DEAFNESS:
Historical Perspectives

A Deaf American Monograph
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THE ASSOCIATION OF LATE-DEAFENED ADULTS
Rationale, Highlights, History

About Late-deafness

Although it has been over 20 years since the last major deaf census, the best estimate we have is that 75% of deaf adults became deaf after the age of 19 (Schein & Delk, 1974). Many of the historical causes of both congenital and adventitious deafness have changed in incidence over the years. A new survey would be needed to see how the proportions have been affected today. Nevertheless, most people in the deaf community probably don’t think of late-deafened people as the majority. Services provided to “the deaf” are overwhelmingly directed at people who became deaf at birth or in early childhood. Funding and subsidies for “deaf” organizations go overwhelmingly to the same population. When you think of access to services for “deaf” people, you think of sign language interpreting. You think of sign language as the native language of the deaf population. And yet the simple numerical majority consists of those who became deaf later in childhood, in young adulthood, during the working years, and later in life.

When people think of adults becoming deaf, they think of Granny losing her hearing, being shouted at during the family reunion. In fact, the image is of the hard of hearing person rather than the deafened person. While many people do become hard of hearing due to normal aging processes, to overexposure to noise, and other causes, there is a big difference between being hard of hearing and becoming deaf.

It has been wrongly asserted that deafened people are first hard of hearing, implying that deafness is the extreme case of hard of hearing, therefore the coping techniques and needs of both are the same. In fact, the majority of deafened people go quickly from hearing to deaf with little preparation.

Adults become deaf in different ways, many of them through the same mechanisms as children. Understanding late-deafness requires a short detour through some of this information. Some people develop an infectious disease like spinal meningitis, or are given medications for a severe illness and end up deaf as a side-effect of that medicine, or develop Menière’s syndrome. A large number are dismissed with the explanation that their deafness was caused by “a virus.” (Doctors don’t seem to realize how meaningful it is to be able to have a reason for something as important as deafness. Because this virus is never given a name, we call it “The Virus,” to mock the doctors.) We call these ‘medical’ causes of deafness. Medical hearing losses may occur overnight, or progressively (often over five or ten years). The person may have more residual hearing than some people who have functioned as hard-of-hearing from childhood, but the shock of the unexpected hearing loss makes them unable to function with lipreading and assistive listening devices that experienced hard of hearing people can use.

Other adults develop tumours on the auditory nerves as part of the disease...
neurofibromatosis type 2. Removal of the NF-2 tumours on both auditory nerves causes absolute deafness. We call these 'surgical' causes. These people have no residual hearing at all. They also may have ongoing complications of the neurofibromatosis. Surgical deafness occurs instantly, and the person often knows going into the hospital that he or she will be deaf coming home.

'Traumatic' hearing losses are sustained in a variety of adventurous ways: motorcycle collisions, a rumble in the alley behind a bar, fall from a ladder, and so forth. These losses are typically sudden. Like a medical hearing loss, the person may be recovering from other physical problems when the deafness begins.

The final group consists of people with 'progressive' hearing loss. If hard of hearing Granny lives long enough, she may fall in this category. However, many people with progressive deafness appear to have hereditary reasons for their deafness. Some have deaf relatives, making the genetic connection obvious. Others exhibit common timelines: hard of hearing in high school, no longer able to use the telephone in the young 20s, a declining awareness of vowels and environmental sounds by the 30s. The ability to exploit the residual hearing at any age varies, resulting in a range of ages when these people begin to consider themselves 'deaf.' Some are exposed to a combined deaf and hard of hearing school as students, and have the opportunity to become functional deaf people while relatively young. Others are pressured by family and friends "not to give up" and only begin to question the value of this daily struggle in their 70s.

A 1984 National Association of Deafened People (NADP) survey of over 100 people indicated that 13.4% were deafened from congenital/familial causes, 57.7% from medical and surgical causes, and 3.9% from accidents (Heath, 1987). Among 348 responses from members of the Association of Late-Deafened Adults (ALDA), 41.5% reported experiencing progressive losses including the apparently hereditary, 40.5% had medical losses, 12.8% had surgical losses, and 5.2% became deaf as a result of traumatic injury (Boone & Scherich, 1995).

