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Employment Issues Survey

Findings From a Survey of Employment Issues Affecting Persons With HIV/AIDS Living in Los Angeles County

Final Report

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This survey was conducted by AIDS Project Los Angeles (APLA) with funding provided by the City of Los Angeles, Office of the AIDS Coordinator and the Los Angeles County Department of Health Services, Office of AIDS Programs and Policy.

Erratum: The median viral load was incorrectly listed as 50 copies/ml on pages vi and 8 of this report. The correct median viral load is 500 copies/ml.

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For additional copies of this report, please contact the Los Angeles City Office of the AIDS Coordinator at (323) 485-6320. For any questions regarding the contents of this report, please contact Dr. Ronald Brooks, Research and Evaluation Specialist at AIDS Project Los Angeles at (323) 993-1522.

Employment Issues Survey
**Findings From a Survey of Employment Issues Affecting Persons
With HIV/AIDS Living in Los Angeles County**

EXECUTIVE SUMMARY

The survey findings exceeded all expectations about employment among the HIV/AIDS population in Los Angeles County. More people were working than was anticipated; approximately a third (35%) of survey respondents were currently employed. Nearly three-quarters (74%) of individuals not working said "yes" they were thinking of going to work now or in the near future. The overwhelming majority (80%) of individuals thinking of work indicated a need for services to help them find work, in particular, job placement, skills training, job training, and benefits counseling services.

The efficacy of combination drug therapies has made it possible for people living with HIV/AIDS who are unemployed or disabled to consider entering or re-entering the work force. However, information about the employment options and concerns of this population is not readily available. Findings from the Employment Issues Survey provide a first-hand view of the employment concerns and needs of these individuals as well as information on the challenges of those living with HIV/AIDS who are currently working.

The Employment Issues Survey was delivered to 5,360 individuals with HIV/AIDS who are case managed by one of thirteen AIDS service organizations located throughout Los Angeles County. Of the delivered surveys, 1,991 usable surveys were returned, representing a 37% response rate for the survey.

Presented below is a summary of key findings:

Health profile of survey respondents

The typical respondent reported being in good health, feeling as healthy as one year ago, having a confirmed AIDS diagnosis, a CD4 T-cell count of 303 (cells/ml), a viral load of 50 (copies/ml), taking 4 medications for HIV or related conditions, and having at least one AIDS-related hospitalization.

Current employment status of survey respondents

- ◆ 35% were currently working
- ◆ 65% were not working
- ◆ 91% were regularly employed before their HIV/AIDS diagnosis
- ◆ 9% had no regular employment before their HIV/AIDS diagnosis

Overview of individuals not working

- ◆ Average length of time unemployed was a little over 3.5 years
- ◆ 73% of individuals had stopped working because of their HIV disease

Current status of individuals not working

- ◆ 6% were retired
- ◆ 27% were completely (permanently) disabled and unable to work
- ◆ 67% were currently disabled or unemployed

Job-seeking status of all disabled or unemployed individuals

- ◆ 74% of them said "yes" they are thinking about going to work now or in the near future
- ◆ 26% of them said "no" they are not thinking about going to work now or in the near future

Job-seeking status of disabled or unemployed men and women

- ◆ 74% of men and 70% of women said "yes" they are thinking about going to work now or in the near future
- ◆ The difference between men and women is not statistically significant

There were significant differences in the proportions of individuals saying "yes" to thinking of work by the number of years they have been unemployed:

- ◆ 85% of individuals unemployed 0 to 2 years
- ◆ 73% of individuals unemployed 2.01 to 4 years
- ◆ 69% of individuals unemployed 4.01 to 6 years
- ◆ 62% of individuals unemployed 6.01 or more years

There were significant differences in the proportions of individuals saying "yes" to thinking of work by their last viral load:

- ◆ 79% with a viral load of 0 to 400 (copies/ml)
- ◆ 76% with a viral load of 401 to 10,000 (copies/ml)
- ◆ 67% with a viral load of 10,001 or more (copies/ml)

Major barriers to employment identified by individuals thinking about going to work

- ◆ Changes in health insurance and income benefits (e.g., the loss of current health insurance including Medi-Cal, ability to get adequate health insurance from a new employer, and loss of disability benefits).

- ◆ Health concerns relating to work (e.g., concern over day to day changes in health, fear that stress of work might affect health, and fear that they will not have rest periods they might need while working).
- ◆ Work-related concerns (e.g., concerns over out of date job skills, changes that would have to be made in daily routine if they work, and HIV and AIDS related discrimination in the workplace).

Service needs of individuals thinking about going to work

- ◆ More than half (56%) indicated that they were not planning to return to their previous type of employment. This finding suggests the need for services to help individuals prepare for work in a new field.
- ◆ The overwhelming majority (80%) of individuals thinking about going to work identified a need for services to help them find work. Out of eight services listed, four services were identified as important by respondents who need services.
 1. Job placement: assistance in finding work suited to particular skills, needs, and functional ability.
 2. Skills training: training to update current skills or acquire new skills to successfully enter or re-enter the work force.
 3. Job training: training for specific types of jobs that are suited to functional ability.
 4. Benefits counseling: assistance in understanding changes that will occur to public and private benefits once employed.

Issues affecting the majority of individuals currently working

- ◆ Most working respondents indicated that their employer does not pay for their health insurance.
- ◆ Most working respondents had not told their employer or co-workers of their HIV status.
- ◆ Most working respondents did not identify any major challenges to their ability to work (e.g., taking HIV medications at work, ability to see their doctor, health interfering with their ability to work, or work negatively affecting their health).

Implications for public policy

Below are recommendations to address issues affecting people with HIV/AIDS who are entering or re-entering the work force.

Health insurance and income benefits

- ◆ Insure that individuals receive accurate and adequate information on the effects of employment on disability benefits (e.g., SSDI, SSI, private disability) and publicly sponsored health insurance (e.g., Medi-Cal).
- ◆ Insure that individuals have adequate health insurance coverage. In particular, provide for uninterrupted health coverage in the transition from unemployment to employment. This should include both private health insurance, such as health maintenance organizations, and publicly sponsored health insurance, such as Medi-Cal (Medicaid).

Health concerns and work

- ◆ Support a “transitional work period” to allow for incremental increases in work hours, adjustments to changes in daily routine, and adjustments to the physical demands of work.
- ◆ Insure that individuals receive reasonable accommodations in the workplace to address medical and health needs (e.g., ability to take prescribed HIV medications at work, to take time off to see a doctor, or to have adequate rest periods during a work schedule).

Work-related concerns

- ◆ Insure that adequate legal protections against HIV and AIDS related discrimination exist in the workplace.
- ◆ Provide for workplace HIV/AIDS education to inhibit unlawful HIV/AIDS disclosure, harassment, and discrimination.

Pre- and post-employment services

- ◆ Provide individuals with information about and access to job placement services, benefits counseling, skills training, and job training programs in their community.
- ◆ Insure that a safety-net of services is available if individuals need to leave their employment because of declining health.

Employment Issues Survey

Findings From a Survey of Employment Issues Affecting Persons With HIV/AIDS Living in Los Angeles County Final Report

Introduction

Advances in medical treatments for HIV disease have made it possible for persons to live longer, healthier, and more productive lives. As a result of their improved medical condition, many individuals are now considering returning to work or entering the labor market for the first time. This trend has raised a number of questions among policy makers and agencies seeking to address the employment needs of the Los Angeles County HIV/AIDS population. The lack of information on issues of entering and re-entering the work force among persons living with HIV/AIDS prompted this countywide study.

Goal of the Study

The goal of this study was to gather and to analyze information on employment issues affecting persons with HIV/AIDS living in Los Angeles County. The main research questions addressed by the study included:

- 1. What proportion of individuals with HIV/AIDS in Los Angeles County is currently unemployed and interested in entering or re-entering the work force?*
- 2. What are the differences in demographic, social, economic, and health characteristics of those who are interested in entering or re-entering the work force?*
- 3. What are the incentives for entering or re-entering the work force (e.g., economic, psychological, emotional well-being, etc.)?*
- 4. What are the disincentives or barriers against entering or re-entering the work force (e.g., loss of public benefits, loss of health coverage, impact on health, etc.)?*
- 5. How will medical or health issues affect individuals who are entering or re-entering the work force (e.g., adherence to a HIV drug regimen, ability to keep medical appointments, etc.)?*
- 6. What is the status of individuals who are interested in entering or re-entering the work force (e.g., actively seeking or not seeking employment)?*

7. *What types of services or programs are needed to assist people to enter or re-enter the work force (e.g., job training, additional education, job search skills, job placement, etc.)?*
8. *What proportion of individuals with HIV/AIDS who are currently employed have disclosed their HIV status to their employer and co-workers?*
9. *What are the employment challenges faced by individuals with HIV/AIDS who are currently working (e.g., taking medications as prescribed, ability to see their doctor, discrimination, health insurance coverage, etc.)?*

Significance of the Study

The findings from the survey will provide the city and county with the first comprehensive profile of the needs and concerns of persons with HIV/AIDS who are considering entering or re-entering the work force and of those who are currently employed. Information provided from the survey can be used to inform policy makers' decisions in this area and to assist individual AIDS service providers in addressing the employment needs of their own clients.

Research Methodology

The survey was conducted under the direction of Co-Principal Investigators Dr. Ronald Brooks of AIDS Project Los Angeles and Dr. David Martin of Harbor-UCLA Research and Education Institute.

The survey was mailed to 5,653 individuals with HIV/AIDS who are currently case managed by one of thirteen AIDS service organizations located throughout Los Angeles County. See Appendix C for a complete list of participating agencies by their corresponding HIV Planning Region. Agencies were selected to reflect a representative sample of the County's HIV/AIDS population.

Clients were mailed surveys between June and September of 1998. The survey was mailed to both English and Spanish speaking clients, in their primary language. Each survey included a cover letter describing the study, a one dollar bill as an incentive to complete the survey, and a postage paid business reply envelope to return the survey. A week after the survey was mailed each client was then mailed a reminder letter encouraging them to return the survey.

