

---

## Applications of Data from the CDC Family of Surveys

IDA M. ONORATO, MD  
MARTA GWINN, MD, MPH  
TIMOTHY J. DONDERO, JR, MD

The authors are associated with the Public Health Service, Centers for Disease Control and Prevention (CDC). Dr. Onorato is with the National Center for Prevention Services, Division of Tuberculosis Elimination, where she is Chief of the Surveillance and Epidemiologic Investigations Branch. Dr. Gwinn and Dr. Dondero are with the National Center for Infectious Diseases, Division of HIV/AIDS. Dr. Gwinn is in the HIV Seroepidemiology Branch, where she is Chief of the Clinic and Special Surveys Section. Dr. Dondero is Chief of International Activity.

The surveys in the CDC Family of Surveys are carried out by State and local health department personnel. Technical and operational aspects of the surveys are supervised by staff members of the Division of HIV/AIDS through its Field Services Branch and HIV Seroepidemiology Branch.

Teasheet requests to CDC, NCID, Technical Information Activity, MS E49, 1600 Clifton Rd., Atlanta, GA 30333; tel (404) 639-2070, fax (404) 639-2007. Dr. Onorato's address is CDC, NCPS, DTE, MS E10, Atlanta, GA, 30333; tel (404) 639-8116; fax (404) 639-8604.

### Synopsis .....

*The CDC Family of Surveys is a national serologic surveillance system set up to characterize the extent of human immunodeficiency virus (HIV) infection in the United States. The now Centers for Disease Control and Prevention (CDC) and participating State and local health departments began the system*

*in 1987. HIV seroprevalence data are collected by unlinked (anonymous) surveys of particular components of the population that include childbearing women; clients of sexually transmitted disease clinics; injecting drug users; tuberculosis patients; and several special populations, such as adolescents, prisoners, and homeless persons. The data obtained have been used extensively on both national and local levels to assist HIV-prevention programs.*

*Data from the surveys have been used to identify specific demographic groups at risk for HIV infection so that health education programs may be planned and made available to them in clinical settings. Local serosurvey results have been used in planning and implementing prevention programs and in planning health services for HIV-positive persons. The completeness, or coverage, of HIV counseling and testing programs has been evaluated by comparing seroprevalences among clients tested voluntarily with those tested in the unlinked survey.*

*Survey data are used in formulating recommendations and standards of care for health practitioners, in allocating resources, and in carrying out long-range planning for HIV prevention and treatment services for at-risk groups. Such data are essential to the decision-making process in forming public health policy and recommending practices involving the HIV epidemic.*

---

**S**EROSURVEILLANCE DATA ARE ESSENTIAL to the decision-making process in forming public health policy and recommending practices involving human immunodeficiency virus (HIV) infection prevention efforts in the United States.

In 1987, the now Centers for Disease Control and Prevention (CDC) began a collaboration with State and local health departments to conduct national HIV serosurveillance through a system called the CDC Family of Surveys (1, 2). After all identifiers have been removed, leftover serum specimens, originally collected as part of routine clinical care, are tested for HIV antibodies. Using that unlinked, anonymous survey design, data have been collected for the past 5 years from different groups of persons who are receiving routine medical care (see box). The groups

include persons at high risk for HIV infection, such as

- injecting drug users (IDU) (3),
- tuberculosis patients (4),
- clients of sexually transmitted disease (STD) clinics (5),
- women of the general population who deliver live infants (6) or seek reproductive health care (7),
- patients at acute care hospitals (8), and
- special populations, including prisoners (9) and homeless persons (10).

Data from the surveys have been summarized annually (11, 12). The reports, available through the National AIDS Clearinghouse, are distributed by

CDC to all State and local health departments, to other Federal agencies, and to private groups and persons. More than 9,000 copies of the first summary have been requested to date. The published data describe the prevalence and distribution of HIV infection by racial and ethnic group, sex, age group, and self-reported behaviors associated with risk for HIV infection.

A major objective of the surveys is to provide data for public health action. They have contributed essential information to the process of formulating programs to prevent HIV infection. As with other diseases, public health physicians and policy makers often must use incomplete or imperfect data to draw valid conclusions and make useful decisions. On the national level, data from the surveys have been used to assess the scope of the HIV epidemic, to track trends in infection, and to assist Federal officials in planning national programs related to the acquired immunodeficiency syndrome (AIDS) epidemic. Locally, the data have been used to meet the needs of local and State health departments and clinics participating in the surveys to manage treatment and prevention activities.

