

History and genetics: Stories of Deaf people

Carol Padden

University of California, San Diego

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The Pennsylvania Institute for the Deaf and Dumb (PIDD) has the distinction of being one of the first schools for deaf children in the United States, opening its doors in 1820. As we explain elsewhere (Padden & Humphries, 2005), the school had among its first Board of Directors some of the leading philanthropists, doctors, lawyers and businessmen of Philadelphia. Perhaps because there were lawyers on the Board of Directors, the school maintained meticulous records about its operation during the earliest years of existence. Among the documents that have survived is a “Record Book,” containing information on each deaf child who was admitted to the school. At first, the notation for each child was brief, listing the age when they were first admitted to the Institute, the names of their parents or guardians, the county of residence, and cause of deafness. A few years later, the Institute demanded more detail about the cause of deafness and parents or guardians were asked to identify for the record whether their child “Was born deaf, or did...lose hearing through disease, and at what age?”

James C. Murtagh was born in December of 1806 and was admitted to the Institute in November of 1820. As with a number of other deaf children recorded in the book, he is listed simply as “Born deaf.” James McCauley, born in 1807, falls in the category of those who became deaf. McCauley’s record lists no cause, but Sarah Ann Ankings, admitted in June of 1821, “lost hearing by poison-laurel at about 2 years old.” Another

young girl who joined the Institute in 1825 “became deaf by a fall at 16 months. Those with some hearing were recorded as “not entirely deaf,” as in the case of Charles Stull, and Isabella Gossler whose stay at the Institute was “on trial because she hears but cannot speak.” She stayed only two days.

Those petitioning to have their children admitted to the Institute were asked to report whether the child had deaf relatives. William Longacre, of Union County, noted as “Born deaf on April 22, 1812,” had “one other of the family deaf.” John Carlin’s entry listed him as born deaf and that he had a “D&D [deaf and dumb] brother, Andrew.” Elizabeth Williams, accepted as a student in 1821, “has a D&D brother, Edward.” Catherine and Mary Hartman, two deaf sisters admitted to the school, had parents who were “both born deaf.”

Andrew Carlin’s entry had an additional notation at the bottom, in different handwriting and ink, evidently recorded at a later date that he had “Married Anna M. Turner (deaf)..12 h. children,” or that he and his deaf wife had twelve hearing children. In fact, a number of the records in this Book contained additional notes about the student’s life after leaving the Institute: who they married, how many children they had, what occupations they took up, and whether deafness persisted into the next generation.

From the earliest years of deaf education in the United States, there has been a differentiation between deaf children who “lose their hearing through disease,” and those with deaf relatives, having inherited the condition. Though modern genetics, or Mendellian genetics, did not become recognized until the second half of the last century, it was known through the nineteenth century that deafness could be inherited as well as

induced by illness (Greenwald, 2006). And to the present day, the twin categories of illness and inheritance are still active: Contemporary textbooks or websites on deafness will list the two categories as causes of deafness. Through the lens of almost two hundred years of science and medicine, we can retrospectively evaluate these reports from the nineteenth century as likely or unlikely causes of deafness, but as I will discuss shortly, this is not the point I wish to make here.

In her classic collection of essays, *Illness as Metaphor*, Susan Sontag (1977) drew our attention to *illness* as a category thought about and written about in metaphoric ways. To demonstrate, she contrasted two illnesses: tuberculosis (“consumption”) and cancer. Though both are “wasting” and painful illnesses, tuberculosis is likely to be presented in popular imagery as providing an “easy death,” unlike cancer which is “invariably, excruciatingly painful.” Individuals with these illnesses are likewise imbued with metaphoric content; tuberculars are “reckless and sensual,” but cancer patients are “repressed,” and show symptoms of negativity such as such as frustration and stress. The two illnesses commandeer the body in different ways: Tuberculosis is a disease of an organ, the lungs, so the affliction of tuberculosis focuses on acts of breathing, coughing and other respiratory events. Cancer on the other hand is a more broad and insidious disease voraciously consuming the entire body, as those dying from it face bodily deterioration. She persuades us that the imaginary of illness divides the universe of disease and affliction into categories, and for each there is a cultural currency of ideas about illness. For Sontag, the facts of the illness stand apart from how we present the illness to ourselves and others.