Where deafened and Deaf meet

Many deafened people are introduced individually to their local deaf communities. The success of this varies widely. Acquisition of signing skills does not occur as rapidly as most hearing loss, leaving the deafened person with a gap between need and ability. In communities where Deaf people shun or ridicule those who sign poorly or didn’t attend the right deaf residential school, deafened people experience rejection. If those who sign poorly are discouraged from going places where their sign skills can improve, then many late-deafened people will continue to exhibit a conspicuous struggle with sign language. This leads to the claim that late-deafened people do not learn to sign. After rejection by the local deaf community, or perhaps warned off it by doctor, audiologist, or counselor, those people may look for support in hard of hearing groups such as Self Help for Hard of Hearing People (SHHH). Others are warned that learning sign language will prevent them from keeping jobs or friends in the hearing world (the logic of which is a little weak).

Those who learn sign language skills more readily can immerse themselves fully with Deaf culture and hope to pass for Deaf. It is not the place of this article to “out” anyone, but many recent and current Deaf leaders were also deafened later than early childhood, remember the auditory world, and benefit from their years spent familiarizing themselves with Hearing customs and values. Only recently have some deafened people begun to admit that they had previously been hearing, and even enjoyed music, although they accepted sign language as their adopted language and considered themselves deaf. The rejection of those not-Deaf-enough has extended to late-deafened Gallaudet President L. King Jordan, whose joyous appointment was soon followed by complaints that a born-deaf president should have been selected. However, this discrimination appears to apply only to living deafened people. Many people held out as distinguished historical deaf figures were in fact late-deafened, including Edison and Beethoven. Of the first 23 presidents of the National Association of the Deaf (NAD), 12 were deafened at age 10 or later (Gannon, 1981). Three were deafened at age 15, 16 and 18.

Other than those who felt rejected, many deafened people felt unsatisfied with the type of support they received when they joined deaf or hard of hearing groups. Many felt that deaf people did not allow them to value both the Deaf culture and the Hearing culture and expected an all-or-nothing decision. Joining hard of hearing groups was no solution. Many deafened adults found that hard of hearing people could not understand why amplification, loops, T-switches, and other assistive listening devices would not be as helpful for the deafened person as it was for themselves. Neither deaf or hard of hearing group, they felt, really understood the impact of the change from being hearing (or hard of hearing) to being deaf, and the demands created on the person, the family, the work situation. At various times, in various places, deafened people have said “we need a group for people like us.”

In 1983, Jackie Metzger, Joe Weber and Johni Shields circulated a 15-page survey that yielded 100 late-deafened
responses and a workshop at ADARA (American Deafness and Rehabilitation Association), but regrettably the national association of which they dreamed did not materialize at that time (Shiels, personal communication).

The National Association of Deafened People (U.K.) was founded in 1984. NADP members had been a segment of the British League for the Hard of Hearing and Deafened (Heath, 1987). It is a sign of the age of such a group when one must lament the loss of its records, destroyed when the headquarters was bombed in the war! However, Heath cited a source ("The saga of the ear-handicapped," Randle, 1954) referring to recognition of deafened adults back to 1923.

Deafened social worker Michel David started a Deafened Adult Support Group at the Canadian Hearing Society head office in Toronto in 1986. This group was the seed of the Canadian Deafened Persons Association, named in 1990, and the group continues to meet. Many members also belong to the Association of Late-Deafened Adults.

