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## **HIV SERVICES FOR MENTAL HEALTH CONSUMERS WITH HEARING IMPAIRMENT: RISK ASSESSMENT AND PREVENTION STRATEGIES**

**Lisa Razzano  
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This paper describes an HIV risk assessment screening for deaf clients with severe mental illness at a large psychosocial rehabilitation agency in Chicago, IL. The agency has developed education, prevention, and ongoing support services to respond to the needs of this at-risk population. The results of an HIV risk assessment screening of 39 clients with this dual diagnosis are presented, detailing the numbers and characteristics of clients who report engaging in high risk sexual and drug use behaviors. Reported rates of sexual activity, number of partners, sexually transmitted disease history, intravenous and recreational drug use behaviors, and alcohol use are reported along with knowledge levels about HIV and modes of transmission. Also discussed are issues and concerns relevant to people with mental illness who are deaf, including a summary of an agency HIV education group conducted in sign language.

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The HIV education and service needs of deaf persons with psychiatric disabilities are not clearly understood by researchers or service providers. Recently, risk assessments of both inpatient and outpatient consumers of psychiatric services have indicated that clients engage in numerous high risk behaviors (Cook, Razzano, Jayaraj, Myers, Nathanson, Stott & Stein, in press). Furthermore, because they constitute a somewhat closed community due to language, there are additional reasons for concern that deaf people may be at heightened risk for HIV infection compared to non-deaf consumers with psychiatric disabilities. This analysis addresses these issues by summarizing the results of an HIV risk assessment conducted at a psychiatric rehabilitation program for deaf clients and describes prevention and education services developed for this population.

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### Review of the Literature

Studies of inpatient populations indicate that a substantial proportion of psychiatric clientele participate in high risk sexual practices and use drugs (Meyer, Cournos, Empfield, Schrage, Silver, Rubin & Weinstock, 1993; Sacks, Perry, Graver, Schindledecker & Hall, 1990; Sacks, Silberstein, Weiler & Perry, 1990). This finding has been corroborated by studies of outpatient mental health consumers as well (Cook et al., in press; Cournos, McKinnon, Meyer-Bahlburg, Guido, & Meyer, 1993; Kalichman, Kelly, Johnson & Bulto, 1993).

In addition to the identification of HIV risk behaviors, researchers and clinicians have acknowledged the participation of persons with long term mental illness living in the community in intimate, sexual relationships. Such partnerships are similar to those found among same-aged cohorts in the non-disabled population (Abernathy, 1973; Coverdale & Aruffo, 1989; Test & Berlin, 1981). These findings challenge a prevailing view of persons with severe psychiatric disorders as asexual people, with little or no interest in or opportunities for sexual expression (Carmen & Brady, 1990). In an effort to counter these myths, services responsive to clients' sexual expression and needs have been addressed by several psychiatric rehabilitation programs (Dincin & Wise, 1979; Pepper, 1983; Steiner, Luisser, Maust, DiPalma, & Allende, 1994). Ironically, these responsive services may promote opportunities for client-to-client HIV transmission when the program context encourages consumers to share residences, participate in common social and leisure time activities, and cultivate intimate relationships (Cook et al., in press).

The deaf community is often considered a somewhat "closed community" as far as sexual activity and drug use behaviors are concerned because the social networks of deaf people are generally comprised of other deaf individuals (Padden & Humphries, 1988). The deaf community may be further circumscribed by the tendency for persons with mental illness to have social networks consisting of a substantial proportion of other mental health consumers (Goering, Durbin, Foster, Boyles, Babiak, & Lancee, 1992; Pattison, Llamas, & Hurd, 1979; Weinberg & Marlowe, 1983). Thus, this homogeneity of social and sexual networks may exacerbate the infection risks for network members, promoting transmission of the virus.