State and local health departments, as part of CDC's annual review of funding recommendations, are required to summarize their program activities, including ways in which they have used survey data. We have reviewed those data applications described under State cooperative agreements, as well as published and unpublished reports and abstracts, and have compiled representative examples of the uses of the surveys that may serve as models for other health departments to consider (see box).

### **Health Education and Public Information**

An almost universal application of data from the surveys has been in education programs. While many media AIDS education efforts are directed to specific subgroups, such as adolescents or gay men, persons who do not perceive themselves at risk for HIV infection may not respond to such campaigns. Information on a personal level and directly related to the individual risk group has more effect.

For example, the Delaware State Health and Social Services Department has focused an education campaign on persons attending a STD clinic and drug treatment center where unlinked HIV seroprevalence surveys were performed. Pamphlets that were given all new clinic attendees pointed out, based on survey results, the probability of a person being infected with HIV whose age and racial group were similar to those of members of a group that had recently

### **Sentinel Populations in the CDC Family of Surveys**

STD clinic patients  
Drug treatment center clients  
Women's health clinic clients  
Tuberculosis clinic patients  
Hospital patients  
Childbearing women  
Primary care outpatients  
Blood donors  
Military applicants  
American and Alaskan natives  
Job Corps entrants  
University students  
Prisoners  
Homeless persons

attended the clinic (figure 1) (13). The message, "AIDS can happen to you," was coupled with the telephone number of an AIDS hot line.

State and local health departments have communicated the findings of the surveys to the medical community and the public through news reports, conferences, and newsletters (14-18). Other health departments have prepared detailed summaries of local data for legislatures, policy makers, and other agencies (19-21). The reports have included projected estimates of the numbers of infected persons in the State, based on AIDS case surveillance and HIV seroprevalence data (figure 2).

### **Prevention Program Planning**

Results from the CDC Family of Surveys have been used to identify population subgroups most in need of prevention services and in developing appropriate programs. As part of the surveys, 44 States, the District of Columbia, and Puerto Rico annually test for HIV antibodies all heel-stick blood specimens obtained from live born infants.

New York State has analyzed data for infants born in New York City by the ZIP code of the mother's residence (figure 3) (22). High rates of newborn HIV infection were found to correlate with some ZIP codes with high rates of injecting drug use. That information that was used in formulating HIV-prevention initiatives. Contracts for family planning and prenatal programs were amended by the New York State Department of Health to include a requirement to make HIV counseling and testing available in clinics within those ZIP codes. Obstetricians and other physicians working in those areas

## Uses of HIV Serosurveillance Data in Managing HIV Prevention Programs

**Health education:** clinic brochures, neighborhood campaigns

**Planning and implementing prevention programs:** voluntary HIV counseling and testing, risk reduction counseling, community-based outreach, and drug treatment

**Evaluating prevention programs:** assessing coverage of HIV counseling and testing programs and identifying missed groups

**Planning and implementing health services:** medical assessment, tuberculosis testing, CD4 testing, AZT therapy, pneumocystis prophylaxis, drug abuse treatment, and psychosocial counseling

**Assisting policy makers:** recommendations for HIV testing of pregnant women and others, setting standards of care

**Developing thresholds for interventions:** recommendations to implement counseling and testing programs based on seroprevalence

**Resource allocation:** estimating funding needs for programs for HIV-infected persons

**Long range planning:** numbers of HIV-infected pregnant women and incidence of perinatal HIV infection

were advised of the need to provide education and counseling services for women of reproductive age. Community health workers were trained and assigned to neighborhoods with large numbers of HIV-infected women. Those workers conduct outreach programs to promote enrollment in prenatal care. Finally, local programs to prevent and treat drug abuse were strengthened.

### Evaluation of Prevention Programs

Unlinked surveys have been used to evaluate the completeness, or coverage, of HIV counseling and testing programs in health care facilities where both activities are conducted concurrently and to determine the characteristics of HIV-infected persons who do not avail themselves of testing (23–25).

