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Nationwide Poll in USA Shows That AIDS Continues To Be A Stigmatized Disease

*Geneva, Switzerland (July 1).* Although some of the worst aspects of the stigma attached to AIDS have abated in the past decade, a large portion of the American public still expresses discomfort about being around people with AIDS and harbors misinformation about transmission of HIV, the virus that causes AIDS, according to a study presented today at the World AIDS Conference in Geneva.

The study, conducted by Dr. Gregory Herek, a research psychologist at the University of California at Davis, used scientific telephone survey methods to ask a representative sample of more than 1700 American adults their opinions about people with AIDS and various AIDS policies.

“More than one American in four feels uncomfortable about being around a person with AIDS,” Dr. Herek said. “And a large proportion of the population still doesn’t understand that AIDS is not spread through casual social contact. Moreover, the extent to which people with AIDS are blamed for their illness seems to be increasing.”

Approximately half of the survey respondents incorrectly believed that AIDS might be transmitted through sharing a drinking glass with a person with AIDS, being coughed or sneezed on, or using a public toilet. These figures represent a slight increase since 1991, when Dr. Herek conducted a similar survey. He speculates that the rise in the public’s misinformation about HIV
may be due to the fact that AIDS information campaigns in recent years have placed less stress on the safety of casual contact.

More than half of the survey respondents believed that most people with AIDS are responsible for having their illness. 29% agreed that people who got AIDS through sex or drug use have gotten what they deserve, compared to 20% who felt that way in 1991.

Dr. Herek regards these patterns as ominous signs.

“We know from past research that the public is more likely to stigmatize persons with AIDS to the extent that they believe that AIDS is easily spread and that people with AIDS should be blamed for their illness,” he said. “As these perceptions increase, there is a real possibility that prejudice and discrimination against people with AIDS will also increase.”

The study also indicates that the public still perceives AIDS as largely a gay disease, even though the epidemic is increasingly transmitted through heterosexual contact. In addition, gay and bisexual men with AIDS get more blame and less sympathy than heterosexual men and women with the disease, regardless of whether they were infected through sex with one or many partners.

The survey also shows that the public has little sympathy for people who contract AIDS through sharing needles for injecting drugs.

Some Good News

According to Dr. Herek, the study’s findings also contain some good news about public attitudes surrounding AIDS.

“An encouraging sign is that support for extremely coercive policies, such as quarantine and public identification of people with AIDS, has declined over the past decade,” said Dr. Herek. He noted that 17% of the public now supports quarantine, and 19% would have the names of people
with AIDS made public. In a 1991 national survey conducted by Dr. Herek, these policies were supported by, respectively, 36% and 30% of the US public.

In addition, fewer people today say that they would actively avoid social contact with a person with AIDS in the workplace or a neighborhood grocery store. Only 12% would avoid an office coworker with AIDS today, compared to 20% in 1991. 33% would avoid shopping at a neighborhood grocery store whose owner has AIDS, compared to 47% in 1991.

Even though these figures represent a decrease in some aspects of AIDS stigma, Dr. Herek notes that they should be lower still.

“As a society, we have been living with AIDS for more than 15 years,” he observed. “We should have reached the point by now where no one would support quarantine or avoid a person because he or she has AIDS.”

**Policy Implications**

Another finding from the study is that nearly 4 out of 5 respondents agreed that people with AIDS are unfairly persecuted by society.

Dr. Herek believes that this widespread perception of stigma has important implications for AIDS policies. He suggests that advocates of mandatory reporting and contact tracing for people who test positive for HIV should consider the possible effects of such policies on those who are at risk for infection.

“People who expect to face persecution if they have HIV may be discouraged from being tested or seeking treatment if they believe that their name will be placed on a government list,” said Herek. If mandatory reporting and tracing laws are to avoid discouraging high-risk people from being tested, he suggested, those people will need to be convinced that their civil rights and privacy will be vigorously protected.
Dr. Herek also stressed the importance of including anti-stigma messages in educational programs about AIDS.

“It is not enough simply to tell people how to avoid infection or get treatment,” he said. “We also need to keep repeating the message that people with AIDS deserve our respect and compassion.”

**Background Information**

The poll was conducted by the Survey Research Center of the University of California in telephone interviews between September of 1996 and March of 1997. The margin of error due to sampling is approximately plus-or-minus 2 percentage points. The research was supported by grants to Dr. Herek from the National Institute of Mental Health.

