Abstract

This article will try to address the reasons that the messages brought by massive HIV/AIDS prevention campaigns in several countries literally fell on deaf ears within the Deaf community, and how this in turn made it possible for Deaf people’s health and human rights to be violated. Then it will show how the Deaf community has gradually geared up to protect itself against the spread of the HIV virus. Attention is given to the importance and meaning of “effective communication” and the role of Sign Language interpreters. Finally, recommendations are offered towards better protection of Deaf people’s health and human rights.

Cet article tentera de montrer pourquoi les messages lancés par les massives campagnes de prévention contre le VIH/SIDA dans plusieurs pays sont littéralement restés inaudibles pour les Malentendants et comment cela a conduit à une atteinte à leur santé et aux droits de la personne. Il montrera ensuite comment la communauté des Malentendants s’est progressivement prémunie contre l’expansion du VIH. L’attention est portée sur l’importance et la signification de la communication efficace et sur le rôle joué par les interprètes en Langage des Signes. Enfin, des recommandations sont proposées pour une meilleure protection de la santé et des droits de la personne parmi les Malentendants.

Este artículo trata sobre las razones por las que los mensajes que se difunden en las campañas de masas sobre el VIH/SIDA caen en oídos sordos entre la comunidad de sordos/as, de muchos países, y cómo esto a su vez viola la salud y los derechos humanos de las personas sordas. Más adelante el artículo muestra cómo la comunidad de sordos/as se ha preparado para protegerse de la propagación del VIH. Se presta atención a la importancia y al significado de la “comunicación eficaz” y al rol de los/as intérpretes del lenguaje por señas. Al final se ofrecen recomendaciones para una mejor protección de la salud y de los derechos humanos de las personas sordas.
AIDS, NOT HEARING AIDS: Exploring the Link Between the Deaf Community and HIV/AIDS

Helga Stevens

Deaf people face many barriers in communication and it is difficult to find HIV/AIDS information and projects that respect and are adapted to our language needs. By language, we mean not only Sign Language, but also how our methods of communication reflect our community's culture and how we relate to each other. We have to adapt ourselves to a world which is often unwilling to understand and accept differences.1

Anne Scully, a lecturer in law at Brunel University, rightly wrote that AIDS and its relationship to human rights protection should be viewed as a complex web of fear and prejudice.2 In addition to dealing with fear and prejudice, Deaf people must face an additional obstacle: conventional society's rejection of any departure from perceived normality. This exposes Deaf people in the context of HIV/AIDS to multiple discrimination.3,4

Thus, we see once again that an important feature of discrimination is that it is cumulative: one person may be victimized by discrimination on many different grounds. The fact that discrimination is a multilayered phenomenon makes the application of human rights guarantees difficult: once a layer of discrimination has been peeled off, another appears below.5

In other words, discrimination is still abundant in many forms, even though it is prohibited under most every human rights instrument.6 The 1989 Convention on the Rights of the Child, the United Nations human rights treaty with the
largest number of ratifications, is the only human rights treaty to make specific mention of disability in its nondiscrimination provisions. The fact that nondiscrimination provisions in most human rights documents do not specifically refer to disability reflects the historical ignorance of the drafters. Disability discrimination is as unacceptable as other forms of adverse treatment of people on the basis of individual qualities or group attributes.

In this context it should be noted that the human rights of Deaf people appear to be given less protection than those of people with other disabilities, as the United Nations Special Rapporteur on Disability, Bengt Lindqvist, pointed out to the World Federation of the Deaf (WFD) in May 1997. A good illustration of the fact that Deaf people always tend to fall in between two chairs is that, on the one side, they are not regarded as "disabled" enough to be assigned special attention. On the other side, the nature of their disability—deafness—is all too often not understood at all. But the fact is that our society is dominated by "normally" hearing and speaking people, so Deaf people are disabled—it is probably more correct to write "handicapped"—in an area that constitutes one of the basic abilities and rights of every human being: communication. Of course, deafness implies more than just a communication limitation in our communication and information society, but in essence for many Deaf people it just boils down to that. For them, the use of Sign Language is one way to circumvent their communication limitation. However, society is generally not fluent in this mode of communication; therefore, Deaf people may need the intermediary services of a Sign Language interpreter to enter into communication with the society they live in.

