

**InterGroup Services  
Client Report**

**An Assessment  
of the Needs of  
Deaf and  
Hard-of-Hearing  
Persons with HIV in  
the Baltimore Area**

**Client:** Associated Black Charities, Baltimore, Maryland

**Project:** Assessment of Health-care needs of Deaf, HIV-positive population

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## 1. EXECUTIVE SUMMARY

This study was undertaken by InterGroup Services (IGS), a Baltimore-based consulting company, under a contract with Associated Black Charities (ABC), the “administrative agency” for the Baltimore eligible metropolitan area’s (EMA’s) Title I program under the Ryan White Comprehensive AIDS Resources Emergency Act. (The “administrative agency” is authorized to receive Title I funds and distribute them to service providers according to priorities established by the Greater Baltimore HIV Health Services Planning Council.) The study’s purposes are threefold. First, it provides a review of relevant literature on the classification and prevalence of hearing disabilities in the U.S. and an assessment of the risk for and prevalence of HIV/AIDS in the deaf/hard-of-hearing (D/HH) community. Second, it presents the results of a survey of providers of HIV/AIDS services in the Baltimore EMA to determine the extent of hearing disabilities among their clientele and the nature of the services they offer, as well as the results of two provider focus groups and follow-up discussions. Third, it offers the results of a second survey of 91 D/HH individuals residing in the Baltimore EMA to ascertain their HIV status and other medical conditions, the nature of their interaction with health-care providers, and their unmet service needs.

### 1.1. Background on Hearing Impairments and HIV

At minimum, 10 percent of Americans are estimated to have some degree of hearing impairment. This group confronts substantial cultural and linguistic barriers in utilizing the health-care system. There is a noteworthy shortage of culturally competent providers capable of meeting their medical and related social services needs.

For purposes of this report, the most important categorization of hearing disabilities involves three groups: (a) the “hard of hearing,” who retain some hearing ability and benefit from such assistive technologies as hearing aids; (b) the “late deafened,” who lost their hearing after developing language skills; and (c) the “culturally deaf,” who are either congenitally deaf or lost their hearing in infancy, and whose first language is sign.

Deaf people usually employ one or more sign languages; the most common is American Sign Language (ASL), used by 70 to 75 percent of deaf Americans. The deaf also avail themselves of other means of communication, such as drawing, reading, lip reading and gesturing. They have differing abilities to produce speech, related to the nature of their hearing loss and the age of its onset.

Written communication with the deaf is impeded by the fact that their average reading capacity is at the fourth-grade level. This affects their ability to comprehend a variety of media. The most commonly employed means of overcoming obstacles to communicating with the deaf is the use of interpreters. In addition to interpreters, there are a variety of other types of “auxiliary aids” such as telephone handset amplifiers, written materials, telecommunications devices for the deaf (TDDs), videotext displays, and exchange of written notes. Ultimately, it is essential that deaf people be consulted by health-care providers and others about their preferences for use of interpreters or other auxiliary aids.

Among the qualities sought in the ideal interpreter are impartiality — something not always present in family members — and an ability to utilize specialized vocabulary (e.g., medical). Confronted by the challenges of obtaining qualified interpreter services, some health-care providers may tend to rely on printed materials and written notes. However, when a discussion is

likely to be long or complex, there is generally no substitute for an interpreter.

The most recent data from the National Health Interview Survey indicate that 14.7 percent of the population has “a little trouble hearing,” while 3.1 percent has “a lot of trouble hearing” or is deaf. Poverty is often correlated with deafness, but the causal linkage is typically such that deafness leads to poverty, not vice versa.

While little empirical information is available on the number of deaf and hard-of-hearing individuals living with HIV, the consensus is that HIV/AIDS is more prevalent in this group than in the non-deaf population. The best estimates available from the U.S. Centers for Disease Control and Prevention (CDC), based on two limited studies, are that between 1 and 5 percent of the deaf population is HIV positive, contrasted with 0.31 percent or less among the general population.

The deaf population shares risk factors with the hearing population, including engaging in unprotected sex and use of illicit intravenous drugs. However, the deaf population also confronts certain special risk factors, including greater risk for sexual and physical abuse, higher rates of substance abuse, ineffective sex and health education, limited HIV outreach, substantial obstacles to access to health care, and certain aspects of deaf lifestyles and preferences. These risk factors place them in greater jeopardy of contracting HIV.

While Maryland is the only state that uses HIV counseling and testing forms to collect data on HIV/AIDS prevalence among the D/HH population, there are limitations to the information available in Maryland. All we can say with safety is that in calendar year 2001, throughout Maryland there were administered 79,887 HIV tests. Positive results came from 1,384 of these (1.7 percent). Of the 79,887 test takers, 48,065 responded to the question about deafness (60.2 percent). Of these 48,065 answering the question, 707 answered in the affirmative, saying they were deaf (1.5 percent). And of these 707 respondents, 32 proved to be HIV positive (4.5 percent of 707). It is important to point out that this does *not* tell us that the HIV rate among the deaf is 4.5 percent, as against 1.7 percent in the general state population. For a start, the 1.7 percent rate is probably high, given that this is the rate among tests taken, and people motivated enough to take such a test may very well be prone to riskier behavior than others. Second, as for the rate among the deaf, all we can say is that 32 of 707 (or 4.5 percent) test takers known to be deaf tested positive for HIV, and that this more or less corresponds to the CDC’s upper-limit estimate of a 5 percent prevalence among the deaf. However, these Maryland data do not speak to the 39.8 percent of the statewide overall pool of test takers who did not answer the question about deafness and nor do they speak to the unknown — but certainly very large — number of people, deaf or not, who are never tested for HIV. As shall be discussed in the main body of this report, the situation in the Baltimore EMA is even more muddled, given a far smaller proportion of test takers answering the question about deafness.

## **1.2. Provider Survey and Focus Group Follow-Up**

Partly because of the dearth of information about provider experiences in providing HIV services to the deaf community, IGS conducted surveys of providers of HIV services in the Baltimore EMA. IGS initially distributed a questionnaire to 21 providers of such providers, 11 of which responded. Seven provided estimates of the percentage of their clients with hearing difficulties. Five of 7 estimated that between 0 and 10 percent of their HIV clients have trouble hearing what is said in normal conversation or have serious difficulty understanding other people when they talk.

A second step with providers entailed convening two focus groups, including seven representatives of six HIV service agencies. First, however, a second questionnaire was distributed, containing questions addressing the needs of hearing-impaired HIV clients. From this questionnaire, it was learned that only two of the seven representatives had access to on-site interpreters; others had to make special arrangements to secure interpreter services. On a scale of 1 to 10, with 10 being the best, providers were asked to rate their organizational referral network; responses ranged from 1 to 7, with 3.2 being the average.

During the course of focus-group discussions, the cost of hiring outside interpreters emerged as a concern. (The typical cost is \$90 per hour, with a two-hour minimum.) Yet providers also recognized a number of problems related to clients' bringing their own interpreters, the most important being confidentiality, objectivity and expertise about technical medical information. Possible client distrust of agency-provided interpreters and the need for continuity of interpreters were also discussed. While agencies had TTY (teletypewriter) capacity, the equipment was rarely used, partly because of its slowness.

Among the recommendations that emerged from the providers' discussions were making available cultural-competency training in working with deaf clients, production of a resource guide for referrals to other supportive services providers, and capitalizing on shared resources and other opportunities for collaboration.

### **1.3. Client Survey**

In the client survey component of this report, IGS contracted with the Deaf AIDS Project (DAP) to administer a 47-item questionnaire to adults with hearing impairments in the Baltimore EMA. Interpreters were used to assist clients individually in completing the questionnaires. Ninety-two people were interviewed, though only 91 sets of responses were usable.

Of the client group as a whole, 60.4 percent were deaf, 8.8 percent were late deafened, and 30.8 percent were hard of hearing. A sizable minority (13.2 percent) had left high school without graduating; respondents such as these may present special challenges to health-services providers because of limited literacy.

Slightly over 13 percent of the total group (or 12 individuals) were HIV positive — 5 were HIV positive with symptoms, while 7 were asymptomatic. None of those surveyed was diagnosed with AIDS. The relatively small total numbers — especially for the HIV-positive subgroup — suggest great caution in generalizing from this survey.

More than half of the HIV-positive and non-HIV-positive subgroups of the survey rated themselves in either excellent or very good health. While none of either subgroup rated his or her health as poor, 25.0 percent of the HIV-positive subgroup assessed it as only fair, twice as high a percentage as the HIV-negative subgroup.

In keeping with national data on HIV/AIDS, the HIV-positive subgroup included a higher percentage of African-Americans than the residual subgroup of clients — 75.0 percent versus 62.0 percent — and a slightly higher concentration of Hispanics (8.3 percent versus 6.3 percent).

The birth genders of the total client group were 57.1 percent female and 39.6 percent male, although the HIV-positive subgroup split evenly, half male and half female. All of those who were HIV-positive were under the age of 40, while the HIV-negative subgroup included 7.6 percent between the ages of 40 and 54.

With respect to household income, as might be expected from national data on HIV/AIDS, the

HIV-positive subgroup had a greater concentration of people at very low income levels — 75.0 percent had incomes of no more than \$7,500 annually, as contrasted with 59.3 percent for the non-HIV-positive subgroup.

Turning to sexual preferences, 58.3 percent of those who were HIV positive indicated that they were heterosexual, while 25.0 reported a gay/lesbian preference. This contrasted with the HIV-negative subgroup, of which 67.1 expressed a heterosexual preference, 6.3 percent a gay/lesbian preference, and 17.7 percent a bisexual preference. Altogether, almost 10 percent of the total client group declined to express a sexual preference.

Looking at risky behaviors, none of the HIV-positive respondents indicated that they had *not* engaged in the behaviors that were surveyed, for all of them apparently had. Almost 60 percent of the subgroup indicated that they had had sex without a condom and/or used alcohol or non-insulin needle drugs. Just over 40 percent noted that they had had sex with someone for drugs or alcohol. In contrast, 31.6 percent of the non-HIV-positive subgroup indicated that they had never engaged in any of these behaviors.

With respect to preventive interventions, it is striking that 33.3 percent of those who were HIV positive reported that they had *never* learned about safe sex, certainly a target of opportunity for health educators. Both subgroups of respondents showed a decided preference for receiving HIV/AIDS information from HIV/AIDS deaf clinics as against other potential sources.

One of the strongest findings to come out of the survey is that slightly over 40 percent of the HIV-positive subgroup did not know about HIV/AIDS deaf services but would use them if they did — clearly a major prospect for outreach by such services providers. Roughly a quarter of each subgroup — HIV-positive and non-HIV-positive — reported already using HIV/AIDS deaf services.

Sizable percentages of the client group as a whole (33.0 percent), and of the HIV-positive subgroup in particular (50.0 percent), reported getting regular attention from primary-care physicians, varying from once a month to once every 4 to 6 months. This seems to suggest that primary physicians with sizable practices among the hearing impaired might be a vehicle for outreach about deaf HIV/AIDS services as well as an important source of preventive education.

Of the HIV-positive subgroup, 75.0 percent indicated that they are sometimes or often confused about medications, while 67.1 percent of the non-HIV-positive subgroup indicated such confusion. Major obstacles to obtaining health care cited by the client group as a whole included: other bills to pay (19.8 percent), the distance to medical offices (18.7 percent), and being ignored or discriminated against by a nurse (17.6 percent). In the HIV-positive subgroup, one third cited each of these concerns, and one quarter reported problems with public transportation.

The survey results underscored the importance of interpreters to D/HH patients in their medical transactions. Fewer than 10 percent indicated that they did not use interpreters. Only 27.5 percent of the total client group reported never taking an interpreter with them during physician visits. An even smaller fraction of the HIV-positive subgroup — 8.3 percent — said they never took interpreters along when visiting physicians.

Turning to social services, the survey found a complex mixture of problems impeding access, including transportation, limited cash availability together with bills for other essentials, vocational rehabilitation services, attitudes towards clients' deafness, and lack of child care and counseling. While only 33.3 percent of the HIV-positive subgroup indicated that they knew where to get help with social services and health care, 41.7 percent of the subgroup reported that they had a counselor, an important resource in gaining access to these services.

Shifting focus to the care and needs of D/HH clients who are HIV positive, only 7 of the 12 people in this subgroup indicated that they had been tested for HIV. (It is not clear how the other five knew they were positive.) By far the most commonly cited problem confronting the HIV-positive subgroup involved the attitudes of nurses; fully half of the subgroup felt that they were ignored or discriminated against by nurses. Only 2 of the subgroup of 12, both in the symptomatic category, reported currently taking prescribed medications for HIV/AIDS. But five indicated that they had previously taken such prescription drugs and had discontinued them. Only three HIV-positive clients reported currently having a case manager — remarkably none of them in the HIV-positive-with-symptoms category. Three indicated that they did not know how to get a case manager. It is noteworthy that none of the 12 indicated that he or she did *not need* or did *not want* a case manager. Thus, case management for the HIV-positive D/HH population appears to be a major unmet need.

Once again, it is worth remembering that the small total numbers — especially in the HIV-positive subgroup — warrant particular caution in generalizing from the survey.

— *InterGroup Services, Inc.*

## 2. BACKGROUND

In December 2002, Associated Black Charities (ABC) contracted with InterGroup Services, Inc. (IGS), a project-management consulting company in Baltimore, to conduct a needs assessment of the health-care needs of deaf and hearing-impaired persons with HIV and/or AIDS in the area. The Baltimore City Health Department contracts with ABC to serve as the “administrative agent” for the Baltimore eligible metropolitan area’s Title I program under the Ryan White Comprehensive AIDS Resources Emergency Act, generally known as the CARE Act. The administrative agent is the “lead, or administrative, agency...authorized to receive funds and distribute them to service providers following service priorities established by the pertinent planning body” (IGS 2002:74). In Baltimore, the recipient of federal funds is the municipal health department, which passes these moneys to ABC for distribution to area HIV service providers. ABC also monitors the providers’ compliance with their contractual obligations for service delivery. The administrative agent distributes funds to providers in a manner congruent with the service priorities established annually by the local Title I planning entity, the Greater Baltimore HIV Health Services Planning Council (usually just known as the planning council).

In August 2002, the planning council identified the deaf and hard-of-hearing population as having special unmet needs. In September, the council requested funds for a needs assessment targeting this subpopulation, providing specific attention to D/HH infected persons who know they are positive but who are not receiving primary medical care. Findings from this report are intended to provide the council with information to plan for service dollars that have been set aside under the Ryan White service category of case management for the deaf and hard-of-hearing population.

The approach that IGS employed was three-pronged. First, a literature review was undertaken to ascertain basic facts about hearing disabilities in the United States, including categories of disability, modes of assisting people with hearing disabilities, prevalence of such disabilities, special risk factors for HIV/AIDS among those with hearing disabilities, and prevalence of HIV/AIDS among the deaf and hard of hearing. Second, IGS sent a survey to 21 providers of HIV/AIDS services in the Baltimore EMA, to determine the fraction of their clientele who had hearing disabilities and the services that were made available to them; responses were received from 11 providers, and two focus groups were subsequently held with providers. Information about best practices in serving the D/HH population was also solicited from all providers. Third, in collaboration with the Deaf AIDS Project (DAP) at the Family Service Foundation, IGS developed a detailed survey questionnaire. This was then administered by the DAP to 92 people (rendering 91 usable sets of data), with varying degrees of hearing disability, to learn such things as their HIV status, basic demographic information, their health status and the nature of their interaction with the health-care system, their need for and use of interpreters when receiving medical attention, the modes by which they were educated about safe sex and HIV/AIDS, and their engagement in risky behaviors. The survey was only administered after the questionnaire had been presented to the Baltimore City Health Department’s Human Subjects Review Committee to assure that it met the department’s standards for participants’ confidentiality and safety. The results of all three of these efforts constitute the body of this report. Copies of the questionnaires used are included in the appendices.

### 3. HIV AND THE DEAF COMMUNITY

“People with hearing loss form the largest disability group in this country.”

— *Stebnecki and Coeling 1999*

It is estimated by the American Social Health Association that there are about 28 million hearing-impaired individuals in the United States — approximately 10 percent of the U.S. population (HRSA 2001a:1). The deaf and severely hearing impaired are at a great disadvantage when attempting to utilize the existing health-care system. From both the provider and patient perspectives, the biggest impediments to serving deaf and hard-of-hearing individuals are cultural and linguistic barriers. These communication barriers make it difficult for providers to understand and address the needs of D/HH patients. Likewise, D/HH patients are frustrated in their attempts to convey their needs or understand their treatment, which in turn leads to non-compliance. As a result, lack of adequate “access to health care combined with a shortage of culturally competent providers [result] in poorer health status and quality of life for many individuals who are deaf or hard of hearing” (HRSA 2001a:1).

#### 3.1. Medical Categories of Hearing Loss

There are two scales upon which to measure sound: (a) loudness, measured in units called decibels (dB) and (b) pitch, measured in units called hertz (Hz). Hearing impairments can occur in one or the other or both of these dimensions, and in one or both ears. According to the National Information Center for Children and Youth with Disabilities (NICCYD), “Hearing loss is generally described as slight, mild, moderate, severe, or profound, depending upon how well a person can hear the intensities [i.e., loudness] or frequencies [i.e., pitch] most greatly associated with speech” (NICCYD 2003).

