

## **Deaf & Hard of Hearing: HIV Prevention Needs**

A summary of literature citations  
prepared by

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## Introduction

Although the prevalence of HIV among the deaf and hard of hearing (D&HH) in the US is estimated to be greater than among the general population (HRSA, 2001), there is still very little information on HIV and deafness, few prevention or treatment services, and scarce research (Peinkoffer, 1994). By summarizing a review of the available literature regarding D&HH individuals and HIV/AIDS, this report: (1) offers a definition of D&HH; (2) identifies categories within the D&HH population; (3) presents an overview of the epidemiological trends in HIV among D&HH; (4) discusses factors that may be associated with HIV/STD risk behavior among D&HH individuals; (5) describes the strengths and resources among D&HH individuals and their allies; (6) provides an overview of existing approaches and strategies to reducing HIV risk behaviors; and (7) offers recommendations for services and interventions for this population.

## Population Definition

Deaf people have a wide range of hearing loss, ability to process sound, and to understand speech. Deaf people have varying abilities to produce speech, related to the degree and frequency range of hearing loss and their age at its onset (HRSA, 2001). The deaf community consists of people who are culturally deaf known as *Deaf* people -- native and longtime users of American Sign Language (ASL) -- as well as *deaf* people who have hearing impairment but do not participate in Deaf Culture. This community is considered close-knit and homogenous and includes a number of hearing people -- parents, relatives of deaf children, friends, families and spouses of deaf adults, supporters, advocates, teachers, administrators, professionals and service providers (Kennedy & Buchholz, 1995).

## Population Categories

- Deafness is a hearing loss that precludes the learning of language through hearing (Northern & Downs, 1991).
- Hard of hearing describes hearing loss that, although serious, is less severe than deafness and usually permits understanding of spoken language through hearing aids (HRSA, 2001).
- Hearing impairment refers to all degrees of hearing loss, from slight to profound (Hunt & Marshall, 1999).
- AIDS Education/Services for the Deaf identify five categories of deaf and hard-of-hearing individuals:
  - Members of the *Speech Emphasis Group* call themselves “hearing impaired” rather than “deaf”; usually lack knowledge of the Deaf Culture and its values; prefer to socialize with members of the Speech Emphasis Group and hearing peers.
  - Members of the *Deaf Emphasis Group* are strong users of ASL and have a strong identification with the “Deaf World”; and socialize exclusively with Deaf peers.
  - Members of the *Pidgin Accultured or Contact Variety Group* are often leaders in the deaf community; they are able to function in both Deaf and hearing cultures; and they are often fluent in English, ASL and manual English.

- Members of the *Highly Visual Group* have minimal knowledge of English and ASL; they rely heavily on gestural and body expressive language; they tend to have poor social/interpersonal skills and don't use community resources and TTYs (Text Telephones).
- Members of the *Deaf Educated Group* tend to use English more than ASL when communicating; usually don't interact with the Deaf Emphasis Group and Highly Visual Group; have had formal advanced education; make extensive use of community resources.

### **General Epidemiology**

- The American Social Health Association estimates that approximately 10% of the US population is hearing impaired -- about 28 million individuals (HRSA, 2001).
- According to CDC, between 8,000 and 40,000 D&HH individuals are living with HIV disease in the US (HRSA, 2001). This wide range is based on two limited studies, one indicating a seroprevalence rate of slightly less than 1% and the other of about 5%. A Maryland study yielded a 4.3% rate based on test results at federally funded counseling and testing centers; however, these data do not present a complete picture since federally funded counseling and testing sites historically account for no more than 12-15% of all HIV-positive test results (HRSA, 2001).
- Since 1998, the CDC has evaluated medical records in 11 cities to estimate HIV prevalence among the D&HH, but to date no wide-scale seroprevalence study has been conducted.