Now, with this in mind, this article will further describe the complex relationship between Deaf persons and AIDS/HIV matters, as seen from two angles: prevention and treatment. The reader will see that there is a razor-thin line between respect for and violation of the health and human rights of Deaf people. In addition to issues specific to HIV/AIDS, the needs and concerns of Deaf people are frequently not understood and consequently not respected. There are signs of improvement or awakening but these are few and far between. This article mainly concentrates upon Europe, but it
also draws upon useful knowledge gained from Australia. In conclusion, recommendations are made towards better protection of the health and human rights of Deaf people.

**HIV/AIDS and Deaf People: 1997 Figures**

Because many government bodies, such as the Paris Department of Social, Child and Health Affairs (DASES), did not judge it necessary for Deaf people to receive information on HIV/AIDS specifically designed for them, nowadays many Deaf people find themselves HIV-positive, ill, or dead of AIDS: recent statistics indicate that 26,000 Deaf persons, including 200 Deaf children, are HIV positive. In addition, more than 500 Deaf individuals have already died of AIDS.

**Deaf People’s Right to Health**

The Declaration of Alma Ata (1978) calls for equity in primary health care for all members of society. Unfortunately, in many countries, Deaf people are frequently denied full and equal access to health care, which often not only amounts to a violation of their right to health but also implies a violation of their right to life. The latter human right has been considered binding for all States by virtue of customary international law.

Deaf people’s right to health with regard to HIV/AIDS issues is inter alia related to full and equal access to information. For Deaf people, the main risk factor for HIV infection is not, in the first instance, their sexual behavior, nor the availability of condoms, but the lack of access to information. Deaf people face an information gap at the prevention stage, in that one needs proper information in order to know how to avoid infection. At the treatment stage, the right to full and equal information is an important part of the Deaf person’s right to health which includes inter alia the right (of access) to health care (in order to know the status of one’s case and also to make informed decisions, the Deaf patient needs to be well informed as well).

The above mentioned aspects of Deaf people’s right to health are frequently ignored, i.e., violated. It should be noted that violations connected to lack of access to information are not limited to HIV/AIDS issues, but extend to many of the issues impacting on the health of deaf people.
Why Did Early HIV/AIDS Prevention Campaigns Fall on Deaf Ears Within the Deaf Community?

There are many reasons and factors why the Deaf community has remained largely uninformed about HIV/AIDS risks. Deaf people generally have limited access to mainstream mass-information systems, such as newspapers, magazines, television, commercials and advertisements. Moreover, Deaf people generally are discriminated against within the health care system, due to poor communication and cultural insensitivity. Furthermore, Deaf people are hard to target, since they do not form a homogenous group. These three main factors are explained in greater depth below.

For people who are deaf, i.e. have a hearing impairment, the nature of their disability limits the sources of information that are easily accessible to other [hearing] people. Nevertheless, Deaf people also have a right to information, especially when it can have a direct bearing on their future well-being. However,

\[W\]ithout provision of specially adapted services to meet the specific communication and information needs of deaf people, this group becomes isolated.\textsuperscript{14}

It is therefore particularly important for Deaf people to have access to accurate, current, meaningful information. Nevertheless, their right to information has been and continues to be ignored.

Information, via public service announcements and pamphlets, is targeted at the general population who can hear and read a spoken language such as Dutch, French, or English. However, many Deaf people have difficulty understanding a spoken language and may not read well because it is essentially their second language. Their primary language is Sign Language, a visual language. It is easy to understand how this lack of [access to] spoken and written information contributes to an ignorance of the elementary knowledge that hearing people possess. This unwittingly exacerbates the risk behavior of Deaf people, and in turn increases their vulnerability to HIV/AIDS. Articles and advertisements in newspapers and magazines too are difficult to understand because
they contain ambiguous messages and thus are not straightforward enough for Deaf people. Televised HIV/AIDS campaigns and ads are rarely subtitled, captioned, and/or interpreted into Sign Language. Where there are TV programs in Sign Language (available in only a few European countries: France, Germany, Spain, and United Kingdom), they address HIV/AIDS issues only sporadically, e.g., when a large HIV/AIDS campaign is mounted.

