

Society for American Sign Language Journal

Volume 7
Number 1 *What to Learn from Undergraduate
Research in ASL/Deaf Studies*

Article 4

October 2024

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Recommended Citation

LaVigne, Danielle (2024) "Hereditary Deafness and Society: The Quest for Ethical Awareness," *Society for American Sign Language Journal*: Vol. 7: No. 1, Article 4.
Available at: <https://open.clemson.edu/sasj/vol7/iss1/4>

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HEREDITARY DEAFNESS AND SOCIETY: THE QUEST FOR ETHICAL AWARENESS

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ABSTRACT

An excellent study of genetics and deafness is Martha's Vineyard, a small island off the Massachusetts coast that was once known to have a sizable deaf population. This community that prevailed during the eighteenth and nineteenth centuries relates many genetic concepts, giving insight as to why the deaf population was larger in proportion than that on the mainland. The paper will cover hereditary deafness in more depth than what has been discussed in the American Sign Language/Deaf Studies literature. This includes understanding the significance of population genetics. The paper also takes into consideration that many hearing residents of Martha's Vineyard knew how to sign and where deaf and hearing individuals could communicate with each other effectively (e.g., Groce, 1985). Recently, this sociolinguistic phenomenon has been connected to shared signing communities that prevail in various places around the world (see Kisch, 2008, 2012). Martha's Vineyard, as a shared signing community, inspires many as humans transition into the 21st century with emerging genetic tools, prompting scholars to better understand what it means to be an inclusive society for deaf people. Requiring attention is how deafness has been viewed by many in modern American society as something to eradicate, especially considering the capabilities of genetic engineering. Ethical conversations are thus essential for the field of genetics. Some considerations for social change are made to help facilitate acceptance of the genetic diversity in humanity that encompass a strong sense of ethical awareness.

INTRODUCTION

To understand genetic deafness and society, one must ask this question: What constitutes the common view of deafness? How parents react upon having a deaf child produces insights on the nature of acceptance (or lack thereof) of deafness in the family. The parental emotional reaction often differs between hearing parents and deaf parents. Please keep in mind two factors. One is that the cause of deafness varies from hereditary to accidental to illness-related. The second relates to demographics, with over 90% of deaf children born to hearing parents, whereas the rest, a small minority (less than 10%), are born to deaf parents (Mitchell & Karchmer, 2004).

As a group, hearing parents are known for reacting with shock and grief to the news of having a deaf child. When these parents are told about their child's hearing loss, it is often informed with sadness (Lane et al., 1996; Scheetz, 2004). Hearing parents' responses, as described, can be attributed to how society at large perceives deafness. Deafness is frequently seen as a deficiency and an undesirable trait for anyone to have. The reaction that these hearing parents have is thus predictable.

Deaf parents, on the other hand, do not react to the news of having a deaf child in a traumatic manner, at least in general terms.¹ There are reasons for this outcome, as discussed in the American Sign Language/Deaf Studies literature (e.g., Lane et al., 1996). Deaf parents and the deaf community view deafness as part of their lives instead of living with a negative perception of having hearing loss (e.g., Kannapell, 1989; Ladd, 2003; Lane et al., 1996; Woll & Ladd, 2011). One reason for this positive outcome lies in deaf people, as signers do not see complications associated with language and communication. Over the centuries, deaf people have been known for creating and maintaining their own signing communities that are vibrant and close-knit under the banner of Deaf culture. Deaf people succeed in avoiding the adverse impact of hearing loss by knowing and using a signed language, which is most likely to be American Sign Language (ASL) as prevalent in the United States and part of Canada (e.g., Padden, 1980; Rutherford, 1989; Stokoe, 1960/2018; Valli et al., 2011).

The next question to ask is: What can be done to improve the situation so that hearing parents will have a better and more accepting experience in having a deaf child? One simple, yet profound social bias against deaf people is identified when a deaf and a hearing individual meet and try to communicate. It is common for the hearing person to ask the deaf individual if they can lipread. This question suggests that deaf people must accommodate hearing people by communicating in spoken English regardless of the complications of their hearing loss (see Cripps & Supalla, 2012 for further discussion on the power of spoken language that has not been questioned regarding the deaf community until recently). In a more egalitarian society, the encounter would be different, with the hearing person apologizing to the deaf person for not knowing any signed language. Better yet, the hearing person knows ASL and proceeds to communicate with the deaf person with full access for both.

