

1 *Introductions*

IN THE PREFACE, we said that being deaf is not about hearing, but about communication. To communicate requires full access to language. To clarify this observation, it makes sense to begin with terminology. What do we mean when we say that people are *deaf* or *hard of hearing*, and to whom, precisely, do these terms refer?

There's a good explanation for the confusion that surrounds these questions: Deaf and hard of hearing people do not constitute a homogenous group; rather, they form a group that is diverse in many ways. Yet as our peer, Dr. Thomas Holcomb, notes, they do have the four following common threads that tie them all together:

1. the desire for full access to communication and language,
2. the capability to access information about things around them,
3. the need for developing a positive self-identity, and
4. the ability to make their own decisions, or self-determination.¹

We cover all of these topics in one way or another in this book, often in overlapping ways.

Certain terms and labels can be confusing, such as *hard of hearing* and *deaf* with a lowercase *d* or a capital *D*, depending on identity or membership in the Deaf community. Some terms, such as *hearing impaired* and *deaf-mute*, are currently considered passé and even offensive. Also, it is usually unnecessary to use “people first” language, as in “people who are deaf.” Using the terms *deaf people*

or *hard of hearing people* is perfectly acceptable and is the format we follow here, as you may have already noted. Finally, as with any other sort of label, the best approach is often to just ask individuals what they personally prefer. Some may proudly proclaim themselves Deaf, whereas others would rather nobody knew and declare that their hearing status does not define them at all. We have decided to use *deaf* only for the sake of brevity and not to single out or exclude any particular identities that we have in this diverse population.

Here is a partial list in alphabetical order of some the possible self-identifications that people may use to describe themselves:

- Deaf
- Deaf and cochlear implant user
- Deaf and partially sighted
- Deaf-Blind
- Deaf with cerebral palsy
- deaf
- deaf and cochlear implant user
- deaf-blind
- deaf and partially sighted
- hard of hearing
- hard of hearing and partially sighted
- hard of hearing and blind
- hearing
- late-deafened
- late-deafened with neurofibromatosis Type 2
- oral deaf

Given the wide variety of people within the deaf population, it is not surprising that outsiders are often confused about who we are. In recent years, as writers and researchers have tried to describe us with greater precision, it has become obvious that generalizations are futile without reference to agreed-upon criteria. The following questions outline the ten distinguishing features that are used to define the spectrum of possibilities within the deaf population.

1. *How much hearing ability does the person have?* Hearing people often wonder why some people benefit from wearing hearing aids or cochlear implants while others receive no benefit at all. They

wonder why some deaf people can talk on the phone while others cannot. Levels of hearing loss vary from person to person, ranging from slight loss to mild loss, moderate loss, severe loss, and profound loss. Only a handful of deaf people have what most people would call total deafness.

2. *At what age did the hearing loss occur?* Keep in mind some people were born with their current hearing status and thus never “lost” what they never had in the first place. Conversely, there are those who did lose their hearing ability after birth. We know of people who are deaf, speak very well, and can play the piano brilliantly. Many people marvel at what to them is a contradiction in terms—a deaf musician—but in one instance, we know a person who took piano lessons for twelve years before she contracted spinal meningitis and lost her hearing completely at the age of seventeen. She sometimes gives in to the temptation to mystify hearing folks by pretending she has always been deaf. It is not uncommon for deaf people to amuse themselves by taking advantage of hearing people’s naiveté with regard to deafness.

3. *What type of hearing loss does the person have?* Hearing loss can be defined as any loss of sound sensitivity, partial or complete, produced by abnormality anywhere in the auditory system. For the purposes of this discussion, we will define the four following types of hearing loss.

a. *Conductive hearing loss* is caused by a disruption or blockage within the ear canal or a defect in the bones of the middle ear that inhibits sound from reaching the inner ear. People who have conductive hearing losses often benefit from corrective surgery and/or wearing hearing aids.

b. *Sensorineural hearing loss* is caused by disruption of the transmission of sound information to the brain in one or more of three possible locations: The hair cells of the cochlea in the inner ear, the nerve synapse between the inner ear and the auditory nerve, or in the auditory nerve between the cochlea and the cortex of the brain. Sensorineural hearing loss is usually incurable, and hearing aids do usually provide some benefit for most people. This type of hearing loss is specifically targeted by the use of cochlear implants, as we will discuss later.

c. *Mixed hearing loss* is a combination of conductive and sensorineural hearing loss. Mixed hearing loss is the sum of losses resulting from abnormalities in both the conductive and the sensorineural mechanisms of hearing. In such a case, the hearing loss caused by conductive problems usually is treatable, but the treatment of sensorineural loss currently available does not restore the physiological structure of the cochlea or nerves used for hearing.

d. *Auditory neuropathy* is a condition in which sound enters the inner ear normally, and the inner hair cells react normally, but the transmission of signals from the inner ear to the brain is disrupted. People with auditory neuropathy may, at times, appear to have normal hearing, or hearing loss ranging from mild to severe; but they usually have poor speech-perception abilities. They may be able to hear sounds, but they have difficulty recognizing spoken words. Although few people have it, we are learning that more and more people have this condition.

