Assigning Voices:
Interactions among Human, Parental and Cultural Rights over Deaf Children

by

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Introduction

When I was working at the National Association of the Deaf (NAD), a large part of my job was to write press releases about issues currently affecting the Deaf community. One of my first days on the job, searching for a synonym for my repeated use of the term “deaf and hard of hearing people,” I mistakenly used the word “hearing impaired.” Immediately after I sent my boss the draft, he popped up on my instant messenger. The NAD, he informed me, never uses words like “hearing loss” and “hearing impaired,” which place a value judgment on the ability to hear. “We prefer to think of it as gaining a new way of being,” he explained.

Later that summer, I was driving with my brother, Peter, who is himself hard of hearing, and asked him about my boss’ remark. “Of course I have a hearing loss!” he declared, smacking the steering wheel. “Maybe I don’t care, maybe it doesn’t affect me, maybe I like it better this way, but the fact of the matter is that I don’t hear the same things you do. No one can tell me that I’m not hearing impaired.”

Despite their disagreement about labels like “hearing impaired,” my brother and my boss both expressed agreement about one thing: neither would want to be hearing. While Peter might have been fine with the words “hearing impaired,” both of them expressed a certain degree of skepticism about the medical model which this term is often thought to express. Not only do many deaf people I know want to remain deaf themselves, but many take offense to the idea that anyone would suggest, much less research, a “cure” for deafness at all.

To many hearing people, this attitude is absolutely baffling. After all our bodies, and our ears, are normal and, more importantly, functional. Further, our
normal, functional ears allow us to hear everything from approaching cars and running water to language and music. To be cut off from our hearing would cause us to lose a major part of ourselves. We are open minded, tolerant people—but why would we want to tolerate something that must hurt others so badly? We are generous, we are kind, and we have been taught to help the less fortunate. Who could be less fortunate than someone deprived of an essential sense? And what, we puzzle, could be wrong with curing them? Do they really understand what they are missing?

While I may be exaggerating somewhat here, hearing people have very real intuitions about deafness, and most of them follow what disability scholars refer to as the “medical model.” According to this model, deafness is a disabling problem due to medical defects in the ear or other organs. It can be treated with hearing aids or cochlear implants, accompanied by intensive therapy in oral/aural skills and speech-reading—although it cannot be cured. Recently, it has become possible to prevent deafness, or, rather, the birth of deaf children, through prenatal genetic testing. The problem and the solution are both, in this case, conceived as essentially medical.

The reality, many deaf people point out, is a little more complicated. To illustrate, I would like to give you a little quiz. Which of the following activities requires you to hear?

1. Communicating fluently and comfortably in your native language
2. Dancing to music
3. Developing a regional accent
4. Enjoying a myriad of languages around the world
5. Developing a community with unique institutions, art forms and values
6. Becoming a poet or storyteller

The answer is, *none of the above*. Living in a world without sound can be isolating.\(^1\) It can mean living your entire life without ever developing fluency in any language. In many parts of the world, it often means a life of hard labor in a world that you do not fully connect to or understand. It does not, however, *need* to mean any of these things. Deafness can mean developing fluency in a silent language which conveys complex messages as quickly and expressively as English. It can mean poetry filled with “rhyming” hand shapes and beautiful pictures in the air; turning up music until you feel the vibrations of the bass line and dancing; and it can mean becoming involved in a community so distinct and exciting that it calls itself a visual culture.

Many of us instinctively credit hearing with accomplishments which really belong to the mind or the spirit. Language is only one example of this.

Nonetheless, many hearing readers would point out (rightfully) that deaf people are still at a disadvantage in society in a variety of important ways. I would agree. The fundamental question, however, is not whether deaf people are disabled. It is *why* they are disabled, *how* they are disabled and, according to some models, *who* disables them. The previous paragraph has implicitly alluded to a different model of deafness, one well-known to disability rights activists of all sorts: the “social model” of disability. It states that deafness itself is not disabling, but that the construction of a set of social, economic, and political institutions that presume that all people can hear has inadvertently served to disable deaf people. If a deaf child is not able to

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\(^1\) It is somewhat misleading to think that deaf people live in a world without sound. Most deaf people, and all hard of hearing people, retain some residual hearing. Many people who have difficulty understanding a human voice nonetheless enjoy other sounds, such as extremely loud music with heavy bass lines.
communicate properly, for example, adherents to the social model would point out that perhaps the problem is not with the child but with the teaching, or even the choice of language. Likewise, a deaf man who cannot find a job may be facing discrimination or he may be the product of an unaccommodating educational system or otherwise be the victim of a society that is based on the notion that normal bodies do certain things and all other bodies are, unfortunately, defective.

While the medical and social model exist for all disabled groups, many deaf people take a step further and claim to belong not just to a particular class of people marked by certain physical characteristics, but additionally to a unique culture. This framework, which I will call the “cultural model” of disability, is distinct from (and perhaps more radical than) the traditional social model. For those that identify with the cultural model, being deaf does not just mean that one cannot hear: it means that one sees differently, relates to others differently, and speaks and acts differently because one can experience a vibrant visual language, culture, and community. Deaf people who identify themselves as part of a cultural and linguistic minority, rather than simply as members of a disabled group, are normally labeled Deaf with a capital “D,” and form a distinct subset of lower-case “d” deaf people, who simply cannot hear. While roughly 10% of Americans have some type of hearing loss, only about one half to one million identify as culturally Deaf.

People who are Deaf are set apart not just by their lack of hearing but by their involvement in a vibrant visual community. Often, they can be recognized by their

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fluent use of American Sign Language (ASL), their familiarity with Deaf history, their interactions with Deaf institutions, and their individual and communal self-identification. Many profoundly deaf people, including nearly everyone deafened later in life, choose not to identify with the Deaf community. Conversely, people with more moderate hearing loss, and deaf and hard of hearing people with good speech skills, may self-identify as Deaf for a variety of reasons. Even hearing people may share a strong sense of identity with the Deaf community. In particular, hearing adults who were raised by culturally Deaf parents and learned ASL as their first language often feel this way. These people, commonly called CODAs (Children of Deaf Adults), hold a hotly debated status vis-à-vis the Deaf community. For the purposes of this thesis, “Deaf people,” “Deaf individuals” and other such terms will be used to mean all deaf and hard of hearing people who identify as Deaf, whereas “the Deaf community” may be taken to include some hearing people, including CODAs.

Each of these three models—the medical, the social and the cultural—carries a set of assumptions about the nature of deafness and its disabling power, which lead to strong normative conclusions about the way that deaf children should be treated. The medical model typically suggests pre-natal screening or a medical cure; the social model generally calls for the reformation of various institutions including the

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4 Late deafened adults and others who lose their hearing later in life generally experience deafness very differently from those who were born deaf. Not only do they remember what it is like to be hearing, but they may have been raised using a verbal language, participating in a sound-driven culture and relying on sounds for environmental cues which the prelingually deaf might have learned to pick up by other means. A late-deafened individual, then, has much more to lose by going deaf than someone who has been deaf for the course of his or her lifetime. They may also, depending on their age, have more difficulty assimilating into the Deaf community and learning American Sign Language or other visual modes of communication. I will discuss this distinction more later in the chapter.
educational system; and the cultural model normally demands that the Deaf community be allowed a certain degree of cultural and linguistic tolerance or promotion. Debates over the education of deaf children or even the basic rights afforded to these children and their families often reflect underlying disagreements over which model most accurately describes the situation of deaf people in this country. While each of the models has something to offer, I would ask the reader to keep in mind that the medical model, with which he or she is likely most familiar, has certain limitations. In particular, try to keep in mind that hearing comes with baggage which may seem so natural to most hearing people that we are often unaware that it exists. Hearing comes with a lifestyle, a culture, and a set of expectations, and the desire to make children hear reflects not only one’s own generous spirit but also certain assumptions that one has about what is valuable. Readers need not discard the medical model entirely, but they should be cautious and self-aware about jumping to conclusions based on medical concepts alone.

This thesis will focus on one subset of deaf Americans in particular: prelingually deaf children of hearing adults. A prelingually deaf child is any child who is born deaf or becomes deaf before learning spoken language. Prelingually deaf children interest me for several reasons. Perhaps the most salient of these is that prelingually deaf children have never learned spoken language, experienced the hearing world, or integrated into hearing culture before becoming deaf. Being deaf, naturally, means something very different for those who have been raised using a

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5 It is important to note here that I am speaking of the *American* Deaf community. There are different signed languages, different deaf cultures, and different degrees of deaf culture (that is, places where the deaf community is larger or smaller, is more or less culturally homogenous, has stronger or weaker institutions) around the world. The United States happens to have one of the largest, most vibrant and best institutionalized Deaf communities in the world, as we will see.
silent language and been involved in a Deaf community than for those whose language and community once made regular use of spoken language and other sounds. Prelingually deaf children are distinguished in part, then, with the ease in which they could (and some argue should) become culturally Deaf.

Conversely, prelingually deaf children tend to have a much more difficult time acquiring any skill with speaking and listening. Having never experienced hearing or vocal speech, prelingually deaf children are forced to operate with incomplete information and understandings that late-deafened individuals can remember or reconstruct. They tend to have poorer outcomes with certain devices, such as cochlear implants, than those deafened later in life. An unfortunate corollary of their difficulty is that they are also set apart by the urgency of their situation. Their emotional, social, intellectual, and academic development depends on their ability to learn language. But just what sort of language they can—or should—learn is hotly debated.

For these reasons, debates about the treatment and education of prelingually deaf children are among the most impassioned in the Deaf community and, for that matter, the educational one. The fervor that activists on all sides feel when discussing the lives of prelingually deaf children is multiplied dramatically when hearing parents are in the picture. Hearing parents are at the center of a controversy not only over what sort of education their children should have but also over what sort of education the children must have. Their children, some will proclaim, have a human right to learn a visual language. Others will declare that the Deaf community should have a cultural right to some say in the way that deaf children are educated. Parents may be told that they have the right to demand services that they have never heard of, or they
might be blamed for failing to enroll their children in educational programs about which they were never adequately informed. If they chose the “wrong” program, activists for other educational services might call them ignorant, evil, or both.

It is this relationship between hearing parents and prelingually deaf children which fascinates me. Here we have a situation where a parent has a child, and shortly afterwards is told that that child is different. The child needs services but no one agrees on which ones are best. The child should have rights, but there are conflicting stories about what those rights should be and who the child should be able to hold them against. Most importantly, people seem to agree that the child is “different” but the parent must wonder who, exactly, his or her child is different from. Prelingually deaf children of hearing adults have the unusual position of being claimed by two communities—that of the Deaf and that of their families. Just how these groups interact, and just what these interactions mean for the children in question, is a fascinating test case for a variety of philosophical, political, and educational debates.

This thesis enters these debates with reasoned advocacy for how prelingually deaf children should be educated. It uses two separate lines of argument, based on certain notions of individual and cultural rights, respectively, to argue that deaf children have (or ought to have) the right to access a bilingual education in ASL and English. It also proposes certain policies that ought to be adopted or changed as a way of implementing these rights. While it may seem absurd to argue that children have linguistic rights separate from their parents, I ask the reader to keep an open mind. Many things about the education of deaf children and, especially, the existence of a Deaf community, will surprise the typical hearing reader.
The first line of reasoning follows a rather straightforward logic based on the concept of individual rights—straightforward because this concept is a familiar one in the political culture of the United States and in that of the United Nations. American civil rights and international human rights both encompass a variety of rights, such as the right to meaningful participation in the political sphere (through freedom of expression, conscience, etc.) and the right to understand any criminal charges brought against oneself and others, which I believe are nearly meaningless without full access to a language from an early age. Even with current hearing technology, I do not believe that oral/aural programs can provide adequate language access for many deaf children. As such, deaf children ought to have access to a true language which is both visual and of equal communicative power to any spoken language from birth. Signed languages, including American Sign Language, are uniquely capable of filling this need. This may not require every family to learn ASL from birth but, as I will discuss later in the thesis, current early intervention and special education policy does not provide parents with sufficient access to information about linguistic, educational, and cultural options, nor does it provide families with sufficient access to a variety of schools and services.

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Lawrence Siegel makes this point in his argument in favor an interpretation of the first amendment which guarantees language access for deaf children or, failing this, the passage of a new amendment which would do so. I have been greatly inspired by Siegel in my discussion on individual rights, but our works do differ in important ways. Namely, Siegel grounds his argument in the individual rights guaranteed in the American constitution, while I make use of international human rights theory and cultural rights theory, all three of which I believe converge to similar policy recommendations. This also influences the way in which I argue for individual rights. For example, I believe that children as individuals should be entitled to access to a community in which they can participate fully. The logic of this conclusion parallels Siegel’s argument in favor of linguistic access, but demonstrates that we differ in important ways. In particular, I agree with Siegel that children should be entitled to language access but this is, for me, only one layer of the justification for policy change and only one of a set of rights which deaf children deserve. I also come to my own conclusions about the sort of policy changes which might be necessary to remedy the situation. In particular, he concludes that children should have the right to an educational program which addresses their communication needs, while I come down more strongly in favor of a specific program, bilingual ASL/English education.
My second line of argument will seem counterintuitive to many Americans. The Deaf community, I contend, represents a unique cultural and linguistic group within American society. In fact, it is a group of such a nature that, once it is properly understood, the rights laid out for minority language communities by the United Nations, along with the rights implicit in the U.S. Constitution and the judicial interpretation of it by the Supreme Court, together require that we afford a certain set of rights to members of the Deaf community. This is especially surprising given that the Deaf community is fundamentally not intergenerational. As I will discuss later, the vast majority of deaf children are born to hearing parents, and many deaf parents have hearing children. The existence and, in fact, longevity, of an entire culture and language which is not passed through family lines pose a rather dramatic challenge to the way in which we normally think about cultural groups and the rights they possess. Thinking through these challenges will require careful analysis of what is involved in being a cultural group, and of the obligations that governments in general, and educational institutions in particular, have toward members of such a group.

As I will discuss later in my thesis, however, these challenges actually pose surprisingly few problems as far as policy is concerned. In particular, I argue that hearing parents are the best decision makers for their deaf children but that, since they have given birth to a child whose cultural options differ from their own, they can only act as such an agent effectively when provided with ample sources of unbiased information and affordable access to a variety of educational resources. If hearing parents are ill-informed and, in particular, if they are given medically-biased information by a state funded early intervention program, this may constitute a
forcible removal of a child from the Deaf community. A similar problem arises if hearing parents wish to secure services related to ASL or Deaf culture but are unable to do so in an affordable, timely manner.

The outcome of this debate affects a variety of groups within American society. Most obviously, it affects the one half to one million Americans who use ASL as their primary language and who identify as culturally deaf; it also affects the estimated 12,000 deaf and hard of hearing babies born each year and their families. However, it has the potential to affect much larger groups through the public school system (85 percent of deaf students are mainstreamed, and mainstreaming is rapidly increasing in popularity), as well as cochlear implant centers and Early Intervention programs. More broadly, deaf cultural rights claims provide a unique and revealing test case through which we can examine what sort of balance between cultural and individual rights might be appropriate for progressive liberal societies.

In the following four chapters, I hope to provide a thorough analysis of these issues and a strong case in favor of bilingual/bicultural education for Deaf children. Chapter One will provide the reader with a basic background about prelingually deaf children, including their educational, technological, and linguistic options. It seeks, amongst other things, to provide a more complex and accurate portrait of the options

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7 While hospitals are required to screen newborns for hearing problems under the Early Hearing Detection and Intervention (EHDI) act, many parents whose infants fail the initial screening fail to bring their children in for follow-up tests. It is thus difficult to count the exact number of DHH children born each year.


available to deaf children than the simplified medical model familiar to most hearing people. This chapter will provide the information necessary to understand both lines of argument, the individual rights based line and the cultural rights based line, presented later in the thesis. Chapter Two will focus entirely on Deaf culture. In it, I seek to demonstrate that the Deaf community does represent a distinct cultural minority in the United States and to address some concerns about a culture that is based on a common sensory experience rather than a bloodline. I hope to show that, while this and other characteristics make the Deaf community unique and difficult to categorize, they do not detract from its being a culture towards which we have certain duties. By the end of Chapter Two, it should be clear that, for some deaf children, access to spoken English and hearing culture will be limited. For all deaf children, however, barriers to learning ASL and integrating into Deaf culture are no higher than barriers into American culture are for hearing students, and, further, their ability to access Deaf culture is unique.

Chapters Three and Four will use this information to frame a discussion of deaf rights. Chapter Three will deal with these issues in the abstract, drawing from legal documents such as United Nations Declarations and the United States Constitution, as well as some theoretical works in political theory. It will show that deaf children have individual and cultural rights to access ASL, but that these rights do not necessarily conflict with the ability of hearing parents to make informed decisions for their children. It may be useful to think of these lines of argument as corresponding to the models of disability discussed above. That is, the individual rights argument is grounded in a social model of disability, and supposes that
different educational programs might enable or disable deaf children. Likewise, the cultural rights argument is rooted in a cultural model of disability. Chapter Four will apply these ideas to actual institutions, beginning with a discussion of current US policy surrounding special education and moving onto an examination of potential reforms. In particular, I suggest revisions to the Early Hearing Detection and Intervention Act (EHDI), the Individuals with Disabilities Education Act (IDEA), and the funding structure and administration of schools for the deaf such that parents receive more information about linguistic, educational and cultural options for their children and can access services more easily and affordably.
Chapter One: Perfect Babies, Broken Ears

Imagine a deaf child is born. Let’s call her Susie. Like 90 percent of deaf children, Susie was born to hearing parents.⁹ While some of these hearing people have close family members who are deaf or ample exposure to deaf people and deaf issues, Susie’s parents, like most, do not. They have never before met a deaf person. They have no special knowledge or skills: they do not know how a cochlear implant works or how people can make a language with their bodies instead of their voices. They have never heard of cued speech, TTYs, Deaf culture or speech reading, and they certainly do not like having their language referred to as “oral/aural communication.”

Susie’s mother has nightmares about her child, wires dangling from her ears, being mocked by the other children. “Susie Cyborg,” they call her. Sometimes, in these dreams, Susie sits like a monkey in a chair, making noises over and over again as she tries to learn the sounds of the English language. “Aaaaahhh… Eeeehhh…. Ohhh… Repeat! Aaaaahhh… Eeeehhh…. Ohh… Repeat!” Other times, she tries to speak and fails. And when she tries to talk to the little boy down the street, their communication is rudimentary, filled with simple words and simple thoughts.

Susie’s father’s nightmares are different. They are nightmares about a child talking with her hands when everyone else talks with their voices. His Susie can form complex thoughts, but she cannot express them to her parents. She talks to everyone through an interpreter. She brings over friends who speak her strange language, and

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⁹This number is cited by a variety of parent guides and books about the deaf. I cite Jankowski here because her citations include one of the more detailed lists of the studies from which this number was originally drawn.
goes to festivals with a strange culture, all the time resenting her parents for not
learning fast enough. “Dad, Dad-” he loses her in a fluttering of angry hands. “Slow,
Susie, please slow,” he signs. His daughter lives in a big world, but between them
pass only simple words, and simple thoughts.

Both parents are afraid that their child will be unable to communicate with
them, or to function “normally.” As they learn more, their fears balloon. Seventeen
and eighteen year old deaf students have reading comprehension scores at the fourth
grade level, falling nearly a decade behind their hearing peers by the time they
graduate from high school. In 2010, when the unemployment rate for hearing people
was around 9 percent, a full 15 percent of disabled people were unemployed, and it is
widely believed that communication difficulties, workplace discrimination and
inadequate access to education, training, and accommodative services contribute to a
high rate of unemployment among deaf people. Susie’s parents begin to realize that,
if their daughter is to live up to her potential as a student or employee, she will need
to defy very high odds.

Susie’s parents, like millions of other parents across the country, will begin
searching for an educational program for their child. They will be plunged into the
center of a debate over what sort of services deaf children are entitled to, who is
required to provide them, what rights they and their children have, and who ought to

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10 It should be noted that these scores reflect reading comprehension only in written English, and not
necessarily language proficiency or even literacy in other areas. In particular, some deaf people and
educators of the deaf feel that deaf children should be assessed on their language skills holistically,
including tests of their sign language proficiency. For students who are fluent in sign, an assessment of
their reading comprehension in English might understate their ability to receive information in other
forms, their vocabulary, or their language skills more generally, arguably by a rather large margin.
“Literacy and Deaf Students,” Gallaudet Research Institute, accessed April 2, 2011,
http://research.gallaudet.edu/Literacy/index.html

11 “Employment,” Commission of Deaf, Deaf-Blind and Hard of Hearing Minnesotans (MCDHH),
be first to advise them on educational decisions. Before they can enter this debate, however, or even fathom how their children can fit into it, they need to understand their child’s basic medical and educational options.

They will ask themselves exactly the same questions many readers will ask when introduced to the notion of Deaf cultural or linguistic rights. *Can we fix this? With modern technology and educational programs, can’t we make our deaf kids like normal kids?* Perhaps parents, and even academics, would not phrase it so bluntly. Still, hearing people place great value on their hearing, and, if they have never met a deaf person, their greatest hope for deaf children is often to make them hearing. I will address these assumptions about what constitutes normality, and how valuable it is, at length later in the thesis.

For now, however, I should note that these assumptions betray a legitimate underlying concern. One of the defining characteristics of a liberal society is its ability to tolerate differences but its unwillingness to compel them. While Deaf people would be rightly enraged at the idea that every child should be made to be “normal,” or that hearing people are superior, at this point Susie’s parents really only want Susie to be able to function. Even if they are receptive to involving their child in the Deaf community, they likely consider this to be a private decision and demand, at most, the right for her personal Deaf identity to be tolerated by others. The idea that deaf children should be afforded a special set of rights, different from those rights afforded ordinary children, is still not a thought they have considered and would, in any case, require a higher standard of proof to justify such a claim. Specifically, deaf children would need to possess a set of linguistic or cultural needs sufficiently
compelling and abnormal so as to justly warrant the existence of special rights and protections. I will argue in this thesis that indeed such special rights and protections are in fact warranted.

To the extent that such needs are social and cultural, and can be proved through social and cultural evidence, they will be discussed in Chapter 2. However, any claims that deaf children as individuals require special rights will need to be based on a thorough understanding of their medical and educational options, and so I will discuss those first.