Features associated with audiological impairment also may affect deaf persons' knowledge about HIV risk and prevention in ways which are not true for non-deaf persons with mental illness. This group, for example, may have less access to health information than the hearing community (Burke, 1993; Van Biema, 1994), and cognitive difficulties related to thought disorders and neurological impairments often intensify the barriers that hinder deaf consumers' ability to understand information that is obtained (Cook, Graham & Razzano, 1993). Moreover, HIV educational materials published for hearing individuals may not be appropriate

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for the subpopulation of deaf mentally ill people with fewer skills for either spoken or signed language. Based upon these issues, deaf persons with psychiatric disabilities may require specialized programming which can be tailored to individual client comprehension abilities and communication preferences. To accomplish this, service providers require more information regarding deaf people's sexual and drug risk behaviors and the types of services which are effective and desired by them. The purpose of the following analysis was to identify deaf clients' participation in behaviors related to risk of HIV infection and to provide this information to direct service staff.

### Method

#### Sample

A screening assessment interview was completed by 89% or 39 out of 44 eligible clients at a large psychiatric rehabilitation agency located in Chicago. Eligibility to participate in the screening was defined as being an open case for at least six months on 4/1/93 as well as on the date the screening was attempted during the following months. Of the five clients who did not participate, three refused participation and two were hospitalized and unable to complete the assessment at the time it was attempted. Another hospitalized client was able to complete the assessment and was included in the analysis.

Sixty-two percent ( $n=24$ ) of the clients were men and 38% were women ( $n=15$ ). Of these, 56% ( $n=22$ ) were Caucasian, 39% ( $n=15$ ) were African American, and 5% ( $n=2$ ) were Latino/Hispanic. The average age of these clients was 36 years old. Eighty-seven percent ( $n=34$ ) reported that they had never been married, 8% ( $n=3$ ) had been divorced, and 5% ( $n=2$ ) were separated. None were currently married and none reported having been widowed. Forty-six percent ( $n=18$ ) were currently living in an agency group home for the deaf, 21% ( $n=8$ ) were living with family, 31% ( $n=12$ ) were living in the community, and 2% ( $n=1$ ) were hospitalized. Ninety percent ( $n=35$ ) of these clients were profoundly deaf, defined as "hearing loss precluding successful processing of linguistic information through audition, with or without a hearing aid" (Levine, 1981, p. 41). Regarding their communication skills level, 10% ( $n=4$ ) were rated as "poor" (meaning that they lacked basic vocabulary, syntax and grammar structure in their use of signed or spoken language), 49% ( $n=19$ ) were rated as "fair" (meaning that they had some awareness of the use of structured language but had serious deficits in using correct structure and no fluency), and 41% ( $n=16$ ) were rated as "good" (meaning that they could communicate their thoughts fluently in signed or spoken language). Their average number of years of

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education was 10 years. Twenty-six percent (n=10) had attended residential schools for the deaf, 20% (n=8) had attended non-residential special education programs for deaf students, 41% (n=16) attended regular public schools and 13% (n=5) did not attend school.

All of the clients are persons with a DSM-III-R, Axis I or Axis II diagnosis of mental illness, with 65% (n=25) diagnosed as having schizophrenia and 36% (n=14) having another diagnosis such as major depression. At the time of the HIV risk assessment screening interview, 72% (n=28) reported taking psychotropic medications. The average number of lifetime psychiatric hospitalizations at the time of the screening interview was five, with a median number of two hospitalizations. The average number of weeks spent in institutions was 144 (about 36 months), with a median of 25 weeks. The average tenure of membership in the program (calculated from time of program intake until the date for completion of the HIV risk assessment interview) was approximately four years.

### Setting

This research was conducted at a psychiatric rehabilitation program for deaf clients with severe mental illness called the Thresholds Bridge Program for the Deaf (TBPD). Using the assertive community treatment model developed by Stein and Test (Stein & Test, 1980; Test & Stein, 1980), the program includes all of the features of a psychosocial rehabilitation program with particular emphasis on the development of skills essential for living within the community. This includes job placements and a full range of residential options ranging from group homes to supported apartments. Sixty-five percent of the case management staff at TBPD are deaf and 100% are fluent in sign language. Case management services include individualized visits to the clients' homes and surrounding neighborhoods. During these visits, clients and case managers design strategies to address the specific life goals a client needs and wants to achieve such as money management, leisure time activities, cooking, shopping, and making friends.