4. *What caused the hearing loss?* Although there are just four types of hearing loss, the number of possible causes, or etiology, is much greater. The known causes of hearing loss are heredity, disease, toxicity, noise exposure, and injury. Medical professionals estimate that inherited genes are the cause in half of all babies born deaf. In 25 to 40 percent of cases in children, the cause is unknown. Hearing loss may occur at any point in the life cycle—before, during, or after birth. During pregnancy, for example, the mother having rubella or cytomegalovirus (CMV), or ingests certain drugs can cause hearing loss in a fetus. During delivery, complications in the birth process, the presence of a sexually transmitted disease in the mother, or Rh incompatibility between mother and child may result in hearing loss. After birth and throughout life, a host of possibilities exists: otitis media (infection of the middle ear), spinal meningitis, bacterial or viral infections, automobile accidents, allergies, the ingestion of toxic substances, and so on.

Some causes of hearing loss, such as maternal rubella, CMV, trauma, or prematurity, are associated with other health problems or disabilities. Deafness that is genetically inherited is the least likely of all kinds of deafness to be accompanied by additional disabilities.

5. *Are the parents deaf?* According to commonly accepted estimates, about 5 to 10 percent of deaf children have deaf parents. Deaf children of deaf parents tend to score higher in cognitive, language, and academic areas than do deaf children of hearing parents.² Three factors have been proposed for this finding: (1) Most deaf parents have a fluent and intelligible communication system in place in the form of ASL, which they use to communicate with their infant from birth; (2) deaf parents are more likely than hearing parents to expect and identify deafness in their child; and (3) they are accepting, and surprisingly to many people, hopeful of having a deaf child.³ You will read and learn a great deal about these factors in this book. Early diagnosis of hearing loss, access to fluent language models, and Deaf parents' response and acceptance of the diagnosis of deafness in an infant can often serve as a model for hearing parents who are unexpectedly thrust into a new and (to them) unexplored world. Deaf parents are also good models for how constant exposure to language and communication globally affects a child's overall development in positive ways. Of course there are exceptions with some not-so-great deaf parents, just as there are not-so-great parents in the general population.

6. *How much and what kind of education has the person had?* Deaf and hard of hearing children can attend a variety of school programs. Some go to schools specifically for deaf students, either private or public, which can be far from home. Most are mainstreamed in classes with hearing children, with or without support services, such as interpreters, note takers, tutors, and resource specialists. Children who have hearing aids or cochlear implants should receive appropriate support for the use of these devices in and out of the classroom.

The education levels of deaf people are as varied as those of hearing people. Some deaf students attend mainstream colleges, which are now required by the Americans with Disabilities Act (ADA) to provide support services when requested. Others take advantage of the college programs specifically targeted to deaf students that are available throughout the United States.

7. *What are the person's distinguishing personal characteristics?* With regard to personality, intelligence, genetic makeup, and the other

characteristics that contribute to each person's uniqueness, the deaf population is no different from the hearing population. Humans who are deaf do not differ from those who are not, except in their levels of hearing and modes of communication. Nevertheless, throughout history and until recent decades, educational and employment opportunities for deaf and hard of hearing people were extremely limited, and these limitations squeezed much of the deaf population out of the mainstream of society and into "special" (often specially *limited*) schools and jobs. In recent years, the Deaf community has succeeded in defining itself more clearly to the hearing community and in actively taking advantage of expanded educational opportunities. As a result, career possibilities have become unlimited. We know of doctors, veterinarians, lawyers, professional magicians, accountants, contractors, automobile mechanics, actors, and actresses, all of whom are deaf. And, by the way, we have known obnoxious deaf people, deaf slackers, deaf criminals and convicted felons, and deaf alcoholics and drug addicts. The only limits on what deaf people can be are those that make all of us human together.