To aggravate the problems for Deaf people, service providers and health professionals view their Deaf clients as “hearing impaired,” not as Deaf people. In doing so, they completely ignore the cultural dimensions of deafness. This is symbolically represented by the capital D in the word “Deaf.” Most people who were born deaf or became so in early life and who grew up as part of the Deaf community see themselves as fundamentally visual people, with their own visual language, social organization, history, and mores—in short, with their own way of being, their own language and culture.15 Because of their culture, including their language, Deaf people should be approached as a linguistic and cultural minority, rather than as disabled people. This implies that service providers and health professionals should be able to converse in Sign Language or at least understand its importance as the preferred communication tool for Deaf people—thus recognizing the role (and importance) of Sign Language interpreters. Only then will they be able to enter into meaningful communication with Deaf people.

Ignorance of these facts contributes to many misunderstandings, and even clashes, between Deaf people and the health care sector.16 Even though many organizations working in the HIV/AIDS field may be sympathetic to minorities such as Deaf people, many are unaware of the specific needs of Deaf people. This is due to the fact that the Deaf community constitutes a small and often unknown or misunderstood minority.

In addition, Deaf people are not a homogenous group, and Deaf people who are both unable to speak for themselves by voice and lack the services of a professional Sign Language interpreter are often hardly visible to health policy makers and health care professionals. Also, many Deaf people, just like many persons with disabilities, are completely unaware
of their rights, and consequently do not claim them. They are also unaware that self-advocacy and representative advocacy can help them know about and obtain their rights.\textsuperscript{17}

Considering the above, it is not hard to grasp why the Deaf community is vulnerable to HIV/AIDS infection and to HIV/AIDS-related myths. Indeed, if one is not properly informed about the risks and consequences, how can one possibly change one’s behavior and habits? It may be helpful to think of the police officers’ duty to inform those being arrested about their rights: some people may not be aware of these rights, and so, to be safe, anytime somebody is arrested, his or her rights are read.

The Importance of “Effective Communication” and the Role of Sign Language Interpreters

Prior to any discussion of the connections between the Deaf community and HIV/AIDS, attention must be paid to the role of Sign Language interpreters. Their impact with regard to HIV/AIDS prevention, treatment and care strategies should not be ignored or minimized.

The Deaf population encompasses diverse groups of individuals whose language abilities vary from speaking and lip-reading a spoken language (e.g., Dutch) to using a Sign Language (e.g., Flemish Sign Language or Dutch Sign Language), which is a language linguistically separate and different from spoken Dutch.\textsuperscript{18} Although a number of Deaf people who seek advice may be able to speak and lip-read enough to allow some communication with the average hearing doctor or nurse, the majority use their national or regional Sign Language. Most, if not all, service providers and health professionals themselves possess such low Sign Language competence that meaningful communication with Deaf clients can be accomplished only through an interpreter. Use of signed communication and interpreters, rather than writing notes back and forth, is preferred by most Deaf clients.

Taking into account the nature of deafness, which impedes the flow of traditional, i.e., oral, communication, it is vital to understand the meaning of a “qualified Sign Language interpreter.” U.S. legislation and regulation could serve as a guide in defining and clarifying the meaning of this term. A qualified Sign Language interpreter is “an interpreter who is
able to interpret effectively, accurately, and impartially, both receptively and expressively using any specialized vocabulary. This definition focuses on the ability of the interpreter to facilitate effective communication between the service provider or health professional and the Deaf client. This is an important definition as currently (often well-meaning) family members who know a limited number of signs are (ab)used as interpreters.

The word “qualified” should not be confused with the word “available.” Few service providers and health professionals understand the difference between a qualified interpreter and an available person who knows a few signs or how to finger-spell. Being able to sign does not mean that one can translate into proper signs, nor does it mean that one possesses the skill to translate someone’s signed or finger-spelled communication into spoken words. This distinction is relevant as, very often, Deaf persons are asked by service providers and health professionals to provide family members or friends to interpret. Sometimes, notwithstanding the fact that the family member or friend is able to interpret or is a certified interpreter, he or she may not be qualified to render the necessary interpretation due to emotional or personal involvement or considerations of confidentiality which may adversely affect the ability to interpret “effectively, accurately and impartially.” The obligation to provide “impartial” interpreting requires service providers and health professionals to provide, upon request, an interpreter who does not have a personal relationship to the Deaf individual in question. In fact, this obligation is an embodiment of the Deaf person’s right to privacy and confidentiality.