**Medical Options**

**Cochlear Implants**

Figure 1:

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A Cochlear Implant (CI) is a medical device that helps deaf people to hear some sounds. An external microphone picks up sounds, which a speech translator selects and interprets. These sounds are then converted into electrical impulses by a receiver, and sent directly to the auditory nerve through an array of electrodes. For most deaf children, a CI is able to circumvent the damaged part of the ear, thereby providing some sense of hearing.\(^{13}\)

Before receiving an implant, children must be evaluated by a team of medical professionals, usually starting with a surgeon or audiologist, that determines whether the child is a good candidate for implantation. This evaluation is often done according to the Children’s Implant Profile (ChIP), an assessment method developed by the Manhattan Eye, Ear and Throat Hospital. It evaluates not only a child’s medical potential for implantation, but also factors such as age, the degree of support the child is likely to receive (both from the family and from educational services), the existence of other disabilities, and the child’s speech skills. Any residual hearing that a child has will be destroyed by the implantation process and replaced by the implant, so the ChIP also seeks to measure a child’s residual hearing and ensure that an implant would represent a net gain for the child.\(^{14}\)

Insurance companies normally cover the surgery for approved children, although they may specify that parents need to use a certain implant center or doctor, as well as the extent to which they cover follow-up services. Since centers vary in their philosophies and services, this can significantly restrict some parents options for their children. In particular, some centers choose not to allow children to receive

\(^{13}\)Ibid
implants unless their parents commit to an educational program which does not include ASL.\textsuperscript{15} Parents who wish to give their children a high-quality bilingual education, then, are especially restricted in their choice of implant centers.

Approved children are then implanted in a surgery called a Tympanomastiodectomy. It is generally a low-risk surgery, although children may suffer from facial nerve damage or contract bacterial meningitis, both of which are rare. There is also a risk of postoperative infection, dizziness, or mild facial weakness, which normally resolves quickly. As always, there is a risk of complications from anesthesia. After the surgery, the child is given time to heal and recover before the external portion of the implant is introduced and the implant itself is switched on for the first time.\textsuperscript{16}

One of the most common misconceptions about cochlear implants is that, once the implant is turned on, the child can hear. In reality, implantation is just the beginning of years of hard work during which the child will learn to use the implant. The switch-on process alone normally takes about two days. During that time, the implants settings are adjusted and the parents are taught how to use and care for the implant. “Auditory comprehension,” or the ability to understand and effectively use spoken speech, is actually the final stage of a long process of learning to listen. Children must first be taught to detect sounds, then taught to listen to rhythms and patterns, and, finally, taught to identify individual segments of a message, or words. We might imagine a child at the first stage turning his head when the doorbell rang; at the second stage the child might be able to distinguish a car horn from a lawn mower,

\textsuperscript{15} Chute and Nevins, \textit{A Parent’s Guide}, 10-11,15. \\
\textsuperscript{16} Chute and Nevins, \textit{A Parent’s Guide}, 43-49.
or a long from a short sentence; at the third stage the child could separate words; and at the fourth he might be able to answer questions. It is essential that, as a child learns to use spoken language, parents are committed to providing a rich auditory environment for their child and are able to access excellent educational and follow-up services.  

According to the Food and Drug Administration (FDA), after cochlear implant surgery “hearing ranges from near-normal ability to understand speech to no hearing benefit at all.” Although many of the factors that influence implant success are known, it is impossible to predict what hearing, speech, and language outcomes any one child will have. In general, it is somewhat misleading to think of implants as being able to restore the hearing of deaf children. A cochlear implant uses between sixteen and twenty-two electrical “channels” to substitute for the 12,000 hairs in the human ear. Some implanted children gain awareness of environmental sounds, but have unintelligible speech. Others can converse with support. The best of them can understand spoken speech on its own, and speak intelligibly to others.

It should be noted that all children with cochlear implants are completely deaf when they take off the external component of the implant. Children must take off the implant if they will be exposed to static electricity (for example, if they want to go down a slide), or if there is any risk that the implant will be exposed to moisture,

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including excessive humidity or sweat (for example, if they child plays a sport). Even when it is in and turned on, some activities may interfere with the functioning of a cochlear implant. Other electronics, including telephones, may sometimes interfere with the device because it uses an FM signal.\footnote{Chute and Nevins, \textit{A Parent's Guide}, 62-64.}

The notorious difficulty in predicting how children will respond to implants makes it difficult to determine which services are appropriate for any given deaf child. This confusion is compounded by the existence of an extensive hard of hearing community, containing individuals with a wide-range of hearing and speaking abilities. Later, we will see that this complicates the question of “deaf rights” considerably. For this and other reasons, many deaf people claim that deaf children and deaf people are entitled, as a community, to a wide range of \textit{options}, and support programs that provide resources and education to parents, rather than sweeping mandates. It also helps to explain the fact that most Deaf people argue not for ASL-only programs, but for bilingual education or schools for the deaf which provide speech training to those who might benefit.

\textit{Hearing Aids}

A hearing aid, unlike a cochlear implant, makes use of the residual hearing that a deaf or, more commonly, hard of hearing person already possesses. Unlike a cochlear implant, it does not circumvent any part of the natural ear. Instead, it simply picks up and amplifies sound. Hearing aids are thus used primarily by individuals with enough residual hearing that the hearing which would be destroyed by the implantation surgery is greater than the hearing that the individual is likely to gain.
from such a surgery. As such, people with hearing aids in general are more likely to be hard of hearing than deaf, and tend to have better hearing than those with cochlear implants or with no aids.

Hearing aids have some drawbacks. They cost thousands of dollars, and are often not covered by insurance. They must be removed when exercising or going in the water or when it is raining. Most young children repeatedly try to pull the aids out of their ears when they first get them, and older children may lose or destroy their aids. However, in general, they carry far fewer risks or drawbacks than a cochlear implant.

Genetic Testing

The technology now exists to screen either the parents or the fetus, prenatally, for the genes which cause the majority of cases of prelingual deafness. (Of course, such a medical option is not available with regard to Susie, but it is an option that her parents might explore for future children, or that members of her extended family might use if they are concerned about having a deaf child). The tests are still controversial, however, and the availability of the tests, or the likelihood of the doctor to recommend them, may vary. At the current time, some doctors do not offer the test because the condition is not considered “severe” or “life-altering,” while others offer the test but are reluctant to recommend it. The test is normally offered only to those

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22 My brother, for example, ran his through the washer, wore them in the rain, and, once, ran them over with the car.


patients who have at least one known relative with the gene or their partners, as the
carrier rate in the general population is low and universal screening is considered
imprudent.\textsuperscript{25} Thus, while prenatal screening for genetic causes of deafness is
available, it is not yet widespread.

It should be noted that, while in the majority of cases prenatal genetic testing
would likely be used by hearing parents to avoid having deaf children, some Deaf
parents hope desperately to have Deaf, rather than hearing, children. Several Deaf
couples have made the news either by screening prenatally in the hopes that they will
be able to have a deaf child or, in the case of one lesbian couple, by selecting a sperm
donor with a long family history of genetic deafness.\textsuperscript{26} While it is true that prenatal
 genetic testing could be disastrous for the Deaf community, its effects may be more
complicated than they first appear.

An entire thesis could be written about the ethical debates involved in prenatal
genetic testing for deafness and other disabilities. There is no room to discuss the
issue in detail here. Nonetheless, I would like to note that even widespread prenatal
genetic testing would not eliminate the deaf community. During its formative years,
the American Deaf community was composed largely of individuals who had lost
their hearing due to a variety of communicable diseases.\textsuperscript{27} Yet the community
survived, and thrived, after these diseases were eliminated. It survived the invention
of hearing aids, and it survived a eugenics fad that argued that deaf people should not

\textsuperscript{25}“CIGNA Medical Coverage Policy,” CIGNA, Accessed April 2, 2011,
http://www.cigna.com/customer_care/healthcare_professional/coverage_positions/medical/mm_0254_
coveragepositioncriteria_genetic_test_congenital_profound_deafness.pdf
\textsuperscript{27}Christopher Krentz, ed. \textit{A Mighty Change: An Anthology of Deaf American Writing, 1816-1864},
be allowed to intra-marry or reproduce. The Deaf community is more enduring, even entrenched, than most hearing people realize. And it may put up more of a fight than most genetic scientists are expecting. It is dangerous to assume that a group of people that is threatened will automatically disappear, or that a group that may disappear is not worth studying or protecting.

Forgoing Treatment

Some parents of deaf children chose to forgo medical treatment. In the past, this was often because profoundly deaf children gained little benefit from hearing aids. Embracing their deafness and letting go of technology which was not helping them in any case had few costs, and the benefit of allowing children to focus on a language they could understand and an identity to which they could relate could be substantial. Cochlear implants have greatly increased the effectiveness of treatment options for profoundly deaf children, and have made it much less likely that parents, especially hearing parents, will choose not to attempt to help their child hear in some way.

Nonetheless, parents chose to avoid implantation or amplification for a number of reasons, and it is dangerous to assume that any option, particularly implantation, is appropriate for all children. The benefits and risks of the surgery, particularly when performed on a small child, must be realistically assessed by each family, and many families find that cochlear implantation is not the right option for them. Families may also chose to avoid implantation or even amplification for social or cultural, rather than for medical, reasons. This is particularly true of culturally Deaf families, but may also be true for hearing parents who embrace their child’s potential
for a Deaf identity or who object, on ethical grounds, to unnecessary surgery on small children or the fundamental alteration of their child’s life experience.

Some children receive no treatment simply because they, or their parents, get lost in the system. Since the passage of the Early Hearing Detection and Intervention (EHDI) law, 94 percent of newborns are screened before one month. Of the 1.8 percent who fail the initial testing, 45 percent receive no follow up services of any kind. A pathetic 43 percent of those referred for further testing receive it, and many families completely disappear from the process at this stage. Newborn screening is difficult, and only 6 percent of those who fail their initial tests are found to have a hearing loss following further testing. However, problems with follow-through on initial testing, coupled with the fact that only 64 percent of those diagnosed with a hearing loss actually receive early intervention services, contribute to a massive deficit of early education for deaf children. Of the estimated 12,000 deaf or hard of hearing babies born each year, only 2500 receive early intervention services.28

*Educational Options*

*Oral/Aural*

An oral/aural-only education seeks to teach children to speak, listen and read, and excludes other communication options such as signed language or cued speech. For many hearing parents, the oral/aural option appeals because it requires minimum adjustment on the part of the parent, it seeks to include the child in the parent’s language and culture, and hopes to familiarize the child with mainstream culture,

communication and education. In short, the oral/aural approach treats deafness as an obstacle to oral language learning, which can be overcome through the use of technology and specialized instruction, in order to allow the child to live as “normal” a life as possible.

The oral/aural approach has traditionally been quite popular, but recent research on the outcomes of children in oral and in other programs has not been favorable to a purely oral approach. For profoundly Deaf individuals, speech-reading is notoriously difficult, as only a small percentage of the information contained in speech is available visually through the lips and face.\(^29\) One study reported that “even the best speech-readers in a one-to-one situation were found to understand only twenty-six percent of what was said and many bright deaf and hard of hearing individuals grasp less than five percent.”\(^30\) As I will discuss below, advocates of bilingual education and cued speech can each cite studies suggesting that their children outperform oral only children on tests of literacy or even speech skills. Nonetheless, with the growing popularity of cochlear implants and other aids, oral/aural education will likely remain popular for years to come, and may initially have the greatest appeal for parents like Susie’s.

\(^{29}\) Speechreading is more commonly known as lip-reading. The term has been changed in recent years to reflect the fact that that visual information about what is being said is available not only on the lips, but also on other parts of the face.

\(^{30}\) Speechreading is even more difficult in other situations than a one on one conversation. In particular, it is difficult to speechread if there are multiple speakers, the speaker is not facing the recipient or is at an odd angle, the speaker has facial hair, the room is not well-lighted or the speaker uses unusual words or improper grammar, or speaks with an accent.

National Association of the Deaf, Legal Rights, 7.

I would also like to note that late-deafened individuals, who have had full access to the English language earlier in their lives, generally speechread more easily than prelingually deaf people.
Many Deaf people feel that an oral-only education is oppressive, both to the child receiving it and to the Deaf community as a whole. They have coined alternative terms for the method, including “hearization,” “English is Intelligence syndrome,” “communication violence,” and “ASL-as-problem” values.\(^{31}\) The backlash from the Deaf community immediately after the invention of cochlear implants was even more intense. Some deaf rights movements have even accused hearing parents and oralist educators of genocide. Most notably, the British National Union of the Deaf formally charged their government with genocide under the United Nations Convention on the Prevention and Punishment of the Crime of Genocide. An institutionalized oral culture, they claimed, had caused “children of one ethnic/linguistic minority group, that is, deaf people [to be] forcibly transferred to another group, that is, hearing people.”\(^{32}\) Deaf activist Paddy Ladd once called cochlear implants “the final solution,” and others, including MJ Bienvenu, agreed. “Like the Nazis,” she proclaimed, “they [hearing people] seem to enjoy experimenting on children.”\(^{33}\)

Such accusations might seem extreme to most hearing people, but it should be noted that they are rooted in the history of deaf communities all over the world. Deaf children in the nineteenth century were sometimes subjected to bizarre and painful “treatments” by doctors who claimed to be able to cure deafness. Later, the “cure” was selective breeding and, in the United States, oralism was initially born out of, and shared close ties to, the eugenics movement. The destruction of the deaf language and culture was seen as necessary to prevent deaf people from intra-marrying and thus

\(^{31}\) Jankowski, *Deaf Empowerment*, 80.
\(^{32}\) Jankowski, *Deaf Empowerment*, 93.
\(^{33}\) Jankowski, *Deaf Empowerment*, 143-144.
from producing children like themselves. The most powerful advocacy organization for oral education in the country, the Alexander Graham Bell Association, was founded out of such fears.\textsuperscript{34} To this day, many Deaf people note, 9 percent of AG Bell’s members are deaf, and a full 53 percent are hearing medical professionals.\textsuperscript{35} Thus, it is not surprising that the first reaction of many deaf people to oralism and cochlear implants alike is defensiveness.

As cochlear implants have become more popular, and more implanted children have also learned sign and become involved in the Deaf community, Deaf attitudes towards CI have softened. The National Association for the Deaf (NAD), for example, called CIs “ethically offensive” and a form of “experimentation” in the 1990s,\textsuperscript{36} but their current position statement on implantation takes a much more tolerant stance towards the procedure, acknowledging that “The NAD recognizes the rights of parents to make informed choices for their deaf and hard of hearing children, respects their choice to use cochlear implants and all other assistive devices, and strongly supports the development of the whole child and of language and literacy.”\textsuperscript{37}

\textsuperscript{34}Bell did not consider himself and extremist and did not support certain methods, such as forced sterilization. His opposition to such programs, however, was more scientific than ethical. He stated, for example, that “even if we were to go to the extreme length of killing the undesirables altogether so that they could not propagate their kind, this would not lead to an increase in the quantity and quality of the desirables.” Instead, he hoped that by oral training the deaf could be “improved” and that, by educating them in speech to the maximum possible degree and encouraging them to interact with hearing people, rather than other deaf individuals, their intramarriage could be avoided and thus the probability of further deaf offspring reduced.


\textsuperscript{35}Deaf Bilingual Coalition, “Language Begins with Early Intervention: the Need for Systemic Change,” (Presentation at the 50\textsuperscript{th} Biennial Conference of the National Association of the Deaf, Philadelphia, Pennsylvania, July 6-10, 2010).

\textsuperscript{36}Jankowski, \textit{Deaf Empowerment}, 143-144.

I will discuss these attitudes further during the chapters on Deaf culture. For now, the most important thing to note is that, for many deaf people, the true enemy of the Deaf community is not implantation, but oralism.

Thus, parents who are considering an oral/aural education for their child should be aware that doing so would certainly alienate themselves, if not their children, from the Deaf community. This is, in fact, one of the stated goals of an oral-only education. As a result, an oral/aural education carries a strong risk of isolating or alienating a child from his or her peers, as well as reducing the chance that a child will feel a sense of identity with or pride in his or her deafness.

**American Sign Language and Deaf Culture**

Another option for Susie is to learn American Sign Language (ASL) and become a member of the American Deaf Community. Since Chapter Two will take a detailed look at the claim that the American Deaf community possesses its own culture, at this point I will just briefly discuss ASL in order to indicate the nature of this option for children like Susie (ASL is a pre-requisite for entering and participating in the American Deaf community).

ASL is a true language, which can convey messages with equal speed, clarity and efficiency to that of any spoken language. Its unusual visual nature, however, led it to be misinterpreted as an inferior, gestural form of English until the 1960s, when William Stokoe, a hearing researcher at Gallaudet University, became the first to study its phonetics. Each sign, he discovered, had three phonemes: placement, hand configuration, and action. If one knew its phonemes, one could make any sign
clearly. ASL did have some gestural signs, but these were roughly equivalent to English onomatopoeias (for example, the sign for “knock” closely resembles the act of knocking on a door, just as the English word “knock” is based on its sound). Rather than being assembled in a linear order, ASL words are arranged in a four-dimensional grammar. Stokoe found that signers usually began in a position of repose, signed their statement, and then returned to their original position (Stokoe parallels this to viewing speech as a structure which exists between periods of silence). However, when a signer asks a question he or she holds his or her hands in the final position (and possibly move them forward slightly). Stokoe found that hearing professionals who were otherwise able to sign but returned to repose immediately after asking questions were often frustrated when deaf clients looked at them expectantly rather than answering the question. His research showed, however, that this was actually the appropriate reaction to the hearing person’s grammatically incorrect inquiry. Similarly, fluent signers freeze in place if interrupted, and continue their message once the interrupter has finished speaking.

Some of the more interesting aspects of sign make grammatical use of space rather than words or timing. For example, ASL uses a number of “classifiers:” hand shapes that represent certain objects, such as a car, person or plane. When telling a story, a signer might show the “car” moving over hills, parking in a lot, or colliding with another car or a tree. All of this could be done with classifiers, rather than words.

39 Stokoe, *Dictionary*, xxiv-xxv.
41 Stokoe, *Dictionary*, 276.
Similarly, when a signer is speaking about another person, he or she will “index” that person, establishing a very specific location for them in space. Once established, this location can be referenced in place of third-person pronouns (first and second person pronouns use the actual location of the people present as the established placement).

Further, a variety of verbs in ASL are “directional,” meaning that the direction of the sign conveys information about the subject and the object of the sentence. A signer can thus say “He gave it to her” or “Do any of you need help?” with a single sign.43

Space is also used grammatically when describing travel between localities or the position of objects in a room. Even more striking, signers do not conjugate verbs or use a “to be” verb, but instead relate time to space. A signer first establishes the time period of the sentence (for example, “yesterday” or simply “in the past”) and then proceeds to sign normally. All signs for the past move towards the space behind the speaker and all signs for the future move forwards, allowing the speaker to condense signs such as “three years ago” or “next week” into a single movement. Other examples of ASL’s efficient use of space abound.

This gives ASL a distinct advantage of MCE, Cued Speech or other attempts to make English visible. This use of a spatial grammar allows ASL to convey messages as quickly and effectively as any spoken language despite the fact that individual signs are more cumbersome than spoken words.44 It also adds greatly to the subtlety and complexity of the message which an individual word, or just a few

43 Once a person is established in space, their place remains constant for all speakers. For example, if I were talking about my friend Joe and I signed his name and then pointed to my right, you would point to your left, at roughly the same point in space, to indicate that you were talking about Joe. The space between us would have taken on a grammatical nature.
words, can convey. The meaning of a word or phrase might vary greatly based on facial expression alone, while reversing the direction of a verb can completely reverse the subject and object of a sentence. For this reason, ASL can be extraordinarily sophisticated, expressive and poetic.

Since ASL is fully visually accessible, and adapted to the visual medium rather than from the verbal one, it is able to provide deaf children with the opportunity to use a language with equal communicative potential without any of the barriers to access which they might experience with a spoken language. ASL also has the advantage of being easy to acquire: deaf children of fluent signers reach the same linguistic milestones, at the same time, as hearing children of hearing adults. This may have lifelong benefits. In fact, early access to any language, including sign language, has a strong positive correlation with later reading skills. One ASL researcher, Francois Grosjean, believes that “Having to wait several years to reach a satisfactory level in oral language that might never be attained, and in the meantime denying the deaf child access to a language that meets his/her immediate needs (sign language), is basically taking the risk that the child will fall behind in his/her development, be it linguistic, cognitive, social or personal.” Indeed, it is believed that the ability to acquire native fluency in one’s first language (as opposed to subsequent languages, which may “piggyback” off development in the language

47 Francois Grosjean, qtd. in “Frequently Asked Questions.”
oriented parts of the brain) requires that the individual have full access to that language before the age of five.\textsuperscript{48}

ASL, as the only true visual language, has the advantage of being for deaf children exactly what English is for hearing children, at least in terms of face to face communication. ASL, however, has no written form. Furthermore, it is an entirely new language for most parents of deaf children. Both of these have significant costs for both Susie and her parents.

\textit{Signed English}

Manual Coded English (MCE) or Signing Exact English (SEE) use much of the same vocabulary as ASL, although many signs are initialized. That is, the signs use the hand shape of a letter in the manual alphabet that corresponds to the first letter of the English word, but all other phonetic characteristics, such as movement and hand placement, match the sign in ASL. MCE and SEE differ from ASL, however, in that they use the word order and grammatical structure of the English language rather than the spatial grammar of ASL. As a result, signed English systems use signs for verb tenses, “to be” verbs, articles and other parts of speech that are unnecessary in ASL.

As I mentioned, while each sign in ASL takes longer to complete than a single English word, because true ASL makes grammatical use of space, it can convey messages with speed and clarity equal to that of English.\textsuperscript{49} Signed English does not make use of space in this way, and thus must use many signs to convey a single


\textsuperscript{49} Sacks, \textit{Seeing Voices}, 83-91.
thought. In addition to being much slower and (reportedly) rather cumbersome, neurologist and ASL researcher Oliver Sacks notes that “fundamental neurological limitations— in particular, of short-term memory and cognitive processing” make it difficult if not impossible to convey complex messages through this system. In short, it simply takes too long to convey a single thought.

Since it can be difficult for hearing adults to master a visual grammar, but English grammar’s linear structure is visually inefficient, many individuals and families use signing systems that fall somewhere in between. A spectrum of such styles, broadly known as Pidgin Signed English (PSE), exists between ASL and MCE. Most of the time, signers from varying points on the spectrum find each other mutually comprehensible. Many Deaf people will sign in fluent ASL with each other, and switch to PSE or MCE when communicating with a hearing person who is learning sign language. Likewise, many teachers who allegedly teach MCE (or ASL) will resort to some form of PSE.

MCE was popular in the early nineties, largely because it worked well in Simultaneous Communication (SC) systems. It has become less fashionable as Bilingual/Bicultural programs have replaced SC and Total Communication (TC) systems as the favored combined program (these will be discussed below).