The NICCYD notes that there are four types of hearing loss: (a) “conductive hearing loss,” caused by diseases or obstructions in the outer or middle ear (the conduction pathways for sound to reach the inner ear); (b) “sensorineural hearing loss,” resulting from damage to the delicate sensory hair cells of the inner ear or the nerves which supply it; (c) “mixed hearing loss,” a combination of conductive and sensorineural loss, meaning that a problem occurs in both the outer or middle and the inner ear; and (d), finally, a “central hearing loss,” resulting from damage or impairment to the nerves or nuclei of the central nervous system, either in the pathways to the brain or in the brain itself. Conductive hearing loss generally affects all frequencies evenly. It can often be helped by hearing aids, surgery and/or medication. Sensorineural hearing loss, on the other hand, often affects a person’s hearing of certain frequencies more than others, which can result not only in diminished hearing but also in distorted hearing, limiting the usefulness of hearing aids.

#### 3.2. Cultural Categories of Hearing Loss

Section 3.1 outlines deafness as a medical condition, but it is vital to understand that there is a distinct cultural element to deafness as well. As defined by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services, “deafness” is a hearing loss that precludes the learning of language through hearing, while the term “hard of hearing” describes hearing loss that, although serious, is less severe than deafness and usually permits understanding of spoken language through hearing aids. The general term, “hearing

impairment,” refers to all degrees of hearing loss, from slight to profound (HRSA 2001a:1).

There are essentially three distinct groups within the deaf and hearing-impaired population: (a) the hard of hearing, (b) the “late deafened,” and (c) the “culturally deaf.” The largest of these groups is the hard of hearing. Members of this group usually retain some residual hearing and can benefit from hearing aids and assistive listening technologies. Most hard-of-hearing individuals do not know sign language, and view their hearing loss as a disability.

The members of second group self-identity as “late deafened.” These people are audiologically deaf, but lost their hearing after developing language skills, that is, relatively late in life. If they sign, it is a second language, tending to follow the English pattern of speech. People in this group also generally consider themselves disabled but see themselves as living between the two worlds of hearing and deafness.

The third group is comprised of the “culturally deaf,” individuals who are either born deaf or lose their hearing in infancy. Because their hearing was lost before the development of oral communication skills, their first language is sign. In light of their personal history, this group is in some respects very different from the previous two, its members considering themselves to have a unique culture and describing themselves as “different,” not “disabled.”

### 3.3. Deaf Culture

“Hearing people often don’t realize the need to be culturally sensitive to this minority because it doesn’t occur to them that this is another culture,” says Mary R. Lester, author of “AIDS in the Deaf Community” (Lester 1999). Most Americans, including the majority of health-care providers, view deafness and hearing loss as a disability, but deaf people “don’t want to be viewed as disabled people needing to be ‘fixed,’” according to Nancy Emory of the Minnesota Communication Service for the Deaf (Emory n.d.).

Instead, deaf people view their lack of hearing as a difference. The sharing of common language, experiences, history of struggle and ridicule, mannerisms, social activities, publications, values and concerns creates a sense of community and a distinct culture. One result of this cultural identity is that deaf people who do not use sign language may *not* be considered part of the deaf community, while some hearing people who do sign *are* considered part of it (Stebnecki and Coeling 1999).

A label like “hearing impaired,” “deaf and dumb” or “deaf mute” is considered undesirable because it refers to a presumed disability. Deaf people prefer to view deafness not as a handicap but as a shared experience underlying their sense of community. As a symbol of pride and identity within this community, the word Deaf is often capitalized when referring to this group (Stebnecki and Coeling 1999).

### 3.4. Communicating with the Deaf

The deaf usually converse using one of several different sign languages, or sometimes a combination of two or more. Communication can also include drawing, reading, flashing lights, lip reading and gesturing (e.g., pointing, shoulder tapping and waving). The ability to lip read varies by individual and is considered ineffective, as spoken words often look similar. And “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 2001a:2).

The most common sign language is American Sign Language (ASL), which is used by 70 to 75

percent of the deaf population in this country. This makes ASL, which is the native language of an estimated 500,000 to 1 million users (Emery n.d.), the third most common language in the U.S. (HRSA 2001a:2). Sign languages are visual languages of signs and gestures that have their own structure, grammar, syntax and vocabulary. Accordingly, many of these methods of communication have more in common with the Chinese language than with English communication (Shupe 2003). Further complicating translation are the use of (a) “home signs,” made up and used by the family and (b) regional signs, specific to certain geographical areas and analogous to local spoken dialects (Duvall 2000). In addition, the lack of direct translation between sign and English is further complicated by the use of English phrases or idioms for which there is no comparable sign. As a result, English for the deaf and culturally deaf population can be considered “a second language” (Lester 1999).

Written and passive communications are also obstructed to varying degrees. For instance, effective written communications are impeded by the fact that the average reading ability of the deaf is at the fourth-grade level (Sleek 1998). “Because members of the general public often assume that the deaf read and write English without difficulty, a great deal of important information is never translated appropriately and thus never communicated” (HRSA 2001a:2). The same is true of passive communications. “Public service announcements have often not been closed captioned. Education and prevention curricula in the schools have not accommodated the communication skills of deaf or hard-of-hearing children and have been insensitive to their culture” (SAMHSA 1998). All of these factors impede the direct translation of information imparted by hearing individuals, and make comprehension of English instructions very difficult (Determan *et al.* 1999).

### **3.5. Qualified Interpreters and Limited-English Written Materials**

Given the verbal and written limitations in communicating between a deaf person and non-signing hearing person, described above in section 3.4, the most common solution is to use an interpreter. In most instances, this method is consistent with the requirements of Title III of the Americans with Disabilities Act of 1990 (ADA), as long as the translator is a “qualified interpreter.” The ADA defines such a qualified individual as “an interpreter who is able to interpret effectively, accurately and impartially both receptively and expressively, using any necessary specialized vocabulary.”

There are three important concepts in this definition, especially relevant to health-care settings. The first is the ability to communicate effectively with both parties. According to the U.S. Department of Justice, which has responsibility for enforcing the ADA,

Signing and interpreting are not the same thing. Being able to sign does not mean that a person can process spoken communication into the proper signs, nor does it mean that he or she possesses the proper skills to observe someone signing and change [his or her] signed or finger spelled communication into spoken words. The interpreter must be able to interpret both receptively and expressively (DOJ 1991/1994).

At the outset, the health-care provider, who is responsible for arranging for the type of “auxiliary aid” needed to ensure effective communication, should consult with the client, though the provider “is not obligated to comply with the unilateral determination by the patient that an interpreter is necessary.” The provider may select another form of auxiliary aid although, if the patient is not satisfied, he or she may sue or file a complaint under Title III of the ADA (DOJ 1991/1994). The Department of Justice gives as examples of auxiliary aids and services: “qualified interpreters, note takers, computer-aided transcription services, written materials,

telephone handset amplifiers, assistive listening systems, telephones compatible with hearing aids, closed-caption decoders, open and closed captioning, telecommunications devices for deaf persons (TDDs), videotext displays, and exchange of written notes” (DOJ 1991/1994). Deciding the most suitable form of auxiliary aid is no easy matter. For instance, a hard-of-hearing person who is “oral” — that is, hearing impaired but able to communicate verbally — may use a TDD/TTY to schedule an appointment over the telephone, but not require the services of an interpreter during the in-person medical visit. (“TTY” stands for “teletypewriter.”) Likewise, given the multiple sign languages and methods of communication, an effective interaction means that “the interpreter’s communication must be compatible with that of the deaf individual; therefore, it is important that the deaf individual be consulted on the choice of interpreter,” according to the Registry of Interpreters for the Deaf, or RID (RID 1997).

The second notable component in the definition of a “qualified interpreter” is impartiality. Family members are rarely impartial, which is one of the reasons not to rely on them to provide interpretation for the client. “The relative may have attitudinal or emotional issues that could affect objectivity and impartiality and prevent accurate communication. For example, a family member might feel compelled to ‘protect’ the patient from painful news, or to withhold potentially embarrassing information,” says the RID (1997). Other drawbacks of relying on someone close to the patient are: (a) the potential for a breach of medical privacy; (b) the inability or unwillingness of the patient freely to express problems, especially in situations of domestic abuse; and (c) the lack of assurance that the translator can adequately interpret medical information.

The third important factor in defining a “qualified interpreter” is the ability to use any necessary specialized vocabulary. Even certified interpreters “may not meet this standard in all situations, e.g., where the interpreter is not familiar with the specialized vocabulary involved in the communication at issue” (DOJ 1991/1994). This is particularly true in a health-care setting where a practitioner with years of scientific and specialized training communicates medical terms and treatment modalities. Further exacerbating this communication barrier is the lack of formal education and incidental information about health issues on the part of the deaf. In many instances, the communication barriers may impede true informed consent. “Inaccurate or incomplete communication in general can cause greater risk than no communication. This may jeopardize patient care and become a liability issue” (RID 1997).

Given the many challenges in obtaining qualified interpreter services, health-care providers may be tempted to rely on written notes and other printed materials. In some instances, such as routine visits, this may be adequate. However, when the discussion is likely to be long or complex, the services of an interpreter are likely to be necessary. This extends beyond the physical examination and may include intake, counseling, case management, referrals and assistance with paperwork for insurance or other benefits.

One other caution with regard to printed materials relates to reading proficiency of many D/HH clients: the comprehension level of written communications in the non-native language is often limited. This is especially true of many in the deaf population who, “although intelligent, do not have a good command of written English” (HRSA 2001a:2). Beyond this group lies another group, proficient in neither English nor sign language. These people are known as “minimally language skilled” (MLS) deaf individuals. MLS individuals are not fluent in ASL, English or any other language, according to Jason Barth, former director of the DAP (HRSA 2001a:2, 6), which administered the surveys used for this study.

Therefore, providers should not be complacent about relying solely on text-heavy brochures and instructions as their primary means of communication with the D/HH population. These materials

may not be an effective form of communicating, especially when the client has difficulty comprehending information due to the stress of the situation. Instead, advocates for this population emphasize that, when it comes to prevention and treatment, “the best method for communicating with the deaf and hard of hearing is through graphics, photographs and diagrams” (HRSA 2001a:4). Visual aids are always helpful for reinforcing instructions, for conveying complex concepts and intricate processes (e.g., how the body works or medication schedules), and as reference materials that can be continually utilized by the client.

### **3.6. Prevalence of Deafness and Hearing Impairment**

There is a general lack of information about the prevalence of hearing impairments within the U.S. population. As a result, a very large number of households must be sampled in order to generate valid statistical estimates of the population size, which makes data collection through surveying extremely costly to implement. Such data collection is therefore rarely undertaken.

One traditional source of data for estimating prevalence is from health-care claims. Unfortunately, any chronic disabilities an individual may have are generally not recorded as part of the claims format. Moreover, few services or products that would identify a hearing impairment are covered by third-party payers. For instance, Medicare does not provide reimbursement to cover routine hearing exams or hearing aids, and only in some cases does Part B cover hearing exams (CMS 2003:24). Similarly, interpreter services are non-billable and thus do not appear on claims for reimbursement.

One available data source that can provide an estimate of the prevalence of hearing impairment within the U.S. population is the National Health Interview Survey (NHIS), which is “a multistage probability sample survey conducted annually by interviewers of the U.S. Census Bureau for the National Center for Health Statistics, Centers for Disease Control and Prevention, and [which] is representative of the civilian noninstitutionalized U.S. population. Data are collected during face-to-face interviews” (CDC/NCHS 2002). This survey, funded and conducted by the federal government, is the only one on health issues large enough to generate reliable statistical estimates on the deaf. The two most recent NHIS surveys with information on the deaf were conducted in 1994 and 1997.

#### **3.6.1. National Health Interview Survey/Disability Module, 1994**

The Disability Module of the 1994 National Health Interview Survey (NHIS-D) estimated that 4.5 million Americans “use hearing aids, amplified telephones, closed-caption television, and other assistive devices for hearing impairments” (CDC/NCHS 1997). This is about 1.6 percent of the nation’s population. (The number of persons and percentage distribution of persons using assistive-technology devices by age of person and type of device appear in table 1.) There is reason to believe that this figure gives only an approximate picture of the prevalence of deafness and severe hearing loss within the population. First, the intent of the survey was to estimate the use of assistive technologies. Therefore, the survey categories are not mutually exclusive, since an individual with a hearing impairment can rely on more than one assistive technology. In this respect, the figure probably overstates utilization of assistive devices. Second, for those methods of communication most likely to be relied upon by the severely deaf — interpreters and signaling devices — the sample size “does not meet the standard of reliability or precision” (Russell *et al.* 1997:3, 4) and understates utilization.

**Table 1**  
**Number of Persons and Percentage Distribution of Persons Using Assistive Technology Devices**  
**by Age of Person and Type of Device: United States, 1994**

Type of assistive hearing device	All ages† (x 1,000)	44 years and under (x 1,000)	45-64 years of age (x 1,000)	65 years and over (x 1,000)
Any hearing device	4,484 100.0%	439 9.8% (0.78)	969 21.6% (1.02)	3,076 68.6% (1.20)
Hearing aid	4,156~ 100.0%	370 8.9% (0.77)	849 20.4% (1.05)	2,938 70.7% (1.21)
Amplified telephone	675 100.0%	73 10.8% (2.13)	175 26.0% (2.66)	427 63.2% (2.97)
TDD/TTY	104 100.0%	58 56.2% (9.01)	*25 24.0% (7.00)	*21 *19.8% (7.26)
Closed caption television	141 100.0%	66 47.0% (8.18)	*32 22.7% (5.55)	43 30.3% (6.84)
Listening device	106 100.0%	*26 *24.1% (7.34)	*22 21.1% (6.21)	58 54.8% (8.70)
Signaling device	95 100.0%	*37 38.8% (9.53)	*23 *23.9% (7.58)	35 37.3% (9.46)
Interpreter	57 100.0%	*27 46.4% (11.38)	*21 37.5% (11.13)	*9 *16.2% (9.09)
Other hearing technology	93 100.0%	*28 30.0% (8.95)	*24 26.0% (7.36)	41 44.1% (8.67)

Source: Russell *et al.* 1997:3, 4.

Note: Figures are in thousands; standard errors are in parentheses.

\* Figure does not meet standard of reliability or precision.

† Numbers do not add to these totals because categories are not mutually exclusive; a person could have used more than one device within a category.

~ Figure should be 4,157 but is rendered 4,156 on original CDC publication.

### 3.6.2. National Health Interview Survey, 1997

The other NHIS survey providing relevant data on the prevalence of severe hearing impairment within the population was conducted in 1997. Respondents were asked about the hearing of each member of the household, and responses were classified as (a) “having no trouble hearing,” (b) “having some trouble hearing,” (c) “having a lot of trouble hearing” or (d) being deaf. For reporting purposes, the latter two categories were combined by CDC. A summary of the survey’s findings by race, ethnicity, sex and age appear in table 2 (all data from CDC/NCHD 2002:31-32).

Of the 195,276 persons interviewed by the survey, 28,789 (or 14.7 percent) reported having a little trouble with hearing and another 5,963 (3.1 percent) categorized themselves as “having a lot of trouble hearing” or “being deaf.” (The figures in table 2 add up to only 187,602 and 5,811, the difference being accounted for by those to whom no race classification could be attributed.) The frequency of hearing impairment increased with age. Of the survey’s respondents, 1,111 18-to-44-year-olds reported having a lot of trouble hearing or being deaf (1.0 percent of this group), compared with 1,718 45-to-64-year-olds (3.1 percent), 1,192 65-to-74-year-olds (6.6 percent), and 1,942 of those over 75 (14.3 percent).

Regarding gender, overall, deafness affects men more often than women: 3.7 percent of men

Table 2

**Deafness by Race, Age and Gender:  
Deaf Respondents as Proportion and Percentage of National Health Interview Survey Respondents, 1997**

<i>Demographic characteristic</i>	<i>All respondents 18 years of age and over</i>	<i>A lot of trouble or deaf</i>	<i>Deaf as percentage of all respondents</i>
<b>White non-Hispanic male</b>			
18-44 years	38,086	583	1.5%
45-64 years	20,911	988	4.7%
65 years and older	11,514	1,553	13.5%
<b>White non-Hispanic female</b>			
18-44 years	38,259	395	1.0%
45-64 years	22,161	481	2.2%
65 years and older	15,683	1,288	8.2%
<b>Black non-Hispanic male</b>			
18-44 years	6,195	34	0.5%
45-64 years	2,435	47	1.9%
65 years and older	1,013	91	9.0%
<b>Black non-Hispanic female</b>			
18-44 years	7,447	34	0.5%
45-64 years	3,069	55	1.8%
65 years and older	1,561	70	4.5%
<b>Hispanic male</b>			
18-44 years	7,104	16	0.2%
45-64 years	2,017	36	1.8%
65 years and older	695	25	3.6%
<b>Hispanic female</b>			
18-44 years	6,360	30	0.5%
45-64 years	2,143	41	1.9%
65 years and older	949	44	4.6%

Source: CDC/NCHS 2002:31-32.

versus 2.5 percent of women reported having a lot of trouble hearing or being deaf in the 1997 NHIS survey. However, this tendency is far more pronounced among whites than among other racial and ethnic groups. Among white respondents, for each age group, the male deafness rate was considerably higher than the female rate. This was less the case for black respondents where, among the 18-44 and 45-64 age groups, the deafness rates were about equal. Only among the African-American senior-citizen group (65 and over) was the male rate double the female rate. Among Hispanics, the situation was reversed altogether: in each age group among the Hispanics, the female deafness rate was slightly higher than the corresponding male rate.

