Silence=Deaf

In the translation from English to sign language, HIV education loses something: Lives

April 1, 1998 By Steve Friess

Janie Denver, a deaf woman in Georgia, asks me if I'm writing this article because it was assigned to me or because I have a personal interest in the issue of HIV in the deaf community.

"A bit of both," I say. "The editor assigned it to me in part because I am hearing-impaired."

To Denver, this is the ultimate slur. "What's wrong with your self-esteem that you would consider yourself 'impaired?'" she snaps. I try to tell her that this is how my parents have always referred to my disability, but it's too late: As with others I've interviewed before her, everything was fine as long as she assumed I was deaf -- after all, we were speaking on a TTY phone, a tiny black keyboard with a one-line screen. Yet once I was exposed as a "hearie" (albeit an impaired one), each person erected seemingly unscalable walls, and, one after another, the interviews came to an abrupt halt.

Days later, when I call Denver again and ask her about our spat, she apologizes. "It's not very difficult for a deaf person to stop trusting someone who can hear," she says.

Clearly, a separatist zeal exists, and Denver blames this as much as anything else for her HIV infection. "Look at how I reacted to you just because you referred to yourself as 'hearing impaired,'" she says. "I see now that information about AIDS was out there, but I was too suspicious to listen. 'That's just the hearies trying to control us again,' we'd say to each other. We didn't want anything to do with them."

There are up to two million deaf Americans, and estimates of those who have HIV range from 7,000 to 26,000. However, the precise number remains elusive, largely because the Centers for Disease Control and Prevention (CDC) doesn't classify infection rates by physical disability. Incredibly, when asked for casualty figures, even deaf AIDS activists used to cite only the number of panels dedicated to the deaf dead in the Names Project Memorial Quilt, as if it were an official body count.

Since some deaf PWAs tend not to seek medical help -- add a distrust of doctors to the more widespread suspicion of hearies -- it's hard to track the impact of the epidemic on the deaf community. Many deaf activists suggest the best they can do is to assume that the deaf have been hit at least as hard as the Latino population because, like Spanish-speaking Americans, few

deaf adults can read English at above a fifth-grade level. “Almost all the printed literature discussing HIV is written at a level higher than that,” says Chad Ludwig, senior supervisor of the CDC National AIDS Hotline’s TTY service.

This functional illiteracy might come as a surprise to those of us who hear. After all, it seems only reasonable that the deaf would master the printed word as a necessary compensation for their loss of hearing. I, for one, devoured written words on signs and movie subtitles -- wouldn’t that skill be even more important to people with more severe hearing loss? The difference is: English is my first (and only) language. “More than seventy percent of deaf people consider American Sign Language (ASL) their first language, and English their second,” says Scot Pott, president of the National Coalition of the Deaf Community and HIV.

A combination of signs and gestures, ASL is not a substitute for English. People who hear tend to view ASL as a kind of charades, in which words are “acted out,” when in fact it is its own language -- not a party game. For example, the ASL gesture for “chair” doesn’t mean the English word chair, but rather the concept of a chair; gestures are directly connected to specific units of meaning. Not only is English not the common term in this correspondence, it plays no role at all. Even words for which ASL has no single gesture and so must be spelled out -- such as proper names, brand names, obscure idioms -- are interpreted as whole words, not letter by letter.

This language barrier is arguably the cause of the cultural chasm between the deaf and the hearing. “English and ASL are different languages,” says Daniel Langholtz, a deaf, HIV positive social worker at the University of California San Francisco. “Most deaf people stay among themselves, and among themselves they only need ASL.”

Even for deaf people who read well, the written word isn’t enough, since, as deaf activists point out, that’s not the way hearing people get most of their information. “The hearing world doesn’t notice it, but they depend on their car radio, telephone, TV news, even eavesdropping on other people’s conversations to acquire what they know about AIDS,” says the CDC’s Ludwig. Ludwig says that deaf people know only about a quarter of the HIV prevention information that hearing people know, and their understanding of AIDS treatments is about 10 years behind the mainstream’s. The result is a rate of infection among the deaf that most observers agree is dramatically higher than the 0.3 percent rate in the general population. “I’ve been on the CDC’s case for two years now to acknowledge that ’deaf’ belongs among the high-risk categories,” says University of Pittsburgh researcher Karen L. Sadler, who is deaf.

