HIV Education for the Deaf, A Vulnerable Minority

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Synopsis ....

Large numbers of deaf and hard-of-hearing people are in danger of becoming infected with the human immunodeficiency virus (HIV). The deaf are particularly vulnerable because of language barriers, their unique culture, and the paucity of community services, educational programs, and general information directed to this population.

The particular barriers that the deaf must face in learning about HIV protection range from inadequate schooling about human sexuality to the scarcity of locally available education programs outside the cities with high rates of HIV infection.

The programs for the deaf in Houston, Los Angeles, and New York City are described as well as the array of national efforts directed to this special population.

THE PORTRAIT of the AIDS epidemic among the deaf differs from that of the hearing community. The deaf lack public forums devoted to educating them about the human immunodeficiency virus (HIV), comprehensible HIV-AIDS brochures in medical waiting rooms, or the empathetic ear of the mental health therapist. For the deaf, these are signs of neglect across a nation.

Little has been published about HIV-AIDS and the deaf (*1-5*). Even less has been published in the form of specifically directed educational materials. With such a paucity of information, how can the members of the deaf community react to this immense public health crisis?

A Community Examined

The last formal review of the size, distribution, and characteristics of the deaf population in the United States was completed in 1974 by Schein and Delk (*6*). In "The Deaf Population of the United States" they estimated that, in 1971, the rate of those persons who were prelingually deafened was 203 per 100,000. This group, thought to be the "true deaf," shares a common language—American Sign Language (ASL), as well as a common culture (*7-9*). Today's deaf community ranges demographically from 350,000 to 2 million as estimated by the National Information Center on Deafness at Gallaudet University in Washington, DC.

Seroprevalence of HIV and the deaf. Generally, studies show 1 out of every 250 people in the United States is infected with HIV (*10, 11*). Applying this ratio to the population of deaf Americans shows that a substantial number of people within this group could be infected. In June 1991, Bares estimated the potential number of deaf persons with AIDS in the United States to be approximately 2,640 (*1*). To date, no statistical data exist regarding HIV transmission within the deaf community, although the National Coalition on the Deaf Community and HIV, Inc. (NCDH) has begun an audit of health care facilities across the nation that are treating deaf persons with HIV or AIDS. Because of information gained during the research for this article, I believe that the 1 to 250 HIV infection ratio is much greater among the deaf; the pertinent factors will be examined later.

General barriers to HIV-AIDS information. Finding resources and information about any medical topic can be done with some ease by the nation's hearing population. Television, books, radio, and other mediums bring HIV-AIDS to society's attention. Yet many barriers prevent even basic information from reaching the community of the deaf. Even though the Centers for Disease Control and Prevention's (CDC) National AIDS Hotline TDD Service has been active for more than 5 years (*12*), such local community services as TDDs, (Telecommunication Devices for the Deaf) interpreted lectures, captioned video or television programs, and literature which is candidly written currently do not reach a sizable portion of deaf society.

Deaf people depend greatly on visual elements for learning new information. Pictures, slides, videos, and

live presentations used in HIV education provide a greater impact than a mere written format (*13*). Yet few national organizations have developed and produced literature specifically targeted for the deaf about HIV–AIDS (*14*). Eight sign language educational videotapes have been produced in the United States to address HIV-AIDS in the deaf community, whereas 15 videos, targeted for a hearing audience, have been open or closed-captioned (*15*). Complete listings of videotapes and brochures designed for deaf people are available from CDC's National AIDS Hotline TDD Service (see box).

AIDS Related Telecommunication Devices for the Deaf (TDD)

- AIDS Education and Services for the Deaf (AESD)—(213) 478-8000 TDD/V
- CDC's National AIDS Hotline TDD Service—(800) 243-7889 TDD
- CDC's National AIDS Clearinghouse—(800) 243-7012 TDD; (800) 458-5231 voice
- Deaf Pride Inc.'s Project AIDS—(202) 675-6700 TDD/V
- GMHC's Deaf AIDS Project—(212) 645-7470 TDD; (212) 807-6655 voice
- Montrose Clinic of Houston—(713) 528-3719 TDD/voice
- National Information Center on Deafness—(202) 651-5052 TDD/V
- National Coalition on the Deaf Community and HIV, Inc. (415) 476-7600 TDD; (415) 476-4980 voice
- New York Society of the Deaf (NYSD)—(212) 777-3900 TDD/V
- Whitman-Walker Clinic's Deaf Access Services—(202) 797-3547 TDD; (202) 797-3500 voice