Socio-economic status is also a factor. Among the respondents to the 1997 survey, 802 respondents living below the federal poverty level reported complete or severe hearing impairment (4.0 percent of this group). Likewise, among those with income between 100 and 200 percent of the poverty level, 1,221 reported deafness and severe impairment (4.1 percent). By contrast, 2,853 of respondents above 200 percent of the poverty level reported similar disability, just 2.6 percent. However, here one must be wary of reversing causality: in all likelihood, such respondents were for the most part poor because they were deaf, not deaf because they were poor. The deaf tend to be underemployed or unemployed. About 30 percent of the country's D/HH population lives below the poverty line, a rate some 20 percent higher than that for people without disabilities.

Whites appear more inclined to hearing impairment than are African-Americans or Hispanics: 5,288 of 146,614 white respondents (3.61 percent) reported being deaf or severely hearing impaired in the 1997, as against 331 of 21,720 black respondents (1.52 percent), and 192 of 19,228 Hispanic respondents (just under 1 percent). This discrepancy is only partially explained by the relative youth of the black and Hispanic respondent pools. (Among white respondents, 18.55 percent were 65 or older, compared to 11.85 percent of African-Americans and just 8.53 percent of Hispanics.) However, as table 2 shows, among whites, for each age group, the deafness rate is higher than among the corresponding black and Hispanic age groups. For example, 10.44 percent of whites 65 and older report deafness or severe hearing impairment (2,841 of 27,197 respondents in this group). This is considerably higher than the corresponding African-American and Hispanic figures: 6.25 percent of blacks (161 of 2,574) and 4.20 percent of Hispanics (69 of 1,644).

All this said, the 1997 NHIS may have underestimated the size of the D/HH population in this country, and the inexplicably low rates of deafness among minority respondents cited may be particular evidence of this. The lower prevalence among racial minorities may also be an artifact of self-reporting and a desire to hide disabilities (especially by responding family members), instead of being a reflection of truly lower rates of deafness among non-whites. This hypothesis is consistent with two studies of children that found considerably higher prevalence rates among black male children (Drews *et al.* 1994: 1164-5; Van Naarden *et al.* 1999: 570-5). If it is true that the deafness rate at least among African-Americans is higher than reported by the NHIS study, then it follows that the overall, nationwide rate of deafness and hearing impairment is rather higher, too (due to the addition of blacks not reported by the NHIS).

### 3.7. Prevalence and Causes of HIV/AIDS among the Deaf

According to HRSA, "Whatever the exact number of deaf and hard-of-hearing individuals living with HIV disease, there is little question that seroprevalence among this minority is higher than among the general population" (HRSA 2001a:2). Little empirical information is available on this subpopulation. Since 1998, the CDC has, for the purposes of making estimates, examined medical records from 11 cities, but has conducted no more comprehensive study (HRSA 2001a:2). The best the CDC can do is to estimate that "between 8,000 and 40,000 deaf and hard-of-hearing individuals are living with HIV disease in the United States," reports *HRSA Care ACTION* journal (HRSA 2001a:2). This wide range is based on two limited studies, one indicating a seroprevalence rate of slightly less than one percent and the other of about five percent (HRSA 2001a:2). Among the general population, the HIV prevalence rate is between 0.280 and 0.315 percent (based on an estimated national total of 800,000-900,000 cases) (HRSA 2001b:1).

Certainly, the D/HH population is at risk for HIV/AIDS as the result of practicing “the same risk behaviors that cause hearing persons to become infected: primarily, unprotected sex and sharing of injecting drug paraphernalia with infected people” (Lester 1999). Beyond this, the deaf and culturally deaf population is at even higher risk for contracting HIV due to the prevalence of other risk factors. These include greater risk for sexual and physical abuse, high rates of substance abuse, little education about HIV and other sexually transmitted diseases (STDs), inappropriate HIV-outreach efforts, impeded access to and underutilization of health-care services, and other issues related to impaired hearing. “Each of these life problems increases the individual’s risk of substance-use disorder, makes treatment more complex, and heightens the possibility of relapse. Coordination with an agency providing case-management services for people with disabilities should be a priority,” according to the U.S. Substance Abuse and Mental Health Services Administration or SAMHSA (SAMHSA 1998).

### **3.7.1. Child Sexual Abuse**

Researchers have shown that D/HH children are more prone to suffer sexual abuse than hearing children: some 54 percent of D/HH boys and 50 percent of D/HH girls, as compared to 10 percent and 25 percent, respectively, of hearing boys and girls (Duvall 2000). As with all children, “Sexual abuse is a strong indicator for risky sexual and substance abuse behavior and HIV infection as an adult” (Determan *et al.* 1999).

In addition, most of the perpetrators are not apprehended. Therapists and researchers have identified a number of reasons for this phenomenon. The most obvious factor is the communication barrier. “A child that communicates in a language that most do not understand is a perfect victim,” notes Janet Duvall (Duvall 2000). Second, deaf children often have less knowledge of sexuality than hearing peers: “They do not, for example, overhear conversations and must rely heavily on what their parents and teachers tell them” (Elder 1993).

Associated with the lack of sexual knowledge is the fact that, between the child and trusted adults (parents, teachers, and investigators), there can frequently be a lack of suitable vocabulary to discuss the incident. According to Mackay Vernon, a Florida psychologist who has worked with deaf clients for 50 years, “Most parents don’t know sexual signs. And only one percent of teachers do. Even if kids try to tell, they may not be understood” (Teichroeb 2001). Even when the child is believed and an objective interpreter is called in, there are a number of factors that can prevent the pertinent information from being quickly and accurately obtained. For instance, the interpreter’s gender and the willingness of the child to accept the interpreter can impede an investigation of the alleged incident (Duvall 2000).

Two other issues that increase any child’s vulnerability to pedophiles are (a) emotional insecurity and (b) the degree of “conditioned compliance.” First, all children want to feel accepted, but the deaf child may feel “different” and isolated due to the inability to hear. A child whose emotional needs are not being met by his or her family may be more vulnerable to sexual predators, who may take advantage of the child’s desire for closeness (Elder 1993). Second, every child is taught to respect authority figures and do as he or she is told. This is “conditioned compliance” and unless children are taught, with continuous reinforcement, that there are times when disobedience is permitted, they are at increased risk for sexual abuse (Duvall 2000).

One issue that is unique to children who communicate using sign language is the fear of law-enforcement officers — because police officers have the ability to “tie their hands,” thus “silencing” them. (This fear also extends to ambulance attendants who strap patients onto stretchers). To D/HH children, and many adults, the loss of the use of their hands is tantamount to

robbing them of their freedom. Thus, the uniform may be associated with power and the ability to abuse that power. Children who are not frequently exposed to law-enforcement personnel in uniform are not likely to file sexual-abuse charges or be forthcoming during the investigation (Duvall 2000).

In sum, for a variety of reasons, D/HH children are at increased risk for sexual abuse. There appears to be more sexual abuse of deaf children than hearing children. Furthermore, the sex ratio is reversed among deaf children, with more boys than girls being abused, in contrast with the situation among hearing children. Among deaf students attending regular schools, most are abused at home, while the residential students, not surprisingly, tend to be abused at school. Approximately 20 to 25 percent are abused both at school and home (Duvall 2000). All this in turn leads to an increased likelihood of sexual and drug experimentation in later life.

### **3.7.2. Substance Abuse**

Studies have found that substance-abuse rates are higher among the deaf and hard of hearing than among the general population (Determan *et al.* 1999). Clients at the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals (MCDP) indicate that “[a]lcohol is the most commonly preferred chemical (57%), followed by cocaine (18%), marijuana (12%), and crack (9%)” (Sandberg 1996). Most of these D/HH individuals are polysubstance users, mixing both alcohol and other drugs.

There are a number of identified factors that contribute to the increased use and abuse of alcohol and drugs among the D/HH population. These include socialization, comorbid mental illness, a limited knowledge of substance abuse, and various other life issues. As to the lack of information about the effects of excess alcohol use, individuals “who are deaf or hard of hearing (and probably those with other disabilities as well) generally know less about addiction and recovery when they enter treatment than non-deaf (or non-disabled) people, and therefore they will often require lengthier treatment. Treatment providers should be prepared to allow for longer treatment times for clients with disabilities” (SAMHSA 1998). This is in part attributed to the difficulty in explaining the abstract words and concepts used in substance-abuse outreach and treatment (e.g., “addiction” or “alcoholism”), which are hard to convey in sign language. In some instances, there are no comparable signs. Therefore, the “presenter/counselor may need to give an in-depth explanation of the vocabulary to ensure a genuine understanding of the word or concept. This prolonged explanation of vocabulary may require a longer presentation or stay in treatment” (RIT n.d.). Given the chronic lack of funding frequently suffered by substance-abuse programs, such prolonged treatment may not be available.

The other identified issues contributing to substance abuse among this population are related to the individual’s mental health and lifestyle. Many D/HH persons, because of their “different” status, feel isolated and suffer from low self-esteem and depression. This in turn plays “a role in some individuals’ victimization, and in turn their substance use” (SAMHSA). Identification and treatment for substance abuse is made more difficult due to the presence of other compounding life issues. For instance, clients of the MCDP “often present with issues related to physical health, mental health, abuse, sexually transmitted diseases, family issues and legal or employment status” (Sandberg 1996).

Whatever the reasons for it, the high incidence of substance abuse among the deaf is a concern because of its potential in turn to increase the incidence of HIV/AIDS within this population. As alcohol and/or drugs impair judgment and lower inhibitions, their use can contribute to unsafe sex practices. Support of these habits can also lead to exchanging sex for money or drugs or other

crimes leading to incarceration. Finally, intravenous drug use dramatically increases the risk for contracting HIV, given the well-known propensity for the virus to be spread by the sharing of dirty syringe needles. All of these factors increase the potential for contracting HIV/AIDS.

### **3.7.3. Sex and Health Education**

Many researchers and advocates for the deaf have identified the lack of formal education on sexual and health issues as a contributing factor in the higher prevalence of sexual abuse, substance abuse and HIV/AIDS among the D/HH population. The underlying risk factors include the individual's lack of vocabulary and instruction on sex and sexual matters.

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 (Determan *et al.* 1999).

Most D/HH children are schooled either in residential schools or in the public school system. Since the passage of a 1975 law requiring public schools to provide services for disabled children, including the deaf, the number of pupils in residential schools has plummeted. Today, only about 10 percent of school-aged deaf children (ages 5 to 21) are enrolled in residential schools. The remaining children are "mainstreamed" in public schools. Of those that are mainstreamed, close parental supervision can be a double-edged sword. These children, 90 percent of whom grow up in hearing families (Teichroeb 2001), are frequently not permitted to enroll in sex-education classes because of parental concern about "protecting" them. In addition, they usually do not have private time with health-care providers. Therefore, when freed from direct parental supervision, the normal exploration and experimentation of adolescents result in risky patterns of behavior such as unprotected sex (Weise 2003). According to Harry Woosley, Jr., an HIV educator and case manager with the Maryland Deaf AIDS Project, most of the deaf clients who learn about AIDS from him, as opposed to anyone else, have attended public schools as mainstreamed students (Woosley 2003).

An underlying factor is the deaf person's need for an appropriate sign-language vocabulary:

It may be difficult for an individual to relay information about abuse or mistreatment if the person lacks a way to communicate this clearly. Building vocabulary regarding body parts and action words is an important step to providing the individual with a communication system that will last a lifetime (Belote 2002).

One of the benefits of having such a vocabulary is gaining an understanding of HIV/AIDS. Unfortunately, this is not occurring. A recent risk assessment of 250 individuals by the MCDP found that only "15 percent of respondents from the [D/HH] community demonstrated knowledge of HIV transmission facts" (HRSA 2001a:3). According to Alan Marcus, director of community services at Gallaudet University's Mental Health Center, "Unlike the hearing population, deaf people have far less ability to passively garner information, like listening to the news on the car radio, and thus may miss a lot of HIV-prevention messages that millions of other Americans hear every day" (Sleek 1998).

### 3.7.4. HIV Outreach Efforts to the Deaf

Factors contributing to the lack of awareness and knowledge about HIV/AIDS within the D/HH population are (a) a lack of appropriate education materials and (b) message-dissemination failures (Sleek 1998). The federal HIV/AIDS Bureau notes:

The under-supply of useful materials results in individuals not understanding HIV disease. They remain unaware of the differences between HIV and other sexually transmitted diseases, do not comprehend basic treatment concepts, and may not understand the full import of an HIV-positive test result (HRSA 2001a:4).

Moreover, as other observers note:

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 (Determan *et al.* 1999).

Instead of relying on just formal presentations, these programs “should incorporate physical activities, longer time for discussions, pictures, dolls, graphic manuals in ASL and captioned videos to make sure concepts are understood” (Determan *et al.* 1999).

There are also failures in communicating the HIV-prevention messages specifically. Perhaps the most critical gap is in qualified interpreters and peers to relay the message. “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” (Determan *et al.* 1999). An example is using ASL to tell someone that he or she is HIV positive; upon receiving this news, the patient may well seem happy. This is due to divergence between the grammar and syntax of English and American Sign Language, as in ASL anything “positive” is considered good. As a result, a significant number of “deaf people interpret the signed word ‘positive’ as something good and don’t recognize it as a diagnostic term” (Sleek 1998). The use of peers to relay the message has been used successfully in Paris, France, where

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 (Determan *et al.* 1999).

For outreach efforts to be effective, the message must reach the target audience. This means understanding the D/HH population and how to best accommodate its needs. One underutilized avenue of communication is through the schools, though they are often slow to respond. “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” (Determan *et al.* 1999).

Survey data collected as part of the 2000 Price Fellowship identified the best HIV-outreach strategies for the deaf as: (a) peer interaction (90 percent of respondents), (b) deaf clubs (82 percent), and (c) parent education (72 percent) (Emery n.d.). Based on this information, a comprehensive plan is needed to address the disparities in HIV-prevention efforts geared toward the D/HH community. The best use of resources may be to create a multi-topic education and outreach plan. As with other health prevention programs, the HIV/AIDS “outreach needs to focus on the facts of the HIV epidemic and incorporate long-term positive communication. This communication needs to come from a credible program to ensure establishment of trust” (Emery 2000).

### 3.7.5. Access to Care

There appear to be significant disparities between the health-care service access experienced by the deaf and hard of hearing, on the one hand, and that enjoyed by the general population, on the other. This may be attributed to both service providers and deaf individuals themselves. General provider ignorance and the lack of culturally competent practitioners create serious impediments to the dispensation of effective, quality care:

Inadequate communications are the major barrier to treatment for people who are deaf and hard of hearing. Without accommodation, people who are deaf, whether they use sign language or not, will experience barriers to communication that significantly reduce their ability to benefit from a treatment program and to receive services equivalent to those hearing clients receive (SAMHSA 1998).

This sentiment is echoed by an activist for this minority population who writes that “health-care utilization studies in the deaf community are scant but over 20 years of working with deaf community members in social service and advocacy settings has highlighted, to me, a gross underutilization of health-care services” (Emery 2003).

There is a clear distinction between the *pathology* of deafness, as taught to most health-care professionals, and the *culture* of deafness, as experienced by the D/HH population. Service providers’ foci tend to be on the underlying medical cause of the impairment and ways to overcome the disability. In contrast, “Deaf community members do not like to be perceived as ‘broken’ and to be ‘fixed.’ This causes resistance to [preventive] care and in turn lack of motivation to future health concerns” (Emery 2000). Because the medical community fails to accept the existence of a specific deaf culture, there is a lack of recognition of the need for health-care providers to furnish culturally competent services to the D/HH community. As a result, many health-care professionals frequently “do not understand the effects of culture on how individuals process information, make decisions, and live their lives” (HRSA 2001a:4). In addition, “Deaf people do not trust health-care professionals because confidentiality has been broken and miscommunication has happened. Informed consent is often not technically accomplished in many health-care settings” (Emery 2000). Consequently, effective, quality health care is impeded, which further reinforces the perception within the deaf community that health-care providers are indifferent to their needs. (To help remedy matters, SAMHSA makes a number of recommendations for providers in its paper, “Substance Use Disorder Treatment for People with Physical and Cognitive Disabilities” [SAMHSA 1998]. These are summarized at appendices 9.1 and 9.2. The recommended steps pertain to all disabilities, not just deafness.)

For many D/HH individuals, communicating with health-care professionals often requires an interpreter. Although the ADA prohibits providers from requiring a D/HH person (a) to pay for an interpreter or (b) to bring someone to act as an interpreter, “these practices are still common to this day due to lack of education (on the part of the professionals), lack of activism on the part of the client to demand equal rights in standards of care, and lack of enforcement (the law cannot intercede without a complaint)” (DAP n.d.). From a provider’s perspective, however, the expense of providing a qualified interpreter is a serious issue, as is the basic matter of even finding one. Currently, in Baltimore, Maryland, interpreters charge \$90 per hour with a two-hour minimum fee. Since most third-party payers do not compensate the provider for interpreter fees, the appointment (which may last for only 15 minutes) can cost the practitioner more than the reimbursement for the services provided (DAP n.d.). Even if the practitioner pays for an interpreter, there are no guarantees the services will be effective, as explained by the Deaf AIDS Project:

If an interpreter is provided for care, it is almost never the same interpreter at each session, which presents serious concerns in terms of adherence. Most interpreters are not specially trained to provide HIV or other medically oriented material, thus effectiveness is sorely limited. Having a different interpreter at every meeting jeopardizes the effectiveness of the meeting by changing the relationship between the service provider and the client. The process of interpretation is designed to make as little intrusion as possible into the relationship between the caregiver and the deaf consumer. The reality is that it truly impedes the process to the point that it can make the entire session a waste of time and valuable money (DAP n.d.).