Here I would like to demonstrate an imaginary tied to illness of a different kind, the kind that cause deafness. This imaginary, as I have outlined in preliminary form above, reliably cleaves into two: on the one side, deafness induced by disease and on the other, deafness transmitted by genetic cause. As we see from PIDD's admissions records, the divide is quite visible. For those deaf children who have deaf brothers and sisters, or deaf parents, there is no further description about their deafness and how it was acquired. Over time, they bear more scrutiny as notations are added to their records about their marriages and subsequent children. For those who became deaf by illness, we read a litany of causes: poison-laurel, falling, fever. We imagine a child ingesting a plant by accident, or falling by accident, or becoming ill through no fault of one's own. Even as early as 1820, an outline of the two causes emerges: one is accidental, surprising, and arrives without expectation, and the other is less so. In the latter case, if one is deaf and has deaf relatives, we look to see if they have transmitted the condition to their children.

Because this is a conference of scholars interested in deaf people's own history, I will limit my task here and focus on stories that deaf people tell about their own deafness. Here, categories of deafness exist in a parallel realm, interacting with but different in palpable ways from institutional definitions of deafness. Where institutions like PIDD use illness as a category for purposes of social classification, namely who is eligible for state support in a specially built institution, stories of deaf people about themselves are more emblematic of the self, etched into their lives very early in their development and carried like identity badges as they move through life.

Let me illustrate the palpability of one's own story with an example: my personal story. I have deaf parents and deaf grandparents on my father's side. My grandmother on my mother's side is hard of hearing. I have an older deaf brother, and I describe myself as deaf, also as someone who wears hearing aids and uses spoken English. My brother and I grew up in different circumstances; he attended a school for deaf children through graduation. I also attended a school for deaf children but at age 8, I transferred to a public school with a small program for deaf and hard of hearing children. I never returned to my deaf school, and spent the rest of my education with hearing classmates. The story my parents tell about my brother is that he is born deaf, and he inherited deafness from my parents and grandparents. In my case, however, my mother says I lost my hearing at age two from high fever accompanying measles. I became deaf by illness.

I never contested this story until I went to college and in the course of a casual conversation, a friend asked if I didn't think it odd that I lost my hearing from measles when everyone else in my family inherited the condition. It was a moment of existential surprise: Why would my brother and I be given different descriptions of ourselves? Was it because he was deaf and I wore hearing aids? Was it because I had some hearing unlike my brother and my other family members, that my mother believed I might have acquired my deafness differently? We could conclude, too easily, that because genetic testing did not exist when my brother and I were children, families like mine are free to offer one or the other as possible causes for our condition. Such a conclusion does not explain why these stories have tremendous circulation still today. Deaf actors' personal websites, for example, in which they list their accomplishments and upcoming appearances on television include these types of stories explaining their deafness. It is not enough to say

simply that the actor grew up in a small town (or a large city), and that their parents encouraged (or didn't encourage) their interest in acting. The actor is compelled to say in what way she is deaf, specifically which of the two causes applies in her case. A bio for a young deaf actress, Shoshannah Stern, says: "Born into a fourth generation deaf family, Shoshannah's first language is American Sign Language."

Because there is such necessity to identify oneself in these stories, I want to move to a different and subtle argument. Together and in opposition, stories about causes of deafness present as Snyder and David Mitchell (2001) claim about disability narratives in general, the "scenario of a cultural production, writ large." Stories about the condition of deafness, whether by illness or inheritance, individually are small productions, but collectively, construct an active cultural imaginary. As the ground shifts over time, as new vaccines are discovered and genetic testing expands, stories of deafness change, yet in some ways have perceptible narrative threads.

To illustrate, I begin with a number of examples from the middle of the last century. These are personal stories appearing in monthly issues of a news magazine published by the National Association of the Deaf, called the *Silent Worker* between September 1949 and August 1953. Popular through the 1940s and 1950s, the magazine was a principal source of news within the deaf community. Local deaf clubs took advantage of the *Silent Worker's* broad subscription base in the national community to advertise their hours to members as well as outside visitors passing through town. Each issue of the magazine features at least one story about a deaf worker. As the title of the magazine suggests, the focus was on the capable and productive deaf worker. In addition to stories of work lives,

there are pages describing community activities around the country, ranging from church socials to beauty pageants in deaf clubs. In these pages, deaf people are commonly introduced with a description of how they came to have their condition.