Survey Development

The survey instrument was constructed using information from AIDS Project Los Angeles' "Back-to-Work" focus groups conducted in March of 1997 (Brooks & Klosinski, 1998), preliminary data from the HIV vocational rehabilitation program headed by Dr. David Martin at Harbor-UCLA Research and Education Institute, and a review of findings from small-scale studies on return-to-work issues affecting HIV/AIDS populations in other parts of the

country (see, Northwest AIDS Foundation, 1997; Timmons and Fesko, 1997a; Timmons and Fesko, 1997b). In addition, a thorough review of the literature on employment issues faced by persons living with HIV/AIDS and other disabilities was also completed prior to developing the survey instrument (e.g., Curtin et al., 1996; Goldberg, 1975; Greenwald et al., 1989; Mallette & Franco, 1987) .

Survey development involved identifying important areas of concern regarding employment, developing a set of questions to address each of these areas, and pilot testing the questions that were assembled as part of the instrument. The main areas identified in the focus groups and review of the research were health maintenance and health status, barriers against employment, types of desired employment, services needed by persons living with HIV/AIDS, and issues of those who were currently employed. In addition, the SF-24, a standardized measure of several aspects of health, was included as part of the instrument. The remainder of the instrument was developed by Dr. Ronald Brooks, Dr. David Martin, and Daniel Ortiz, M.A.

The 12-page survey instrument was pilot tested with a sample of 20 participants, from AIDS Project Los Angeles, to ensure its readability and clarity for survey respondents. The instrument was revised to include pilot test participants' comments. There were seven revisions of the instrument before the final version was completed. During this process, the instrument was reviewed by Gunther Freehill and other staff at the Office of AIDS Programs and Policy and Ferd Eggan, the City AIDS Coordinator. A copy of the survey instrument is included in Appendix B.

Spanish Translation

A backward translation method was used to insure the accuracy of the Spanish translation of the survey instrument, cover letter, and reminder letter. The translation involved multiple steps. First, a professional translator provided a translation of the survey from English to Spanish. Second, the Spanish version of the survey was independently reviewed and proofread by two bilingual individuals. Third and finally, the independent reviewers forwarded their comments and editing remarks on the Spanish translation to the original translator, who then made final corrections to the Spanish translation. This systematic process helped to insure the accuracy and clarity of the Spanish version of the survey and the contact letters.

Survey Response Rate

A total of 5,653 surveys were mailed to clients of participating agencies. Of the surveys mailed, 272 surveys were not deliverable: 256 because of an incorrect address and 16 because the client was deceased. Of the surveys

returned, 21 surveys were ineligible for use because respondents did not meet our criteria (e.g., did not have an HIV/AIDS diagnosis ($n = 4$); respondent sent a duplicate survey ($n = 3$); survey was largely incomplete ($n = 6$); respondent was under 18 years of age ($n = 8$)). A total of 1,991 usable questionnaires were collected and used in the analyses for this report. An overall survey response rate was calculated by subtracting the undeliverable surveys from the total number of surveys mailed, and dividing 1,991 by the remainder. The countywide survey response rate was 37 percent.

SOCIAL DEMOGRAPHIC CHARACTERISTICS OF SURVEY RESPONDENTS

The following information provides a demographic profile of all individuals countywide that completed the Employment Issues Survey. The total number of survey respondents was 1,991.

Gender

88% male
11% female
1% transgender

Age

The average age of respondents was 41 years old. The range of ages for all respondents was 18 to 78 years old.

Racial/Ethnic Breakdown

46% White/Caucasian
16% African-American/Black
31% Latino/Hispanic
2% Asian/Pacific Islander
1% Native American
4% Other races

Primary Language

83% English speaking
17% Spanish speaking

Sexual Orientation

21% Heterosexual (straight)
70% Homosexual (gay or lesbian)
9% Bisexual

Education Level

17% 11th grade or less
24% High school graduates
32% 1-3 years of college
25% College graduates
2% Other types of education such as technical training programs

Annual Income

33% Under \$7,740
23% \$7,741 to \$10,000
16% \$10,001 to \$15,000
8% \$15,001 to \$20,000
6% \$20,001 to \$25,000
4% \$25,001 to \$30,000
10% \$30,001 or above

Source of Income

30% Employment
2% Unemployment compensation
25% Supplemental Security Income (SSI)
36% Social Security Disability Insurance (SSDI)
4% Social Security (SSA-based on retirement)
4% State Disability Insurance (SDI)
7% Private Disability Insurance
23% All other sources

Note: Each source of income was analyzed separately and was mutually exclusive of the others.

Health Insurance

20% Health Maintenance Organization (HMO)
10% Private Policy Preferred Provider Organization
22% Medi-Cal
8% Medicare
23% Medi-Cal/Medicare
3% Veteran's Administration
18% No Insurance
5% Other

Note: Each type of health insurance was analyzed separately and was mutually exclusive of the others.

Demographic Profile of Survey Respondents

The typical respondent was a male who was 41 years old, Caucasian, an English speaker, gay, had some college education, earned less than \$10,000, and was on some form of public assistance.

HEALTH CHARACTERISTICS OF SURVEY RESPONDENTS

The following information provides a health profile of all individuals countywide that completed the Employment Issues Survey. The total number of survey respondents was 1,991.

In general, would you say your health is:

- 9% Excellent
- 19% Very Good
- 34% Good
- 32% Fair
- 7% Poor

Compared to one year ago, how would you rate your health in general now?

- 22% Much better than one year ago
- 23% Somewhat better than one year ago
- 36% About the same as one year ago
- 15% Somewhat worse than one year ago
- 4% Much worse than one year ago

HIV/AIDS Status

- 24% HIV Positive, no symptoms
- 22% HIV Positive, with symptoms or infections
- 54% Confirmed AIDS diagnosis

Year Respondents Received Their HIV Positive Diagnosis

- .4% 1980
- .5% 1981
- .5% 1982
- 1% 1983
- 3% 1984
- 6% 1985
- 6% 1986
- 6% 1987
- 5% 1988
- 7% 1989
- 7% 1990
- 8% 1991
- 9% 1992
- 7% 1993
- 8% 1994
- 8% 1995
- 9% 1996
- 6% 1997
- 2% 1998

Note. The years listed above were reported by the respondents. We recognize that a test for the HIV antibody was not available until 1985.

Last CD4 T-Cell count

- 7% 50 or less T-cells
- 24% 51 to 200 T-cells
- 48% 201 to 500 T-cells
- 21% 501 or more T-cells

Note: The median CD4 T-cell count was 303 (cells/ml).

Last Viral Load

- 47% 0 to 400 (undetectable)
- 30% 401 to 10,000
- 23% 10,001 or more

Note: The median viral load was 50 (copies/ml).

Respondents Reporting They Had Received an AIDS Diagnosis

- 41% No
- 59% Yes

Number of HIV Medications Respondents Were Taking

- 5% not taking any medications
- 10% 1-2 medications
- 40% 3-4 medications
- 27% 5-6 medications
- 12% 7-8 medications
- 4% 9-10 medications
- 2% 11 or more HIV medications

Note: The average number of medications respondents were taking was 4.

Number of Times Hospitalized for an AIDS-Related Illness

- 54% no hospitalizations
- 30% 1-2 hospitalizations
- 9% 3-4 hospitalizations
- 4% 5-6 hospitalizations
- 3% 7 or more hospitalizations

Note: The average number of times hospitalized was 1.

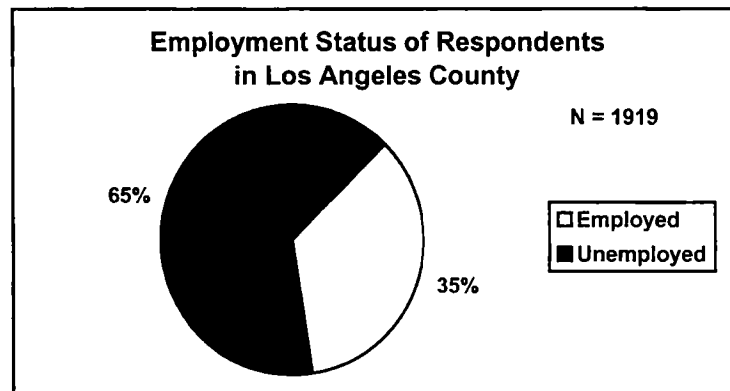
Health profile of survey respondents

The typical respondent reported being in good health, feeling as healthy as one year ago, having a confirmed AIDS diagnosis, a CD4 T-cell count of 303 (cells/ml), a viral load of 50 (copies/ml), taking 4 medications for HIV or related conditions, and having at least one AIDS-related hospitalization.

CURRENT EMPLOYMENT STATUS OF RESPONDENTS

We found over a third (35%) of respondents reported that they were currently working in some capacity with the remaining (65%) reporting that they were not working (see Figure 1). In addition, we also found that the overwhelming majority (91%) of respondents had been regularly employed before they were diagnosed with HIV/AIDS.

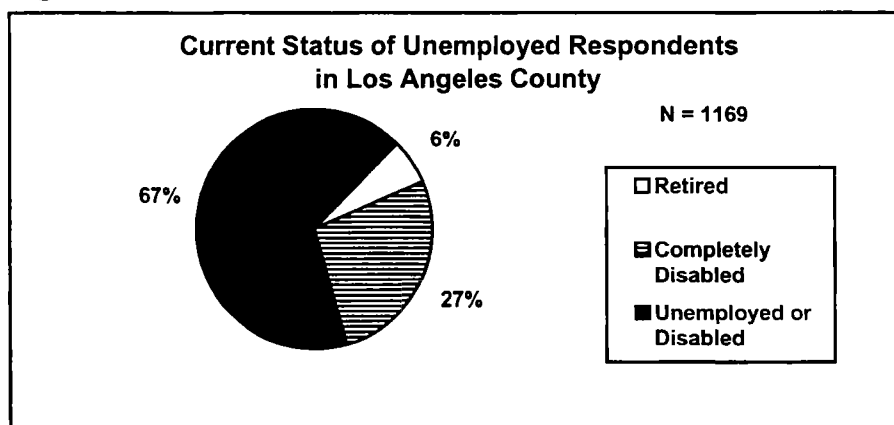
Figure 1



From among those working, over half (57%) were working regular, full-time jobs with the remaining (43%) engaged in part-time work.

Among individuals not working, we found the average length of time unemployed was a little over 3.5 years. We also found that 73% of those unemployed had stopped working because of their HIV disease. The current status of those not working was as follows: 6% were retired, 27% were completely (permanently) disabled and unable to work, and the remaining 67% indicated that they were currently unemployed or disabled (see Figure 2).

Figure 2



WHAT ARE THE ISSUES OF INDIVIDUALS INTERESTED IN ENTERING OR RE-ENTERING THE WORK FORCE?

