

# The Deaf Community:

## Range and Gaps in Services and the Role of Independent Living Centers for People with Hearing Loss

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# Introduction and Overview

Most people are aware of celebrities who have disabilities, especially those who deal with them in very public and constructive ways. However, the loss of hearing is a hidden disability that may go undetected, depending on the severity of the loss, and often is associated with an assumption of a lack of intellectual capacity.

Several well-known individuals have functioned successfully without divulging the extent of their hearing loss, including Rob Lowe and Brian Wilson; there are others, including Marlee Matlin, Franklin Delano Roosevelt and Helen Keller, of which the hearing loss was better known. These are individuals who have had access to sufficient resources and support, which contributes to an assumption that all people with hearing loss function in a similar manner. This is not the case.

Of the estimated 1,038,126<sup>1</sup> Deaf and hard of hearing in California, there is a broad spectrum of individuals with hearing loss ranging from mild to severe to profound. The causes can vary widely, i.e., genetic, illnesses, damage to the inner ear, loud noises, aging, etc. The level of loss ranges from missing a few words or word endings in a conversation to profound or complete deafness where sounds must be loud enough to cause detectable physical vibrations. However, with all of these variations, one constant remains — all members of the group share invisibility.

The varying needs of people with hearing loss are staggering. For example, while many Americans have trouble hearing a telephone dial tone without adaptive equipment or miss at least some spoken information, only 1-5 percent of the population identifies themselves as part of the “Deaf Culture” according to *Deaf Culture*<sup>2</sup> researched by Sarah

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<sup>1</sup>American Community Survey 1-Year Estimate data for 2008, for “non-institutionalized civilians”

<sup>2</sup>Deaf Culture researched by Sarah Cole, Kaitlyn McCormack and Aimil Parmelee

Cole, Kaitlyn McCormack and Aimil Parmelee. The use of an uppercase “D” refers to those for whom American Sign Language (ASL) is the preferred or native language. These individuals, who comprise a hidden minority in our society, have shared values, history and humor in the unique experience of being Deaf in America. A lowercase “d” refers to the medical condition or pathology of deafness.

Every day, people who are Deaf or hard of hearing face obstacles, such as not having a shared language in face-to-face communication, that prevent them from being fully included within their local communities. Considering approximately half a million people use ASL, it’s important to allocate resources and make needed changes to ensure they are included as members of their communities at all levels. The independent living (IL) philosophy is one avenue by which those changes can be made.

The IL movement began after the passage of the Civil Rights Act of 1964 when people with disabilities, who were protected under the Act, developed a taste for inclusion and change. The basis of the IL philosophy is that people with disabilities have the right to live, work and play in the community, rather than being told they can’t do so or are relegated to institutions by “authority figures” such as medical professionals, social workers, rehabilitation specialists or parents. Recognizing equality is a civil rights issue, people with disabilities, including those who are Deaf and hard of hearing, began questioning the assumptions that limited their activities.

Although strides have been made, nearly 50 years after the Civil Rights Act passed, barriers continue to exist for people with disabilities, especially those with “invisible” disabilities such as those who are Deaf or hard of hearing. Incorporating accessible features (such as interpreters, real-time captioning) that accommodate individuals with hearing loss is more complicated and necessitates more than a single action.



# Deafness: Disability or Culture?

“Deafness is a disability that is so unique, its very nature causes a culture to emerge from it. Participation in this culture is voluntary.” Mark Drolsbaugh.<sup>3</sup> Rather than seeing themselves as a part of a disability group, many Deaf people see themselves as members of a specific sociological group and are proud of their culture. In addition, the Deaf culture includes people who are not deaf or hard of hearing but use sign language to communicate. Together, these people are known loosely as the Deaf community.

