

Measuring the Science of Hereditary Deafness

Jaipreet Virdi, NIH Keynote

Irreducible Subjects: Disability and Genomics in the Past, Present, and Future

[Title Slide: illustration of a Mendelian chart for a deaf and hearing family overlaid with a white square graphic featuring the text “Measuring the Science of Hereditary Deafness, Jaipreet Virdi Associate Professor, University of Delaware”]

Introduction: A Crisis of Care

Good morning, thank you for joining us. I am pleased to be deliver this keynote and want to thank Dr. Donohue for the invitation and to the interpreters and captionists for their work.

The topic of this symposium, on disability and genomics, asks us to think deeply about the entangled roots of ableism within science and medicine, both historically and in our present-day clinical encounters. The topic, I find, also prompts us to consider questions about authority: whose authority matters within healthcare, whether in the laboratory or in the clinical space? And how does authority shape, or is shaped by, encounters of ableism?

These are questions that I address in my current book project, provisionally titled *Medicalizing Deafness: Aural Surgery in 19th Century Britain*. I will be sharing aspects of this project today, namely on how increasing statistical studies on deafness and ear diseases in the late nineteenth century presented worrying data about hereditary deafness, thus sparking greater medical and state intervention at the site of these concerns: deaf schools.

[SLIDE 2: Text says “Introduction: A Crisis of Care”. There is a beige graphic on the right.]

To contextualize this history, I want to begin by briefly sharing an anecdote about a crisis of care, or the challenges of what historians refer to as the “silence of the archive,” or more specifically, the difficulties of encountering deaf and disabled perspectives in the archive that are not presented through an auditory standpoint.

As a historian of medicine, science, and technology, my approach to writing deaf history tends to be skewered through the perceptions of those who are engaging with medical care and knowledge—namely, the practitioners who specialized in deafness and ear diseases, who referred to themselves as “aurists” or “aural surgeons”—and by the end of the 19th century, as “otologists.” While they predominately approached deaf people as subjects for developing theories on disease causation and hearing loss, some of these practitioners considered access to language and education as essential as medical care for a deaf person’s wellbeing. As a result, they extended their reach beyond the clinical

space to schools for the deaf. Centering disability history, however, my research considers how deaf people and the concept of deafness, both in its suppression and active resistance to intervention, has shaped the ways aural surgeons thought about their roles as medical experts within the various institutional roles they crafted for themselves.

[SLIDE 3: Text says “Introduction: A Crisis of Care”. On top of the beige graphic is an illustration of a typical large 19th century institution surrounded by trees. Text below in script says “Asylum for the Deaf and Dumb”]

Beginning in 2009, when I first embarked on this project as part of my doctoral dissertation, I was focusing on the institutional and medical history of the London Asylum for the Deaf and Dumb. Initially founded in 1792 as the Asylum for the Support and Education of the Deaf and Dumb Children of the Poor, this was the first public school providing education and training to deaf children in the United Kingdom, expanding and relocating several times before being settled in the twentieth century as the Royal School for Deaf Children in Margate, Kent.

Correspondence with the administration at the school revealed that there were archival materials available for researchers, some of which dated to the school’s founding. Certainly, I was overjoyed, but repeated requests for access went unacknowledged, if not completely rejected. After reaching out to members of the British Deaf History Society who had previously accessed the material and helped in its organization, I learned that the materials were not maintained in any fashion adhering to archival standards—boxes were essentially dumped in a trailer, some of which encountered water damage. I spent the next five years requesting to view the materials, and not even a letter of introduction from the President of the British Deaf History Society would grant me access.

Reluctantly, I moved on from this project.

[SLIDE 4: Text says “Introduction: A Crisis of Care”. On top of the beige graphic is an article titled “UK’s oldest deaf school closes amid concerns children are being let down,” below there is a photo of a classroom with a teacher assisting two children who are at work. The children have cochlear implants.]

Meanwhile, in 2016, after 224 years of service, the Royal School permanently closed when the John Townsend Trust went into administration after decades of neglect and mismanagement and following reports of a longstanding history of physical abuse against the pupils; some records as late as 2014 testified that multiple pupils reported staff mocking them for being unable to hear and even physically restraining them to ensure they avoided signing.

