

## Conducting HIV Prevention Programs for the Severely Mentally Ill: An Assessment of Capacity Among HIV Prevention Programs Providers in the City and County of San Francisco

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### Abstract

Recent studies have shown that the severely mentally ill (SMI) are at higher risk for HIV infection than the general population. At the same time, the number of HIV prevention programs available for this priority population is extremely low. The purpose of this study was to identify the extent to which community-based organizations conduct HIV prevention for severely mentally ill people. Telephone interviews with HIV prevention program managers in San Francisco were conducted over two weeks in 2003. Of the 21 agencies funded by the San Francisco Department of Public Health, only three agencies included severely mentally ill people as a priority population for their prevention efforts. However, 16 agencies reported that they provided prevention services to the SMI, even though they were not considered a priority risk population. Three providers reported no SMI among the population they served. Additional studies are also needed to examine the capacity building elements that are necessary for HIV prevention program providers to plan, design, and implement prevention programs tailored for SMI individuals.

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### Introduction

The term “Severely Mentally Ill” (SMI) refers to a range of psychiatric diagnoses among individuals who have symptoms that persist over time and that interfere with their ability to perform activities of daily living, disrupting family relationships, social role functioning, academic achievement, and occupational productivity. SMI includes those with schizophrenia, schizoaffective disorder, bipolar disorder, major depression, autism, and obsessive-compulsive behaviors (National Institute of Mental Health, 2000).

Studies have reported that individuals with severe mental illness are vulnerable to HIV infection and that rates of HIV infection are disproportionately higher among the SMI compared to the general population (Cournos et al., 1994; Sacks, Dermatis, Looser-Ott, & Perry, 1992). Among the SMI, reported rates of HIV infection have varied from 4% among long-stay

patients in a psychiatric hospital (Meyer et al., 1993) to 22.9% among psychiatric patients with a history of primary substance-use disorders (Silberstein et al., 1994).

That chronic mentally ill patients are sexually inactive is a commonly held misconception (Chuang & Atkinson, 1996). Many SMI individuals are sexually active and many of their sexual behaviors place them at increased risk for HIV infection. Deficits in knowledge about HIV (Kelly et al., 1992), a tendency toward multiple sexual partners (Lyketsos, Sakka, & Mailis, 1988), deficits in problem-solving, planning, and judgment (Gewitz et al., 1988), impulsivity (Carmen & Brad, 1990), and a tendency to exchange sex for either money or a place to stay (Cournos et al., 1994) all contribute to the increased risk of HIV transmission for this population.

Fortunately, SMI individuals can not only reduce their risk behaviors, but the changes that they make may be sustained overtime. Kalichman, Sikkema, Kelly, and Bulto (1995) tested the effectiveness of a behavioral skills training program in preventing HIV infection among chronically mentally ill adults. Individuals in the experimental group (compared to the control group) demonstrated significant increases in AIDS-related knowledge and intentions to change risk behaviors, while reporting significant reductions in unprotected sexual intercourse upon a one-month follow-up period. In a follow-up study, although behavior change effects were evident during three-, six- and nine-month follow-up assessments, many of the effects had diminished after one year (Otto-Salaj, Kelly, Stevenson, Hoffmann, & Kalichman, 2001), suggesting a need for follow-up behavioral reinforcement sessions. HIV prevention interventions that teach risk reduction skills and subsequently encourage participants to advocate behavior change to others, appear to strengthen participants' capacity to change their behavior to reduce HIV risk, even those from a disenfranchised group such as SMI adults (Kelly et al., 1997). Although the SMI are at high risk for HIV infection, they do have the ability to understand the risk factors for HIV infection and to reduce their behavioral risk.

Despite the high rates of HIV infection among SMI, little is known about community HIV prevention services for this population (Satriano, Rothschild, Steiner, & Oldham, 1999). The purpose of this study was to determine the extent to which HIV prevention services are provided to the SMI and to identify staff training needs and barriers to providing these services.

## **Methods**

### **Setting and Participants**

After obtaining IRB approval from San Jose State University Committee on Human Research, representatives from HIV prevention agencies from a list provided by the San Francisco Department of Public Health, AIDS Office were invited to participate in the study. A total of 21 participants served as the study sample and included executive directors, prevention directors, or persons with equivalent

responsibilities, who: 1) worked in HIV prevention programs; 2) could provide specific information about their agencies' HIV prevention activities, and 3) agreed to participate in a 30-minute telephone or in-person interview. Prior to interviews, participants were advised that all data collected from the interview would be confidential, and that no personal identifiers would be used in the reporting of data. Responses were recorded and interview data were analyzed using standard content analysis procedures.

### **Findings**

A total of 21 telephone interviews were conducted over a two-week period in 2003. Providers had been involved in HIV prevention activities within their agencies from three months to 19 years. Three types of HIV prevention providers were identified: 1) programs which included the SMI as a primary population with programs specifically designed for them; 2) programs that did not have SMI as a primary population but saw them as part of the population they served, and 3) programs where the SMI were not a priority population and there was no documented evidence that the SMI were among the population they served.

Priority populations served by agencies included males who have sex with males (MSM); males who have sex with males and females (MSM/F), youth, youth of color, individuals recently released from prison/jail, transgender people, the homeless, sex-workers, and injection drug users (IDU).

