

# what are deaf persons' HIV prevention needs?

## are deaf persons at risk for HIV?

Yes. It is estimated that 7,000 to 26,000 deaf persons in the US are infected with HIV.<sup>1</sup> However, the Centers for Disease Control and Prevention (CDC) does not currently collect information on deafness and HIV or AIDS. Maryland was the first state to include questions about deafness in its HIV counseling and testing forms. In Maryland, 4.3% of the deaf population is HIV+ (infected with HIV).<sup>2</sup>

*There are about two million deaf Americans, and one out of every ten Americans has some hearing loss. The deaf have long struggled for equal access to medical and social services, and equality in jobs and education. In the US today, there is still very little information on HIV and deafness, few prevention or treatment services and scarce research.*<sup>3</sup>

## what are risk factors for HIV?

High rates of substance use exist 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.<sup>3</sup> 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.

*There is very little HIV or sexuality education in schools for the deaf, especially for adolescents. Because of this, deaf persons have much less knowledge and awareness of HIV transmission, prevention and treatment. If deaf children don't learn about HIV and other sexually transmitted diseases, they won't have the vocabulary necessary to talk about these topics with each other. One study of students at schools for the deaf found that adolescents in 9-12 grade had extremely limited knowledge of AIDS. Students knew correct answers to only 8 of 35 basic questions asked about AIDS.*<sup>4</sup>

Deaf men who have sex with men (MSM) may face discrimination from within the deaf community. For this reason, deaf MSM often conceal their identity and may engage in furtive, anonymous and high risk sexual behaviors. Many deaf MSM also seek out hearing MSM for relationships, which makes communication about safer sex practices difficult.<sup>3</sup>

*Children with disabilities, including deaf children, have been found to be at greater risk for sexual abuse, both at residential schools and at home. One study of deaf and hearing children at a language institute found that 54% of the deaf boys reported abuse, compared to 10% of hearing boys. Deaf girls reported 50% rates of abuse, compared to 25% of hearing girls.*<sup>5</sup> *Childhood sexual abuse is a strong indicator for risky sexual and substance use behavior and HIV infection as an adult.*<sup>6</sup>

## what are barriers to prevention?

For the majority of deaf persons in the US, American Sign Language (ASL) is their primary language, and English the second language. ASL is a complex language of signs and gestures with its own grammar and syntax. The only way to communicate in ASL is face to face. There are only sporadic materials on HIV/AIDS available in written, graphic ASL. Although some deaf persons can read written materials such as pamphlets used in HIV prevention, for deaf persons with limited English skills, they are ineffective.<sup>7</sup>

*ASL communicates largely in concepts, so many English phrases and idioms don't make sense to persons with limited language skills. For example, there is no word for AIDS in ASL, and HIV-positive cannot be interpreted in ASL because "positive" means something good. ASL interpreters for HIV/AIDS issues may require special training to be able to address openly and frankly complex issues of sexuality and drug use.*

The deaf community is very tight knit, which can offer strong support and strong condemnation at times. Confidentiality is very important in this community where news travels fast. Many deaf persons would rather go alone to an all-hearing HIV testing and counseling clinic and risk miscommunication and misunderstanding, than bring an interpreter or go to a deaf clinic and risk being recognized and losing confidentiality.<sup>8</sup> Home test kits are no more confidential, as deaf persons must use an interpreter using a regular phone or call through a Relay Service agent to get test results.

## Says who?

1. Friess S. Silence = Deaf. *Poz Magazine*. April 1998. p.60-63.
2. Personal communication. Department of Health and Mental Hygiene, State of Maryland. 1999.
3. Peinkoffer JR. HIV education for the deaf, a vulnerable minority. *Public Health Reports*. 1994;109:390-396.
4. Baker-Duncan N, Dancer J, Gentry B, et al. Deaf adolescents' knowledge of AIDS. Grade and gender effects. *American Annals of the Deaf*. 1997;142:368-372.
5. Sullivan PM, Vernon M, Scanlan JH. Sexual abuse of deaf youth. *American Annals of the Deaf*. 1987;132:256-262.
6. Whitmire Johnsen L, Harlow L. Childhood sexual abuse linked with adult substance use, victimization, and AIDS-risk. *AIDS Education and Prevention*. 1996;80:44-57.
7. Campbell D. AIDS and the deaf community. *ADVANCE for Speech-Language Pathologists & Audiologists*. April 26, 1999; p.10-11.
8. Morrone JJ. Peer education and the deaf community. *Journal of American College Health*. 1993;41:264-266.