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50 Sacks, *Seeing Voices*, 112.
51 It is common for people at different parts of the spectrum to communicate with each other, or even for an individual language learner to take classes at different points on the spectrum as they learn the language.
52 Lane, “Ethnicity, Ethics, and the Deaf World,” 44.
Cued Speech

Above is a chart which contains instructions for using one of the newer communication methods for deaf children: cued speech. Cued speech was designed to
overcome the difficulty which many children had speech-reading. Only between 30 and 35 percent of spoken English is available visually through speech-reading.

Although some speech-readers may be extremely skilled at making educated guesses or using context to decipher visually indistinguishable sounds, there is a large gap between the message that a person attempts to convey through speech and the portion of that message available through a visual form. In 1967, physicist R. Orsin Cornet invented Cued Speech in an attempt to bridge this gap. It uses a series of eight hand-shapes and four placements around the mouth, as shown. In combination with speech-reading, these make every English phoneme visually available to deaf children. While each hand shape might stand for more than one consonant; each placement more than one vowel; and each mouth movement for more than one sound, the combinations are constructed such that there are no overlaps. That is, phonemes which are difficult to distinguish on the mouth will have very different cues, and those which use the same cue will look very different on the mouth.

Cued speech is easier for hearing parents to learn than ASL, faster than MCE, and is a fully visually accessible form of the English language. Advocates of cued speech also tout its benefits as a literacy tool. Spoken English relies on phonemes, but signed English is morphemic (meaning that it shares words with the English language) and fingerspelling is graphemic (meaning it shares sub-phonemic symbols.

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53 Cued speech actually exists in 63 languages and dialects, with minor variations to account for different phonemes.
55 Cued Speech does slow spoken language by about 30%, but this is much less than MCE. Thomas F. Shull and Kelly Lamar Crain, “Fundamental Principles of Cued Speech and Cued Language,” in *Cued Speech and Cued Language for Deaf and Hard of Hearing Children*, ed. Carol LaSasso, Kelly Crain and Jacqueline Leybaert, (San Diego, California: Plural Publishing, 2010), 34.
with the English language). Since Cued Speech is phonemic, deaf children can “cue out” words just as their hearing peers sound them out. They can appreciate rhymes and homonyms. In fact, research suggests that cued speech improves reading comprehension, speaking and speech-reading skills over an oral-only program.

Despite mounting evidence of its benefits, Cued Speech is unpopular and used far more infrequently used than the alternatives. It poses an interesting theoretical challenge for the reader, however. A fully visual form of English may be the greatest threat to the argument that children are entitled to signed languages because of their unique accessibility.

**Combined Programs**

It is a common misconception among the hearing that Deaf people advocate an ASL-only program. In reality, most Deaf people and Deaf rights organizations advocate a Bilingual/Bicultural (Bi-Bi) program. In fact, Edward Miner Gallaudet, the first president of Gallaudet University beginning with its founding in 1864, believed that schools for the deaf should provide instruction in sign language but also

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56 LaSasso, “Why a Book about Cued Speech?,” 7

The Intermediate School District 917 Program for Deaf and Hard of Hearing Learners (ISD 917) in Minneapolis/St. Paul uses an educational system not mentioned in this chapter: it teaches children bilingually in ASL and Cued Speech. While the average deaf child in the United States gains .2 grades of reading level for every year of schooling, deaf children enrolled at ISD 917 gain, on average, a full grade level of reading for each year they attend the school. In short, children at ISD 917 learn to read with speed comparable to that of hearing students. Later, when I discuss the cultural rights of deaf children to ASL and/or Bilingual Education it should be noted that I leave open the possibility that other systems, such as cued speech, may be used to reinforce the English portion of the curriculum without violating a child’s right to ASL, provided that the ASL portion of the curriculum remained intact. In fact, a truly bilingual program might well use Cued Speech or similar tools in order to ensure that the children had complete access to English as well as ASL. For more information about ISD 917 and the latest research regarding cued speech as a tool for reading, please see: Kitri Larson Kyllo, “‘A Bilingual ASL and Cued American English’ Program for Deaf and Hard of Hearing Students: Theory and Practice,” in *Cued Speech and Cued Language for Deaf and Hard of Hearing Children*, ed. Carol LaSasso, Kelly Crain and Jacqueline Leybaert, (San Diego, California: Plural Publishing, 2010), 217-241.
make speech-training available to their students. Thus, American schools for the deaf and the American Deaf community have always favored some sort of combined approach. The oral movement in the United States has been opposed primarily by a movement in favor of the combined approach, not a demand for ASL-only education.

The Bi-Bi movement is only the most recent manifestation of the popularity of combined programs. In particular, Total Communication (TC), and its close cousin Simultaneous Communication (SC or Sim-Com) are important predecessors to the Bi-Bi movement. SC used signed and spoken English at the same time in order to reinforce communication. TC was even more popular, although vaguely defined. The idea of TC was that any method that enhances the ability of the child to communicate can, and should, be used. Signing, speaking, pictures, gestures, cuing, and other methods might all be used in turn in a TC household or classroom.

Bi-Bi differs from TC in that it attempts to make children comfortable with two languages and two cultures, rather than one culture presented in a variety of ways. It uses true ASL, not MCE or PSE. Unlike other methods, Bi-Bi assumes that Deaf people have a culture which is just as real and rich as that of hearing people. Deaf children will have the highest quality of life, Bi-Bi proponents believe, only if they are comfortable both in their own culture and that of the mainstream hearing world. Likewise, fluency in ASL and written English are both equally respected, and speech training is offered to those children who will benefit from it. For much of the history of the Deaf community, ASL has been treated as a back-up plan in the event of an oral failure, as something that can be Anglicized without ill-effect or as a tool to be incorporated in a child’s life as necessary. Bi-Bi education upends this system by
presenting ASL as a language in its own right, and Deaf culture as equal to anything found in hearing communities. Its hope is that deaf children can have the best of both worlds: a strong deaf identity and language base, and the best possible success in a predominantly hearing world.

Understood in this way, Bi-Bi might appeal most to Susie’s parents. However, this approach involves significant costs and places significant demands on both parents and deaf children; moreover, it also requires a significant change in attitude about what a good life for a deaf child entails. I will discuss these costs, demands, and philosophical re-orientations in the next chapter.

Conclusion

It ought to be clear from this brief overview that a plethora of options are available to Susie’s parents and to the parents of deaf children in the United States. With such a variety of advantages and drawbacks, it can easily be overwhelming for these parents and their deaf children. But perhaps the most important of these options involves the choice between whether a deaf child such as Susie should be a member of the deaf community and culture or whether they and she should try to function entirely in terms of the hearing culture that predominates the wider world in which she must live.

As I alluded to in the Introduction, there is a Deaf community and culture, of which many hearing people are completely unaware. It is this community which I shall answer in the next chapter, for it is only when Susie’s parents can appreciate what it might mean for her to enter Deaf society that they can be fully informed about the options available to her.
Chapter Two: A Culture of Hands and Eyes

An estimated one half to one million people in the United States use ASL as their primary language, and identify as “culturally deaf.” But what does this mean? When Deaf people identify themselves as culturally Deaf, are they speaking in the colloquial sense, as one speaks of an office culture? Or are they speaking about something deeper, something that sociologists and political philosophers would recognize as a culture in the strongest sense of the word? What does it even mean for a non-intergenerational, territorally dispersed group of people to claim that they have a “culture?”

Questions like these reach far beyond the identity of individual members of the Deaf community. They are closely connected both to positive questions, for example, about the educational potential of Deaf children if they remain immersed in the community, as well as to normative questions about the treatment of Deaf people. If the Deaf community possesses a culture, this would have far-reaching consequences for the rights of its members both individually and collectively. While the existence of a Deaf culture would certainly solve some debates surrounding the rights of Deaf people, it might produce more questions than answers. It may lead us to wonder, for instance, if people have a right to be involved in some sort of culture generally. If Deaf people possess their own culture, and have comparatively limited access to certain aspects of hearing culture, they might make a wholly original claim to cultural rights not based on an individual culture, but on the notion of culture itself and the importance of interaction with it. On the other hand, they might end up

58 Lane, “Ethnicity, Ethics and the Deaf World,” 41.
shooting themselves in the feet. Most hearing people, after all, would be reluctant to believe that a person could be part of an original culture for the same reason that they are disabled, and entitled to both cultural protections and accommodative services at the same time. For better or for worse, the existence of a Deaf culture would raise important questions about Deaf rights and about culture itself. For this reason, I will devote this chapter to the question of Deaf culture and its significance.

It is important to note, of course, that I am speaking of the American Deaf community here, as I am throughout my thesis. Among countries with large, well-institutionalized Deaf communities, there are immense variations in the histories, languages, and traditions of those communities. Twelve nations in the European Union, for example, as well as the Dutch and French-speaking communities in Belgium, give sign language an official legal status. According to the European Commission on Multilingualism, virtually every spoken language in Europe has a corresponding signed language. Signed languages do not always follow spoken language borders, however. American Sign Language (ASL), for example, is very different from British Sign Language (BSL) or Australian Sign Language (Auslan), although all three countries speak English (it is, however, used in Canada). It is, instead, a creole descended from French Sign Language and a variety of indigenous signing systems. While sign languages and Deaf communities are as vibrant and varied as spoken languages and hearing cultures, it is important to remember that the history which most of us know is the history of the hearing world. The history of the

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American Deaf community is not simply a Deaf parallel to the history of Hearing America. It is entirely distinct.

We are left, then, with a community of Deaf people, distinct both from the surrounding hearing community and from the variety of other Deaf communities around the world, a community that claims to possess a unique culture. Our first task, which we shall address in this chapter, is to determine what it means to have a culture, and whether or not American Deaf people do, in fact, possess such a thing. Later, we shall attempt to specify more finely the nature of American Deaf culture, and to determine the implications of our findings for the general question of whether or not members of the American Deaf community possess special cultural rights.

**Defining Culture**

Definitions for what constitutes a culture are as varied as cultures themselves. Since there appears to be no consensus on a universally agreeable notion of culture, I have here attempted to create my own definition, one that is essentially an amalgam of several definitions from respected cultural rights theorists. For the purposes of this thesis, a culture is defined as: A learned pattern of values, rules for behavior, knowledge, and beliefs, shared by a group whose members are significantly and consistently affected by a common experience (often in the form of a unique language or history) and are actively involved in its maintenance; these factor shape the experiences of group members and provides resources for changes in their behavior, organization, and thought. The active maintenance of a culture involves, at the very least, the passing of the culture to new members, but also requires members to use
and interpret their culture in interactions with others, often in the form of shared arts, literature or institutions.  

This definition is convenient in that it provides us with a number of factors on the basis of which we can assess whether the American Deaf community possesses a culture. We might ask ourselves, for example, whether or not its members possess shared values, rules for behavior, cultural knowledge, shared beliefs, or common experiences. We might also look at the relationship between these initial factors and the community members affected by them. Do these factors shape the experiences of the community members? Do community members, in turn, shape and maintain these factors? How does change take place within this community? Each of these factors and questions functions, in its own way, as a test of some aspect of a culture. If the Deaf community fails these tests, our debate over Deaf cultural rights is solved. But if the community passes, then a number of ethical and moral questions about the treatment of this unique culture and its numerous members can be raised. It will be the burden of the rest of this chapter to show that the American Deaf community does indeed possess its own culture.

My definition, then, serves to break down the definition of culture into a series of discreet traits which can be qualitatively examined. In order to pass the test, Deaf

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culture must possess nine such traits. The group must share a set of learned values (1), rules for behavior (2), knowledge (3) and beliefs (4). Group members must be consistently and significantly affected by a common experience (5) and be actively involved in the maintenance of their community (6). This set of values, rules, knowledge, beliefs, experiences and maintenance activities must shape the experience of group members (7) and provide resources for change (8). We can examine each of these traits individually in order to determine whether or not Deaf people possess a culture according to our definition. Since the common experience of the Deaf community has greatly influenced the values which community members share, I have moved the discussion of the latter until immediately after the former. For that reason, we will begin by analyzing the Deaf community’s rules for behavior.

An Analysis of Deaf Culture

Rules for Behavior

People who call themselves culturally Deaf often identify themselves, and each other, by certain sets of behaviors. Perhaps the most important conduct required of members of the Deaf community is to be proud of one’s deafness, and to be vocal about that pride. Deaf people, for example, consider it patronizing when hearing people attempt to do certain “favors” for them. For instance, if a hearing person and a Deaf person go out to lunch, it is considered impolite for the hearing person to order for the Deaf person unless he or she is asked to do so. Many Deaf people prefer to point, to write down their order, to use their voice (if they have good oral skills), or to communicate with the waiter or waitress by some other means that allows them to retain their independence. Some also resent the “assistance” given to certain deaf
people by hearing society. A number of Deaf people look down upon Deaf homeless people, and many are uncomfortable with Deaf beggars, particularly if they blame their poverty on their deafness. Social Security Disability Income (SSDI) can also be a contentious issue in the Deaf community for similar reasons. Numerous Deaf people consider accepting SSDI contradictory to their conviction that they are a cultural minority, not a disabled group. Others concede that receiving SSDI is acceptable only because discrimination from the hearing majority has made unemployment in the Deaf community higher than it otherwise would be. Whatever their feelings on SSDI, most Deaf people are offended by the idea that being Deaf makes them less qualified to work or interact in the hearing world.

Another important aspect of Deaf culture is the conception of deafness as a rich visual experience, rather than an incomplete aural one. As a result, visual cues take on great importance in the Deaf community. Facial expressions have linguistic significance in ASL, and can change the meanings of words, and Deaf people who speech-read rely on a clear view of a speaker’s face in order to best understand them. Eye contact, as a result, is extremely important in the Deaf community. Deaf people make eye contact with each other before starting a conversation, and eye contact is maintained throughout the conversation. It is considered polite to flash the lights, stomp on the ground, pound on tables or tap on people’s shoulders in order to gain eye contact before speaking. It is impolite, however, to multitask by taking your eyes away from the speaker in order to look at a mirror, window or object. Deaf people are deeply offended when hearing people fail to make eye contact with them when speaking, especially if they are looking at the interpreter instead.
Perhaps the most interesting manifestation of this enriched visual world is the study of “Deaf space.” Gallaudet University has been researching for years (and offering classes in) “Deaf space,” or the study of architecture for Deaf people, through its Department of ASL and Deaf Studies. Good Deaf spaces, researchers believe, are large, open spaces, with ample lighting and rounded corners for easy communication in sign language. They have wide sidewalks so that students can walk next to their friends while signing, and ramps instead of stairs. “Architecture is one of the key ways a culture manifests itself in the physical world,” explains architect Hansel Bauman. “Deaf culture centers around the language. The language has all the elements of architecture- the spatial kinesthetic of sign language, the desire of deaf people for the visual access that open space affords- lends itself to express the deaf way of being.”

In my experience, hosts of events or parties are expected to provide a Deaf-friendly venue, including providing lots of open spaces and good lighting. Lighting and space considerations are a frequent topic of conversations at restaurants, hotels, and gatherings, and help to determine the success of a Deaf event.

These are not the only behaviors associated with Deaf communities, of course, but they serve to illustrate an important point: Deaf culture is a visual culture. It is based upon a visual language, visual art forms, visual spaces, and complex visual-expressive skills. It requires that everything, from doorbells to fire alarms, be made visual. It also expects that speakers have certain visual skills, including excellent peripheral vision that allows Deaf people to call one another by waving their hands, or to follow group conversations by noticing the person next to them talking out of

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the corner of their eye. It is for this reason that some Deaf people that I have met call themselves “people of the eye.”

Cultural Knowledge

In addition to fluency in ASL and the ability to create and function in a highly visual environment, Deaf people are expected to possess a variety of cultural knowledge. Harlan Lane, for example, suggests that “Deaf people have culture-specific knowledge such as who their leaders are (and what their characteristics are), the concern of rank and file members of the Deaf world, important events in Deaf history, and how to manage in trying situations with hearing people. Knowing when and with whom to use American Sign Language and when to use English-marked varieties of sign language is an important part of being recognized as Deaf.”

This sort of knowledge is used by members of the Deaf community to distinguish other Deaf people from their deaf counterparts. It also may play a role in Deaf cultural events. For example, when I attended the Fiftieth Biennial Conference of the National Association of the Deaf, Deaf culture played a prominent role at many events. There was a section on Deaf history/culture during the Deaf College Bowl and a plethora of workshops and exhibitions related to Deaf current events.

Additionally, many Miss Deaf America contestants used their knowledge of Deaf culture, either in their platform speeches or their artistic performances, to woo the judges. Miss Deaf Illinois, who won the competition, performed a poem entitled

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62 George Veditz coined the term “people of the eye” to describe Deaf people at the Ninth Convention of the National Association of the Deaf in 1910. Quotations from his speech are popular on Deaf blogs.
“Deaf Role Models: ASL Poem from A-Z” for her artistic performance. This required not only knowledge of Deaf history and Deaf role models, but also knowledge of Alphabet poems, a type of poetry exclusive to ASL. An alphabet poem plays with bilingualism by using a series of hand shapes that correspond to the manual alphabet to tell a story in ASL. Since ASL and English are distinct languages, a hand shape for one letter might be used to make a word which, in English, would start with a different letter, or it may be used as a classifier or in another grammatical structure that does not exist in the English language. Still, the sequencing of the hand shapes is determined by the manual alphabet, which is used to spell out English words or names. Cynthia Peters suggests that this not only reflects the bilingual nature of Deaf culture, but also its delight in playing openly with aspects of the English language, making a defiant statement about which language is primary and which language is available for others to co-opt or dominate. Alphabet poems, and other ASL art forms which will be discussed later, are an important part of Deaf culture. Miss Deaf Illinois, by signing an Alphabet poem, was making a statement about her Deaf identity. This statement was driven home by the fact that she requested that the interpreters present at the event refuse to provide an interpretation of her poem, since Alphabet poems play on visual activity and structures that are unique to signed languages and are impossible to translate fully into spoken words. Her decision to choose a topic related to Deaf history and culture, and present it in an art form

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64 For example, the hand shape for F might be used to make “decide,” “postpone,” “judge,” “cat,” “fruit,” “if,” or “oversleep.” Likewise, the number 3 might be used to illustrate the motion of a car, or variants of the letter V might be used to show a person standing, sitting, kneeling or engaging in other activities.

exclusive to the Deaf community, was as much a strategic statement of identity for Miss Deaf Illinois as discussions of patriotism and singing nationalistic songs about America are common ploys for hearing contestants. Knowledge of certain subjects is expected not only of Miss Deaf America contestants, but of proud Deaf Americans more generally.

Common Experience

We have already discussed many aspects of the common Deaf way of life, including the sensory experience of living in a highly visual world and the linguistic one of using American Sign Language to communicate. These understandings tie together current members of the Deaf community, but, like hearing cultures, Deaf people are also a historical community. It is not only their current circumstances which shape their values and lifestyle, but also their communal past.

Early Deaf American History

The American Deaf community possesses its own creation story, which can be found in nearly every book on deaf history and culture, as well as at least one children’s book, and is often re-told orally at Deaf events. It is the true story of the creation of the first schools for the deaf in the country and the birth of American Sign Language, but it has taken on somewhat of a legendary status in the Deaf community.66 I will try to retell the tale much the same way that it has been told to

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66 In writing my version of the story, I have drawn primarily from the version found here: Krentz, A Mighty Change, viii-xxiv. This is the version that I will cite throughout the story, in part because it is so detailed. Those interested in the life of Clerc will also find that excerpts from Laurent Clerc’s speeches and personal journals form the basis of the first chapter of the book. Nonetheless, I feel that it is important to note
me: that is, in the slightly idealized version which represents the popular history of the Deaf community, just as heroic stories of George Washington represent the popular history of America, if not the complicated realities of the Revolution.

It began in the early nineteenth century with an eight-year-old deaf girl, Alice Cogswell, whose plight seemed to symbolize the struggles of early deaf Americans. Alice had no access to language: American Sign Language did not yet exist, there were no schools for the deaf, and oral tutoring was almost totally unknown. Luckily, she lived next door to a kind young minister, Thomas Hopkins Gallaudet. Gallaudet saw that she was a bright young girl, and that she had been deprived of the Lord, and decided to try an experiment. He showed her his hat and wrote “H-A-T” on the ground in the dust. Alice seemed to understand, and so Gallaudet found his calling. After some initial success teaching Alice to read and write, Gallaudet and Alice’s father, Mason Cogswell, hatched a plan to start a school for the deaf in the United States, in large part in order to bring God to deaf Americans. They raised money and, in 1815, Gallaudet set out for Europe.

Gallaudet traveled first to Great Britain, where he encountered a strange problem. The education of the deaf in Britain was monopolized by a family called the Braidwoods, who ran oral schools throughout the country. Gallaudet was told that their methods were “secret” and that they would not teach him how to educate deaf children. Fortunately, Gallaudet’s trip, as it happens, coincided with Napoleon’s

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that this story is available in nearly any book on Deaf culture or history. It also forms a part of the shared knowledge of the Deaf community and is frequently alluded to by Deaf individuals, particularly when they are making a point about Deaf culture or Deaf pride. Thus, while Krentz is cited here to verify the historical veracity of the tale, the storytelling style which I use alludes much more to the way that I have seen the story is perceived in the Deaf community than to Krentz.

67 A Mighty Change, ed. Krentz, xiii.
68 A Mighty Change, ed. Krentz, xiv.
return to France in 1815. As a result, several important men had decided to leave the National Institute for the Deaf in Paris for Britain, in order to give presentations about their school’s methods while things in Paris calmed down. Thus, he met Abbé Roch Sicard, successor to Abbé Charles Michel de l’Epee, the first hearing man to try to learn and formalize the signs used by deaf communities in Paris and to use them to educate deaf Parisians. He was traveling with Jean Massieu, a deaf teacher of the deaf, and Massieu’s former student, Laurent Clerc (also deaf).69

In July, 1816, Gallaudet visited the National Institute for the Deaf, where he learned about the education of the deaf through signed languages. The following June he left for the United States, taking with him Laurent Clerc with the intention of making him the first teacher at the new school. On the ship, Gallaudet taught Clerc to read English and Clerc taught Gallaudet French sign.

Clerc became indispensible to Gallaudet upon his return to America. Clerc was able to convince skeptical Americans that deaf people could be educated with his written speeches, which Gallaudet would read to skeptical audiences. When the audience asked questions, Gallaudet translated them into sign and Clerc wrote his responses on a blackboard. In this way, they collected $5,000 and a matching donation from the CT state legislature. In 1817, they founded what is now called the American School for the Deaf (ASD), in Hartford. It opened with 7 students, including Alice Cogswell.70

ASD, which now claims to be the oldest school for the deaf in the United States, and the oldest special education institution in the Western Hemisphere,

69 A Mighty Change, ed. Krentz, xiv-xvi.
70 A Mighty Change, ed. Krentz, xv.
became the birthplace of ASL. At ASD, the French Sign brought over by Clerc mixed with indigenous sign languages from small, isolated deaf communities (such as Martha’s Vineyard); bits of English that students picked up from their lessons in written English and, later, oral-training; and a variety of “home signs,” or signs invented within an individual family in order to communicate. The result was American Sign Language (ASL), which some now call a creole, and which gradually standardized and spread throughout the nineteenth century.