The archive was initially lost, but then recovered and now are maintained by the Kent County Council; while I have thus been able to restart my research, the unfortunate

closing of the Royal School captures broader cultural shifts about the place of deaf people within British society and the legacy of medical intervention within educational spaces.

Deafness is classified as the second most common disability in the UK, with approximately 11 million people diagnosed with hearing loss, 900,000 of whom are severely or profoundly deaf and communicate with BSL. Yet deaf people report significant barriers to education, employment, and access to health services. At least 40% of deaf people—and even more who are signers—reported mental health issues brought on by barriers in social and welfare services and struggles with accessing healthcare. One study revealed that 77% of deaf people whose primary language is BSL have difficulty communicating with their doctors; at least 30% avoid the doctor altogether out of fear or frustration.

Not even the passing of the Equality Act in 2010, which limits disability as one of the nine protected characteristics against discrimination, has reduced misconceptions and assumptions about deaf people and the problems of accessing health services, including discrimination caused by communication difficulties. In 2021 for instance, an elderly deaf man in Edinburgh was given a do-not-resuscitate order without his knowledge or consent; such issues and more were compounded during the height of the covid pandemic when lockdown regulations, mask mandates, and increased telephone contact at clinics complicated communication for deaf signers and lip-readers.

[SLIDE 5: Illustration of a male physician examining a child's ear. The child is held by a mother. Below is text titled "Medicalizing Deafness: Aural Surgery in 19th Century Britain" and summary points for what is being spoken]

In my book manuscript, I argue the roots of this crisis of communication and care can be traced to arguments by nineteenth century British aural surgeons who claimed that education and medicine would produce self-sufficient deaf citizens who would otherwise be "lost in perpetual science." Their perspectives held steadfast toward the start of the twentieth century, when nativist and eugenic concerns about the costs and of treating and caring for "degenerate" or "deficient" people significantly shaped education discourses. Acting out what historian Mark Jackson defines as the "medico-pedagogical approach," aural surgeons secured their authority by extending the roles outside of the clinic, and more crucially, by offering intellectual respectability for translating statistical data into social policy.

My talk centers on one issue within this broad history, that on how increasing concerns about hereditary deafness in the late nineteenth century were shaped by statistics and eugenics, transforming the tenets of deaf education. As we shall see, concerns about hereditary deafness were by no means standard, nor universally agreed upon, but the alarmist rhetoric was powerful and worrying, thus shaping the lives of deaf people for generations to come.

[SLIDE 6: Text says “Statistical Authority.” There is a beige graphic on the right.]

Statistical Authority

The professional expansion of aural surgery and the authority of aurists occurred within the broader context of Victorian optimism about the application of scientific medicine to solve a range of social problems. The optimism appeared self-evident in a society rife with perceptions of imperialism in the applied sciences, and in which expectations of progress required new, promising scientific strategies for understanding the social calculus.

Social problems became issues for statistical analysis.

Of course, while discourses on the application of statistics for moral and social reform were by no means homogenous, numbers, graphs, and formulas possessed immense rhetorical power, especially when enhanced by bureaucratic management.

[SLIDE 7: table of different diseases of the ear as treated at St. Mark’s Hospital in Dublin]

Aural surgeons had long compiled narrative case studies of their patients and maintained records within hospital annual reports; the data lent support for how they assessed the prevalence of deaf populations, and how they interpreted and categorized ear diseases—especially hereditary deaf-mutism which proved difficult to treat, let alone cure. British educators of the deaf as well, maintained records of their pupils’ health status, including details about probable or actual causes of deafness, the rates of hereditary deafness, and the presence of deaf-mute people in a given population.

Congenital deaf-mute people with generations of hereditary deafness—particularly through deaf intermarriage (marriage between deaf persons)—fell at the center of eugenic debates. Otologists and oralists alike raised several questions: was hereditary deaf-mutism a single variation easily transmitted through deaf families who intermarried? Was congenital deafness a hereditary trait? Would marriages between hereditary deaf and hearing partners further spread deafness and thus pollute the national stock?

[SLIDE 8: Text says “Statistical Authority”. There is a beige graphic on the right with text overlaid summarizing the points that are being spoken.]

