obstacles in a society designed for those who are neurologically typical. For instance, Grace and her husband were in shock when the pediatrician diagnosed their two-year-old daughter with autism. The prognosis at the time was bleak: "I wasn't really being given any information except she'll never be independent..." Their daughter's future seemed uncertain and fragile. Meanwhile, Hil, an autistic rights activist and social worker, explained that acquiring an autism diagnosis as an adult was the key to understanding and accepting their own eccentricities: "It seemed like this whole huge collection of different things that were fucked about me. And all of a sudden, they were one thing. And all of a sudden, I recognized that there were other people who had the same constellation of differences." The diagnosis gave Hil clarity and direction. Importantly, neither Grace nor Hil was satisfied with the way professionals talked about and approached autism. Grace and the other parents in my study had limited faith in the standard therapies, which to them did not seem effective or ambitious enough; instead, they turned to the alternative biomedical movement because it offered radical "recovery." In contrast, Hil and other autistic people joined the autistic rights movement to oppose their medicalization and form community. By entering these two movements, members reject dominant knowledge (and its limitations) in favor of hopeful promises.

Second, social movements serve as spaces for the production and practice of contentious knowledge. The two movements provide the epistemic, material, and social resources to reconstruct autism as a dysfunction of the body and as an empowered identity, respectively. Through the alternative biomedical movement, parents gain access to a network of specialized practitioners, private laboratories, compound pharmacies, and treatment purveyors. They use laboratory tests to render autism visible and quantifiable, even though scientific research has yet to discover unambiguous and reliable biomarkers. "Seeing" autism opens up opportunities to measure and assert control over it. Similarly, the autistic rights movement is a

space where members model autism acceptance within their own community by normalizing autistic traits and nurturing autistic culture. At meetings and special events, members construct temporary spaces where autism can be taken for granted—a luxury of ease that does not exist outside the movement. This means that autistic traits and eccentricities—like hand flapping, vocalizations, obsessions, and sensitivities—are not merely tolerated but validated. There is also a physical aspect to building such a space; members engineer an environment that is mindful of autistic social and sensory needs. Autistic rights members collectivize around a shared diagnosis, but within this socio-spatial environment, they transform autism from condition to culture, from disorder to neuro-diversity.

Third, social movements protect contentious knowledge. Perceived threats inform the strategies that members deploy to protect their community, ideas, and practices. While alternative biomedical members fear negative attention, which could have legal consequences (charges of malpractice or medical abuse) and disrupt their access to treatment-related resources, autistic rights members fear invisibility. Movement members perform boundary work to claim legitimacy and negotiate their position within the broader field of autism discourse. Alternative biomedical members focus on maintaining *internal* legitimacy to insulate their community from the criticisms of medical professionals. Internal legitimacy is also important for their hope of recovering autistic children with unorthodox treatments. Comparatively, autistic rights activists are more concerned with achieving *external* legitimacy to change policies and shift cultural views. Autistic rights members recognize parents of autistic children as the biggest threat to their political endeavors because parents play key roles in steering research and supporting therapy. Thus, to reclaim representational rights and authority, they distinguish their embodied knowledge from parental expertise.

*Challenging Autism* is about the persistence of contentious knowledge. As I show, resistances against dominant knowledge and ways of knowing are collective processes. The tenacity of these resistances depends on a sophisticated, complex infrastructure. Movement members challenge experts by engaging in a community that is furnished with the resources to transform unorthodox ideas into lived realities. Furthermore, this study illustrates how the expanse of the autism spectrum engenders incongruent ideas about what is best for autistic people. Comparing the perspectives of autistic adults and parents of autistic people, I identify the competing values and stakes that complicate autism politics and ideas about well-being. The alternative biomedical and autistic rights movements highlight the social and cultural failures to value disabled populations and support families.