Dr. Herek received his doctorate from UC Davis in 1983, and taught at Yale and the Graduate Center of the City University of New York before returning to Davis in 1989. He has published numerous scholarly papers about AIDS-related stigma, including a multi-authored paper on the topic that will appear later this year in the *AIDS and Public Policy Journal*. He was the 1996 recipient of the Early Career Award for Distinguished Contributions to Psychology in the Public Interest, bestowed by the American Psychological Association.

Dr. Herek will make an oral presentation of his research in Geneva on July 1 at 1:00 pm (Geneva time) in a conference session titled “Stigma and Discrimination” in Hall 1.

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[NOTE: SUMMARY OF SURVEY FINDINGS FOLLOWS]
AIDS-related stigma historically has interfered with effective societal response to the epidemic, and has imposed hardships on people living with HIV, their loved ones, caregivers, and communities. In the United States, concerns about such stigma and its effects on AIDS prevention and treatment led to the institution of public policies specially designed to protect the privacy and confidentiality of PWAs and people at risk for HIV.

Recent debates about public health policy have raised the question of whether these extraordinary measures are still needed, or whether AIDS should now be treated in the same way as other communicable diseases. Proponents of the latter perspective have argued for the institution of measures such as mandatory contact tracing and reporting of the names of persons with HIV to the federal government. Underlying these proposals has been the assumption that AIDS stigma has sufficiently abated so that fear of prejudice and discrimination no longer plays a significant role in personal decisions to seek HIV testing, counseling, and treatment. Empirical data concerning the accuracy of this assumption have been lacking, however.

The present study assessed the prevalence of AIDS stigma in the USA in 1997, and compared current levels with those assessed in a 1990-91 survey.

**Method**

List-assisted random digit dialing (RDD) was used to generate a probability sample of telephone numbers, representing private households in the 48 contiguous states. Telephone interviews were conducted with 1712 English-speaking adults, with each respondent randomly selected from among the members of her or his household. The analyses reported here were conducted with respondents who self-identified as heterosexual and who did not report that they had tested positive for HIV. The margin of error due to sampling is approximately plus-or-minus two percentage points.

**Prevalence of stigma.** Questions were asked about multiple factors related to AIDS stigma. These included affective reactions to PWAs, beliefs about PWAs and HIV transmission through casual contact, levels of comfort with PWAs, intentions to avoid PWAs, attitudes toward AIDS policies, and other AIDS-related attitudes and beliefs.

**Groups associated with AIDS.** We also asked respondents about the first group or type of person that came to mind when they heard the word *AIDS*. 
Symbolic stigma. Finally, a substitution experiment was performed to assess the extent to which AIDS-related stigma reflects symbolic expressions of disapproval for particular social groups and behaviors. In the experiment, we compared public reactions to a hypothetical PWA depending on the PWA’s race, gender and sexual orientation, and source of infection.

Each respondent was posed a description of a hypothetical person with AIDS. We randomly varied the PWA’s race (Black or White), sex and sexual orientation (heterosexual woman, heterosexual man, bisexual man, homosexual man) and route of infection with HIV (receiving a blood transfusion approximately 15 years earlier, having sex with one partner over the past 15 years, having sex with multiple partners over the past 15 years, sharing needles for drugs over the past 15 years). Combining these three variables yielded 32 different descriptions of the hypothetical PWA. Each respondent received one description, and was asked to report his or her beliefs about the PWA’s responsibility for being infected, feelings toward the PWA, and willingness to help the PWA.

Key Findings

Prevalence of Stigma

- The majority of the US public — 77% — believed that people with AIDS are unfairly persecuted in our society.

- The proportion of the population supporting extreme coercive policies against PWAs has declined since 1991. In the 1997 survey, 17% supported quarantine for PWAs and 19% supported public disclosure of the names of PWAs. In a 1991 survey, these policies were supported by, respectively, 36% and 30% of the US public.

- The vast majority of the public supported mandatory HIV testing for immigrants (77%), people considered to be at high risk for AIDS (74%), and pregnant women (84%).

- Compared to 1991, fewer people said that they would avoid a PWA in various hypothetical situations. 10% would have their child avoid another schoolchild with AIDS (compared to 16% in 1991), 12% would avoid a coworker with AIDS (compared to 20% in 1991), and 33% would avoid shopping at a neighborhood grocery store whose owner has AIDS (compared to 47% in 1991).