It is at this juncture that hereditary deafness became a pressing issue, as notions of prevention and medical surveillance became intertwined with eugenicist ideology. Largely perceived as an ideology of the professional middle class, but also attracting attention from scientists, policy makers, and social reformers from across the political spectrum, eugenics was hailed as a solution to the pressing problems of British society—urbanization, disease, pauperism, moral degradation—and a tool for augmenting class, gender, and race-based divisions. It offered intellectual respectability by translating scientific data about heredity into social policies, particularly to quell broader evolutionary

debates about human nature, and to reduce costs of treating and caring for “degenerate” populations. While evidential findings of degeneration tended to be anecdotal rather than statistical, fears of degeneration nevertheless influenced public health policies and legislative reform.

[SLIDE 9: Text says “Statistical Authority”. There is a beige graphic on the right with a table showing the selection of large families with generational deafness and the propensity of generation in which a deaf child was produced]

Between 1890 and 1930, eugenicist policies took root across deaf institutions. Oralism, the pedagogy of speech, rather than sign, was presented as a way to “give teachers the responsibility and ability to instill spoken language in deaf people, returning them to hearing society and thus human evolution.” Indeed, as one medical practitioner asserted, the issue of teaching deaf children speech “is so largely a social and eugenic one.” Oralism then, was presented as a method for providing deaf children with respectability, literacy, and mannerisms as manifested for social mobility, especially when supported by state provisions.

[SLIDE 10: Text of quote]

Education was positioned as the site where different experts could meet to apply eugenicist ideas for tackling concerns of deaf inheritance, a point stressed by one instructor: “Education is the only remedy that can in any way mitigate the ills which mankind are liable to transmit to their descendants.” This eugenic impulse to stratify deaf children through questions of heredity was thereby part of a larger process of normalizing and standardizing deaf education and tied to progressive goals of health, prevention, and efficiency.

That is, the ultimate goal was to reduce, if not eliminate the “risk” of hereditary deaf-mutism “spreading unchecked” through the population.

While British aurists were entangled with issues of deaf education throughout the nineteenth century, the level of their engagement steadily increased after the 1880s, as they faced greater responsibility for protecting the health and welfare of deaf schoolchildren, including through early prevention programs to halt progressive deafness.

[SLIDE 11: Text summarizing the key events outlined in presentation]

Several key events occurred in the late nineteenth century that would drastically transform aurists’ role within deaf education.

First was the results of the Second International Congress on the Education of the Deaf that occurred in Milan in September 1880. A multi-national event drawing 164 educators, physicians, and laypersons—dominated by Italy and France, with a combined 143

delegates—the discussion exclusively focused on the issue of methods of instruction for educating deaf children. Only one deaf delegate attended, as the convention was mainly managed by promoters of oralism.

At the end, the convention passed eight resolutions declaring the “incontestable superiority of speech over signs in restoring the deaf–mute to society, and in giving him a more perfect knowledge of language,” and proclaiming that the “Oral method ought to be preferred to that of signs for the education and instruction of the deaf and dumb.” By no means, however, was the resolution universal nor did it completely eradicate sign languages from schools for deaf children; in fact, many British schools continued with a combined system of speech and sign.

Second, was the result of several surveys undertaken by headmasters at deaf schools as well as charitable societies to assess the social problems of blindness and deafness with the aims of formulating policies to ameliorate the conditions. The surveys provided essential data for pressuring state action, especially when coupled with the 1861 UK census, which revealed the inadequacy of educational facilities for blind and deaf children.

Third, was the Royal Commission to consider extension of the 1870 Education Act, which established compulsory schooling for children ages 5–12, but did not include special provisions for blind, deaf, epileptic, or physically disabled children, thus allowing many school boards to refuse to include them within compulsory education. The resulting report from the Commission led to the Elementary Education (Blind and Deaf) Act being passed in 1893 to provide every blind, deaf, and disabled child the right to education paid by local rates and Parliamentary grants. By 1907, the costs were covered entirely by taxpayers.

Such state and bureaucratic control gave greater authority to aural practitioners and set guidelines for the education department to incorporate extensive medical policies and to assess—and where possible, even treat—disabled schoolchildren. It meant that deafness was also formally classified as a medical condition requiring certification by a medical practitioner.

In deaf education, then, oralism became identified with rationality, a way of ensuring progress through reason, science, and effectiveness. Yet, the issue of hereditary deaf-mutism appeared resistant to these efforts, and, as I’ll show next, invoked greater alliances between oralists and otologists to ameliorate the worrying potential of a “deaf variety” unresponsive to medical intervention.