Only three of the twenty-one agencies (14%) delivered HIV prevention programs that were specifically designed for the SMI and also had designated the SMI as one of the priority populations for their programs. These programs included an array of interventions, including prevention case management, individual risk reduction counseling, referral and partner counseling, and psychotherapy. One of the three agencies provided the above-mentioned services to 60-70 severely mentally ill individuals per year. Two organizations were unable to determine the number of SMI for whom they had provided services, and one of the three

agencies reported vulnerability to funding loss because the SMI were not a priority population for funding, and thus, they were out of compliance with the terms of their contract.

Agencies that offered programs specifically for the SMI reported that their clients were at high risk for acquiring HIV infection through self-medication, exchanging sex for a place to stay or for food, injection drug use, and homelessness. At the same time, they were not able to identify the magnitude of HIV infection among the SMI due to the lack of HIV epidemiological data on the population. Based on their experience providing HIV prevention services for the SMI, all three respondents perceived the SMI as being capable of understanding and changing HIV risk behavior and believed that they could sustain these changes provided they were in a stage of remission of their mental illness and follow-up HIV prevention programs were available for them.

Sixteen program representatives (76%) reported that while their respective agencies served the SMI in their HIV prevention programs, these programs were not specifically tailored for the SMI. Four of the sixteen respondents reported that they referred the SMI to mental health providers. These providers estimated that the SMI comprised from 2% to 60% of their client census. Depression and bipolar disorders were the most commonly reported mental illnesses experienced by their SMI clients. According to all participants, the most important detriments to providing HIV prevention programs for the SMI were: 1) the organization was not designed to serve the SMI (69%); 2) funding was limited (44%), and 3) lack of expertise in serving the SMI (31%) (Note: Respondents could choose more than one option; hence the percent exceeds 100).

Sixty-nine percent of respondents named at least one HIV risk factor specific to the SMI that they perceived made the SMI at higher risk for HIV infection than the general population in San Francisco. Three respondents, whose priority populations were the SMI, provided no answer about risk factors specific to SMI, but agreed that SMI are at higher risk of HIV than the

general population. One respondent stated that SMI should be "institutionalized" and that their risk factors are similar to the general population.

Considering the magnitude of HIV among the SMI, nine respondents indicated that they assumed the rates of HIV infection among the SMI was higher than other risk groups; five reported having no knowledge about this issue. At the same time, 81% agreed that the SMI are capable of understanding HIV risk factors and are capable of changing HIV risk behavior and sustaining safe behaviors.

The essential capacity building elements suggested by providers can be categorized into four areas:

1. Approaches should be multi-level and include needs assessment, community involvement, and umbrella services within community based organizations.
2. The structure of the program should offer low threshold programs and maintain consistency, frequent accessibility, and flexibility.
3. Trained professionals should provide services, that is, mental health professionals trained in HIV prevention and HIV prevention professionals trained in mental health.
4. Intervention methods should include one-on-one and small group interventions, referral, and consistent follow-up.

### **Discussion**

The purpose of this study was to identify the extent that HIV prevention programs were engaged in the provision of HIV prevention programs for the SMI. The main limitation of this study is that participants were general providers of HIV prevention services and not licensed mental health professionals, limiting their capacity to accurately identify the SMI as part of the population they served.

Study results revealed HIV prevention programs providers' low level of awareness of HIV infection among the SMI. Even though the prevalence of HIV infection among severely mentally ill people is 10 to 76 times greater than

rates found within the general population (Carey, Carey, Weinhardt, & Gordon, 1997), only three HIV prevention program providers tailored their programs for the SMI. However, these providers had no expertise in providing the SMI with appropriate behavior change strategies. Instead, they reported using similar strategies as with other non-SMI vulnerable populations, even though, according to Ostrow (1989), psychiatric symptoms are likely to affect patients' perception of their HIV risk and need to be addressed accordingly. Additional studies are needed to examine the capacity building elements that are necessary for HIV prevention program providers to effectively plan, design, and implement prevention programs tailored for SMI individuals.

Only a few HIV prevention agencies (n=3) reported programs that were specifically designed for serving SMI individuals. Nevertheless, the number of HIV prevention programs serving SMI individuals is greater than it was during the 1990s. In 1995 there was only one agency in the City and County of San Francisco (with a budget of only \$19,000) to serve SMI populations (Schechtel, 1997).

However, in light of the overall budget for HIV prevention - seven million dollars during 2003 to fund 55 HIV prevention programs (San Francisco Department of Health AIDS Office, 2006) - more funding is necessary to meet the increased need for community-based HIV prevention among the SMI. A large number of the SMI who have been released into the community through medical de-institutionalization either become homeless or are incarcerated. According to the U.S. Department of Health and Human Services (1993), one-third out of an estimated 600,000 homeless people in the US are severely mentally ill. Furthermore, savings could be realized in medical care costs associated with the long-term care of HIV positive individuals. If 10 percent of SMI individuals are HIV infected (a conservative estimate), the medical costs associated with caring for them would be approximately \$28.6 billion (National Institute of Mental Health, 2000). Community-based programs aimed at preventing HIV infections among the SMI and implemented by mental health professionals who possess the necessary intervention skills could alleviate much of this health care burden.

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