Within years of its opening, the ASD began training other teachers for the deaf, allowing signing schools to open New York, Pennsylvania, Kentucky, and many other states. In 1864, the United States took another leap forward in deaf education and founded, by an act of Congress, The National Institute for the Deaf and Dumb (now Gallaudet University). It was the first institution designed to provide higher education to deaf people in the country. Gallaudet’s son, Edward Miner Gallaudet, became the first president of the college.

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72 In happy situations, a home sign might be used to supplement ASL. For example, my family has a home sign for “Ninja Turtles” (my brother’s favorite show around the time of his diagnosis). It is not uncommon for families to produce such home signs, especially when the family is just learning sign language. Some sign language teachers discourage the use of home signs because they feel that it may interfere with the learning of true ASL and worry that parents may inadvertently produce highly inappropriate signs.

However, in 1816, home signs had a very different nature. Since no schools for the deaf existed in early nineteenth century America, home signs were often elaborate gestural systems invented by deaf individuals as their sole means of communication with the surrounding world. A single person cannot invent a language, and home signing systems left much to be desired. However, deaf individuals often carried with them what few gestures or signs they had invented when they entered the school for the deaf, and home signing systems may have been a bit of a “wild card” in the development of ASL.
74 “Sound and Fury- Deaf History Timeline.”
Gallaudet’s founding represented a great triumph for the Deaf community. However, it would not be long until ASL and Deaf Culture were threatened with extinction by a new educational movement known as oralism. Oralists believed that Deaf children could, and should, learn to speak English and behave, as much as possible, like their hearing peers. Culturally Deaf people saw oralism as an attack not only on their language, but also on their culture and lifestyle. This solidarity against a perceived destructive power, as well as the rhetoric which Deaf people eventually used to fight that power, shaped many of the shared beliefs and values of the Deaf community. For that reason, I will continue my discussion of Deaf history in the section below.

*Shared Beliefs and Values*

The shared beliefs and values of the Deaf community have strong historical roots. This history is perhaps best understood as taking place in two parts. The first represents what many Deaf people believe to be a shared history of oppression, a time when oralism nearly wiped out their language and culture. The second involves an explosion of Deaf culture in the late twentieth century, culminating with the Deaf President Now (DPN) protests at Gallaudet, which represent to Deaf people a moment in which, by acting collectively, Deaf people were able to throw off the audist chains.75 The two sections would be seen by many Deaf people as representing the ebb and flow of their language, culture and empowerment, if not an upward trajectory from a time of evil and oppression to a time of increasing autonomy.

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75 Audism is a word used by Deaf people to describe someone who discriminates on the basis of hearing. It is to the deaf what racism, sexism, heterosexism, and other –isms are to a variety of other groups.
**Challenges of Oralism**

By the mid-nineteenth century state-funded, residential schools for the deaf, which offered instruction in ASL and written English, were increasingly common in the United States. They were one of the few options available to deaf children and one of the only options affordable for most families. These schools became the birthplace not only of American Sign Language, but also of Deaf culture. Children often had little or no language exposure before being sent away to a residential deaf school, where they lived with other deaf children and communicated predominantly in sign language. The ties formed at residential schools were only strengthened by the continued isolation experienced by many deaf people after graduation as minority language speakers. By 1896, 95 percent of deaf people married other deaf people and mixed couples were three times more likely to divorce. The Deaf community now extended beyond schools for the deaf into rapidly forming Deaf families.76

Just as the Deaf community was beginning to form, however, oralism began to take root. Closely linked to the ideals of scientific progress prevalent at the time, the oral movement hoped that deafness might be prevented through eugenics, cured through technology, or made invisible through new speech-reading techniques. In 1880, the International Congress on Education for the Deaf (ICED) passed a resolution denouncing signed languages and calling for oral-only education in schools for the deaf. The American Deaf community, however, was already prepared to fight back. The National Association of the Deaf (NAD) was founded that same year, and

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76 Jankowski, *Deaf Empowerment*, 48-49.
one of its fundamental goals was to protect and preserve ASL. Additionally, Edward Miner Gallaudet remained a strong voice for ASL even as oral education became increasingly popular and dogmatic.

In the United States, the early oral movement was synonymous with a single name: Alexander Graham Bell. Bell’s paper, “Memoir upon the Formation of the Deaf Variety of the Human Race,” which he presented in 1883, became a manifesto for the movement. Bell explained his fears that residential schools for the deaf, ASL, and the emergent deaf culture were encouraging high intra-marriage rates among deaf people, and thus the perpetuation of a “defective” type of human beings. While he avoided the issue of sterilization, Bell did discuss “repressive measures,” such as forbidding by law the marriage of one congenitally deaf person to another. However, he worried that this may not be effective (in part due to the difficulty of preventing hearing individuals from families carrying deafness from intermarrying). Instead, he strongly advocated “preventative measures,” such as the elimination of residential schools, the suppression of ASL, and the systematic firing of deaf teachers.

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78 For excellent coverage of this subject, see Winefield, *Never the Twain Shall Meet*. It focuses on the heated debates over deaf education which took place in the late nineteenth century, when Gallaudet and AG Bell, heroes of their respective movements, were each alive and passionately involved in convincing the world that the other was mistaken if not misleading.

of the deaf; and he called upon all deaf individuals, their families, and their educators, to work to prevent the marrying of deaf couples.\footnote{Ibid.}

Eugenics was not, however, Bell’s only motivation. His mother was deaf and, eventually, he married one of his deaf pupils, Mabel Hubbard. Bell wanted desperately to bring speech to deaf people, and as a young inventor whose father was an elocutionist, he firmly believed that this was possible.\footnote{Winefield, \textit{Never the Twain Shall Meet}, 12-16.} He may well have had good intentions. His treatment as a villain in Deaf folklore is due primarily to his methods, which included isolating deaf people from each other and suppressing ASL and Deaf culture. Even on an individual level, many Deaf people resent that, historically, the deaf have been made to talk to candles or drums, to feel the faces of hearing people, and to otherwise concentrate hours of each day on speech training when a fully accessible visual language has been readily available.\footnote{For spectacular historical photos from oral schools and interviews with deaf graduates of oral institutions, see \textit{Through Deaf Eyes}, directed by Diane Garey and Lawrence R. Hott, (2007; Public Broadcasting Service) TV.} Bell’s good intentions, then, are seen by most Deaf people as paralleling the “good intentions” of patriarchal men who have historically assumed that women cannot support themselves or colonial powers who believed that people in other parts of the world needed “education” and “protection.”

Although the AG Bell association has changed over time, the fact that they continued to distribute his “Memoir upon the Formation of the Deaf Variety of the Human Race” long after Bell’s death, that the organization continues to bear the name of a known eugenicist, and that AG Bell’s membership is composed primarily of medical professionals has left many Deaf people with a sense of lingering
bitterness. When I first began researching Deaf culture, one person remarked that the AG Bell Association was “the Boogeyman of the Deaf community.” The discontent against the AG Bell Association which I have seen in casual settings, however, is contrasted by a working professional relationship between the AG Bell Association and the NAD.

Partly as a result of the AG Bell Association and other oralist groups, from 1880 until the 1960s, ASL was discouraged in many schools for the deaf. Students at oral schools were severely punished for using sign, and often had their hands tied together or behind their backs as punishment for signing. In the documentary, *Through Deaf Eyes*, one man reports that, when he attended an oral school as a child, he was forbidden to sign and made to wear white gloves which were carefully strung together if he disobeyed. Rodney Kunath, a graduate of the Clarke School, a famous

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83 Only nine percent of AG Bell’s members are deaf, while fifty three percent are medical professionals. Deaf Bilingual Coalition, “Language Begins with Early Intervention.” Some deaf people feel that, since medical professionals stand to profit from cochlear implant surgeries, a significant portion of the AG Bell Association does not have deaf children’s best interests at heart. However, this is not the official stance of most organizations, including the NAD, which greatly values cooperation with the AG Bell Association in certain areas.

84 Apparently, this characterization of AG Bell the person is quite common, although I am not sure how often it is applied to the organization. Deaf author Tom Humphries, for example, is pictured in *Through Deaf Eyes*, signing “Alexander Graham Bell is a very important figure in Deaf folklore. He offers and antagonist perspective, because he’s like the boogeyman.” *Through Deaf Eyes*, directed by Diane Garey and Lawrence R. Hott, (2007; Public Broadcasting Service) TV.

oral institution, confirms that the discipline continued off campus. Once, he went into downtown Northampton and “there was a policeman in plainclothes. I did not know that he was watching me. But when I went back to the Clarke School, the teachers told me ‘Rodney, you were seen waving hands downtown,’” and warned me not to go downtown again.” For the late nineteenth and early to mid-twentieth century, schools for the deaf in the United States were predominantly oral, and stories like these were not uncommon.

The Deaf community survived, in part, due to the strong religious tendencies of many American educational institutions. At oral schools where signing was normally forbidden, exceptions were often made during bible study and church services. It was hoped that these privileges would encourage religious devotion and make God easily accessible to children as they learned to speak. But the practice had the unintended effect of providing many students with their only access to Deaf, signing adults and to a language and community which was otherwise forbidden to them. Church services at oral schools inadvertently helped to preserve the Deaf community through some of its darkest times. In some areas, Deaf people continue to share strong religious beliefs.

Churches, however, are not the only reason that the Deaf community survived these dark times: many Deaf people went to great lengths to preserve their language and culture. In particular, from 1910-1920, the NAD raised funds to film fluent signers in order to preserve ASL in the event that the increasing popularity of oral

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86 Through Deaf Eyes, directed by Diane Garey and Lawrence R. Hott, (2007; Public Broadcasting Service) TV.
87 Ibid.
88 Burch, Signs Of Resistance, 40.
education caused it to disappear entirely. While ASL never died, the films made by the NAD demonstrate both the extent to which the Deaf community feared the oral movement, and the lengths to which Deaf people were willing to go in order to preserve their identity.\textsuperscript{89} The films and the tenacity they represent; the willingness of signing schools in the United States to switch to combined programs rather than purely oral ones; and the tendency of some oral schools to continue to allow ASL in religious contexts, created an atmosphere which allowed ASL to survive during a time when sign languages around the world were under attack. In fact, the galvanizing effect that these experiences had on the Deaf community may help to explain the strength of the Deaf identity today. Later, when Deaf people turned their attention from survival to liberation, they would be able to look back on a history not only of oppression but of defiance.

\textit{Empowerment and the “Deaf President Now” (DPN) Protests}

As I mentioned in the first chapter, William Stokoe first discovered that ASL was a true language in the 1960s, disproving the longstanding oralist claim that signed languages were inferior, savage substitutes for the English language. This was followed by an explosion of Deaf art, theater, literature, and poetry that encouraged many Deaf individuals and educators to move closer to the ASL end of the ASL-MCE spectrum. I will discuss this explosion of ASL and ASL art forms later in the chapter. For now, the only thing which the reader needs to know is that an expansion of ASL literature following Stokoe’s discovery took place, and that it led to a great

\textsuperscript{89} Burch, \textit{Signs of Resistance}, 61.
increase in the self-esteem and sense of empowerment of the Deaf community. An increasing sense of self-worth helped to fuel Deaf demands for autonomy in the control of institutions for the deaf, demands that climaxed in the Deaf President Now (DPN) protests at Gallaudet University in the late 1980s.

Before DPN, Gallaudet had never had a deaf president, and very few schools for the deaf had deaf superintendents. In fact, the board of directors for Gallaudet was almost entirely composed of hearing people, most of whom knew little or no sign. In 1988, however, hopes for a Deaf president were raised considerably. The board named three finalists for the new President of Gallaudet University: two deaf people and one hearing woman. Many students believed that this was an indication that Gallaudet University was ready to turn over some of its key positions to Deaf individuals. When the only hearing candidate, Elizabeth Zisner, was finally selected, the Deaf community was severely disappointed, and Deaf students were outraged. Perhaps they had gained a sense of empowerment and pride afforded to few of their predecessors from the growing acknowledgement of ASL as a legitimate language and the nascent disability rights movement. Whatever the cause, Gallaudet’s campus erupted in protests as soon as Zisner’s selection was announced.

Students shut down the entire campus for a week, barricading the grounds and even marching on the Capitol. The administration’s initial reactions only further enraged students. Several trustees made dramatic mistakes, such as claiming that deaf individuals were incapable of handling finances or that deaf people could not

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90 Jankowski, *Deaf Empowerment*, 99-100.
91 Jankowski, *Deaf Empowerment*, 100-102.
93 Jankowski, *Deaf Empowerment*, 118.
function in the hearing world.\textsuperscript{94} Deaf students who had always suspected that hearing administrators did not respect them nor have their best interests at heart held up such statements as proof of the indignity of having audist, hearing people in charge of educating intelligent, Deaf adults.

In expressing their discontent and advocating for a new president, DPN protestors began to rapidly invent forms of civil disobedience uniquely available to Deaf people expressing dissatisfaction with the action of hearing authorities. For example, when Spillman, the head of the board of trustees, came to speak to the students, they set off all of the fire alarms in the building, screaming and making as much noise as possible. “We aren’t going to hear you if you scream so loudly that we can’t have a productive dialogue,” hollered Spillman. The students spoke and signed sarcastically in response, making comments such as “What noise?” and “If you signed, we could hear you.”\textsuperscript{95}

The students made four demands: that Zisner be replaced with a deaf president; that Jane Bassett Spillman, the Chair of the Board of Trustees, resign; that 51\% of the board be deaf; and that there would be no retaliation against the protesters. The administration, seemingly blindsided by the sudden empowerment of its deaf students, met all of them. It was a remarkable success for students not used to protesting, and not used to seeing other Deaf people in positions of power. Its effects would cascade into the following years: Gallaudet established a Deaf Studies Department in 1994 and made Deaf Culture a required class in 1996.\textsuperscript{96}

\textsuperscript{94} Jankowski, \textit{Deaf Empowerment}, 103.
\textsuperscript{95} Jankowski, \textit{Deaf Empowerment}, 120.
\textsuperscript{96} Jankowski, \textit{Deaf Empowerment}, 107, 120.
The rhetorical significance of the protest and its surrounding events for the Deaf community cannot be overestimated. Particularly popular stories often involved hearing people who had severely underestimated the Deaf people in their lives. Before the protests, for example, the president’s wife had laughed openly when an electrician asked her if he should install wiring for a flashing doorbell in the presidential house, in case a deaf president should ever be selected. The electrician secretly installed the wiring anyways, which was activated after the protests were successful. 97

The movement changed the way that Deaf people thought about and talked about themselves. It was not long before people began to create a number of new words in ASL, including “Can the ‘can’t syndrome,’” a reversal of the sign for “can’t syndrome” which deaf students used to describe hearing people who stated that “deaf people can’t.” 98 Similarly, some Deaf people have played with signs for mainstreaming in order to emphasize feelings of isolation. The traditional sign for mainstreaming involves two hands that come together with open palms and extended fingers. This hand shape is similar to the classifier used for a crowd of people, and the two hands coming together represent two streams of people intermixing. The new mainstreaming sign uses one open palmed hand and one pointer finger, the classifier for an individual. The “individual” is submerged under the “crowd” in the new sign, representing feelings of isolation, loneliness and oppression. 99 Deaf people have also invented new English terms, including “hearization” and other negative terms to describe oralism mentioned in Chapter One, and “signing impaired,” “hard of

97 Jankowski, *Deaf Empowerment*, 103-104.
98 Jankowski, *Deaf Empowerment*, 134.
99 Jankowski, *Deaf Empowerment*, 90.
fingerspelling” and “dexterity disabled” as ways of describing people who cannot sign.\textsuperscript{100}

The protestors even revolutionized the Deaf sense of humor. Old jokes, such as this one, emphasized the difficulties of dealing with the hearing world.

A deaf man is driving and reaches a set of train tracks, where he is stopped by a crossing signal. After waiting a long time, he gets out of the car, walks to the station, and writes a note to the hearing attendant asking him to “please but.”\textsuperscript{101}

The joke, which is only accessible to signers, is that the signs for “gate” and “but” look very similar. The Deaf man is at the butt of the joke, because he has translated the word incorrectly. Conversely, jokes that became popular during and after the DPN protests emphasized deaf pride. The reader should have no problem understanding who is at the victim of this joke:

A deaf man, a Cuban and a Russian are on a train. The Russian drinks half a bottle of vodka, throws the other half out the window and says “we have plenty of vodka in Russia!” The Cuban does the same with a cigar. The deaf man sees a hearing passenger walking by, throws him out the window and says “We have plenty of those in the US!”\textsuperscript{102}

The success of the DPN protest revolutionized Deaf attitudes and started a nationwide movement, with a series of successful protests at schools for the deaf across the country. Such protests occurred in the early nineties at the Wisconsin School for the Deaf and the Lexington School for the Deaf. By the mid-nineties, most schools for the deaf had reorganized in some way, either because of protests at their

\textsuperscript{100} Jankowski, \textit{Deaf Empowerment}, 80, 144.
\textsuperscript{101} Jankowski, \textit{Deaf Empowerment}, 140.
\textsuperscript{102} Jankowski, \textit{Deaf Empowerment}, 141.
own institutions or indirect effects of the movement. The sense of pride and
culture, as well as the desire for Deaf leaders, were legacies of the DPN protests that
spread to the entire Deaf community and that continue to influence the discourse
surrounding Deaf rights. If you are looking for a moment in which the Deaf rights
movement as we know it was founded, this is it.

This history has produced a series of shared beliefs, one of the most important
of which is that Deafness is an identity, not a disability. The new sense of humor,
signs and methods of protest that came out of DPN all emphasized the Deaf people as
independent, capable and culturally distinct. Deaf people today have maintained these
attitudes. They may call themselves signing people, “people of the eye” or, most
commonly, just Deaf. But they normally will not call themselves “hearing impaired”
or refer to themselves as having a “hearing loss,” and they will certainly be offended
by the term “mute.” Some Deaf people also disapprove of hearing aids or cochlear
implants, and most disapprove of strict oral programs. Many members of the Deaf
community, in fact, were raised orally and were either labeled as “oral failures” or
found the program to be isolating (or both). Often, Deaf adults who were raised orally
and entered the Deaf community later in life resent oral programs (and sometimes
their hearing family members) for teaching them that deafness was a disability. In
general, then, the members of the Deaf community take great pride in their Deafness,
and are offended by programs and words that suggest that their deafness is something
to overcome, something which should make them feel inferior or ashamed.

103 Jankowski, Deaf Empowerment, 144-155.
Maintenance by the Active Involvement of Community Members

Deaf people, then, developed a sense of pride which both reflected and furthered their desire to help their culture grow and thrive. One of the most obvious ways in which members of the Deaf community maintain their culture is by incorporating new members and facilitating access to their community for potential members. Members of the Deaf community are normally strong advocates of state schools for the deaf, early exposure to ASL, bilingual/bicultural education, and other programs that serve the dual purpose of promoting the perceived individual interests of others and of promoting the Deaf community to those individuals.104 Politically active Deaf people advocate for cultural rights not only for themselves, but for potential community members (that is, deaf children). This is evidence not only of the strength of their conviction that their culture is beneficial to individuals such as themselves but also of their willingness to engage in costly activities (in terms of time, effort, and perhaps donations) in order to recruit and incorporate new community members.

In the next section, I will discuss a series of Deaf institutions which shape the experience of members of the Deaf community. It is useful to note that, since most Deaf people are born to hearing parents, these institutions serve both to shape

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104 See, for example:
members of the Deaf community and to recruit them. They are thus involved both in the maintenance of the culture and in its capacity to shape the experience of its members.

*Capacity to Shape the Experience of its Members*

The American Deaf community has a pervasive influence on its members, in part through a vast array of Deaf organizations and institutions. A Deaf person might be educated, from early childhood through his or her doctorate, at Gallaudet and affiliated institutions alone. The University runs two model schools through the Laurent Clerc National Center on Deaf Education: the Kendall school (birth through 15) and the Model Secondary School for the Deaf (MDDS, high school). Gallaudet University itself is the only university in the world in which all programs are designed for deaf and hard of hearing students and campus life revolves around deafness. Gallaudet has also become the center of the largest deaf community in the world, and a leading research institution on deafness. Its library is home to the largest collections on deaf history and culture in the world, and claims to contain nearly all materials ever published on deafness. Not only does Gallaudet offer a complete array of educational options, then, but it also offers those options in an environment that embraces and studies Deaf culture, and offers a variety of cultural opportunities to students and the surrounding community.

Gallaudet and its affiliates are not the only educational options available within the Deaf community. The United States is also home to the National Technical Institute for the Deaf (NTID), the world’s first and largest technical school for deaf and hard of hearing students.\textsuperscript{106} The array of primary and secondary educational options at schools for the deaf is even more impressive. The Conference of Educational Administrators of Schools and Programs for the Deaf (CEASD), an organization that accredits schools for the deaf, counts 64 member programs in 40 states, as well as DC and British Columbia.\textsuperscript{107}

In addition to a variety of educational institutions designed exclusively for Deaf people, the Deaf community possesses a variety of political organizations. Each of the fifty states (as well as the District of Columbia) possesses its own state association of the Deaf. These state associations are affiliated with the National Association of the Deaf (NAD) organizationally, although each state’s association of the Deaf is an independent nonprofit. The NAD, in turn, represents the United States in the World Federation of the Deaf (WFD), which counts 130 member countries and has consultative status in the United Nations.\textsuperscript{108} At every level of the political process, then, from state governments up to the UN, Deaf Americans can count on having political organizations that not only represent the interests of their community but also see themselves as representing a distinct cultural group (or groups).

There is a plethora of other Deaf organizations within the United States. Specialized organizations represent Deaf victims of domestic violence, Deaf women with breast cancer, and Deaf Americans with a variety of other needs. The Deaf community maintains its own Deaflympics and a National Theatre of the Deaf (NTD) for their own entertainment.\textsuperscript{109} Deaf clubs, Deaf churches, Deaf festivals and other gatherings provide Deaf people with ample social opportunities within their community.

These Deaf institutions are both a cause and an effect of the powerful influence that the Deaf community can have on the lives of its members. Additionally, they reflect and perpetuate the cultural values, knowledge, beliefs and norms discussed above.