The lack of culturally competent health-care professionals affects the access to and utilization of HIV/AIDS services. “Advocates report that health-care providers are less likely to offer HIV screening to the deaf and hard of hearing than to their hearing clients” (HRSA 2001a:4).

This is not due to a lack of training opportunities for providers, according to deaf activists. For instance, Gallaudet University’s Mental Health Center provides HIV/AIDS training to mental-health professionals who work with the deaf (Determan *et al.* 1999). Likewise, DAP has offered some training to medical professionals and sign-language interpreters in Maryland. However, DAP lacked funding for continuing medical education credits (CMEs), and only a few individuals attended the workshops (Woosley 2003). As with outreach efforts, medical practitioners need to communicate clearly, to use visuals and demonstrations, to employ highly visual medication adherence and dosing strategies, and to support quality referrals to other culturally competent providers. A seemingly missing component is HIV/AIDS case managers who can advocate for the deaf and hard of hearing (Woosley 2003).

### **3.7.6. Deaf Lifestyles and Personal Preferences**

According to Robert Q. Pollard, of the Strong Memorial Hospital in Rochester, New York, young D/HH individuals have typically relied upon family members to oversee their health-care needs and, thus, when they are on their own, they lack the experience to take control of their own care (Sleek 1998). Compounding problems posed by D/HH patients’ lack of medical knowledge are the frequently intimidating atmosphere of the health-care setting and the perceived lack of empowerment on the part of the patient. As a result, D/HH individuals “don’t feel they have the ‘right’ to ask for an interpreter for communication. It is a serious deaf community empowerment issue for some community members as well as a health-care disparity” (Emery 2003).

As previously referenced, the deaf describe their condition not as a *disability*, but as a *difference*. This “difference” tends to isolate them from most people in the mainstream population. As 90 percent of people with very limited or no hearing have hearing parents, they also feel isolated even within their biological families (RIT n.d.). These individuals also feel a lack of social acceptance and isolation from the mainstream population (RIT n.d.). Research has shown that individuals with disabilities tend to be more isolated because of “their families’ efforts to protect them, the physical difficulty of getting out to social settings...and non-disabled people’s discomfort with people with disabilities” (SAMHSA 1998). One result of this isolation is that the deaf tend to rely on a small social or support network that is often composed of individuals with similar life experiences, i.e., other deaf people. “The deaf community is very tight knit, which can offer strong support and strong condemnation at times” (Determan *et al.* 1999). In addition, the members of this community share “an extensive ‘grapevine’ that shares information, which is not always supportive and positive” (RIT n.d.). Therefore, maintaining confidentiality is difficult, but very important in this community where news travels fast (Determan *et al.* 1999). Fear of being ostracized from the community can mean that the “lack of confidentiality [can] prevent a person from reaching out for help and treatment” (RIT n.d.).

Two areas where concerns about medical confidentiality can deter an individual from seeking treatment are substance abuse and HIV/AIDS. “The deaf community itself stigmatizes anyone with a chemical-dependency problem. This perspective of the deaf community discourages deaf alcoholics from admitting their problem with drinking or drug use and getting treatment” (RIT n.d.). Likewise, most D/HH people find the prospect of having acquired HIV overwhelming due to the homophobia and potential discrimination *within* the deaf culture (Emery 2000). Gay deaf men “often conceal their identity and may engage in furtive, anonymous and high-risk sexual behaviors. Many deaf MSM [men who have sex with men] also seek out hearing MSM for relationships, which makes communication about safer sex practices difficult” (SAMHSA 1998). Members of the deaf community often prefer to

go alone to an all-hearing HIV testing and counseling clinic and risk miscommunication and misunderstanding, [rather] than bring an interpreter or go to a deaf clinic and risk being recognized and losing confidentiality. 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 (Determan *et al.* 1999).

### 3.8. Program Development

There are no clear-cut answers as to which is better, (a) a program that specializes in providing services to the deaf or (b) a general program that is willing to accommodate the special needs of this minority population. For programs specializing in deaf services, as long as individuals with severe hearing impairments were not barred from obtaining services from their provider of choice, the ADA would not prohibit the creation of a target AIDS clinic with a culturally competent staff fluent in various sign languages (SAMHSA 1998). (That is, such a clinic might be established as an option for the deaf, but they could not be mandated to go to it in preference to other clinics.) However, there are two drawbacks to this concept. First, the larger segment of this special population is composed of late-deafened individuals, and

These individuals will generally prefer to be served by programs for the general population alongside clients who can hear. The types of accommodations they need will differ from what is needed to effectively treat clients who identify with Deaf Culture. These accommodations will usually consist of the use of devices either to amplify sound or to print what individuals in the program are saying. These people have grown up using English as a primary language and do not have the second-language issues that are common to individuals who are deaf whose primary language is ASL (SAMHSA 1998).

Another concern involves the lack of confidentiality of being seen entering a known “HIV clinic.” For example, the mobile French program (discussed earlier) 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 (Determan *et al.* 1999).

The only manner of determining which option is preferred is to seek the input of the clients that would be expected to utilize the program. That is one of the purposes of the survey included in this study.

## 4. HIV AND THE DEAF IN MARYLAND

Maryland is the only state to use HIV counseling and testing forms to collect statistics on HIV/AIDS prevalence among those who are deaf or hard of hearing. Although the data on the deaf in Maryland are very good in comparison to other states, they are not comprehensive. The testing and counseling form is used in most — but not all — Maryland federally funded counseling and testing sites. But, at best, these centers “account for no more than 12 to 15 percent of all HIV-positive test results” (HRSA 2001a:2). Furthermore, the data-collection form is voluntary, allowing individuals to elect not to furnish the information. In addition, the questions are often answered *for* a person and not *by* the individual himself or herself, which creates the potential for observer error. An example would be when the person completing the form for the patient does not readily identify a hearing impairment because the patient is successfully using a hearing aid or reading lips (Flynn 2003a).

### 4.1. Deafness and HIV in Maryland

As noted in the executive summary, in 2001, 32 of 707 test takers known to be deaf (or 4.5 percent) tested positive for HIV (Flynn 2003c), though this does not necessarily imply an HIV rate of 4.5 percent in general among Maryland’s deaf community. The reader should bear in mind (a) that people taking an HIV test are more likely to be HIV positive than people not taking such a test and (b) that some 40 percent of HIV test takers in Maryland that year did not indicate whether or not they were deaf, anyway. (In the paragraphs below, for the sake of stylistic simplicity, we use the term “test takers,” when in fact the more cumbersome term “tests taken” would be more accurate. In fact, the actual number of human test takers is likely to be slightly lower than the numbers of tests taken, as some people make take the test more than once in any given year, adding to the number of tests but not to the number of test takers.)

The situation in the EMA is even murkier because fewer people are either asked or answer the question about being deaf — only a third. This is what we know for the EMA. In calendar year 2001, there were conducted within the EMA 45,992 HIV tests. Of these 45,992 tests, 737 gave positive results, a rate of 1.6 percent. Of those 45,992 tests, 15,357 test takers answered a question about being deaf (a response rate of only 33.4 percent). Of these 15,357 test takers, 332 said they were deaf. Of these 332 deaf test takers, 24 were positive, giving a rate of 7.2 percent (all figures from Flynn 2003c). However, because so few test takers stated if they were deaf or not, by no stretch does this figure mean that 7.2 percent of deaf people throughout the EMA are HIV positive. If the situation in the EMA is unclear, it is worse in Baltimore City itself, where in 2001 only 11.6 percent of HIV test takers gave an answer about their hearing status. Of the 167 answering that they were deaf, 18 were also HIV positive (10.8 percent).

However, aggregate figures can hide much. The reason the rate of response about deafness is so low in the EMA (33.4 percent) and at the state level (60.2 percent) is because so few people in Baltimore City answer the question about deafness, dragging down the overall EMA and state response rates. In fact, outside the city, the vast majority of HIV test takers give an answer about their deafness: 96.9 percent in Anne Arundel County, 98.0 percent in Baltimore County, 97.2 percent in Carroll County, 98.9 percent in Harford County, 95.3 percent in Howard County, 93.3 percent in Queen Anne’s County, and 96.0 percent in the rest of the state (excluding the city). Among incarcerated test takers, 98.5 percent respond about being deaf (all figures from Flynn 2003c). These figures are satisfactorily high as to allow us to come to some tentative conclusions about the HIV rate among deaf HIV-test takers, if not among the deaf in general.

Table 3  
**HIV Prevalence Among Tests Taken by Known Deaf and Assumed Hearing Persons in Maryland by Jurisdiction, 2001**

<i>Jurisdiction</i>	<i>All HIV tests</i>	<i>Tests among assumed hearing</i>	<i>HIV positive among hearing</i>	<i>HIV pct. among hearing</i>	<i>Tests among known deaf</i>	<i>HIV positive among deaf</i>	<i>HIV pct. among deaf</i>
Anne Arundel Co.	3,799	3,782	23	0.61%	17	0	0.00%
Baltimore Co.	3,771	3,689	42	1.14%	82	2	2.44%
Carroll Co.	1,299	1,272	2	0.16%	27	1	3.70%
Harford Co.	1,218	1,200	17	1.42%	18	2	11.11%
Howard Co.	1,403	1,385	16	1.16%	18	1	5.56%
Queen Anne's Co.	219	216	1	0.46%	3	0	0.00%
Dept. of Corrections	7,360	7,260	345	4.75%	100	4	4.00%
Rest of Md. (w/o City)	26,535	26,260	294	1.12%	275	4	1.45%
Total	45,604	45,064	740	1.64%	540	14	2.59%

Source: Flynn 2003c.

As shown in table 3, excluding Baltimore City, there were in 2001 throughout Maryland 45,604 HIV tests taken. Of these, 540 were taken by people known to be deaf. The other 45,064 were presumably taken by people who were not deaf. We assume that all test takers that either (a) responded in the negative to the deaf question or (b) did not respond at all were not deaf. There were 740 positive test results among the non-deaf test takers, giving an HIV rate of 1.64 percent. This compares to 14 of 540 deaf test takers, a rate of 2.59 percent (all figures derived from Flynn 2003c). This does not mean that, exclusive of Baltimore City, 2.59 percent of the deaf are HIV positive in Maryland (for we do not know how many deaf people did not take any HIV test), but it does imply that the rate of HIV among the deaf is at least somewhat higher than among the hearing population. According to Colin Flynn, an epidemiologist with the Maryland AIDS Administration, possible explanations for the higher HIV rates within the D/HH population may include motivated testing, lack of access to health care, and a higher proportion of associated risk factors in this population (Flynn 2003b).

According to data on the DAP's Internet site, 64 of the organization's clients with significant hearing impairment tested positive for HIV between 1996 and 1999 (DAP 2003). Of these 64 people, 19 were male (29.7 percent) and 45 female (70.3 percent). This is an interesting reversal of the ratio among the general population, where 70 percent of new HIV infections each year occur among men and 30 percent among women (CDC n.d.), though it should be added that the DAP's sample was entirely self-selected. Within the DAP sample, the mode of transmission was primarily drug-related — 50 percent of the 64 tests — and was due to intravenous drug use or exchanging sex for drugs or money. This is in accord with general transmission figures for the Baltimore EMA, where 51 percent of transmission is accounted for by drug use (IGS 2002:30). Contracting the virus from a sex partner accounted for 28 percent of the DAP's 64 cases. Twenty-six percent of male cases cited having sex with other men as the transmission mode. Of 64 cases records by DAP, 37 resided within the EMA (57.8 percent) and 34 within Baltimore City itself (53.1 percent).

#### 4.2. Next Steps

There is reason to believe that failure on the part of health-care providers to ensure cultural competence and to facilitate effective communications may have contributed to significant care-access problems for the D/HH population. Without efforts to overcome linguistic and cultural barriers, the result will continue to be a lower quality of life for the deaf and hard of hearing who are HIV positive or at risk of contracting the disease.

Based on the literature review and other information presented so far, there clearly appear to be unmet HIV-related health-care needs in the deaf community. The remainder of this document presents the findings of a gap analysis conducted by InterGroup Services in collaboration with the Deaf AIDS Project. This study was conducted by examining the impediments to care from both a client and provider perspective. By providing increased awareness of the barriers to care faced by the deaf and hard of hearing, knowledge provided by the incorporated needs assessment, and information on the gaps in services, this report may serve as a first step to reducing the disparities in access to prevention and treatment services.

## 5. PROVIDER SURVEY AND FOLLOW-UP

Little published information is available about the experiences and challenges faced by health-care providers serving patients that are deaf or profoundly deaf. To gain an understanding of the perspective of providers furnishing HIV services in the Baltimore EMA, IGS used a multi-pronged approach, including: (a) a preliminary survey, including questions about the percentage of agency clients that are deaf or severely hearing impaired, (b) a written review of issues associated with serving deaf and severely hard-of-hearing clients, (c) two qualitative discussions or focus groups, and (d) a pre/post sensitivity test.

### 5.1. Initial Provider Survey

IGS first sent questionnaires to 21 providers of HIV services in the Baltimore EMA. Responses were received from 11 of them, these being:

- Anne Arundel County Health Department,
- Baltimore County Health Department,
- Bon Secours Baltimore Health Systems,
- Chase Brexton Health Services,
- Greater Baltimore Medical Center Weinberg Community Health Center,
- Health Care for the Homeless,
- Johns Hopkins Adult HIV/AIDS Service,
- Johns Hopkins Bayview,
- Johns Hopkins Obstetrics/Gynecology Women’s HIV Health Program,
- People’s Community Health Center, and
- Queen Anne’s County Health Department

Contacts identified included those individuals directing social-work and case-management services or handling data; it was felt that they could furnish information on primary medical care for hearing-impaired clients. Providers were asked how many HIV-infected patients were seen in the most recent month. The average was 205, with a range of 25 (Queen Anne’s County Health Department) to 1,152 patients (Johns Hopkins Adult HIV/AIDS Service).

Providers were also asked for their estimates of the percentage of patients with hearing difficulties. Of the seven providers who responded to this question, the responses were distributed as shown in table 4: two providers said that none of their clients had “trouble hearing what is said in normal conversation,” while five said that fewer than 10 percent of clients had such trouble. No one said that more than 10 percent had any trouble. One provider said that no clients had “serious difficulty understanding other people when they talk or ask questions,” while five said that fewer

Table 4 Distribution of Hearing-Impaired Individuals among Baltimore EMA Providers of HIV Services			
<i>Hearing-related problem</i>	<i>None (0%) of HIV clients</i>	<i>Less than 10% of HIV clients</i>	<i>10 to 25% of HIV clients</i>
Have trouble hearing what is said in normal conversation	2	5	0
Have serious difficulty understanding other people when they talk or ask questions	1	5	1

Source: IGS provider survey.

Table 5 <b>Supportive Services Provided by Baltimore EMA Providers of HIV Services</b>	
<b>Service</b>	<b>Number providing (n=11)</b>
Transportation services/assistance with public transportation	9
Flexible/convenient office/clinic hours	8
On-site child care	0
Sliding fee scales or uncompensated care	9
Mobile services or in-home care	3
Assistance with financial or billing difficulties	8

Source: IGS provider survey.

than 10 percent had this sort of difficulty; one provider said that over 10 percent of its clients had such trouble. One may infer from these findings that a significant, though not enormous, fraction of these providers' HIV-infected client population requires some sort of hearing-related accommodation to realize the fullest possible benefit from their services.

Providers were also asked about the supportive services they provided, and responded as shown in table 5. Nine of 11 provided or paid for transportation. Eight tried to offer flexible clinic or office hours. Nine offered reduced fees or free services, while, relatedly, eight gave assistance with billing difficulties. Three provided mobile or in-home care. However, none provided child care. The importance of this table will become more evident when the client survey is discussed later in this report. (Clients were surveyed about obstacles they faced when obtaining health services in general and HIV services specifically; results are shown in tables 25 and 32, below.)

## 5.2. Provider Information Exchange

Another component of the research into the challenges faced by providers when serving this population entailed conducting two qualitative information-exchange sessions or focus groups. Seven individuals from six of the agencies in the original sample attended one of the two sessions. Of this group, five had experience with directly providing care to the D/HH population.

The seven representatives who attended one or the other of the information-exchange sessions were first presented with a written questionnaire about their agencies' experiences with deaf and severely hard-of-hearing clients. This document was intended to provide IGS with quantitative data as well as facilitate the pending discussion by raising care-related issues relevant to the D/HH population.

