

AIDS Hotline Signs on Deaf Consumers

By Jennifer Brooks

Closing the Gap, Disabilities • October/November 1999

Deafness/hard of hearing is the second most common chronic health condition in the United States. More than 28 million Americans have some form of hearing loss, and 80 percent of those have irreversible and permanent hearing damage, according to the National Association of the Deaf. Yet the deaf community is an underserved “subculture” that often relies on other deaf people for health information.

The Centers for Disease Control and Prevention (CDC) established a National AIDS Hotline TTY Service to provide confidential and reliable information on HIV/AIDS and other STDs to the deaf community. This service is the only one of its kind in the country.

The following is an interview with Chad Ludwig, BSW, senior supervisor of the TTY Service.

Q: Does the deaf community have special needs when it comes to obtaining health information?

Chad: The deaf community is broken into sub-groups that have a variety of special needs when it comes to obtaining health information. It could be through written communication, TeleTYpe (TTY) communication, community’s grapevine, using interpreters, speech reading, verbal communication, and signed communication. But not every member within the deaf community is fluent in each of the modes of communication as mentioned.

It is the responsibility of each party to ensure that the health information is accessible. Normally, members within the deaf community are aware and familiar with the best methods of gaining health information. Health care providers should be attentive to their patients and make an attempt to fulfill their needs in obtaining health information.

Q: What barriers to prevention and treatment information do deaf people face?

Chad: The health care community either isn’t willing, doesn’t have the option, or lacks the resources or information to have the ability to fulfill the service needs of members within the deaf community by providing the health information. One report states that the average reading level among members of the deaf community is between the 4th and 5th grade levels. Many magazines, newspapers, captions on TV, brochures, and other information sources are written in English well above this reading level. This is another barrier to health information across the deaf community.

It is important to note that more than half of the United States has recognized American Sign Language (ASL) as a foreign language.

The ASL is commonly used by deaf people as their first language. The ASL is a visual language, and the way to express the information is a lot different than spoken English. To attempt to mix the spoken English language and ASL creates yet another barrier.

For example, a doctor had an interpreter present with a deaf patient who is living with HIV. The patient

questions if he needs to finish his bottle of medicine. The doctor explained that he must finish it. The patient came back to the doctor for his quarterly visit and the doctor asked how he doing with the medicine. He said that he had finished it a while ago. The doctor questions why he didn’t have it refilled. He explained that he thought he only had to finish one bottle of pills and not the refills. This type of misunderstanding that had occurred between the patient and doctor—an information communication barrier—raises concern about the patient’s health.

Q: What is the deaf community’s most common vehicle for obtaining information?

Chad: A common vehicle for getting information to the deaf community is through the community grapevine. The grapevine may be viewed negatively, although it is very useful for many members within the deaf community. There are some members that don’t have access to written information. There are some members who are educated in certain specialties. There are some members who are actively involved in other areas. These members attend social gatherings, club meetings, and main events and would exchange information among the members so that the information could be constantly updated among themselves.

There are also many electronic bulletin boards, newspapers, magazines, and videotapes that are used to disseminate the information among deaf community members.

Q: Are deaf people more or less at risk for HIV/STDs than other populations?

Chad: Some research has shown that “high rates of substance abuse exists among the deaf community, one in seven (1 in 7) deaf persons has a history of substance abuse, compared to one in ten (1 in 10) in the hearing population.” Substance abuse can be a risk factor for HIV by lowering inhibitions and impairing judgement, which can lead to unsafe sexual behaviors. Sharing injection equipment is also a risk for HIV transmission. (See “What are risk factors for HIV?” in the University of California, San Francisco Center for AIDS Prevention Studies fact sheet, *What are deaf persons’ HIV prevention needs?*)

Given that information, auditory and communication barriers could create risks for members of the deaf community to become infected with HIV/AIDS and sexually transmitted diseases (STDs). If a member cannot access spoken English and/or comprehend the English language, this could increase the risk of becoming infected with HIV/AIDS and STDs.



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Q: Are deaf people discriminated against in health care? As with many minority groups, is cultural competency an issue among deaf people trying to obtain health services?

Chad: Discrimination occurs when a health care professional refuses to fulfill a deaf person's communication needs such as providing an interpreting service. Some deaf people attempt to obtain the health service and are refused just because they don't know the resource, information, or who to contact.

Some deaf people attempt to contact the health service by using the relay service, but are hung up on just because the health care facility was not able to handle the relay call or felt that it would take too much of their valuable time. And, a cultural issue may arise when language and/or communication becomes a barrier between a deaf person and a health care provider—this would make a deaf person feel that the service is not adequately fulfilling his or her needs.

Q: How does the CDC National AIDS Hotline TTY Service address those issues and meet the health information needs of the deaf community?

Chad: The CDC NAH is available as an information, resource, referral, and technical assistance service. It contributes to health care by providing a better service to the members within the deaf community.

Q: Do you do any outreach to deaf minorities?

Chad: Yes, the CDC NAH does outreach to the deaf minority community by promoting materials via the electronic mail, Internet, newspapers, magazines, newsletters, mass mailings, mass e-mails, video conferences, group calls, classroom calls, and by participating in the deaf-related events such as conferences and community gatherings. By doing so, we increase the visibility that allows the deaf community to use the CDC NAH as an information, resource, referral, and technical assistant.

Q: How does someone access the Hotline?

Chad: Callers can access our service by using TeleTYpe (TTY) equipment. TTY is equipment that allows the individual to place a call to another party who has TTY equipment and/or using the Relay Service to get connected to another individual who doesn't have TTY. The TTY is a machine that allows an individual to effectively communicate the information to a person on another end. To access the CDC NAH's TTY Service, one needs to use either TTY or relay service to get through to the TTY operator.

More information: The CDC NAH is operated under contract by the American Social Health Association (ASHA).

For further information write to P.O. Box 13827, Research Triangle Park, NC 27709, or browse the Web site: <http://www.ashastd.org>; or the teen Web site: <http://www.iwannaknow.org>. Access the hotline at 1-800-AIDS-TTY; 919-361-8454 TTY; 919-361-8484 TTY2; 919-361-4855 FAX

Note: between December 15th and the end of this year, the ASHA will be launching a new, video-enhanced Web site which allows ASL users to click on the Internet and be able to view signed information and prevention messages on HIV/AIDS.

In addition to his role at the CDC National AIDS Hotline, Chad Ludwig is chair of the National Coalition on Deaf Community and HIV/AIDS (NCDH). He can be contacted by e-mail at: chadludwig@earthlink.net. The NCDH's address is - Dann Trainer, IV; NCDH Secretary; PO Box 8401; Minneapolis, MN 55408. ❖

CDC National AIDS Hotline TTY Service

Many people have questions about HIV/AIDS and don't know where to get answers. The CDC National AIDS Hotline TTY Service can help.

- Trained staff are available to answer questions and talk about HIV and AIDS and other sexually transmitted diseases.
- They can mail informational brochures that explain details about HIV and AIDS testing, prevention, and more.
- They can put people in touch with many different services all over the country.



1-800-243-7889 • All calls are free and private.