### **HIV/STD Risk Behaviors**

As with any human, individuals belonging to this community may become at-risk for HIV infection transmission if they participate in the following risk behaviors: by having sexual intercourse (anal, vaginal, or oral sex) with an HIV-infected person; by sharing needles or injection equipment with an injection drug user who is infected with HIV; and from HIV-infected women to babies before or during birth, or through breast-feeding after birth. Currently, the number of HIV infections among the D&HH transmitted through heterosexual or same-sex sexual contact is unknown (HRSA, 2001). Below is a summary of factors reported among members of the D&HH community that may be associated with risk behaviors.

#### IDU/Substance use

- One in seven deaf persons has a history of substance abuse, compared to one in ten in the hearing population (Peinkoffer, 1994).

#### Access to Care, Information and Prevention

- The D&HH are at risk for poor access to society's educational, religious and social institutions. Moreover, there appears to be a shortage of prevention and care providers equipped to serve this population effectively (HRSA, 2001).
- As early as 1992, experts estimated that the deaf population was about 8 years behind the hearing population in HIV knowledge and awareness.
- There is a shortage of culturally competent providers as reflected in the dearth of culturally appropriate prevention and treatment education materials (HRSA, 2001).

- One study found that deaf undergraduate college students had significantly lower scores on an HIV/AIDS knowledge index than hearing students (Heuttel & Rothstein, 2001) with another study indicating that there were significant gaps in the amount of HIV/AIDS knowledge among D&HH students age 12-21 (Luckner & Gonzales, 1993). Another study of students at schools for the deaf found that adolescents in 9-12 grade had extremely limited knowledge of AIDS (Baker-Duncan et al., 1997).
- Although there may be attempts to share HIV/AIDS knowledge with D&HH students, deaf institutions may not be open to such assistance or topics. For example, in 1998, although the National AIDS Hotline sent over a thousand letters to state schools for the deaf offering an educational program on AIDS for D&HH students, only three school responded to the program (Campbell, 1999).

### Psychosocial Factors

- Potential poor self-esteem, isolation, learned dependence, and deficient social skills within the deaf community are risk factors for developing social problems. The high incidence of social problems such as rape/incest, domestic violence, and substance abuse within the deaf community may put many individuals at increased risk for HIV (Kennedy & Buchholz, 1995; Peinkoffer, 1994).
- Deaf men who have sex with men (MSM) may face discrimination from within the deaf community. For this reason, deaf MSM may conceal their identity and may engage in furtive, anonymous and high-risk sexual behaviors. Deaf MSM may also seek out hearing MSM for relationships, which makes communication about safer sex practices difficult (Peinkoffer, 1994).
- Children with disabilities, including deaf children, experience higher rates of sexual abuse than children who do not have disabilities. For example, 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 (Sullivan et al., 1987). For a collection of articles on sexual abuse and HIV visit the following website: [http://www.thebody.com/whatis/sex\\_abuse.html](http://www.thebody.com/whatis/sex_abuse.html).

### Communication

- Many deaf people, although intelligent, do not have a good command of written English. Lip reading ability varies from person to person and is generally ineffective for communicating since many spoken words look alike.
- 75% of the D&HH use the American Sign Language (ASL) with the most common second language being English and read, on average, on the 4<sup>th</sup> grade level (HRSA, 2001). ASL is a visually based language with little relation to English grammar or syntax thus making it impossible to sign true ASL while speaking at the same time (Joseph, 1993). Pidgen Signed English, Cued Speech, gesturing, drawing, lip reading, and signed English are also used among deaf individuals (HRSA, 2001).
- Lack of communication increases risk for a host of problems for the D&HH, including poverty, lack of education, disenfranchisement, and poorer health (HRSA, 2001).

- Access to interpretation services may be limited by financial resources, perceptions by providers that there is no need for such services, and a shortage of qualified interpreters (HRSA, 2001).
- Low literacy levels and hearing limitations reduce the ability of the deaf population to acquire accurate information about HIV/AIDS from sources that are widely used by the hearing population, including television, radio, and print media.

