

BOOK REVIEW/COMPTE RENDU

Steven Epstein, *Inclusion: The Politics of Difference in Medical Research*. Chicago: University of Chicago Press, 2007, 424 pp. (Chicago Studies in Practices of Meaning). \$US 29.00 hardcover (978-0-226-21309-5).

Inclusion: *The Politics of Difference in Medical Research* is an impressively rich account of the recent push in the United States to displace the “standard human” as a basis for generalizing in medical research in favour of inclusion of subjects from underrepresented groups, namely women, racialized people, children, and the elderly.

Never mind that the critics’ claim that researchers always took only the apparently ubiquitous 70 kg, 35-year-old white male body as the norm, to the exclusion of other groups, is an ahistorical oversimplification. As Epstein demonstrates, certain developments have encouraged that tendency but it is by no means a truism across the history of Western medicine; indeed, biological difference has long been a preoccupation. Moreover, “different” bodies (women’s, racialized/black bodies) have also served as the biomedical standard at various times — not least because of the practical need for subjects. Never mind that standardization of the human for medical purposes is, in fact, a development of the 20th century, and that even then — witness Tuskegee — we cannot say that the (straight) white male has always served as the norm. And finally, never mind the deep irony of reformers arguing the importance of biological differences for antiracist and antisexist ends, given that in the not-so-distant past the very same types of claims were used in precisely the opposite way — to argue for the superiority of white men. Never mind these hiccups in the critics’ arguments. What matters more is that these American reformers seeking to achieve “biocitizenship” for underserved groups through policies of full inclusion in the selection of research subjects have been enormously successful at making diversity an official concern. For Epstein the central question is, how?

Since the 1980s, a heterogeneous and tacit coalition of sympathetic members of the US Congress, scientific experts, and advocacy groups have managed to introduce an “inclusion and difference paradigm” into the world of medical research and funding that has forced both researchers and pharmaceutical companies to significantly change the way they go about their business. This biopolitical paradigm, comprising new

policies, practices, bureaucratic offices, monitoring systems, and more, is informed by two central principles: the active inclusion of members of diverse groups as research subjects and the measurement of outcome differences between them. Key to reformers' success in bringing about this move towards "niche standardization" at the level of groups was their achievement of what Epstein calls "categorical alignment," or the merging of social categories from the worlds of medicine, social movements, and state administration. With this new concept Epstein demonstrates how different social worlds with seemingly divergent agendas can sometimes come together, however unexpectedly. An important by-product of this new prioritizing of diversity in research is the rise of what Epstein calls "recruitmentology" — the applied study of research recruitment and the most effective means of enrolling targeted groups.

But have critics been *as* successful at actually redressing the health disparities so endemic in the United States — the disparities they invoked as the *raison d'être* for research reform? Not so much. As Epstein also demonstrates, the changes have had important unintended consequences that, in his view, trump whatever positive benefits legislated inclusion has brought. This reader agrees. There is no denying that the inclusion and difference paradigm has drawn attention to health disparities in the United States, but as Epstein shows us, health and social justice for underserved groups has by no means been realized as a result. If anything, the inclusion and difference paradigm may well have helped to further entrench health and social *in*justice, what with raising the risk of racial and sex profiling in health care, reifying biological notions of difference between groups, obscuring differences within groups, and diverting attention away from the ways in which health risks are known to be unequally distributed in society by such social factors as class, education level, and geographic location.

There are very good reasons this book received the ASA's Robert K. Merton Professional Award (2007) for the best recent book published in Science and Technology Studies. To begin with, it is a delightful read. Epstein's writing is accessible without oversimplifying, making the book a real option in both undergraduate and graduate courses. Second is the incredible thoroughness with which Epstein has woven together a complex story with numerous key players, without bogging the reader down in excessive detail. Indeed, the enormous amount of interview and textual data that informs this analysis, and Epstein's ability to navigate us through all of it without (us) breaking a sweat is nothing short of enviable. Third, *Inclusion* is exemplary not only for the compelling account that it provides, nor just for the reams of convincing evidence Epstein incorporates, but also for its deftness in marrying together different disci-

plinary perspectives of Science Studies, Sociology, History, and Politics, to name a few.

There are also important substantive reasons this book is award-worthy. First, *Inclusion* brings something new and welcome to debates over the politics of difference. Take, for example, the current preoccupation with the human genome and especially the rise of population genetics and the study of so-called ethnic diseases. This book tackles a glaring contradiction in medical research discourse that maintains there is no such thing as biological race or, more specifically, no genetic basis for such a means of categorizing. At the same time, the drive to uncover predictive significance in the small fraction (0.1–0.2 percent) of the human genome (SNPs) that does account for individual differences persists, along with much debate over whether these differences correspond to racial categories.

Second, *Inclusion* gives us a way to think about the reification of biological sex, which, as Epstein argues, we tend to accept much more uncritically than the reification of race even though its political implications are no less problematic. *Inclusion* forces us to look at what happens when you shift the frame of reference in debates over difference from that which is excluded (full stop), to that which is excluded *by virtue of being included*. In other words, it appears that including the excluded in medical research does not actually resolve or eliminate the logic of their previous exclusion — it just reconfigures or channels it by reifying their difference in new sorts of ways. Relations of difference are thus retained, even in inclusion.

That said, two elements of the book left me wanting more, though I will emphasize only one. Apart from expanding his analysis of age as a source of difference, Epstein also might have further developed his theoretical framework. He uses Foucault's concept of biopolitics to describe how humans are known, classified, administered, and treated within the inclusion and difference paradigm. He argues that this is a *biopolitical* paradigm insofar as it is a framework of ideas, standards, and formal procedures for addressing concerns that are the focus of both biomedicine and the state. Epstein sees this as a story of how governing has been biomedicalized in the sense that health research has become an appropriate site for state intervention and regulation.

This approach is very useful in that it enables Epstein to demonstrate that the inclusion and difference paradigm has something important to say about biological citizenship, or the way in which the biology of a population becomes grounds for social membership and the basis for making claims for inclusion in society and the polity. But Epstein largely restricts his theoretical analysis to one chapter and does not return to

it much until the very end of the book. Had he touched base with his theoretical framework more regularly throughout the text, he might have found opportunities to flesh out his use of Foucault.

For example, the concepts of biopolitics and government, in addition to evoking notions of state intervention, regulation, and the like, also evoke the idea of getting people to care for themselves, to self-monitor, to govern themselves. In other words, with biopolitics comes individual responsibility, yet Epstein does not go there. The theme of self-care would have been a fascinating additional layer to an otherwise strong analysis. Given that a major dimension of this story is about reformers fighting for the right to be subjected to medical authority, or the right to be responsible research subjects, one has to ask what all this means for the individual selves who constitute the niche groups that inform the new and improved inclusive research. As Epstein recently acknowledged when I asked about this following a public presentation of the book, at least part of an answer is contained in his discussion of recruitmentology, where he describes the imperative placed on individual members of targeted groups to be “part of the answer,” i.e., to be socially responsible (and become) research participants.

This is a small criticism of a strong book. A pleasure to read from beginning to end, I highly recommend it.

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