Tracking Inter marriage

[SLIDE 12: Text says “Tracking Inter marriage”. There is a beige graphic on the right.]

One concern raised by the Royal Commission was the issue of hereditary deaf-mutism arising from inter marriage and consanguineous marriages, as outlined by the census and

statistical studies of deaf families. They especially placed stock on the increasing hereditary transmission of deaf-mutism as evidence of the importance of oralism. If deaf-mute children were left to their own guises at predominantly signing schools, then they were more likely to form a community of likeminded signers unwilling, if not incapable, of assimilating into the broader society.

[SLIDE 13: Text of quote from Royal Commission report]

The situation in the United States was particularly revealing for comparison, as outlined in the Royal Commission report: “it is said that before education was imparted to deaf-mutes, and before they were congregated in various educational institutions, hardly any intermarried.” In Germany, Switzerland, and Italy, where oralism dominated, the incidence of deaf intermarriage was much lower than in the United States or England.

Although educators at deaf institutions had previously tabulated the incidences of deaf intermarriages, the proliferation of eugenics raised additional fears about heredity, reproduction, and degeneracy. Historian Joseph Murray notes that, while eugenics was not a clearly delineated scientific field during the 1880s—Francis Galton coined the term in 1883—what did exist was “a loose international network of corresponding scholars and scientists interested in the transmission of hereditary traits and its impact on particularly nations or groups of people.”

Tabulating data on the existence of large families of deaf-mutes or that deafness “runs in the family” were maintained by individuals and deaf schools to track the incidence of hereditary deafness. The London Asylum for the Deaf and Dumb, for instance, published in 1859 a list of 23 poor and working-class families. Of the 160 children among these families, 105 were deaf.

[SLIDE 14: Photo of Bell’s *Memoir*. Next to the photo is text saying: “A Deaf Variety” and summarizing the details discussed in presentation]

To weed through the varying statistics on hereditary deaf-mutism, the Commissioners principally drew testimony from Alexander Graham Bell. Earlier in 1883, at the meeting of the National Academy of Sciences, Bell raised the issue of “the fact that in this country, *deaf mutes marry deaf mutes*.” His resulting publication, *Memoir Upon the Formation of a Deaf Variety of the Human Race*, which combined empirical data from American residential schools for the deaf with statistics and probabilities, worryingly concluded that a “deaf variety” was becoming increasingly possible and that there was no signs of the trend slowing down. Bell’s alarmist perspective thereby advocated for eugenicist control through oralism by restricting the segregation of deaf people and encouraging them to socialize in hearing communities. Any formal restrictions or legal bans on deaf intermarriage, he added, would merely promote immoral behavior—and possibly even increased rates of hereditary deafness.

Preventive measures were recommended as most likely to succeed. Prevention was especially successful when disguised as educational reform: eliminate residential schools, forbid sign language use in classroom, and prohibit deaf adults from becoming teachers of deaf children. These reforms would encourage deaf people to focus on developing their oral skills and make them figuratively less deaf, and these perspectives led to *Memoir* becoming an oft-cited source on deaf history. It also drew the wrath of deaf people, who considered Bell's eugenicist views damning to their communities.

Bell's views were summarized and repeated in newspapers, magazines, and speeches worldwide. Considered cutting-edge research at the time, his *Memoir* drew inspiration from Galton's statistical empiricism and viewed deaf people as an ideal example to study how "continuous selection" influenced evolution. While this scientific stance was not new to those who worked with deaf people, Bell's reputation drew wider public attention to the topic of hereditary deafness.

His study of 757 cases of intermarriage between deaf-mutes was especially persuasive for the Commissioners' stance on the topic. Bell found that of the 1,514 persons who intermarried, 1,443 were deaf-mutes, 5 percent of whom married hearing persons while 95 percent married other deaf people.

The Commissioners professed that Bell's studies and supporting research was "sufficient evidence to prove that there is a real danger of an increase of congenital deafness," and they recommended that intermarriages of congenital deaf-mutes "should be strongly discouraged."

Their resolution exemplifies how the issue of deaf intermarriage reflected changing ideals about expectations for deaf people to assimilate into society and the costs that taxpayers and state aid were required to cover.