The introduction can be as brief as a sentence or a phrase, as in an article about a deaf printer: “Having lost his hearing at nine, Porter could talk some...” A deaf sculptor: “...he lost his hearing and speech when he was five years old.” In a sports article, “At a very early age, he lost his hearing.” In another article, “Bumann, who has been deaf since early childhood, is a graduate of...” The phrases read as matter-of-fact as the mention of a spouse, or the number of children in the family, or the school they attended. These are well-rehearsed details of identification, belonging to the individual.

Many descriptions in the *Silent Worker* fall in the general and neutral category of “born deaf,” such as: “Deaf since birth, Lonnie Tubb, now 41 and unable either to speak or read lips, is one of the central figures in this little town of 7,000. He is owner and operator of the sole shoe-repair shop in that area...” “Robert Stokes, the genial young owner of the business, was born deaf...” Sometimes the phrase stands by itself, “born deaf,” or there is a brief explanation of overcoming this condition, as in the case of Lonnie Tubb. Without overt reference to a deaf family, these are cases where the cause is unknown, such as an illness that did not clearly manifest itself as causing deafness.

When there is mention of a cause, they can include a certain amount of dramatic detail. Stan Muslovski, the featured deaf worker in the March 1953 issue “has made more than ordinary success of an occupation somewhat unusual among the deaf. [He] is not only a successful barber, but also an official in an association of barbers.” After a few

paragraphs, the author explains: “One day when Stan was just 18 months old, he was pedaling a tricycle across the street directly in front of his home. A truck under poor control struck little Stan and threw him off. His head struck the curb. Stan was unconscious for several days following the accident...It left Stan almost totally deaf.”

In another issue the same year, Edwin Meade Hazel, a parliamentarian is introduced thus: “When Edwin was two months old, a nurse applied the wrong solution for the alleviation of an earache, thereby seriously impairing his hearing. Today he has 55% residual hearing in his left ear with which he can and does use a hearing aid device with some benefit. Only 5% hearing remains in his right ear.” Falls cause deafness in 1953, as they did in 1825, “Blanche Miers was born in Avon, Colorado. A fall from a table when she was eleven months old caused her to lose her hearing.”

Not autobiographies or “life writing” (Couser, 2002), these are briefer statements of fact, expressions of self-definition that are carried around for a lifetime. They are not intended as reflective, but something to be said about oneself, as if identifying a hometown neighborhood. Looking back at stories from 1820, “lost hearing by poison-laurel,” or 1953, “the wrong solution for the alleviation of an earache,” the stories date themselves and that is exactly the point. They are small but revealing examples of “cultural production,” linking a biological fact with a cultural practice, in this case, framing one’s condition with fantasies about that condition.

Stories about losing one’s hearing typically are framed as accidental, surprising or unexpected: a truck veering out of control, or a nurse who used the wrong solution. Or, as in earlier times, accidentally ingesting poison-laurel, known today by its contemporary

name, mountain laurel, or by falling. There is no agent for these accidents, or if there is one, it was a careless or unaware agent. Deafness by such causes descends on the individual, through no fault of her own.

The older the child, the more straightforward the cause presumably because the relationship to the illness is easier to recognize. A common cause for older children is spinal meningitis: “During his early childhood, he lost his hearing following an attack of spinal meningitis.” In a story about a deaf watch-maker the same illness is described thus: “while still a lad, he contracted brain fever, which led to his loss of hearing, a result of a deep, wet chill.” With younger children, the causes seem more suspect, even fanciful, because the onset of deafness is often not recognized at birth by unaware hearing parents. In the case of the infant who was given “the wrong solution” for an earache, it is entirely possible he was deaf from birth, and the event of the earache coincided with recognizing deafness in the infant for the first time. Identifying the cause becomes a retrospective act and sometimes, an opportunity for a dramatic personal story.