ALDA: The Association of Late-Deafened Adults

A support group for deafened adults that had been meeting at Ravenswood Hospital in Chicago suspended operations in the spring of 1986, leaving behind a craving for community. ALDA is considered "founded" on the occasion of the resulting party of support group members and other late-deafened "strangers" on March 28, 1987 at the home of Bill Graham. Thirteen deafened people are recorded as having attended. Even the association’s name has small-scale beginnings: ALDA: The Association of Late-Deafened Adults was chosen from among 14 suggestions by the 21 "eligible" voters in 1987. The name has been criticized for various reasons: "late" also means tardy and deceased, it’s frequently sign-interpreted wrong (no, it isn’t signed NOT-YET DEAF.) People think it refers only to people in late-adulthood (i.e. old) or is limited to those who are adults already. ALDA first defined its target membership as those who cannot hold regular conversations on an ordinary phone and typically felt in limbo among both deaf and hearing groups. Currently, the principle of self-identification governs. If you consider yourself deafened (or "late-deafened") you are. There are people who consider themselves late-deafened who became deaf in the pre-school years. Yet the combination of their early hearing memories plus a hearing-culture education, perhaps, gives them a sense of not being fully ‘of’ one of the other groups.

With the privilege of authorship, I will describe (rather than define) the deafened person as a person who was formerly hearing or hard of hearing then either suddenly or gradually became deaf at any time after early childhood. A deafened person from the ALDA point of view includes those who are currently experiencing progressive hearing loss that is expected to continue to deafness. Although Late-Deafened Adults is a sometimes misunderstood term, the acronym ALDAs is frequently and affectionately used to refer to members of the group, and this has hitherto prevailed against serious campaigns for renaming the association along the lines of the other "deafened persons associations" that have formed elsewhere before and since ALDA formed.

By the way, the generally accepted way to sign "deafened" is to point to the ears then draw the A-hands down wiggling at the wrists (HEAR-DETERIORATE).

Rapid Growth

ALDA was for many years very much a Chicago club. Its culture was founded in parties hosted and attended by a couple dozen people from in and around Chicago. Its main sources of financial and in-kind support were in Illinois. A large proportion of the names on the ALDA mailing list were in Chicago. The early newsletters had the character of play-by-play complete with color commentary: who was first to arrive, who brought what beverage, and who was last to be ushered out the door. As ALDAs became more numerous, this was obviously too much to sustain.

Awareness of ALDA grew through deliberate efforts such as a letter to scientists and engineers with disabilities, and representation at NAD conventions and the Deaf Way. The mailing list at the one-year point was approximately 100 names. It doubled in seven months, and doubled again in seven more. ALDA added over a thousand more names over the next two years; however many were professionals or service businesses who never became paying members. The lack of distinction between ‘mailing list’ and ‘membership roll’ as well as an early decision not to distinguish membership privileges between deafened people and anyone else who supported the interests of deafened people became a hindrance to determining how well ALDA had reached deafened people, and in 1992, ALDA began attempting to sort out who was who among the names, by then exceeding 2,000.

Organized chapters arose, as did groups not yet petitioning to be recognized as formal chapters, and some lapsed again into inactivity. Groups in Canada also became associated with ALDA and overseas contacts remained steady. Each group has its own flavor, whether oriented towards education, or self-help, or parties, or

A Deaf American Monograph, 1996
even political intrigue, just as the different regions they exist in have distinct cultures.

ALDA went through the same transition most young organizations experience, when entrepreneurial serendipity and governance rooted in personal relationships are no longer feasible, and more formalized systems replace them. As ALDA grew to span a continent and reach around the globe, the early majority of members who knew their Board became a minority. At this stage in any organization’s life, the desire of veterans to preserve the exhilarating early days and respect traditions conflicts with the desire of newcomers to be included in the process and try new things. Through the mid-1990s, ALDA has been working to redefine its governance, a task made difficult by the economic environment and lack of paid staff.