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## PROPOSED CHAPTER OUTLINE

### (1) Warriors and aliens

Chapter One introduces the alternative biomedical and autistic rights movements with the case of Melissa, the mother of an autistic child, and Codey, a young autistic man. Melissa and Codey both wanted better lives for autistic people and were dissatisfied with what was available to them. Yet they held different ideas about what a better life meant and how it could be achieved. Melissa joined the alternative biomedical movement to access unconventional treatments that promise to help her son become more 'typical,' less autistic. Codey became involved in an autistic rights movement because he wanted to improve the lives of fellow autistic people through activism and public policy (not treatment). These two movements hold conflicting ideas, objectives, and strategies. Yet both are struggling against the same

dominant autism framework. This study asks: How are controversial ideas sustained? How do people uphold unorthodox ideas? How do they act on unorthodox ideas? What does it take to challenge experts? Next, I lay out a history of autism controversies as a means of contextualizing the two movements. I describe how this study contributes to sociological literature on health social movements, distrust in experts, and free spaces. At the intersection of medical sociology, the sociology of scientific knowledge, and social movement studies, this book argues that social movements are important free spaces for the enactment and maintenance of unorthodox ideas. Finally, I provide an overview of the book and its chapters.

## **(2) Pathways to community**

Chapter Two examines the different paths that lead parents, practitioners, and autistic individuals into their respective movement communities. Parents and practitioners expressed disappointment with the limits of conventional medicine and indicated that alternative biomedical methods renewed their hope of treating autistic children and patients. Comparatively, autistic adults articulated their frustration with the social implications and consequences of having a “disorder” and joined autistic rights organizations to gain a sense of community, empower their autistic identity, and fight for social justice. In this chapter, I argue that participants’ search for new community exposes the immediate challenges of navigating medical and support services. Moreover, the intolerability of these challenges led participants to question the authority and knowledge of experts.

## **(3) Reimagining autism**

Chapter Three shows how movements challenge experts by offering members a competing (and more hopeful) epistemic framework. Members produce alternative autism knowledge to overcome the shortcomings and limits of conventional medicine that they perceive. I compare the alternative biomedical and autistic rights frameworks to illustrate how their reconstructions of autism create opportunities for action and empowerment. Hoping for the chance to recover their autistic children, alternative biomedical parents reimagine autism as a set of physiological dysfunctions triggered by harmful environmental exposures (including vaccines). However, this means accepting partial blame for compromising their children’s immune systems during the critical stages between preconception and early childhood. Accordingly, I show that parents’ pursuit of treatment is also an act of repentance. In contrast, autistic rights activists resist medicalization and call for a radical shift in autism discourse. They frame the acceptance of autism as a political, ethical, and moral issue. Rejecting individualized treatment, participants advocate for social changes that would improve autistic people’s day-to-day living and increase their participation in public life. I demonstrate that movement communities are spaces where members reconstruct what means to be healthy, normal, and valuable.

## **(4) Laboratories and experimentation**

Chapter Four explores how the alternative biomedical framework is put into practice. I argue that participation within movement communities is important for accessing the social, material, and epistemic resources necessary to transform unorthodox ideas into lived realities. Here, autism is transformed from a disability to a physiological disorder. Members mobilize the alternative biomedical framework to create empirical and experiential knowledge about autistic bodies. Through close collaboration, parents and practitioners collect and interpret laboratory tests and behavioral patterns to locate autism within—but as distinct from—the child. Previously enigmatic behaviors, like self-injury and aggression, are given biological language and meaning, such as inflammation, yeast overgrowth, gluten allergy, or high levels of heavy metal concentration. This knowledge is then used to tailor and assess the efficacy of alternative and experimental interventions. This chapter details the types of interventions prescribed to autistic children—such as dietary change, supplements, and more experimental methods, like stem cell therapy, helminth worm therapy, and hormone therapy (to stop/delay puberty)—and describes how they are evaluated. Most treatments are not supported by clinical research, and some are deemed potentially dangerous. I find that within this movement community, autism becomes perceptible and measurable in a

way that is not possible within mainstream medicine, supporting parents' use of risky treatments on children.