There were three major themes in the questionnaire. The first dealt with provider access to interpreters qualified to provide medical translations. Of the seven representatives, two had staff access to interpreters (either dedicated agency interpreters or institution-wide staff), while four had no on-site sign language interpreters, and one did not know. Of the four providing applicable responses, all knew that their organization used outside sign-language interpreters. However, of the six agencies, only one indicated that efforts were made to provide interpreter continuity for the client, while four did not know and one said no effort was made. Likewise, of the six agencies, only two indicated that the interpreters used had been specifically trained to provide translations in a medical setting, while three did not know, and one responded in the negative.

The second major theme of the questionnaire related to provider knowledge of non-HIV

resources for the deaf and severely hearing impaired. Of the five respondents rating their organizational referral networks (using a 10-point scale with 10 being the best), the average score was a 3.2, with scores ranging from 1 to 7. The highest self-ranking was by the agency representative with a sign-language interpreter on staff and available to provide translations for the on-site addictions and mental-health counseling services. Again, most of the respondents (three of the remaining four) did not make referrals to specific counselors able to directly communicate (without a translator) with severely hearing-impaired clients.

The last theme of the questionnaire addressed clients' knowledge about and involvement in their own treatment. Four respondents rated their agencies on the involvement of their deaf and severely hard-of-hearing clients in the development of their own treatment plans. Two representatives rated their organizations as having these clients "very involved" in their own treatment plans and associated this with a commitment to effectively communicate with this special population about relevant lifestyle issues. These two representatives also believed that these severely hearing-impaired clients were highly satisfied with their services. Of the two who responded that their severely hearing-impaired clients were "somewhat involved" in the development of their own treatment plans, there was a consistently low ranking of effective communication about related lifestyle issues, and no rating of client satisfaction.

### **5.3. Qualitative Discussions or Focus Groups**

Following the written assessment of services to the deaf and severely hard of hearing, a facilitator from IGS led two discussions of providers' experiences. There were four components to the discussion: (a) whether the agency had provided services to the deaf and severely hearing impaired, (b) barriers to providing care, (c) treatment experiences, and (d) resources used or needed in providing comprehensive care.

The five participants with direct experience providing care to deaf patients all reported facing a number of challenges when serving this population. The most obvious limitation was not having ready access to a sign-language interpreter, since only the hospital-affiliated agency had ready access to interpreter services. (However, it was not known whether the hospital provided interpreters for satellite campuses or to outside agencies.) For most of the organizations, the communication barrier had usually been handled by hiring an external interpreter, but the cost was definitely a concern. Information provided indicated that the cost of an interpreter is \$90 per hour, with a two-hour minimum. This fee is charged even when patients fail to keep appointments. Additional costs involve staff time to arrange outside interpreter services. In those relatively rare instances of walk-in D/HH patients, communications were reported to be conducted on paper.

There is definitely a disinclination among providers to use a family member or friend to provide interpretation services. While some providers will not refuse to use interpreters brought by clients (without cause), other providers have a policy that insists on the use of independent parties as interpreters. Participants cited concerns about client confidentiality and privacy, possible inability of personal interpreters to deal with technical medical information, and objectivity towards the client.

Possible patient distrust of agency-provided translators was also raised as a concern, especially when there is no interpreter continuity. One provider who has served a number of deaf clients stated that the agency tries to arrange for the same translator for each visit, and also encourages the client to establish a relationship with the individual translator. (For example, the patient's communicating directly with the interpreter to schedule follow-up appointments begins a

dialogue between the two parties). In another instance, the interpreter did not use the client's signs, impeding client comprehension.

Another means of communication between a severely hearing-impaired client and staff is the use of assistive technology. The most widely used device for this special population is TTY/TDD services. All of the providers reported having TTY capacity, but most stated that their equipment had never been used. In those instances where staff had used the equipment, the experience was negative; staff disliked using the apparatus because they found it to be a time-consuming, slow form of communication.

In general, the extra resources required when providing services to the D/HH population were a major issue. Of particular concern was the extra staff time required per patient. In addition to the interpreter fees, the representatives cited the staff time to provide coordination for the interpreters; extra casework time (intake, clinicians, etc.), since communications took longer; and above all, the extra case-management time required. Additional demands on the case managers included the need to make special referrals, because the normal network of service providers might not be appropriate for this population; the need to secure ancillary services, such as housing and counseling; complications caused by comorbidities; and frustrations when clients were lost to follow up.

#### **5.4. Pretest/Posttest Sensitivity Assessment**

Both before and after the discussion, meeting participants were asked whether their agency had provided services to deaf or profoundly deaf clients and how they would rate their organization at being prepared to meet the needs of this special population. This step was meant to assess whether the sharing of experiences increased sensitivity to the barriers faced in communicating effectively with a severely hearing-impaired client. Overall, the respondents rated the capacity of their organizations slightly lower after the information-exchange session, indicating that the sessions had in a sense opened the providers' eyes to their own shortcomings. The discussions, which focused on the needs of deaf and severely hard-of-hearing clients, clearly raised awareness of the complexities of serving this special population.

When viewed in retrospect following the discussions, the representatives believed their agencies did a commendable job of overcoming the barriers to care related to communication problems. Each participant recognized the importance of special efforts undertaken to serve this clientele, but recognized that improvements could still be made.

#### **5.5. Provider Recommendations**

The providers made a number of recommendations, which can be summarized as follows.

##### **5.5.1. Outreach**

The providers expressed concern about the isolation of the deaf and profoundly deaf population. These individuals have their own culture and special sense of community. Providers are seeking guidance on how to identify the community and provide appropriate health-care outreach. Particular concern was expressed about HIV/AIDS awareness and prevention, since the cultural identity of this special population has created a somewhat closed community with a high incidence of contributing risk factors.

### ***5.5.2. Deaf Cultural Competency Workshop***

As demonstrated by changes in the pretest and posttest scores, the information-exchange sessions raised the awareness of the providers concerning the barriers faced in communicating effectively with severely hearing-impaired clients. A number of staff had recently attended general cultural-competency training, and remarked that no information was conveyed about the deaf community. Providers expressed a desire for a deaf cultural-competency workshop to enable staff to provide care more effectively and responsively to this special population.

### ***5.5.3. Resource Guide***

The providers also expressed the need for a resource guide, which would be useful when referring deaf and severely hard-of-hearing clients to other support services. Knowledge of those medical practitioners, substance-abuse and mental-health counselors, and other service providers who personally know how to sign or have on-site staff that can directly communicate with these clients would expedite referrals. Providers also believe that expedited access to culturally competent clinicians would increase both client satisfaction and compliance with statutory mandates.

### ***5.5.4. Opportunities for Collaboration***

The providers voiced concern about their responsibility for making reasonable accommodations to provide effective care to all individuals (especially to all special population clients), given their limited resources. The participants expressed a desire to explore opportunities to share resources (e.g., interpreters, limited-English-proficiency and other culturally competent materials, procedures) and develop cooperative agreements to form linkages.

## 6. METHODOLOGY FOR THE CLIENT SURVEY

Having completed the provider survey, the report's researchers then turned to surveying the needs of deaf HIV clients. The problems encountered in trying to conduct the client survey primarily entailed barriers to communication with clients. Most notably, telephone surveys would have required the use of TDD/TTY equipment, making the process very long and difficult, and making identifying a representative random sample nearly impossible. Likewise, the use of written survey methodologies was impeded by the potential respondents' average fourth-grade reading level and use of non-standard English. As discussed below, the selected research method was to use convenience sampling and have a field researcher manually sign the survey questions/responses or, if the respondent wished, to personally complete the written survey or to provide translations as necessary. Nonetheless, even with these safeguards, there are some inconsistencies in the outcomes of the survey, which may reflect some residual misunderstanding on the part of those surveyed. For example, while 12 of 91 respondents indicated that they were HIV positive, only 7 of the 12 indicated that they had been tested for HIV. It is possible that, despite the effort to translate the questionnaire to them individually, some respondents still found the survey instrument "too English" (i.e., phrased too much for those whose first language is literal English) or confusing.

In late spring and early summer 2003, IGS contracted with the Deaf AIDS Project, a program of the Family Service Foundation, for the administration of a survey of the health-services needs of the Maryland deaf community. The DAP was founded in January 1990 by Harry Woosley, a deaf Marylander, with the assistance of the FSF. (The FSF, which is headquartered in Baltimore, had previously been providing counseling and treatment for deaf Marylanders battling addictions.) The DAP provides HIV-prevention and education services as well as counseling and testing services. It offers unique entree to the Maryland deaf community and has established a special sense of legitimacy and trustworthiness among deaf Marylanders with HIV/AIDS.

The survey was based on a written questionnaire with 47 questions, designed to accommodate those whose native language is American Sign Language (ASL). The questionnaire was developed in collaboration between IGS and the DAP, specifically with the active cooperation of Harry Woosley, who has lengthy experience in providing services to the Maryland deaf community. Mr. Woosley also enjoys national recognition as a leader and expert in addressing the needs of hearing-impaired people with HIV/AIDS. IGS's final rendition of the questionnaire was submitted to DAP for final comment on May 14; none was received, although comments were received from DAP on previous drafts of the questionnaire. In addition, on April 30, IGS received written approval from the Baltimore City Health Department (BCHD) to use the questionnaire and proceed with the survey.

None of the questions was open ended — i.e., all of them had specified answers among which the individual surveyed was asked to choose. Because of the complexity and length of the questionnaire, three DAP staff members administered it to D/HH individuals on a one-on-one basis, interpreting each question; each of these interpreters was professionally trained and credentialed, and two of them were deaf themselves. (The DAP staff members were Harry Woosley, who has a bachelor's degree in social work from the Rochester Institute of Technology; Edward Cheh, a graduate of Gallaudet University; and Amy Letcher, who is certified for counseling and testing and has taken college-level courses in deafness.) The questionnaire used for the survey included a consent form, which had been approved by BCHD.

Respondents to the survey were recruited by the DAP at a number of different events and

presentations for the deaf community. The survey yielded 91 responses, of which 12 (13.0 percent) were completed by people with HIV or AIDS. Five were HIV positive with symptoms, and seven were HIV positive but asymptomatic. A ninety-second questionnaire was not tabulated or included in the results, since the person who completed it (a) failed to specify the degree, if any, of his or her deafness and (b) checked “don’t know” in response to the question about being HIV positive.

## 7. RESULTS OF THE CLIENT SURVEY

The results of the client survey are described over the next few pages. In some cases, cell columns do not sum to 100 percent because non-responses (blank boxes) have been excluded.

### 7.1. Client Hearing Disability and Education Levels

As shown in table 6, 60.4 percent (55 people) of those surveyed were deaf, 8.8 percent (8) were late deafened, and 30.8 percent (28) were hard of hearing. There is a noteworthy difference between the HIV-positive and non-HIV-positive subgroups, in that none of the HIV-positive respondents was late deafened. Instead, the HIV-positive group included 66.7 percent who were deaf and 33.3 percent who were hard of hearing — slightly higher percentages of both groups than was true for the non-HIV-positive subgroup. While the numbers here are small enough that one should be cautious about drawing conclusions, it may be that the late deafened had or have better sources of health information or lower risk factors in general than the deaf or the hard of hearing. Differences in the use of interpreters were generally not remarkable, except that members of the HIV-negative subgroup who were deaf tended to use sign-language interpreters slightly more than twice as often as the HIV-positive subgroup.

Table 7 provides information on the educational background of those surveyed. While the two subgroups (HIV positive and HIV negative) are not dramatically different in school attended, a slightly higher percentage of the HIV-positive group attended the Maryland School for the Deaf or other, private schools, while most of the HIV-negative group (54.4 percent) attended a public school. With respect to educational attainment, the majority of both the HIV-positive and non-HIV-positive subgroups had ceased their formal education with a high-school diploma (72.5 percent and 58.3 percent, respectively). A considerably higher percentage of the HIV-positive group (33.3 percent versus 8.9 percent) had some or a complete college education. A sizable minority — 13.9 percent of the HIV-negative subgroup and 8.3 percent of the HIV-positive subgroup — had left high school without graduating. Their level of literacy may present special challenges for health and services providers.

### 7.2. Client HIV and General Health Status

Table 8 provides a synopsis of the HIV status of the entire group surveyed. Most — slightly over 60 percent (55 of 91) — did not know their HIV status, while slightly more than one quarter indicated that they were HIV negative. (The lack of knowledge or the response of “HIV negative” did not always relate to whether the client had been tested for HIV, since only 34.1 percent (31) of all respondents indicated that they had been tested. Rather, in many instances, these responses were based on a self-assessment, which might have entailed weighing such factors as personal knowledge of risky behavior in which the client might have engaged.) Slightly over 13 percent — 12 individuals — reported that they were HIV positive, 7 without symptoms and 5 with symptoms. No clients were AIDS defined.

Curiously, as shown in table 9, self-assessment of overall health status was not necessarily directly linked to current HIV status. While 25.0 percent of those who were HIV-positive considered themselves in only “fair” condition — about twice the percentage of those who were non-HIV-positive — the combined percentages of those who rated themselves in either “excellent” or “very good” health did not differ greatly across the two subgroups (58.4 percent for

Table 6 Survey Respondents' Hearing Disability Status and Use of Interpreters			
<i>Respondent characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
<b>Deaf</b>	<b>60.4%</b>	<b>66.7%</b>	<b>59.5%</b>
Use sign language interpreter	34.1%	16.7%	36.7%
Use oral interpreter	12.1%	16.7%	11.4%
Do not use interpreter	4.4%	0.0%	5.1%
<b>Late Deafened</b>	<b>8.8%</b>	<b>0.0%</b>	<b>10.1%</b>
Use sign language interpreter	0.0%	0.0%	0.0%
Use oral interpreter	2.2%	0.0%	2.5%
Do not use interpreter	4.4%	0.0%	5.1%
<b>Hard of Hearing</b>	<b>30.8%</b>	<b>33.3%</b>	<b>30.4%</b>
A little trouble hearing	9.9%	8.3%	10.1%
A lot of trouble hearing and use an interpreter	13.2%	16.7%	12.7%
A lot of trouble hearing and do not use an interpreter	1.1%	0.0%	1.3%

Source: IGS client survey.

the HIV-positive subgroup and 54.4 percent for the HIV-negative subgroup). However, in the “good” health category, the percentage of those in the HIV-positive category who assessed themselves at this level was only about half the percentage of those in the HIV-negative group who rated themselves at this level. While only limited conclusions can be drawn from the data, the self-assessment on the part of HIV-positive clients may have been correlated with the presence or absence of symptoms or the quality of medical attention they were receiving. It is also noteworthy that none of the respondents rated himself or herself as being in “poor” health.

Table 10 indicates the possible presence of non-HIV chronic conditions (comorbidities). It is notable that a far lower percentage of HIV-positive respondents (41.7 percent) reported the presence of *none* of these conditions than did the non-HIV-positive subgroup (73.4 percent). This difference is perhaps related to the comorbidity of other chronic illnesses among those who are HIV positive. Furthermore, with the exception of personal problems and cancer, the other chronic illnesses were at least twice as prevalent in the HIV-positive as in the non-HIV-positive subgroup.

### 7.3. Client Demographics

Table 11 presents information on client race and ethnicity. In keeping with national HIV/AIDS

Table 7 Survey Respondents' Educational Background and Attainment			
<i>Educational characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
<b>School Attended</b>			
Maryland School for the Deaf	44.0%	50.0%	43.0%
Public school	52.7%	41.7%	54.4%
Other school	3.3%	8.3%	2.5%
<b>Total Education</b>			
Finished high school	72.5%	58.3%	74.7%
Some or full college	12.1%	33.3%	8.9%
Left high school without graduating	13.2%	8.3%	13.9%

Source: IGS client survey.

Table 8  
**Survey Respondents' HIV Status**

<b>Current HIV status</b>	<b>Number of Respondents</b>	<b>Percentage of Respondents</b>
Don't know	55	60.4%
HIV negative	24	26.4%
HIV positive without symptoms	7	7.7%
HIV positive with symptoms	5	5.5%
AIDS diagnosed	0	0.0%

data, the concentration of African-Americans is higher in the HIV-positive than in the non-HIV-positive subgroup (75.0 percent versus 62.0 percent, respectively). This reflects the higher risk of African-Americans for HIV disease. The HIV-positive subgroup also has a slightly higher

concentration of Hispanics than does the non-HIV-positive subgroup (8.3 percent versus 6.3 percent, respectively), though, with this small sample size, no particular inference can be drawn.

Table 9  
**Survey Respondents' Health Status**

<b>Health characteristic</b>	<b>All respondents</b>	<b>HIV positive</b>	<b>HIV negative</b>
Excellent	24.2%	16.7%	25.3%
Very good	30.8%	41.7%	29.1%
Good	29.7%	16.7%	31.6%
Fair	14.3%	25.0%	12.7%
Poor	0.0%	0.0%	0.0%

Source: IGS client survey.

Table 10  
**Survey Respondents' Chronic Conditions or Comorbidities**

<b>Condition characteristic</b>	<b>All respondents</b>	<b>HIV positive</b>	<b>HIV negative</b>
Diabetes	4.4%	8.3%	3.8%
Kidney problems	2.2%	8.3%	1.3%
Drug and/or alcohol problems	7.7%	16.7%	6.3%
Cancer	2.2%	0.0%	2.5%
Heart problems	5.5%	16.7%	3.8%
Personal problems	8.8%	8.3%	8.9%
None of the above	69.2%	41.7%	73.4%

Source: IGS client survey.