Members of the Deaf community encounter access issues daily. It’s generally agreed that accommodations should be made for individuals seeking services or resources who speak a “threshold language” (defined in Medi-Cal as the primary language of 3,000 individuals or 5 percent of the beneficiary population, whichever is lower) such as Spanish, Cambodian or Japanese. Because we live in a “hearing world,” people who are Deaf or hard of hearing are surrounded by hearing individuals, including employers, co-workers, medical professionals, educators, law enforcement officers and neighbors. Deaf or hard of hearing people encounter multiple situations daily in such places as grocery stores, malls, banks, gas stations and restaurants where people are neither conversant with sign language nor sensitive to and aware of ways to maximize communication.

In general, a big misconception exists that people with hearing loss compensate by reading lips or wearing hearing aids. It is estimated, however, that only 30-40 percent of sounds in the English language are distinguishable from sight alone, making lip-reading very difficult. In addition, lip-reading is a skill that needs to be developed, and most people with hearing loss do not acquire the skill. Comprehension can decrease during a critical, stressful or emotionally charged situation, and even a competent lip-reader finds participating in a group discussion, under the best of circumstances, almost impossible.

<sup>3</sup>*Deaf Again (Handwave Publications, 2005)*

There also are many misconceptions about the usefulness of technology. For example, hearing aids do not return full auditory function, but only enhance remaining function. Cochlear implants, often viewed as a medical panacea, have similar drawbacks.

Another widely held misconception is that ALL Deaf and hard of hearing people communicate successfully by writing. This may not be the case for those who learn English as a second language, but do not become proficient in written or typed English.

All of the issues identified above can impact effective communication, which, in turn, can impact safety. Law enforcement officers, firefighters, first responders and emergency medical personnel, who are rarely prepared to interact with people who are Deaf or hard of hearing, put themselves and those they are helping at risk of greater danger in a crisis. Nearly every year, a Deaf person is shot by police for not responding when addressed. Deaf children and adults die in fires because smoke alarms with visual strobes are not installed or working. Additionally, the exchange of information during a disaster often does not include signing in ASL or media captions; therefore, people dependent on visual media for safety information are left out. It is important that professional public safety officers are educated and participate in sensitivity and awareness trainings to increase their understanding of the Deaf community and how best to communicate with them. In California, the Emergency Management Agency has trained and credentialed dozens of interpreters to promote emergency interpreting with media, shelters and first responders. More needs to be done.

Before interpreters were available, hearing children in Deaf families were relied upon by medical professionals to convey critical information to their parents and/or community members. This not only placed the hearing child in a precarious position, but often created long-term emotional scars when, for example, a child had to tell his or her mother that she had cancer. This example exemplifies the need for accessible information and training relative to the Deaf community by providing individuals with the autonomy and ability to make decisions on what's best for their families and children.

# What Is Available in California for Individuals Who are Deaf or Hard of Hearing?

There are, without question, significant gaps in both the understanding of and services for people who are Deaf and hard of hearing. Their ongoing needs for access vary widely and cannot simply be addressed by installing a ramp or remodeling a bathroom. For example, when considering the importance of voting, televised information about the issues, events, candidate speeches and ads often are not captioned. Although some organizations have a good understanding of what is needed to appropriately respond to the Deaf community, significant opportunities exist for improvement within a number of organizations and resources.

In California, there are approximately 220 workforce investment “one-stop” sites, with at least two in each county, that offer businesses, job



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seekers and youth with innovative employment and training services. Sixteen sites have staff members are fluent in ASL. Where fluent ASL staff members aren't present, consumers are forced to avail themselves of mainstream services. To be fully responsive, one-stop sites must incorporate the features that allow people with hearing loss to successfully take advantage of their services.

For many years, the California Department of Rehabilitation (DOR) has been one of the larger agencies providing services and support to people with significant disabilities. DOR's mission focuses on access to gainful, competitive employment and assistance with employment retention. DOR's Rehabilitation Counselors for the Deaf and Hard of Hearing are fluent in sign language and work closely with consumers; unfortunately, large caseloads prohibit in-depth training in this setting.

The California Department of Social Services, Office of Deaf Access oversees eight Deaf Access Program Service Providers in the state. Their services are similar to those offered by Independent Living Centers (ILCs); however, reductions in funding have negatively impacted their reach. They are located in larger population centers, which means those individuals living in rural settings who are Deaf and hard of hearing do not have connections or support for their access needs.



