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When Risk, Doubt, and Difference Converge: A Review Essay

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By Elizabeth Lewis

[On Immunity: An Inoculation](#)

By Eula Biss

Graywolf Press, 2014, 205 pp.

[The End of Normal: Identity in a Biocultural Era](#)

By Lennard J. Davis

University of Michigan Press, 2013, 155 pp.

[Autism and Gender: From Refrigerator Mothers to Computer Geeks](#)

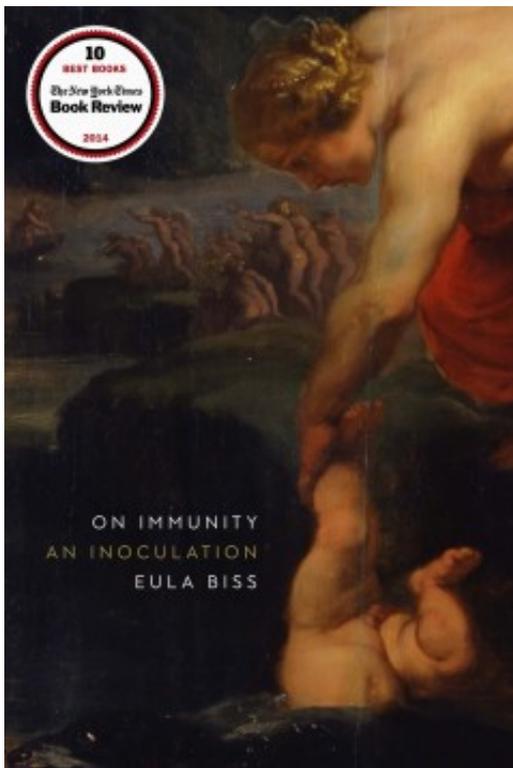
By Jordynn Jack

University of Illinois Press, 2014, 306 pp.

Disability themes have become an increasingly central figure in the media, popular culture, and everyday life. Rates of disability diagnosis have risen sharply among children in the U.S. in the past decade. Disability has exploded in the popular press in such acclaimed recent books as Steve Silberman's [*Neurotribes: The Legacy of Autism and the Future of Neurodiversity*](#), Andrew Solomon's [*Far From the Tree: Parents, Children, and the Search for Identity*](#), Akhil Sharma's [*Family Life*](#), and Lisa Genova's [*Still Alice*](#). Similarly, scholarship on disability has gained new momentum. Somatosphere's [*Inhabitable Worlds*](#) series, edited by [Michele Friedner](#) and [Emily Cohen](#), featured cutting-edge writings on the study of disability within the social sciences, and the program for the 2015 American Anthropological Association's annual meeting included over 50 papers, panels, and posters on disability themes. Without question, disability has emerged from the margins of scholarship and public interest.

Three recent books – Eula Biss' *On Immunity: An Inoculation*, Lennard Davis' *The End of Normal: Identity in a Biocultural Era*, and Jordynn Jack's *Autism and Gender: From Refrigerator Mothers to Computer Geeks* – make important insights regarding the contours and textures of disability in the contemporary U.S. Biss, an essayist and social critic, offers a fascinating analysis of the persistent anxiety surrounding childhood vaccinations, particularly among a vocal minority of parents who oppose

vaccines entirely. Davis, a scholar of Disability Studies, makes a compelling and provocative argument that the concept of *normal* has given way to a seemingly more inclusive umbrella of *diversity*, yet disability remains excluded. Jack, a rhetorician, has written the first book-length examination of the role of gender in autism. Together, these writers make important contributions that are long overdue and will prove useful to both academic and applied audiences. Themes of race, class, and gender are addressed to varying degrees, a critical shift from the tendency to flatten disability intersectionality. Ultimately, all three authors speak to questions of authority, risk, intimacy, and fear, enriching contemporary understandings of disability in different, yet overlapping, ways.