For example, in a San Francisco STD clinic, all clinic clients during a certain period (854 persons) were tested for HIV infection as part of an unlinked survey. Of them, 568 were volunteers for HIV counseling and testing, 67 percent of the total number

of clients. HIV seropositivity was 14.5 percent among those in the survey group and 9.5 percent among those who had volunteered for HIV testing and counseling. Comparison of the two groups indicated that voluntary testing detected only 44 percent of the HIV-infected STD clients and that voluntary testing underestimated the prevalence of HIV among clinic attendees by 35 percent.

HIV prevalence among homosexual men in the unlinked survey was found to be 1.4 times higher than among the volunteers. Unlinked HIV-prevalence rates were 2.5 times higher for injecting drug users and 3.3 times higher for heterosexuals who did not report other risks than in the voluntary sample. The survey showed the need for more effective prevention efforts specifically for drug users and heterosexuals, in addition to efforts for homosexual men, who had been the focus of much of the education efforts by the clinic.

### Planning and Implementing Services

With the recent development of recommendations for followup care of HIV-infected persons, information is needed on how to plan such programs and evaluate their outcomes. All clients at the major STD clinic in Portland, OR, were offered HIV counseling and testing. An unlinked HIV seroprevalence survey was conducted using blood routinely drawn at the clinic for syphilis serology (26). Of the clients found to be seropositive on the unlinked survey, 73 percent had declined HIV counseling and testing. Seropositive persons who declined were more likely to be gay men who had previously been tested for HIV and were HIV positive. Such indications that HIV-infected clients are likely to decline testing and to continue to put themselves at risk for acquiring and transmitting STD were the impetus for developing Oregon's Seropositive Wellness Program.

The program consists of six weekly counseling sessions designed specifically for persons who know they are HIV-positive. Services include behavioral modification techniques, instruction in safer sex and drug-using practices, psychological support and medical services (immunization, tuberculosis screening and therapy, monitoring CD4 cell counts, and referral to treatment for HIV infection and pneumocystis pneumonia prophylaxis).

### Assistance to Policy Makers

Data from seroprevalence surveys have focused the attention of policy makers, legislators, and officials of State agencies responsible for health, education, and

Figure 1. An example of HIV health education materials that use data from the CDC Family of Surveys, a pamphlet produced by the Delaware Department of Health and Social Services (reference 18)

**FACE THE FACTS**

*Yesterday* was the day to stop thinking "AIDS CAN'T HAPPEN TO ME."

**Because the Truth is...**

1 out of 20 people going to the clinic had HIV

- 1 out of 18 **Blacks** going to the clinic had HIV
- 1 out of 28 **Hispanics** going to the clinic had HIV
- 1 out of 63 **Whites** going to the clinic had HIV
- 1 out of 25 **Females** going to the clinic had HIV
- 1 out of 19 **Males** going to the clinic had HIV

HIV was found in **Teenagers**  
1 out of 5 **Blacks** between **30 and 40** with gonorrhea had HIV

A study was done of blood taken from people going to a STD (Sexually Transmitted Disease) clinic in Delaware.

Figure 2. A surveillance and seroprevalence report produced using data from the CDC Family of Surveys by the Texas Department of Health (reference 21)