Research Questions and Analyses

The analyses we conducted were guided by the main research questions outlined in the goal of this study. The purpose of these research questions was to identify important issues and differences among people living with HIV/AIDS who are interested in entering or re-entering the work force.

Research Question Number 1:

What proportion of individuals with HIV/AIDS in Los Angeles County is currently unemployed and interested in entering or re-entering the work force?

We found that of those who were unemployed or disabled respondents, almost three quarters (74%) of them said "yes" they are thinking about going to work now or in the near future. The remaining 26% said "no" to thinking about going to work now or in the near future.

Research Question Number 2:

What are the differences in demographic, social, economic, and health characteristics of those who are interested in entering or re-entering the work force?

We found statistically significant differences ($p < .05$) in the proportions of respondents who said "yes" and "no" to thinking about going to work by the following variables: language, age, race/ethnicity, education, viral load, years unemployed, general health, and change in health over the past year (see Table 1). There were no differences between the groups by gender, income, number of years since AIDS diagnosis, CD4 T-cell count, or number of medications individuals were taking.

Table 1. Differences Between Respondents Saying No or Yes to Thinking of Working

	Thinking of Working	
	No	Yes
<u>Language</u>		
Spanish	15%	85%
English	28%	72%
<u>Age</u>		
34 years and above	18%	82%
35 to 39 years	22%	78%
40 to 44 years	32%	68%
45 years and above	33%	67%

Table 1. Continued

	Thinking of Working	
	No	Yes
<u>Race/Ethnicity</u>		
White	30%	70%
Latino	21%	79%
Black	31%	69%
Asian	14%	86%
Other	15%	85%
<u>Education</u>		
11th grade or less	33%	67%
High School or GED	31%	69%
Some College	23%	77%
College Graduate	22%	78%
<u>Years Unemployed</u>		
0 to 2 years	15%	85%
2.01 to 4 years	27%	73%
4.01 to 6 years	31%	69%
6.01 or more	38%	62%
<u>Viral Load</u>		
0 to 400	21%	79%
401 to 10,000	24%	76%
10,001 or More	33%	67%
<u>General Health</u>		
Excellent	19%	81%
Very Good	18%	82%
Good	23%	77%
Fair	33%	67%
Poor	34%	66%
<u>Health Compared to a Year ago</u>		
Much Better	18%	82%
Somewhat Better	24%	77%
About the Same	28%	73%
Somewhat Worse	35%	65%
Much Worse	48%	52%

We also found statistically significant differences ($p < .05$) in the proportions of respondents who said “yes” and “no” to thinking about going to work by various obstacles and concerns with employment. In most cases, a greater proportion of respondents who were not thinking of seeking employment were more concerned with obstacles or fears than those who were thinking about employment. Put succinctly, the more barriers anticipated by individuals, the less likely they were to be thinking about looking for work. Out of the 23 survey items relating to obstacles and concerns with work, we chose to include here those that best reflected the practical considerations of entering or re-entering the work force (see Table 2).

Table 2. Differences Between Respondents Saying No or Yes to Thinking of Working by Obstacles and Concerns

		Thinking of Working	
		No	Yes
I will be able to take my medication at work	Agree	31%	54%
	Neutral	27%	22%
	Disagree	42%	24%
I will be able to take time off to see my doctor if I work	Agree	18%	36%
	Neutral	26%	24%
	Disagree	56%	40%
I am concerned over changes in my health day to day	Agree	86%	77%
	Neutral	9%	12%
	Disagree	5%	10%
I am afraid my job skills are out of date	Agree	49%	52%
	Neutral	27%	19%
	Disagree	25%	30%
I might not get adequate health insurance if I work	Agree	81%	69%
	Neutral	11%	16%
	Disagree	8%	15%
I am afraid the stress of work will affect my health	Agree	84%	65%
	Neutral	9%	20%
	Disagree	7%	16%

Table 2. Continued

I will lose my housing assistance if I go to work	Yes	38%	28%
	No	21%	33%
	Not Applicable	41%	39%
I will not have the rest periods I need if I go to work	Yes	81%	70%
	No	12%	23%
	Not Applicable	7%	7%

We also identified issues that were of concern to all unemployed respondents whether or not they were currently looking for work (see Table 3). The high percentages of individuals agreeing with many of these statements points to the importance of each of these concerns. In addition, there are areas which we would have predicted to be important to respondents but were not.

Table 3. Employment Concerns of Unemployed Respondents Saying No or Yes to Thinking of Working

		Thinking of Working	
		No	Yes
I am worried about HIV/AIDS discrimination	Agree	65%	66%
	Neutral	19%	17%
	Disagree	40%	33%
I am afraid I will lose my disability benefits if I go to work	Agree	75%	73%
	Neutral	15%	14%
	Disagree	10%	13%
I am afraid my co-workers will find out I have HIV	Agree	49%	50%
	Neutral	26%	25%
	Disagree	25%	25%
I am afraid I will lose my health insurance if I go to work	Agree	74%	67%
	Neutral	10%	14%
	Disagree	16%	19%
I will have child-care if I go to work	Yes	2%	4%
	No	19%	16%
	Not Applicable	79%	80%

Research Question Number 3:

What are the incentives for entering or re-entering the work force (e.g., economic, psychological, emotional well-being, etc.)?

We asked respondents to tell us how important the following factors were in their desire to look for work. Below are the factors that a majority of respondents identified as either "extremely important" or "important". The number in parentheses indicates the percentage of respondents that identified this factor.

- ◆ increasing income, (85%)
- ◆ getting out of debt, (70%)
- ◆ feeling useful or productive, (87%)
- ◆ ability to contribute to society, (82%)
- ◆ being around people, (72%)
- ◆ being physically active, (77%)
- ◆ feeling normal, (78%)
- ◆ increasing a sense of accomplishment, (86%)
- ◆ reducing the burden on family, (53%)
- ◆ contributing to the support of the family, (55%)
- ◆ getting out of the home, (54%)

Research Question Number 4:

What are the disincentives or barriers against entering or re-entering the work force (e.g., loss of public benefits, loss of health coverage, impact on health, etc.)?

From the survey we were able to identify the major disincentives and barriers perceived by individuals who are looking for work. Respondents indicated that they either "strongly agree" or "agree" with the items below. The areas of most concern were changes in health insurance and income benefits, health issues in the workplace, and work related issues.

Changes in Health Insurance and Income Benefits

- ◆ the loss of their current health insurance including Medi-Cal, reported by 67% of respondents
- ◆ the ability to get adequate health insurance from a new employer, reported by 69% of respondents
- ◆ loss of disability benefits (income), indicated by 73% of respondents

Health Concerns Relating to Work

- ◆ concern over the day to day changes in their health, reported by 77% of respondents
- ◆ fear that the stress of work might affect their health, indicated by 65% of respondents
- ◆ fear that they will not have the rest periods they might need while working, noted by 70% of respondents

Work-Related Issues

- ◆ concern over job skills that are out of date, indicated by 52% of individuals
- ◆ concern over changes they would have to make in their daily routine if they work, reported by 55% of respondents
- ◆ concern over HIV and AIDS related discrimination in the workplace, reported by 66% of respondents

Research Question Number 5:

How will medical or health issues affect individuals who are entering or re-entering the work force (e.g., ability to adhere to a HIV drug regimen, ability to keep medical appointments, etc.)?

Treatment adherence, time off to see a doctor, and housing assistance eligibility were not major concerns among those seeking employment. These were the least of their worries when compared to the items identified in Research Question Number 4. The proportions of people who either “strongly agree” or “agree” with the items below were noticeably lower than the proportions of people concerned about items presented in the previous section.

Other Health Concerns Relating to Work

- ◆ concern over taking medications as prescribed in the workplace, indicated by 45% of the respondents
- ◆ concern about taking time off from work to see their doctor if they go to work, noted by 30% of the respondents

Housing Assistance Eligibility

- ◆ fear that they will lose their housing assistance if they go to work, indicated by 28% of respondents

Research Question Number 6:

What is the status of individuals interested in entering or re-entering the work force (e.g., actively seeking or not seeking employment)?

When asked when they plan to go to work, a large proportion (45%) of job-seeking respondents reported that they were "not sure" when they planned to enter the work force, and 25% indicated that they hoped to enter the work force "as soon as possible" or "within the next three to six months".

We also asked respondents which job schedule was most suitable for them. In terms of schedules, 58% of respondents indicated that they were looking to work 21-40 hours per week. In addition, almost three-quarters (73%) of all job-seekers were looking for a permanent rather than a temporary position.

We asked individuals to tell us what type of jobs they were looking for. Among job-seekers, 56% indicated that they were not planning to return to the same kind of work they had done before. We compared previous employment experience with future employment interests and found a wide range of responses for the different types of employment listed (see Table 4). While a sizable proportion of people would like to return to professions they were experienced in, most individuals are not considering going back to the same profession they worked in previously. These findings suggest that many of these individuals will need some type of assistance or training to help them find work in a new field. The information included in Table 4 suggests which professions are least appealing and which are more appealing based on previous experience in the field.

Table 4. Previous Employment and Future Employment Interest

Type of Employment	Percent of all respondents previously employed in this area	Percent of respondents previously employed in this area and interested in returning to this area
Professional	14.4%	63.7%
Technical	6.6%	64.3%
Managerial	18.8%	44.5%
Clerical	16.1%	52.0%
Sales	14.9%	30.9%
Service Occupations	16.0%	29.7%
Skilled Trade	16.3%	38.8%
Student (full-time)	5.8%	32.4%
Other	17.7%	39.3%

Research Question 7:

What types of services or programs are needed to assist people to enter or re-enter the work force (e.g., job training, additional education, job search skills, job placement, etc.)?

We found that the overwhelming majority (80%) of individuals seeking employment indicated a need for services to help them find work. Out of eight services listed, the most important services identified by a majority of respondents were:

- ◆ job placement, reported by 71% of respondents
- ◆ skills training, reported by 61% of respondents
- ◆ job training, reported by 60% of respondents

Skills training in the survey was described as training in specific skills such as computer, accounting, administration, etc. Job training, on the other hand, was described as training for specific types of jobs such as lab technician, paralegal, floral design, etc. The other services listed, but which were not selected by a majority of respondents were:

- ◆ benefits counseling, reported by 49% of respondents
- ◆ career counseling, reported by 44% of respondents
- ◆ job search skills, reported by 37% of respondents
- ◆ additional education, reported by 40% of respondents
- ◆ support groups, reported by 31% of respondents

We did find statistically significant differences ($p < .05$) in service needs by various sub-groups of respondents. Figures 3, 4, and 5 show differences in service needs by age, language, and gender.