It is important to note that society is becoming more aware now than ever about deaf people having their own language, ASL. This includes ASL's rapid growth as a foreign language to study and learn for hearing students in high schools and higher education institutions (see Rosen, 2017 for a review of the status of ASL in American society). There are ample numbers of TV shows and films that portray deaf characters. Deaf people have long been thought to be living pitifully in a world of silence and suffering from a lack of language and communication (Avon 2006; McCullough, 2018; Schuchman 1999), but that is now corrected through Hollywood and other avenues. Finally, the common appearance of a signed language interpreter for emergency broadcasts on TV helps the general public to become more receptive to the idea that deaf people are signers in the same way that hearing people are speakers.

One group of 'holdouts' in society are scientists and physicians with negative views about deafness (Harris et al., 2009; Lane, 2005; McKee et al., 2013; Van Cleve & Crouch, 1989). While this does not include everyone in the field, these professionals typically embrace the concept that deafness is an illness that

¹ As additional demographic information, 90% of deaf parents have hearing children, with 10% having deaf children. These hearing children are known as Children of Deaf Adults or CODA (see Singleton & Tittle, 2000 for more information about CODAs).

needs to be treated or cured. This includes the potential capacity to erase deafness altogether through what is known as genetic engineering. The ‘deafness as disease’ point of view has had the strongest impact on societal views of the deaf community, which has resulted in a complex relationship between genetics and deafness (e.g., Burke et al., 2016; Nunes, 2006).

Readers of this paper are welcome to consider Nora Groce’s seminal work that was published in 1985: “Everyone Here Spoke Sign Language: Hereditary Deafness on Martha’s Vineyard.” Groce is a scholar who captured a unique sociolinguistic phenomenon on Martha’s Vineyard, an island off the Massachusetts coast. For many years, hearing residents on the island knew signed language and used it to communicate with others who were deaf. The widespread use of signed language on the island affected the perception of deafness to the point that hearing islanders saw deaf islanders in a positive light. The hearing islanders did not find deaf islanders to be disabled. The hearing islanders saw deaf people as equals in many different aspects of social life (see also Bahan & Poole Nash, 1996; Groce, 1980/2020, 1985; Lee, 1998).

Also important is Groce’s report on the greater proportion of Martha’s Vineyard residents being deaf (vs. hearing) than for the American mainland. She reported that 1 out of 155 islanders was deaf, while 1 out of 5,728 mainlanders (referring to the mainland of the United States) was deaf. The time period for this ratio was during the eighteenth and nineteenth centuries. It is also noted that 85% of deaf children were born to hearing parents on the island, which is less than the typical over 90% seen in the rest of the United States. This indicates that more deaf children were born to deaf parents, causing an increase in the deaf population on this island as compared to other places in the United States. Genetic deafness is what Groce discussed in her book as contributing to the demographics of the island community.

The author of this paper recognizes that the scientific background on hereditary deafness in Groce’s book could be examined at a deeper level. The author is thus committed to covering hereditary deafness in more depth here. The next area of discussion covers the population genetics that the author believes will give readers new insights into the island demographics of Martha’s Vineyard. Ethical considerations in the field of genetics is the last area that the author will discuss to help scientists and physicians in aligning and improving their view on deafness for the benefit of all in society.

A DEEPER LOOK AT HEREDITARY DEAFNESS

Hereditary deafness is when a person is born deaf or born with the genetic information that predisposes them to become deaf in their lifetime. In the United States, one out of every 1,000 to 2,000 people is born with hereditary deafness (UC Irvine Medical Center, n.d.). Many forms of inheritance have been recorded for hereditary deafness, including autosomal dominant, autosomal recessive, and X-linked recessive (Nunes, 2006). However, over 75% of cases present with an autosomal recessive inheritance pattern (UC Irvine Medical Center, n.d.; Duman & Tekin, 2012). Hereditary deafness in a person differs from people who become deaf due to an illness or accident.