Illiteracy is just one factor contributing to the increased risk of HIV for the deaf. “Certain characteristics of the community itself -- including high rates of substance and alcohol abuse -- lead to behaviors that create an AIDS risk,” social worker James Peinkofer says. Peinkofer, author of a widely quoted 1994 article on the topic for *Public Health Reports* magazine, notes that approximately one in seven deaf people has a problem with drug use, which lowers sexual inhibitions and may include shared needles. In addition, children with a disability are more commonly victims of sexual abuse or incest, which are correlated with a higher incidence of adult unsafe sex. Add to that the isolation of a marginalized group, and it’s not hard to understand the

low self-esteem that might seek approval through sex, safe or not.

Janie Denver was 25 when night sweats, diarrhea and chronic bronchitis prompted her to see a doctor, one of the few at her local -- or, for that matter, any -- health facility to speak ASL. She recalls her impatience as he pored over the green folder that contained the results of her blood work. “Finally, he came around the desk and told me I was HIV positive,” says Denver, now 28. “I didn’t know what HIV was, and being positive sounded like a good thing,” she says. But her doctor was near tears. “This sounds so stupid now, but I asked him, ’Then what’s wrong with me?’”

Denver was in the dark until her diagnosis, and even though most deaf people are aware of AIDS, many view it essentially as a hearies’ disease, the way that straight people once thought of it as a gay disease.

Then there’s the problem of getting deaf people with HIV to see a doctor. “I don’t care if you have the friendliest deaf clinic around,” says Jacob Alexis, a deaf, HIV positive computer programmer in Detroit whose CD4 count was well below 100 when he finally got tested for HIV. “Deaf people see it as a risk to be tested because we don’t trust the hearing doctors to respect our confidentiality.” An ASL interpreter can bridge the communication gap between doctor and deaf patient, but this may also compromise the patient’s privacy. “All our lives, hearing people have been in the driver’s seat. We need to be dealing with other deaf people so we don’t think what we’re being told is just more of hearies being paternalistic and treating us like children,” Alexis says.

If all this sounds like paranoia, consider the following example of safe-sex education offered to a group of deaf adults in Michigan in 1994. “You like apples?” instructor Cindy Stemple asked, using ASL. They nodded. “So do I,” she said. “But this apple isn’t what it seems.” Here, she sliced the apple open to reveal its insides drenched with red food coloring. “This apple is infected with HIV,” she said, as if sharing the moral of an Aesop’s fable about AIDS, “but it looks good enough to eat.”

“Their mouths dropped open in surprise,” Stemple recalls, though only nine mouths were there -- the peak attendance in a five-city tour of the state.

Stemple blames her conservative Midwest locale for the poor showing, but even in major coastal cities, where deaf AIDS activism has developed in recent years, few attend workshops arranged by established AIDS agencies. “There are at least 750,000 deaf people living in Los Angeles, and it’s so hard to get to them,” says Emmett Hassen, a deaf activist at AIDS Education Services for the Deaf. “There’s no cooperation from the deaf community in general.” Gay deaf groups seem to be the only ones that have met with any success in AIDS education. The Rainbow Society for the Deaf, a social group with 20 chapters nationwide, and the Deaf Queer Resource Center in Washington, DC, have both drawn big crowds to their workshops.

Tom Plummer is an 18-year-old senior at Woodson High School, one of 40 deaf students at this mainstream Fairfax, Virginia, school. It’s a progressive place, where safe-sex presentations are ASL-interpreted for the deaf students. Unfortunately, many interpreters are not as up-to-date as the material they present. “The ’terps would be finger-spelling ’anal’ and ’oral,’ and I was like, ’Just sign it!’” says Plummer, who insists that spelling out words that can be communicated with a

single gesture interferes with intelligibility. "The sign for ’oral sex’ is an ’o’ in front of your mouth that you move back and forth, and ’anal sex’ is the pinkie in the back of a fist. Just think if the teacher spelled out *a-n-a-l s-e-x*, letter by letter, for the hearing students," he says, another example of the ways in which the deaf are infantilized.

Deaf youth are of particular concern to deaf activists; they possess the same feelings of invincibility that put hearing youth at risk for HIV. Besides, parents of deaf children -- 90 percent are hearing, and never master ASL -- only rarely provide any useful sex education. That leaves it up to the schools, but residential schools for the deaf tend to be even more puritanical than those for the hearing.