### Instrument

An agency HIV Task Force developed an HIV Risk Assessment Screening tool based upon an instrument used by Carmen and Brady (1990, p. 654). This screening assessment presented items relevant to HIV risk behaviors including use of intravenous drugs, use of other recreational drugs and/or alcohol, sexual history, past sexually transmitted disease (STD) history, and the frequency of condom use. Also recorded was the caseworker's recommendation to the client about whether he or she should consider having an HIV test.

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### Procedure

All clients open to the agency on 4/1/93 for at least six months were considered eligible for participation. This criterion was used at the request of case managers who felt that the screening instrument would be perceived as intrusive by clients who were in new casework relationships. HIV screenings in clients' preferred communication mode(s) were completed by their case managers in one-on-one interviews, typically at clients' homes. Screenings were conducted using combinations of American Sign Language (ASL) (used in 69% of all screenings), Pidgin Signed English (PSE) (13%), signed English (10%), speech (8%), and home signs (5%). Hearing aids were used by 10 clients (26%) during the screening interviews. Clients were offered the opportunity to decline participation in the screening or to stop at any time if they wished. Special attention was paid to procedures which maintained confidentiality of the screening assessment information as well as the client's identity on the assessment form both while it was being elicited as well as after it was sent by the case manager to research staff.

### Results

#### HIV Risk Assessment Screening Interviews

Initial analyses consisted of the examination of frequency distributions and percentages of all sexual or substance use risk behaviors and education variables, as well as caseworker recommendations. Table 1 summarizes clients' reported risks related to sexual and drug use behaviors as well as case worker's recommendations for HIV testing. The top of Table 1 lists the self-reported frequency of condom use among these clients. Thirty-one percent (n=12) reported that they "never" use condoms, 10% (n=4) indicated that they "sometimes" use condoms, none reported that they "mostly" use them, and 10% (n=4) responded that the "always" use condoms. Forty-four percent (n=17) of the clients reported being sexually active at the time of the interview. Among all clients, 24% (n=9) reported that they were worried about HIV exposure.

The next section of Table 1 presents the proportion of clients who reported engaging in each of the activities which have been identified as **primary** risk behaviors for HIV infection (Perry & Markowitz, 1988). One client (3%) reported having ever injected drugs. Heroin (not shown) was the only drug identified as having been used intravenously. One client reported having shared needles or injection drug paraphernalia. A tenth (n=4) of all clients reported current or past relationships with IVDU (intravenous drug using) sex partners.

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Fifteen percent (n=6) of all clients reported a history of STDs. These included (not shown) gonorrhea, syphilis, herpes, genital warts, and pubic lice (clients could list more than one STD and several did). Of all clients, 5% reported that they had more than 25 sex partners over the past five years. The average number of sexual partners reported by all clients in the past five years (not shown) was 15 individuals (with a median of one partner); however, this average is skewed because of two clients who reported 250 partners over the past five years. These clients were not sexually active, however, and removal of these two outliers reduced the average number of sexual partners in the past five years reported by sexually active clients to 4 individuals (with a median of two partners). For male clients only, 10% reported exclusive or occasional sex with men. Only one client reported having received a blood transfusion prior to 1985.

With regard to behaviors which are considered **secondary** risks for HIV infection (Schleifer, Keller, Franklin, et al., 1990; Stall, McKusick, Wiley, et al., 1986), almost one third of all clients (n=12) reported that they used alcohol and almost a fifth (18%, n=7) said they used recreational drugs. Of the seven clients who reported recreational drug use (not shown), 13% (n=5) reported using marijuana and 8% (n=3) reported using cocaine (clients could list more than one type of recreational drug).