For this paper, it is necessary to focus on the autosomal recessive form of hereditary deafness, as this was most likely the case at Martha’s Vineyard. For context, everyone is born with 23 pairs of chromosomes for a total of 46 chromosomes. One set of 23 chromosomes comes from a female (i.e., mother), and the other set of 23 comes from a male (i.e., father), making up the 46 chromosomes that make people as unique as they are. Twenty-two of these pairs are known as autosomes, while the last pair consists of the sex chromosomes X and Y. Chromosomes contain pieces of DNA that code for traits and functions in the body, which are referred to as genes. Genes can come in different forms, which are called alleles (Mendel, 1866).

In Mendelian inheritance, one allele is dominant over the other, whereas the other allele is recessive to the dominant allele (Mendel, 1866). The dominant allele typically covers up the recessive, hence its name. The gene for autosomal recessive hereditary deafness occurs on an autosomal chromosome and is recessive to other alleles. This means two copies must be inherited in order to see an effect, or two copies must be present for a person to be born deaf. If someone has a dominant allele along with their recessive deaf allele,

then they will not be deaf. However, since half of their genetic information is passed on to their children, they will either pass on the dominant allele or the deaf allele.

This pattern can be seen in what geneticists refer to as a pedigree. Figure 1 shows the pedigree for the Lambert family from Martha's Vineyard (from the late 1600s to the late 1700s) that displays an autosomal recessive inheritance pattern for hereditary deafness. Recessive alleles like the deaf allele noted here are known to skip generations. From a genetics perspective, this means that the deaf allele is inherited in each generation but is covered up by the dominant allele most of the time. It is not until two of the deaf alleles come together that it is then seen, making it appear as though deafness is "skipping" generations when, in fact, it depends on which alleles are being passed on through each generation (Mendel, 1866; Strachan & Read, 1999).

In order for two copies of the recessive deaf allele to be inherited, the parents must either be deaf and have two copies themselves or be what is known as a carrier. A carrier is someone who has one copy of the recessive allele but also has one copy of the dominant allele. The dominant allele is typically represented by a capital letter (A), while the recessive allele is represented by a lowercase letter (a) in genetics textbooks (Strachan & Read, 1999). When a person has two of the same alleles, either dominant or recessive, this is known as having a homozygous genotype (AA or aa). If a person has one of each allele, having a dominant allele with a recessive allele, this is known as being heterozygous (Aa). All carriers are heterozygous as they carry a recessive allele with a dominant allele. In the case of hereditary deafness, a carrier would be a hearing person, as the dominant allele covers up the deaf allele, yet they still carry the gene for deafness. This deaf allele could then be passed on to their offspring by chance, as the children inherit only one copy of either allele as both parents contribute half of their genetics to their offspring.