“I went to the Rochester [New York] School for the Deaf to present a program about my volunteering at AIDS Rochester Inc., and the principal told me that I wasn’t allowed to respond to any sexual questions from the audience that might flip their drive because she didn’t want to deal with the PTA,” says Chad Ludwig. “And this principal was liberal -- I could see that she doesn’t mind about gays or lesbians. Her concern was for her job and the pressure from parents and the state.”

This pressure is resisted at the California School for the Deaf in Riverside, where AIDS Education Services for the Deaf in Los Angeles has helped design a relatively explicit program. The superintendent, Kenneth Randall, says that in the five years since the program was started, he has heard far fewer complaints from parents than he had expected. To safeguard against problems, though, Randall informs parents that the material includes displaying condoms and graphic pictures; parents can remove their child from the class for the day.

As they paint this grim picture, deaf activists insist that the situation has definitely improved. Several AIDS service organizations in major cities have hired deaf-services coordinators, and others cater specifically to deaf people. Dozens of AIDS telephone hotlines nationwide now also have special lines for TTYs, and the Internet is home to an increasing number of websites devoted to AIDS information for the deaf. (Most sources for this article were found through websites or AOL.) Of course, you have to read English well to use the Web.

Indeed, whether English-illiterate deaf people actually access the available services remains in doubt. A 1996 profile of callers to the CDC National AIDS Hotline’s TTY line shows that two-thirds were proficient in English, and almost as many asked to receive a pamphlet or referral, indicating that they’re at least able to read English. “We’re not reaching the people we need to reach,” says Ludwig, who was hired to increase call volume after TTY traffic on the CDC line slumped from 12,961 in 1994 to 6,343 a year later. (More recent numbers are not yet available.) “It just kills me that there are so many people out there we haven’t been able to reach,” says Dave Johnson, a deaf AIDS educator in New York City. “But you know what? It’s killing them more.”

Even when deaf people like Janie Denver and Jacob Alexis seek medical help, the doctor’s office is often the scene of miscommunication. “There’s a lack of sign-language vocabulary for science and its diseases,” Karen Sadler says. “It’s difficult to get across the meaning of words such as positive,

which in medical terminology has the opposite meaning from the traditional definition."

It's a clash less of semantics than of culture. Many in the deaf community see ASL as not just different from -- but better than -- English. For them, ASL is the doorway to a world as enchanted as it is exclusive -- and through which only the non-hearing can pass. Noting that hearing people are at the helm of the AIDS info network, Natasha Kordus, a researcher at Washington, DC's Gallaudet University, the world's only four-year liberal-arts college for the deaf, says, "Hearing people often don't think they need to be culturally sensitive to a minority because it doesn't occur to them that this is another culture. It's like a white person going into a black neighborhood and saying, 'Let me teach you how to conduct your sex life.'"

Which is one reason that I was assigned this article: My editor thought I could relate to the subject more directly than a 100 percent hearie. Not that I ever learned ASL. Though I grew up wearing two hearing aids that hung over my earlobes like chocolate half-moons, I was determined to be "normal." "I wasn't like 'them,'" I say to Janie Denver, "and 'they' weren't like me."

I await her response, which flashes across my TTY screen like green lightning. "That kind of division was sad before AIDS," she says. "Now it can be deadly."

Illustrations: [images not available] The Red Book*, National Service Center for the Deaf and Hard of Hearing, San Antonio, Texas*

Hearing AIDS

See Dick and Jane get HIV

"People with minimal reading and writing skills rely on visual pictures," says Kat Schwab, an instructor at the National Service Center for the Deaf and Hard of Hearing in San Antonio, Texas. Hence *The Red Book,* the center's 1994 tomato-colored manual that uses a cartoon-and-stick-figure mix to illustrate the difference between safe and unsafe in sex and needle use.

Another pamphlet, published jointly in 1996 by GMHC and the New York Society for the Deaf, takes a Saturday-morning-cartoon approach: HIV itself is depicted as a hairy, pear-shaped bug with an eye patch, two antennae and eight legs. When the sex is unsafe, the devilish virus is a crafty stowaway hitching a gleeful ride into another body; when safe, it's trapped inside the tip of a condom.

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http://beta.docker.poz.com/article/Silence-Deaf-1609-1512