Cultural barriers to HIV–AIDS information. The deaf have struggled for decades with such issues as equal access in medical and social service areas, self-determination in the classroom and the workplace, and a general sense of societal acceptance without cultural discrimination (*7,9,16*). The deaf, though a minority within any given municipality, are closely knit. The great percentage of deaf people interact socially with other deaf people (*16*). Gossip and hearsay travels quickly within the deaf community. Those who are anxious about sensitive topics (such as HIV transmission) will tend toward rumor promulgation (*17,18*). Fear of isolation from his or her own community becomes so great that using medical and social services may be compromising for deaf persons with HIV. Confidentiality is of great importance. Walking into an HIV testing site or to an AIDS treatment clinic may be postponed indefinitely if the person fears being seen by a deaf acquaintance. Although many deaf people with HIV–AIDS indeed have been welcomed and supported by their peers, many others have also been shunned. One review has examined how HIV sensitivity training, using peer education, can lead to ultimate acceptance when the participants witness the disease firsthand in a friend or acquaintance (*19*). Successful education about HIV must begin at an early age at school and at home.

Ninety percent of deaf children have hearing parents (*7,13*). Because there is usually no preparation for having, and subsequently raising, a deaf child, parents know little about deafness and the accompanying cultural aspects (*9*). Close interaction within the family depends on attentive, natural communication shared by all members. When one member cannot participate in this process as other members do, a smooth connection is lost. The deaf child may feel inferior. If such feelings go unnoticed, future paths of coping may lead the deaf adult to harmful life patterns.

Behavior modification efforts fail when parents do not consider ways in which to cope with their child's "differentness" (*20*). Often the deaf child's parents will attempt to deny the child's true culture by keeping the child from associating with other deaf children, learning sign language, and so on. Yet, from the perspective of HIV education, hearing parents who learn the language and culture of the deaf community may assist in preventing their children from surreptitiously, and dangerously, discovering for themselves the realities of illicit drug use and unsafe sexual practices.

The majority of deaf children are taught English grammar and structure so that they might live comfortably as working adults in the larger hearing world. Although American Sign Language exists as a true language and is different from English in a syntactical sense, an average deaf person generally reads English on a fourth grade level (*21*), but this level does not correlate with the intelligence of the deaf child or adult. Learning English, without being able to hear the repetition of rules of grammar in daily conversation, is a tremendous task. Similarly, hundreds of concepts and idiomatic meanings of words in the English language are difficult to translate into sign, as is often the case in translating from one foreign language to another. Because the HIV–AIDS literature is written for the average hearing adult, the majority of deaf Americans miss out on such relevant information.

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Schools for the deaf generally have no specific programs on HIV–AIDS as part of their health curriculum. General sex education is also underemphasized at such schools (*22*). The percentage of deaf students going on to receive a formal college education is smaller than their hearing counterparts, so many who enter the work force will most likely have ended any HIV–AIDS training at the high school level.

Limited access to accurate information about sexuality also puts a deaf adolescent at a special disadvantage. School counselors and educators need to explore concepts of sexuality more thoroughly within institutional walls, and parents need to foster such discussion at home using the language which can be easily understood by their children (*22,23*).

Typically, there are no outlets for deaf children to express their personal feelings surrounding their own sexuality. Because of this, patterns of homosexual exploration begun at the high school or junior high school level may be continued as an adult, either as an established way of living or in the more clandestine bisexual world.

National and State public health departments should be active participants in developing educational programs not only for children, but also for deaf adults. Deaf persons should not suffer the programming constraints of inappropriate access to public health information. Instead, forums should include in-service training to agencies and corporations with deaf workers; sign language interpretation provided at community lectures on HIV; visual and readable brochures about substance abuse, STDs, and HIV; up-to-date HIV and the deaf resource information available for distribution to interested participants; and dedicated people intent on working with the deaf. Such responses will allow for more caring provision of services.