For example, the Australian National Deaf HIV/AIDS Education Program acknowledged that it was essential that interpreters be able to deal with sensitive issues like homosexuality and intravenous drug use, and that they were educated about HIV/AIDS. Consequently, the program presented workshops examining the issues of ethics and impartiality specifically aimed at Sign Language interpreters.

**Deaf People and HIV/AIDS Prevention Campaigns**

In many countries, steps were taken during the past few years to decrease the risk of Deaf people unknowingly be-
coming HIV-infected. In certain countries, mainstream HIV/AIDS organizations were the major force behind this effort; in others, it was done by Deaf gay people, often strongly supported by their National Deaf Association. This has resulted in a wide array of projects and programs aimed at Deaf people and their environment. It should be noted that when compared with the facilities available to hearing people, rather few structured projects exist for Deaf people.

Following are some examples of projects in Europe and Australia, selected because they represent varied strategies and approaches. It should be noted that these projects work only because the local Deaf communities decided to make HIV/AIDS a top priority and to act upon it. For Deaf communities to tackle HIV/AIDS and to successfully demand appropriate services for HIV/AIDS patients, well-organized national and/or regional Deaf associations are needed.

Belgium (Flanders region): Aidstelefoon

After 10 years of operation, the Aidstelefoon (AIDS telephone), which offers anonymous counseling and referral services over the telephone, discovered Deaf people as a particular target group.23

Notwithstanding that government strategic planning did not label Deaf people a priority group, and the lack of scientific information related to Deaf people and HIV/AIDS, Aidstelefoon realized that this forgotten group had a right to information and communication, rights that hearing people take for granted. Thus, a text telephone and fax machine were added to their regular communication equipment.

To advertise the text telephone and fax facilities, two Aidstelefoon volunteers with some basic knowledge of Sign Language gave presentations in Deaf clubs and schools, assisted by a Sign Language interpreter. In addition, the text telephone facility was widely advertised via posters and leaflets distributed in Deaf schools, clubs and magazines. AIDS-related information was a secondary component in these messages.

In Deaf clubs, attendance at HIV/AIDS presentations was good. Paradoxically, Deaf response to the text telephone facility was very poor and below expectations: in 1996 only 10 text telephone users called Aidstelefoon. A number of fac-
tors may be considered to explain the low response from the Flemish Deaf community to the Aidstelefoon: contrary to hearing people, Flemish Deaf people do not regard the text telephone as an important part of their lives, for a number of historical and psychological reasons. Even though Aidstelefoon can also be contacted by fax, this method does not offer the same degree of anonymity as a text phone call. Another important factor is that the volunteers were all hearing, with only a basic knowledge and understanding of Sign Language and Deaf culture, and hence were not able to converse in depth. Consequently, the initiative is currently under review.

Other AIDS education programs

Both the French and British National Deaf Associations established health departments and employed Deaf gay men to organize and coordinate HIV/AIDS efforts aimed at Deaf people. Both associations cooperated closely with mainstream HIV/AIDS organizations, and provided Deaf-adapted educational materials and support. In addition to counseling Deaf people, both associations developed prevention courses and peer support groups. Moreover, in France, a national network was set up of trained Deaf volunteers to give presentations at Deaf schools, clubs, and regional organizations.

In January 1994, the British Deaf Association hosted the first European Deaf Lesbian and Gay Conference on HIV/AIDS, titled “Lifestyle and Care.” A second conference is planned for 1998.

In Australia, three projects have been successfully run in the past years:

- The National Deaf HIV/AIDS Education Program, which ran for nine months, was funded by the New South Wales Health Department. This project conducted a series of varied workshops throughout Australia for Deaf gay men, the general Deaf community, workers within the Deaf community, and Sign Language interpreters.
- The New South Wales Deaf Education Program, which ran for three years, provided workshops for Deaf gay men about education, prevention, and information
referral. In addition, the program offered a peer support group for Deaf gay men. Through this program, a resource kit was produced that was designed by members of the Deaf community for the Deaf community and implemented into New South Wales schools. The kit consists of a video entitled “AIDS, Not Hearing Aids,” which provides general HIV/AIDS information. It also has an educational support package and additional resources, including a comic about the Deaf Community in relation to HIV/AIDS and sexuality. Separately, a video entitled “Three Way Traffic” looks at the role of interpreters in counseling settings, with specific reference to HIV/AIDS. Both videos are presented by Deaf people in Australian Sign Language (Auslan) and are subtitled/captioned.

