Garratt on Schmidt, 'Eradicating Deafness? Genetics, Pathology, and Diversity in Twentieth-Century America'

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In Eradicating Deafness? Genetics, Pathology, and Diversity in Twentieth-Century America, historian Marion Andrea Schmidt explores the complex relationship between the d/Deaf community and genetic researchers. She makes an in-depth study of genetic counseling and the varying, sometimes unexpected, motivations of the scientists involved. Alongside this is the story of d/Deafness in twentieth-century America, specifically how hearing loss was perceived and how this created new d/Deaf communities. Schmidt complicates the usual dichotomy of the medical versus scientific models of d/Deafness and disability, investigating where they overlap and at times work in harmony.

Schmidt structures the book around case studies: the establishment of a research department for heredity and genetics at Clarke School for the Deaf in Massachusetts (1900-40); the development of heredity research and genetic counseling with outside collaborators at the Clarke School (1930-60); the evolution of specialized psychiatric and genetic counseling at the New York State Psychiatric Institute (1955-69); the contrast between eugenic ideas of eradicating Usher's syndrome using genetic science and the lived experience of those with the condition (1960-80); and geneticist Walter Nance and his colleagues' shift from a medical-pathological to a sociocultural model of d/Deafness after encountering those within the d/Deaf community (1970-90). Through these case studies, Schmidt demonstrates how, across different institutions and decades, the purpose of genetic counseling transformed from researchers seemingly preoccupied with the prevention of deafness to those sensitively working alongside d/Deaf people who were seeking to learn more about themselves and their families. As Schmidt points out, however, the story is not linear, with even early genetic counselors in the Clarke School for the Deaf formulating ideas of d/Deaf people as a social group with their own culture and identity, rather than people with an undesirable condition. In exploring this, Schmidt offers new evidence that the social model of disability, often dated to the end of the twentieth century, had its roots far earlier.

Schmidt carefully and critically handles the uncomfortable history of eugenics, delving into the complexity and legacy of eugenic figures and their ideas. Central to the book are the careers of scientists and those working within genetic counseling. How their research, work practices, and relationships with d/Deaf individuals developed over time reveals an unexpected intersection between social activism and science. Schmidt extensively covers the well-worn story of d/Deaf activism;
however, by doing so, he never fails to connect what developments in genetic counseling meant for the d/Deaf community—a not just interesting but also necessary element.

How professionals in genetic science communicated with the d/Deaf people they were counseling, as well as the wider d/Deaf community, is a running theme in Schmidt’s work. Researchers connected through a variety of methods. This included traditional oralist communication and sign language interpreters, while some learned sign language themselves in the latter part of the century. How scientists manufactured their encounters also changed, as the production of promotional material such as flyers and the location of their research hubs demonstrates. In exploring this topic, Schmidt presents a rich picture of not just the aims of genetic science but also its practice, and what this reflected about the position of d/Deaf participants in the research.

In addition to connecting professionals within genetic counseling to the social activism surrounding d/Deafness in the twentieth century, Schmidt offers fascinating, often neglected details in two other areas. Firstly, she looks at the impact of d/Deafness and mental health, which could easily be labeled as a modern phenomenon. Secondly, Schmidt tackles Usher’s syndrome, a condition that leads to the individual being d/Deaf-blind. She makes it clear that she is not offering a comprehensive history of d/Deaf-blindness, rather a case study of one condition. Nevertheless, she draws out themes rarely discussed in disability and d/Deaf histories, such as what it meant to have multiple sensory differences within a community, how professionals viewed d/Deaf-blindness, and what happened when those with a certain condition were able to participate in the medical conversations around them.

Schmidt is aware throughout the book that by nature the history of both those working in genetic counseling and those who received genetic counseling in twentieth-century America were largely white and middle class. This creates a narrative that does not tackle intersectional matters of d/Deafness and race, class, or sexuality; however, it does offer these topics up as potential foundations for future work. While including a lot of material on d/Deaf communities and some of the experiences of d/Deaf and d/Deaf-blind individuals, the book is largely a story of hearing and sighted professionals and the transformative effect encountering d/Deaf and d/Deaf-blind people had on their work. This poses the question of how d/Deaf and d/Deaf-blind people responded to developments in genetic counseling; the level of importance d/Deaf and d/Deaf-blind people placed on counseling could perhaps be determined by exploring where the topic does, or does not, appear in material relating to them.

Overall, this is a fascinating work that creatively connects case studies that, through another lens, may seem disjointed. It serves as both an important work in its own right and a springboard for potential new and exciting endeavors.


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