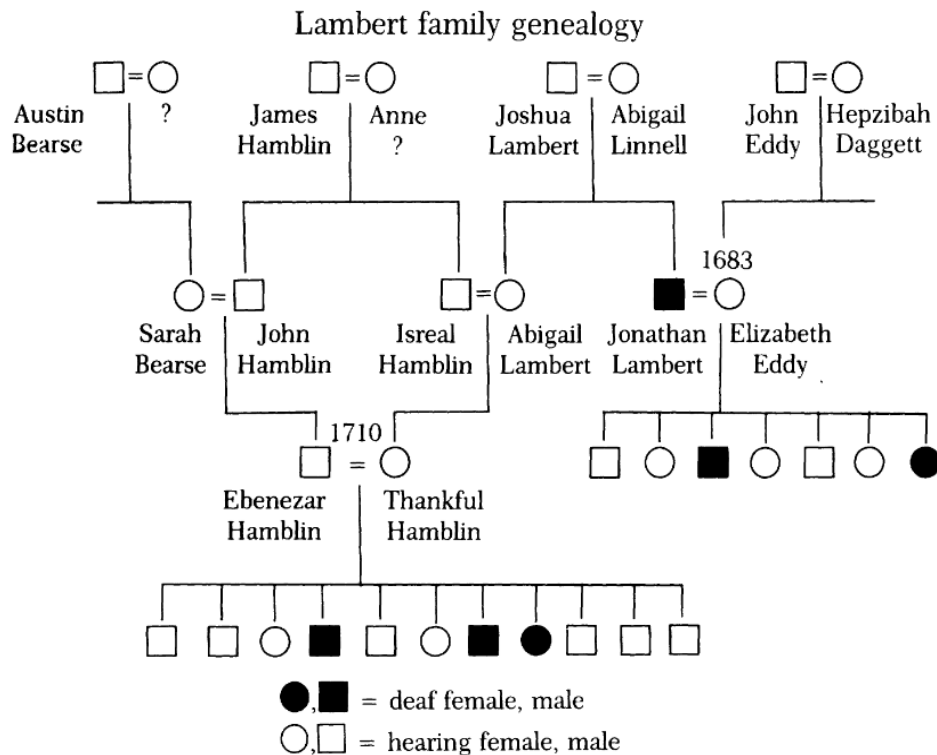


Figure 1. Pedigree of the Lambert family from Martha's Vineyard (Groce, 1985).²

EVERYONE HERE SPOKE SIGN LANGUAGE: HEREDITARY DEAFNESS ON MARTHA'S VINEYARD by Nora Ellen Groce, Cambridge, Mass.: Harvard University Press, Copyright © 1985 by Nora Ellen Groce. Used by permission. All rights reserved.

² Double lines typically represent inbreeding, indicating that the individuals who have produced offspring are related. Groce provides evidence of consanguinity in the first generation (Groce, 1985).

The possibility of two people having a deaf child can be predicted using a Punnett square (Davis, 1993). If two carriers have a baby, the chance of the child being born deaf would be 25%. The chance that these two carriers have a child who is also a carrier is 50%, while the probability that this child is born without any deaf allele(s) is 25% (see Figure 2a). Each child's chances are the same, regardless of the birth order. However, when a carrier and a deaf person who was born with hereditary deafness have a child, these chances of having a deaf child increase. The chances become 50% that the child will be born a carrier and 50% that the child will be born deaf (see Figure 2b). The deaf allele is passed on to all offspring, but these children have a 50% chance to inherit the dominant allele from the parent who is a carrier, resulting in the 50/50 chance of either being hearing or deaf. Lastly, when two of these deaf parents have a child together, the chances increase to 100% as these parents only have the deaf allele to pass on to their offspring. This means all of their children are bound to be deaf as well, disregarding mutation (see Figure 2c). However, these deaf offspring can still have hearing children if they reproduce with either a carrier or homozygous dominant individual where the Punnett squares start over again.

a)	A	a	b)	A	a	c)	a	a
A	AA	Aa	a	Aa	aa	a	aa	aa
a	Aa	aa	a	Aa	aa	a	aa	aa

Figure 2. Punnett squares representing the probability of offspring inheriting a deaf allele from various groups of parents.³

Image inspired by the work of Mendel and Punnett.

These Punnett squares and statistics can be applied to the pedigree of the Lambert family, who resided on Martha's Vineyard, to visualize this predicted inheritance pattern. Following Groce's family tree of the Lambert family above, it is seen that Jonathan Lambert is deaf⁴, indicating he has two recessive alleles. His wife, Elizabeth Eddy, is hearing, indicating she has at least one dominant allele. However, these two produce deaf children, meaning Eddy is likely a carrier, as some children inherited two copies of the deaf allele and only received one allele from each parent. This couple had 7 children. It is clear from Figure 2b that the chance that these children are born deaf is 50%. However, this is equivalent to tossing a coin for each pregnancy to determine if the child will be deaf or hearing. In this case, it just so happens that only 2 of the 7 children were born deaf, which is less than would be expected. However, it is important to understand that these statistics are not exact frequencies but instead predictions.

When looking at Ebenezer and Thankful Hamblin, it can be seen that they are both hearing yet produce deaf children, indicating that they are likely both carriers for the deaf allele. Figure 2a shows that the chance of two heterozygous individuals producing deaf offspring is 25%. The other 75% are hearing but can either have one dominant allele or two. However, homozygous dominant and heterozygous individuals result in the same outcome of being hearing. The Hamblin's had 11 children, where it would be expected that 2.75 of these children would be born deaf. Since someone cannot have $\frac{3}{4}$ of a child, this number can be rounded to 3. In fact, 3 out of the 11 Hamblin children were born deaf following the predicated inheritance pattern based on the statistics describing inheritance patterns of an autosomal recessive trait. While it is

³ Figure 2 portrays three parts: a, b, and c. To make it clearer, (a) represents two carriers as the parents resulting in offspring potentially being homozygous dominant, heterozygous, or homozygous recessive in a 1:2:1 ratio, while (b) represents a carrier and a deaf parent resulting in offspring either being heterozygous or homozygous recessive in a 1:1 ratio, and (c) represents two deaf parents resulting in all offspring being homozygous recessive.