### **(5) Knowing one's tribe**

Chapter Five illustrates the process by which autistic rights activists create autistic identity and culture. In this companion to the previous chapter, I show how participation within movement communities is important for accessing the social, material, and epistemic resources necessary to construct a demedicalized self and nurture an autistic culture. Activists are brought together by shared experiences of neurological atypicality and marginalization. Like other health social movement activists, they politicize their collective identity to advance a political agenda—autism acceptance. Yet, in this case, I show that collective autism-as-identity is not just a political tool; it is also an objective and achievement in its own right. I first illustrate how the autistic rights movement community is a space where activists collectively construct and reinforce a cohesive autistic identity by comparing experiences and affirming shared knowledge. Second, I demonstrate how this community also creates temporary physical and social spaces to *enact* autistic rights. At meetings and retreats hosted by movement groups, the principles of acceptance structure the rules of interaction and the organization of the physical environment (e.g., accessibility, sound, lighting, scents) to respect autistic identity and differences.

### **(6) Expert enemies**

Chapter Six compares how members of the two movements protect their unique reconstructions of autism and manage legitimacy. I first present two parallel vignettes describing significant deaths within both communities. These two vignettes illustrate how each community understands its own contentiousness, vulnerability, and position within the broader autism landscape. Perceived threats influence the defense strategies that movement members deploy. When these deaths occurred, alternative biomedical members were more focused on maintaining *internal* legitimacy to insulate themselves from criticisms of their autism framework and treatment practices. In contrast, autistic rights activists were more concerned with cultivating *external* legitimacy to gain political representation and cultural recognition. Whether protecting their movement from overt attack or quiet diminution, members performed boundary work to identify insiders and outsiders, describe the relationship they share, and define key characteristics that legitimize their activities. The findings show that movement participation is important to sustaining contentious knowledge and defending it against outside attack.

### **(7) Conclusion**

First, Chapter Seven summarizes the theoretical contributions and findings of *Challenging Autism* to the sociological literature on knowledge, health, and movements. Ultimately, movement communities are critical spaces not only for resisting the experts and parents who dominate autism discourse but also for enacting contentious beliefs. I review how the theoretical contributions of this book shed light on how other forms of contentious beliefs and practices are sustained. This concluding chapter then looks toward the future. I argue that the existence of the alternative biomedical and autistic rights movements is indicative of unmet needs. The span of the autism spectrum and its multiple uncertainties leave many parents, practitioners, and “higher functioning” autistic adults searching for help outside established medical and educational institutions. I discuss how the findings of this study identify ways to improve autism services and support. As autism research continues, I propose strategies that may offer immediate help to autistic people and their families.

## **AUTHOR INFORMATION**

I am an assistant professor in the Department of Sociology at Vassar College. I received my PhD in sociology from Brandeis University in 2018. My scholarship focuses on issues related to knowledge, expertise, contestation, experience of illness, and disability. My research has been published in *Social Studies of Science* (from this study in 2021: “Defending ‘snake oil’: The preservation of contentious knowledge and practices”), *Social Science and Medicine* (from this study in 2018: “‘I’m a normal autistic

person, not an abnormal neurotypical”: Autism Spectrum Disorder diagnosis as biographical illumination”), *Socius*, *Genetics in Medicine*, and *Journal of Contemporary Ethnography*.

## MARKET

*Challenging Autism* is written for an academic market, specifically for scholars of medical sociology and science, knowledge, and technology. Autism is a subject of both popular and academic interest because of its many uncertainties, increasing rates, and cultural relevance. Beyond its sociological contributions, this book will appeal to readers interested in autism, disability, neuro-diversity, and knowledge production. The approachability of my cases, illustrative narratives, and themes relating to knowledge, bodies, and identity make the book suitable for undergraduate and graduate course assignment. In particular, *Challenging Autism* can be assigned in courses related to medical sociology, public health, disability studies, scientific knowledge, and introductory sociology. The chapters are designed to stand alone as course readings.