**TEXAS HIV AND AIDS:**

*A Surveillance and Seroprevalence Report*

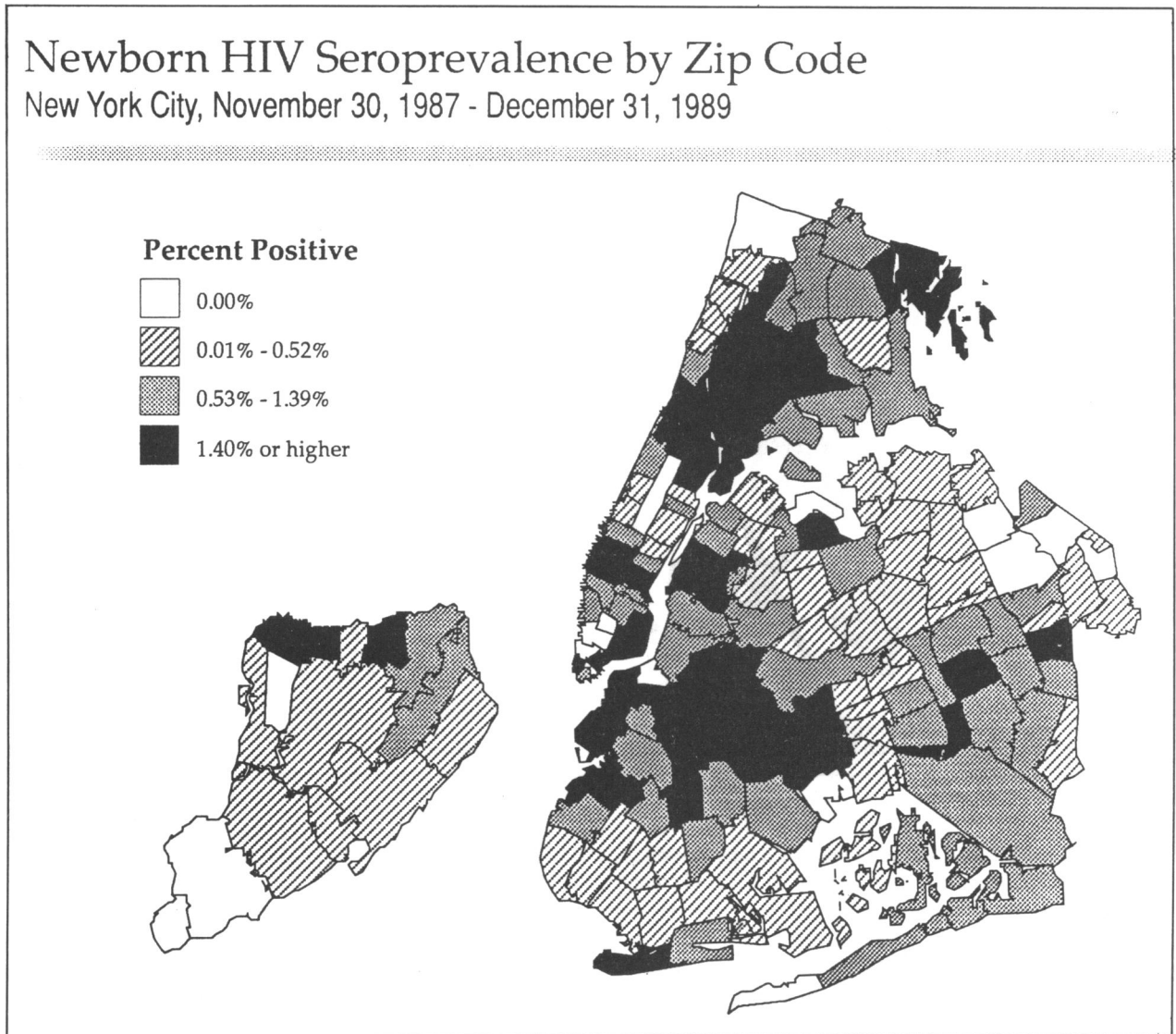
**Figure 25**  
73,000 Texans Estimated to be HIV-Infected

Minimum	Most Likely Estimate	Maximum
47,500	73,000	102,000
1 in every 370 Texans	1 in every 240 Texans	1 in every 170 Texans

Prepared by TDH, November, 1990

Texas Department of Health  
Bureau of HIV and STD Control  
HIV Division  
October, 1991

Figure 3. Newborn HIV seroprevalence in New York City, analyzed by ZIP code, using data from the CDC Family of Surveys



social services on the need to make recommendations regarding care for persons with HIV and to help prevent transmission of infection. The detection of HIV-infected persons in every geographic area, every age group, and every racial and ethnic group led New York State to develop a Five-Year Inter-Agency Plan to coordinate and support the activities of 19 State agencies that have responsibility for populations tested in different components of the seroprevalence surveys (27).

The appreciable number of HIV-infected women documented by the Survey of Childbearing Women has led to a discussion of the risks and benefits of prenatal screening programs on both the national and local levels (27-31). Citing data from the survey, the American College of Obstetricians and Gynecologists issued recommendations for their members that in-

clude HIV counseling and testing for women at risk of HIV infection (30). The Department of Health of the State of New Jersey issued recommendations on HIV counseling and testing of pregnant women, citing the data from their statewide survey, which showed an estimated 600 HIV-positive births occurring throughout the State per year. HIV education, counseling, and voluntary testing of all pregnant women and women contemplating pregnancy was set as a standard of care for practitioners in the State (29).

