

## Silence is Death ? —AIDS-Education for the Deaf in Great Britain and Germany—

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"Silence is Death" was a slogan to break the taboo surrounding people having to live with HIV and AIDS. The taboo was in many cases a double one, on the one hand it is connected with the fact that HIV is transmitted mostly sexually. On top of that there was initially a high percentage of gay people with HIV and AIDS (a figure which today is greatly outnumbered by heterosexual HIV carriers, especially a growing number of women). However, sex and homosexuality have long been treated as something to keep quiet about in many a society. Yet, in order to beat the disease, it is crucial that the silence is broken and that everybody understands the nature of AIDS, its transmission through HIV and the measurements to protect oneself and others against it. But how about the people who are often thought of as having to live in silence - people who have been labelled the "deaf and dumb" ? How does HIV and AIDS affect their lives? What do they know about it ? How do they acquire today's vital information ?

When in the late 1980ies the death toll of AIDS victims in Great Britain reached 200, five of them were found to be deaf citizens. Taking into consideration that in Western Europe about one in a thousand people is deaf, these 2.5 percent of deaf AIDS deaths seemed to be way out of proportion. Further investigations brought to light that campaigns to educate the public about AIDS had taken off well among the hearing, yet they had not got through to deaf citizens.

Contrary to the assumption that the deaf have no difficulties in reading written material, as their impairment is not a visual one, the nature of deafness in connection with reading as a highly complex skill is often underestimated. For a hearing person reading means to look at a text, to recognize the individual words, many of which one has come across before (when heard in other situations), to look at the way these words are combined syntactically and to interpret the meaning underlying the sentences and paragraphs - ideally as it was intended by the author/ess. A prelinguistically deaf person (i.e. someone born deaf or turned deaf prior to language acquisition) has hardly had a chance to perceive the many words surrounding a hearing person from the age of early childhood and to acquire their meaning in a great variety of contexts. Sign language can be used very effectively to educate deaf children, but in most schools for the Deaf in Europe teachers do not accept it as a means of instruction because it is seen as counterproductive to the training of articulation and lipreading. This method is based on the assumption that the deaf child has to grow into a society of hearing people, where speaking and lipreading are very important. However, the power of sign language as a basis for reading and acquisition of world-knowledge is acknowledged by only very few schools for the deaf. Thus, most deaf persons are deprived of sufficient vocabulary and linguistic skills to understand even simple texts.

With regards to AIDS education for deaf people, some attempts have been made to overcome these difficulties. The TWO-CAN-PROJECT, based in Derby, Great Britain, has produced a cartoon-like brochure with lots of illustrations (partly drawn signs) to explain the nature of the disease, the ways of transmission and how to prevent it. I have translated and adapted the brochure for the deaf people in Germany. In close cooperation with the health authorities of my hometown, Kiel, with the DEUTSCHE AIDS-HILFE, a federal organisation based in Berlin and the Ministry for Health and Family in the federal state of Schleswig-Holstein, all steps from draft, design, finance, publication, distribution and evaluation were carried out by local

Deaf organisations and me.

An answer card was sent to all clubs, schools and other organisations of the Deaf to evaluate the brochure. Around 98% of all responses were absolutely positive (only few people complained about the sexually explicit nature of some of the drawings). With these results in hand, the Deaf Association of Schleswig-Holstein approached the Federal Ministry for Health to have some 30,000 copies printed for the 80,000 prelingually deaf citizens living in the now reunited Germany.

While doing research for the brochure, I came across five different signs for AIDS used by German deaf signers alone. These varied not only regionally but within smaller groups, like in a local deaf club. There was no established sign for AIDS, neither in the schools for deaf children nor in the few minutes of weekly television provided for the Deaf on German television. All this reflects the poor standing of sign language in the educational system for the Deaf and the mass media. Until 1995 coverage on the AIDS topic was by no means sufficient, and earlier requests by Deaf organizations and researchers at the university of Hamburg to get funding for a sign language film project on AIDS had fallen on deaf ears with the health authorities in charge, who in the end at least financed my brochure (which I still consider only second best to a sign language film).

I tried to break the involuntary silence of the Deaf and to make AIDS a topic among them by putting the AIDS sign used by the Berlin Deaf on the front page of the brochure, so that all Deaf readers could refer to AIDS nationwide by the same sign, thus literally taking the topic into their own hands. I chose the sign version of the Berlin Deaf because they had the most experience with the disease - and therefore reason enough to communicate about it as by now at least 7 are reported dead and 50 % of the gay Deaf in Berlin are estimated to be HIV-positive. In a 1994 TV docu-

mentary (which was luckily broadcast with sign language interpretation by the private TV station PRO 7), a self-support group of young men being HIV-positive explained how they had to invent signs for terms like "virus", "positive" etc. The word "positive" suggests something good and would - by a naive (deaf) person - be signed with the two index fingers crossed to form a PLUS shape (+). In order to refer to the HIV-related meaning of the medical term "positive", the Berlin group invented a sign resembling the initial letter P from the two-handed manual alphabet used by the British Deaf.

In order to establish and standardize these signs and others, much more TV coverage and use of sign language in the educational institutions for the Deaf are necessary. The Deaf are a very unique group, who have a strong bond among its members like no other, for want of people who they can freely communicate with. Within their group, deaf people are no longer handicapped, but rather constitute a fully functioning language community. Most of them find their friends and (sexual) partners in the Deaf community. This fact may partly explain the fast spread of HIV in such a small group as the Deaf (latest estimates for Germany run by 4%, i.e. every 25th person !). However, this should not lead to the conclusion that the blame is to be put on the Deaf themselves. Instead, we should ask why the Deaf in so many and often highly developed countries are denied free access to vital information, the AIDS issue probably being one of the most recent and most drastic examples.

Silence is Death ? - The silent but yet expressive culture of the Deaf may have fewer reservations to talk about AIDS than other people and they are less likely to keep quiet about AIDS. But the Deaf people everywhere deserve all our respect and support to be able to ask all the questions the hearing people have the chance to ask - and to understand all the answers given - not only about AIDS.

As the term "deaf and dumb" is somewhat misleading and therefore considered discriminating by the people concerned I shall follow well-established practice and refer to the group in question as "deaf" as far as a handicap is concerned, and as "Deaf" whenever the group can be seen as a cultural entity or a linguistic minority of sign language users.

(Lecture in English)