- The Victorian Deaf Education Program, which ran for approximately 18 months, provided services similar to the New South Wales Deaf Education Program.

Currently there are no funded HIV/AIDS education programs specifically for Deaf people in Australia. However, the New South Wales Deaf Education Program resource kit is still available. Each Australian state AIDS Council is now responsible for ensuring that Deaf people have access to education and information. Many do this by providing workshops in conjunction with Deaf societies and social groups.

It should be noted that Australia has gained an international reputation for its education campaigns on HIV/AIDS issues. The pandemic in Australia has affected mostly gay men, and it is the gay community that has achieved most of Australia’s prevention and education success targeted specifically at Deaf gay men.

Deaf HIV/AIDS Patients and Treatment

As already indicated, doctors and other health care professionals who are able to communicate in Sign Language, or are strongly willing to enlist the services of a Sign Language interpreter, are a rare breed. Even more scarce are doctors and health professionals who have devoted much of their time and efforts into ensuring appropriate care for Deaf persons with HIV/AIDS.
Jean Dragon, a physician at the Pitié-Salpêtrière hospital in Paris, learned French Sign Language (LSF) to communicate directly with Deaf patients because he believed that Deaf people, especially HIV-positive Deaf patients, should receive an equal standard of care. He was instrumental in setting up an AIDS clinic at his hospital, where Deaf people are welcomed in their own language for free and anonymous HIV testing. The clinic can also be reached by text telephone. In addition, when seeing specialists Deaf patients are provided with a LSF interpreter. Dr. Dragon also helped to arrange a LSF course for doctors at the hospital who wanted to communicate with Deaf people. This pilot project was expanded to the national level in 1997 with the goal of 12 physicians becoming regional referral points for other physicians who see Deaf patients but cannot communicate in LSF.

Another example is from Linz, Austria. There, a doctor learned Austrian Sign Language and set up a unit at the local hospital specifically aimed at Deaf patients, with the support of the local Deaf Community. Deaf patients with HIV/AIDS are therefore provided with appropriate care and treatment.

In the Netherlands, there is an official “Deaf Buddy,” a Deaf man who visits Deaf AIDS patients to offer and give assistance and support where needed.

These are exceptional cases, and often Deaf HIV/AIDS patients have to struggle their way through treatment, sometimes without a Sign Language interpreter because many hospitals and doctors refuse to provide one. In only a few countries can the Deaf patient exercise a right to the services of a Sign Language interpreter; in other countries, they are left at the mercy of social services. This is absolutely unacceptable.

A Call for Action

The current void between the Deaf community and the medical community must be bridged. This can be done by increasing awareness on two fronts: by increasing Deaf awareness within the medical community and through education of health professionals about their responsibilities towards Deaf patients; and by ensuring that members of the Deaf Community are informed about and understand important
health care concerns such as HIV/AIDS. This includes raising the Deaf patient's awareness of his or her own health care needs and legal rights.26

Because of the low levels of AIDS awareness among Deaf people, prevention and education campaigns should be set up in every country. Sign Language should be used, and simple and explicitly illustrated texts provided, while utilizing all information channels that reach Deaf people: signed videos, text telephone, television, schools for the Deaf, and Deaf clubs. Specific groups within the Deaf community should be targeted: Deaf gay men and lesbians, Deaf heterosexuals, Deaf drug users, Deaf prisoners, etc. Most importantly, Deaf people themselves should be involved in the planning, design, and organization of these campaigns. AIDS clinics and centers should be made fully accessible for Deaf clients, and their right to confidentiality should be respected. The quality of information and services provided to Deaf clients should be up to date and equivalent to the services offered to hearing people. In addition, studies should be undertaken to find out how many Deaf people are HIV-positive or ill with AIDS, and to learn more about their specific problems and difficulties, in order to offer appropriate health care to them. Health care facilities, especially those offering specialized HIV/AIDS-related health care, should take into account the communication needs of Deaf patients, so that they too receive the best possible health care.