\textit{Resources for Change}

Deaf institutions not only perpetuate Deaf culture, but also provide ample resources for change within the Deaf community, as well as for Deaf people to effect change on externally. Political organizations provide a structure through which change can take place politically, social organizations (such as the NTD) encourage cultural dialogue, and educational institutions provide a forum through which Deaf culture can be reproduced and transformed. These institutions might not always work

\textsuperscript{109} The Deaflympics were first organized in 1924, and have grown rapidly ever since. Seventy-seven countries participated in the most recent summer Olympics in 2009. “About,” International Committee of Sports for the Deaf, accessed April 7, 2011, available at http://www.deaflympics.com/about/

The National Theatre of the Deaf and its children’s theater division, the Little Theatre of the Deaf, tour around the country and the world.

perfectly, but neither do those of the hearing. Deaf people are at least as capable of effecting change within their own community as are hearing citizens.

The changes that an individual wishes to make, and the mechanisms through which that individual may think it is appropriate to enact change, are greatly influenced by that individual’s knowledge, beliefs, and values. To the extent that Deaf culture influences its members in this way (and I have shown that it does so to a considerable degree) it inherently provides them with resources for change (or stability).

_A Word on Other Definitions_

I have chosen to exclude here two characteristics often associated with cultural groups: namely, an intergenerational community and territorial concentration. It is unquestionable that nearly all human cultural groups share one or both of these characteristics. The question, however, is not whether these are common, but whether they are necessary for a group to be considered a culture. It is my argument that they are not, but instead are a common way of satisfying other requirements and hence of flagging groups which satisfy those standards. However, the Deaf community satisfies these in different ways.

For most hearing people, it is hard to imagine a culture which is not intergenerational. But for most hearing people their values, norms, beliefs and knowledge were largely acquired from their parents. Certainly, they share a common experience, including a language, history and literature with their parents. Deaf people, however, may have difficulty in sharing in some aspects of their parents’ culture. At the very least, they find Deaf culture to be more accessible and desirable,
and identify more with its values, history, arts, etc. than with those of their parents. They have inherited the same basic package of cultural goods normally passed from parent to child from non-familial elders (or even peers).

Likewise, territorial concentration is typical of most hearing communities, but not necessary for a culture to exist. Since cultures emerge only through interpersonal interactions, and for most of human history people have spent most of their lives in one area, interacting with a limited number of people, it is not surprising that people expect cultures to be territorially concentrated. But it is not the territorial concentration itself which creates the culture, it is the shared experience that territorial closeness tends to create (including common histories and languages), and the beliefs, knowledge and norms built around this experience which creates the culture. Similarly, since cultures must be maintained by groups, and territorial concentration is often a good proximity for group size and conformity (that is, a minority group which is a majority in a certain area will be able to maintain a uniform culture more easily than a minority group which is a minority in several areas), territorial concentration can also often be used as a proxy for the existence of a group which is actively involved in its own re-creation. But we can see that, despite being territorially scattered, Deaf people have a vibrant community. Further, the risk of integration into the wider society is lowered by the unique language and sensory experiences involved with being deaf. In both cases, territorial concentration has been used, in hearing cultures, as a proxy for a variety of other traits already possessed by the Deaf community.
First Conclusion: On the Existence of a Deaf Culture

I began our chapter by defining a culture as a learned pattern of values, rules for behavior, knowledge, and beliefs, shared by a group whose members are significantly and consistently affected by a common experience (often in the form of a unique language or history) and are actively involved in its maintenance, an experience that shapes the experiences of group members and provides resources for changes in their behavior, organization, and thought. The active maintenance of a culture involves, at the very least, the passing of the culture to new members, but also requires members to use and interpret their culture in interactions with others, often in the form of shared arts, literature or institutions. The Deaf community possesses all eight traits mentioned in this definition, and is therefore undoubtedly a culture as I have defined it.

Possible Categorizations of Deaf Culture

Whether or not we are aware of it as such, most people routinely categorize other cultures in order to assess the standing of their members. Most Americans, for example, feel very differently about the cultural rights of a Native American person than an immigrant to the United States from France and would distinguish both from a French-speaking Quebecois. Some might be more articulate about the distinction than others, but most would recognize that there is something different about the status of certain groups, such as Native Americans, that makes them deserving of rights which we do not afford to members of every culture who find their way over our border. As simple as it sounds, cultural rights theorists use a number of
techniques to categorize different cultures, and to determine which governments have obligations to certain peoples. It is worthwhile here to explore the shortcomings of classification systems based upon hearing cultures to fully explain our case.

Initially, it was my hope to categorize Deaf Culture according to the work of well-known theorists, and to use this pre-existing framework to determine whether or not Deaf people should be entitled to special rights or protections. To a certain degree, I succeeded, in that I have found that the Deaf community does constitute a language community as defined by the UN. However, by and large, more abstract cultural rights theories based on hearing cultures fall short of fully categorizing, or explaining, Deaf culture. In particular, the vast majority of hearing cultures come from intergenerational, territorially concentrated communities whose members possess fundamentally similar bodies with reference to members of the surrounding cultures, such that physical limitations will not reinforce cultural and linguistic barriers. The Deaf community possesses all of the traits which we normally associate with a culture while operating under circumstances which most cultural rights theorists, as hearing people, never imagined.

To illustrate, let us attempt to reconcile Deaf culture with some of the categories laid out by prominent cultural rights scholar William Kymlicka. Kymlicka carefully distinguishes between national minorities, such as Native Americans in United States or the Quebecois in France, and ethnic or immigrant groups. Ethnic groups, for Kymlicka, are groups which “do not occupy homelands. Their distinctiveness is manifested primarily in their family lives and in voluntary
associations, and is not inconsistent with their institutional integration.‖

Providing special rights to members of ethnic minorities, beyond the basic rights of toleration afforded to every member of a liberal society, is not necessary because members of the ethnic minority expect to be included in the same institutions and exchanges associated with the dominant culture. Ethnic minorities are nearly always immigrant groups, who have left their homeland and, by doing so, their home institutions and a certain right to cultural isolationism, in order to settle in a new country.\textsuperscript{111}

Other cultures, however, may need special protections. These normally include national minorities, which form “a historical community, more or less institutionally complete, occupying a given territory or homeland, sharing a distinct language and culture.”\textsuperscript{112} However, since the term “culture” is so often used, to mean such a variety of things, Kymlicka further defines what he calls a “societal culture,” or a culture deserving special protections. By setting off a category of cultures called “societal,” Kymlicka has managed to avoid a good deal of colloquial baggage and to create a term for those cultures which possess certain characteristics which makes their protection compatible with liberal values.

A societal culture in Kymlicka’s view is a culture that “provides its members with meaningful ways of life across the range of human activities, including the social (i), educational (ii), religious (iii), recreational (iv) and economic (v) life, encompassing both public and private spheres. These cultures tend to be territorially

\textsuperscript{110}Kymlicka, \textit{Multicultural Citizenship}, 15.
\textsuperscript{111}Kymlicka, \textit{Multicultural Citizenship}, 14-17.
\textsuperscript{112}Kymlicka, \textit{Multicultural Citizenship}, 11.
concentrated (vi), and based on a shared language (vii).” We are left, then, with five required characteristics for a societal culture, and two more that are almost invariable tendencies.

If we examine these traits carefully we see that the Deaf community meets some of Kymlicka’s requirements, but not others, and that it does so in an unusual pattern. Let us examine each numbered characteristic individually:

i. **Social opportunities:** Deaf culture undoubtedly provides a wide-range of meaningful social opportunities. There are Deaf clubs, Deaf political organizations, Deaf theater groups and Deaf support or advocacy groups for nearly every aspect of life. However, some deaf individuals, particularly Deaf individuals, would question whether or not hearing society provides meaningful social opportunities for all deaf people.

ii. **Educational opportunities:** Schools for the deaf run from Pre-K/Early Intervention programs all the way through graduate study.

iii. **Religious opportunities:** American Sign Language (ASL) was used by Christian preachers and priests to attempt to bring God to deaf people, and Deaf churches have historically helped to preserve ASL and Deaf culture. Deaf people also possess a number of shared beliefs which, although not religious, may deeply impact their spiritual and personal lives. Whether or not a Deaf person is religious, his or her connection to whatever religion he or she does or does not practice will be impacted by his or her cultural values and beliefs.

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113 I have added the numbers for ease of reference when discussing individual traits with reference to Deaf culture.
iv. **Recreational opportunities**: Just as the Deaf community provides social opportunities, it also provides a variety of recreational opportunities. While many of the organizations are the same, it is worth noting that Deaf people have their own art forms, storytelling styles, theatrical traditions and social gatherings.

v. **Economic Opportunities**: The extent to which the Deaf community is able to employ its members is hotly debated. Unemployment rates tend to be much higher among the deaf than amongst the hearing, although there is significant debate about whether or not this is due to the quality of deaf education, discrimination from the hearing world, etc. At any rate, it is clear that some deaf people find employment with schools for the deaf or deaf political, social, or theatrical organizations, but that many deaf people work alongside hearing co-workers in mainstream jobs. Most Deaf people, however, feel strongly that providing Deaf people with the opportunities for economic success should be a community priority, and many feel that jobs within the community (such as those at schools for the deaf, deaf advocacy organizations, videophone companies, or other organizations dealing primarily with deaf consumers) should be given preferentially to Deaf individuals.

vi. ** Territory**: There is no deaf territory. The genetics behind deafness are complicated and, while it does run in families, 90% of deaf children are born to hearing adults and most deaf couples have hearing children.\(^{114}\) A

\(^{114}\) Jankowski, *Deaf Empowerment*, 45.
territorial community of deaf people, then, is arguably impossible. During the mid-nineteenth century, some people did, in fact, suggest starting a deaf-only settlement somewhere in the West. One of the most common objections of other Deaf people at that time was that their hearing children might not be afforded full inclusion in such a community and, if the majority of hearing children chose not to stay, the community would not last for more than a generation or two.\textsuperscript{115} It is clear, then, that Deaf people not only lack a territory currently, but have few ambitions for or realistic possibilities of establishing a territory at any point in the foreseeable future. However, it should be noted both that Kymlicka listed territorial concentration as a tendency, not a requirement, of societal cultures. Further, we have already discussed the fact that the Deaf community satisfies many requirements for which territorial concentration is sometimes used as a proxy.

vii. \textbf{Distinct Language}: American Sign Language (ASL) is, as we have discussed at length, a distinct language with all the beauty and communicative power of any hearing language.

Our analysis thus produced extremely odd results. The culturally Deaf community possesses many of the characteristics of a societal culture, despite the fact

\textsuperscript{115} \textit{A Mighty Change}, ed. Krentz, 161-191.
If this seems a bit far off for the average reader, consider that a similar movement took place in the early twenty-first century, when a group of Deaf people (with a mysterious, unnamed source of funding believed to be the Mormon Church), attempted to convince others to start an ASL-only town in the Dakotas. It failed as well, and the website has since been taken down. I do, however, have a printed copy of their brochure available upon request.
It is important to note, however, that the failure of both movements is evidence of the fact that the vast majority of deaf people are not separatists.
that it is, for the most part, not intergenerational and not all deaf people belong to it. Additionally, some hearing people, such as Children of Deaf Adults (CODAs) and interpreters, are sometimes considered part of the community. In light of this and the other characteristics I have cited, it is perhaps best to label the Deaf community as a “quasi-societal” or “quasi-national” culture: it possesses many of the traits of a societal culture, but diverges from our traditional conception of a national culture in important ways (in particular, it is both more difficult to isolate due to its non-intergenerational nature, and more difficult to integrate due to the physical realities of deafness).

Furthermore, we would expect a societal culture to make nationalistic demands (for example, to seek self-government rights). However, its nature as a quasi-societal non-intergenerational culture has caused Deaf rights activists to make a fascinating mix of demands normally associated with what Kymlicka would call national and immigrant/ethnic minorities. They support isolation in some ways (for example, many feel that mainstreaming fails to provide deaf students with full access to the social, academic, and linguistic resources available to hearing students at most schools) but they expect integration in other areas (in particular, economic integration and employment in predominantly hearing workplaces have long been valued by the Deaf community).

Kymlicka is one of the more thorough cultural rights theorists, and even his categorical scheme is insufficiently complex as to explain the situation of the Deaf community. Models based on hearing communities, which are intergenerational, territorially concentrated, and physically similar to the surrounding cultures, simply
do not account for some of the unique aspects of the Deaf community. It is not tautological to note that Deaf culture is not a hearing culture; it does not always fit the same models or follow the same rules that we might expect based on our experience with other hearing peoples. In particular, barriers out of the culture are less permeable than barriers between hearing cultures. That is, not all deaf people can acquire fluency and comfort in spoken English, and there are certain ways in which hearing culture (which is based on the assumption that members can receive auditory cues) is itself disabling. Further, the common sensory experience which defines the Deaf community is shared even with some non-members, and provides a powerful incentive for new members to join, particularly if those individuals are “oral failures.”

The deviation, then, is not so much in the culture itself, but in the barriers that it faces (or does not face) from members of the majority culture. Given the fact that the culture itself originates from a sensory experience and resulting communicative barrier, this is not surprising. Deaf culture, then, might best be categorized as an essentially national culture with preferentially permeable borders. That is, it is much easier for most deaf people to become Deaf than to integrate into hearing America, while it virtually impossible for a hearing person to become Deaf.

Deaf culture, then, is a culture that defies the definitional framework normally associated with cultural rights. Searching for parallels in the hearing world which will provide us with a clear analytical framework from which to approach deaf rights is

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116 Deaf culture is not the only culture that does not fit into a national minority/ethnic group binary as adumbrated by Kymlicka. African Americans, as Kymlicka acknowledges, do not possess a homeland in the United States or a group history of self-government, yet they were not willing immigrants nor were they readily incorporated into American institutions. Refugees sometimes have a similar status. (Kymlicka, *Multicultural Citizenship*, 97-108). I have no intention of trying to classify African American culture here, I mean only to point out that typifying cultures is a difficult and complicated task.
likely to produce theories which are remarkably effective at explaining some issues faced by deaf culture, and dangerously off-base in explaining others. For instance, Deaf culture closely parallels “oral” cultures in a number of important ways. Cynthia Peters, for example, argues persuasively that Deaf culture is “oral” in that it is “a culture that has not fully developed, or cannot easily or wholly adapt to, literacy.”

Deaf literature, then, would include not only what has been written down in English, but the artistic styles that have been passed down through generations of deaf users of a visual-kinetic language with no written form (ASL). The model of an oral culture translates remarkably well to the numerous face-to-face storytelling and poetic traditions which Deaf community members have passed down for generations.


118 ABC stories, discussed earlier, are one of the best examples of such a storytelling tradition. Number stories, and other similar styles, are also popular.

The Deaf also have a number of poetic techniques. Hand shapes are roughly equivalent to rhymes. The signs for “stars” and “socks,” for example, share the same hand shape and action, but differ on the placement (primarily by varying the palm orientation), meaning that they share two phonemes and differ on one, much like verbal rhymes. Deaf poets might use a single hand shape, with few disruptions, for an entire poem, continually returning to similar images.

It is important to note, if it is not obvious already, that Deaf poetry is far less word-centric than hearing poetry. That is, a Deaf person might write an entire poem using very few words, but instead drawing on various classifiers, facial expressions, and miming techniques. For this reason, Deaf poetry can be extraordinarily hard to interpret accurately and, while wonderful translations may capture much of the spirit of a poem, much beauty is ordinarily lost in translation.

Interested readers may want to visit YouTube for brief examples of various Deaf art forms. An excellent example of the use of hand shapes in poetry is available in this poem by Clayton Valli. In it, he illustrates a man trying to rid his lawn of dandelions, but every time he cuts down a dandelion its seeds only spread further. It is meant to be a metaphor for Deaf culture.


A variety of well-known ASL poetry is available from Peter Cook, whose artistic partner voices the poems:


An example of an alphabet poem:


A number story:
However, Deaf people cannot hear and do not use an oral language. Furthermore, their “oral” culture has survived and thrived despite the fact that the majority of the Deaf community is literate and that such traditions often pass through community rather than family ties. Deaf culture, then, both does and does not fit a model of an “oral” culture.

**Second Conclusion: On the Difficulty of Categorizing Deaf Culture According to Models Based on Hearing Groups**

Not only does the American Deaf community represent a unique culture, but it appears to be a unique type of culture not previously considered by hearing scholars. It is a unique, indigenous culture which provides its members with a wide-array of meaningful life opportunities which might otherwise be unavailable to them, possesses an expansive set of institutions, and has its own language, history and artistic forms. It has all of the substantive characteristics normally thought to make a culture worthy of special protections. Yet, it defies our preconceptions of what such a culture should look like. It is not intergenerational, it has no homeland or territory and the borders surrounding the community are oddly, and selectively, permeable. No model based on hearing cultures will be able to provide us with a framework which exactly fits the Deaf community or a pre-packaged set of policies which can be readily applied to Deaf people.

In order to find a cohesive theory of Deaf cultural rights, then, we ought to look not only to the conclusions reached by contemporary cultural rights theorists, but

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to the underlying values, and the perceived relationships between individual and communal rights, which ground our current cultural rights discourse. Indeed, incorporating the Deaf community into an understanding of liberal and cultural rights which is based on the assumption that all citizens and all peoples have fundamentally similar bodies will require careful thought not only about Deaf people, but about the entire sociopolitical system from which we view their situation. In this way, we may be able to construct a modified framework that fully embraces the exceptional nature of signing communities.

I will attempt to explore these issues in Chapters Three and Four. In Chapter Three, I will try to reconcile our understanding of the Deaf community and its claims to individual and communal rights with liberal conceptions of civil, human, and collective rights. It is my belief that the Deaf community, when properly understood, warrants more protection than it is currently afforded. Deaf children, similarly, are not always able to effectively exercise their civil or human rights under the current system of special education. These arguments both serve to support a similar set of policy recommendations. In the next chapter, I will present my arguments in favor of these rights in the abstract. Chapter Four will move on to discuss these rights as a practical matter and examine their political implications.
Chapter Three: Rights to Any Language, Sign Language and Deaf Culture

In this chapter, I hope to show that a certain broad set of assumptions implicit in both the legal system in the United States and the international human rights movement lead us naturally to the conclusion that members of the American Deaf community are entitled to some set of linguistic rights. It is not my intention to justify this broader system of values. Instead, I hope to show that we already have a robust system for defining which people and groups are entitled to certain types of rights and protections, and that the Deaf community, when properly understood, has been treated in a manner which diverges from this system and goes against its underlying values.

It is useful to approach the topic from two angles. First, I will argue that United States has a system of constitutional rights based on the belief that individual autonomy is essential for both personal and societal development. Individual liberty, I will argue, is meaningless if not impossible without the ability to readily communicate in a language. Given that not all deaf children are able to access spoken English fully, and signed languages such as ASL are the only true visual languages, this leads to the conclusion that Deaf children should be afforded ready access to a bilingual education throughout their time as a student. In this I am not trying to convince Americans to value ASL. Instead I am arguing that, when ASL and the Deaf community are properly understood, most Americans will find that they already do value ASL (or at least the liberation that it can bring to deaf children). The American legal and political system is not alone in valuing personal liberty, and we will see that
a similar argument has been made internationally. As a matter of fact, the United Nations Convention on the Rights of Persons with Disabilities strongly supports the linguistic rights of deaf people.

Second, I will make a parallel claim regarding the cultural rights of the Deaf community. To the extent that the United States or the international community has discussed and recognized cultural and linguistic rights, these rights have been based on an underlying set of values which emphasize group autonomy in a way which closely parallels our value for personal freedom. Just as American constitutional rights are based on a value for individual liberty, the international conception of linguistic rights is based on a value for linguistic and cultural self-determination. Once again, we will see that, when the Deaf community is properly understood, the only way in which we can treat its members in accordance with our value system is to afford them certain linguistic rights. In particular, we should give deaf children the right to access high-quality bilingual/bicultural education from birth.

In this chapter, my goal is to lay out these arguments and explore them in search of broad conclusions. In Chapter 4, I will probe these issues in greater detail and make specific policy recommendations. Those who are particularly interested in linguistic policy in the United States should note that certain aspects of the more policy-oriented discussion, including an examination of a variety of Supreme Court cases regarding special education or bilingual education, will take place in Chapter 4. Our current interest is in the general goals which a program should have in order to live up to certain values, not in the specific policies which will be used to achieve those goals.
Visual Language as an Individual Right

The United States affords all citizens with a certain set of rights. These rights include freedom of speech, press, assembly, and conscience. They ensures that criminals have full knowledge of why they have been accused and have an opportunity to defend themselves, and that no one is deprived of their freedom without due process of law. This Bill of Rights reflects a certain set of fundamental values, including autonomy, freedom of expression, and self-development. We must ask ourselves if our society can live up to these values without guaranteeing that children are able to communicate comfortably and fluently in a language from an early age. Can one speak or assemble without language? Can one freely develop one’s conscience if one is denied the services necessary to provide one with equal access to an education? Can people understand their rights, or even their crimes, without a certain degree of language and educational access? More importantly, where do we draw this line? Is it good enough that an adult be able to understand 85% of what is spoken? What about 60%? 40%? Further, how much language comprehension must adults have had while in school in order to effectively understand and exercise their rights today?

One critic who believes that the United States Constitution and the values it represents should be seen as promoting language access is Lawrence Siegel. Siegel has publicly advocated in favor of a constitutional amendment guaranteeing language access for deaf children as an intellectual, special education attorney and founder of the National Deaf Education Project (NDEP). Working with the NDEP, he argues
that “the need and right to communicate is the most fundamental of human rights. To deny it is to harm the human spirit. To foster communication is to reveal all the possibilities of life.” 119 Siegel elaborates on his views in the book The Human Right to Language, in which he advocates for an interpretation of the rights to speak and receive information in the First Amendment and the right to equal treatment under the Fourteenth Amendment that requires us to provide full language access to deaf and hard of hearing children. Since the Courts clearly have not interpreted the Constitution this way, Siegel believes that a constitutional amendment may be necessary. 120

Children whose access to language is limited or delayed, he points out, may face a series of barriers to full participation in politics and civil society. Unfortunately, children who do not have full access to language early in life may never catch up to their peers in terms of fluency or literacy. Without language, after all, children cannot receive an education, interact freely with their peers or understand their teachers. Such children are susceptible to long-term academic, emotional, and other difficulties. 121 These children will grow into adults, who we expect to be able to effectively utilize basic rights of citizenship, including freedom of expression and freedom of conscience. We expect them to be able to readily understand their rights in criminal proceedings. Furthermore, we implicitly expect them to be able to develop themselves as human beings and, I would add, workers in a complex modern economy. Siegel argues that children have rights, and I agree. Even if we believe,

121 Siegel, The Human Right to Language, 29-36.
however, that children have no rights of their own until they reach adulthood, we must accept that a lack of access to language early in life will have a direct effect on that child’s ability to function as citizen and human being as an adult.