## COMPETITION

### Sociological books on challenging experts

*Challenging Autism* joins recent books on resistances against expertise, like Jennifer Reich’s acclaimed book *Calling the Shots: Why Parents Reject Vaccines* (NYU Press, 2016), which analyzes vaccine hesitancy, parental expertise, and distrust, and Jonathan M. Berman’s *Anti-Vaxxers: How to Challenge a Misinformed Movement* (MIT Press, 2020), which traces the history of vaccine hesitancy. This book also advances health social movements research, like Phil Brown’s *Toxic Exposures: Contested Illnesses and the Environmental Health Movement* (Columbia University Press, 2007) and Michelle Murphy’s *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (Duke University Press, 2006). Unlike either of these books, *Challenging Autism* compares two movements with very different aims, which makes it possible to highlight the role of embodiment in their projects. Finally, this book examines how actors negotiate controversy and legitimacy, like Danielle Giffort’s *Acid Revival: The Psychedelic Renaissance and the Quest for Medical Legitimacy* (University of Minnesota Press, 2020), but directs attention to how these processes unfold outside intellectual and academic institutions. In joining published books on challenges to expertise, *Challenging Autism* illustrates the importance of social movements as free spaces in which to transform controversial and unorthodox ideas into lived realities.

### Sociological books on autism

Over the last decade, sociological books on autism have advanced scholarship on expertise, scientific knowledge, inequality, disability, and immigration. Unlike these books, *Challenging Autism* takes the case of autism to theorize contentious knowledge and its structures. Gil Eyal et al.’s *The Autism Matrix* (Polity, 2010) and Jennifer Singh’s *Multiple Autisms: Spectrums of Advocacy and Genomic Science* (University of Minnesota Press, 2016) trace the historical formation of present-day understandings of and approaches toward autism. While these important works focus on the emergence of autism experts (e.g., researchers, medical professionals, therapists) and expertise, *Challenging Autism* explores resistances to these dominant actors and frameworks. While Chloe Silverman’s *Understanding Autism: Parents, Doctors, and the History of a Disorder* (Princeton University Press 2011) studies alternative autism treatments to highlight parents’ emotional labor, *Challenging Autism* is oriented toward movement members’ construction of a disordered body and management of controversy. With the exception of Joyce Davidson and Michael Orisin’s edited book *Worlds of Autism: Across the Spectrum of Neurological Difference* (University of Minnesota Press, 2013) and part of Singh’s *Multiple Autisms*, scholarship on autism often amplifies parents’ experiences. Thus, while there is much public interest in autistic lives (as exemplified by literature, film, and television), current scholarship continues to privilege non-disabled voices. However, *Challenging Autism* demonstrates the importance of elevating autistic perspectives to see the full landscape of autism discourse.

### ADDITIONAL INFORMATION AND SPECS

I anticipate that *Challenging Autism* will be completed by Fall 2021. I expect the book will be approximately 80,000 words. No additional research is needed. Currently, I have two chapters fully drafted, "(1) Introduction" and "(4) Laboratories and experimentation." Versions of "(5) Knowing one's tribe" and "(6) Expert enemies" have been published as articles in *Social Science and Medicine* (2018) and *Social Studies of Science* (2021). Chapter 5 briefly engages with the concept of "biographical illumination," which I developed in my *Social Science and Medicine* article, titled "'I'm a normal autistic person, not an abnormal neurotypical': Autism Spectrum Disorder diagnosis as biographical illumination." Chapter 6 compares how the alternative biomedical and autistic rights activists protect contentious knowledge; some of these strategies for just the alternative biomedical movement are discussed in my *Social Studies of Science* article, titled "Defending 'snake oil': The preservation of contentious knowledge and practices."

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