⁴ Some researchers question whether Jonathan Lambert was deaf—father or son (e.g., Poole-Nash, 2015; Power & Meier, 2024), but the author of this paper follows Groce's work and wants to provide an example of the genetic situation that is common among deaf people and their parents despite their hearing loss. Lane et al. (2011) and Groce (1985) identified the father as being deaf.

not confirmed that these individuals had autosomal recessive hereditary deafness, the inheritance pattern fits the pedigree, indicating the strong possibility of a recessive allele causing hereditary deafness.

THE SIGNIFICANCE OF POPULATION GENETICS

With Martha's Vineyard, it is important to understand that when a population is small, there are fewer diverse alleles in that area being spread throughout individuals in this population. This ties back to the concept of Punnett squares as a person's chance of being born deaf increases when more deaf alleles are seen among the parents, indicating similar alleles are represented among individuals (as shown in Figure 2). Small populations can be affected by gene flow, which refers to the movement of genes in or out of a given area or population (Slarkin, 1985).

This could be the effects of immigration bringing in new alleles or emigration, where people leave the population, taking their alleles with them. The alleles seen in a given population can change based on the gene flow and can provide insight into why certain traits are more prevalent than others. With smaller populations having fewer possible alleles being inherited by their offspring, it is more likely that two of the same alleles will come together. For example, it is more likely that an individual will become deaf as two recessive copies are more likely to be inherited in a smaller population where both parents are more likely to carry the allele.

With that said, the genetic concepts behind hereditary deafness can be generalized to various traits that also exhibit autosomal recessive inheritance, and gene flow is observed in any population in all organisms, not just humans. Overall, population size determines the effect of genetics on a population as more individuals will increase diversity, and fewer individuals will limit the number of possible alleles being passed onto offspring.

There are some highly relevant ideas that are worthy of discussing regarding population genetics. One way to get a small population is through a genetic bottleneck. A bottleneck is when a population goes through an event that drastically reduces the population (Ali & Roossinck, 2008). For example, a forest fire can kill off wildlife, such as birds, that are not able to escape to safety. However, it is likely that at least a few of the birds in an area will make it out alive. A population of 100 birds could now be reduced to 8 birds because of this forest fire. This is a genetic bottleneck. This event then results in these 8 birds being responsible for building the population in order to avoid extinction.

After the bottleneck, the alleles in this "new" population could be quite different from the original large population. This can be visualized in Figure 3. A bottleneck's drastic effects on a population can be seen by the different color beads. The original population has a lot of orange beads, or alleles. However, only one orange bead survives the bottleneck, and a higher proportion of red beads are left to help repopulate. This shifts the allele frequencies so that the new population looks completely different from the original, as there are primarily red beads and very few orange beads, all based on the chance of survival from the catastrophic event. A bottleneck reduces genetic diversity by limiting the alleles that are represented in the population and being passed onto offspring. This event can also lead to fixation or complete loss of alleles. It is unlikely that every single allele will make it through the bottleneck, which could result in an allele being lost and no longer seen in the population because the individuals with that allele did not survive the bottleneck. Fixation of an allele could occur if all individuals that survive the event carry the same allele, resulting in all offspring inheriting this same allele.

By all accounts, Martha's Vineyard illustrates a type of bottleneck referred to as the founder effect. A founder effect is when part of an original population moves to a new area to start a new population. Typically, the small portion of the ancestral population that moves to a new area are known as colonizers. The colonizers start a new population, which can then differ from the original population's allele frequencies (Zedalis & Eggebrecht, 2018). This effect is a type of bottleneck as the colonizers of the new population may not identically represent the original population and can result in a difference in genetic diversity

(see Figure 4 for the visualization of the founder effect). In her book, Groce notes that families, who had known each other previously, settled in Martha's Vineyard in 1634-1644. The original families had all lived together in southern Massachusetts and moved to Martha's Vineyard together.