When examining groups by age, we found significantly larger proportions of individuals in the younger age groups needing services such as job training, additional education, and skills training.

When looking at differences by language, we found a significantly greater proportion of Spanish speaking respondents indicating a need for additional education and support groups and a greater proportion of English speakers needing career counseling.

When examining gender, we found a significantly greater proportion of men indicated a need for job placement and benefits counseling services and a greater proportion of women identified additional education as an important service need.

Figure 3

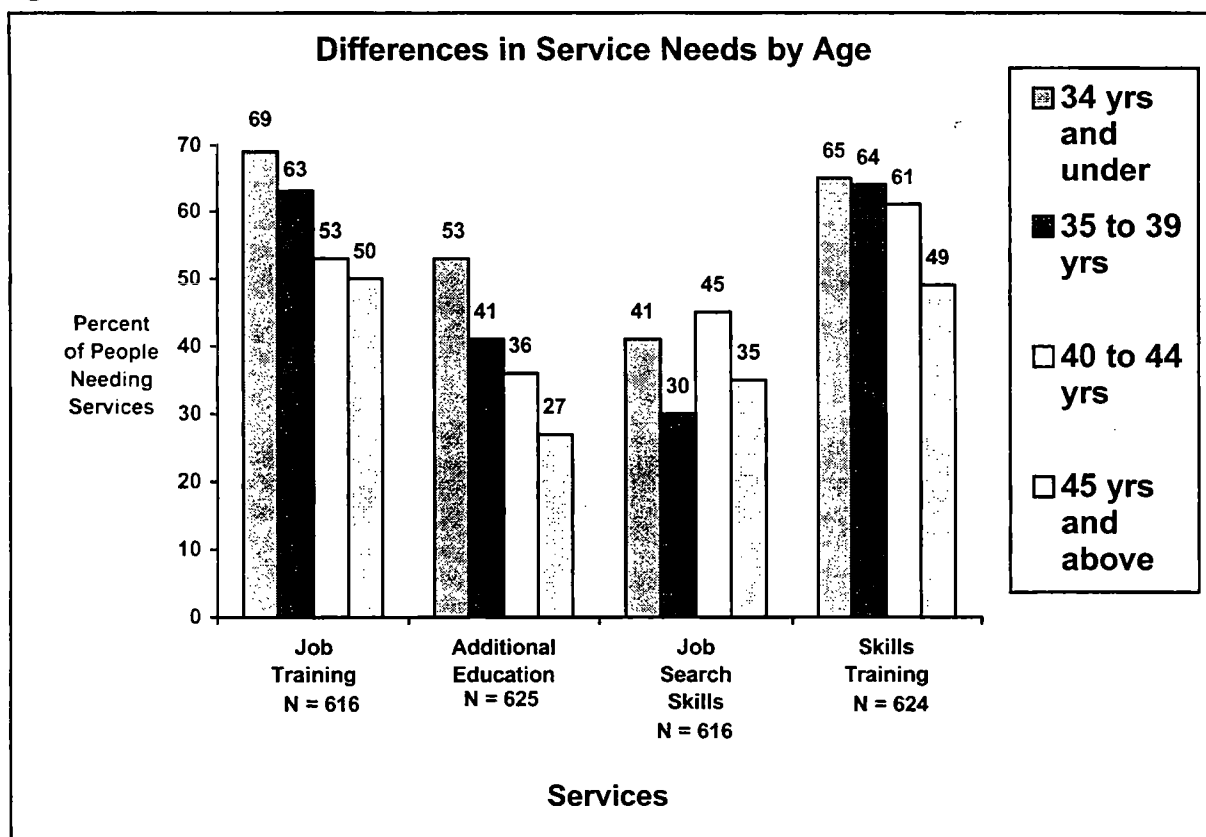


Figure 4

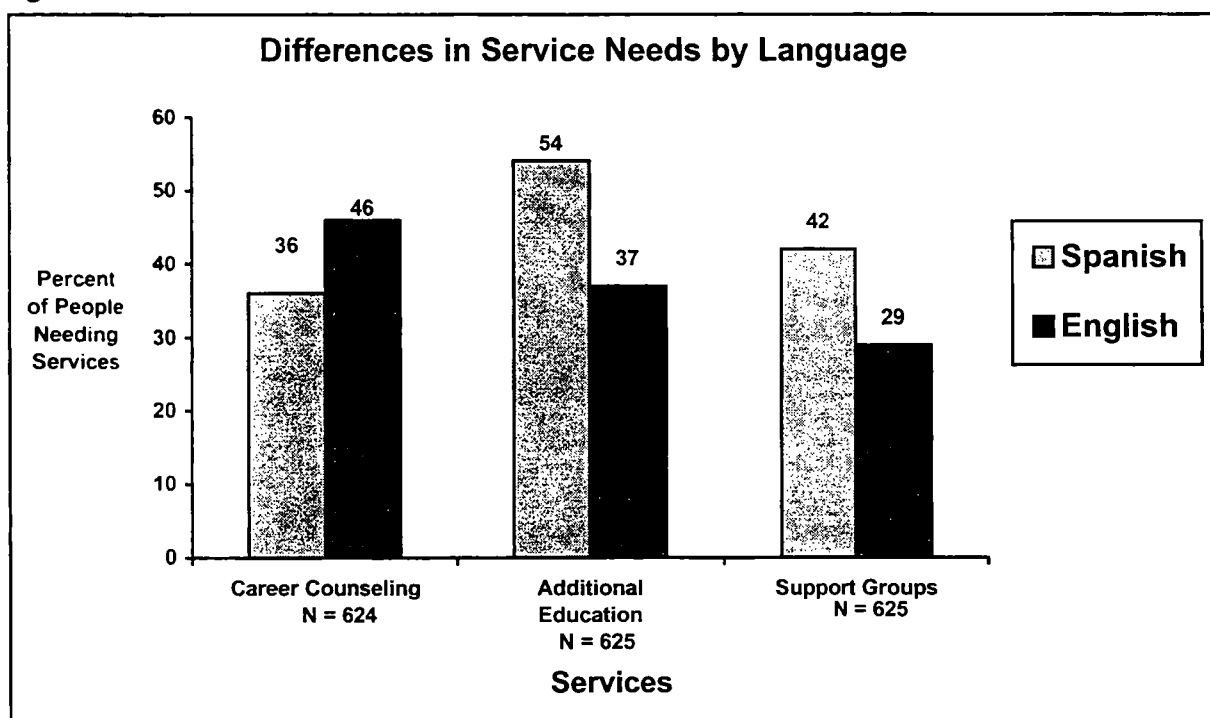
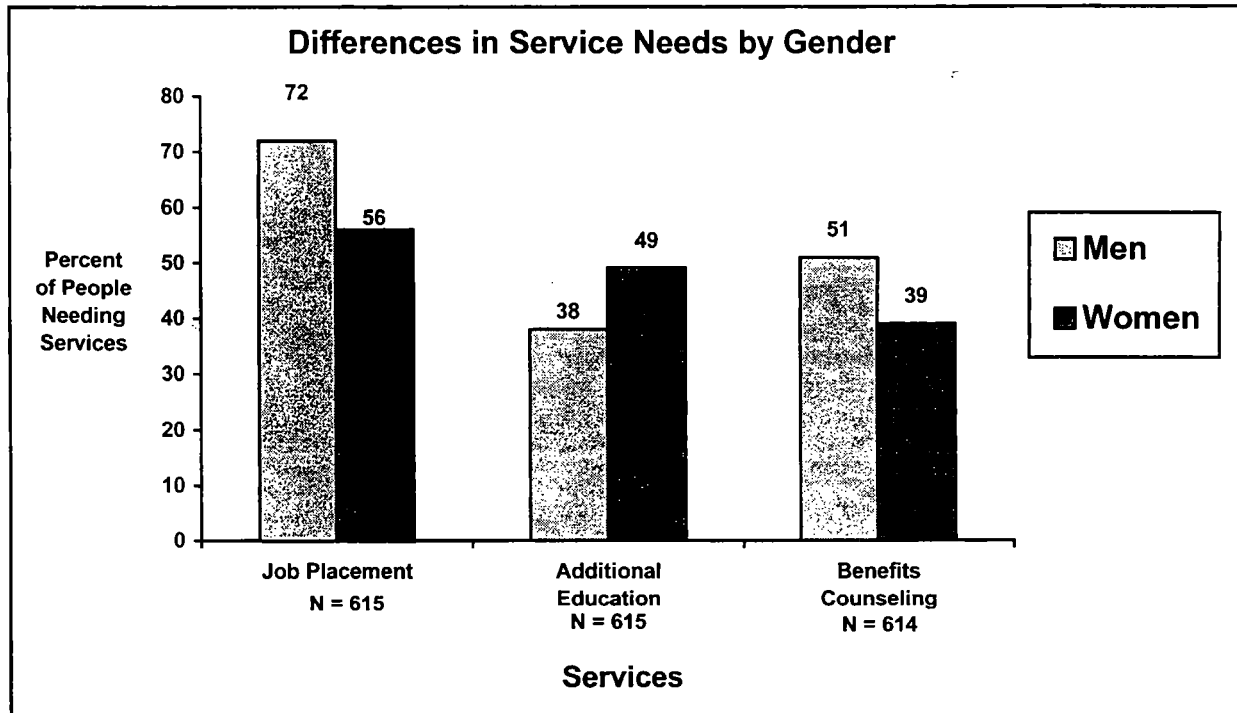


Figure 5



WHAT ARE THE ISSUES OF INDIVIDUALS CURRENTLY WORKING?

Our goal in these analyses was to identify important issues affecting people living with HIV/AIDS who were employed at the time of the survey. These analyses offer a profile of the needs and concerns of people in the work force.

Research Question 8:

What proportion of individuals with HIV/AIDS who are currently employed have disclosed their HIV status to their employer and co-workers?

Disclosure continues to remain a controversial and sensitive issue among the HIV/AIDS population. We found that more than half of all respondents who were employed had not disclosed their HIV status.

Disclosure of HIV Status

- ◆ 56% of working respondents had not told their employer of their HIV status
- ◆ 52% of respondents indicated that their co-workers did not know of their HIV status

Research Question 9:

What are the employment challenges of individuals with HIV/AIDS who are currently working (e.g., discrimination, taking medications as prescribed, ability to see their doctor, health insurance coverage, etc.)?

