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❖ THE DEAF AND HARD OF HEARING AND HIV/AIDS ❖

According to the National Center for Health Statistics (NCHS), 3.3 percent of U.S. adults aged 18 years and over were deaf or had a lot of trouble hearing without the use of a hearing aid during the period 2000–2006.¹ Deafness or being hard of hearing increased with age, rising from 0.9 percent among adults under age 45 to 3.1 percent among adults aged 45–64 and 11.1 percent among adults aged 65 and over.¹ In 2006, 37 million adults in the United States had trouble hearing (ranging from a little trouble to being deaf), representing a marked rise from when 31.5 million U.S. adults reported trouble hearing in 2000.^{2,3}

The deaf and hard of hearing exist within a unique and vibrant culture, a fact not always appreciated by hearing individuals. Many advocates believe that recognition by the hearing public that a deaf culture exists is a crucial first step toward educating the Nation about the needs of the deaf and hard of hearing who are living with HIV.

SURVEILLANCE

- ❖ Because studies on the deaf or hard of hearing are limited, it is unclear how many people in this subpopulation are living with HIV/AIDS. Estimates fall into a wide range of 8,000 to 40,000 people, based on two different studies, one indicating a seroprevalence rate of slightly less than 1 percent, and the other of approximately 5 percent.⁴ A Maryland study based on test results at federally funded counseling and testing centers, which historically account for no more than 12 to 15 percent of all HIV-positive test results, yielded a 4.3 percent rate.⁵
- ❖ National AIDS surveillance data do not include information on hearing status; thus, little is known about the

transmission of HIV among the deaf and hard of hearing. In 1992, however, 12 years after the onset of the epidemic in the United States, experts estimated that the deaf population was 8 years behind the hearing population in its knowledge and awareness about HIV/AIDS.⁶

Critical Issues

The NCHS reports that adults with hearing loss have poorer health and increased risk of engaging in health risk behaviors than adults with good hearing.¹ The rate of substance use disorder among deaf or hard of hearing is higher than among the general population.⁷ Substance use, in turn, is linked to higher risk for HIV infection.⁸

Physically disabled persons report low discussion rates with their health care providers on sexuality, sexually transmitted diseases, contraception, and reproductive choices.⁹ A study in the *Annals of Internal Medicine* reported that doctor-patient communication is severely limited for the hearing impaired, leading to negative perceptions of the health care system, difficulty making appointments, and increasing anxiety and medication dosing errors.¹⁰

Undergraduate deaf college students scored significantly lower on the HIV/AIDS Knowledge Index than hearing undergraduate students.¹¹ This lack of knowledge about HIV disease contributes to the fact that the deaf are often not diagnosed with HIV until symptomatic and die sooner than hearing individuals.⁶

Many people erroneously assume that American Sign Language (ASL) and English are closely related and that most ASL users have high English proficiency, but the truth is that ASL has its own grammar and syntax and communicates in concepts.



As a result, HIV prevention and treatment materials are often culturally inappropriate and linguistically incomprehensible for the deaf and hard of hearing. Developing communication methods appropriate for the deaf or hard of hearing may help reduce health risk behaviors in this population and ensure equal access to health services.^{12,10,1} These methods may include peer-to-peer communication, as research suggests that the deaf are more likely to learn from each other rather than from formal information sources.¹³

Deaf gay men report feeling additionally stigmatized for being “a minority within a minority.”¹⁴ According to one study, many deaf gay men believe that HIV infection is inevitable.¹⁴

HRSA'S RESPONSE TO THE ISSUES

The deaf and hard of hearing receive services through all Ryan White HIV/AIDS programs. Access to services is facilitated by translators, who can be reimbursed using Ryan White HIV/AIDS Program funds.

The HIV/AIDS Bureau publication *HIV and the Deaf Population in the United States* discusses major issues regarding the diagnosis and care of HIV-positive deaf and hard of hearing individuals. (For copies, contact the HIV/AIDS Bureau's Office of Science and Epidemiology at 301-443-6560.)

The Health Resources and Services Administration (HRSA) took a leading role in the National Meeting on HIV/AIDS and the Deaf and Hard of Hearing Community in 2000.

A follow-up report outlines next steps for raising awareness of the epidemic among the deaf and hard of hearing and improving access to care. (For copies, contact the U.S. Department of Health and Human Services, Office of HIV/AIDS Policy, at 202-690-5560.)

HRSA also published an issue of the *HRSA CAREAction* newsletter on HIV/AIDS among the deaf and hard of hearing (see <http://hab.hrsa.gov/publications/hrsa401.htm>).

END NOTES

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- ¹⁴ Mallinson RK. Perceptions of HIV/AIDS by deaf gay men. *Assoc Nurses AIDS Care*. 2004;15:27–36.