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BOOK REVIEW

Inclusion: the politics of difference in medical research, by Steven Epstein, Chicago, University of Chicago Press, 2009, 432 pp., US$19.00 Paper. ISBN 9780226213101

In *Medical Apartheid*, journalist Harriet Washington presents a harrowing survey of the abuse of African Americans at the hands of medical researchers, from the era of racial slavery to the present. Blacks in the US have borne the brunt of this distinctively intimate and grave exercise of power, Washington maintains, because they have an experience of disproportionate social vulnerability – as the enslaved, as the institutionalized, and as the impoverished – that constituted them as 'accessible' to researchers. Despite this bleak genealogy, Washington surprisingly exhorts readers – especially those members of minority groups – to volunteer as clinical research subjects; its closing page provides information about resources for said purpose.

Medical Apartheid leaves little doubt about the historical reasons why some blacks remain apprehensive of encounters with medical authority, ranging from hospital visits to genetic screening. However, a question left unanswered by this work – yet begged by Washington's optimism about minority participation in biomedical research – is what developments make it conceivable that readers of this daunting account of experimental maltreatment might feel compelled to enlist in clinical studies. For African Americans, in particular, how has the historically risky business of medical experimentation now become a risk worth taking?

Marshaling interviews, policy analysis, archival research and deft theoretical analysis, sociologist Steven Epstein's masterful study, *Inclusion: The Politics of Difference in Medical Research*, reveals that what appears to be a *paradox* of the Washington book in fact reflects the successful formation of a '*biopolitical paradigm*'. Biopolitical paradigms are assemblages of theories, conventions and regulations that stipulate how individuals and populations come to fall under the twin purview of bureaucratic and biomedical regimes. They are the institutional and organizational vectors for the 'politics of life itself' (Rose, 2001), for the ways in which the body, biomedicine and healthcare come to be 'appropriate and important site[s] for state intervention and regulation' (p. 17). One particular biopolitical paradigm – 'inclusion-and-difference' – is the focus of Epstein's deservedly award-winning second book. Inclusion-and-difference refers to 'research and policy focus[ed] on including diverse groups as participants in medical studies and measuring differences across those groups' (p. 17) in such a way as to permit the production of categorical and comparative biomedical knowledge (e.g., 'Blacks are three times more likely than whites to die from heart disease').

The inclusion-and-difference paradigm emerged in the 1980s, Epstein suggests, from a convergence of state policies, research protocols and politicking all aimed at making the practice of biomedical inquiry more 'democratic' by extending

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participation in clinical studies to women, racial and ethnic minorities and, to a lesser extent, children and the elderly, thus unseating the predominance of the white male, middle-aged research subject who, for much of the twentieth century, was regarded by investigators as the 'standard human' (p. 12). Health advocates and community activists united with liberal politicians, public health officials, physicians and bench scientists toward the end of advancing 'diversity' in biomedical research and with the hope of bridging health disparities in turn. From the consensus forged among this 'heterogeneous collection of political actors' (p. 277) there developed a new and widespread 'common sense' (p. 2) – codified in the Revitalization Act of 1993 – that analogized the participation of diverse subjects in medical research to broader social equality. With this new logic, members of populations that had been historically underrepresented in clinical trials became sought after research subjects based upon what was deemed their distinct biological dispositions and their unique health needs. Biological and social epistemologies of identity and population were, in this way, imbricated through a process that Epstein terms 'categorical alignment' (p. 13).

Among the many merits of *Inclusion* are its clarion prose, persuasive argumentation, exhaustive documentation and intersectional approach (i.e., analysis between and across race, ethnicity, gender and age). With such scholarly dedication evident, one is a little remiss to suggest that the author might have delved deeper. Yet, reaching even a decade farther back in time would have permitted the excavation of some of the additional and critical roots underpinning the formation of the inclusion-and-difference paradigm that appear somewhat as epiphenomena in Epstein's account. Affirmative action is a case in point: Epstein considers how the *specter* of affirmative action was, beginning in the 1980s, mobilized as a frame by opponents of inclusion-and-difference; conservative foes of this emergent paradigm decried it as an attempt to politicize research by introducing a 'quota' (p. 9) system that would constrain investigators' ability to conduct 'good' science. For the most, the author's discussion treats affirmative action as a trope, rather than taking it as an analytic point of departure, to the detriment of an explicit consideration of the constitutive role of *actual* affirmative action policies.

Signed by US President Lyndon Johnson in 1965, Executive Order 11246 barred employment discrimination on the basis of race, color, religion, sex or national origin and encouraged proactive steps toward the fuller incorporation of women and minorities into institutions receiving federal funding. It was arguably a significant structural precursor to the practice of inclusion-and-difference. These policies helped to create a class of middlemen and women that would become the glue that holds 'categorical alignment' in place. At medical schools, affirmative action resulted in the opening up of the health professions to larger numbers of racial minorities and women in the US; the same was true of other professional schools during this period (e.g. Keith, Bell, Swanson & Williams, 1985; JBHE, 1997/1998; Rossiter, 1995). By the mid-1970s there was a relatively more representative cohort of 'minority' scientists, politicians, and other influential figures, who could serve an important bridging function, translating biomedical assumptions and policy jargon into the language of shared histories, linked fates and collective rights (Dawson, 1994; Jaynes & Williams, 1989). Not unlike the 'culture brokers' of classic social science literature, these actors, who might be called 'bio-culture brokers', may deploy the 'authentic expertise' (Nelson, 2008) available to them as both minorities *and* community-minded

professionals to forge consensus in and between biomedicine, scientific domains, policy circles and the public. Bio-culture brokers thus play a key role facilitating previously excluded groups' 'recruitment' (p. 182) into clinical studies and, may facilitate as well, their acquiescence to the interpretation of resultant biomedical data in a manner that may border on biological essentialism. Herein lies the rub of policy-driven incorporation: Social identities born of historical exigency and political struggle may not correspond with biomedical ones (Braun et al., 2007) and indeed may be ideologically incommensurate with them. The 'categorical alignment' process that is pivotal to inclusion-and-difference is unwieldy, even with triangulation by bio-cultural brokers.

Delineating the inclusion-and-difference paradigm, Epstein helps us to understand how practices and institutions that were once sites of suspicion and distrust have come to be viewed as sites of reparation. He reveals as well the stakes of inclusion. For the liberal strategy of equality-cum-biomedical research participation in no way guarantees access to healthcare, equal health outcomes, or the diminution of other forms of social inequality. By illuminating these complex and contradictory processes, Epstein proffers an urgently needed 'history of the present'.

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