## what can help in prevention?

Better understanding of the strengths of the deaf community can help HIV prevention efforts. Because the deaf community is tight knit, there is a greater degree of physical and emotional intimacy. The visual nature of ASL requires addressing sexual and drug use issues openly and frankly. When these topics are brought up, deaf persons often have greater comfort discussing sexuality and drug use, which can help in understanding and negotiating safer behaviors.<sup>8</sup>

*Deaf institutions must address issues that have traditionally been hidden or taboo in their community, such as alcohol and drug abuse, childhood sexual abuse and homophobia. In 1998, the National AIDS Hotline sent over a thousand letters to state schools for the deaf offering an educational program on AIDS for deaf or hard of hearing students. Only three schools responded to the program.<sup>7</sup>*

## what's being done?

A program developed by Gallaudet University's Mental Health Center provides HIV/AIDS training to mental health professionals who work with deaf persons. The training program provides visual tools to use with the deaf community, such as captioned videos, drawings, group activities and models of how HIV attaches to cells.<sup>9</sup>

*In Paris, France, a mobile AIDS prevention unit (EMIPS in French) used a variety of programs to target deaf adolescents both in and out of deaf schools. A young deaf educator visited deaf schools and presented an intervention in sign language. The program created several visual images in public ads that dealt with false beliefs about HIV risk. The program also opened a walk-in HIV testing clinic with a doctor using sign language. However, the clinic was not widely used because it was too much identified with AIDS. When the program opened a sign language HIV test center in a general clinic, it was much more successful.<sup>10</sup>*

The Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals provides treatment for alcohol and other drugs for deaf persons in the US and Canada. All staff members are specially trained in deafness and substance abuse, and they have developed therapeutic approaches without communication barriers. The program also provides training for students and professionals working with deaf persons. They have a resource center that disseminates materials and provides funding for interpreters to attend AA/NA meetings.<sup>11</sup>

## what still needs to be done?

Comprehensive education and outreach are needed in the deaf community, not just around AIDS and HIV, but around the larger issues of sexual health and substance use. Schools for the deaf need to provide education about sexuality and substance use and provide counseling for children and adolescents who have experienced abuse. Programs for the deaf should address issues specific to the deaf community, such as negotiating safer sex with a hearing partner, advocating for health care services and breaking down barriers about sexual abuse and substance abuse among deaf persons.

*HIV prevention programs for deaf persons need to be as clear and as visual as possible. Programs should not be designed as presentations alone, but should incorporate physical activities, longer time for discussions, pictures, dolls, graphic manuals in ASL and captioned videos to make sure concepts are understood.<sup>12</sup> To access deaf communities, researchers and service providers should take advantage of advances in technology such as interactive video and the Internet.<sup>13</sup>*

Although there has been effort to educate the deaf community on HIV/AIDS at all levels, there continue to be great discrepancies in getting crucial information out to the target population. The CDC and states need to add questions about disabilities when collecting HIV statistics in order to document the extent of the epidemic in the deaf population. More programs are needed to help increase knowledge and dispel myths about HIV transmission and risk behaviors of deaf persons. The few popular programs that exist need to be evaluated and replicated across the country.

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9. Sleet S. HIV/AIDS education efforts have missed deaf community. *American Psychological Association Monitor*. 1999.

10. Grivois L, Houette A. Outreach programs towards deaf people targeting prevention of AIDS. Presented at the 11th International Conference on AIDS, Vancouver, Canada. June 1996. Abst. #MoD240.

11. Program celebrates ten years. *Steps to Recovery*. Published by the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals. Spring/Summer 1999. <http://home.earthlink.net/~drbl-ood/minn/minnhome.htm>

12. Gaskins S. Special population: HIV/AIDS among the deaf and hard of hearing. *Journal of the Association of Nurses in AIDS Care*. 1999;10:75-78.

13. Lipton DS, Goldstein M, Wellington Fahnbulleh F, et al. The interactive video-questionnaire: a new technology for interviewing deaf persons. *American Annals of the Deaf*. 1999;141:370-378.

### Resources:

CDC National AIDS Hotline  
TTY Service  
American Social Health Association  
1-800-243-7889  
(same as) 1-800-AIDS-TTY  
[www.ashastd.org/nah/tty.html](http://www.ashastd.org/nah/tty.html)