Risks for HIV

Bares (*1*) states that during the first 8 months of 1991, 20 percent of the 120 deaf persons being tested for HIV at the Montrose Clinic in Houston, TX, were seropositive, compared with 10 percent of a larger hearing sample at the same clinic testing positive over a 12-month period. Several other studies have yielded insights into high-risk activity for HIV transmission among the deaf (*4,13,14,18,21–39*).

Heterosexuality. HIV prevention educators recommend that safer sexual practices include, besides condom usage, knowledge of one's partner and his or her sexual and substance use history. In this instance, a deaf sexual partner of a hearing person is at a disadvantage, quite certainly if the hearing partner is not versed in sign language. Negotiating safer sex with such communication barriers may be very awkward for both parties, and may be lightly heeded. Disclosure of HIV seropositivity prior to intercourse by one or both persons is of the highest importance, yet such a language boundary cannot be easily transcended.

Combining sex education and HIV education into one retainable message for students has been met with limited success, mainly due to the lack of culturally specific ways of teaching in the deaf adolescent's school and home environments. Fitz-Gerald and Fitz-Gerald's study (*27*) found that very few of the 94 deaf students enrolled in a precollege program at Gallaudet University had had any sexual education from their parents (communication barriers were listed as the most frequent deterrent). Instead they received such information, often erroneous, from their peers. Feinstein and Lytle (*28*) observed that deaf children may form "intense, dependent sexual attachments" as a way of dealing with the separation from their parents while coping in the environment of the residential school. Mainstreamed deaf students, on the other hand, may receive cursory sex education in a public school, depending on availability of qualified sign language interpretation or other forms of special education. Health education of deaf adolescents needs to include birth and STD control, refusal skills training, and general health education because research has elicited educational deficits in these areas (*29–32*). A home, school, and community partnership providing an accurate HIV educational foundation is necessary to supplement the deaf adolescent's sexual development. Planning and implementation of HIV education and prevention programs at school is an introductory step, yet they are commonly not provided to, or within, the adult deaf community (*1,14*).

Finally, HIV education of the deaf is problematic in terms of their view of AIDS as a "gay disease" (*4*). Older deaf men and women with a history of blood transfusions, or significant past heterosexual encounters, may minimize their risk for HIV infection for this reason. Programs developed specifically for

the deaf can allow for personal risk examination and antibody testing if warranted.

Homosexuality. Homosexuality, as a lifestyle choice, occurs more frequently among the deaf (*23,25,26*), and deafness occurs more frequently in males than females (*7*). Many deaf males will look for sexual or long-term partners outside the deaf community because of limited choices (*7*). Such a partner may be another male.

One overriding factor for the person who is deaf and homosexual is the notion that they are a minority within another minority. Homosexuality, today, has become more widely accepted by mainstream society, and deafness has become culturally better understood by the larger society. The deaf-homosexual combination, though, is without such support. Barthell (*26*) concurs that this is most potent because of the risk of ridicule from the greater deaf community. Often, deaf homosexuals fearing rejection will conceal themselves through lifelong, furtive, same-sex encounters. As in heterosexual relationships, the deaf homosexual is at greater risk for HIV transmission because of communication differences with a potential sexual partner. Because of issues of shame, misinformation about sexuality, a limited values foundation from home and school, and the ingrained sense of societal paternalism, a deaf gay male will often seek out sexual connections with the hearing, who usually have no background in deaf culture or language. Zakarewsky (*33*) purports that being involved in a specific, unwanted, sexual activity puts a deaf person in an awkward and dangerous position.

The many chapters of the Rainbow Society of the Deaf form a nationwide chain of members who support deaf, gay life and accompanying issues such as HIV. Without such vehicles of support, deaf homosexuals find themselves without feelings of connection.