In *On Immunity: An Inoculation*, selected as a *New York Times Book Review* top 10 books of 2014, Biss uses the controversy surrounding childhood vaccinations as a jumping off point to explore broader notions of risk and the deeply social nature of individual health. Her writings contain a sweeping collection of musings on the embodied, historical, political, and social dimensions of vaccination in the U.S. Why, she asks, do deeply rooted and contentious fears about vaccine safety persist despite an overwhelming lack of scientific evidence to support such claims? (This [piece](#) by Sharon Kaufman offers an anthropological perspective on similar questions.) To answer this, she turns to history, philosophy, medicine, ethics, mythology, anthropology, popular media, and her own experiences as a mother.

Biss frames inoculation as a gamble. We know that vaccines can provoke serious reactions in a tiny portion of the population; we know, too, that the

introduction of standard vaccines dramatically improved child mortality rates over the course of the last century. The question, of course, is whether this gamble is worth it. Despite the successes of modern public health, the fact remains that we cannot inoculate ourselves from doubt, particularly in a climate of widespread and persistent medical folklore of the dangers of vaccines. The vaccine is not simply an event – an isolated shot or jab – but rather a continuous process protecting the health of the patient and also the social body. In Biss' framing, vaccinations become an ethnographic object, around which multiple fears, associations, anxieties, and beliefs converge.

“Immunity,” she writes, “is a shared space – a garden we tend together” (163). Vaccines are intrinsically social. By maintaining herd immunity levels, we protect the broader public good – including people who cannot be vaccinated for one reason or another. Per this logic, vaccinations are an embodied social contract that both emerges from and obscures the permeability of our own bodies. As she explains: “we are protected not so much by our own skin, but what is beyond it. The boundaries between our bodies begin to dissolve here” (20).

Biss deftly navigates the role of socioeconomic class in terms of the vaccine debate. Indeed, as she points out, unvaccinated children tend to have mothers who are white and have higher levels of education, and the families have higher incomes and tend to be geographically clustered (see, too, this [piece](#) by anthropologist Emily Brunson). In contrast, Biss cites CDC data showing that undervaccinated children are more like to have mothers who are younger, single, Black, and lower income. These demographic trends illustrate a critical distinction between vaccination trends as a product of choice versus access. This raises critical questions regarding who can claim the privilege of rejecting vaccines. Who is able to opt out of standard public health measures, by what means, and under what authority? (For a case study of vaccine refusal in a particular school population, refer to Elisa Sobo's recent [article](#) in *Medical Anthropology Quarterly*.)

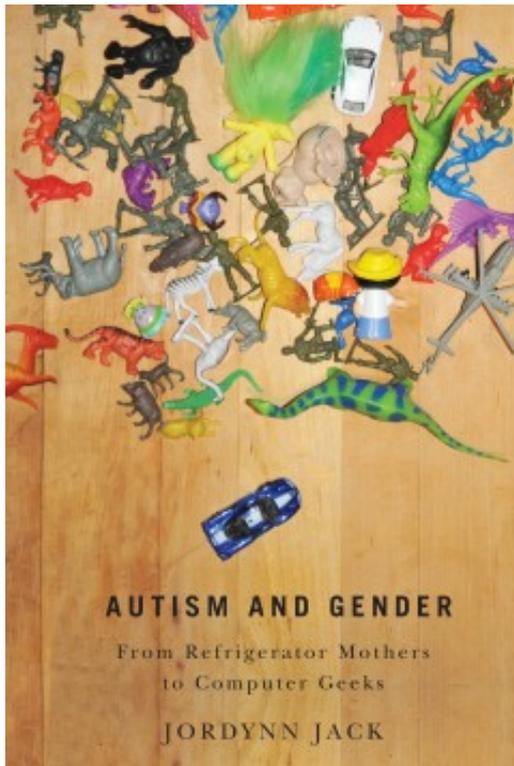
While Biss states clearly that she supports vaccination, she is less interested in the moral or ethical implications of vaccine fears than in how to make sense of their persistence. As she asks, is risk perception about actual quantifiable risk or is it really about immeasurable fear (37)? Our deepest fears are, for Biss, informed by complex webs of history, power, stigma, economics, myths, and shared nightmares (37). They are fundamentally intimate and unavoidable, yet they shift according to the particularities of the moment. And, for Biss, they include disability.

