

Politics of Deafness: The Role of and Agenda for Advocacy Groups



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The National Association of the Deaf (NAD) is the oldest advocacy organization of, for and by Deaf people in the United States and possibly in the world. The NAD was established in 1880, the same year as the passage of the infamous resolution against sign language by the International Congress on Education of the Deaf in Milan, Italy. Since its inception, the NAD has served as a national leader and crusader for rights of Deaf people and global Deaf awareness. Some of its accomplishments have included lobbying for basic rights and entitlements: to drive vehicles, to marry other Deaf people, to adopt children, to insurance, and to jobs and promotions. Advocacy methodologies have ranged from publishing factual, research-based articles and books, lecturing, training, lobbying, litigating to coalition-building. Deaf people themselves determine the agenda, at conventions of the NAD, and become involved in the implementation of the strategies.

The last three decades have marked significant progress for Deaf people. In the 1960s, with the advent of the TDD/modem, Deaf people could finally participate in distance communications, but still needed to wait another twenty five years before relay services became realities in some states. The 1960s also witnessed the birth of the Registry of Interpreters for the Deaf, which elevated interpreting into a profession requiring training, certification and a code of eth-

ics and standards. However, appropriateness, quality and consumer rights still remain critical issues today. The 60s was also a decade remembered for the civil rights for minorities and women and the consumer rights movement in the United States, which, although not yet quite applicable to Deaf people, became building blocks for future legislative action and new mind-sets.

The 1970s brought us closed captioned television programs, making it possible for Deaf people for the first time to receive news, information and entertainment at the same time as their hearing family members, neighbors and peers. This was also the decade that sign language came out of the closet and went public, as did the term "total communication" affirming the Deaf child's right to understand, to be understood, and to participate in the dynamics of the situation, whether it be at home, in school or on the playground, and whatever the methodologies may be. This new philosophy opened many homes and classroom doors to the use of natural, visual, manual communication, American Sign Language and also to the proliferation of manual communication systems. In 1977 P.L. 94-142, now known as the Individuals with Disabilities Education Act, became effective, introducing the "least restrictive environment" concept which was often misinterpreted as the mandate for each local school district to include, in mainstream

fashion, all eligible students with disabilities in regular public schools. A year later, the regulations and amendments for the Vocational Rehabilitation Act of 1973 became effective, which prohibited discrimination, on the basis of disability, in education, employment and services.

The benchmarks of these two decades formed the cornerstones of human rights, dignity and empowerment for Deaf people. Deaf people became more involved in determining their own lives or programs for their own people. Service agencies with the "of, for and by Deaf people" philosophies, such as the GLAD and DCARA in California were born in this era, to lead local efforts at self-determination and self-help and to collaborate, in network fashion, with the state associations of the Deaf and other organizations.

This is in a nutshell the emergence of Deaf Rights, although it does not mean that by magic, equality and human rights became part and parcel of the lives of all Deaf Americans. There were and are still many barriers, the foremost being attitudinal. Example: doctors still give parents the impression that deafness is a tragedy and that it might be fixed with a cochlear implant or perhaps at the least, it might be made to go away by practicing hearing and speaking like normal folks. Example: some people equate speech with intelligence and therefore a better life quality. Example: some believe that phonetics must be learned before one can master language and literacy. Example: some believe that signs will hurt speech and that ASL will hurt English. Example: some believe that the goal in life should be to blend in with society (and the woodwork) as much as possible. And that going to public schools was a mark of normalcy whereas going to special schools indicated deviation and inferiority. Example: some cannot believe that hearing is actually not essential for 99% of the kinds of jobs. Example: Deaf persons or professionals are not generally encouraged to work with Deaf toddlers or their families or in mainstream schools. Example: some did not believe that a Deaf person could be president of Gallaudet University. And the saddest truth of it all, these examples are not just limited to non-deaf people. Deaf people, victims of the years of oppression from the cradle onwards, become their own perpetrators of suppression and deaf-defeatism.

Little did the Board of Trustees of Gallaudet University dream that they would change the course of history and redefine human rights when they initially chose a non-deaf president in 1988! Gallaudet became the center of the universe for that one week as the world watched, became engulfed by, and became active supporters of

the Deaf community in its quest for validation and self-governance. That week everyone, Deaf and non-deaf, became believers of the can-do mindset. The cause was supported by Deaf people, hearing Gallaudet employees, families with Deaf members, people with disabilities, people of color, the media and the Congress! Through unity, there was power. The result was a forever altered perception of deafness and people with disabilities. This crystallized into a launching pad for the successful passage of the Americans with Disabilities Act of 1990, a sweeping civil rights act that encompassed and enabled all life functions in the public and private sectors.