Substance use. Within the hearing community 1 in 10 people have a substance abuse problem, but within the deaf community 1 in 7 people have a substance abuse problem (*21*). Steitler and colleagues (*34*) assert that drug and alcohol abuse is more widespread for the deaf than their hearing counterparts because of tendencies toward poorer self-esteem, isolation, learned dependence, and deficient social skills. Kusche and colleagues (*35*) add to the premise of poor self-esteem by suggesting other issues that motivate a deaf person to abuse substances: less opportunity for gaining knowledge about health-related social issues and nonacceptance within the deaf community for drug using behavior.

Just as deafness isolates people from the larger hearing society, deaf adolescents may turn to drug or alcohol use if they are without the emotional stability of a parent who knows the youth's language and culture. The substance becomes their new relationship, "being one of easy intimacy in which good interpersonal relationship and communication skills are not required" (*36*).

Many Alcoholics Anonymous and Narcotics Anonymous programs in larger cities across the country provide interpreting services for deaf clients, as do inpatient-outpatient rehabilitation centers. Yet, hundreds of outlying cities and towns have only limited services and educational provisions (*24*). Other obstacles for providing care to deaf substance abusers include lack of followup services for those who may relapse, lack of understanding of the 12-step process due to communication or language deficiencies and, often times, a deaf person's mistrust of hearing professionals (*35*).

Finally, integral to all HIV educational programs and literature produced for the deaf should be a discussion regarding the hazards of social drug and alcohol use and their connection to HIV transmission behaviors.

Sexual abuse-incest. Sexual norm naiveté is, in part, the result of an isolation from formalized sex education, and the result is socially inappropriate sexual behavior (*37*). Sexually abusive behaviors are therefore learned and maintained over generations. Children with a hearing handicap have been found to be at a more disproportionate risk for sexual abuse or incestual episodes than their hearing peers (*18, 37–39*). Problems of communication breakdown, fear of authority, and doubts of not being believed all contribute to the fact that a child will be far less likely to report to a parent or school official a situation of abuse. The combination of today's prevalence of HIV and other sexually transmitted diseases, and the deaf child's role as target of sexual assault and his or her potential subsequent role as abuser, is one with serious consequences. Instructing deaf children so they know where they can seek emotional and psychological support in order to prevent a sexually abusive relationship from occurring can be both empowering and life-saving.

The issues just described represent a large percentage of the articles, both anecdotal and research-based, which have been written about the psychosocial trends within the deaf community. Most clearly, further studies are needed to highlight, and subsequently quantify, patterns of need within this vulnerable minority.

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HIV-Related Organizations Serving the Deaf

Programs in three cities. The major centers where HIV education and services are provided for the deaf community are located in California, New York, and Texas. These centers represent a growing commitment to the health care and educational needs of deaf people in this country. Further, some 30 agencies, both large and small, have been developed throughout the country where pockets of deaf people reside. Descriptions of three representative agencies follow.

- *Greater Los Angeles Association for the Deaf: AIDS Education-Services for the Deaf.* This program provides a walk-in center offering one-to-one peer counseling using deaf staff members and volunteers, a women's HIV outreach program with comprehensive education and prevention information specifically tailored to deaf women, client support services to deaf people with HIV-AIDS, and HIV educational literature and videos produced expressly for their clientele.
- *Montrose Clinic of Houston.* Hearing and deaf staff provide a wide range of services to the deaf including HIV testing and counseling, a loaner TDD service, and case management. Their educational resources include "HIV 101," "STD 101," and "Safer Sex Training to the Deaf," clinic-produced HIV information and prevention brochures for the deaf community, and HIV counselor training modified for the deaf consumer.
- *Gay Men's Health Crisis Deaf AIDS Project.* The project, founded in 1986, is a program in New York City whose sole purpose is to provide HIV-related services and education to the deaf. Among its services are a speaker's bureau promoting HIV prevention and education for deaf audiences, two TDDs available at the main hotline of the project to answer general or culturally specific questions from deaf callers, and deaf volunteers who provide case intake and a "buddy" service for deaf clients.

Other well-rooted HIV–AIDS programs for the deaf in the United States include the New York Society for the Deaf's Ryan White Case Management Program for the Deaf; Whitman-Walker Clinic's Deaf Access Services, and Deaf Pride Inc.'s Project AIDS, both located in Washington, DC (see box).