This article has offered some examples of how some HIV/AIDS organizations and physicians in Europe are beginning to pay attention to Deaf people in HIV/AIDS matters, in regard to both prevention and treatment. It is important to note that an international conference on “HIV/AIDS Prevention for Deaf Adolescents” was hosted at Montana State University at Bozeman, Montana, USA, on January 11-14, 1998.27 A follow-up international conference is already planned for October 11-13, 1998 in Charleston, South Carolina. The proposed title of the conference is “A Vulnerable Minority: HIV Prevention Programs for People Who Are Deaf or Hard of Hearing.”28 Hopefully, these initiatives will provide another strong impetus for more HIV/AIDS research and prevention programs aimed at Deaf people, and towards full respect of their health and human rights.
To ignore the moral panic which creates the stigma surrounding AIDS is to fail to provide adequate protection. By contextualizing, rather than totalizing, the experience of different people affected by AIDS/HIV it is possible to arrive at an understanding of the more complex issues involved, and thus it is hoped to address them in a more effective manner. To view AIDS/HIV within the context of an individual’s experience of HIV positivity enables us to see the flaws inherent in the protection afforded to that individual under human rights law. The identification of a moral panic surrounding AIDS/HIV rebuts the validity of addressing AIDS as a discrete entity within human rights law. [...] To accept AIDS as a totalizing quality means that other contributory modes of discrimination (race, gender, sexuality) are not addressed.29,30

Disability is a contributory mode of discrimination. Therefore, with regard to Deaf people and persons with other disabilities who are HIV positive or have AIDS, the above is a very relevant and important observation. These words should serve as food for further thoughts.

Acknowledgments

The title of this article is from an Australian video which is part of an educational kit on HIV/AIDS: NSW Department of School Education & AIDS Council of New South Wales, AIDS, Not Hearing Aids (1992). Title used with permission from the AIDS Council of New South Wales, Australia.

I would like to thank everybody who shared his or her experience, time and information with me.

References

4. This article makes a distinction between deaf people in general, i.e. anybody with a serious hearing disability, and deaf people who view themselves as culturally Deaf, i.e. Deaf people who use Sign Language as their primary means of communication and who view themselves member of a
larger Deaf Community. These latter people are referred to with a capital D. As this article concerns primarily the latter group, the capital D in Deaf is used consistently, unless when reference is made to the general group of deaf people. This distinction is along the lines of the definitional guidelines of the World Federation of the Deaf (WFD).

5. K. Tomasevski, see note 3, p. 132.


12. Ibid.


16. The controversy surrounding Cochlear Implants (CI) in Deaf people, and especially in Deaf children, illustrates this very well. CI are electronic prostheses which are surgically implanted into the inner ear. The fact that CI was hailed by some as a “cure of deafness” provoked heated protest from the Deaf community, parents’ associations and some members of the medical profession who argued that this operation does not guarantee that a Deaf child becomes fully integrated into the hearing world, in other words, that the child remains deaf, and that therefore she or he should be given the opportunity to be and feel part of the Deaf community and to learn sign language.

17. M. Banotti, see note 14, p. 28.

18. Dutch is spoken in both the northern (Flemish) part of Belgium (Flanders) and in the Netherlands. However, Deaf people in Flanders communicate in Flemish Sign Language while their Dutch counterparts in the Netherlands communicate in Dutch Sign Language. It should be noted that both Sign Languages are linguistically different, based on historic
grounds. Contrary to popular belief, sign language is not international and there are as many sign languages as there are spoken languages, or maybe even more.

27. A book is now being written based on the conference proceedings to be entitled: *The Handbook of HIV/AIDS Prevention (an International Perspective)*. A peer video on prevention which is to be part of the book is in the production stage. For details, contact Jack Olson, PhD, Conference Coordinator, Department of Psychology, College of Letters and Science, Montana State University, Bozeman, MT 59717-0344, USA, tel: (406) 994-3801, fax: (406) 994-3804, e-mail: ucsjo@montana.edu.
28. For details regarding the follow-up conference, contact A. Barry Critchfield, PhD, Director, Services to Deaf and Hard of Hearing People, 100 Executive Center Drive, Suite A-13, Columbia, SC 29210, USA, voice tel: (803) 798-6767, texttel/TTY: (803) 798-6761, fax: (803) 731-5524, e-mail: barryc@scsn.net.
29. A. Scully, see note 2, pp. 350-351.
30. A. Scully, see note 2, p. 352.