# The Role of Independent Living Centers

The information and examples cited above make a strong case for ILCs to emphasize the services they offer and make their offices welcoming to Deaf and hard of hearing individuals. Of California's 28 ILCs, some have fully implemented cross-disability services that offer a welcoming and inclusive atmosphere for people with hearing loss.

It's important for ILCs to continuously inform the Deaf community about the services they provide and ensure options include a mechanism for all individuals to communicate comfortably. Similar to working with other cultural and ethnic groups, ILC staff must be sensitive to service delivery issues and advocate on behalf of the Deaf community and individuals who are hard of hearing.

**A recent example of effective ILC advocacy comes out of Modesto, California.** The ILC hired a young Deaf woman, who despite being isolated in her work environment, reached out to another ILC that provided full services for Deaf persons and asked for mentoring. When she learned of consumers being excluded from services offered by a local employment training organization, she worked with her mentor on approaching the organization with information about their obligations under the ADA and how they could accommodate Deaf consumers at meetings. As a result of the woman's efforts, the consumers were successfully enrolled for employment training.

When it comes to education, schools suffer from a shortage of qualified personnel. This is exacerbated by educational institutions being unable to afford expensive support technologies. In the past, school administrators misunderstood the importance of qualified deaf language models. They often hired people with little or no competency to assist students with

hearing loss and failed to determine the need for a qualified interpreter. The use of unqualified signers further exacerbated the problem and was very destructive. Deaf children were held responsible for knowing information taught in class when they did not have reasonable access to the information because of an ineffective or poorly trained interpreter. Hopefully this will improve now that educational interpreters are required to hold levels of qualification.

As a result of the above, Deaf parents with Deaf children often opt to send their children to residential schools for the Deaf to ensure an appropriate educational experience. Hearing parents of a Deaf child may hesitate sending a child away, yet they don't know how to fight for a fully accessible local school district educational experience. The classroom setting can be extremely difficult for a Deaf individual if qualified personnel are not available.

Although it's somewhat better today, educational institutions still fight cost and access issues. ILCs, knowledgeable in access issues for Deaf or hard of hearing children in educational settings, can offer unique and powerful assistance in these situations. Many ILCs already are providing knowledgeable and effective assistance when consumers are confronted with individual education plans and resistance from schools to accommodate members of the Deaf community.

ILCs can be invaluable in providing career assistance to people with hearing disabilities. For example, while an interpreter may be used by adults or transitional youth who are Deaf or hard of hearing during a job interview, the effective use of "soft or interpersonal skills" must be learned before the interview. This is where ILCs can help by teaching the necessary skills to enhance an individual's interactions, job performance and career prospects and assisting them with their choices and decisions. ILCs also have access to partners that can provide additional accessibility services.

ILCs also can advocate on behalf of Deaf and hard of hearing individuals to improve the quality of captioning for emergency situations, medical information and warnings and political information that provides the type of information needed for people with disabilities to vote. ILCs can partner with other organizations to strengthen outreach and understanding of issues important to the Deaf community.



## Conclusion

The barriers described above and others combine to make services seem largely inaccessible for Deaf individuals and people with hearing loss. For a long time, they have been excluded from mainstream services. And many have never felt included in the disability movement, mainly because they regard being deaf or hard of hearing as a communication difference rather than a disability.

In light of funding reductions, an opportunity exists to be more inclusive and dismantle the silos from industry to industry by supporting ILCs and their partners to extend their reach and improve access and services for more individuals in California's Deaf community. ILCs and their partners need to see themselves as truly cross-disability by embracing Deaf and hard of hearing individuals.

ILCs have been effective in tackling physical and attitudinal barriers and improving access for those who are blind or have low vision. Expanding this advocacy and expertise to communication issues would greatly broaden the impact of ILCs within the Deaf community and for people who are hard of hearing.



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## State Independent Living Council

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*The California State Independent Living Council (SILC) is an independent state agency which, in cooperation with the California State Department of Rehabilitation, prepares and monitors the State Plan for Independent Living.*