The consequences of the expectation that deaf children will be able to exercise their rights effectively as adults, together with the failure to provide the educational resources necessary for meeting it, can be devastating. As I mentioned, the average deaf high school graduate reads at a fourth grade reading level. Yet, many hearing people, including many police officers, mistakenly believe that written materials constitute a sufficient mode of communication with a deaf person. Partly as a result of such misconceptions, many state laws fail to provide interpreters to deaf people at the time of their arrest (the NAD contends that this violates the ADA and the Rehabilitation Act of 1973, but it is nonetheless a regular occurrence). Instead, alleged criminals are sometimes given written copies of their *Miranda* rights. However, the NAD notes that “the standard written advice of rights form given to suspects before questioning requires a sixth to eighth grade reading comprehension level.” The average deaf person, then, cannot understand their rights in this form. Indeed, in at least one case a Deaf man, David Barker, had his confession ruled inadmissible by the Court after he signed a written *Miranda* warning and confession despite the fact that no interpreter was present and he had between a second and third grade reading level. When asked later, by an interpreter, if he had understood his initial *Miranda* warning, he signed “a little bit.” In fact, expert testimony stated that the very concept of “‘Constitutional rights,’ being an abstract idea, is extremely
difficult to convey to the deaf, especially, as in this case, when the educational level of the individual is so curtailed." The systemic issues which led to Barker’s unconstitutional confession, including not only inadequate laws for the provision of interpreters but also an educational system that regularly graduates deaf individuals who do not even understand what a constitutional right is, much less how to protect their own, have not been solved. This raises a difficult question. By what means do we expect the “oral failures” of the world to understand or exercise their basic constitutional rights? Will graduates who learn only ASL but have insufficient access to written English fare any better? For deaf children who were raised in an inappropriate educational program for their particular talents, or denied necessary support services by their school district, we may be limiting their access to something as basic to human existence as language itself.

Siegel argues that insufficient language access does a grave injustice to deaf children and adults. He believes that a right to language access is implicit in a variety of other rights guaranteed by the first amendment and other parts of the Constitution. However, he acknowledges that the Court has frequently disagreed with him, at least when it comes to language access for deaf children. For this reason, he thinks that American politicians should acknowledge that the free exercise of certain constitutionally guaranteed rights requires the use of other rights not currently

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124 National Association of the Deaf, Legal Rights, 177
125 He does, however, point out that the Court’s rulings on the right to bilingual education and language access for hearing English language learners is wildly inconsistent with the rights afforded to deaf children. Both of these points will be discussed in detail in Chapter 4. This is essentially the thesis of Siegel’s book, so it is difficult to cite. However, interested parties might see Siegel, The Human Right To Language, 11 (for summary), 44-62 (First Amendment- send and receive information), 63-79 (First Amendment- freedom of association), 93-124 (Fourteenth Amendment).
recognized by our common law tradition by passing a constitutional amendment protecting the rights of children to language access.

Not only is early language access for children necessary for their effective exercise of explicit constitutional rights as adults, but the ability to use language effectively, receive information and think for oneself is essential to one’s personal autonomy, the promotion of which is one of the founding values of our Constitution. Alexander Hamilton perhaps stated this best when he argued, in Federalist 84, that “the truth is, after all the declamations we have heard, that the Constitution is itself, in every rational sense, and to every useful purpose, A BILL OF RIGHTS.”\textsuperscript{126} He goes on to explain that a bill of rights would be unnecessary in the new Constitution, because the entire document is so steeped in the notion of personal liberty and in the notion that the people have not alienated from themselves any powers but those expressly laid out in the Constitution. A bill of rights could be harmful, he argues, because it might imply that the government’s grant of power is limited only by those rights and not by broader concepts of personal liberty.\textsuperscript{127} Indeed, it is evident throughout almost all documents involving the writing and ratifying of the

\textsuperscript{127} Ibid.

One might argue, of course, that these restrictions are meant to provide citizens with \textit{negative} liberty from government intervention, not \textit{positive} liberty to an education of a certain sort. However, the government already provides free public education to American citizens. Further, it already funds special education and early intervention services for deaf children. Demanding that the former be made accessible and the latter effective does not require the government to intervene in a new area, only to undertake its current interventions such that they benefit deaf children and hearing children equally. In short, there may be a Fourteenth Amendment claim here as well. Further, the point here was not to illustrate that the founding fathers would have supported deaf education. Indeed, American Sign Language did not exist when our constitution was ratified. My aim, then, was not to call upon the authority of the founding fathers for my specific policy recommendations, but instead to point out that they valued personal liberty very highly. Americans continue to value such liberties to this day, although contemporary philosophers have increasingly incorporated positive rights into their picture of what true personal liberty might entail.
Constitution that participants of all political leanings valued personal liberty. One can see these values even more explicitly in the constitution itself, the preamble of which states that the government has a duty to “promote the general Welfare and secure the Blessings of Liberty.”\textsuperscript{128} While a bill of rights was, obviously, added to the Constitution, the debates about its value reveal the high value that both sides placed on individual autonomy. The Declaration of Independence contains similar sentiments: “We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness. — That to secure these rights, Governments are instituted among Men.”\textsuperscript{129} One must wonder how one can secure liberty or equality to people who have no language or have such delayed or inadequate language access that they are permanently impaired. How can a person who cannot understand his or her rights be truly free? And how can a person who cannot communicate easily with strangers pursue happiness?\textsuperscript{130}

The United Nations has already made moves similar to recognize the right to access language, including sign language, as a fundamental human liberty. The United Nations Convention on the Rights of Persons with Disabilities, which the United States has signed but not ratified, mentions signed languages at several points. Article 21 states that

States Parties shall take all appropriate measures to ensure that persons

\textsuperscript{128} U.S. Constitution, Preamble.  
\textsuperscript{129} Declaration of Independence.  
\textsuperscript{130} I say “with strangers” deliberately. Many deaf people who have limited language access communicate best with those close to them. It is often easiest to speechread those with whom you are most familiar and family members are often best able to understand deaf people whose speech may be unintelligible to strangers. Full access to economic, political and social (particularly romantic) opportunities, however, require frequent interactions outside of the household.
with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined by article 2 of the present convention, by: … (e) recognizing and promoting the use of signed languages.\(^{131}\)

Similarly, section 3 of Article 24, which discusses the education of disabled persons, asserts that “State parties shall take appropriate measures, including: … (b) facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community.”\(^{132}\) Article 30 section 4 even goes so far as to recognize Deaf cultures. It promises that “persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity including sign languages and deaf culture.”\(^{133}\) There are several further mentions of signed languages and Deaf cultures in the Convention, but I believe that these are sufficient to prove my point. The United Nations recognizes that, in order for deaf individuals to develop themselves fully and to have a free use of their other human rights, governments around the world must protect and promote signed languages.

These rights are particularly powerful when taken in conjunction with other rights created by the United Nations. In particular, the International Covenant on Economic, Social and Cultural Rights, which will be discussed in detail later in this chapter, provides that all levels of education shall be made available to all children. Even higher education “shall be made equally accessible to all, on the basis of

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capacity, by every appropriate means…”134 Arguably, providing certain deaf children with an oral-only education violates this right if they are incapable of understanding classroom materials. Conversely, providing other deaf children with an ASL-only program might violate this right if they have the capacity and desire to learn spoken English.

Thus, one might agree that children should be entitled to language access while still having reservations about what this might mean for educational policy, and in particular whether or not it actually requires that deaf children have access to sign language. While exact policy prescriptions will be discussed in the next chapter, I would like here to address such reservations briefly. First, recall that language outcomes for deaf children, using the same technology and participating in the same programs, can vary greatly. Some children will do exceptionally well with implants and have full access to the English language through oral programs with minimal support systems. But most deaf children will require significant support services of some kind in order to have full access to classroom materials. Some will perform poorly with implants or hearing aids or become “oral failures” incapable of communicating comfortably and effectively in spoken English. Others will only be able to learn English after a long struggle which leaves them dangerously deprived of basic communication during their earliest and most formative years.

The point is not that all children should be required to communicate in American Sign Language all of the time. Instead, it is that a bilingual education system is more likely to satisfy the needs of most children than a program which

stresses only one language or culture. Further, it is the only system guaranteed to provide complete language access to all children. Having said this, one should note that the problem extends beyond a lack of sufficient bilingual education options and that there are flaws in our current system for determining which children are entitled to which services. Some of these flaws make it difficult for parents to make choices for their children. In particular, it is extremely difficult for parents to pressure reluctant school districts into providing support services for their child unless their child has already fallen below grade level. For bright deaf children, particularly those that enter school ahead of their peers, this can make it extremely difficult to secure the services necessary to thrive. These children must fall behind before they can receive the services that they need. In many ways, the low achievement scores of deaf children are the product of a self-fulfilling prophecy. Other problems in the administration of current programs abound. From the medical-model bias in early intervention services to the quality of information given to the parents of newly diagnosed deaf children, the services currently available to deaf children and their parents fail to serve their needs in important ways. These problems, and laws and court cases which have perpetuated them, will be discussed in great detail in the next chapter.

There is much that the United States could do to administer pre-existing special education programs and early intervention programs in a way that more thoroughly embraces ASL and Deaf culture. Further, the United States would do well to fund and promote a system of bilingual education that would seek to give all deaf children access to ASL, written English, and whatever level of spoken language they
are able to achieve. I believe that this system would best satisfy the needs of deaf children, but I recognize that not all parents, particularly hearing parents, would agree. In the next chapter, when I explore potential policy revisions, I will discuss in greater detail the issue of finding a policy which works harmoniously with the families of deaf children.

**Cultural Rights**

*Cultural Rights in the United Nations*

In a world in which cultural rights are an emergent concept, the most salient explication of what sorts of rights cultures should have comes from a variety of documents produced by the United Nations. The UN’s existence as a group that relies on cooperation among large and well-institutionalized cultures has perhaps helped it to become a breeding ground for such ideas. At any rate, it has a variety of institutional mechanisms for discussing cultural rights and interactions, including the Economic and Social Council (ECOSOC) and the Educational, Scientific and Cultural Organization (UNESCO), both of which have been present since 1945. In addition, the Committee on Economic, Social and Cultural Rights (CESCR) was established in 1985 in order to carry out some of the executive functions of the

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The United Nations thus provides not only the first proto-legal framework for cultural rights but also a variety of forums in which debates about cultural rights can take place. The UN’s documents reflect a belief that cultural rights and liberal civil and political rights are compatible and complimentary. Indeed, the International Covenant on Economic, Social and Cultural Rights (adopted in 1966) states that “the ideal of free human beings enjoying freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights.” The Universal Declaration of Linguistic Rights goes further, iterating the following statement on the first page of its preamble and later affirming it: “This Declaration takes as its point of departure the principle that linguistic rights are individual and collective at one and the same time.” It is interesting to note that, in the case of deaf children, I have been arguing that individual and cultural rights point us in the same direction: bilingual education. These statements by the UN suggest that this is not a coincidence, but instead that a respect for minority cultures is necessary for individual liberty.

Specific cultural rights are laid out for the first time in the International Covenant on Economic, Social and Cultural Rights mentioned above. This covenant established that all cultures have a right to self-determination and “free cultural development,” and that those who signed the covenant had duties to protect those

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Article 4 warns that these rights may be limited “only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.”¹⁴⁰ Like future documents, then, the Covenant provides a potential out if certain rights (in our case, the linguistic rights of members of the Deaf community) interfere with the rights of others (parental rights, for example) or if the recognition of these rights undermines the general welfare in significant ways. While our situation is complicated by the fact that the group in question is of a non-intergenerational linguistic type with preferentially permeable borders, we should nonetheless keep such clauses in mind as we move into Chapter 4. We must seek, as far as possible, to respect both the rights of the Deaf community and of hearing parents. In this way, our discussion of cultural rights mirrors our discussion of individual rights. This first Covenant, then, provides the basis for the idea that cultural minorities ought to be given the right to self-determination, with little further discussion on what this might mean.

UNESCO’s Universal Declaration on Linguistic Rights (1996) provides a much more rigorous understanding of what protections a cultural-linguistic minority might merit in practice. First, it is careful to establish that its unit of interest is the “language community.” Language communities are distinct from states, which might contain more than one community, but they are also distinct from “language groups—“immigrants, refugees and other groups which are not historically established.”¹⁴¹ This distinction is useful in that it gives another angle from which to view the problem discussed in Chapter 2. If Deaf people are, in fact, a language community as

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¹⁴¹ “Universal Declaration on Linguistic rights,” 3.
defined by the UN, this would be a powerful argument in favor of affording them special protections. If not, such an argument would be much harder to make.

Article 1 of The Universal Declaration on Linguistic Rights provides a definition of a linguistic community that, at first, does not appear promising for Deaf people. It defines as a language community:

Any human society established historically in a particular territorial space, whether this space be recognized or not, which identifies itself as a people and has developed a common language as a natural means of communication and cultural cohesion among its members. The term language specific to a territory refers to the language of the community historically established in such a space.142

As we discussed in Chapter 2, Deaf people are a historical community, they identify themselves as a people, and they have a common language, ASL. ASL, as a symbol not only of a shared cultural identity but of a shared sensory experience, plays a role both as a mode of communication and as a source of pride and solidarity for group members. In most ways, then, Deaf people do constitute a language community as conceived in the Declaration. But what to make of the requirement that language communities must be established in a “particular territorial space?” Would the United States itself be such a space for a territorially dispersed minority?

Fortunately, the Declaration elaborates on this exact point, stating both that groups are considered language groups “when they are established in a geographical area which they share with the members of other language communities with similar historical antecedents” and that

142.“Universal Declaration on Linguistic rights,” 4.
This Declaration also considers nomad peoples within their areas of migration and peoples established in geographically dispersed locations as language communities in their own historical territory.\textsuperscript{143}

It is clear that the \textit{American} Deaf community would meet either of these standards within the United States. Members of the American Deaf community are geographically dispersed \textit{within} the United States but nonetheless historically tied to the US as a whole. Within the United States, they share a language and a culture. Moreover, they share important parts of their history with the American hearing culture, to which they are intimately tied. From either angle, then, the American Deaf community constitutes a language community as defined by the United Nations.

As a language community, the Deaf community should be afforded certain rights according to the Declaration. Naturally, the Declaration affirms all linguistic rights present in previous declarations, including the right to maintain one’s culture, to be recognized as part of a linguistic community, and to use one’s language publicly.\textsuperscript{144} There are also a great variety of newly stated rights present in this Declaration, including a variety of rights to interact with the government in one’s own language and to have one’s language used by the media.\textsuperscript{145} Of particular interest to the question at hand, however, is Article 8, which affirms that all language communities have the right to “organize and manage their own resources so as to ensure the use of their language in all functions within society” and to “have at their disposal whatever means are necessary to ensure the transmission and continuity of

\textsuperscript{143} Ibid.
\textsuperscript{144} “Universal Declaration on Linguistic rights,” 5.
\textsuperscript{145} Those interested in deaf rights would do well to read the document in full. For the sake of space, I am discussing only those rights that are most relevant to the debate at hand. However, if the Deaf are a language community as defined by the Declaration, then this would have clear implications for their rights in other areas as well.
Throughout the Declaration, such sentiments are repeated, continually affirming the rights of minority language communities to promote and perpetuate their languages.

The implications of such rights, when extended to the education of deaf children, are clear if not precise. The Deaf community is entitled to provide deaf children with the option of ASL education and to encourage its use. Article 28 goes even further, providing an almost explicit endorsement of bilingual education:

All language communities are entitled to an education which will enable their members to acquire a thorough knowledge of their cultural heritage… as well as the most extensive possible knowledge of any other culture they may wish to know.\textsuperscript{147}

If we recognize that deaf children have the right to learn about deaf culture and “any other culture they may wish to know,” such as the hearing culture of their parents and fellow citizens, we have little choice but to provide deaf children with high-quality bilingual education.

While the Universal Declaration on Linguistic Rights provided a thorough explication of linguistic rights, the Convention on the Safeguarding of Intangible Cultural Heritage (2003) elaborates on the sort of cultural protections to which minority groups are entitled. It creates a variety of mechanisms for protecting “intangible cultural heritage” such as “oral traditions and expressions, including language as a vehicle of the intangible cultural heritage,” “performing arts,” and “social practices,” all of which are possessed by Deaf people.\textsuperscript{148} This Convention

\textsuperscript{146} “Universal Declaration on Linguistic rights,” 6.

\textsuperscript{147} “Universal Declaration on Linguistic rights,” 9.

reinforces the declarations previously discussed, by affirming the rights of cultural minorities to “safeguard” their intangible heritage through a variety of means, “including the… protection, promotion, enhancement, transmission, particularly through formal and nonformal education, as well as the revitalization of the various aspects of such heritage.” The Convention gives us a reason to record, respect, and preserve Deaf “oral” traditions. Teaching MCE and other Anglicized forms of ASL is not, from this perspective, in any way an acceptable substitute for ASL instruction. While a deaf child might have a human right to a visual language, humanity has a stake in making ASL the visual language of choice. No other visual language is tied to an endangered cultural heritage.

This series of documents produced by the UN give us at least one possible direction for formulating policy towards the American Deaf community. Deaf people are entitled to self-determination, to the presence and promotion of ASL and written English in the education of Deaf children, and to having their cultural heritage taught to interested deaf youngsters.

Cultural Rights According to Other Models

While each culture is unique and should be examined individually, there are at least two models which the United States might effectively use as a starting point for its discussion of Deaf rights. First, we might look at an entirely different country, Sweden, which has afforded linguistic and cultural rights to its Deaf community. Alternatively, we might look at our own country’s treatment of other cultural groups,

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such as the Native Americans. The situation of each of these groups can shed light on certain aspects of question of the rights of the American Deaf community.

Sveriges Dövas Riksförbund (SDR), the Swedish National Association of the Deaf, was founded in 1922 and replaced the Association of the Deaf and Dumb, which had been active throughout Sweden since 1868.\textsuperscript{150} As of 2008, there were also 40 local deaf clubs.\textsuperscript{151} The Swedish Deaf community, then, is historically rooted and well-organized, and they have succeeded in gaining certain concessions from their government. In particular, since 1981 Swedish government has recognized Sweden’s sign language as the first language of the profoundly deaf.\textsuperscript{152} SDR’s efforts to encourage sign language and bilingual education have also been rather effective. There are five schools for the deaf in Sweden, each of which uses sign language as its primary mode of instruction.\textsuperscript{153} The Swedish, then, have largely gone for the course of action outlined above. They have recognized sign language as an official language and taken steps to ensure its use in schools.

While Sweden may be one of few countries in the world which affords linguistic rights to its Deaf citizens, the United States does possess ample experience with other cultural and linguistic minorities. Linguistic policy in the United States, however, is difficult to understand for two reasons. First, the United States has few overt language policies. Harold Schiffman, a language rights theorist, is nonetheless cautious to point out that the United States might have “covert” or “implicit”


\textsuperscript{153} Ibid.
language policies which favor English despite having few official declarations regarding the importance of the English language. Second, much of linguistic policy, particularly when it comes to education, is determined by the states. What Federal policy does exist often comes from Supreme Court decisions, not federal legislation. In short, American linguistic policy is rarely determined by an overt, coherent, top-down process.\textsuperscript{154} Nonetheless, what linguistic policies the United States does have may reveal important information about our practices and values regarding cultural minorities.

While Supreme Court decisions regarding bilingual education will be discussed in the next chapter, it is useful to note here some of the few federal linguistic laws which have been passed. The Bilingual Education Act (BEA) of 1967-8 (reauthorized and revised repeatedly thereafter) had the goal of providing for multilingual education. However, it is ambiguous whether or not it provided for bilingual education or simply ESL programs, although it was clear that it was intended to assist students in achieving English literacy, not to immerse them in another culture. While the BEA did not provide non-native English speakers with the right to bilingual education, it is a rare example of a statement on the status of linguistic minorities by the United States congress.\textsuperscript{155} There seems to be some sense, implicit in the BEA, that children who are not (yet) fluent in the English language ought to be entitled to some sort of linguistic accommodations in their education. More importantly, the BEA was originally created with native Spanish speakers who had immigrated to the United States in mind. The American Deaf community differs

\textsuperscript{154} Schiffman, \textit{Linguistic Culture}, 211-216.
\textsuperscript{155} Schiffman, \textit{Linguistic Culture}, 240-241.
significantly from these groups because it is a quasi-national culture indigenous to the United States. There is reason to believe, then, that Deaf people should be provided with a more robust package of rights than those afforded to immigrant groups under the BEA or other laws.

It might me more appropriate to point to parallels regarding Native Americans. The Native American Languages Act of 1990, for example, goes further than the BEA and states that “it is the policy of the United States to preserve, protect and promote the rights and freedoms of Native Americans to use, practice and develop Native American Languages.”156 Of course, this differs significantly from historic attitudes towards Native American tribes. Schiffman refers to the measure as “locking the barn after the horse is stolen.”157 Nonetheless, the act may be indicative of shifting attitudes towards minority language communities in favor of greater autonomy of all language communities.

I mention these models here not to make exact policy suggestions, but instead to shed light on the topic of the rights of Deaf people more generally. In addition, I do so to indicate that the suggestions that I will make later in the thesis are not altogether unprecedented. The United States does have other cultural minorities who are demanding cultural rights and the world does have other Deaf people who exercise such rights. While it may seem counterintuitive to many Americans that there is a Deaf cultural minority within the country that warrants certain rights, it is surprising how unsurprising such a conclusion is when looked at from a broader perspective that includes practices in the rest of the world, as well as the deeper assumptions about

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rights implicitly at work in current practice in the United States. Thus, in advocating that Deaf people indeed possess certain rights as individuals and as members of a culture, I am not asking that Americans change their basic values or break significantly with Western tradition. Instead I ask only that they extend the notions of justice that they already have to a group that they may not have realized needed protection.

A Note on Changing Technology

After the invention of the cochlear implant, some hearing people began to question the longevity of the Deaf community in the face of changing technology, and on this basis claimed that talk about the rights of Deaf people was otiose. In response, I would like to note, first of all, that the fact that a culture is currently threatened, much less the fact that it may potentially be threatened at some unknown point in the future, is not a sufficient argument against providing that culture with special rights or protections. Languages around the world die out every day in the face of globalization but this is not a reason to discard the notion of linguistic rights generally. Similarly, the vague promise of a perfect technology that will make it possible for all to hear someday in the future is not a reason to discard deaf rights in the present.