A very small proportion of people said they had experienced HIV/AIDS discrimination at work. In addition, only a third or less of all respondents who were currently employed noted that working had interfered with their health and that their health status had interfered with their ability to work. Lastly, the majority of respondents indicated that they did not receive health insurance from their employer. The percentages presented below are based on respondents who indicated that they either experienced the items "a great deal," "a lot," or "some."

Discrimination in the Workplace

- ◆ 10% of workers indicated that they had experienced at least some degree of AIDS or HIV-related discrimination at work

Health Concerns Related to Work

- ◆ 30% of respondents indicated that work did interfere at some level with their ability to take their HIV medications as prescribed
- ◆ 23% of respondents stated that work had interfered at some level with their ability to see their doctor

- ◆ 34% of respondents indicated that their health has interfered at some level with their ability to work
- ◆ 30% of respondents indicated that working negatively affected their health to some degree

Health Insurance

- ◆ 62% of all workers indicated that their employer does not pay for their health insurance
- ◆ 47% of full-time workers reported that their employer did not pay for their health insurance
- ◆ 88% of part-time workers noted that their employer did not pay for their health insurance

EMPLOYMENT PROFILE OF PERSONS WITH HIV/AIDS LIVING IN LOS ANGELES COUNTY

This report offers the first broad profile of persons living with HIV/AIDS in Los Angeles County who are considering entering or re-entering the work force.

Based on every 100 survey respondents:

- ◆ 38 were working in some capacity
- ◆ 30 were unemployed or disabled and thinking about going to work now or in the near future
- ◆ 11 were unemployed or disabled and not thinking about going to work now or in the near future
- ◆ 21 were retired or completely (permanently) disabled

IMPLICATIONS FOR PUBLIC POLICY

The findings presented in this report suggest directions for public policy. Presented below are policy recommendations to address issues affecting individuals with HIV/AIDS who are entering or re-entering the work force.

Health insurance and income benefits

1. Insure that individuals receive accurate and adequate information on the effects of employment on disability benefits (e.g., SSDI, SSI, private disability) and publicly sponsored health insurance (e.g., Medi-Cal).
2. Insure that individuals have adequate health insurance coverage. In particular, provide for uninterrupted health coverage in the transition from unemployment to employment. This should include both private health insurance, such as health maintenance organizations, and publicly sponsored health insurance, such as Medi-Cal (Medicaid).

Health concerns and work

3. Support a "transitional work period" to allow for incremental increases in work hours, adjustments to changes in daily routine, and adjustments to the physical demands of work.
4. Insure that individuals receive reasonable accommodations in the workplace to address medical and health needs (e.g., ability to take prescribed HIV medications at work, to take time off to see a doctor, or to have adequate rest periods during a work schedule).

Work-related concerns

5. Insure that adequate legal protections against HIV and AIDS related discrimination exist in the workplace.
6. Provide for workplace HIV/AIDS education to inhibit unlawful HIV/AIDS disclosure, harassment, and discrimination.

Pre- and post-employment services

7. Provide individuals with information about and access to job placement services, benefits counseling, skills training, and job training programs in their community.
8. Insure that a safety-net of services is available if individuals need to leave their employment because of declining health.

IMPLICATIONS FOR SERVICES

Among respondents who were unemployed, the findings clearly indicated a need for employment services to assist them in entering or re-entering the work force. Meeting the service needs of individuals with HIV/AIDS who are entering or re-entering the work force will be an additional challenge for government agencies and AIDS service organizations. To lessen the challenge, existing services should be explored before developing new services in this area. Presented below are the most important service needs indicated by respondents who need services.

1. Job placement: assistance in finding work that is suited to particular skills, needs, and functional ability.
2. Skills training: training to update current skills or acquire new skills to successfully enter or re-enter the work force.
3. Job training: training for specific types of jobs suited to functional ability.
4. Benefits counseling: assistance in understanding changes that will occur to public and private benefits once employed.

The findings presented in this report indicated differences in service needs by subgroups (age groups, gender, and language) of the HIV/AIDS population. This information can be used in targeting services to groups that are in need of particular types of services.

SURVEY LIMITATIONS

We identified limitations of the Employment Issues Survey that must be considered when interpreting these findings. One consideration is the representativeness of the study population. Only clients who had agreed to receive mail from the participating agencies were included in the study population. As a result, clients who do not receive mail from their respective agency or were homeless clients, could not be surveyed.

To assess the representativeness of our sample, we compared the gender, age, and racial/ethnic distributions of respondents to the Employment Issues Survey with the distributions for people living with advanced HIV disease (AIDS) in Los Angeles County (Department of Health Services, HIV Epidemiology Program, Special Data Run, February, 1998). The proportions by racial/ethnic, gender and age distributions of survey respondents were similar to the distributions for the county's AIDS population. This is not a direct comparison given that our sample includes individuals who are HIV positive without necessarily having an AIDS diagnosis. In general, however, the two populations appear very similar by race/ethnicity, gender, and age. Compared with the county, our population has slightly greater proportions of Latinos (32% vs. 30%) and Whites (49% vs. 46%) and a smaller proportion of Blacks (14% vs. 19%); by gender, our population has a slightly greater proportion of females (11% vs. 9%) and a smaller proportion of males (88% vs. 91%); by age groups, our population has smaller proportions in the younger age categories 20 to 29 years (6% vs. 18%) and 30 to 39 years (42% vs. 47%) and larger proportions in the older age groups 40 to 49 years (35% vs. 24%), 50 to 59 years (13% vs. 7%) and 60 years and above (4% vs. 2%). Without providing a direct comparison, these figures suggest that the survey respondents were comparable to people living with HIV/AIDS in the general Los Angeles County population.

There is an additional limitation that must be considered when interpreting certain findings of respondents who were working. In the survey, we did not differentiate between individuals who were self-employed and those who were working for an employer. As a result, we cannot distinguish the responses of those who are self-employed as it relates to the challenges faced by individuals who were currently working. Depending on the number of self-employed individuals, this distinction may or may not have influenced how we interpreted findings on questions about employer paid insurance, discrimination in the workplace, and disclosure of HIV/AIDS status to an employer and co-workers.

NEED FOR ADDITIONAL RESEARCH

This study, like other groundbreaking studies, provides data that are the basis for developing a comprehensive and in-depth understanding of employment issues affecting the HIV/AIDS population. In the process of undertaking this study, several other issues were identified that point to the need for additional research. In particular, information is needed on individuals with HIV/AIDS who have actually returned to work after a prolonged absence and how they overcame obstacles. This information will be useful in understanding what is needed to help people maintain their employment without jeopardizing their health. Information is also needed on people with HIV/AIDS who never left the work force. How do they maintain their employment without jeopardizing their health?

Other areas not covered by this study, but where research is needed, is with sub-populations of the HIV/AIDS population. In particular, information is needed on substance misusers and how they are or are not dealing with employment considerations. Is this sub-population entering the work force at the same proportions as non-substance misusers? Does this group need specific types of services to assist them to go to work? Another area where information is needed is with undocumented residents with HIV/AIDS who need and want to work, but cannot do so legally. How are they dealing with employment?

CONCLUSION

The findings from the Employment Issues Survey provide the first comprehensive view of employment issues affecting the HIV/AIDS population of Los Angeles County. By recognizing the barriers, concerns, and fears of this population as it relates to going to work, we can begin to address the very issues that are preventing individuals from seeking employment. At the same time, we can also help those who are already employed stay in the work force.

For a person living with HIV/AIDS who has been unemployed for a substantial period of time, or has never worked, the idea of entering the work force brings with it many new challenges. Returning to work or going to work for the first time is a major lifestyle change for many of these individuals. It is our responsibility as service providers, policy makers, and as a community to insure that these individuals are given the opportunity to explore their employment options. Furthermore, we need to provide the means for these individuals to transition into the work force, without jeopardizing their health.

In completing this study, we recognize that many of the findings from this survey parallel previous findings with other disabled populations. In many respects, the employment concerns and obstacles presented in this report have been noted for other disabled populations. To the extent that issues and concerns are similar, we should look to existing services, programs, and policies to assist people with HIV/AIDS enter or re-enter the work force. At the same time, we must remain cognizant of the fact that HIV disease is constantly changing; there are too many unknowns to have any definitive answer as to how this disease will progress. We know change will occur, and we must continually respond to changes in this disease as it impacts various aspects of an individual's life.

References

- Brooks, R. A. & Klosinski, L. E. (in press). Assisting persons living with HIV/AIDS to return work: Programmatic steps for AIDS service organizations. AIDS Education and Prevention: An Interdisciplinary Journal.
- Curtin, R. B., Oberley, E. T., Sacksteder, P., & Friedman, A. (1996). Differences between employed and nonemployed dialysis patients. American Journal of Kidney Diseases, 27 (4), 533-540.
- Goldberg, R. T. (1975). Vocational and social adjustment after laryngectomy. Scandinavian Journal of Rehabilitation Medicine, 7, 1-8.
- Greenwald, H. P., Dirks, S. J., Borgatta, E. F., McCorkle R., Nevitt, M. C., & Yelin E. H. (1989). Work disability among cancer patients. Social Science Medicine, 29 (11), 1253-1259.
- Mallette S. J. & Franco P. C. (1987). Psychosocial barriers to employment of the cancer survivor. Journal of Psychosocial Oncology, 5 (4) 97-115.
- Northwest AIDS Foundation (1997). [Back-to-Work Client Survey]. Unpublished crosstabs and frequencies.
- Timmons, J. C., & Fesko, S. L. (June 1997). Employment Needs of Individuals with HIV/AIDS. (Available from [Jaimie Ciulla Timmons, Institute for Community Inclusion (UAP) Children's Hospital, 300 Longwood Avenue, Boston, MA 02115]).
- Timmons, J. C., & Fesko, S. L. (June 1997). Employment Needs of Individuals with HIV/AIDS: Service Providers' Viewpoints. (Available from [Jaimie Ciulla Timmons, Institute for Community Inclusion (UAP) Children's Hospital, 300 Longwood Avenue, Boston, MA 02115]).

Appendix A

Complete Survey Findings

Employment Issues Survey

Complete Survey Findings

Spanish surveys	16.8%
English surveys	83.2%

The following questions ask for some general information about yourself.