Two points about the Hispanic group warrant mention. First, like most recent surveys, the questionnaire considered the Hispanic group to be a distinctive *ethnic* as opposed to *racial* group. (That is, there are white Hispanics, black Hispanics, etc.) Because of this, the percentages in table 11 sum to more than 100 percent. Second, since Hispanics represented only 1.7 percent of Baltimore City's 2000 population and 4.3 percent of Maryland's 2000 population, they are somewhat overrepresented in the client survey.

Table 11 Survey Respondents' Race/Ethnicity			
<i>Racial/Ethnic characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
African-American/Black	63.7%	75.0%	62.0%
Caucasian/White	31.9%	25.0%	32.9%
Asian-American/Pacific Islander	1.1%	0.0%	1.3%
Other	1.1%	0.0%	1.3%
Hispanic/Latino	6.6%	8.3%	6.3%

Source: IGS client survey.

Table 12 Survey Respondents' Birth Gender			
<i>Gender characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Male	39.6%	50.0%	38.0%
Female	57.1%	50.0%	58.3%
No gender indicated	3.3%	0.0%	3.8%

Source: IGS client survey.

Table 13 Survey Respondents' Age Distribution			
<i>Age category</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
18 to 19 years old	6.6%	0.0%	7.6%
20 to 24	23.1%	41.7%	20.3%
25 to 29	34.1%	33.3%	34.2%
30 to 34	13.2%	8.3%	13.9%
35 to 39	16.5%	16.7%	16.5%
40 to 44	5.5%	0.0%	6.3%
45 to 49	0.0%	0.0%	0.0%
50 to 54	1.1%	0.0%	1.3%
55 years old or older	0.0%	0.0%	0.0%

Source: IGS client survey.

Table 14 Survey Respondents' Household Income			
<i>Annual household income</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
\$0 to 15,000	59.3%	75.0%	57.0%
\$7,501 to 15,000	20.9%	0.0%	24.1%
\$15,001 to 22,500	12.1%	8.3%	12.7%
\$22,501 to 30,000	3.3%	0.0%	3.8%
\$30,000 and above	1.1%	0.0%	1.3%

Source: IGS client survey.

Table 12 shows an exact 50/50 split of genders among the HIV-positive group, while the non-HIV-positive group had a slightly higher concentration of women (58.2 percent). In contrast, in the general population nationally, the HIV-positive group is more predominantly male.

Table 13 presents information on the age of clients. Not surprisingly, it shows a concentration of HIV-positive respondents under the age of 40 (100.0 percent), while the HIV-negative group includes some individuals over 40 (7.6 percent). It is likely that this difference reflects the greater sexual activity — and thus higher risk for HIV — among the younger population.

#### 7.4. Client Socio-economic and Residential Status

Table 14 shows information on the household income of respondents to the survey and, following national patterns, shows a greater concentration of HIV-positive people at the lowest income levels — almost one quarter more than among the non-HIV-positive subgroup. Conversely, while none of the HIV-positive subgroup has a household income over \$22,500 annually, 5.1 percent (4) of the non-HIV-positive respondents have household incomes over this level. However, given the small sample size, no inference should be drawn from this.

Table 15 Survey Respondents' Income Sources			
<i>Income source</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Working/employed	4.4%	8.3%	3.8%
Homemaker	3.3%	0.0%	3.8%
Training for a job	18.7%	33.3%	16.5%
Supplemental Security Income (SSI)	51.6%	25.0%	55.7%
Social Security Disability Income (SSDI)	15.4%	33.3%	12.7%
Public welfare	5.5%	0.0%	6.3%
Other	1.1%	0.0%	1.3%

Source: IGS client survey.

Table 16			
Survey Respondents' Residential Status			
<i>Housing characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Own home	6.6%	8.3%	6.3%
With family	26.4%	33.3%	25.3%
Rent house or apartment	31.9%	25.0%	32.9%
Section 8 residence	20.9%	8.3%	22.8%
HUD	9.9%	25.0%	7.6%
Homeless	1.1%	0.0%	1.3%

Source: IGS client survey.

Table 15 shows income support and employment status. Contrary to what might be expected, a higher percentage of the HIV-positive subgroup was employed than the non-HIV-positive subgroup (more than twice as much) or in training for a job (almost twice as much). These differences are likely to be statistical artifacts related to the small number of individuals included in the HIV-positive subgroup, however. Moreover, because reliance on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) for both subgroups relates to a complex combination of hearing status, employment history and disability from HIV/AIDS, simply contrasting the percentages for the two subgroups in terms of these categories is fraught with difficulty. What is not surprising is the heavy reliance of all those surveyed on SSI and SSDI (51.6 percent and 15.4 percent, respectively).

Table 16 depicts the residential status of the clients. Given the relation of eligibility for Section 8 and other U.S. Department of Housing and Urban Development (HUD) support to household income levels, it might have been expected that the HIV-positive subgroup might have been a good bit more reliant on these housing-support programs than the non-HIV-positive group. In fact, the figures are about the same: 33.3 percent of the positives were housed under Section 8 or other HUD programs, compared to 30.4 percent of the negatives. A noteworthy difference between the HIV-positive and non-HIV-positive subgroups is the higher percentage of the former group who live with their families, 33.3 percent of the positives versus 25.3 percent of the negatives, about one third again as many.

### 7.5. HIV Risk Factors

Based on national epidemiological data, it is known that both sexual preferences and certain behaviors raise the risk of contracting HIV/AIDS. This higher risk tends to be reflected in the data derived from the client survey.

Table 17, which summarizes the sexual preferences indicated on the questionnaires, shows the HIV-negative subgroup to have a more heterosexual orientation than the HIV-positive subgroup, 67.1 percent versus 58.3 percent, respectively. While the HIV-positive subgroup had a higher concentration of individuals with gay or lesbian preferences — 25.0 percent as contrasted with 6.3 percent of the non-HIV-positive subgroup — the latter group included 17.7 percent with a bisexual preference, as compared to 0 percent for the HIV-positive subgroup. (This probably

Table 17			
Survey Respondents' Sexual Preferences			
<i>Sexual characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Heterosexual	65.9%	58.3%	67.1%
Gay/lesbian	8.8%	25.0%	6.3%
Bisexual	15.4%	0.0%	17.7%
Transgender	0.0%	0.0%	0.0%
No preference indicated	9.9%	16.7%	8.9%

Source: IGS client survey.

relates to the small number of respondents in the HIV-positive subgroup.) Confounding comparisons of sexual preference data is the high percentage of individuals who declined to specify a sexual preference, just under 10 percent of total survey respondents.

Table 18 summarizes information on potentially risky behaviors related to unsafe sexual practices and substance abuse. Respondents were asked to respond to all categories that applied to them, so that multiple positive responses were possible. Almost one-third (31.6 percent) of the non-HIV-positive group indicated that they had *never* engaged in any of these risky behaviors, while all of the HIV-positive group indicated having engaged in risky activities at some point. In particular, the positive subgroup was far more likely to have used intravenous drugs than the negative group: 58.3 percent, as against only 19.0 percent. Among the HIV positives, 58.3 had had unprotected sex, compared to 36.7 percent of the negatives. And 41.7 percent of the positives had traded sex for drugs or alcohol, which could be said for only 16.5 percent of the negative group.

Table 18			
Survey Respondents' Risky Activities			
<i>Behavioral characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Sex without condom	39.6%	58.3%	36.7%
Alcohol or non-insulin needle drugs	24.2%	58.3%	19.0%
Sex for drugs or alcohol	19.8%	41.7%	16.5%
None of the above	27.5%	0.0%	31.6%

Source: IGS client survey.

### 7.6. Preventive Interventions

This section summarizes information related to preventive interventions, particularly education about safe sex and HIV/AIDS.

Table 19 presents clients' responses about their experience involving education about safe sex. The most noteworthy statistic is that 33.3 percent (4 people) of the HIV positives indicated that they had *never* learned about safe sex, underscoring the importance of basic education about safe sex in the D/HH population. (In contrast, only 10.1 percent of the non-HIV-positive indicated that they had not learned about safe sex.) Also remarkable is that more than twice as high a percentage of the non-HIV-positive subgroup were satisfied with how they had learned about safe sex,

Table 19

**Survey Respondents' Sources of Education about Safe Sex**

<i>Source of education</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Parents	4.4%	0.0%	5.1%
Physician	7.7%	0.0%	8.9%
School	15.4%	8.3%	16.5%
Friends	20.9%	33.3%	19.0%
Educator/counselor at hearing agency	14.3%	25.0%	12.7%
Educator/counselor at deaf agency	8.8%	0.0%	10.1%
Other	0.0%	0.0%	0.0%
Don't remember	18.7%	0.0%	21.5%
Did not learn about safe sex	13.2%	33.3%	10.1%
Prefer to learn about safe sex that way	49.5%	25.0%	53.2%

Source: IGS client survey.

further evidence of a target of opportunity for basic sex education among the HIV-positive subgroup.

Table 20

**Survey Respondents' Sources of Education about HIV/AIDS**

<i>Source of education</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Parents	1.1%	0.0%	1.3%
Physician	5.5%	8.3%	5.1%
School	18.7%	33.3%	16.5%
Friends	28.6%	16.7%	30.4%
Educator/counselor at hearing agency	15.4%	8.3%	16.5%
Educator/counselor at deaf agency	16.5%	16.7%	16.5%
Other	1.1%	0.0%	1.3%
Don't remember	13.2%	16.7%	12.7%
Did not learn about HIV/AIDS	3.3%	0.0%	3.8%
Prefer to learn about HIV that way	57.1%	33.3%	60.8%

Source: IGS client survey.

Table 20 presents clients' responses about their experiences involving education about HIV/AIDS. The HIV-positive subgroup indicated that they learned about HIV/AIDS twice as often from school (33.3 percent versus 16.5 percent), which might be interpreted to mean that the schools were not terribly effective as a source of information for them, given that they had, obviously, contracted the virus one way or another. Conversely, the non-HIV-positive subgroup indicated that they learned about HIV/AIDS twice as frequently from friends (30.4 percent,

Table 21 Survey Respondents' Preferences for HIV/AIDS Information			
<i>Source of information</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Private physician (no interpreter)	5.5%	0.0%	6.3%
Private physician (with interpreter)	12.1%	8.3%	12.7%
HIV/AIDS hearing clinic	15.4%	33.3%	12.7%
HIV/AIDS deaf clinic	31.9%	41.7%	30.4%
Don't know	9.9%	8.3%	10.1%
Do not need HIV/AIDS information	25.3%	8.3%	27.8%

Source: IGS client survey.

against 16.7 percent for the positives). A final noteworthy distinction in this table is that the non-HIV-positive subgroup was almost twice as satisfied with the means by which they had learned about HIV/AIDS.

Table 21 presents clients' preferences for obtaining HIV/AIDS information services. Slightly over one quarter of the non-HIV-positive group indicated that they did not need HIV/AIDS information services; this was true of less than one tenth of the HIV-positive subgroup. Both subgroups showed a strong preference for receiving information from HIV/AIDS deaf clinics, although the HIV-positive subgroup also showed an only somewhat less strong preference for HIV/AIDS clinics serving the hearing population. The non-HIV-positive subgroup was more inclined to prefer receiving information from private or family physicians, with or without interpreters.

Table 22 Survey Respondents' Use and Knowledge of HIV/AIDS Deaf Services			
<i>Service utilization</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Use HIV/AIDS deaf services	26.4%	25.0%	26.6%
Don't use HIV/AIDS deaf services	8.8%	8.3%	8.9%
Did not know about, <i>would</i> use	19.8%	41.7%	16.5%
Did not know about, <i>would not</i> use	19.8%	8.3%	21.5%
Don't know	25.3%	16.7%	26.6%

Source: IGS client survey.

Table 22 summarizes responses on use and knowledge of HIV/AIDS services targeted to people who are deaf and hard of hearing. The most striking statistic in this table is the 41.7 percent of the HIV-positive group who did not know about HIV/AIDS deaf services but who would use them — clearly a major target of opportunity for outreach by HIV/AIDS deaf services. Otherwise, roughly a quarter of each subgroup reported using HIV/AIDS deaf services.

Table 23 Survey Respondents' Visits to Primary Care Physicians			
<i>Visit frequency</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Once a month	19.8%	16.7%	20.3%
Every 2-3 months	5.5%	8.3%	5.1%
Every 4-6 months	7.7%	25.0%	5.1%
Only when I feel sick	19.8%	25.0%	19.0%
Never	12.1%	0.0%	13.9%
Don't know	31.9%	25.0%	32.9%

Source: IGS client survey.

### 7.7. Utilization of General Health Care and Medical Resources

This section presents data related to D/HH clients' utilization of general (non-HIV-specific) health-care resources and the nature of their interaction with the health-care system.

Table 23 presents information on the frequency of visits to primary-care physicians. A sizable percentage of the group as a whole (33.0 percent or 30 of 91) and of the HIV-positive group in particular (50.0 percent or 6 of 12) reported getting regular attention from a primary-care

Table 24 Survey Respondents' Interaction with Physicians			
<i>Nature of interaction</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
<b>Discuss/ask M.D. questions about health</b>			
Often	11.0%	16.7%	10.1%
Sometimes	60.4%	66.7%	59.5%
Never	27.5%	16.7%	29.1%
<b>M.D. willing to discuss/answer health questions</b>			
Often	25.3%	25.0%	25.3%
Sometimes	50.5%	50.0%	50.6%
Never	20.9%	25.0%	20.3%
<b>M.D. explains new medications</b>			
Often	26.4%	33.3%	25.3%
Sometimes	38.5%	41.7%	38.0%
Never	31.9%	25.0%	32.9%
<b>Confused about medications</b>			
Often	25.3%	25.0%	25.3%
Sometimes	42.9%	50.0%	41.8%
Never	29.7%	25.0%	30.4%

Source: IGS client survey.

Table 25 Survey Respondents' Problems in Obtaining Medical Care			
<i>Problem characteristic</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Other bills to pay	19.8%	33.3%	17.7%
Too far to go	18.7%	33.3%	16.5%
Ignored of discriminated by nurse	17.6%	33.3%	15.2%
Public transportation	12.1%	25.0%	10.1%
No extra money for M.D./nurse	11.0%	0.0%	12.7%
No child care	7.7%	8.3%	7.6%
Cannot get right appointments	6.6%	8.3%	6.3%
Don't know where to get help w/ health	6.6%	16.7%	5.1%
Don't know location of M.D. office	1.1%	0.0%	1.3%
Other	1.1%	0.0%	1.3%

Source: IGS client survey.

physician, with the frequency of visits ranging between once a month and once every 4 to 6 months. (This seems to indicate that primary physicians with sizable practices among the hearing impaired may be a vehicle for outreach about deaf HIV/AIDS services as well as for preventive education.) Just under one fifth of the non-HIV-positive group and one quarter of the HIV-positive subgroup only visited a physician when they felt sick.

Table 24 summarizes responses about the nature of clients' interactions with physicians. In general, the survey indicates a moderately high degree of comfort discussing medical matters with physicians, without noteworthy differences across the subgroups. The final set of rows in the table indicates a high degree of confusion about medications — 75.0 percent of the HIV-positive subgroup and 67.1 percent of the non-HIV-positive subgroup indicate that they sometimes or often are confused about the use of medications. This is probably linked to the high level of each subgroup that indicated that physicians never explained new medicines — about one third for the non-HIV-positive subgroup and one quarter for the HIV-positive subgroup.

Table 25 summarizes information related to clients' problems in obtaining general medical care (as contrasted with HIV-specific medical care for the HIV-positive group). The questionnaire encouraged respondents to respond affirmatively to more than one problem, if they experienced multiple problems. Problems are arrayed in the table in rank order, with those most frequently cited by the largest percentages of the entire group of respondents first and those less frequently cited last. Major concerns for the client group as a whole included "other bills to pay" (19.8 percent), too great a distance to medical offices (18.7 percent), and being ignored or discriminated against by a nurse (17.6 percent). In the HIV-positive subgroup, one third cited each of these concerns, and one quarter pointed to problems with public transportation.

### 7.8. Use of Interpreters for Medical Appointments and Other Purposes

This section turns to clients' use of interpreters, principally during medical appointments. As noted above, interpreters serve an important intermediary role for the D/HH community in negotiating the health-care and social service systems.

Table 26 Survey Respondents' Use of Interpreters During Visits to Physicians			
<i>Nature of usage</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
<b>My interpreter is with me when I go to M.D.'s office</b>			
Always	23.1%	8.3%	25.3%
Sometimes	46.2%	83.3%	40.5%
Never	27.5%	8.3%	30.4%
Don't use an interpreter	3.3%	0.0%	3.8%
<b>When I schedule appointment, I ask nurse to arrange interpreter</b>			
Always	34.1%	33.3%	34.2%
Sometimes	25.3%	16.7%	26.6%
Never	35.2%	50.0%	32.9%
Don't use an interpreter	4.4%	0.0%	5.1%

Source: IGS client survey.