8. *What are the person's parents or other family members like?* Family climate has a lot to do with the psychological, educational, and vocational opportunities afforded to young people. In the families of deaf children, the decisions affecting the child's schooling and communication opportunities are heavily influenced by the parents' personal, social, and cultural backgrounds; communication style; value and belief systems; economic status; and orientation toward education. We will explore these factors later. One thing we will emphasize here is this: Research has shown that parent involvement and parent expectations are an important factor in deaf children's success.⁴

9. *What is the person's primary mode of communication?* A large portion of this book is devoted to in-depth exploration of modes of communication, both deaf-deaf and deaf-hearing. Members of the public are often surprised to learn that deaf people use a variety of communication modes—a large and impressive variety. In fact, it is not unusual to meet hearing individuals who completely misunderstand the nature of being deaf itself, even confusing it

with blindness—a good number of us deaf folks have been handed braille menus in restaurants. Even worse is being treated as if we have an intellectual disability. Most people believe that deaf people communicate by some combination of speechreading (or “lipreading”), the ease and effectiveness of which is often overestimated, and sign language, which is routinely underestimated, because they lack experience with its power and richness. Uninformed folks who see deaf people signing usually assume that the signs are equivalent to visual shorthand in English. The truth is that there are four major categories of communication practiced in the American deaf population, as follows:

1. ASL, the native language of American deaf people,
2. Listening (with assistive devices) and Spoken Language (LSL),
3. strictly English-based signing with grammatical influence from English (generally called *Manually Coded English*, with specific approaches, such as Signing Exact English and others), and
4. a combination of speech, speechreading, audition, and signing going along an expressive continuum from signing to oral language. It has been called a variety of names such as *simultaneous communication (Sim-Com)*, *Pidgin Sign English (PSE)*, and *contact sign*.

The ultimate choice reflects the person’s own preference, based on facility and comfort with the particular mode. That choice is influenced by a complex interaction of factors, which we will explore in later chapters. The important thing to remember here is that the choice is a personal one, and it is shaped and influenced by all the personal, cultural, social, and genetic factors that make individuals unique.

Just as in the hearing world, where people range from monosyllabic grunters to great orators, in the deaf world, you will find a tremendous range of communicators, including the following:

- fast-and-furious signers,
- people who “mumble” in sign,
- bilingual people who are articulate in both ASL and English (spoken or written),

- people who are articulate in ASL, but not in English,
- people who are articulate in spoken English, but not in ASL, and
- signers who enjoy and develop the natural drama and aesthetic qualities of sign.

Gone are the days of the stereotype of deaf people as depressed and dispirited stay-at-homes. Today, we have made ourselves known in all walks of life for who we are—unique individuals who happen to be, among many other things, deaf or hard of hearing.

10. *What are the person's ties to the Deaf community?* How a person who is deaf relates to the Deaf community is also a matter of personal choice. Some deaf people prefer to live and function primarily in the Deaf community, others exclusively in the hearing society, and others spend varying amounts of time in both worlds or go freely back and forth according to circumstances.

As you can see, deaf people encompass a range of communication styles and levels of community involvement. They contribute in many different ways to the diverse deaf population and to society as a whole. Although our diversity is our strength, it is also the origin of many questions and problems that need to be clarified and understood. For you as parents, facing these issues perhaps for the first time on behalf of your child, the jumble of possibilities to be sorted out no doubt seems overwhelming. Our aim is to take you step by step through this thicket, not as the proponents of a single point of view but as guides and facilitators, helping you gather the information and insights you need to make your own decisions.

In serving as your child's advocate, you will be facing a whole raft of decisions you never anticipated. We hope that this short introduction on the deaf population will help acquaint you with the reality that is the deaf experience. And more, we hope it reassures you that, although different from the hearing experience in its orientation toward communication access, the deaf life can be a rich, productive, exciting world full of promise and potential. The challenges lie in bridging the two worlds. We are writing here with the goal of helping you meet those challenges as you guide your child along the path toward autonomy.

Notes

1. Thomas K. Holcomb. *Introduction to American Deaf Culture* (New York: Oxford University, 2012).
2. Paul Miller, Tevhide Kargin, and Birkan Guldenoglu, “Deaf Native Signers Are Better Readers Than Nonnative Signers: Myth or Truth?” *Journal of Deaf Studies and Deaf Education* 20, no. 2 (2015): 147–62.
3. Thomas K. Holcomb, *Introduction to American Deaf Culture*, 220–21.
4. Stephanie W. Cawthon and Jacqueline M. Caemmerer, “Parents’ Perspectives on Transition and Postsecondary Outcomes for Their Children Who Are d/Deaf or Hard of Hearing,” *American Annals of the Deaf* 159, no. 1 (2014): 7–21.