1. What is your ZIP Code?
Do you live in the City of Los Angeles?

No	36.9%
Yes	63.1%

2. What is your age?

34 and under	23.7%
35 to 39	25.3%
40 to 44	20.0%
45 and above	31.0%

3. What is your gender?

male	88.0%
female	10.9%
transgender	1.1%

4. Which best describes your racial/ethnic background?

White	46.0%
Black	16.2%
Latino	30.9%
Asian/Pacific Islander	2.0%
Native American/Alaskan	1.0%
Other	4.0%

5. Which best describes your sexual orientation?

Heterosexual	21.5%
Homosexual	69.9%
Bisexual	8.6%

6. What is the last grade of school you completed?

11th grade or less	16.9%
High school	19.1%
GED	5.0%
1-3 years college	32.0%
College graduate	15.3%
Graduate school or degree	9.4%
Other education	2.3%

7. What is your marital (partner) status?

Single	57.7%
Married/with partner/with significant other	30.4%
Divorced or separated	7.3%
Widowed	4.2%
Other marital status	.5%

8. What is your current source of income? (Check all that apply)

Sources of Income	
Employment	
Not a source of income	70.1%
Source of income	29.9%
Unemployment comp	
Not a source of income	98.1%
Source of income	1.9%
Supplemental Security Income (SSI)	
Not a source of income	75.2%
Source of income	24.8%

Social Security Disability Insurance (SSDI)	
Not a source of income	64.2%
Source of income	35.8%
Social Security (SSA based on retirement, not disability)	
Not a source of income	95.7%
Source of income	4.3%
State Disability Insurance (SDI)	
Not a source of income	95.8%
Source of income	4.2%
TANF/AFDC	
Not a source of income	98.2%
Source of income	1.8%
General Relief	
Not a source of income	95.9%
Source of income	4.1%
Private Disability insurance	
Not a source of income	93.1%
Source of income	6.9%
Family assistance	
Not a source of income	94.9%
Source of income	5.1%
Spouse/significant other	
Not a source of income	95.7%
Source of income	4.3%
Alimony/child support	
Not a source of income	99.6%
Source of income	.4%
Other income source	
Not a source of income	93.0%
Source of income	7.0%

9. What is your current annual income-- before taxes?

Under \$7740	33.4%
\$7741 to \$10000	22.6%
\$10001 to \$15000	15.5%
\$15001 to \$20000	7.9%
\$20001 to \$25000	6.4%
\$25001 to \$30000	4.3%
\$30001 or above	9.9%

10. What type of health insurance do you currently have? (Check all that apply)

Types of health insurance	
HMO	
Not source of health insurance	79.7%
Source of health insurance	20.3%
Private policy	
Not source of health insurance	89.6%
Source of health insurance	10.4%
Medi-Cal	
Not source of health insurance	77.9%
Source of health insurance	22.1%
Medi-Care	
Not source of health insurance	92.0%
Source of health insurance	8.0%
Medi-Cal/Medi-Care	
Not source of health insurance	77.0%
Source of health insurance	23.0%
Veterans Administration	
Not source of health insurance	96.9%
Source of health insurance	3.1%
No insurance	
Not source of health insurance	81.9%
Source of health insurance	18.1%

Other insurance	
Not source of health insurance	94.9%
Source of health insurance	5.1%

The following questions are about your health and physical activity.

11. In general, would you say your health is:

Excellent	8.5%
Very good	19.1%
Good	33.5%
Fair	31.5%
Poor	7.4%

12. Compared to one year ago, how would you rate your health in general now?

Much better than 1 year ago	21.9%
Somewhat better than 1 year ago	23.5%
About the same as 1 year ago	35.5%
Somewhat worse than 1 year ago	14.9%
Much worse than 1 year ago	4.2%

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Types of activities	
Vigorous activities	
Yes limited a lot	43.5%
Yes limited a little	35.0%
No not limited at all	21.5%
Moderate activities	
Yes limited a lot	13.5%
Yes limited a little	41.1%
No not limited at all	45.4%

Climbing stairs	
Yes limited a lot	24.5%
Yes limited a little	42.4%
No not limited at all	33.1%
Bending, kneeling, stooping	
Yes limited a lot	15.7%
Yes limited a little	40.7%
No not limited at all	43.7%
Walking a block	
Yes limited a lot	8.6%
Yes limited a little	28.6%
No not limited at all	62.8%
Bathing or dressing yourself	
Yes limited a lot	5.1%
Yes limited a little	17.7%
No not limited at all	77.2%

14. During the ***past 4 weeks***, have you had any of the following problems with your work or other regular daily activities ***as a result of your physical health?***

a. ***Accomplished less*** than you would like.

No	37.9%
Yes	62.1%

b. Were limited in the ***kind*** of work or other activities.

No	44.2%
Yes	55.8%

15. During the ***past 4 weeks***, have you had any of the following problems with your work or other regular daily activities ***as a result of any emotional problems*** (such as feeling depressed or anxious)?

a. ***Accomplished less*** than you would like.

No	37.5%
Yes	62.5%

b. Didn't do work or other activities as ***carefully*** as usual.

No	45.3%
Yes	54.7%

16. During the ***past 4 weeks***, how much did ***pain*** interfere with your normal work (including both work outside the home and housework)?

Not at all	26.6%
Slightly	25.0%
Moderately	25.2%
Quite a bit	18.5%
Extremely	4.7%

17. These questions are about how you feel and how things have been with you ***during the past 4 weeks***. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the ***past 4 weeks*** ...

a. Have you been a very nervous person?	
All of the time	6.3%
Most of the time	12.1%
A good bit of the time	15.3%
Some of the time	25.7%
A little of the time	23.2%
None of the time	17.4%

b. Have you felt so down in the dumps that nothing could cheer you up?	
All of the time	4.6%
Most of the time	9.8%
A good bit of the time	15.3%
Some of the time	25.7%
A little of the time	23.2%
None of the time	17.4%

c. Have you felt calm and peaceful?	
All of the time	4.1%
Most of the time	19.3%
A good bit of the time	17.2%
Some of the time	27.9%
A little of the time	23.1%
None of the time	8.4%

d. Did you have a lot of energy?	
All of the time	4.3%
Most of the time	12.5%
A good bit of the time	16.4%
Some of the time	27.8%
A little of the time	26.5%
None of the time	12.4%

e. Have you felt downhearted and blue?	
All of the time	5.5%
Most of the time	11.6%
A good bit of the time	12.5%
Some of the time	29.2%
A little of the time	27.2%
None of the time	14.1%

f. Have you been a happy person?	
All of the time	6.0%
Most of the time	26.2%
A good bit of the time	16.5%
Some of the time	27.2%
A little of the time	18.5%
None of the time	5.7%

g. Did you feel tired?	
All of the time	14.5%
Most of the time	20.4%
A good bit of the time	19.2%
Some of the time	26.8%
A little of the time	15.1%
None of the time	4.0%

18. During the ***past 4 weeks***, how much of the time has your ***physical health or emotional problems*** interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	7.1%
Most of the time	20.4%
Some of the time	35.3%
A little of the time	19.3%
None of the time	17.8%

19. How ***true*** or ***false*** is ***each*** of the following statements for you?

a. I seem to get sick a little easier than other people.	
Definitely true	16.9%
Mostly true	23.9%
Don't know	22.7%
Mostly false	20.9%
Definitely false	15.7%

b. I am as healthy as anybody I know.	
Definitely true	9.9%
Mostly true	25.7%
Don't know	20.2%
Mostly false	23.8%
Definitely false	20.4%

c. I expect my health to get worse.	
Definitely true	11.8%
Mostly true	17.1%
Don't know	39.4%
Mostly false	13.6%
Definitely false	18.0%

d. My health is excellent.	
Definitely true	9.7%
Mostly true	27.8%
Don't know	13.5%
Mostly false	21.9%
Definitely false	27.1%

20. Here is a list of medications. Please read through the list and place a check in the box next to those you are taking. Please do not check medications you are not really taking.

HIV Medications	
Abacavir	
not taking this medicine	97.2%
taking this medicine	2.8%
AZT (Zidovudine, Retrovir [®])	
not taking this medicine	85.2%
taking this medicine	14.8%
Combivir [®]	
not taking this medicine	80.8%
taking this medicine	19.2%
Rescriptor [®] (Delavirdine)	
not taking this medicine	97.2%
taking this medicine	2.8%
ddl, Videx [®] (Didanosine)	
not taking this medicine	84.1%
taking this medicine	15.9%
Sustiva [®] , DMP266 (Efavirenz)	
not taking this medicine	96.2%
taking this medicine	3.8%
3TC, Epivir [®] (Lamivudine)	
not taking this medicine	53.1%
taking this medicine	46.9%
Viramune [®] (Nevirapine)	
not taking this medicine	78.3%
taking this medicine	21.7%
d4T, Zerit [®] (Stavudine)	
not taking this medicine	52.2%
taking this medicine	47.8%

ddC, Hivid [®] (Zalcitabine)	
not taking this medicine	97.2%
taking this medicine	2.8%
Other HIV medicine	
not taking this medicine	96.0%
taking this medicine	4.0%
HIV Protease Inhibitors	
Crixivan [®] (Indinavir)	
not taking this medicine	76.6%
taking this medicine	23.4%
Viracept [®] (Nelfinavir)	
not taking this medicine	69.4%
taking this medicine	30.6%
Norvir [®] (Ritonavir)	
not taking this medicine	76.7%
taking this medicine	23.3%
Invirase [®] , Fortovase [®] (Saquinavir)	
not taking this medicine	72.3%
taking this medicine	27.7%
PCP prophylactic medications	
Aerosolized Pentamidine (Nebu Pent [®])	
not taking this medicine	97.2%
taking this medicine	2.8%
Clindamycin (Cleocin [®])	
not taking this medicine	99.4%
taking this medicine	.6%
Dapsone	
not taking this medicine	92.4%
taking this medicine	7.6%
TMP/SMX (Bactrim [®] , Septra [®])	
not taking this medicine	63.1%
taking this medicine	36.9%