Biss gives readers an overview of the history of the current vaccine fears (discussed also by Jack, below, and examined at length in Seth

Mnookin's [*The Panic Virus*](#). Her analysis of purity and goodness (or healthfulness) is particularly compelling. Biss is interested in our "profound alienation from the natural world" and how it shapes risk perception (40). Anything considered unnatural is now coded as bad, whereas the natural is benign. For Biss, this indicates a broader social anxiety that we are polluted by modernity; the products of our own creations – vaccines, medication, food, technology – are poisoning us from the inside out. But purity is a myth and, as she reminds readers, it has been used historically to justify everything from eugenics and sodomy laws to genocide. The purity/pollution binary is a fallacy. "We are all already polluted," she writes starkly (76).

Biss argues that social anxieties have shifted from fears of bodily pollution by filth to pollution by toxins, the nebulous dangers that animate opposition to vaccines. For a vocal minority, vaccines embody the proliferation of modern toxins and are a metaphor for the excesses of contemporary life (110). They are also fundamentally inseparable from the forces of capitalism through big pharma. Such arguments garner appeal because of what Biss calls "preindustrial nostalgia," a concept that warrants further unpacking (115). Practices and products seen as traditional, natural, and seemingly untainted by big industry are, it follows, deemed good. They are safe and authentic – reflecting the way things *should be* – triggering nostalgia for an imagined past untainted by vaccines and their toxic needles, yet curiously unmarked by outbreaks of preventable disease.

On Immunity's essays are united by the recurring theme of intimacy. The intimacy of parenthood, risk, and biomedical encounters; of kinship, care, and opting in (or out) of vaccinations; of fears and nightmares, however "irrational" or scientifically unsound; and of the 'I' versus the 'we' of public health. What emerges in the spaces in between knowledge and action, history and hope? For Biss, the answer is a gamble.



Similarly, Jordynn Jack's *Autism and Gender: From Refrigerator Mothers to Computer Geeks* uses gaps in current knowledge about autism as a starting point to examine how gendered characters are and have been used historically to shape understandings of and experiences with autism. Here, autism becomes the ethnographic object to which persistent tropes and archetypes stick and gain meaning. The metaphors of autism are well known: breaking down the walls, penetrating the fortress, rescuing the child trapped inside. Jack is particularly interested in analyzing the role of stock characters that, as she explains, make autism narratives translatable, packaged, and socially resonant. She gives a targeted and historically rich analysis of how different characters inform and shape autism discourse, offering a fruitful and contribution to understandings of gender and autism spectrum disorders.

Jack devotes a separate chapter to each primary character: the refrigerator mothers of mid-twentieth century maternal deprivation narratives; anti-vaccination Mother Warriors of the 2000s, popularized by Jenny McCarthy; the computer geeks of today's Silicon Valley and big tech; distant and supposedly divorce-prone autism dads; and neurodiverse self-advocates. She traces these characters' roots from the 1940s until the present, arguing that they help shape understandings of autism itself, as well as possibilities for intervention, care work, success stories, and authority claims. One of her central arguments is that efforts to understand autism often – if unwittingly – draw conclusions based on an uncritical acceptance of these characters. As she writes, "...where knowledge or authority is lacking, gendered characters often fill in" (6).

Jack's examination of the legacy of Bruno Bettelheim and the so-called refrigerator mothers of the post-World War II area is a fascinating addition to other works on the history of autism (see Silberman's [Neurotribes](#)). Bettelheim's theory was closely informed by psychoanalysis and centered on mothers' roles in child development. He argued that the mothers of children with autism shared certain basic characteristics: they were anxious and unstable, had a history of emotional problems predating their children, and were unhappy in their marriages (36). These misleading claims supported existing views in psychiatry that parents of children with autism were cold and distant.