In addition to the individual items included on the screening assessment, a measure of overall risk was constructed. This risk measure was designed to identify clients who were at risk for HIV infection by engaging in one or more of the primary risk behaviors described above. Those clients who engaged in one or more risks were given a "1" while clients who did not report engaging in one or more of the risk behaviors were given a "0" on this measure. The lower third of Table 1 summarizes this overall risk measure. Twenty-six percent (n=10) of the clients were identified to be at risk for HIV infection. In addition, Table 1 presents the proportion of clients at risk when the secondary HIV risk factors are added to the overall risk measure. Inclusion of non-IV recreational drugs in addition to the aforementioned risks increased the proportion of at-risk clients to 33% (n=13); inclusion of both recreational drugs as well as alcohol use increased the proportion at risk to 49% (n=19). On the basis of the screening results, case managers indicated that they had recommended HIV testing to 49% (n=19) of all clients.

The next section of the data analysis examined the relationship between clients' risk behaviors and case workers' recommendations for testing. Pearson correlation coefficients were computed between the overall risk variables and whether or not the case manager recommended HIV testing to the client (scored "1" if the test was recommended and "0" if it was not). Significant relationships were identified for each of the three overall risk variables (i.e., primary

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risks only, primary risks plus recreational drugs, primary risks plus recreational drugs and alcohol). That is, for clients who engaged in one or more of the primary risk behaviors only, case managers were significantly more likely to recommend HIV testing ( $r(38) = .48, p < .002$ ). Adding recreational drugs slightly decreased the size of the relationship between risk and recommendations for testing ( $r(38) = .45, p < .004$ ), yet adding both recreational drugs and alcohol substantially increased the magnitude of this relationship, ( $r(38) = .53, p < .001$ ). In addition to the fact that case workers were more likely to recommend testing to a client reporting primary risk factors, their recommendations also reflect that other recreational drugs and alcohol were identified by them as additional, secondary factors which could contribute to a client's risk for HIV.

In addition to questions regarding sexual behaviors and patterns of drug use, clients were asked a series of questions examining their knowledge and sources of education about HIV. Sixty-two percent ( $n=24$ ) reported that they knew something about HIV. Forty-eight percent reported that they knew what HIV is, 49% indicated that they knew how a person gets HIV, and 54% responded that they knew how to prevent HIV infection. Thirty-eight percent ( $n=15$ ), however, responded that they knew nothing about HIV, its transmission, or prevention strategies.

When asked if they had received any HIV education, 44% of all clients replied in the affirmative. When asked to identify all sources of education (i.e., clients could report more than one source), 8% ( $n=3$ ) indicated that they had received group education from TBPD and 10% ( $n=4$ ) reported receiving education at one-on-one sessions at TBPD. A total of 15% ( $n=6$ ) reported receiving education from another social service agency, 5% ( $n=2$ ) from pamphlets or other written material, 3% ( $n=1$ ) from school, and 3% ( $n=1$ ) from a doctor or another health care provider. No one reported receiving education one-on-one at another agency or through television. Many clients were unable to recall the source of their HIV information.



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**TABLE 1**  
**SUMMARY OF REPORTED RISKS RELATED TO SEXUAL**  
**AND DRUG USE BEHAVIORS AND RECOMMENDATIONS**  
**FOR HIV TESTING**