Other PCP prophylactic medicine	
not taking this medicine	97.5%
taking this medicine	2.5%
MAC prophylactic medications	
Clarithromycin (Biaxin [®])	
not taking this medicine	93.3%
taking this medicine	6.7%
Rifabutin (Mycobutin [®])	
not taking this medicine	97.7%
taking this medicine	2.3%
Other MAC prophylactic medicine	
not taking this medicine	98.5%
taking this medicine	1.5%
Other medications for HIV/AIDS	
Acyclovir (Zovirax [®])	
not taking this medicine	72.6%
taking this medicine	27.4%
Azithromycin (Zithromax [®])	
not taking this medicine	88.2%
taking this medicine	11.8%
Clotrimazole troches (Mycelex [®])	
not taking this medicine	95.8%
taking this medicine	4.2%
Ethambutol (Myambutol [®])	
not taking this medicine	97.2%
taking this medicine	2.8%
Fluconazole (Diflucan [®])	
not taking this medicine	84.5%
taking this medicine	15.5%

Foscarnet (Foscavir [®])	
not taking this medicine	99.4%
taking this medicine	.6%
Ganciclovir (Cytovene [®])	
not taking this medicine	98.0%
taking this medicine	2.0%
Hydroxyurea (Hydrea [®])	
not taking this medicine	93.8%
taking this medicine	6.2%
Isoniazid (INH)	
not taking this medicine	98.8%
taking this medicine	1.2%
Itraconazole (Sporanox [®])	
not taking this medicine	95.9%
taking this medicine	4.1%
Leucovorin (Wellcovorin [®])	
not taking this medicine	99.4%
taking this medicine	.6%
Pyrazinamide (PZA)	
not taking this medicine	99.8%
taking this medicine	.2%
Pyrimethamine (Daraprim [®])	
not taking this medicine	99.0%
taking this medicine	1.0%
Rifampin (Rifadin [®] , Rifamate [®])	
not taking this medicine	99.6%
taking this medicine	.4%
Sulfadiazine	
not taking this medicine	98.4%
taking this medicine	1.6%

Other HIV medicine 1	
not taking this medicine	87.5%
taking this medicine	12.5%
Other HIV medicine 2	
not taking this medicine	91.9%
taking this medicine	8.1%

21. What is your current HIV status?

Current HIV status	
HIV + without symptoms	24.2%
HIV + with symptoms	22.1%
Confirmed AIDS diagnosis	53.8%

22. What was your last T-cell or CD-4 count?

	Minimum	Maximum	Mean
T cell count	0	1800	351.85

When was your last T-cell or CD4 count taken?

1989	.1%
1993	.1%
1994	.1%
1995	.2%
1996	.2%
1997	1.6%
1998	97.9%

23. What was your last viral load?

Non detectable viral load	47.6%
Detectable viral load	52.4%

	Minimum	Maximum	Mean
RNA copies PCR	0	9700000	3411
DNA copies bDNA	0	408964	3980

When was your last viral load test taken?

1989	.1 %
1993	.1 %
1994	.1 %
1995	.1 %
1996	.1 %
1997	1.3 %
1998	98.3 %

24. When did you first find out you were HIV positive?

1980	.4 %
1981	.5 %
1982	.5 %
1983	1.2 %
1984	2.6 %
1985	6.2 %
1986	5.8 %
1987	6.4 %
1988	5.3 %
1989	6.6 %
1990	6.9 %
1991	8.2 %
1992	8.7 %
1993	7.2 %
1994	8.0 %
1995	8.2 %
1996	9.1 %
1997	6.1 %
1998	2.2 %

25. Have you ever been told that you have an AIDS diagnosis?

No	41.1%
Yes	58.9%

Yes → Date

1980	.4%
1983	.3%
1984	.5%
1985	1.0%
1986	1.0%
1987	1.3%
1988	1.4%
1989	2.6%
1990	4.1%
1991	3.8%
1992	6.3%
1993	9.5%
1994	13.2%
1995	18.8%
1996	18.9%
1997	11.0%
1998	5.8%

26. How many times have you been hospitalized for an AIDS-related illness?

	Minimum	Maximum	Mean
Number of hospitalizations	0	50	1

27. Before you were diagnosed with HIV/AIDS, were you regularly employed?

No	9.5%
Yes	90.5%

Yes → What did you do?

Types of regular employment	
Professional	
Not employed in this area	84.5%
Employed in this area	15.5%
Technical	
Not employed in this area	93.4%
Employed in this area	6.6%
Managerial	
Not employed in this area	82.5%
Employed in this area	17.5%
Clerical	
Not employed in this area	84.9%
Employed in this area	15.1%
Sales	
Not employed in this area	87.8%
Employed in this area	12.2%
Service Occupations	
Not employed in this area	84.2%
Employed in this area	15.8%
Skilled Trade	
Not employed in this area	86.4%
Employed in this area	13.6%
Student full-time	
Not employed in this area	95.9%
Employed in this area	4.1%
Other employment	
Not employed in this area	82.2%
Employed in this area	17.8%

28. Are you working regularly now?

No	65.3%
Yes	34.7%

If you are working now, are you working:

Full time	57.0%
Part time 20-30 hours	23.2%
Part time, less than 20 hours	12.2%
Temporary	7.5%

No → How long has it been since you last worked?

	Minimum	Maximum	Mean
Number of years since client last worked	.08	22.00	3.97

Did you stop working because of your HIV disease?

No	26.6%
Yes	73.4%

If you are not working now, are you:

Retired	6.2%
Disabled or unemployed, seeking work	26.4%
Disabled or unemployed, not seeking work	40.3%
Completely disabled	27.0%

29. Please tell us how much you agree or disagree with the following statements:

a. I am afraid I will lose my disability benefits (income) if I return to work.

agree	73.7%
neutral	14.5%
disagree	11.8%

b. I think my health will improve if I go to work.

agree	21.7%
neutral	27.7%
disagree	50.6%

c. I think I will be able to take my medication as prescribed in the workplace.

agree	48.1%
neutral	23.6%
disagree	28.3%

d. I believe I will be able to take time off from work to see my doctor if I go to work.

agree	31.5%
neutral	24.9%
disagree	43.6%

e. I am afraid I will lose my health insurance (including Medi-Cal) if I go to work.

agree	68.9%
neutral	13.4%
disagree	17.7%

f. I am concerned over changes in my health from day to day.

agree	79.3%
neutral	11.6%
disagree	9.1%

g. I am afraid my co-workers will find out I have HIV.

agree	49.8%
neutral	24.9%
disagree	25.3%

h. I think I will be able to keep up with the physical demands of work.

agree	29.0%
neutral	28.5%
disagree	42.5%

i. I am afraid my job skills are out of date.

agree	50.8%
neutral	20.6%
disagree	28.7%

30. Please give us your response to the following statements:

a. I am afraid I will be exposed to new diseases at work.

Yes	43.2%
No	47.8%
Not applicable	9.0%

b. I am worried about changes I would have to make in my daily routine if I work.

Yes	59.4%
No	35.3%
Not applicable	5.3%

c. I am afraid I will lose my housing assistance if I go to work.

Yes	30.5%
No	29.9%
Not applicable	39.7%

d. I will have the transportation I need if I go to work.

Yes	57.3%
No	33.2%
Not applicable	9.5%

e. I will have child-care available if I go to work.

Yes	3.9%
No	16.6%
Not applicable	79.5%

f. I am afraid I will not have the rest periods I might need while working.

Yes	73.1%
No	20.1%
Not applicable	6.7%

31. Please tell us how much you agree or disagree with these statements:

a. I am concerned that I might not be able to get adequate health insurance if I go to work.

agree	72.2%
neutral	14.5%
disagree	13.3%

b. I think I am healthy enough to work.

agree	35.0%
neutral	26.7%
disagree	38.3%

c. I think I am too disabled physically to work.

agree	30.0%
neutral	28.0%
disagree	42.0%

d. I am very interested in working.

agree	59.2%
neutral	26.1%
disagree	14.8%

e. I am afraid the stress of work will affect my health.

agree	69.8%
neutral	16.9%
disagree	13.3%

f. I am worried about AIDS/HIV-related discrimination in the workplace.

agree	66.0%
neutral	19.1%
disagree	14.9%

g. I feel I have enough education to get a job I would like.

agree	47.8%
neutral	17.2%
disagree	35.0%

h. I feel I have the job skills that are needed to go to work.

agree	46.4%
neutral	23.0%
disagree	30.6%

32. Are you thinking about going to work now or in the future?

No	26.5%
Yes	73.5%

33. How important are the following factors in your desire to go to work?

a. Increasing my income.	
not important	12.2%
neutral	3.3%
important	84.6%

b. Getting out of debt.	
not important	17.8%
neutral	12.0%
important	70.2%

c. Owning a business.	
not important	40.0%
neutral	29.5%
important	30.5%

d. Feeling useful and/or productive.	
not important	9.2%
neutral	4.3%
important	86.5%

e. Ability to contribute to society.	
not important	8.8%
neutral	9.6%
important	81.6%

f. Being around people.	
not important	13.6%
neutral	15.0%
important	71.4%

g. Being physically active.	
not important	10.8%
neutral	11.9%
important	77.3%

h. Increasing my free time.	
not important	23.8%
neutral	36.7%
important	39.5%

i. Feeling normal.	
not important	12.0%
neutral	10.4%
important	77.6%

j. Increasing my sense of accomplishment.	
not important	8.2%
neutral	5.7%
important	86.2%

k. Reducing the burden on my family.	
not important	27.5%
neutral	20.0%
important	52.5%

l. Contributing to the support of my family.	
not important	25.8%
neutral	19.4%
important	54.8%

m. Getting out of my home.	
not important	25.5%
neutral	20.4%
important	54.1%

34. When do you hope or plan to enter the work force? (Choose only one)

Now ASAP	25.1%
In 3-6 months	13.7%
In 7-12 months	7.4%
Next year	8.6%
Not sure	45.3%

35. Have you discussed with your doctor the possibility you might go to work?

No	46.2%
Yes	53.8%

Yes → Is he or she agreeable to the idea of you looking for work?