The trickle down effect to the Everyman was a new image which was more positive and made nearer a universal truth. First, as President King Jordan extols, "Deaf people can do anything but hear!" Second, there emerged positive Deaf role models serving as beacons of light and hope for thousands of people, both Deaf and non-deaf. Young Deaf children were made inspired, proud, and motivated to emulate successful Deaf people in all walks of life. Parents were exposed to successful Deaf role models perhaps for the first time in their lives. Professionals and employees became interested in supporting and empowering Deaf people. That one week in the media spotlight was transformed into a synergy of ripple effects. We still need to effect lasting change in the way Deaf people are educated and served.

However, the picture is not rosy. Thus, the goal for the NAD would be to put itself out of business, after advocating for and achieving a world-level perception where being Deaf and different really makes no difference in everyday life.

This brings us to today's Deaf people and the national agenda for the NAD and us all. Shifting paradigms and altering mindsets are the number one priority for us. Specifically, this means changing permanently from old to new perceptions and attitudes:

1. Paternalism to Partnerships:

Changing from doing things *for* or *to* Deaf people to *with* or *under* Deaf people. I once was at a major airport that advertised full accessibility for passengers with disabilities. Out of curiosity, I checked its brochure describing services, specifically the part regarding Deaf travelers, and this is what it said: "Deaf passengers should go to the nearest red telephone and call for a TDD." Obviously the brochure and strategies were developed without involvement of Deaf people by well-meaning but ill-advised

administrators, resulting in inappropriate strategies. As the saying goes "you must walk a mile in another person's shoes before you can understand what it means for that person." Only Deaf persons understand what it means to be Deaf. Deaf people must lead and non-deaf persons need to become supporters and partners for mutually desirable goals.

2. Pathological to Humanistic Approaches:

Changing from medical viewpoints of deafness as a deviation to be fixed to humanistic viewpoints of deafness as one of many human attributes to be fitted in: In other words, it's Dandy to be Deaf! This is one of the reasons why the NAD, along with the World Federation of the Deaf, took a stand against cochlear implants for children too young to make their own decisions, in order that parents can move past grieving, false hopes and denial of deafness to the business of living and loving.

3. Homogenized Society to Cultural Diversity:

Changing from a "one size fits all" mentality or trying to emulate the great American WASP male mold to a cherishing of human differences including variations in ethnicities, races, genders, religions, and many other human differences, including hearing and not hearing.

4. Monolingualism to Bilingualism and Trilingualism:

In many countries, natives are encouraged to know at least two languages, but in the United States, the English language rules supreme. However, there is increasing awareness and acceptance of the legitimacy of native or natural languages in the United States. For Deaf people, bilingualism means American Sign Language and English. Moreover, the true language of signs is one that conforms to visual and linguistic principles appropriate for a three-dimensional (3-D) language, which facilitates natural and comfortable communication for visually-dependent persons. Trilingualism occurs when there are deaf people born to non-English speaking families. Deaf Studies must also be available and infused.

5. Access to Quality:

Access is the law, but Quality still remains an elusive factor. We must move from simplistic access to meaningful quality. It is not enough to have access if one still cannot participate due to the insufficient quality of the access. Quality standards for education must be developed by and with Deaf people. Interpreters need to meet standards determined by Deaf consumers. Communications and safety light systems need to be designed with Deaf people to ensure appropriateness for Deaf people. Programs must meet standards which surpass minimal expectations and thus enable more than just marginal participation. If one cannot access or benefit from programs, he or she might as well stay home.

6. Dependence to Independence:

90% of Deaf children are born to hearing families. The 10% born to Deaf families often become models of excellence in education, communications, leadership and society in general. The challenge, then, is to identify the factors producing a positive self-esteem, educational excellence, affective well-being, and environmental enhancers in all-Deaf families and to transplant these factors into non-deaf families with Deaf child(ren). In addition to more immediate acceptance of deafness, the other factors are high expectations, full and visual communications, and a barrier-free home where Deaf children are privvy to full information and a greater degree of independence. These deaf-friendly homes have a full barrage of assistive technological devices such as TDDs, TV decoders, flashing or vibrating alarm clocks, and flashing light signals for doorbells and phones. Deaf children are also included in discussions during family meals and their opinions are valued on a number of issues.

7. Can't to Can:

Deaf people can do anything! They can be doctors, automobile mechanics, computer programmers, dentists, engineers, construction supervisors, plumbers, administrators, lawyers, and so on..!

Guided by these principles, the major social reforms the NAD and Deaf community seek include:

1. **Early identification** of deafness and appropriate intervention measures, including early involvement of signing Deaf adult professionals with families with Deaf infants. Information for parents must be from the Deaf viewpoint and must include the obvious fact that the deaf child will always be a visually-oriented being.

2. **Full communication access and quality**, as defined by the deaf consumer. We believe that professionals harm instead of help Deaf children when they give parents information on all methodologies without statistics and without involvement of Deaf adults. We do not support giving parents choices without that information and involvement. Parents will naturally want their Deaf child to be as much like themselves as possible and thus struggle with oralism before discovering the fact that their child is DEAF. We believe in telling parents to give their child both sign language and speech -- in short, everything. Research has shown that sign language does not harm oral skills. To the contrary, Deaf children of Deaf parents often demonstrate superior skills in both the native language of signs and the spoken language.