- However, many of those who would not actively avoid a PWA in these situations would nevertheless feel uncomfortable about being around the person with AIDS: 27% of respondents would feel uncomfortable about having their own child interact with the school child with AIDS, 25% would feel uncomfortable working in the same office as the coworker with AIDS, and 30% would feel uncomfortable about shopping in the store whose owner has AIDS.

- The proportion of the public that believes casual social contact might spread HIV has increased somewhat since 1991. 55% believed that it was possible to contract AIDS from using the same drinking glass as a PWA (compared to 48% in 1991), 41% believed that AIDS might be
contracted from a public toilet (compared to 34% in 1991), and 54% believed that AIDS might be transmitted through a cough or sneeze (compared to 45% in 1991). Most of the shift in beliefs since 1991 has occurred as a result of fewer people believing that AIDS definitely cannot be transmitted through these routes, and more believing that these routes are merely somewhat unlikely to spread AIDS. The proportion believing that these forms of casual contact are somewhat likely or very likely to transmit AIDS has remained fairly stable.

- Consistent with widespread inaccurate beliefs about casual contact, 27% of respondents reported that they would be less likely to wear a sweater that had been worn one time by a PWA than if it had been worn once by another person — even if the sweater had been cleaned and sealed in a new package so that it looked like it was new. 28% of respondents said that they would feel uncomfortable drinking out of a glass in a restaurant if a PWA had used the same glass a few days earlier, even if it had been washed and sterilized.

- Compared to 1991, more respondents agreed that people who got AIDS through sex or drug use have gotten what they deserve (29%, compared to 20% in 1991). When the issues of blame and responsibility were posed in less negative terms, 55% of respondents agreed that most people with AIDS are responsible for having their illness. 51% agreed that it’s their own fault if people get AIDS these days. 26% agreed that most people with AIDS don’t care if they infect other people with the AIDS virus.

**Groups Associated with AIDS**

When asked “When you hear the word AIDS, what groups or type of people first comes to your mind,” more than half indicated that they thought first about gay or bisexual men (41%) or gay/bisexual men and injecting drug users (10%). Another 10% thought first of drug users. The remainder thought first of hemophiliacs and the recipients of blood products (2%), other types of individuals and groups (15%), or reported that no group came to mind when they heard the word AIDS.

**Symbolic Stigma**

In the United States, much of the stigma associated with AIDS has resulted from the fact that AIDS has had a disproportionate impact on disliked segments of society, especially gay men and injecting drug users. Our experiment indicated that PWAs are judged more harshly depending on how they contracted HIV and whether or not they are heterosexual.

- PWAs who were infected through sharing needles or through sex with multiple partners were evaluated more negatively than PWAs who were infected through sex with one partner. PWAs who were infected through a blood transfusion were evaluated the most positively.

- When a PWA was described as having contracted AIDS through sex (whether with one partner or many), the PWA was judged differently depending on his or her sexual orientation. Gay and bisexual men were judged more harshly than heterosexual men and women, even controlling for their source of infection. Women respondents tended to evaluate bisexual men the most
negatively, whereas male respondents tended to evaluate gay men the most negatively.

- Somewhat surprisingly, Whites did not judge Black and White PWAs differently. However, Black respondents tended to evaluate Black PWAs more harshly than White PWAs, and this pattern was more pronounced among Black women respondents than among Black men respondents.

**Conclusions**

Although its manifestations have changed in some respects during the 1990s, AIDS stigma persists in the United States. Support for blatantly stigmatizing policies has decreased, but support remains high for mandatory testing of specific groups. A significant minority of the public expresses discomfort at the prospect of personal contact with PWAs. AIDS continues to be a strongly symbolic issue, with much of the US public associating AIDS with gay and bisexual men. Moreover, stigma is more strongly expressed against gay or bisexual men who contracted HIV sexually, compared to heterosexual PWAs.

The understanding that HIV cannot be transmitted through casual social contact appears to be eroding, possibly because public health campaigns in the United States have not reinforced this belief in recent years. Although modest, this trend is a cause for concern because people who overestimate the risks of casual contact are significantly more likely to stigmatize people with AIDS.

The survey results raise concerns that advocates of mandatory names reporting and contact tracing may be underestimating the continuing importance of AIDS stigma in the United States. Indeed, the data indicate that most of the US public believes that stigma is widespread, that is, that PWAs are unfairly persecuted by society. Even if it is inaccurate, this perception may well affect personal decisionmaking about being tested or treated for HIV. Thus, public health officials and policy makers would be well-advised to seriously consider the potential effects of AIDS stigma — both the reality of stigma and the perception that it is widespread — on new policies for tracking the epidemic.

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