National efforts. Following is a listing of HIV services for the deaf that have a national scope.

- In September 1988, the Centers for Disease Control and Prevention (CDC) established an AIDS hotline for the deaf (*12*). Utilizing people with significant backgrounds in deaf culture and three stations equipped with TDD, the hotline answers approximately 800 calls monthly. Questions, received by both deaf and hearing operators knowledgeable in ASL and its accompanying cultural aspects, are similar to those questions asked by hearing callers—some inquiring about HIV transmission, prevention, and testing sites, and others seeking educational or service center advice. This hotline is also designed to give the caller a thorough review of all possible HIV-related information centers and services available to them in their living area. If none are available, a caller is supplied with addresses and phone numbers of HIV-service organizations for the deaf which could offer additional resources. The hotline is the first of its kind in the country in terms of equal access to health services for the deaf.
- All "America Responds to AIDS" public service announcements are closed-captioned for those with television decoders.
- Gallaudet University's National Information Center on Deafness will mail a packet of information about HIV–AIDS in the deaf community to inquiring persons or organizations.
- The CDC's National AIDS Clearinghouse provides, for free, a resources and services data base search of agencies, captioned or signed videotapes, educational brochures, and short journal articles about the impact of AIDS on the deaf community.
- The AIDS Education and Services for the Deaf (AESD) uses deaf persons as educators because they have firsthand knowledge of the cultural and linguistic needs of their deaf consumers. To this end, such a program was created in 1990 and completed in 1993 with a grant provided by the CDC. Trainers from AIDS Education and Services for the Deaf traveled across the country and provided basic HIV educational workshops for a variety of agencies, many of whom are in direct service to the deaf. The three types of workshops included a 1-day workshop for local AIDS agencies wishing to become more accessible to deaf clients, a 1-day workshop designed for sign language interpreter education and ethical

role-playing, and a 3-day workshop for predominantly deaf participants who, in turn, brought HIV education back to their own communities. A basic workshop formula, as well as a formula to make services more accessible to the deaf community, was developed and is thoroughly outlined in the form of a resource book available from AESD at a nominal fee.

• The National Coalition on the Deaf Community and HIV, Inc., established in early 1991, brought together a national network of experts to identify speakers, educational materials, and model programs to be used as principal resources for persons or agencies seeking information on HIV–AIDS and the deaf. Their accomplishments include co-sponsorship of the 1993 AIDS and the Deaf Community conference, a national assessment of health care facilities working with deaf persons with HIV–AIDS, retreats for deaf persons with AIDS, an NCDH Memorial Fund, and a quarterly networking newsletter. This organization has become a vital resource promoting training, education, advocacy, and service delivery to local and national deaf communities.

• During the summer of 1993, the National Conference on AIDS and the Deaf Community was held in Los Angeles. It brought together HIV-positive deaf persons, service providers, sign language interpreters, and the issues that connect them. The goals of the conference were to provide updated HIV information, to share intervention strategies for providing appropriate services to deaf persons living with HIV–AIDS, to discuss ways to increase the number of services accessible to the deaf, and to develop a 5-year plan of HIV education and prevention for deaf people across the country.

Conclusions

The goal of this article has been to heighten the sensitivities of medical and social service providers to the educational and service needs of the deaf community regarding HIV and AIDS.

Supplying media support, interpreter services, deaf speakers, materials produced for the deaf, a videotape library, deaf and hearing volunteers, and cultural sensitivity within medical and social agencies will send a message of accessibility to a population in need. Having only a few deaf people in a community should never be an obstacle when offering HIV prevention or education programs. Rather, the aim should be equal access to such resources. It is hoped that more communities across the United States will become more aware of, and sensitive to, the needs of the deaf for HIV–AIDS education and care. Community task forces need to be established whose purposes are to educate the deaf and prepare for the requirements of deaf PWAs. Until such programs are in place, there will continue to be a void, along with continuing misinformation and further HIV infection.

Offering such initiatives by the hearing community, solely, is paternalistic, and deaf members working within their own community to educate, solely, is restricting. Bringing both groups together for mutual giving and planning needs to be a priority.

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