Table 26 presents information related to use of interpreters during visits to physicians. Only 27.5 percent (25) of the total client group (91) reported *never* taking an interpreter with them when they visited physicians; an even smaller fraction of the HIV-positive subgroup — 8.3 percent — never took interpreters along during physician visits. These statistics underscore the importance

Table 27 Survey Respondents' Relationship to Interpreters			
<i>Nature of relationship</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
<b>My interpreter is...</b>			
Family member	15.4%	0.0%	17.7%
Friend	34.1%	58.3%	30.4%
Member of my church	11.0%	16.7%	10.1%
Affiliated with my school	8.8%	8.3%	8.9%
Other	22.0%	16.7%	22.8%
Don't use an interpreter	6.6%	0.0%	7.6%
<b>My interpreter often...</b>			
Is supportive	11.0%	16.7%	10.1%
Is friendly	27.5%	25.0%	27.8%
Understands me	13.2%	16.7%	12.7%
Is not supportive	14.3%	25.0%	12.7%
Is not friendly	11.0%	8.3%	11.4%
Does not understand me	14.3%	0.0%	16.5%
Other	2.2%	8.3%	1.3%
Don't use an interpreter	7.7%	8.3%	7.6%

Source: IGS client survey.

Table 28 Survey Respondents' Degree of Comprehension of Interpreters			
<i>Degree of comprehension</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
<b>My understanding of interpreter is...</b>			
Very clear	11.0%	16.7%	10.1%
Not very clear	39.6%	33.3%	40.5%
Nothing	40.7%	41.7%	40.5%
Don't use an interpreter	6.6%	0.0%	7.6%
<b>I cannot understand interpreter because...</b>			
Big words	5.5%	0.0%	6.3%
Too fast	12.1%	8.3%	12.7%
Different than my signs	24.2%	16.7%	25.3%
Too English	26.4%	8.3%	29.1%
Other	18.7%	33.3%	16.5%
No problem with interpreter	6.6%	8.3%	6.3%
Don't use an interpreter	9.9%	25.0%	7.6%

Source: IGS client survey.

all D/HH people attach to having interpreters available during physician encounters. Only a very small percentage of the responses in this and the succeeding tables — generally well below 10 percent — indicated no use of interpreters. (There is some inconsistency about the response to this question across the questionnaire.) The lower section of the table similarly reinforces the importance of nurses in physicians' offices arranging interpreting services for D/HH patients.

Table 27 presents information about the identity of interpreters and the nature of their relationships with D/HH clients. Clearly, friends and family members were important providers of interpreting services to the deaf and hard-of-hearing, although the members of the subgroup of HIV-positive clients never used family members, perhaps because of sensitivity about their HIV-positive status. The lower section of the table presents a somewhat mixed picture about the quality of the relationship between interpreters and their clients, with no remarkable patterns, though it bears mentioning that a quarter of the HIV positives said that their interpreters were often not supportive.

Table 28 presents further details on the use of interpreters, emphasizing the quality and comprehensibility of interpretation. Only 11.0 percent of the entire client group indicated that their interpreters were "very clear," while 39.6 percent indicated that their interpreters were "not very clear." Most notably, 40.7 percent of all 91 people surveyed said they understood *nothing* their interpreters told them (41.7 percent of the positives and 40.5 percent of the negatives). In other words, all told, four in five deaf patients has at least some trouble understanding interpreters during medical visits. These are important statistics to bear in mind when services are being rendered to this population. No clear patterns or noteworthy statistics appear in the lower portion of the table, which relates to specific problems with interpreters. (The phrase "too English" means that the interpreter is too prone to use English-language idiom in interpreting.)

Table 29  
**Survey Respondents' Problems in Obtaining Services and Social Services**

<i>Respondent has problems with...</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Transportation	28.6%	25.0%	29.1%
Gas/electric bills or food vouchers	27.5%	25.0%	27.8%
Medicine/pharmacy assistance	26.4%	16.7%	27.8%
Cash assistance	25.3%	33.3%	24.1%
Vocational rehabilitation/DORS	24.2%	41.7%	21.5%
Medical Assistance/MCO	22.0%	16.7%	22.8%
Deafness, respondent acceptance of	20.9%	25.0%	20.3%
Child care	19.8%	16.7%	20.3%
Counseling	19.8%	8.3%	21.5%
Job/work/employment	17.6%	16.7%	17.7%
Food bank/home-delivered meals	17.6%	16.7%	17.7%
Housing	15.4%	25.0%	13.9%
Family	11.0%	25.0%	8.9%
Other	3.3%	8.3%	2.5%
No social services problems	3.3%	0.0%	3.8%

Source: IGS client survey.

### 7.9. Social Services and Counseling

The survey also included questions relating to clients' utilization of social services and counseling, important ancillary services for people who are deaf or hard of hearing and who may also have HIV disease.

Table 29 summarizes responses to a question about possible problems with social services and counseling. Respondents were asked to check more than one category as appropriate. The entries in the table are arranged so that they are in declining order of frequency of citation by the client respondent group as a whole. It is apparent that a complex mixture of problems related to transportation, cash availability, bills for essentials, vocational rehabilitation services (and the Maryland Department of Rehabilitative Services, or DORS), clients' own ability to accept their deafness, and access to supportive services such as child care and counseling affected the group as a whole. The HIV-positive subgroup cited problems related to vocational rehabilitation/DORS and cash assistance more frequently than the non-HIV-positive subgroup did.

Table 30 summarizes responses to questions related to knowledge of and linkage to social services and counseling services. The HIV-positive subgroup seemed slightly less knowledgeable about where to get help with social services and health care — but paradoxically more likely to know where to get a counselor and to have a counselor — than the non-HIV-positive subgroup. The relatively high percentage of clients who had counselors at the FSF may in part relate to the fact that the survey was conducted by the DAP, a program of the FSF.

Table 30

**Survey Respondents' Knowledge of Social Services and Counseling**

<i>Type of knowledge</i>	<i>All respondents</i>	<i>HIV positive</i>	<i>HIV negative</i>
Know where to get help with social services, health care	47.3%	33.3%	49.4%
Have a counselor for personal problems	30.8%	41.7%	29.1%
know where to get a counselor	25.3%	41.7%	22.8%
Have or had a drug/alcohol counselor	28.6%	25.0%	29.1%
<b>If have counselor, where:</b>			
Deaf Addictions Services of Maryland	14.3%	16.7%	13.9%
Druid Hill	4.4%	0.0%	5.1%
Family Service Foundation	38.5%	41.7%	38.0%
Other	1.1%	0.0%	1.3%

Source: IGS client survey.

### 7.10. Care and Needs of D/HH Clients Who Are HIV Positive

The remainder of this section on the client survey focuses specifically on D/HH clients who are HIV positive. As a general caveat, it should be recognized that the numbers of individuals represented in this section are small; only 12 of the 91 respondents indicated that they were HIV positive — 5 had symptoms and 7 were asymptomatic. Thus, great care should be taken in attempting to generalize from the results presented in this section. (Partly to reinforce this point, unlike prior sections, the tables in this section present absolute numbers, not percentages.)

Table 31 presents information on HIV testing and treatment. Perhaps surprisingly, only 7 of the 12 people in the HIV-positive group indicated that they had been tested for HIV. (The fraction did not vary dramatically between those with and without symptoms, with slightly over half in each subgroup being tested.) There seems to have been some confusion about testing as well as about what constitutes regular HIV care, since there is some disparity between the numbers

Table 31

**HIV-Positive Respondents' Testing and Treatment**

<i>Testing and care</i>	<i>All HIV+ respondents (n=12)</i>	<i>HIV+ with symptoms (n=5)</i>	<i>HIV+ without symptoms (n=7)</i>
Have been tested for HIV	7	3	4
Testing service easily available and responsive	8	3	5
Currently in HIV care	4	2	2
<b>How often in care?</b>			
Once a month	2	1	1
Every 2-3 months	2	0	2
Every 4-6 months	3	2	1
Only when I feel sick	2	2	0

Source: IGS client survey.

Table 32 HIV-Positive Respondents' Problems Getting HIV Care			
<i>Nature of problem</i>	<i>All HIV+ respondents (n=12)</i>	<i>HIV+ with symptoms (n=5)</i>	<i>HIV+ without symptoms (n=7)</i>
Ignored or discriminated by nurse	6	3	3
Can't get right appointments	3	1	2
Don't know where to get help w/ health	3	0	3
Too far to go	3	2	1
No child care	3	3	0
Other bills to pay	2	2	0
Public transportation	2	1	1
No extra money for M.D./nurse	1	0	1
Don't know location of M.D. office	0	0	0

Source: IGS client survey.

responding positively to whether they were in regular HIV care and the frequency with which they were seen. This table in particular seems fraught with the problems created by the small number of HIV-positive respondents to the survey.

Table 32 summarizes problems experienced in obtaining HIV care. The questionnaire encouraged respondents to select all that applied, so that multiple positive responses were possible. By far the most common problem cited related to attitudes of nurses, who were said to have ignored or discriminated against their HIV-positive D/HH patients; being dually afflicted by both HIV disease and hearing impairments probably made these patients especially vulnerable to such discrimination. Since nurses often represent the first point of clinical contact in physicians' offices and clinics, this negative interaction of nurses with HIV-positive D/HH patients seems to represent a major obstacle to the effective delivery of medical care to this group. Other relatively commonly cited problems involved getting appointments, knowing where to get help with health problems, lack of child care, and distances to HIV care facilities.

Table 33 HIV-Positive Respondents' Care Characteristics			
<i>Care characteristic</i>	<i>All HIV+ respondents (n=12)</i>	<i>HIV+ w/ symptoms (n=5)</i>	<i>HIV+ w/o symptoms (n=7)</i>
M.D. made effort to explain HIV/AIDS in way you understand	2	1	1
M.D. explained importance of takings meds on time, as prescribed	2	2	0
Currently taking prescribed medications for HIV/AIDS	2	2	0
Never took prescribed HIV/AIDS medications	4	1	3
Used to take prescribed HIV/AIDS meds but decided to stop	5	2	3
M.D. asked if life situation made it hard/easy to take meds	1	0	1

Source: IGS client survey.

Table 34 HIV-Positive Respondents' Case Management			
<i>Case management characteristic</i>	<i>All HIV+ respondents (n=12)</i>	<i>HIV+ with symptoms (n=5)</i>	<i>HIV+ without symptoms (n=7)</i>
Have case manager	3	0	3
Do not have case manager	5	3	2
Do not know how to get case manager	3	2	1
Do not need/want case manager	0	0	0
<b>Case manager at?</b>			
Chase Brexton	1	0	1
Family Service Foundation	2	1	1
Johns Hopkins Hospital	2	1	1
Other	0	0	0

Source: IGS client survey.

Table 33 provides details on aspects of HIV-positive clients' current HIV care. Several facts in this table seem noteworthy, highlighting critical disjunctions in the delivery of medical care. First, patients did not perceive physicians were helpful with respect to explaining their HIV disease. Second, only two patients were currently taking prescribed medications for HIV/AIDS. Five of the group of 12 had previously taken prescription medications for HIV/AIDS, but had decided to discontinue them. In sum, HIV-positive D/HH patients in the survey were not getting the physician attention or pharmaceuticals they urgently needed, and a sizable percentage who had previously taken medications had stopped taking them, underscoring a major gap in their medical care.

Finally, table 34 offers information about HIV case management among those respondents who are HIV positive. Only three currently had an HIV case manager — remarkably none of them in the HIV-positive-with-symptoms subgroup — and three indicated that they did not know how to get a case manager. Significantly, none of the 12 indicated that he or she did not need or want an HIV case manager. In short, of the 12 respondents, all wanted case managers, though only three had them (one quarter). Thus, this seems a clear-cut area of unmet need, and seemingly one in need of urgent attention. (It should be noted in passing, however, that one of the HIV-positive respondents without symptoms did not indicate whether he or she had, did not have, did not know how to get, or did not need or want a case manager; this seems to reflect confusion or misunderstanding on that person's part.)

## 8. CONCLUSION

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

— *Lester 1999*

The literature review presented at the outset of this report makes it obvious that D/HH people are especially vulnerable to HIV/AIDS to begin with, and may encounter special problems related to access to health and social services because of their hearing impairments. Epidemiological data, which demonstrate the greater prevalence of HIV disease among people with hearing impairments, underscore the special importance of targeted preventive interventions in the D/HH community. Moreover, with hearing impairments, a special type of cultural competence is called for on the part of providers of health care and social services. Interpreter services and other assistive modalities are frequently necessary if prevention and treatment are to be effective.

Serving either population — the D/HH or people living with HIV/AIDS — presents challenges. For D/HH individuals who have HIV disease, tailoring medical and social services to their needs requires special sensitivity on the part of providers and a willingness to accommodate both clients' hearing impairment *and* special medical needs related to HIV/AIDS. However, while the client survey reinforced what is known about the importance of interpreters at medical appointments, the provider survey identified the cost of interpreters as a major concern and the lack of available interpreters as a deficit for most of the providers.

### 8.1. Risk

While the D/HH population shares basic risk factors for HIV/AIDS with the non-hearing-impaired population, for a number of reasons, they are at greater risk of developing HIV/AIDS than the general population. These special risk factors include greater vulnerability to sexual and physical abuse, higher rates of substance abuse, less effective sex and health education, limited HIV outreach, substantial obstacles to access to health care, and certain distinctive aspects of deaf lifestyles and personal preferences.

### 8.2. Provider Recommendations

When IGS convened a group of providers of HIV services, the latter made a number of recommendations about how to improve their responsiveness to deaf clients. These included making available cultural-competency training for working with deaf clients, producing a resources guide for referrals to other supportive services providers, and capitalizing on opportunities for sharing resources and other collaboration.

### 8.3. Client Survey

The client survey conducted by the DAP for IGS highlighted a number of special risk factors for HIV/AIDS among deaf Marylanders. These included: gay or lesbian sexual preferences, unsafe sexual practices, using injection drugs or alcohol, and trading sex for drugs or alcohol. Especially noteworthy was the finding that 33.3 percent of HIV-positive respondents (4 of 12) had not been educated about safe sex practices.

With respect to D/HH consumers' preferences about HIV/AIDS information sources, respondents

expressed a decided preference for receiving information from HIV/AIDS deaf clinics, followed by HIV/AIDS hearing clinics. Of the HIV-positive group, 41.7 percent indicated that they did not know about HIV/AIDS deaf services but would use them; this seems a major target of opportunity for outreach by HIV/AIDS deaf services.

The client survey uncovered some major deficiencies in access to medical care by D/HH clients. While clients expressed a moderately high degree of comfort in discussing medical matters with physicians, over two thirds of them expressed some confusion about medications. Major impediments to obtaining medical care for the client group as a whole included other bills to pay (19.8 percent), distance to medical offices (18.7 percent), and being ignored or discriminated against by a nurse (17.6 percent). In the HIV-positive subgroup, one third cited each of these concerns, while one quarter identified problems with public transportation.

The client survey underscored the importance of interpreters for D/HH patients. While only 27.5 percent of the total client group reported never taking an interpreter along during physician visits, among HIV-positive respondents, only 8.3 percent never took interpreters along for such visits. Almost 60 percent of all respondents indicated some reliance on nurses to arrange interpreters when scheduling appointments. However, there is some evidence that interpretation was less than ideal: only 11.0 percent of the entire client group indicated that their interpreters were “very clear,” while 39.6 percent indicated that their interpreters were “not very clear.” Astonishingly, 40.7 percent of all 91 people surveyed said they understood nothing the interpreter told them.

The HIV-positive subgroup tended to be slightly less knowledgeable about where to get help with social services and health care — but paradoxically more likely to know where to get a counselor and to have a counselor — than the non-HIV-positive subgroup.

The client survey yielded some important findings with respect to the care and needs of D/HH clients who are HIV positive. First, this group pointed out certain basic problems with the attitudes of nurses, whom they felt ignored or discriminated against them. Since nurses are often the first actual point of contact with clinical care, such attitudes clearly jeopardize the effectiveness of medical attention for this group. Second, over 90 percent of all patients did not perceive that physicians were helpful with respect to explaining their HIV disease in understandable terms. Third, only two of the twelve HIV-positive patients were currently taking prescribed medications, while five had discontinued taking medications. Finally, only three of the HIV-positive respondents had case managers — remarkably, none of them in the symptomatic HIV-positive subgroup. While the small numbers in the HIV-positive subgroup warrant particular caution in generalizing from the survey findings, these conclusions are nonetheless indicative of disturbing shortcomings in access to health care for this particular population of HIV-positive D/HH patients.

## 9. APPENDICES

### Appendix 9.1. SAMHSA Recommendations for Improving Screening for Disabilities

#### *Screening for Disabilities*

Because many disabilities are not obvious, it is important to screen for them in every person, not just those with obvious functional limitations. Ask all clients entering treatment whether they require any accommodations in order to participate.

It is the level of abilities and of the functioning of the individual — not the simple determination of whether an impairment exists — that must be assessed if screening is to lead to an effective treatment plan. In situations where a diagnosis of disability is needed (e.g., to qualify for special services) treatment providers should refer the client to a disabilities services professional.

Although it is a good idea to get background information from as many sources as possible, interview the person alone, if possible. Having others present often distorts the quality of the interview.

Intake interviews should begin with an open and friendly question, not one that is focused on the person's disability.

An intake interview should address the eye condition and blindness adjustment skills of people who are blind or visually impaired. The counselor should ascertain the pathology of the loss of vision (if it was congenital, adventitious, or traumatic), and precisely how much vision remains.

If there are forms to be completed as part of intake processing, people who are blind must have the option to complete them in the medium of their choice (Braille, large print, audiocassette, or sighted assistance). Individuals who are both deaf and blind will need a tactile interpreter to translate for them during the admissions process and afterward.