[SLIDE 15: illustration of costs of educating children. There are four boys and next to them are circles indicating their costs, with the deaf child's circle being the largest: Normal child, 5-3-0; Deaf 31-7-6; Mentally deficient, 7-17-1; Physically deficient, 11-19-6]

Reports from the London County Council, for instance, indicated that the costs of educating a deaf-mute child amounted to £31 per annum, compared to £5 spent on a normal child. If the numbers of deaf children continued to increase—especially hereditary deafness tracked through deaf intermarriage and for which medical intervention was ineffective—then, as one eugenics textbook asserted, "deaf-mutism is therefore a very expensive condition for any community to maintain, even if the children, when educated, are able to support themselves."

Not all experts agreed that the threat of hereditary deaf-mutism was as deeply concerning as oralists claimed it to be. Arthur Henry Bather, the secretary of the Royal Association in Aid of the Deaf and Dumb, and one of two deaf signers invited to testify for the Royal Commission, strongly opposed to Bell's findings and prescription, as did American

educator Edward Miner Gallaudet. Moreover, while Bell tied the prevention of deaf intermarriage to the health of the nation, statistics provided by deaf people, skeptical educators, and missionaries questioned Bell's evidence and showed that deaf intermarriage only infrequently led to deaf-mute offspring.

[SLIDE: 16: Text says "Prevention as Control". There is a beige graphic on the right.]

Prevention as Control

Meanwhile for otologists, the discourse offered ample opportunities to illustrate the importance of their field for guiding social and educational policies to advise on the issue of hereditary deafness.

[SLIDE 17: Text says "Prevention as Control". There is a beige graphic on the right, with overlay text summarizing points discussed in presentation]

Their roles became more profound after the 1893 Elementary Education Act and its later provisions, which compelled school boards to provide for blind, deaf, epileptic, and disabled children. Medical experts controlled the selection process, examining and certifying children who were referred for special schools or classes, thereby positioning medical surveillance as a quasi-eugenicist approach for managing disability in state-funded provisions for education. Otologists assessed children's hearing, diagnosed their deafness, and, where possible, recommended surgical intervention—especially the removal of tonsils and adenoids—to correct hearing defects before a child could be admitted to school. They especially looked for symptoms of hereditary deaf-mutism to discountenance intermarrying.

Many otologists agreed that early recognition, prevention, and treatment of aural afflictions were essential for identifying causes of deafness for intervention. Some, however, took more extreme views when it came to hereditary deafness.

One of the most outspoken otologists on the issue of preventing hereditary deafness was Percival Macleod Yearsley. In his role as the first Senior Aural Surgeon and medical inspector to the London County Council (LCC) schools, he had ample opportunity to judge the working of the system of deaf education, and opined that "the whole system of deaf education in this country needs thorough reorganization."

[SLIDE 18: Table of London County Council school classification system for deafness as outlined by Percival MacLeod Yearsley, and corresponding educational treatment required]

This was partly because the 1893 Elementary Education Act fixed the starting age for deaf schoolchildren at seven years of age (whereas that of the ordinary child or blind child was five years), thereby curtailing any opportunities for early medical intervention and proper

assessment of the child's mental abilities. The results, then, Macleod Yearsley argued, meant too many deaf children were being placed in deaf schools when they could otherwise benefit from oral classes to obtain speech and make use of their residual hearing.

Even though the causative factors of acquired and congenital deafness were recognized and understood by otologists, Macleod Yearsley argued that too much emphasis was placed on "cure" and not enough on "prevention." As he elaborated, for most cases of deafness, a cure is usually hopeless.

Under Macleod Yearsley's system, all children in the LCC had their hearing preliminary examined during their first year by the school doctor or a nurse under his supervision who attended to the schools daily. All children who were preliminarily diagnosed or suspected of deafness to be recommended to a local otologist or sent to the head office at the LCC medical department for examination. Upon assessment, a child would be classified into three primary groups—the very deaf, the semi-deaf, and the slightly deaf (which later was further divided into the "hard-of-hearing")—and then adequately recommended for treatment, such that "of the whole number of cases detected by this method some 50 per cent would be cured, and of the remainder a good proportion would be capable of considerable improvement."