Moreover, it is important to note that technology is far from perfect. In Chapter One I mentioned that a cochlear implant uses between sixteen and twenty-two electrical “channels” to substitute for the 12,000 hairs in the human ear.\footnote{Leybaert, Colin, and Hage, “Cued Speech,” 108.} The result is that the sounds provided by cochlear implants are far from satisfactory. But even assuming that implants could progress from twenty-two to 12,000 channels in
the near future, and could develop sufficiently sophisticated processors to filter those sounds to send a coherent signal to the cochlea, other problems with the technology would remain. For one thing, the speed with which implants can be used will always be limited by the malleability of the human brain. Even if perfect implants were invented, a child would lose valuable developmental time waiting for surgery, healing, adjusting the settings on the implants, and learning to listen. Likewise, even technology that would allow children to hear perfectly would not make such children identical to their hearing peers. At the very least, they would be able to take it out and, if they so chose, share in the common sensory experience of being deaf in a way which is totally inaccessible to the hearing. For those that did want to hear, deaf children might not be able to wear such a device going down slides, playing sports, or swimming, all of which interfere with current implants. They might be isolated simply by the fact that something mechanical is attached magnetically to each of their heads. In fact, many deaf people have noted that children with implants are still deaf when they take them off. They are deaf when they sleep, play sports, or engage in many other activities.

Even children with perfect bionic ears might find ASL useful to them, and might choose to identify with the Deaf as a community. While it is clear that deaf children should be allowed to have the best technology possible if their parents feel that they would benefit from it, it is not clear that any technology will remove them from the Deaf community. While perfect ears might make it more difficult to argue that deaf children have an individual right to visual language, the cultural rights argument still stands relatively unscathed. There would still be a unique deaf culture,
and the children with implants would still be clearly identifiable by a common sensory, social, and even medical experience.

Finally, we should not take it for granted that every parent would feel that such technology was appropriate for his or her child or that every child would appreciate later in life the decision to be implanted. Implants are not medically necessary, and the notion that they are required is predicated on the assumption that deafness is a disability. Many Deaf people say that, if it were possible for them to take a pill and hear perfectly tomorrow, they would not choose to do so. The view that deafness is a horrible, disabling condition is much more popular among hearing people who have never met a Deaf person than it is among people who are Deaf or have been involved in the Deaf community. Unless a law were passed forcibly implanting children with technology which their parents did not want them to have and which was not medically necessary, it might be much harder to achieve universal implantation than most hearing people would initially imagine. In fact, the Deaf community has thrived over centuries of changing technologies. In the nineteenth century, a large portion of children at schools for the deaf were deafened later in childhood due to infectious diseases which have since been eliminated. Deaf communities have also survived the invention of hearing aids and cochlear implants.

It is possible that a perfect bionic ear will be invented someday, and even that the Deaf community will fade out. But to assume that technology will rapidly advance, that said technology will be so perfect as to render deaf individuals

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159 It is important to note that here I am talking about Deaf people. For those who are not culturally Deaf and do not know ASL, and particularly for those who are late-deafened, deafness has a very different meaning.

indistinguishable from their hearing peers, and that everyone will want to take advantage of such technology is a huge leap. Further, to assume that the possibility of such a thing occurring renders the Deaf culture of today unworthy of protection is inconsistent with basic notions of human freedom and current law.

**General Conclusions about Individual and Cultural Rights of Deaf People**

We have seen that Deaf people possess a unique culture and language community which warrants special protections according to our own norms and those of the international community. Of particular note is the way that individual rights, on the one hand, and cultural rights, on the other, are highly compatible in the situation of deaf children. Earlier I pointed out that the Deaf community has preferentially permeable borders: that is, the barriers of entry into the community are more permeable, for deaf individuals, than the barriers of entry for the surrounding hearing community.\(^{161}\) If we accept that children have the right to learn a language and to be fully and freely involved in a culture, and that the barriers of entry into their parent’s hearing cultural and linguistic community far exceed those of the Deaf community, then we must accept that children have a right to be exposed to the Deaf community. In other words, the rights of the child depend on the existence of a Deaf community, and this further means that for the rights of a deaf child are intertwined with the rights of the Deaf community such that the former cannot be recognized and respected without the latter. In this way, the rights of the individual deaf child are well-harmonized with the rights of the Deaf community.

\(^{161}\) For hearing people, on the other hand, the barriers of entry into the Deaf community are essentially prohibitive. Even CODAs hold contentious status within the community. Interpreters, hearing ASL instructors, and other hearing people may be part of the community in some sense but can never call themselves culturally Deaf.
We might also note that, with both individual and collective rights, the set of rights which we afford individuals and peoples suggests that, though the demands of the Deaf community may be unusual or even unique, these differences may be acknowledged and respected without threatening any of the values on which our notions of civil, human, and cultural rights depend. Still, it is not only possible, but undeniable, that in this case living up to the values which structure our society in so many other ways will require what seem to be strange or foreign policies. This is not because it would threaten, undermine, or contradict the values we hold, but because it would embody them in new ways.

The desire for bilingual education is a wonderful example of this. While it may, on its surface, appear to constitute a partial surrender of the right of Deaf people to education in sign language, it is actually an empowering exercise of the broader right to linguistic self-determination which is totally in keeping with their unique linguistic culture. Deaf culture, I believe, is a rare example of a truly bilingual culture. Two languages, ASL and written English, are highly valued by group members and used regularly within the culture. When Deaf people demand bilingual education, then, they are not surrendering their right to linguistic self-determination, but recognizing their unique, bilingual culture. From this perspective, the low reading levels of many deaf students and the lack of exposure to ASL of others, are each a violation of the linguistic rights of deaf children. As human beings and as potential

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The fact that the Deaf demand bilingual education should be rejoiced not because they have surrendered an otherwise problematic set of rights, but because the way in which they have exercised those rights has demonstrated that our cultures share certain fundamental values, including English literacy.
members of the Deaf community, deaf children deserve to have high-quality instruction in both written English and ASL.

I conclude, then, that the Deaf community is entitled to certain collective rights, including the right to have ASL recognized as one of the official languages of their community and to promote their culture, likely through involvement in government-run early intervention programs, schools for the deaf and the public education system. Deaf children, in turn, have rights of their own. These rights should include the right to an education which affords them with complete access to language and culture from birth, which for many children might mean access to ASL and Deaf culture. How these rights might play out in practice will be discussed in the next chapter.

**A Word on Parental Rights**

When we discuss the individual rights of deaf children and the rights of a culture other than that of their parents, we have to ask ourselves how hearing parents fit into this system. Children have few rights of their own, and parents are generally understood to be the appropriate decision makers for their children. Deaf children, in particular, require a guardian to look after their educational decisions, since outcomes for deaf children using different technologies or educational programs can vary widely. It is natural and correct that parents should be empowered to make such decisions for their deaf children. As far as individual rights are concerned, well informed parents who have free access to information and a variety of affordable educational options are the best qualified to make decisions for their children.
If we view hearing parents as holding the rights of their deaf children in trust until they reach the age necessary to understand and exercise those rights, we see that a similar situation occurs with cultural rights. Kymlicka, for example, distinguishes between internal and external restrictions placed on a culture. An *external* restriction is the right for a member of a culture to learn about and practice that culture without restrictions from other cultures. A Muslim woman who demands the right to wear a burka is demanding freedom from an external restriction. A Muslim man who demands the right to *force* his wife to wear a burka, however, is utilizing an *internal* restriction. That is, he is claiming a right not against another culture but against the individual freedoms of members of his own culture. Kymlicka maintains, and I agree, that external restrictions are fully compatible with Western notions of individual rights, but internal restrictions are not. We can see that, in both our own treatment of minority language groups, and the various UN declarations involving cultural and linguistic minorities, it is external restrictions that are respected and reinforced.

Based on this distinction, it seems evident that when well-educated parents who have access to a variety of educational options and choose to have their child educated orally, this does not violate the cultural rights of the Deaf community. In this case, an individual community member (or, rather, the guardian of that community member) has chosen to leave, and in such a case to force these parents to educate their child a certain way would constitute an internal restriction on them.

However, if the parents have been provided with partial or biased information about the educational options available to their deaf child, then a decision to remove him or her from the Deaf community and to prevent his or her learning ASL does
violate the rights of the child. If government-funded early detection and intervention programs provide parents with information about their medical but not their linguistic options, then the government has, in effect, forcibly removed deaf children from the Deaf community by denying their parents access to information which was necessary to make an informed decision about the cultural status of their child. This is not a merely academic point: our current early detection programs, which are run by the Center for Disease Control (CDC), regularly violate the rights of deaf children in this way. Similarly, when we discuss special education policy in the next chapter we will see that parents are routinely denied supportive services which they request for their children. Disagreements between parents and school administrators about what children need can cause children whose parents would like special supportive services for their child to be denied such services. Likewise, parents who would like to send their child to a school for the deaf are not always able to do so. If parents are not offered access to supportive services and schools and programs for the deaf which they believe are necessary for their children, then those children have been, in effect, forcibly removed from the Deaf community, and in being so removed their rights have been violated.

Among certain members of the Deaf community, it is popular to blame the choices of hearing parents for the problems of deaf children. These attitudes are not restricted to Deaf people: even in other circles, hearing parents are often faulted for their child’s difficulty communicating. I think that this anger is misdirected. Hearing parents do make mistakes, but when a certain class of human beings, of normal intellect and ability, systematically falls far behind the norm, there is something more
at stake than parental error. The hearing parents that I have met have all loved their
deaf children and all did their best to make practical decisions on their behalf.

Blaming hearing parents for making poor choices is an easy way to avoid confronting
the flaws in the system that frames and informs those choices. It is this system, and its
effects not only on the options available to parents but on the way in which they think
about these options, that I hope to address in the next chapter.
Chapter Four: From Silent Survival to a Visual Cacophony--

Language and Education for Deaf Children

We saw in Chapter Three that the rights of deaf children as individuals and the rights of the Deaf community as a unique cultural entity line up surprisingly well. Deaf people possess the right to learn a language. But despite this, many Deaf people feel that they were given inadequate access to any language at all as a child. Nearly all feel that young deaf children routinely receive only part of the language access that they need in order to flourish as human beings. As a result, Deaf adults exercise their right to linguistic self-determination in part by demanding the right to a language. And not just any language, but a language which is accessible to them, which is capable of providing them the means to thrive as individuals and as communities, and to connect to their hearing family members and co-citizens to the maximum possible degree. For most Deaf people, this “language” actually comes in the form of two languages- one which is necessary for them to flourish as individuals and in communities and one which grants them access to the world outside of that community, which allows them to connect to their family members and the global economy. In short, for the goals that most cultures are able to satisfy with one language, Deaf culture requires two: ASL and written or, if possible, spoken English. As a result, the demand for bilingual education has been strong in the Deaf community.

It follows that the high value which we place both on individual autonomy and collective self-determination requires us to recognize ASL and to enable parents to choose the best cultural and linguistic option for their children by providing them
with both the information necessary to make an informed decision and with the services necessary to enact that decision. In this chapter, I will discuss the policies that the federal government of the United States should pursue to further these ends.

In the first section of this chapter, I will draw attention to some court cases regarding linguistic minorities, hoping thereby to glean insights into the appropriate treatment of Deaf people. These cases have trended towards affirming that all children, including children of illegal immigrants, have the right to a public education that respects their linguistic needs. Increasingly, this has meant that schools have been ordered to give these children special classes that assist them in learning English and that provide them with education in certain topics in their native language as they learn how to integrate into an English-speaking school system. This trend stands in sharp contrast to the laws, both as written and as interpreted by the courts, surrounding the education of deaf children.

In the second section of this chapter, I will demonstrate that the other side of this contrast- a system of education which presupposes that deaf children are disabled- is itself disabling. Low expectations, low standards, and inadequate access to schools for the deaf and appropriate services make it difficult for parents to secure a supportive environment for their children. In fact, we will see that public schools are not legally required to provide an education to deaf children that supplies them with access to the school curriculum on a level equal to that of their hearing peers. Even when children can secure appropriate services, they are treated throughout the system as though they are a disabled group with significant medical and supportive needs, rather than a group with unique linguistic needs. The result is that, for a variety
of reasons, many deaf children are offered only a small portion of the spectrum of educational and linguistic services that could help them to thrive.\textsuperscript{163}

Fortunately, the situation can be remedied in a way which embraces the rights of deaf children, their families, and Deaf communities more generally. In the final section of the chapter, I will discuss possible policy revisions. For the most part, the reforms that I suggest would not require the creation of new programs. Instead, I recommend an overhaul of the current system and continued funding to certain aspects of that system (such as schools for the deaf) which might otherwise be cut.

\textit{Linguistic Minorities in the Public Education System}

In the landmark case \textit{Lau v. Nichols} (1974) the United States Supreme Court provided one of the first endorsements of a right to bilingual education and remedial language programs for children with limited English skills. The families of a substantial number of Chinese American students had brought a class action suit against their school district after fewer than half of the students received special services to address their poor English skills. The Supreme Court found that the lack of special programs for students who did not speak English denied them an opportunity to participate in the educational system in a meaningful way, and thus violated section 601 of the Civil Rights Act of 1964.\textsuperscript{164}

\textsuperscript{163} In my discussion of Court cases, particularly regarding the disparity between the education for the deaf and the education of other linguistic minorities, I am deeply indebted to Siegel, who discusses these issues at length in \textit{The Human Right to Language}. For more information on how Siegel has influenced my work, please see the Introduction.

After the ruling in *Lau*, the United States Congress passed the Equal Opportunities in Education Act of 1974. This act expressly forbids “the failure by an educational agency to take appropriate action to overcome language barriers that impede equal participation by its students in its instructional programs.” Thus, as the United States Court of Appeals acknowledged in *Castaneda v. Pickard*, the spirit of *Lau* has now been codified. It is discriminatory and, furthermore, illegal for a school to fail to attempt to surmount language barriers.\(^{165}\) However, in some cases after *Lau*, including *Washington v. Davis* (1976) and *University of California Regents v. Bakke* (1978), though the courts would not explicitly overrule *Lau* they would add that, in order to violate the Civil Rights Act of 1964 or the Fourteenth Amendment, the policy must have discriminatory intent, not just discriminatory effect.\(^{166}\) While *Lau* no longer provided complete protection for linguistic minorities, the 1974 Education Act was seen as codifying the spirit of *Lau* by obligating schools to address language barriers in education regardless of discriminatory intent. Nonetheless, courts have sometimes interpreted the requirements of meeting the obligations imposed by *Lau* and the 1974 Education Act in fairly limited way. That is, they are traditionally seen as guaranteeing classroom access, not bilingual education. Thus, the Ninth District Court case *Guadalupe v. Tempe Elementary School District* (1978) found that remedial English instruction was sufficient to satisfy section 601 of the Civil Rights Act of 1964 and the Fourteenth Amendment for Mexican American children. This

\(^{165}\) *Castaneda v. Pickard* 648 F.2d 989 (Fifth Circuit, 1981).


essentially remedial instruction was considered sufficient to provide the children with meaningful access to the classroom.\textsuperscript{167}

Yet, the relevance of this case to the Deaf community is questionable. Indeed, the case of the Deaf community differs significantly from it in two ways. First, Deaf people are not an immigrant group but an indigenous language minority. Deaf people thus possess a different set of rights and, according to international norms, merit a different standard of protections, than do the children of immigrants. In particular, Hispanic immigrants in the United States are a \textit{language group} in the eyes of the United Nations, while Deaf Americans in the United States are a \textit{language community}. Second, in \textit{Guadalupe} the effectiveness of the remedial English education program was not challenged. Other cases, including \textit{Rios v. Read} (1978), a case from the District Court for the Eastern District of New York, have shown that an ineffective remedial English program violates the \textit{Lau} ruling just as surely as a nonexistent one.\textsuperscript{168} The effectiveness of any oral/aural English education program for Deaf children is hotly disputed and highly variable. There is reason to believe, then, that if the Deaf community was appropriately recognized as a cultural group with unique linguistic needs, they would have both individual and collective claims to bilingual education that expand beyond those envisioned in \textit{Guadalupe} (and indeed those that exist in most school systems today).

It might appear, on the surface, that there is a contradiction between claiming that deaf children may not be able to fully access the English language and that we should view Deaf adults as a cultural minority rather than simply a disabled group.

\textsuperscript{167} \textit{Guadalupe v. Tempe Elementary School District} 587 F.2d 1022 (Ninth District, 1978).
But in fact there is no contradiction between the existence of a culturally Deaf group and the existence of people who are disabled by their deafness. The variety of educational programs and technologies available to deaf children, as well as the wildly varying choices, outcomes, and access to appropriate services, leave plenty of room for variation. Some deaf people find a visual culture, some succeed in assimilating to hearing culture, some achieve both, and some, unfortunately, do not do either. People who are denied access to a language and a culture are undoubtedly disabled. The only debate is whether it is their deafness or our educational system that causes this type of disability. Further, many Deaf people subscribe to the social model of disability and believe that they can be disabled and culturally Deaf at the same time because their disability stems not from their deafness but from their treatment by social institutions and norms.

As we have seen, it is discriminatory and, furthermore, illegal for a school to ignore the language barriers facing its students. The Lau ruling has even been extended to protect black children who speak Black English in school districts that refuse to address their unique language needs.\textsuperscript{169} In fact, education is considered a right so fundamental that children who are illegal immigrants are nevertheless entitled to free public education.\textsuperscript{170} This results in an odd asymmetry: illegal immigrants have the right to a free public education which respects their linguistic needs and is effective in addressing the language barrier, but the United States does not extend these same rights to its deaf citizens.


The reason for this is in part that laws regarding special education, not those that apply to cultural or linguistic minorities, govern the education of the deaf. To understand the education of the deaf in the United States requires, therefore, that we examine special education as it is applied to deaf children.

**Deaf Children in Special Education**

While the laws governing the education of the deaf fall far short of treating them as a cultural or linguistic minority, special education overall has made great strides in the past half a century. Before the 1970s, public schools had no obligation to educate disabled children. As a result, it is estimated that more than one million children with severe disabilities were denied access to the public education system entirely, and more than half of all children with disabilities were unable to access an education that was appropriate for them.\(^{171}\) Tragically, the difficulty in obtaining appropriate educational services at home caused a large portion of such children to be institutionalized.\(^{172}\) In the early 1970s, however, a series of Court cases, including *Pennsylvania Association for Retarded Citizens v. Commonwealth* (1971) and *Mills v. Board of Education of the District of Columbia* (1972), determined that school districts had an obligation, under the Fourteenth Amendment, to provide all children, including children with special needs, with a public education.\(^{173}\)


\(^{172}\) “History: Twenty-Five Years of Progress,” 2.

\(^{173}\) “History: Twenty-Five Years of Progress,” 3.
In 1975, Congress responded by passing the Education for All Handicapped Children Act. Renamed the Individuals with Disabilities Education Act (IDEA) in 1990, and updated most recently in 2004, the Act has governed the education of disabled children in schools receiving federal funding ever since. Under IDEA, each public school must provide a Free Appropriate Public Education (FAPE) to any student with a qualifying disability (hearing loss and speech problems are both qualifying disabilities). A FAPE must prepare the student for independent living and, if possible, the workforce. IDEA was a landmark piece of legislation because it gave disabled children the right to an education tailored to their disabilities in their local school system for the first time.

Since the passage of IDEA, special education in the United States has improved dramatically. Most disabled children can now receive education through their neighborhood school and stay with their families. Moreover, graduation rates have been rising and the employment rate for those children who have graduated after IDEA was passed is twice that of older adults educated before IDEA. Even more striking, the percentage of college freshmen with disabilities has tripled since 1978.

I mention these numbers in part to show that, while I take issue with the way that IDEA has been implemented with respect to the education of the deaf, I want to stress that IDEA has, overall, been a very good thing.

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174 Section 504 of the Americans with Disabilities Act and No Child Left Behind also influence special education laws. In particular, the ADA may cover some disabilities not listed under IDEA, so some students qualify for protections under section 504 who would not receive special education under IDEA alone.


175 “History: Twenty-Five Years of Progress,” 3.
Nonetheless, there are issues with the way that IDEA governs the education of the deaf. Some of these problems are rooted in the unique nature of deafness among other disabilities (even assuming that deafness should be thought of as a “disability”). In particular, as Lawrence Siegel rightly notes, the requirement that a child be placed in the Least Restrictive Environment (LRE) possible has harmed deaf children even as it has provided children with a variety of other disabilities greater autonomy. A LRE is a carefully defined term; it means in part placing a child in the most mainstream environment possible. For many children with disabilities, being placed in a more mainstream environment means higher expectations, better academics, increased interaction with typical peers, and a better chance of being educated close to home under the care of their own family. For this reason, mandating that children be placed in a LRE makes sense for many types of disabilities.