### **Resources and Strengths**

- The D&HH are protected under the Americans with Disabilities Act of 1990. With specific regard to medical treatment, the legislation provides a variety of accommodations such as TTY access, signal lights that are used to visually display fire alarms, doorbells, and closed captioning services.
- A study of state boards of education and state schools for the D&HH in 39 states/territories found that most of the schools are aware of and concerned about establishing and refining policies and procedures for managing HIV infected students in an educational settings. These efforts include the prevention and spread of the disease to students and personnel; safeguarding the student's right to an education; ensuring the rights of school personnel to a safe working environment; and educating students, personnel, parents, and the community about this important topic (Deyo, 1994).
- There is a networking system or deaf grapevine used to share information among the members of the deaf community. They are more likely to learn information from each other via this communication route rather than from formal information sources. A danger of this mode of communication is that myths, fallacies, and misinformation may be construed and shared as truth and facts (Gaskins, 1999).
- Bette Mentz-Powell from the WI Bureau for the Deaf and Hard of Hearing, Southern Region, conducted a survey among Wisconsin ASOs to determine the accessibility of services for deaf consumers. These services include TTY availability, qualified interpreters, deaf-specific educational materials, testing sites, etc.
- Nancy Emery, a health educator for D&HH communities at Communication Service for the Deaf in St. Paul, Minnesota, received a CDC Foundation Price Fellowship. This program provides leaders in non-governmental, community-based organizations the opportunity to spend a month at CDC gathering knowledge about HIV prevention among the deaf community.

### **Existing Approaches and Strategies to Reducing HIV Risk Behaviors**

- The best method for communicating with the D&HH is through graphics, photographs, and diagrams (HRSA, 2001).
- The Deaf AIDS Project in Maryland receives public funds to provide HIV prevention, technical assistance, HIV counseling and testing, and limited HIV case management. The Deaf AIDS Project provides educational opportunities and outreach to schools, rehabilitation centers, and organizations serving the deaf including social groups.
- Gallaudet University, located in Washington, DC, the world's only liberal arts university of deaf students, established a peer health education program in 1991. Peer health educators were recruited and trained to present workshops on HIV infection

and other sexually transmitted diseases, safer sex, contraception, and rape (Joseph, 1993). Another program 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 (Sleek, 1999).

- In Paris, France, a mobile AIDS prevention unit 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 (Grivois & Houette, 1996).
- 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 also have a resource center that disseminates materials and provides funding for interpreters to attend AA/NA meetings (Program celebrates ten years, 1999).

### **Recommendations for Intervention Approaches**

*(HRSA Care Action: HIV/AIDS in the Deaf and Hard of Hearing, 2001)*

- **Advocacy training and community involvement** is needed to improve the awareness among the D&HH of their legal rights, including access to care.
- **Surveillance and needs assessments** are needed to establish the scope of the epidemic among the D&HH population. To access deaf communities, researchers and service providers may take advantage of advances in technology such as interactive video and the Internet.
- **Technical assistance, provider education and capacity building** are needed for both members of the D&HH community and providers for this community.
- **Prevention and treatment materials for the D&HH** are crucial toward improving prevention and treatment education among the D&HH. 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.
- **Outreach to the D&HH** that is both culturally appropriate and based on social marketing theory is required to reach D&HH.
- **Program evaluations** of current prevention programs for the D&HH must be conducted in order to determine effective strategies for this population.

## Resources

- Deaf AIDS Support Services at the University of California, San Francisco Center on Deafness 415-476-7600 TTY, [uccd@itsa.ucsf.edu](mailto:uccd@itsa.ucsf.edu)
- Deaf AIDS Project, Baltimore, MD 410-889-8077 TTY, [www.deafvision.net/dap](http://www.deafvision.net/dap)
- AIDS Initiative for Deaf Services Task Force, Hartford, CT 860-951-4791 TTY [www.aidsprojecthartford.org/defaidsct.html](http://www.aidsprojecthartford.org/defaidsct.html)

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