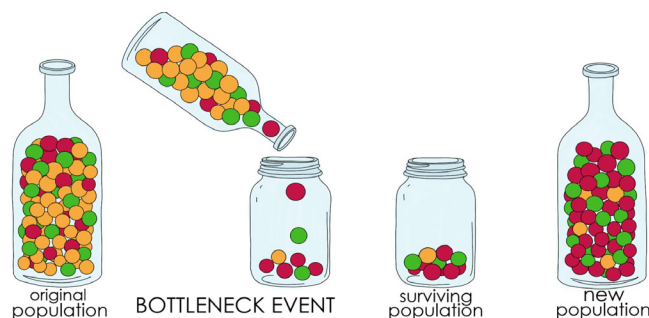


Figure 3. Visualization of a genetic bottleneck. Beads represent the populations, and the colors represent different alleles, or genotypes, before and after a bottleneck event (March 26, 1958 by Broadbent). Photo: Open source – Timetoast timelines (Joanna Servin, “Theories about life and evolution,” published in 2016. timetoast.com, <https://www.timetoast.com/timelines/theories-about-life-and-evolution>)

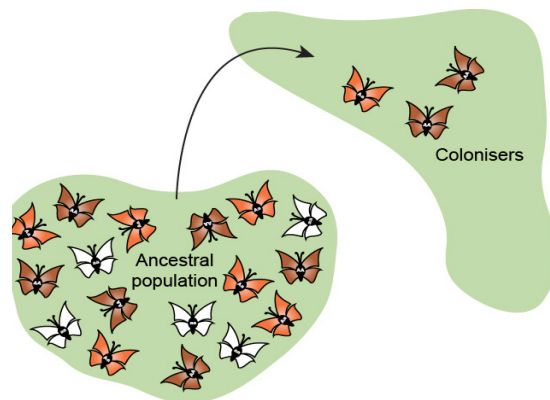


Figure 4. Illustration of the founder effect (April 21, 1942 by Ernst Mayr).
Photo: Open source – Timetoast timelines (Joanna Servin, “Theories about life and evolution,” published in 2016. timetoast.com, <https://www.timetoast.com/timelines/theories-about-life-and-evolution>)

Groce explains that these families all came from the same small group from the English county of Kent known as the Weald. Kitzel (2014) challenged the notion that the deaf genes of Martha's Vineyard residents were connected to those of the Weald residents due to difficulty tracking the kinship. There were also limited deaf ancestors in the 17th and 18th centuries in the Weald. However, a number of scholars believed otherwise because the ancestors of Martha's Vineyard residents came from the Weald as these families originally lived in Barnstable, Massachusetts, when they first emigrated to the United States (e.g., Carty et al., 2009; Crouch, 1986; Lane et al., 2000/2020, 2011; Padden, 2010). It is known that Jonathan Lambert's parents came from the Weald (Morrison, 1987). Perhaps a genetic explanation below will alleviate this dispute between researchers on whether there are carriers of deaf alleles from the Weald and how it affected the genetic situation on Martha's Vineyard.

The families in question represent the colonizers of Martha's Vineyard and only represent a small portion of the original population from which they came. It is likely that the same deaf allele was among these families. With a small population to begin with and limited alleles to start populating the island, it is no surprise that the deaf allele started to become more pronounced on the island when compared to the mainland. The deaf allele that these settlers carried may have been “covered up” by previously dominant alleles in the original Vineyard and the New England population (see Lane et al., 2011 for further details on the deaf ancestry in the New England region, including Martha's Vineyard). However, the founder effect

made it so that the deaf allele was present in the population at a higher frequency and more likely to be passed onto offspring, resulting in more homozygous recessive individuals who were deaf.

Not only is Martha's Vineyard a real example of the founder effect, it also illustrates gene flow, describing how deaf alleles were distributed among the small population. Back in this time period, travel was infrequent as many modes of transportation had not been invented yet. The island itself created a barrier from the rest of the world as travel by boat was the only mode of transportation to and from the island. Because of this, Groce explains that not many people moved in and out of the island during this time. This led to limited gene flow among the population, where new alleles were rarely introduced into the population, resulting in less genetic diversity. There was even limited movement of people on the island as many towns were also isolated from each other due to transportation constraints. This led to many people marrying their neighbors and even their cousins.

As discussed before, when a population is small, it is more likely that two of the same alleles will come together in an individual, which was seen on Martha's Vineyard. With people marrying their cousins, the same alleles were being passed down in each generation, which did not allow for much diversity among the population's genetics.