However, for Deaf children, a LRE as legally defined may in fact be far more restrictive for the child than other options. For a deaf child who knows sign language, an ASL interpreter can provide the child with basic access to the teacher’s lectures. That child, however, will not have access to the incidental language input, such as overhearing the conversations of her peers or being able to eavesdrop on the teacher, things taken for granted by her hearing peers. More importantly, even if the interpreter is willing to walk from class to class with the child, attend recess and lunch hour and otherwise follow the child from place to place, and the school is willing to pay for it, the necessity of using an interpreter to communicate with one’s

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176 In fact, Siegel notes that “a child cannot be ‘removed’ from a regular classroom unless there is proof that the child cannot ‘achieve satisfactorily’ even with the use of supplementary aids and services.” For children who wish to attend schools for the deaf, this is devastating. 
Siegel, The Human Right to Language, 4-5.
peers can itself be socially isolating. It can make other children less likely to interact with the deaf child or limit the types of interactions that can realistically take place.\textsuperscript{177} For children who communicate in sign language, Siegel argues, the least restrictive environment may not be the mainstream environment at all. Instead, classrooms or schools full of children and teachers who speak their language and with whom they can interact casually provide that child with much greater freedom. With other native signers, a child can interact informally, directly, and spontaneously. Sometimes, this might mean talking behind the teacher’s back or interrupting one another in an enthusiastic debate. Other times, he points out, it might be something more important, like making friends who speak your language.\textsuperscript{178}

Other problems come not from the structure of IDEA itself, but from the way that it has been interpreted and implemented. In theory, for example, parents have a great degree of control of their child’s education under IDEA. They work with the school officials and others (for example, audiologists or teachers) to determine an Individualized Education Plan (IEP) for their child. An IEP must contain specific, quantitative goals that allow the parent to track their child’s progress and hold the school accountable if they fail to satisfy the IEP.\textsuperscript{179} However, in practice parents and school officials frequently disagree over the type of services that a child needs. Normally, since special services can be expensive and a school will lose its funding for that child entirely if the IEP entitles the child to attend a state school for the deaf, these debates begin with the school denying that a student needs some type of service

\textsuperscript{177} Ibid
\textsuperscript{178} Ibid.
\textsuperscript{179} National Association of the Deaf, Legal Rights, 59-61.
which the parents feel is essential to their child’s success.\textsuperscript{180} Unfortunately, if parents disagree with school officials, the opinion of the school is presumptively valid, and the parent must show that their child is not making “satisfactory [read: grade-level] progress” under the current system in order to legally obligate the school to change.\textsuperscript{181}

One problem with this policy is that it makes it more difficult for students who wish to do so to enroll in schools for the deaf, which has been a contributing factor to rapidly falling enrollment at schools for the deaf.\textsuperscript{182} For example, Siegel represented a second-grader, Jean, who was progressing at grade level academically but unable to make friends at school or interact comfortably with her hearing peers. She was Deaf, as were her parents, and fluent in ASL. The entire family desperately wanted her to attend a residential school for the deaf, but the request was denied because Jean was

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\textsuperscript{180} If it is shown that a child requires certain services, a school district cannot refuse to provide that assistance on the basis of the financial burden. National Association of the Deaf, \textit{Legal Rights}, 67. However, since such obligations only apply if it is shown that a child cannot benefit from his or her education otherwise, in practice the degree to which a student is able to procure above-minimal services may depend upon the financial situation of the school district, the personality of the school administrators, or other factors.\textsuperscript{181} The expenses of challenging an IEP compound the difficulties facing parents of deaf students. Even for parents who can afford an attorney and win in Court, not all expenses can be recouped. Parents are entitled to ask for attorney’s fees if they win a case, but not for fees for other services, such as fees charged by expert witnesses. The NAD is working to pass an IDEA Fairness Restoration Act which would remedy this situation. “NAD Supports IDEA Bill Calling for Recovery of Expert Witness Fees,” National Association of the Deaf, accessed April 7, 2011, available at http://www.nad.org/news/2011/4/nad-supports-idea-bill-calling-recovery-expert-fees\textsuperscript{182} While students at all state schools for the deaf need to have IEPs, the process for enrolling in a school for the deaf varies by state. In Florida, for example, parents can choose whether or not to enroll students in a school for the deaf. In Pennsylvania, on the other hand, parents need the approval of the Local Education Agency (LEA), the Intermediate Unit (IU), and the State Department of Education. Parents in different states, then, have varying degrees of autonomy when choosing their child’s school. In all states, however, parents who wish to obtain support services for their child at their local school must do so through an IEP. Buckley, Bravin, Maul, Finnegan, Lybok and Gordan, “Collaborative State/National Advocacy on Behalf of America’s Schools for the Deaf.”
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making “satisfactory progress” and had no “mental disturbances.” While Siegel notes this case as an egregious violation of individual rights, I would like to add that it also shows contempt for Deaf culture. Here, we do not even have the conflict of a deaf child of hearing parents who might belong to either culture. We have a Deaf child of Deaf parents, raised in Deaf culture and asking to attend a Deaf school. In this case I believe, as pointed out in Chapter 4, that the denial of Jean’s request represents an attempt at forcibly removing Jean from the Deaf community.

Unfortunately, the problems created by such a policy are far greater than the sum of the difficulties it creates for individual deaf students. Schools for the deaf around the country are now facing declining enrollment and, with it, the threat of major budget cuts or closure. There is a very real, and unfortunately realistic, fear among members of the Deaf community that state funded schools for the deaf will disappear entirely within our lifetime.

It would be bad enough if such a policy only limited the autonomy of parents seeking to educate their children in schools for the deaf. As a number of court cases demonstrate, however, it is not just signing children, and not just children who hope to attend special schools, who are limited by this policy. It is parents seeking interpreters and other supportive services for their children, parents who want to send their children to oral-only schools, and any parent who wants to have autonomy over decisions which will affect not only their child’s education, but their ability to communicate with others and to use language comfortably for the rest of their lives.

While the petition was initially denied, as were the parent’s repeated requests that their daughter be transferred, and the parents had no legal recourse, Jean did eventually attend a school for the deaf. She packed a suitcase and left it by her door for the day that her parents found a way to send her and her father, upset, picketed the school with a large sign bearing a picture of the suitcase for three weeks. 

Perhaps the most appalling of these is a case discussed by Siegel, \textit{Board of Education v. Rowley}, (1982). Amy Rowley was a Deaf child of Deaf parents. By the time she entered the public school system, she was fluent in ASL, which she used with her parents at home, and she was actually ahead of her peers academically. However, she was profoundly deaf and her speech skills were limited. When seated in a quiet room where a single evaluator spoke one word at a time, Amy was able to pick out the correct picture (of four) about 60\% of the time. She almost certainly understood less than that in a classroom environment where background noises, multiple speakers, and varied lighting would make speech-reading and listening more difficult and the language tasks required were far more complex. When Amy’s parents requested that the school provide Amy with an ASL interpreter, the school refused. Amy’s parents, outraged, sued the school and took the case all the way to the Supreme Court.\footnote{\textit{Board of Education v. Rowley}, 458 U.S. 176, 102 S. Ct. 3034, (1982). Siegel, \textit{The Human Right to Language}, 3-11.}

The fact that an interpreter was required in order to maximize Rowley’s potential and to provide her to access the educational system in a manner equal to that of her hearing peers was not contested by any of the parties in this case. Instead, the school district argued that the Education of the Handicapped Act (now IDEA) did not legally obligate them to provide that level of service. The intention of the act, they claimed, was not to provide disabled children with equal access to the educational system but to entitle them to an education from which they could receive some benefit. Amy Rowley, they claimed, continued to pass grades easily (Amy’s parents contended that this was because she had entered school ahead of her peers and that it
disguised the fact that she was falling behind). Clearly, she must be receiving some benefit from her education and, since she was making satisfactory progress, the school district believed that they had fulfilled their legal obligations.\textsuperscript{185}

The school district won, setting a clear legal precedent which stands to this day: disabled children are not entitled to an education which will allow them to maximize their potential or even receive an education parallel to that of their typical peers.\textsuperscript{186} As long as they are making satisfactory progress and showing some benefit from their education, the law is satisfied \textit{even if the parents are not}. When a school system is allowed to admit a child into a classroom where it knows that she will understand less than 60\% of what is said and to call that a satisfactory education over the outcry of her parents, there is a problem. Since 86\% of the 73,000 deaf and hard of hearing children with IEPs are mainstreamed (and mainstreaming continues to gain popularity),\textsuperscript{187} the disastrous effects of this decision will be felt by entire generations of deaf students until legislators realize that all Americans deserve the opportunity to pursue a life that is more than “satisfactory.”

It is not just Deaf parents, and not just signing children, who are victims of this system. A remarkably similar case, \textit{Brougham v. Town of Yarmouth}, was brought before the United States District Court for the District of Maine in 1993.\textsuperscript{188} Citing the decision in \textit{Rowley}, which stated that disabled children were not entitled to maximize their potential but only to receive an education from which they could benefit, the Court denied a mother’s petition to move her child to an oral school. The precedent

\textsuperscript{185} Ibid
\textsuperscript{186} Ibid
\textsuperscript{187} Buckley, Bravin, Maul, Finnegan, Lybok and Gordan, “Collaborative State/National Advocacy on Behalf of America’s Schools for the Deaf.”
\textsuperscript{188} \textit{Brougham v. Town of Yarmouth} 823 F. Supp. 9 (D. Me. 1993).
set by *Rowley* not only denies children the right to ASL, it denies them the right to language itself.\(^{189}\)

IDEA, then, provides children with the right to free education in their neighborhood school as long as it provides them with some benefit. In many ways, this is a huge step forward for disabled children. In others, tragically, it only marks the walls of a slightly larger prison cell. For deaf children, IDEA does not provide them with the right to a classroom in which they can communicate or a language which they can fully understand. It does not provide them with the right to an education that will allow them to maximize their potential. In this way, the inability to hear rapidly becomes the inability to access an education that treats a child as the intellectual or moral equal of his or her peers. The legislature and the courts have been very clear: IDEA entitles disabled students to an education but not to one that is equal to that of their typical peers.

An important part of special education is early intervention programs, and these too are important in the education of deaf children. Indeed, like special education in the public school system, early intervention programs for deaf children have been a significant gain for the Deaf community—but they are nonetheless problematic. Early education for the deaf is governed in part by IDEA, which allows families to write Individualized Family Service Plans (IFSPs) which parallel the role of IEPs for older children.\(^{190}\) However, early intervention services are also influenced

\(^{189}\) See also Siegel, *The Human Right to Language*, 58-59.
\(^{190}\) While the federal government does provide funding for early intervention services from birth, the IDEA act technically does not apply until a student reaches three years of age. Thus, while schools are required to provide certain services to infants in order to receive certain funds, they have no absolute legal obligations under IDEA until the student is three.
by the Early Hearing Detection and Intervention Act (EHDI). EHDI was passed in 1999 in an attempt to remedy one of the greatest problems facing the education of the deaf: late diagnosis. At the time, deafness often went unnoticed until the deaf child had fallen behind in speech and language development (this, in fact, was often the reason the child was brought in for testing). The average deaf child, in fact, was not diagnosed until two and a half years of age.\footnote{By mandating newborn infant screening for hearing loss in hospitals receiving federal funds and by regulating certain follow-up services, EHDI went a long way towards solving the problem of diagnosis.} It is thus no surprise that the Deaf community is for the most part \textit{thrilled} with EHDI. It allows children to be diagnosed earlier, and to receive language support as early as possible. The NAD and other deaf rights organizations were major advocates of the original bill, and are currently working on getting its renewal passed. I am not in any way denying that EHDI has been a wonderful thing for deaf and hard

\footnote{My brother, Peter, was diagnosed when he was three years old. Diagnosis, however, is only the first step in getting a child the support services he or she needs. Once my brother was diagnosed, my parents had to research educational programs and support services, find a good audiologist, figure out how to pay for hearing aids (which can cost thousands of dollars and are not covered by many insurance plans, including ours at that time), find a teacher and begin learning American Sign Language. Thus, while the average deaf child may have been \textit{diagnosed} at age three, I suspect that this age actually understates the delay in his or her access to services and, therefore, language. It takes a significant amount of time to research, choose, and secure support services for a deaf or hard of hearing child. That delay still exists for a child that is diagnosed as a newborn, but it takes place at a different point in a child’s life.}

\footnote{It is somewhat misleading to say that EHDI governs anything, in theory, although this has been the continued effect. EHDI was passed in 1999 but expired in 2002. However, federal funding to EHDI programs continued and 94¥% of newborns are still screened before one month. Also, Congress is considering a bill (H.R. 1246) which would officially renew EHDI.}

\footnote{“Historical Moments in Newborn Hearing Screening,” Center for Disease Control, accessed April 4, 2011, available at \url{http://www.cdc.gov/ncbddd/hearingloss/ehdi-history.html}}


\footnote{Raimondo, “Educational Policy and Deaf Children- What’s Up?”}
of hearing people across the country. As we will see, however, I do not believe that it goes far enough.

EHDI is handled by the Center for Disease Control and has seven goals. These include ensuring that all infants are tested by one month of age; that all of those who fail the initial screening receive follow-up testing by three months; and that early intervention services are provided to children with confirmed diagnoses by six months of age. Each child should also have a “medical home,” or a primary care doctor capable of assisting with his or her medical options, by three months of age. One can see, then, that EHDI does an excellent job of addressing the medical aspects of deafness. It ensures that children are diagnosed at a young age and have a medical professional to oversee their treatment. However, this strength is also its weakness. The government treats EHDI “hearing loss” as a medical issue rather than, for example, “communication loss” as a social one. It ensures that children have “medical homes” but not that parents who are well informed about their cultural, linguistic, and educational options. It does not mandate that children have an “educational home,” “language home,” or “holistic home” which might provide them with a variety of non-medical follow-up services. Thus, while EHDI has been remarkably helpful in diagnosing children and helping them to hear, it could do a lot more to follow up with deaf children to help them to communicate.

EHDI and IDEA both have sound, well-intentioned policies but operate from a set of assumptions that are false and damaging. The former assumes that deafness is

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primarily a medical problem. While the inability to hear is a medical fact, the
difficulties that many deaf children have communicating, that deaf teenagers have
reading, and that deaf adults have finding work are not a necessary consequence of
this fact, nor are they fully explained by it. Further, these problems cannot be
surmounted by medical means alone, but instead require that educational, linguistic,
and cultural options be made available to deaf children. However, these children
move straight from an early intervention program that treats their problems as merely
medical to a public school system that provides them with no safeguards to ensure
that they can adequately access the curriculum. Deaf children are treated as diseased
from birth and, since they cannot be cured, they are expected to make only
“satisfactory progress” later in life. If we want deaf children to succeed, and if we
want to live up to our values as a liberal society, we have to change this system. We
have to create a system that focuses not on hearing and disability, but instead on
language, culture and individual abilities.

 Successful Education for a Visual America

Improving the educational system for the deaf begins with improving the
information and services available to parents of deaf infants. When a child is first
diagnosed, it is these parents who need to make decisions for their child. And it is
these parents as well as their children who we cheat when we fail to provide them
with a full spectrum of information about how they can communicate with their child.
For every Deaf person that I have met who resents his or her mother for failing to
educate him or her in sign language or embrace his or her deafness, I have met a
hearing mother who resents doctors, audiologists, and school officials for failing to
give her complete information.\textsuperscript{194} Parents are fully capable of making decisions for their children, but at present we skew those decisions by failing to dispel common misconceptions about the Deaf community and, in some cases, providing incomplete information to parents.\textsuperscript{195} It is important to note that, as I mentioned earlier, this is not just a matter of preference but a matter of rights. When parents are not informed about the options available to their children, they are not able to make informed decisions for that child. And when this disparity of information skews in favor of the majority culture, it effectively removes children from the Deaf community by force. It denies parents the right to make knowledgeable decisions about their deaf children, a situation that violates both the human rights of the deaf children and the cultural rights of the Deaf community.

Fortunately, remedying this situation is relatively simple. Currently, the seven goals of EHDI include ensuring that a child has a “medical home” and that parents receive early intervention services. The goals of EHDI should be expanded to include assigning children a “language home,” a qualified, experienced and non-biased person or organization capable of helping to coordinate the child’s educational and linguistic options. This would not take the place of a medical home, but instead would

\textsuperscript{194} I went to several presentations by the Deaf Bilingual Coalition while I was at the 50\textsuperscript{th} Biennial Conference of the National Association of the Deaf. Tami Hossler, a hearing mother of a deaf child, was one of the presenters. She complained that “parents like me get no information from a Deaf person,” and that she wished that she had been given more information about ASL when her child was young. She even said that once a presentation by a Cochlear Implant group “made me feel oppressed as a mother of deaf children.” John Egbert, Tami Hossler, David Reynolds, “Deaf Babies’ and Children’s Human Rights to ASL and English,” (Presentation at the Fiftieth Biennial Conference of the National Association of the Deaf, Philadelphia, PA, July 6-10, 2010).

Tami’s experience resonates with the experience of my own mother and many of our friends. Many hearing parents feel that inaccurate or incomplete information, or difficulty accessing certain services, have cheated them of an opportunity to connect with their child or to better their child’s life.\textsuperscript{195} I say incomplete and not inaccurate for a reason. EHDI programs are run by the CDC and have a medical focus. I am not contesting the accuracy of the information that they give parents about their medical options, only the completeness of the picture offered by an image of deafness that centers on its medical aspects.
augment the work with medical care providers to ensure that the child is receiving appropriate services and that parents are well-informed about educational decisions. Language homes should be required to encourage parents to meet with members of the Deaf community and to provide interpreters for such meetings, all as part of the home’s duty to educate parents about a wide variety of options. Preferably, language homes would also provide ample opportunities for parents to interact with each other and with parents of older children, such that a community of parents dealing with these issues would be readily available. In addition, free family ASL classes and the option of Early Intervention Programs in ASL taught by qualified teachers for the deaf should be available to all families as part of EHDI. While some Early Intervention programs already do this, making it an explicit requirement of EHDI and ensuring that the centers were staffed with professionals with degrees in deaf education would ensure that families could more readily access ASL. Additionally, the state might do well to make some less fundamental but symbolically important changes. For example, running EHDI programs under the Center for Disease Control is disturbing to those who conceive of the Deaf community as a cultural and linguistic minority and not as a medically at-risk population.

The reforms I propose for IDEA are even simpler, if more radical. IDEA violates the individual rights of Deaf children because it does not ensure that children have full access to a language, to the classroom, or to an education equal to that of their hearing peers. Additionally, IDEA does not mention the cultural rights of the Deaf community at all. As we have seen, Deaf and hearing parents alike who want to obtain ASL services for their children, or send their children to schools for the deaf,
must have such services included in their child’s IEP. When Amy Rowley was denied an interpreter in ASL, her native language and an essential part of her native culture, it violated her cultural rights. When other Deaf children were unable to attend schools for the deaf, the only schools in the area that used their native language and culture, their cultural rights were violated as well. These children were forced to attempt to assimilate into hearing culture and, to the extent that this was not possible, they were denied access to an education. The requirement that they attend classes taught in a hearing language, almost exclusively with peers from a hearing culture, may not have been effective in making a profoundly deaf child assimilate to the hearing world. It may instead have deprived them of full access to any language or culture whatsoever. At the very least, it robbed them of an important part of their education not only as individuals, but as members, or potential members, of a unique cultural/linguistic group. They were treated as though their native language and culture were a remedial service, which could be appropriately withheld from them as long as they could function in majority culture, according to the most minimal standards.

If the requests of parents were treated as presumptively valid and the standards for education for the deaf were raised, it would solve both of these problems simultaneously. Instead of forcing parents to prove that their child has fallen behind before he or she is entitled to services, schools should be forced to prove that a child is able to access an education equal to that of their hearing peers without a service before the school can deny it. And parent requests that are based not on the educational needs of the child but on a desire to include the child in the Deaf community should never be denied on any grounds. This would ensure not only that
children had full language access to the classroom but also that those families who want to raise their children in the Deaf community are able to do so. It would guarantee that, to the extent that children were removed from the Deaf community, that move was consensual. Similarly, it would provide security that those children who were not taught ASL were able to access the curriculum comfortably in English.

In order to guarantee that a wide range of educational options were available to deaf children, the state would also need to continue supporting state schools for the deaf. While schools for the deaf have faced a problematic decline in enrollment in recent years, I think that the other reforms which I have proposed might increase enrollment at such schools. It would also be prudent to have a non-partisan committee examine the status of schools for the deaf to determine how schools for the deaf might move forward. If they hope to survive as educational options, this might mean reforming these schools or improving student outcomes. There may also be ways to preserve schools for the deaf as pillars of and resources for the Deaf community without relying as heavily on residential schooling. Whatever happens with schools for the deaf, however, closing the only schools which provide deaf children with an education in ASL and in Deaf culture more broadly would be a great loss to deaf students and Deaf communities alike, and extremely difficult to justify in light of the rights which we have just discussed. Whatever changes may or may not need to be made in order to make schools for the deaf more financially stable, these changes should not include closing the schools and should take place under the leadership of the Deaf community.
Public schools are not the only institutions that can limit parent’s options in educating their deaf children. As discussed in Chapter 1, cochlear implant centers sometimes require that parents enroll their children in a particular type of educational program, and insurance companies sometimes regulate the centers that children can use or other aspects of their education. Oral schools often forbid signing and, while schools for the deaf do provide speech training, these programs are often reputed to be inferior to the speech training available at other schools. While these issues are less directly involved with the government and, thus, may not constitute a human or cultural rights violation directly, the government might do well to regulate them. In particular, it would be an appropriate response by the government if insurance companies were required to cover the CI center of a parent’s choice, CI centers were required to implant those children who wanted implants regardless of their educational program, and all schools were required to respect a child’s linguistic wishes. This would not mean that oral schools should be required to hold ASL classes, but only that oral schools should allow children who know sign language to use that language in the hallways or cafeteria.

It should be noted that, while the focus of my thesis has been primarily on the basic structural changes which would be required to improve the treatment of deaf students and respect their cultural and human rights, there are problems in the administration of the current system of education which would also require change. For example, there is currently a great shortage of interpreters and, unfortunately, interpreter quality varies widely. With the National Association of the Deaf and the Registry of Interpreters for the Deaf certify interpreters, there is currently no
requirement that interpreters be certified in order to practice. According to Siegel, nearly 90 percent of the educational interpreters in Oregon and 81 percent in West Virginia were not certified in 2004. Uncertified interpreters understand, on average, only 29 percent of what is said in ASL. Certified interpreters, surprisingly, fare little better. They understand only about 57 percent of what deaf students sign.¹⁹⁶ An interpreter who cannot voice a deaf child’s sign with speed, accuracy and fluency or cannot fully communicate a teacher’s message to a child clearly cannot provide that child with full access to language or education. It is not sufficient, then, for the state to provide a child with an interpreter and then look the other way. Interpreters should be licensed and standards should be rigorous.

Below is a table summarizing my proposed reforms.

<table>
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<th>Proposed Policy Changes</th>
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| **Early Childhood Education** | • Require children to have a “language home”
| | • Free family ASL classes
| | • Bilingual preschools staffed with qualified teachers for the deaf readily available
| | • Have EHDI administered by educational, not medical, authorities.
| **Elementary and Secondary School Education** | • Make parental claims that a child needs services presumptively valid
| | • Treat schools for the deaf as a cultural option, not simply a supportive service. Allow any parents who so choose to send their children to a school for the deaf or signing program regardless of that child’s abilities

| Schools for the Deaf | • Continue funding schools for the deaf  
| | • Research and, when necessary, reform educational practices at schools for the deaf such that they provide high-quality, effective bilingual education. |
| Other | • Regulate CI implant centers and/or insurance companies such that children’s language options are not restricted by their medical options and visa versa.  
| | • Forbid any school from punishing a student for using or attempting to use a communication mode not favored at that school outside of class.  
| | • Require interpreters to be licensed |

I understand that the changes I propose may be expensive. First and foremost, I would like to point out that I have not argued simply that these changes will be a moral good, but instead that they are a moral and political obligation in order to satisfy a certain set of rights. They do not belong in a category with funding to optional programs, subsidies or services. Instead, these costs are much like the costs associated with public defenders, a respect for peaceful but potentially disruptive civil disobedience, and the cost of providing free public education equally to children of all races. These are not optional things. They should not be taken as such. Even if this were not the case, I am not asking that Congress suddenly pull resources out of
nowhere for an unprecedented experiment. We already fund free public education and special education programs and services. My reforms have to do at least as much with ensuring that the funding that we currently spend on deaf students is used properly and to their maximum benefit as it does with requests for additional monies.

Changes like these could bring our treatment of Deaf people in line with our treatment of other minorities, our deeper values, and our broader moral obligations. They would fully respect the human rights of deaf children and the cultural rights of Deaf communities. Allowing deaf children to grow up without full access to linguistic, educational, and cultural options is both an injustice and a tragedy. Fortunately, it is one that Americans have the power (and the duty) to correct. With the appropriate information, thousands of parents, including Susie’s, can select the best possible services for their child. With full access to those services, Susie can grow up into a highly successful adult, capable not only of understanding comfortably what others say, but also of eloquently communicating ideas of her own.
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