In 2019, Russian scientist Denis Rebrikov announced that he was using CRISPR technology in embryos to repair GJB2 – a gene mutation linked to deafness – to prevent offspring of deaf parents being born with hearing issues. The controversial announcement has sparked debates on the risks and benefits of gene editing and the ethics of such technological intervention, but the research is another waymark in a long history of biomedical attempts to eradicate the pathology of deafness. Thus, the relationship between technological progress and the deaf community is strained, continuously marked by distrust, as scientific promises of normalization are perceived by the community as a masquerade for cultural genocide.

Marion Andrea Schmidt’s book Eradicating Deafness? is a necessary and relevant intervention for historicizing these relationships and understanding changing ideas about biological and cultural diversity, reproductive rights, and genetic intervention. Tracing how perceptions of deafness and deaf people emerged in the United States within early twentieth century eugenic ideals, Schmidt chronicles how hereditary research evolved alongside researchers’ interactions with patients, educators, and the broader field of genetics research. At the core were ideas about the creation of a “modern, progressive, and productive citizen” (p. 6) that aimed both to protect and distance deaf people from more coercive eugenics policies targeted to disabled people. What becomes clear, Schmidt argues, is that changing and divergent definitions of disability influenced cultural expectations of deaf people as “normal” citizens – including, for instance, by advocating for them to marry hearing people to limit the hereditary risk of deaf offspring.

Although Alexander Graham Bell’s 1883 essay, Memoir Upon the Formation of a Deaf Variety of the Human Race, has been vilified by deaf activists for propagating harmful audist perceptions of deaf people, his views were adopted by researchers through his advocacy of oralism – education through speech rather than sign language – as a “prime eugenic tool” (p. 22). After all, it was at residential schools for the deaf, Bell explained, where the tendency for deaf intermarriage occurred, sparking fears of class (and racial) separation. Educational reform and oralist assimilation were essential for preventing the further spread of a “deaf race.” Thus, Schmidt begins her analysis at the Clarke School for the Deaf in Northampton, Massachusetts, the first oralist school in the US, where eugenic ideas about normalcy and social reform were implemented by educators and researchers. She argues that it was at Clarke in the early twentieth
century, where “psychologists first produced a sociological study of deafness as a relational, interpersonal phenomenon and of deaf people as a social minority – long before such definitions became fashionable in linguistics or social science” (p. 35). This sociological framing of deafness is reflective of how heredity research and eugenics were central to the school’s oralist mission and the complications of professional alliances. Clarke’s research department was established in 1928 and presented as a “triumphant story” for normalizing deaf children through science, but Schmidt unravels how the department actually served as a microcosm of differing professional approaches to addressing the “problem of deafness.”

The early roots of sociocultural models of disability that were devised at the Clarke School significantly shaped professional perspectives on hereditary deafness. Chapter Two outlines how collaborations with the school and leading research institutions, including the Eugenics Record Office and the National Institutes of Health further stressed divergent approaches for how deafness should be scientifically managed. Schmidt outlines a dizzying array of scientists – genetics, physicians, biologists, anthropologists – to trace how the school’s heredity research shifted against the backdrop of the coercive state-driven eugenics of the 1920s and 1930s, to the modern medical genetics of the 1950s and 1960s that emphasized individual autonomy (p. 43). While oralist educators argued that heredity counseling was necessary to restrict the reproductive agency of deaf couples so as to advocate assimilation to hearing society, the increasingly sophistication of genetics research pushed for the opposite. Science, geneticists argued, was democratic, and thus heredity counseling should enable, rather than restrict, reproductive choices (p. 64).

The second half of the book moves away from the Clarke School and examines other institutions of genetic deafness research. The work of psychiatric geneticist Franz Kallmann and his colleagues at the New York State Psychiatric Institute significantly influenced psychotherapeutics to genetic counseling (Chapter Three). Complicating Kallmann's historical reputation as a “hard-line eugenic determinist,” Schmidt argues that Kallmann's last project on deaf people is reflective of a paradigmatic shift in how mid-century health reform in New York State constructed psychiatry as a service and consumer good (p. 76). It was at NYSPI where genetic counseling was presented as a collaborative community service between professionals, deaf community leaders, members, patients, and activists – deaf people came to be defined as a minority with their own culture and language, and thus entitled to medical services in sign language.
Not all scientists, however, agreed on the sociocultural minority model of deafness. In the 1970s and 1980s, genetic counseling and “therapeutic abortion” remained the primary avenue for preventing Usher Syndrome, a genetic disorder characterized by progressive deafness and blindness (Chapter Four). Despite the increasing number of professionals embracing the sociocultural minority model and rallying with Deaf activists to challenge oralism, Schmidt argues that these same professionals considered deaf-blindness as a tragic disability that should be prevented at all costs. McCay Vernon, for example, a life-long ally of deaf culture, argued that Usher Syndrome was “a grave congenital disability that threatened unborn children, and burdened public health with the cost of care for a group of people whose lives were barely worth living” (p. 109). Schmidt’s discussion of deaf-blind activists – including Arthur Roehrig and Linda Annala – provides a fascinating disability perspective against scientific ableism and how activists negotiated “the borders of disability and difference” to manage intertwined identities as deaf, disabled, and as patients within their communities and medical spaces. (p. 128). This is also a crucial chapter for examining the intersectional and often conflicting identities among deaf and disability activists within the broader disability rights movement of the 1970s and 1980s. The final chapter deals with the same period, focusing on how geneticists Walter Nance, Joann Boughman and Kathleen Arnos committed themselves to non-directive, client-centered counselling. By forming alliances with deaf communities, they rooted their research at the Gallaudet Genetics Service Center (est. 1984) to promote an “empowering dimension to genetic self-knowledge” (p. 157). Doing so required scientists to assimilate themselves to deaf communities and blur the line between experts and subjects, thereby reconstructing deafness not as a pathology in need of a fix, but as a cultural and biological diversity.

A masterful study of the history of genetic deafness research, *Eradicating Deafness?* exemplifies how new historical perspectives can be developed by merging disability history with the history of science. Hereditary deafness research is one aspect in a larger narrative of scientific progress and medical charity; it is rooted in transforming deaf identities and the need to center disability perspectives in traditionally paternalistic spaces, a point that is all the more relevant for examining contemporary spaces where disabled people are restricted from accessing the proper medical care that they need. Schmidt is careful, however, to acknowledge that these spaces were advocated mostly for white and middle-class respectability and the (perhaps charitable) need to turn “worthy” deaf people into good, productive citizens. It would have been
interesting, nevertheless, to examine how non-white deaf people who might have also intersected these spaces would have been perceived and whether they could have benefited from the same form of heredity counseling that was essentially rooted in eugenics ideals.

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