ALDA Mission and Principles

Perhaps logically, because it began as a self-help group, ALDA’s predominant mission has been to serve as a support group for deafened people. Rather than functioning as a clearing-house for professional advice (or even peer-to-peer advice), ALDA has aimed to provide a safe environment where deafened people could find support and role models among other deafened people and ultimately make their own decisions about how to cope with deafness. ALDA has weathered its controversies about how these principles are put into operation. Getting “through a day, deafly,” is achievement enough for role-model status, but the prestigious roles within ALDA are particularly important. Relying on deafened people to fill these positions has been an achievement and a symbol to all ALDAnS that our embrace of interpreters, court reporters, professionals, and our families does not require us to surrender our independence and self-determination.

The average member sees two consistent things that we think differentiate ALDA from many other groups. First, ALDA discourages advising. A person is certainly free to obtain advice from hearing professionals, deaf professionals, the butcher, the baker, and the candlestick maker, but decisions are the individual’s right and responsibility. A ‘good’ ALDA will not give advice but will share their experiences with various coping approaches, and how they feel about them. We try to remember that we have deafness in common but many things may differ between us and need to be taken into account when making important decisions. Sometimes individuals feel so strongly about the choices they have made that it’s difficult not to recommend, but few principles are as fundamental in ALDA as this one.

A second fundamental principle is ALDA’s official communication policy: “whatever works.” If that entails standing on your head and blinking in Morse code, then we try to work with that. Pencil and paper, keyboards, cochlear implants, fluent sign language, lousy finger spelling, lipreading, and a great deal of laughing are all observable at ALDA gatherings. People who have been convinced that their signing skills are awful discover that they can communicate just fine with people who want to communicate.

Because deafened peoples’ needs are so poorly understood, ALDA also is thrust into the position of providing education and advocacy. However, advocacy activities and the development of materials for education have been problematic. ALDA’s membership has vigorously endorsed democratic, even populist, principles. However, with almost no source of funding on the national and international level, ALDA’s economy is essentially plutocratic. External representation has had to be carried out mainly by those who can underwrite their own time and expenses on ALDA’s behalf, or whose jobs or location of residence permit them to attend events, meetings, conferences, or hearings. Overall, ALDA has been blessed with generous, talented, effective volunteers who have made this obstacle invisible to the average late-deafened person. There isn’t one of those burned-out souls who doesn’t dream of a funded staff, toll-free lines, printed matter, and other association infrastructure, to make it possible to reach out and connect with the vast number of isolated deafened people.

ALDA News

The young ALDA thrived by publishing a newsletter that focused on the everyday deafened experiences—including the tedious, the frustrating, the demoralizing—and laughing at them. Bill Graham’s easy-going “southwest Chicagoan” sense of humour took the edge off the uneasiness of being deafened for the readers and his honesty created a sense of quid pro quo that liberated people to share their feelings in writing. Bill shamelessly quoted these deepest revelations in subsequent newsletters, forging a kinship among these increasingly far-flung deafened people who had never yet felt ‘at home’ in any established hard of hearing or deaf group. Although Bill had curtailed his writing by 1990, he retained his status in ALDA folklore as a ‘cult figure’ (Lovley, 1992). Dozens of other ALDAnS ably took up the task, however, and ALDA continues to cherish the written word, frank personal sharing, and humour.
An informal but increasingly formalized editorial policy was insistent on not recommending any particular approach to dealing with deafness. Considerable rancor arose from time to time over the refusal of articles advocating cochlear implants, hearing dogs, and lipreading. However, ALDA News has continued to emphasize personal experiences and feelings, leaving the decisions about the ‘best’ approach to the readers. Popular continuing features include the ALDAnonymous question, in which anonymous readers respond to a question posed by a fellow member in an earlier issue, such as “how do you handle family functions?” and “do you tell sales clerks that you are deaf?”

Responses to ALDA News pour in. After receiving a sample copy, people who may have for years believed themselves to be the only deafened person in the world are moved to write the most exquisitely personal revelations “to whom it may concern” at the ALDA post office box.

ALDAcon

ALDA held the first ALDA leadership workshop in October 1989. This was the event that later became known as ALDAcon. (The workshop was free to ALDA members, but those who did not attend were asked to send money. Now there’s an innovative idea for getting attendance up!) It was attended by 42 people, from all over the USA and Canada.