	%	N (N=39)
Frequency of Condom Use:		
Never	31%	12
Sometimes	10%	4
Mostly	—	0
Always	10%	4
Sexually Active at Time of Screening:	44%	17
Worried About HIV Exposure:	24%	9
<b><u>Primary HIV Risk Behaviors</u></b>		
Using Intravenous Drugs:	3%	1
Having Shared IV Drug Needles:	3%	1
Intravenous Drug Users as Sex Partners:	10%	4
History of Sexually Transmitted Disease:	15%	6
More than 25 Sex Partners in Last Five Years:	5%	2
Men Having Sex with Men or with Both Men and Women:	10%	4
Received a Blood Transfusion Prior to 1985:	3%	1
<b><u>Secondary HIV Risk Factors</u></b>		
Using Alcohol:	31%	12
Using Recreational Drugs:	18%	7
<b><u>Clients Engaging In One or More Risk Behavior</u></b>		
Engaging in One or More Risk	26%	10
Engaging in Risks (including drugs only)	33%	13
Engaging in Risks (including drugs and alcohol)	49%	19
<b><u>Case Worker Recommendations</u></b>		
HIV Test Recommended by Screener:	49%	19

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### HIV Education for Deaf Persons with Mental Illness

Along with the HIV screening, TBPD staff participated in training covering basic HIV transmission and prevention knowledge, education techniques for clients with disabilities, and current service delivery models for HIV infected persons who are deaf or have mental illness. Staff also researched available written materials appropriate for use with clients who have special communication or content needs. This search yielded little in the way of educational materials appropriate for deaf clients with cognitive impairments communicating with rudimentary language. Also observed was the absence of HIV services such as testing, counseling, and HIV support groups accessible to deaf people with emotional difficulties, as noted elsewhere (Burke, 1993).

Following training, a group of three staff designed an education program for clients at very low signed or spoken language levels. The intent was to impart basic HIV information focusing on transmission and prevention in ways that were both behavioral and explicit yet suitable for clients with limited language skills. Group education sessions were pilot-tested with six clients and were conducted in ASL using a booklet written by Gary Crawford (1990) at the Southwest Center for the Hearing Impaired. This creative manual uses pictures and colors illustrating many key behaviors and situations that are part of HIV education. Following each education session staff tested clients' understanding with simple questions (e.g., AIDS, what is that? What do you do if you see blood?) to assess understanding.

Before the training, none of the clients had any knowledge about HIV and its transmission. At the first session, clients received basic information, in multiple signed modalities, about the HIV virus and how it is transmitted. Using an AIDS caricature to illustrate points, the location of AIDS in blood inside the body was described, symptoms were presented, and ways the virus is transmitted and not transmitted were illustrated. By the end of the session clients had learned the sign for AIDS and were able to answer questions about the negative aspects of AIDS, as described in the case notes below:

Presented AIDS. Equated AIDS with "bad," [and] "sick." Discussed symptoms. Discussed AIDS in blood inside body; importance of not touching blood. Used pictures and a caricature of AIDS. [Clients] attentive, learned sign for AIDS, answered questions about AIDS as "bad" (Session notes #1).

Yet, within one week only one of the clients was able to identify the AIDS caricature and equate the virus with the concept "sick." Clients appeared to have confused the concept of sex and AIDS, indicating that all types of sexual activity were "bad." As case notes illustrate:

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Discussed risk behavior specifically anal, oral, and vaginal intercourse. Showed pictures and, before signing anything, all [clients] (except D who just looked on) indicated sex as "bad" and that they did not want to do it (Session Notes #2).

This led staff to describe and represent types of behaviors that are "safe" and to illustrate that only blood and semen could transmit HIV. While clients were described as having "focused, serious affect" their understanding was still questionable, as staff learned through post-session questioning. For example, when one client was asked "AIDS, what's that?" he responded "Don't know" (Session Notes #2).

At a third session, clients reviewed AIDS and the risks involved in different kinds of sexual activity. The idea of personal space was described and illustrated by putting tape on the floor. Staff showed clients how to recognize and respect other people's personal space and clients were able to request that other staff and clients "stop" at the edge of their personal space. Case notes indicated:

[Clients] practiced testing [and] recognizing others' personal space. [They] made representations of their own space... demonstrated good understanding, appeared to understand [the] concept of personal space. Some [clients] equated the invasion of personal space with AIDS (Session Notes #3).