In fact, Groce found that island deafness could be traced back to a few people, including a man named Jonathan Lambert (see Figure 1 for this man and some of his offspring being deaf). This mode of inheritance is called Identical by Descent (Kerns et al., 2007). This occurs when two of the same alleles are inherited from a common ancestor, as seen in Figure 5. The squares represent males, and the circles represent females. The rectangles underneath each individual represent alleles where each person receives two copies, or a pair. The green rectangle represents the deaf allele. The female in the fourth generation is born deaf due to her parents being cousins and has inherited the same allele from the same grandparent who is now the deaf girl's great-grandfather.

This pedigree is common when cousins marry each other as the chances are high that each cousin inherited the same allele from the same grandparent and then passed both copies of this allele to the new child, who is then born with two copies of the same allele. In this case, a deaf allele typically hidden by dominant alleles becomes more known in the population as deaf alleles are inherited from the same people and descendants, coming together to result in deaf offspring. Overall, Martha's Vineyard was an island, implicating low genetic diversity, and displayed various concepts of population genetics.

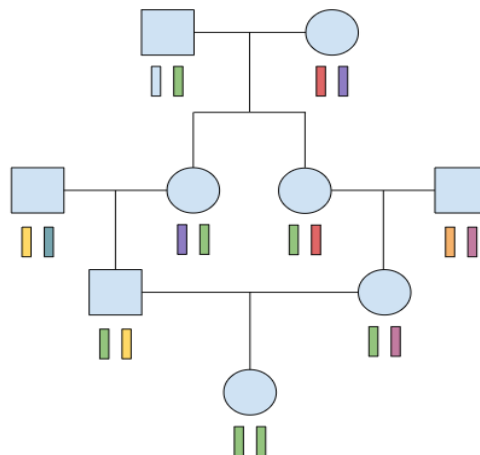


Figure 5. Pedigree showing Identity by Descent.
Image inspired by Kerns et al., 2007.

ETHICAL CONSIDERATIONS IN THE FIELD OF GENETICS

The situation at Martha's Vineyard has shed light on many lessons regarding genetics and inclusion, which can be insightful into the ethical awareness of the modern United States. Genetics continues to be a popular topic as more is being learned about this newly emerging field. Genetic tools are currently being discovered that could be used to edit the genome of individuals (e.g., Carroll, 2017; Cermak et al., 2011; Doudna & Charpentier, 2014; Kim, et al., 1996; World Health Organization, 2022). This has shown potential for many therapeutic options, such as curing hereditary diseases that are currently untreatable. There is a common understanding that the ethical line in regard to genetic manipulation revolves around if the situation is life threatening or not. There is a difference between altering one's appearance in a way that is unnecessary and saving one's life. A common example is believing there is an ethical line between curing disease and, for example, changing one's eye color using these genetic tools. But where does deafness fall on this moral spectrum?

In terms of genetic engineering, these ethical dilemmas need to be discussed as society has differing views regarding topics such as deafness. Nunes (2006) uses the term "dysgenics" to describe this phenomenon. This term refers to selecting genetic traits that are accepted by cultural and societal standards as a disabling condition. Nunes explains there are positive and negative dysgenics. Positive refers to increasing the number of people that have a specific trait, whereas negative dysgenics involves eliminating a specific trait from the population. It is commonly accepted that it is not morally correct to genetically change someone unless the change is curing a disease and improving the quality of life for an individual who may have a terminal illness. However, Nunes highlights that deafness involves a community of signers (when referring to the American deaf community). Nunes also expresses that deafness being viewed as a disease is based on the cultural standards of those who do not recognize the language (i.e., signed language or ASL) that differs from the majority of society.

With genetic engineering on the rise, one can wonder what it means if these tools become a possibility to edit the genomes of unborn children. While the safety of these tools remains a concern, discussions regarding the creation of "designer babies" and "playing God" have been circulating since these tools were introduced (Green, 2007; Hoggatt, 2015; Knoppers & Kleiderman, 2019; Ledford, 2023). Genetic testing and counseling have become prevalent for families at risk of having a child with a genetic disorder. These counselors discuss pedigrees and statistics of inheritance similar to this paper (Heller, 2005; Uhlmann et al., 2011). However, if one day, a family can decide to alter the genes of their unborn child to avoid the child being born with an illness at all, how would this be applied to scenarios outside of the treatment of diseases? Where is the line for editing the genomes of infants?