Of 42 ALDAcon people, 30 returned to ALDAcon II, along with over two hundred newcomers. ALDAcon has since been held in Boston, Toronto, and Rockford, Illinois, and at press time plans are underway for ALDAcon 1996 in San Francisco. A feature of every convention to date has been the self-help leadership training conducted by Laurieann Chutis, LCSW. Laurieann’s method is a vital part of ALDA’s belief system that there is no single way to cope with deafness, that each of us will help ourselves, as and when we are ready. Trained ALDA group leaders acquire the skill to lead a group through sharing of feelings and experiences and avoiding advising. Attending the training at ALDAcon enables those participants to go back to their hometown and lead a group if they choose.

ALDAcon workshops range from self-help sessions running throughout the convention, sessions on using the relay service, sign language basic training, cochlear implants, and other deafness related topics, through to lifestyle topics inaccessible to deafies in the typical hometown, from ballroom dancing to Tai Chi. Relationship topics are always popular as many deafened people struggle to redefine relationships with hearing partners, work colleagues, and their family of origin, and families are encouraged to attend the conference. Many workshops in recent years have featured a panel of deafened people, discussing how they have dealt with a particular challenge, whether it be addiction or parenthood.

In addition to the self-help training, several ALDAcon traditions have already taken root. The buddy program ensures that newcomers can always count on someone to help them break the ice and feel at home. The karaoke soiree provides the opportunity to screech off-key many fondly remembered tunes, some of which have become ALDA anthems (“Jeremiah was a bullfrog/He was a good friend of mine/I never understood a single word he said...”). The Sunday branch is a perfect excuse to take the stay-Saturday saver airfare and also avoid cluttering the ALDA banquet evening with awards presentations. Meals are an important part of the ALDAcon program because so much of the candid sharing, bonding, and learning takes place while trying to figure out whether the waiter is offering coffee or tea “and by the way how do you communicate when people have foreign accents?”

Based on years of feedback, ALDAcon is the single most enlightening and important experience for any individual who becomes deaf. ALDAcon veterans go to participate in panels and presentations and renew friendships, but ALDAcon newcomers have reported that the experience has been a life-altering experience.

Access

With very few exceptions, even those deafened people who go on to acquire fluent sign language skills and prefer interpreters over other access media begin the deaf portion of their lives as non-signing people who require access to communication. The solution is found in the printed word.

At the first support group under the ALDA communication was facilitated by a typewriter and four carbons, with pauses to pass around the copies and let everyone catch up. Steve Wilhelm began tinkering with a TRS-80 computer to develop “ALDA Crude,” which consisted of exploiting a sign language interpreter’s well-honed ability to ‘listen fast’ and type as best they can, allowing all participants of the self-help group to read the discussion on the computer display.

ALDA began a partnership with NCRA (National Court Reporters Association) in 1989. It seems good ideas are universal: the use of Palantype (British court reporting) to

A Deaf American Monograph, 1996

159
provide access was reported in 1987 (Heath, 1987). NCRA now offers certification in real-time reporting which is a special skill required by television captioning and real-time reporting at meetings. Many court reporters offer services to self-help meetings on a pro bono basis, while real-time reporting is now considered an access service under the Americans with Disabilities Act.

Summary

ALDA's rationale is clear: deafened adults are different from Deaf and hard of hearing people because a significant part of their identity entails the transition to deafness. ALDA's history is still in formation. In less than a decade, it has made a mark on the deaf community landscape. Despite the exhilaration of its early explosion and the enthusiastic "where have you been all my life" reception individuals have given to it, its highlights lie ahead.

References


Shiels, personal communication.

Persistence

Follow your dreams, for even when they seem impossible, they chart life's destiny; and surely one will grow and blossom into reality.

I do not have the strength of Hercules, but I have learned that following a dream with time and patience, one can move a mountain, stone by stone.

—Robert J. Smithdas
(Deaf-blind poet)