In education, the workplace or the community is vital to ensure that the Deaf person involved in meetings or programs receives the quality communication support service, as determined by the consumer him/herself.

3. **Bill of educational rights**, including the right to be in a fully enabling environment. In line with the national goals of regular education, Deaf children should also be able to enter school ready to learn and to attain skills to graduate from school on grade level. Deaf children of Deaf parents usually start school ready to learn. Deaf children of non-deaf parents must have the same right. Moreover, hearing children expect to go to school where they can understand and be understood by the other children and adults there. This means limiting options to only those schools which can provide a fully enabling environment with peers and adults who can communicate comfortably, fluently and masterfully. This means creating or continuing with magnet schools. This also means having both deaf and non-deaf teachers and administrators who have fluent communication skills and knowledge about Deaf people.

4. **Bilingualism and biculturalism** need to become the birthright of each deaf child. Families need to understand that the visual dependency of their child mandates visually clear communication and an understanding of one's essence and identity, in order to become fortified enough to bridge languages and cultures, rather than to be doomed a twilight child without a solid language, culture or identity. Knowing both American Sign Language and English, understanding both the Deaf and non-deaf cultures is empowering.

5. **Employment** is an essential life function contributing to one's sense of self-worth. It becomes imperative that Deaf people not only become gainfully employed but also choose their vocation based on their interests and abilities. By law, vocations may be altered in order to accommodate individuals with disabilities. Therefore, a broad career education is essential not only for Deaf students but also career counselors, families and employers in order for them to become enhancers.

6. **Community life** for Deaf people needs to be no different from those for non-deaf people. In short, community services and features such as libraries, museums, theaters, welfare and health services, transportation, housing, and suchlike, need to be both accessible and appropriate for Deaf people. Deaf people must be both informed and involved in determining the standards for accessibility and quality.

7. And finally **Empowerment**, which means full involvement and leadership for Deaf people. For example, if a school, whether special or mainstreamed, has a significant number of Deaf students, does its board include provision for a number of appointed Deaf adults representing the interests of the Deaf students there? If a new program in the company or community is being planned, are Deaf leaders part of the planning team? If it is a program basically for Deaf people, do Deaf people constitute a majority of the planning team or Board, or are they just tokens? If a new policy or law is being considered, are Deaf people consulted? Empowered Deaf people also means empowered parents and professionals who feel successful and positive in their roles as partner-advocates for positive respect, identity and abilities of Deaf people!

In the United States, the recognition of the right to be different and to assemble with one's kind has led to the establishment of many different groups within the Deaf community. The Deaf community itself has a wide variety of organizations to choose from which relate to interests ranging from sports to religion. There are also smaller consumer organizations, related to ethnicities, races, degree and age of onset of deafness: Black Deaf Advocates, National Association of Deaf Hispanics, Self-Help for the Hard of Hearing People, Association of Late Deafened Adults, Oral Deaf Adults Section of the Alexander Graham Bell, and Cochlear Implant Club International.

In addition to this network are the organizations of the service providers: Telecommunications for the Deaf, Inc, Conference of Educational Administrators Serving the Deaf, Convention of American Instructors of the Deaf, American Deafness and Rehabilitation Association, Registry of Interpreters for the Deaf, and the family-based organization supported by the NAD, American Society of Deaf Children. As a sidenote, I want to quote the late Fred Schreiber, "Deaf People and Parents are natural allies. We are your children fully grown! We have mutual goals."

The NAD has supported and provided assistance to Council of Organizational Representatives (COR), which is an informal organization of representatives of these and other related organizations, which meet once monthly to share information, legislative issues and periodically to come together to support mutual goals. However all but two of the representatives on the COR are hearing and represent non-consumer organizations.

The NAD is also starting up a separate coalition of affiliates composed of organizations which are themselves of, for and by Deaf people, in order to gain a broader base of representation of Deaf America. This idea was enacted at the 1990 NAD convention and will require a bit of time before it becomes fully operational as a consumer-driven entity seeking social and political action. One illustration of why this is needed is in the recent COR action, lending support to minimal requirements for the ADA section on Telecommunications, such as 35 word per minute typing skill of telephone relay operators. The NAD dissented, sending in its own version of

comments to the COR and the Federal Government, insisting on quality standards including at least 60 wpm. The outcome was the adoption of a final standard of 60 wpm within two years, assuring satisfactory agent performance expectations for Deaf and hearing consumers. We, the Deaf people of America, believe that Deaf consumers should be in the forefront of political changes and standards that translate back to everyday impacts for Deaf people. We need and welcome non-deaf partners and non-deaf allies, but it is essential that services for, by and of Deaf people be defined by, of and with Deaf people. To do otherwise is a travesty of human rights and a mockery of the self-determination rights inherent in each and every human being.

Where do we go from here? Join with us, walk beside us, and be our partners towards a more progressive future where each person is accepted for him/herself rather than in spite of him/herself.

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