#### Developing Thresholds for Interventions

Following a public meeting in May 1990, an expert committee of the Institute of Medicine of the National Academy of Sciences considered the issue

of prenatal HIV screening (28). After reviewing national data from the Survey of Childbearing Women, the committee concluded that, at this time, a recommendation for universal screening was not warranted, given the wide variation across States in HIV seroprevalence among childbearing women.

Rather, the committee selected the prevalence of HIV infection as measured by the unlinked survey as a guide for local public health authorities to determine when to institute screening. In that approach, each local health jurisdiction would decide a threshold seroprevalence level above which screening would be appropriate, given available health care resources and the needs of other public health programs. The committee expected that "most, if not all jurisdictions with HIV seroprevalence among childbearing women of 1 infected women per 100 will find it appropriate to implement prenatal screening." Furthermore, they expected that "many jurisdictions with seroprevalence between 1 per 100 and 1 per 1,000 will consider prenatal HIV screening to be an appropriate expenditure of health resources." For areas where seroprevalence was not high enough to warrant consideration of screening, they recommended that existing recommendations for testing of persons with identified risks for HIV infection should be observed. It is likely that the recommended threshold seroprevalence will decrease as benefits of early treatment of HIV infection become defined and publicized. Similar recommendations based on a threshold seroprevalence among pregnant women and newborns of 1:1000 have been published by the American Academy of Pediatrics (31).

Serosurveillance studies in sentinel hospitals throughout the country have indicated that about two-thirds of hospital patients with HIV infection are being treated for conditions other than symptomatic HIV and AIDS (32). The studies further provided the rationale for recommending routine, voluntary HIV testing of all patients 15 to 54 years old at hospitals with at least 1 newly diagnosed AIDS case per 1,000 discharges per year (corresponding approximately to 1 percent seroprevalence among hospital patients) as a way of potentially identifying in a health-care setting more than 100,000 persons with previously unrecognized HIV infections (32).

## Resource Allocation

One of the most frequent applications of data from the surveys has been in allocating resources based on needs demonstrated by the surveys. Clinics that had previously not been able to confirm the need for HIV counseling and testing within their facility (and

*'The surveys have been highly influential with officials of local health departments and clinics where the surveys are conducted. The results are immediate and directly related to their everyday mission of ensuring care for persons with HIV infection or at risk of infection and to preventing infection.'*

therefore did not provide those services) are now able to document the number of infected persons who would be detected by a program. The establishment of HIV prevention programs within family planning clinics was prompted by data from New York State surveys in those clinics (19). The high rate of infection among homeless adolescents led to a grant program for that facility. Institution of HIV counseling and testing programs was the direct result of the recognition of high rates of HIV infection. The data were responsible in part for the development of school-based curriculums to reach children before and during adolescence (19). The need for this education program was supported by the demonstration of seroprevalence in adolescents and young adults.

To estimate the need for services by HIV-infected patients of STD clinics in New York City, data from an unlinked survey that showed an 8.6 percent seropositivity were used to predict that 6,880 seropositive patients would be seen in city STD clinics in 1 year (33). According to immunologic studies of HIV-infected cohorts, 20 percent, or 1,376 persons, could be expected to have a CD4 count less than 200 cells per microliter and would require anti-HIV and anti-pneumocystis therapy (33). Another 2,064 persons with CD4 cell counts in the 200–500 range would need anti-HIV drugs, and 3,440 persons would need T-cell monitoring and medical assessment periodically. Because, for example, a 1-year supply of zidovudine (AZT) costs about \$3,000 per patient, the total annual cost for AZT for HIV-infected clients in New York City STD clinics would exceed \$11 million a year. Such data-based estimates of the need for services and their projected costs are essential to obtaining support through the legislative and budget processes.