Under Macleod Yearsley's method, this dual process of "efficient education and efficient treatment" would detect a considerable number of cases of early deafness and "could thus materially diminish the number of acquired deaf-mutes and of those deaf children who need special education."

[SLIDE 19: Text of quote]

By no means was Macleod Yearsley diminishing the value of special education, though he did make his position on oralism abundantly clear: "Hearing is the most important education sense because it channels through which the child obtains the speech and language which he cannot think and reason clearly." Rather, he claimed that the medical failure to properly assess deaf and deaf-mute children's physiological and psychological abilities for language and speech led to increased costs:

[SLIDE 20: Text of Quote]

Recent statistics show that the cost of education, per head, of the deaf-mutes in the London County Council Schools is £31 7s. 6d. *per annum*. This includes both residential and day scholars; if we deduct the former, the cost is £23 6s. 1d. The expense of educating the normal child in the elementary schools is £5 3s. *per annum*, so that we are paying no less than £18 3s. *per annum* extra for the education of one section of our defective children. This is an appeal to the pocket which should have some effect upon the ratepayer.

Deaf education, he argued, could only be improved through different aspects—medical, hygienic, physiological, social, eugenic, and financial—such that the present system could be remodeled to “justify any increased expenditure and will greatly increase the happiness, usefulness, and value to the state.” Yet the system of deaf education, Macleod Yearsley explained, was a “comparative failure,” and too many children were being placed in special education and becoming “oral failures.” Requiring deaf children to associate with their hearing counterparts and less with each other—and, hence, reducing signing—was better for assimilation.

Indeed, Macleod Yearsley’s research of deaf children in the LCC schools indicated that, of 691 children, 284 children, or over 41 percent, were diagnosed as congenitally deaf-mute. To diminish the number of congenitally deaf-mute children requiring special education and to address social and educational issues of “true hereditary deafness,” Macleod Yearsley advocated the “application of eugenic principles.” It was impossible to totally eradicate congenital deafness, but he argued that, through eugenics, the restriction on “deaf-mute marriages, the union of blood relations, and the union of alcoholics, syphilitics, and those with a family taint of insanity could be prohibited,” thus enormously reducing the numbers of hereditary deaf-mutism.

Macleod Yearsley’s eugenicist stance was abundantly clear: “There is another important suggestion which would do much to eliminate the congenital deaf-mute ... It is sterilisation. Every congenital deaf-mute should be sterilised. I am afraid that this statement is a bold one, but I do not fear to say it here. Science has, fortunately for Eugenics, made sterilisation possible with a minimum of danger.” Were those 284 congenitally deaf-mute children sterilized, he concluded, then educators and medical practitioners could better attend to the 407 acquired cases and get “better results.”

Far from being an outlier, Macleod Yearsley’s stance was an extension of his colleagues’ views, as he argued that any treatment or study of the deaf child required cooperation between the eugenicist, the hygienist, and the legislator. Moreover, he added that where surgery failed, oral training—and, if necessary, segregation or sterilization—was required to reduce the incidence of deafness in future generations. As he declared: “Where deaf-mutism does not pre-exist, intermarriage will not create it.”

[SLIDE 21: Photograph of a group of deaf children in a classroom looking stoically at the camera; overlay text says “Conclusion”]

Conclusion

What does this history of statistical studies and concerns about hereditary deafness tell us then? For one thing, it underscores how eugenics deeply informs much of modern medicine and deaf education. Statistical data compiled by aurists and educators of the deaf presented a somewhat worrisome picture of what would occur if deafness, especially

hereditary deafness, was not adequately managed: a “deaf variety” would emerge, social programs would be drained, and taxpayers would bear greater burden for financing deaf education.

Secondly, despite the rich history of sign language, deaf communities, and Deaf culture, deafness is perceived primarily as a medical “problem” that requires a “fix.”

The increasing inequities and barriers deaf people faced—and continue to face—are further complicated by the fact the eugenicist agenda of “eliminating” deafness—or at the very least, preventing a “deaf variety” as Bell cautioned—remains an ultimate goal for medical science. Yet far from being a sinister dystopian scenario led by ambiguous and callous scientists, these eugenicist perspectives are so thoroughly embedded in society that the future potential of a “deafness cure” is regularly celebrated as a triumph of science, though the moral implications remain debatable concerns.

Thank you.