Autonomy is an important concept in bioethics and the foundation of informed consent as a patient's moral right to their own medical decisions. When parents are given the choice of choosing the fate of their unborn children, this can be viewed as taking away the child's autonomy. Perhaps a hearing couple finds out they are expecting a deaf child due to hereditary causes. Would it be ethical to allow these parents to edit the child's genome to replace the deaf allele so the child can be hearing?

What society seems to need the most is understanding the alternatives over what was discussed up to this point. Ethical issues with genetical engineering and deaf people are quite significant. According to Supalla et al. (2012/2020) and Cripps and Supalla (2012), the push for widespread signed language use in the United States constitutes an important incentive to help society become accepting towards deaf people. The widespread use of signed language, as reported for Martha's Vineyard, is not an isolated incident when it comes to the research done on a variety of what is called shared-signing communities worldwide (e.g., Bickford, 2020; Bickford & McKay-Cody, 2018; Kisch, 2008, 2012). In those communities, the common practice or action is for the hearing members to accommodate the deaf members by becoming signers themselves. Signed language knowledge is then no longer limited to deaf members (as is now largely the case for the United States), but it expands and becomes part of larger society, as discussed for Martha's

Vineyard. The perceptions of deafness are expected to change from negative to positive. Critically, the hearing members of society (being signers) will be more inclined to see the deaf members as equals.

Recall that ASL has been taught as a foreign language through American education institutions. Deaf people may be proud of ASL being introduced as a foreign language for study, but such achievement has its drawbacks. If hearing students have the option of learning Spanish or French over ASL, for example, students might miss the opportunity to learn the signed language.

What this suggests is that *more* needs to be done regarding ASL instruction. Given that diversity, equity, and inclusion are of top priority for the United States, it is sensible to pursue the idea of having ASL taught to all students to study and learn in schools and higher education settings (Supalla et al., 2012/2020; Cripps & Supalla, 2012). In time, deaf people will find society changing and becoming similar to the shared signing community status that Martha's Vineyard achieved.

The universality of ASL instruction will help guarantee that hearing students who start families of their own will be better prepared for the prospect of having one or more deaf children. These parents would, this time, know ASL and their perspective on deafness should improve versus being something that is dreadful and frightening. The same holds true for the ASL students who decide to study to become the country's future scientists and physicians. They will be more mindful of ethics associated with deaf people and can be in sync with parents who come to them for advice.

In any way, it is both practical and ideal that the perspectives of society at large and the deaf community be aligned. Ethical awareness is essential in the scientific/medical fields. With genetic tools becoming more well-understood and developed, it is vital for geneticists to understand the power of ASL in shaping societal perspectives and continue spreading knowledge of ethical awareness. Most people would agree that it is unethical to genetically edit every person they meet. It is essential to be aware of deaf people's perspectives on their lives as there is still much to do with improving ethical awareness in the 21st century.

CLOSING REMARKS

Overall, hereditary deafness is commonly an autosomal recessive trait, meaning two of these recessive alleles must be inherited for a person to be born deaf. Many factors contribute to the distribution of alleles in a given population, including population size, bottlenecks, and gene flow. Martha's Vineyard is a great example of genetics and deafness, as well as understanding inheritance patterns through statistical analysis and pedigrees. As humans shift into the 21st century, more is being understood about genetics and possible gene editing tools. Ethical conversations must continue to be discussed, not only concerning deafness but all aspects of genetics.

The much-needed ethical conversations include the idea of social change, which is that society is made up of hearing members who know how to sign and will thus be able to communicate with deaf members. This is where Martha's Vineyard, as a shared signing community, emerged as a highly relevant topic for discussion. Limiting ASL use to only deaf people does not encourage a level of sensitivity or understanding for American society with its top priority in diversity, equity, and inclusion. ASL, or rather any signed language, is supposed to be a remarkable human achievement that deaf people have been trying to show society all along, but not fully realized. Hearing people will need to ask themselves the hard question: Why do we limit ourselves to speaking one or more spoken languages when we can also sign a language like deaf people do? The current lack of appreciation for deaf people's language abounds and needs reform. Hopefully, the idea of ASL being taught to practically everyone in American society will receive more attention for the research and scholarship work. By educating the general public about deaf people and their language, ASL, everyone can help support a diverse society and advocate for the inclusion of all people. As a society, it is important to embrace what makes people different on all levels of humanity's genetic diversity.

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