Due to the wide range of reading abilities among people who are deaf, paper and pencil should never be utilized to gather detailed assessment information. Written English forms and questionnaires should be interpreted into sign language for these clients.

When screening people with cognitive disabilities, be as specific as possible — rather than asking if they “use alcohol,” ask if they like to drink beer, wine, wine coolers, etc. It may help to use props such as different glass or bottle sizes rather than asking how many ounces were consumed.

Source: SAMHSA 1998.

**Appendix 9.2. SAMHSA Organizational Recommendations*****Organizational Commitment***

Providers must be prepared to act as advocates for their clients when services and supports that are normally readily available and effective prove inaccessible for the client.

When treatment teams make the effort to accommodate individuals with coexisting disabilities, the quality of care improves for all clients. All clients can get more out of treatment that is individualized and that takes their specific functional capacities and limitations into account.

To ensure full organizational support for treating people with coexisting disabilities, the Consensus Panel recommends that a treatment program develop a policy statement that articulates the program's willingness to accommodate any individual with a disability who chooses to attend the program.

When a program makes a commitment to serving people with coexisting disabilities, board membership of people with disabilities may be implemented immediately or considered as a goal to be reached as the program begins to serve a greater number of people from these groups. A program should try to obtain regular input from the community it seeks to serve; creating a permanent task force or an advisory committee is an ideal way to address this need.

The organization must make a commitment to continually reexamine the program's effectiveness for people with coexisting disabilities. Such inquiry can take place both formally, using quality assurance methods and consumer satisfaction surveys, and informally, through opportunities for individual and group feedback with program staff.

It is not enough for a program simply to be ready to serve people with coexisting disabilities. Rather, the program should be proactive in making the disability community aware of its services to ensure that disability organizations will support referrals to the program.

Another sign of organizational commitment is to hire people with disabilities to work in the treatment program. Hiring people with disabilities also benefits other staff members, who can learn from these coworkers.

The Consensus Panel recommends an "open door" policy that states that all clients are entitled to an assessment if they are presenting with a chemical dependency problem, regardless of whatever other problems they may appear to have. If the proper course of treatment is not available at the facility, it is still possible to perform a substance use disorder assessment and refer the client for treatment elsewhere.

Source: SAMHSA 1998.



**Appendix 9.3. IGS Provider Survey**

**IGS Survey – Serving Special Populations**

Distribution date: January 2003

Please take a few moments to fill out the following survey. Individual responses from each site will remain confidential. Responses will be aggregated and analyzed for use in Ryan White Title I planning.

Provider/Organization: \_\_\_\_\_

Organization's address: \_\_\_\_\_

Name and title of the person completing this survey:	
What is your primary role at this provider site serving HIV+ clients?	
How long have you worked there?	
How long have you worked with patients/clients who are diagnosed with HIV/AIDS?	
Please estimate the number of HIV-infected patients who have been seen in this office/clinic in the past month.	

On average, how often does your site schedule to see the following kinds of patients in your practice?	Once a month or less	Every 2 to 3 months	Every 4 to 6 months	Every 7 to 12 months	Don't know/can't remember
HIV-infected asymptomatic clients					
• with substance-use problems					
• with mental-health problems					
HIV-infected symptomatic patients					
• with substance-use problems					
• with mental-health problems					
AIDS-diagnosed clients					
• with substance-use problems					
• with mental-health problems					

Do you offer the following (check all that apply):			
Transportation or assistance with public transport		Sliding fee scale or uncompensated care	
Flexible/convenient office/clinic hours		Mobile services or in home care	
On-site child care		Assistance with financial/billing difficulties	

What are your organization's funding sources (check all that apply)?			
Federal funding		Other insurance (HMO, PPO, individual, etc.)	
Medicare		Patient/client revenue	
Fee-for-service insurance		Medicaid	
Grants (describe)		Other (describe)	



What proportion of your HIV-infected clients (in percent):	0	<10	10-25	26-50	51-75	76-100
Are severely/chronically mentally ill						
Are chemically dependant						
Are diagnosed with HIV/AIDS & mental-health issues						
Are diagnosed with HIV/AIDS & substance-use issues						
Are diagnosed with HIV/AIDS, mental-health & substance-use issues						
Have a history of incarceration						
Are homeless						
Are men who have sex with men						
Are women						
Are pediatric clients						
Are youth (13-24 years old)						
Are adults over 50 years old						
Are partners of substance users						
Are racial and/or ethnic minorities						
Are from out of state						
Are from: Balt. City or A.A., Balt., Carroll, Harford, Howard or Q.A. cnties						
Are migrant/seasonal farm workers						
Are recent immigrants						
Are eligible for Medicaid						
Are uninsured/underinsured						
Have serious trouble seeing, even with glasses or contact lenses						
Have trouble hearing what is said in a normal conversation						
Have serious difficulty understanding people when talk/ask questions						
Have serious difficulty learning how to do things most people can learn)						
Have significant mobility limitations						
Are frequently depressed or anxious						
Lack an adequate social support network of family/friends						
Lack an adequate social support network of professionals/volunteers						
Lack an effective case manager/advocate						
Must get help or supervisions from another person:						
• with shopping for personal items						
• with managing money						
• with heavy housework						
• with light housework						

Thank you for taking the time to fill out this survey. For further information on this project, please contact: R. Kelly Heilman, IGS, 116 East 25<sup>th</sup> Street, Baltimore, MD, 21218; e-mail, heilman@intergroupservices.com; phone, 410-662-6253; fax 410-662-7254.

This project is funded by the Ryan White Title I funds through Associated Black Charities & the Baltimore City Health Department.

**Appendix 9.4. IGS Client Survey*****Questionnaire Consent Form***

The purpose of this community-input survey has been explained to you or you have read its purpose. Your participation in this community-input project is completely voluntary. You have the right to withdraw from the project at any time. Your responses will be reported to no one, including your employer and your health-care provider.

You may ask the investigator questions about the process and the purpose of the study. The investigator is the person reading the questions to you or who has given you the question form to fill out.

If you want to talk to someone about the project because you think you have not been treated fairly, you may contact the company coordinating the project, which is:

InterGroup Services, Inc.  
116 E. 25th Street  
Baltimore, MD 21218  
E-mail: [igs@intergroupservices.com](mailto:igs@intergroupservices.com)  
Telephone: 410-662-7253

Or you may call the Baltimore City Health Department's Human Subjects Review Committee at 410-396-9944.

The Baltimore City Health Department, the City of Baltimore and the federal government do not have any program to provide compensation to you if you experience injury or other bad effects, which are not the fault of the investigators, as the result of this questionnaire.

I understand the questionnaire consent form and agree to participate in the survey. I understand that all individual responses will be kept confidential.

Check here:



ZIP code of respondent's home: \_\_\_\_\_ Last four digits of Social Security No.: \_ \_ \_ \_

ALL ANSWERS ARE 100% CONFIDENTIAL AND ANONYMOUS.

**Deaf and Hard-of-Hearing Health and HIV Survey**

**A. Introduction**

Deaf AIDS Project is conducting a health-care and HIV-services survey for Associated Black Charities and InterGroup Services to find out need of local Deaf and hard of hearing. The result of survey is the hope that government will improve HIV services to Deaf and hard of hearing. Thank you for your participation. All answers are private and your opinions are very important to survey success.

The wording of this questionnaire is designed to accommodate those whose native language is American Sign Language (ASL). As such, it is not written in Standard English. This is intentional.

**B. Background Information**

Here are some background questions. Remember, all answers are private.

1. Check one category (for example, deaf) and one subcategory (for example, use a sign language interpreter). You are:

<input type="checkbox"/> Deaf, and I	<input type="checkbox"/> Late deafened, and I	<input type="checkbox"/> Hard of hearing, and without hearing aid I have	<input type="checkbox"/> Hearing, and without a hearing aid I have	<input type="checkbox"/> Other, please specify
___ Use a sign language interpreter	___ Use a sign language interpreter	___ A little trouble hearing	___ No trouble hearing	
___ Use an oral interpreter	___ Use an oral interpreter	___ A lot of trouble hearing and I use an interpreter	___ A little trouble hearing	
___ Do not use an interpreter	___ Do not use an interpreter	___ A lot of trouble hearing and do not use an interpreter	___ A lot of trouble hearing	

**C. School**

Please answer these two questions about your schooling. Check only one box for each question.

2. I attended school at:	3. Highest schooling:
<input type="checkbox"/> Maryland School for the Deaf	<input type="checkbox"/> Finished high school
<input type="checkbox"/> Public school	<input type="checkbox"/> Some or full college
<input type="checkbox"/> Other school (explain):	<input type="checkbox"/> Left high school without graduating



**D. Living Standard**

Please answer these two questions about the way you live. Check only one box for each question.

4. I am:	
<input type="checkbox"/>	Working/employed
<input type="checkbox"/>	Homemaker
<input type="checkbox"/>	Training for a job
<input type="checkbox"/>	SSI (Supplemental Social Security Income)
<input type="checkbox"/>	SSDI (Social Security Disability Income)
<input type="checkbox"/>	Public welfare
<input type="checkbox"/>	Other (explain):

5. I live:	
<input type="checkbox"/>	Own home
<input type="checkbox"/>	With family
<input type="checkbox"/>	Rent house or apartment
<input type="checkbox"/>	Section 8 residence
<input type="checkbox"/>	HUD
<input type="checkbox"/>	Homeless
<input type="checkbox"/>	Other (explain):

**E. Health**

The following questions are about your health and your access to medical care. It is important that we know how accessible health care is to you.

6. My health is (check one):  Excellent  Very good  Good  Fair  Poor

7. Please check all conditions that apply. I have:

- Diabetes  Cancer
- Kidney problems  Heart problems
- Drug/alcohol problems  Personal problems
- None of the above

8. What is your current HIV status?

- Don't know
- HIV negative
- HIV positive, but I do not have symptoms
- HIV positive with symptoms
- AIDS diagnosed (date diagnosed): \_\_\_\_\_

9. Do you always go to the same primary care provider or doctor?  No  Yes

9b. If yes, who and where: \_\_\_\_\_

10. How often do you see a primary care provider or doctor?

- Once a month
- Every 2-3 months
- Every 4-6 months
- Only when I feel sick
- Never
- Don't know

11. Do you have health insurance?  No  Yes

11b. If yes, please say which (check one):

- Medicare
- Medicaid/Medical Assistance
- Other public coverage
- Private insurance

12. In the past year, have you had problems getting general medical care?  Yes  No

12b. If yes, was it because of (check all that apply):

- Public transportation
- Can't get right appointments
- I was ignored or discriminated by nurse
- I have other bills to pay
- I do not know where I can get help with health problems
- Other (explain): \_\_\_\_\_
- Too far to go
- No babysit or childcare
- No extra money for doctor or nurse
- I do not know where doctor's office is

13. I often discuss/ask questions with my doctor about my health:

- Yes
- Sometimes
- No/Never

14. My doctor is often willing to discuss/answer questions about my health:

- Yes
- Sometimes
- No/Never

15. My doctor often takes time to explain why I am taking new medicines or what it is used for:

- Yes
- Sometimes
- No/Never

16. I am often confused about what medicine is used for:

- Yes
- Sometimes
- No/Never

17. I went to emergency room at hospital near my home (for me), how many times in six months?

\_\_\_

### ***F. Interpreter***

Please answer the following questions about your access to and your satisfaction with interpreter services. It is important that we know about interpreter services in relation to your overall health care.

18. Every time I see doctor, I have interpreter with me:

- Yes
- Sometimes
- No/Never
- Do not use an interpreter

19. When I set up appointment, every time I ask nurse to set up interpreter:

- Yes
- Sometimes
- No/Never
- Do not use an interpreter

20. Please check all boxes that apply. Sometimes I bring my own interpreter. He/she is:

- One of my family
- My friend
- From my church
- From my school
- Other (explain): \_\_\_\_\_
- Do not use an interpreter



28. Did your doctor make the effort to explain about HIV/AIDS to you in a way you could understand?  Yes  No

28b. Please check all that apply. If yes, was it information that:

- You could read
- Was sent by TTD
- Was on videotape
- Was sent by e-mail
- Was on the Internet
- Involved role playing
- Involved classroom lectures
- Other (explain): \_\_\_\_\_

29. Do you currently take any prescribed medication(s) for your HIV/AIDS condition?

- Yes  No

29b. If no, please say which is applicable to you:

- I have never taken any prescribed HIV/AIDS medications
- I used to take prescribed HIV/AIDS medications but decided to stop

29c. If you took medications but stopped, please explain why: \_\_\_\_\_

30. Your doctor explain importance of taking medications on time, and as prescribed?

Did you understand? Did you know what to do if you have problems?

- Yes  No  Don't remember

31. Your doctor ask if your life situation make it easy or hard to take medication as prescribed?

- Yes  No  Don't remember

32. Your doctor discuss any help you could get taking medicines as prescribed (check all that apply)?

- Weekly or daily pill boxes
- Timers
- Pagers
- Support groups
- Support from family or friends
- Referral for case management
- Referral for peer education
- Referral to a pharmacist
- Other (explain): \_\_\_\_\_
- None, no discussion or referral

33. Please check one. Do you have an HIV/AIDS case manager?

- I have an HIV/AIDS case manager
- I do not have an HIV/AIDS case manager
- I don't know how to get an HIV/AIDS case manager
- I don't need/want an HIV/AIDS case manager



- 33b. If HIV/AIDS case manager, he/she at:
- CBHS (Chase Brexton Health Services)
  - FSF (Family Service Foundation)
  - CSSD (Community Support Service for the Deaf)
  - JHH (Johns Hopkins Hospital)
  - DASAM (Deaf Addictions Services At Maryland)
  - Church (Christ United Methodist Church has Shalom Zone case management)
  - Other (explain): \_\_\_\_\_

**H. Social Services and Counselor**

Please answer the following questions about your access to social services and counseling.

34. Please check all that apply. I have problems with:
- Deafness (my acceptance of being deaf)
  - Housing
  - Gas/electric bills or food vouchers
  - Food bank or home delivered meals
  - Cash assistance
  - Transportation
  - Medicine/pharmacy assistance (MADAP)
  - Medical Assistance/MCO
  - Family
  - Childcare
  - Counseling
  - VR/DORS (vocational rehabilitation or Department of Rehabilitation Services)
  - Job/work/employment
  - Other (explain): \_\_\_\_\_
  - I have no social services problems

35. If I need help (home, food, more medicine, HIV/AIDS test, other), I know where to get help:  Yes  No

36. I have a counselor for my personal problems:  Yes  No

37. If I need a counselor, I know where to go:  Yes  No

38. I did/do have drug/alcohol counselor  Yes  No

- 38b. If yes, where?
- DASAM (Deaf Addictions Services at Maryland)
  - Druid Hill
  - FSF (Family Service Foundation)
  - Other (explain): \_\_\_\_\_



**I. HIV Prevention**

Please answer these questions about safe sex and HIV prevention. All answers are confidential.

39. Please check all that apply. I learned about safe sex or condoms from:

- My parents
- My old school
- Educator/counselor at hearing agency
- Don't remember
- Did not learn about safe sex
- My doctor
- Friends
- Educator/counselor at deaf agency
- Other (explain): \_\_\_\_\_

39b. Prefer to learn about safe sex or condoms that way?  Yes  No

40. I learned about HIV/AIDS from:

- My parents
- My doctor
- My old school
- Friends
- Educator/counselor at hearing agency
- Educator/counselor at deaf agency
- Don't remember
- Other (explain): \_\_\_\_\_
- Did not learn about HIV/AIDS

40b. Prefer to learn about HIV/AIDS that way?  Yes  No

41. I did:

- Have sex with anyone without condom
- Use any needle drugs (not insulin) or alcohol
- Have sex with someone for drugs or alcohol
- None of these

42. For HIV/AIDS information/services, I prefer to go to (check one box):

- Private/family doctor (no interpreter)
- Private/family doctor (with interpreter)
- HIV/AIDS hearing clinic
- HIV/AIDS deaf clinic
- Don't know
- I do not need HIV/AIDS information services

43. For HIV/AIDS deaf services (check one box):

- I use HIV/AIDS deaf services
- I do not use HIV/AIDS deaf services
- I did not know about HIV/AIDS deaf services, but would use
- I did not know about HIV/AIDS deaf services, but would not use
- Don't know



**J. About You**

Please answer these questions about your background. Answering them correctly will help us define the HIV service needs of the deaf and hard-of-hearing community.

43. Please check one. Are you:

- African American/Black                       Asian  
 White/Caucasian                                 Other (explain): \_\_\_\_\_

43b. Are you Hispanic or Latino(a)?

- Yes     No

44. Please check the age group that applies to you:

- 18 to 19 years old  
 20 to 24 years old  
 25 to 29 years old  
 30 to 34 years old  
 35 to 39 years old  
 40 to 44 years old  
 45 to 49 years old  
 50 to 54 years old  
 55 to 59 years old  
 60 to 64 years old  
 65 years old or more  
 Other (explain): \_\_\_\_\_

45. Birth gender:  Male     Female

46. Sex preference:

- Heterosexual                                       Gay/lesbian  
 Bisexual     Transgender

47. What was your total household income for 2002 (check one):

- \$0-7,500  
 \$7,501-15,000  
 \$15,001-22,500  
 \$22,501-30,000  
 \$30,001 and above

Thank you very much for participating.

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