By contrast, deafness by inheritance is revealed by the path of transmission. Johnny Miller, an athlete par excellence, “is the son of deaf parents, Mr. and Mrs. John Miller, Sr....His dad is a Kendall [School for the Deaf] graduate.” A young deaf woman is described thus: “The youngest of the famed Watson family, Babette Krayeski, first saw the light of day in old Mexico, where her deaf father was running a store. In fact, all in the family but one were deaf...” and “Race Drake made a name for himself in athletics when he was a student at Gallaudet... [he] has a young son at our school [for the deaf] and we are all interested to see if Race, Jr. will follow in his father’s footsteps...” These

are stories about inheritance from one generation to the next, and often include mention of attending schools and having connections with the community.

Transmitting deafness to the next generation has a tinge of agency. Deaf people having deaf children seizes the public imagination in wild and unpredictable ways. Throughout its pages, the *Silent Worker* tries to calm the public imaginary by having stories about successful deaf children of deaf parents (both hearing and deaf). In one issue, the editor is moved to address the issue directly:

The idea prevalent among a great number of persons unacquainted with the deaf is that children of the deaf are likewise deaf, or that they are below par mentally, or that they possess some other woefully inadequate physical equipment. The truth is, of course, that children of deaf parents are no different from other children, except in the occasional instance where two parents whose deafness is an inherited family affliction come together. Even in this case, children of such parents are not always deaf.

When some stranger inquires as to whether a child of deaf parents is deaf, the best advice to give him is to tell him to visit a school for the deaf. There he will find 200 to 400 deaf pupils, and he will find that only a handful of them are the offspring of deaf parents...It has often been said that there is no more reason to believe a child of a deaf parent will be deaf than there is to believe that the child of a one-legged parent will himself have but one leg.... [1949, 2: 31]

Appearing just prior to the discovery of the DNA molecule in 1953, these articles in the *Silent Worker* present “popular genetics” of the time which includes capable observation

about incidence of genetic deafness, that two deaf parents do not always have deaf children. But the account of course does not state the facts of Mendellian genetics, or what we know today about dominant and recessive inheritance. Nonetheless, the editorial has a marked defensiveness on the subject of deaf parents with deaf children.

Now that we are “better informed,” and have access to genetic testing, what happens to stories about the condition of deafness? As some recent news articles have demonstrated, the idea of deaf people having deaf children *still* seizes the public in wild and unpredictable ways. An article appearing in the *Washington Post Magazine* (Mundy, 2002) set off a firestorm around the world, resulting in a flurry of articles in ethics and philosophy journals (Anstey, 2002; Levy, 2002; Mills, 2002). A lesbian couple who are both deaf decide their child will be conceived using the sperm of a deaf friend who has deaf relatives. As Candace McCullough, who herself has deaf parents and deaf siblings, explains to the reporter: “we wanted to increase our chances of having a baby who is deaf.” Here she and her partner claim agency, and judgments of both extremes descend upon them, mostly condemnation and occasional admiration. The fact of the matter is, we operate today in a new kind of “popular genetics,” which is still about deafness brought about by one of two causes: illness or inheritance. This story is decidedly modern: about seeking out the best donor, acquiring sperm, undergoing artificial insemination, and boldly announcing agency instead of being defensive about it. What’s old about this story is that agency is still an issue.

Candace McCullough and her partner did not undergo genetic testing to be sure their choice of sperm donor was in fact a genetic match because such testing was not possible

at the time they tried to conceive. Because Candace herself had deaf relatives, as did the donor, they made a reasonable assumption that genetics was involved in both their conditions. But now, as more genes are identified in dominant and recessive conditions of deafness, routine genetic testing is very near at hand (Arnos, 2003; Nance, 2004).

Shoshannah Stern, the deaf actress, describes herself on a website as “born into a fourth-generation deaf family,” a little different from the story about Babette Krayeski in 1953 where “all in the family but one were deaf.” It is still about inheritance, but over more generations than one or two. Because of vaccines to prevent meningitis, measles, rubella and the eradication of other childhood diseases, it is rare today to hear personal stories about becoming deaf during middle childhood. But in cases where deafness was caused by an illness, that type of story is readily available. Recently I saw a young deaf man announce he had just learned from genetic testing that his deafness is of the Connexin-26 type, now viewed to be one of the primary causes of genetic deafness. Another woman jokingly suggested he should now ask each of his dates if they too tested for Connexin-26. The group laughed, then there was a perceptible pause. How will all these events change the “popular genetics” of the twenty-first century? We will soon know.

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