A fourth session involved a test of HIV transmission and prevention knowledge using the pictures from Crawford (1990). The results indicated that clients still were confused about the kinds of behaviors that could and could not transmit HIV. The percentage of correct answers ranged from 0% to 81% with the average proportion correct at 37.5%, indicating low levels of understanding. Staff subsequently found that they needed to review and reinforce the material frequently with clients.

This case illustrates many of the pitfalls and frustrations of HIV education for clients at lower levels of communication who may have difficulty grasping education information. The key to client understanding was often the ability to present information in a variety of different ways in order for comprehension to occur. Some clients needed refresher training to reinforce learned material since they were unable to remember what they had understood from previous sessions.

The confusion of sexual risk behaviors with all sexual behavior among this group is noteworthy. Clients quickly made the jump from understanding certain types of sexual activity as being risky to defining all sex being dangerous or "bad." The ease with which clients equated

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sexual activity with negative concepts suggests that they may previously have been told negative things about their own sexuality. Their negative appraisals may have been designed to please social service personnel by creating the appearance that they would abstain from sexual activity. For whatever reasons, this tendency toward over-generalization to all sexual activity can mask client misunderstanding. Without careful probing, staff would not have uncovered inaccuracies in clients' knowledge about how transmission occurs and what is effective prevention.

### Summary and Conclusions

The results presented in this paper indicate that deaf clients participating in community-based mental health services engage in a substantial number of high risk behaviors associated with substance use and high risk sexual behaviors. Moreover, case managers can use a structured assessment of these risks to make individualized recommendations to clients regarding whether or not they should be tested. Additionally, assessments of this variety can be valuable tools in developing HIV education programs and establishing prevention efforts which accommodate deaf people with mental illness.

Nearly one half (49%) of all clients assessed in this survey were at risk for HIV infection because of one or more of the following factors: IV drug use, sharing IV drug needles, sex with an IV drug user, homosexual sex with men, having more than 25 sex partners in the past five years, having a history of STDs, recreational drug use, alcohol use, or having had a blood transfusion prior to 1985. Forty-four percent reported being currently sexually active, yet overall, clients responded that they **always** use condoms only 10% of the time. Furthermore, the significant correlational relationships between case workers' recommendations for HIV testing and the overall risk factor measures reveal that service providers can use the information gathered in screening assessments such as these to make more informed decisions regarding who is at a higher risk for HIV infection and would, therefore, benefit from having an HIV test. Interestingly, while almost half of these clients were identified to be at risk, recommendations for HIV tests were made for approximately half (49%) of them.

Clearly, these clients require the education and training in HIV prevention necessary to assist them in recognizing and avoiding these risky behaviors. Additionally, it is essential that these education and prevention programs are structured such that they present information which is relevant and accessible to people with a dual diagnosis of deafness and mental illness. Furthermore, these programs should be prepared to work with HIV+ persons with additional diagnoses of psychiatric disorder and deafness.

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Noteworthy in the results presented for the training of clients in the deaf program is the fact that although the clients were able to identify the risks related to HIV infection at the end of each session, their understanding of these risks did not persist over time. Furthermore, some of these clients developed false understandings of all types of sexual activity as "bad" and related to AIDS. Thus, it is essential for service staff to not only identify the areas in which clients require education and training, but they must not abandon their efforts after the completion of one or two groups.

As case management staff in community-based rehabilitation programs pursue their goals of helping clients attain independent living, social integration, and the establishment of fulfilling interpersonal (including sexual) relationships, they also must be prepared to help these clients to avoid HIV infection and to cope with it when it does occur. The challenges that lie in making HIV services accessible to deaf people and those with mental illness are formidable, as previously noted (Burke, 1993; Cook et al., in press). However, these results suggest that accessibility may become an issue as clients seek HIV services such education and testing. Given that one half of this group were affected by one or more HIV risk factors, it is likely that accessibility for deaf persons with mental illness will be an issue of increasing importance.

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