## Long-Range Planning

It may be possible to predict the numbers of HIV-infected persons in various population groups and to

*'It may be possible to predict the numbers of HIV-infected persons in various population groups and to forecast the direction of the epidemic with mathematical models using seroprevalence data, together with AIDS case surveillance data and HIV infection reporting.'*

forecast the direction of the epidemic with mathematical models using seroprevalence data, together with AIDS case surveillance data and HIV infection reporting.

For perinatal HIV infection, data from the Survey of Childbearing Women provide a direct means for the CDC to estimate the incidence of perinatal HIV infection each year (6). For each State, the estimated number of births to HIV-infected women was calculated by multiplying the total number of births by the seroprevalence rate in the survey. Assuming that 25–30 percent of infants born to infected mothers will be HIV infected, the number of infected infants was calculated for each State for each year of the survey. In 1989, 4.0 million births occurred in the United States, an estimated 6,079 infants were born to infected mothers, and an estimated 1 in every 2,200 infants was infected perinatally with HIV (6).

## Conclusion

One of the major objectives in establishing the CDC Family of Surveys was to assist in preventing HIV infection. The clinics participating in the surveys were chosen by the health departments to provide information on different segments of their population that were deemed important to the health departments' disease tracking and prevention efforts.

Because the clinics chosen to participate in the surveys were not randomly selected, there are important statistical limitations in analyzing and interpreting the data (34). HIV seroprevalence rates collected from any one clinic or groups of clinics may not represent all clinics or persons with a given disease or risk behavior in the population. In contrast, the Survey of Childbearing Women reflects all women by including a representative sample of all women giving birth in the State. However, only limited demographic data and no risk behavior information are collected in that survey.

In spite of some limitations, the surveys have had a major role in describing the current HIV epidemic. Other countries have begun using serologic surveys to determine the extent of HIV infection in their populations. A less obvious and less well-publicized aspect of the surveys is the many uses of data from the surveys in public forums to assist public health planners and other groups in charting programs. The surveys have been highly influential with officials of local health departments and clinics where the surveys are conducted. The results are immediate and directly related to their everyday mission of ensuring care for persons with HIV infection or at risk of infection and to preventing infection.

Two unique aspects of the HIV prevention effort are the amount of information about the extent of the problem that has been collected through surveys and the number of direct applications of survey results that have resulted in a short period.

## References.....

1. Dondero, T. J., Pappaioanou, M., and Curran, J. W.: Monitoring the levels and trends of HIV infection: the Public Health Service's HIV surveillance program. *Public Health Rep* 103: 213–220, May-June 1988.
2. Pappaioanou, M., et al.: The family of HIV seroprevalence surveys: objectives, methods, and uses of sentinel surveillance for HIV in the United States. *Public Health Rep* 105: 113–119, March-April 1990.
3. Allen, D. M., Onorato, I. M., Green, T. A., and Field Services Branch: Human immunodeficiency virus infection in intravenous drug users entering drug treatment, United States, 1988–89. *Am J Public Health* 82: 541–546 (1992).
4. Onorato, I. M., McCray, E., and Field Services Branch: Prevalence of HIV infection among patients attending tuberculosis clinics in the United States. *J Infect Dis* 165: 87–92 (1992).
5. McCray, E., Onorato, I. M., and Field Services Branch: Sentinel surveillance of human immunodeficiency virus infection in sexually transmitted disease clinics in the United States. *Sex Transm Dis* 19: 235–241, July-August 1992.
6. Gwinn, M., et al.: Prevalence of HIV infection in childbearing women in the United States. *JAMA* 265: 1704–1708, Apr. 13, 1991.
7. Sweeney, P. A., et al.: Sentinel surveillance of HIV infection in women seeking reproductive services in the United States, 1988–89. *Obstet Gynecol* 79: 503–510 (1992).
8. St. Louis, M. E., et al.: Seroprevalence rates of human immunodeficiency virus infection at sentinel hospitals in the United States. *N Engl J Med* 323: 213–218, July 26, 1990.
9. Guerena-Burgueno, F., Onorato, I. M., and Field Services Branch: Seroprevalence of HIV in correctional facilities, United States. Paper presented at VIII International Conference on AIDS, Amsterdam, July 19–24, 1992.
10. Allen, D. M., Lehman, J. S., and Onorato, I. M.: HIV infection in homeless adults and 'runaway' youth. Paper presented at VIII International Conference on AIDS, Amsterdam, July 19–24, 1992.
11. Centers for Disease Control: National HIV seroprevalence