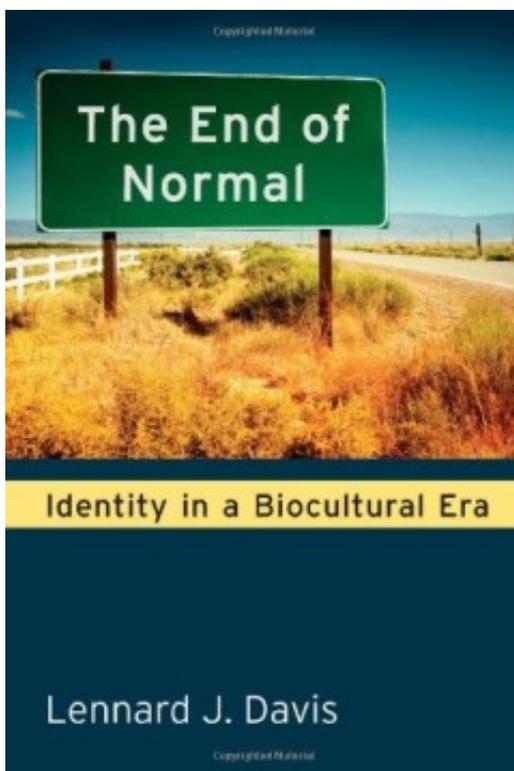
In the post-War climate marked by psychoanalysis plus general anxieties about women's roles in the home, the theory of maternal deprivation caught on. As Jack explains: "Once mother blaming is imposed as a framework, it can recolor all sorts of perceptions and events as potential causes of autism" (47). Jack cites the twentieth century shift from conceptualizing motherhood as the product of innate knowledge to a formal, scientific approach governed by experts. Paradoxically, the increasing public attention to motherhood diminished maternal authority itself, which shifted from the domain of women to the world of research and, in the case of autism, psychiatry.

Bettelheim was later found to have fabricated his credentials and the research findings, and thus a generation of people with autism and their families suffered irreparable harm with no justification. However, Jack cautions readers not to use him as a scapegoat. His ideas only caught on at all because the archetype of the bad, unloving, distant, emotionally fragile mother loomed large at that cultural moment. They resonated, and thus it became codified in the history of autism.

Jack contrasts the refrigerator mother character with twenty-first century "Mother Warriors," using Jenny McCarthy's anti-vaccination campaigns as her primary illustration. Emboldened by moving stories, unprecedented access to digital information, and social networking platforms, these mothers believe that autism is a product largely of environmental triggers and toxins, which might include vaccines, gluten, mercury, and processed foods. The women are united by a shared politics of suspicion, coupled with the insistence that they have the authority *as mothers* to interpret scientific evidence. These are the relatively privileged populations discussed by Biss – the anti-vaccination pockets that tend to appear on the nightly news with each measles outbreak or whooping cough scare. Within this group, surveillance of one's child combines moral and medical judgments with a distinctly libertarian ethos, and is a uniquely maternal responsibility. The emotionally charged Warrior Mother performs motherhood through her vigilance. As we have seen through the persistence of the anti-vaccine movement, this character has proven

perhaps surprisingly resilient.

Jack contrasts these maternal figures with what she argues are the dominant stock characters for men in the autism world: the computer geek; paternalistic physician; and emotionally distant father who wants to “fix” his child. As a whole, these portraits suggest a persistent separation between affect and reason, or care and science, in our understandings of gender and autism. This impacts not only the parents and professionals working within the autism field, but undoubtedly the increasing numbers of people with autism diagnoses. While autism is closely associated with young white males, [CDC figures](#) show that both gender and race are key aspects of who receives a diagnosis and of what type. While this topic is outside of the scope of Jack’s book, she leaves it open as a promising area for future scholars.