- surveys—summary of results: data from serosurveillance activities through 1989. Publication No. HIV/CID/9-90/006. Atlanta, GA, 1990.
12. Centers for Disease Control: National HIV serosurveillance summary: results through 1990. Vol. 2. Publication No. HIV/NCID/11-91/011. Atlanta, GA, 1991.
  13. Delaware AIDS Program Office: Face the facts—AIDS can happen to you! Delaware Health and Social Services, Division of Public Health. Wilmington, 1991.
  14. San Francisco Department of Public Health: HIV seroprevalence report 1. AIDS Office, San Francisco, CA, 1990.
  15. New York City Department of Health: HIV serosurvey unit report 1. Office of AIDS and HIV Surveillance. New York, NY, 1990.
  16. Michigan Department of Public Health: Michigan HIV/AIDS report. January 1991.
  17. Colorado State Department of Health: Colorado disease bulletin 18 (6). March 1991.
  18. HIV seroprevalence surveys in Delaware, 1989—1990. Delaware Health and Social Services, Division of Public Health, Wilmington, September 1991.
  19. New York State Department of Health: AIDS in New York State. Albany, 1989.
  20. Massachusetts Department of Public Health: Developing AIDS/HIV Services in Massachusetts: a blueprint for action, 1990–1994. AIDS Office, October 1990.
  21. Texas Department of Health: Texas HIV and AIDS. HIV Division, Austin, October 1991.
  22. Novick, L. F., et al.: HIV seroprevalence in newborns in New York State. *JAMA* 261: 1745–1750, Mar. 24/31, 1989.
  23. Bolan, G., et al.: Comparison of HIV seroprevalence methodologies in a high prevalence population: blinded and non-blinded surveys in a sexually transmitted disease clinic. Paper presented at VI International Conference on AIDS, San Francisco, June 22–24, 1990.
  24. Borden, L. S., et al.: Characteristics of a high risk population refusing routine confidential HIV testing offered in a sexually transmitted disease clinic. Paper presented at VI International Conference on AIDS, San Francisco, June 22–24, 1990.
  25. Ford, W., Kerndt, P. R., Rose, T. P., and Nahlen, B. L.: Comparison of acceptors and refusers of confidential HIV testing among patients in sexually transmitted disease clinics in Los Angeles County. Paper presented at VI International Conference on AIDS, San Francisco, June 22–24, 1990.
  26. Fleming, D., et al.: HIV-infected STD clients who decline HIV counseling and testing. Paper presented at V International Conference on AIDS, Montreal, June 4–9, 1989.
  27. Novick, L. F.: HIV seroprevalence surveys: impetus for preventive activities. *Am J Public Health* 81 (suppl): 61–63 (1991).
  28. National Academy of Sciences: Report of the Committee on Prenatal and Newborn Screening for HIV Infection, edited by L.M. Hardy. Institute of Medicine. National Academy Press. Washington, DC, 1991.
  29. Grant, C. M., and Coye, M. J.: A statewide program of identification and early intervention of HIV positive women and children. Paper presented at VI International Conference on AIDS, San Francisco, June 22–24, 1990.
  30. American College of Obstetricians and Gynecologists: Human immunodeficiency virus infections. ACOG Technical Bulletin No.165. Washington, DC, 1992.
  31. Task Force on Pediatric AIDS: Perinatal human immunodeficiency virus (HIV) testing. *Pediatrics* 89: 791–794 (1992).
  32. Janssen, R. S., et al.: HIV infection among patients in acute care hospitals. Considerations for a national strategy to target counseling and testing. *N Engl J Med* 327: 445–451, Aug. 13, 1992.
  33. Rautenberg, E. L., and Weisfuse, I. B.: Using seroprevalence and immunologic data to estimate ambulatory, laboratory and pharmaceutical needs of a largely asymptomatic population. Paper presented at VI International Conference on AIDS, San Francisco, June 21–24, 1990.
  34. Onorato, I. M., Jones, T. S., and Forrester, W. R.: Using seroprevalence data in managing public health programs. *Public Health Rep* 105: 163–166, March-April 1990.