While Jack and Biss’ writings hinge on textual analyses and the social and historical shaping of disability, Lennard Davis’ *The End of Normal: Identity in a Biocultural Era* seeks explicitly to bring bodies to the center to the center of the conversation. As he writes: “Bodies can be the sum of their biology; the signifying systems in the culture; the historical, social, and political surround; the scientific defining points; the symptom pool; the technological add-ons all combined and yet differentiated” (7). That is, bodies are fundamentally bicultural. From this starting point, he examines how historical notions of the “normal” bodies have given way to a broader umbrella of diversity frameworks. While largely positive about this shift, Davis is concerned that disability continues to fall outside of the scope of diverse bodies. What if

diversity's appeal and universalism depend in part on the exclusion of the truly abject and marginalized? As he argues, we are all the diverse and equal because we are "not *that kind* of different" (14).

The crux of the matter, for Davis, is that disability is still perceived as a medical designation and diversity omits medicalized bodies. Diversity, he argues, does not apply to the disabled, ill, or dying. Those are of a different conceptual ilk, namely the pathological. As he writes: "Disabled bodies are, in the current imaginary, constructed as fixed identities. Outside of the hothouse of disability studies and science studies, impairments are commonly seen as abnormal, medically determined, and certainly not socially constructed" (7). Here, the old distinctions of normal versus pathological continue to reign. As a de-historicized bodily condition perceived of as needing a cure, disability cannot be welcomed by a diversity paradigm.

Davis also offers useful a critique of diagnostic certainty, add a more nuanced disability studies perspective to the texts by Biss and Jack. He has long been interested in the dynamic, shifting manifestations of disability identity, and in *The End of Normal* he turns this lens toward the ontological status of diagnosis and diagnostic certainty. As he writes: "What I am wondering about is the aura of faith that accompanies the process of diagnosis" (82). Tellingly, both Davis and Jack include lengthy discussions of the role of the *Diagnostic and Statistical Manual (DSM)* in shaping contemporary understandings of disability categories.

Instead of autism spectrum disorder, Davis uses obsessive-compulsive disorder (OCD) as his case study. He argues that diagnosis constitutes a particular form of difference as a thing – an object – and is also loaded with symbolic value. As he writes: "Having created this category that makes 'sense' of random or seemingly linked behaviors, we can then assign people and their behaviors to those categories" (83-4). The *DSM* provides the authority to categorize diagnostically, grouping people with seemingly aberrant behaviors or symptoms under particular – and changing – umbrellas. For Davis, the contingency of diagnosis is illustrated by the fact that the *DSM* is revised with each new edition. One cannot help but wonder what he would have to say about the recent removal of Asperger's Syndrome from the *DSM*.

Davis concludes *The End of Normal* with a Biocultures Manifesto, co-written with David Morris, followed by asserting that biocultural knowledge is necessary for theorizing and truly making sense of contemporary experiences of race, gender, disability, bodies, and identity (134). He calls on scholars to reframe culture and history in terms of their relationship to biology, and vice versa. We are to probe the boundaries of humanism and science, forming a robust and multi-faceted intellectual

movement that spans medical anthropology, public health, science and technology studies, bioethics, disability studies, the medical humanities, and beyond. The language of disability today includes a more diverse and diagnostically delineated population than ever before. We need robust theories and methods to approach these questions of bodies, minds, and moments, following Rapp and Ginsburg's [call](#) to acknowledge disability as a universal facet of the human experience. While such goals might sound lofty, one cannot help but wonder whether emerging works on disability themes, including the three texts featured here, are beginning to do just that.

Elizabeth Lewis is a doctoral candidate in anthropology at the University of Texas at Austin. Her current work examines undiagnosed disabilities in the contemporary U.S., with a focus on family experiences with undiagnosed children. She is engaged in multiple applied and scholarly projects on a variety of disability themes. More information about Elizabeth's work, writings, and background is available on her blog, [Disability Fieldnotes](#). Find her on Twitter at <https://twitter.com/lizlewisanthro>.

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