No	26.6%
Yes	73.4%

36. How many hours do you think you could work in a week?

1-10 hours	13.1%
11-20 hours	29.4%
21-40 hours	57.5%

37. Do you hope to find work that is:

temporary	27.0%
permanent	73.0%

38. Do you need services to help you find work?

No I don't need services	19.9%
Yes I need services	80.1%

Career counseling

Not an important service	55.6%
An important service	44.4%

Job training

Not an important service	40.5%
An important service	59.5%

Job placement

Not an important service	29.8%
An important service	70.2%

Job search skills

Not an important service	62.7%
An important service	37.3%

Benefits counseling

Not an important service	51.0%
An important service	49.0%

Additional education

Not an important service	60.3%
An important service	39.7%

Support groups

Not an important service	68.6%
An important service	31.4%

Skills training

Not an important service	40.1%
An important service	59.9%

39. What kind of work do you think you would be **most** interested in? (Choose only one)

Professional (for example, teacher, lawyer, registered nurse)	
Not interested in this area	81.7%
I am interested in this area	18.3%
Technical (for example, drafting, lab technician, optician, physical therapist)	
Not interested in this area	87.3%
I am interested in this area	12.7%
Managerial (for example, supervisor, project director, event coordinator)	
Not interested in this area	84.0%
I am interested in this area	16.0%
Clerical (for example, administrative assistant, word processor, receptionist)	
Not interested in this area	81.2%
I am interested in this area	18.8%
Sales (for example, retail, wholesale, marketing)	
Not interested in this area	90.3%
I am interested in this area	9.7%
Service Occupations (for example, gardener, waiter, delivery services)	
Not interested in this area	90.1%
I am interested in this area	9.9%
Skilled Trade (for example, chef, cashier, contractor)	
Not interested in this area	86.7%
I am interested in this area	13.3%
Student (go to school full-time)	
Not interested in this area	88.8%
I am interested in this area	11.2%

Other	
Not interested in this area	81.8%
I am interested in this area	18.2%

40. Are you planning to go back to the same kind of work you have done before?

No	55.7%
Yes	44.3%

Do you have any additional comments regarding your concerns or needs in finding work?

Did not write in comment	79.0%
Wrote in comment	21.0%

The following responses are only for individuals who reported they are currently employed.

41. Have you told your employer of your HIV status?

No	55.9%
Yes	44.1%

42. Do any of your co-workers know that you have HIV?

No	52.0%
Yes	48.0%

43. How much has work interfered with your ability to take your medications as prescribed?

Little or not at all	70.0%
At some level	30.0%

44. How much has work interfered with your ability to see your doctor?

Little or not at all	76.2%
At some level	23.8%

45. How well have you been able to keep up with the physical demands of your work?

Little or not at all	13.3%
At some level	86.7%

46. How much has your health interfered with your ability to work?

Little or not at all	65.4%
At some level	34.6%

47. How much do you think your working has negatively affected your health?

Little or not at all	69.2%
At some level	30.8%

48. How much AIDS/HIV-related discrimination have you experienced at work?

Little or not at all	89.5%
At some level	10.5%

49. Does your employer pay for your health insurance?

Insurance not paid by employer	63.0%
Insurance paid by employer	37.0%

50. Do you have private disability insurance?

Yes I have this insurance	17.0%
No I do not have this insurance	67.8%
Not sure if I have this insurance	15.1%

51. Have you talked with your doctor about your working situation? (Working with HIV)

No we have not discussed this	40.1%
Yes we have discussed this	59.9%

Appendix B

Employment Issues Survey

(Agency Name)

Employment Issues Survey

Your response to this survey will help in developing a profile of employment issues affecting persons living with HIV/AIDS. Your answers are anonymous and will only be used for information purposes. Please do not put your name on this survey. Thank you.

The following questions ask for some general information about yourself.

- | | Yes | No |
|--|--------------------------|--------------------------|
| 1. What is your ZIP Code? _____ Do you live in the City of Los Angeles? | ☐ | ☐ |
| 2. What is your age? _____ | | |
| 3. What is your gender? | | |
| ☐ Male | | |
| ☐ Female | | |
| ☐ Transgender | | |
| 4. Which best describes your racial/ethnic background? (Choose only one) | | |
| ☐ White/Caucasian | | |
| ☐ African-American/ Black | | |
| ☐ Latino/Hispanic | | |
| ☐ Asian/Pacific Islander | | |
| ☐ Native American/Alaskan | | |
| ☐ Other (specify): _____ | | |
| 5. Which best describes your sexual orientation? (Choose only one) | | |
| ☐ Heterosexual (straight) | | |
| ☐ Homosexual (gay or lesbian) | | |
| ☐ Bisexual | | |
| 6. What is the last grade of school you completed? (Choose only one) | | |
| ☐ 11 th grade or less | | |
| ☐ High school graduate | | |
| ☐ GED (High school equivalency) | | |
| ☐ 1-3 years of college | | |
| ☐ College graduate | | |
| ☐ Graduate school or degree | | |
| ☐ Other: _____ | | |

7. What is your marital (partner) status?
- ☐ Single
 - ☐ Married/partnered/significant other
 - ☐ Divorced/separated
 - ☐ Widowed
 - ☐ Other: _____
8. What is your current source of income? (Check all that apply)
- ☐ Employment
 - ☐ Unemployment compensation
 - ☐ Supplemental Security Income (SSI)
 - ☐ Social Security Disability Insurance (SSDI)
 - ☐ Social Security (SSA-based on retirement, not disability)
 - ☐ State Disability Insurance (SDI)
 - ☐ TANF (formerly AFDC)
 - ☐ General Relief (GR)
 - ☐ Private disability insurance
 - ☐ Family assistance
 - ☐ Spouse/significant other assistance
 - ☐ Alimony/child support
 - ☐ Other (specify): _____
9. What is your current annual income-- before taxes? (Choose only one)
- ☐ Under \$7,740
 - ☐ \$7,741 to \$10,000
 - ☐ \$10,001 to \$15,000
 - ☐ \$15,001 to \$20,000
 - ☐ \$20,001 to \$25,000
 - ☐ \$25,001 to \$30,000
 - ☐ \$30,001 or above
10. What type of health insurance do you currently have? (Check all that apply)
- ☐ Health Maintenance Organization (HMO) such as Kaiser, CIGNA
 - ☐ Private policy preferred provider organization
 - ☐ Medi-Cal
 - ☐ Medi-Care
 - ☐ Medi-Cal/Medi-Care
 - ☐ Veteran's Administration (VA)
 - ☐ No Insurance
 - ☐ Other: _____

The following questions are about your health and physical activity.

11. In general, would you say your health is:

- (1) Excellent
- (2) Very good
- (3) Good
- (4) Fair
- (5) Poor

12. Compared to one year ago, how would you rate your health in general now?

- (1) Much better than 1 year ago
- (2) Somewhat better than 1 year ago
- (3) About the same as 1 year ago
- (4) Somewhat worse than 1 year ago
- (5) Much worse than 1 year ago

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. <i>Vigorous activities</i> , such as running, lifting heavy objects, participating in strenuous sports.	(1)	(2)	(3)
b. <i>Moderate activities</i> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	(1)	(2)	(3)
c. Climbing <i>several</i> flights of stairs.	(1)	(2)	(3)
d. Bending, kneeling, or stooping.	(1)	(2)	(3)
e. Walking <i>one block</i> .	(1)	(2)	(3)
f. Bathing or dressing yourself.	(1)	(2)	(3)

14. During the *past 4 weeks*, have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?

	Yes	No
a. <i>Accomplished less</i> than you would like.	☐	☐
b. Were limited in the <i>kind</i> of work or other activities.	☐	☐

15. During the *past 4 weeks*, have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?

	Yes	No
a. <i>Accomplished less</i> than you would like.	☐	☐
b. Didn't do work or other activities as <i>carefully</i> as usual.	☐	☐

16. During the *past 4 weeks*, how much did *pain* interfere with your normal work (including both work outside the home and housework)?

- (1) Not at all
- (2) Slightly
- (3) Moderately
- (4) Quite a bit
- (5) Extremely

17. These questions are about how you feel and how things have been with you *during the past 4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the *past 4 weeks* ...

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Have you been a very nervous person?	(1)	(2)	(3)	(4)	(5)	(6)
b. Have you felt so down in the dumps that nothing could cheer you up?	(1)	(2)	(3)	(4)	(5)	(6)
c. Have you felt calm and peaceful?	(1)	(2)	(3)	(4)	(5)	(6)
d. Did you have a lot of energy?	(1)	(2)	(3)	(4)	(5)	(6)
e. Have you felt downhearted and blue?	(1)	(2)	(3)	(4)	(5)	(6)
f. Have you been a happy person?	(1)	(2)	(3)	(4)	(5)	(6)
g. Did you feel tired?	(1)	(2)	(3)	(4)	(5)	(6)

18. During the *past 4 weeks*, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

- (1) All of the time
- (2) Most of the time
- (3) Some of the time
- (4) A little of the time
- (5) None of the time

19. How *true* or *false* is *each* of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.	(1)	(2)	(3)	(4)	(5)
b. I am as healthy as anybody I know.	(1)	(2)	(3)	(4)	(5)
c. I expect my health to get worse.	(1)	(2)	(3)	(4)	(5)
d. My health is excellent.	(1)	(2)	(3)	(4)	(5)

20. Here is a list of medications. Please read through the list and place a check in the box next to those you are taking. Please do not check medications you are not really taking.

HIV Medications:

- ☐ Abacavir
- ☐ AZT (Zidovudine, Retrovir[®])
- ☐ Combivir
- ☐ Rescriptor[®] (Delavirdine)
- ☐ ddl, Videx[®] (Didanosine)
- ☐ Sustiva[®], DMP266 (Efavirenz)
- ☐ 3TC, Epivir[®] (Lamivudine)
- ☐ Viramune[®] (Nevirapine)
- ☐ d4T, Zerit[®] (Stavudine)
- ☐ ddC, Hivid[®] (Zalcitabine)
- ☐ Other: _____

HIV Protease Inhibitors:

- ☐ Crixivan[®] (Indinavir)
- ☐ Viracept[®] (Nelfinavir)
- ☐ Norvir[®] (Ritonavir)
- ☐ Invirase[®], Fortovase[®] (Saquinavir)

PCP prophylactic medications:

- ☐ Aerosolized Pentamidine (Nebu Pent[®])
- ☐ Clindamycin (Cleocin[®])
- ☐ Dapsone
- ☐ TMP/SMX (Bactrim[®], Septra[®])
- ☐ Other: _____

MAC prophylactic medications:

- ☐ Clarithromycin (Biaxin[®])
- ☐ Rifabutin (Mycobutin[®])
- ☐ Other: _____

Other Medications for HIV/AIDS:

- ☐ Acyclovir (Zovirax[®])
- ☐ Azithromycin (Zithromax[®])
- ☐ Clotrimazole troches (Mycelex[®])
- ☐ Ethambutol (Myambutol[®])
- ☐ Fluconazole (Diflucan[®])
- ☐ Foscarnet (Foscavir[®])
- ☐ Ganciclovir (Cytovene[®])
- ☐ Hydroxyurea (Hydrea[®])
- ☐ Isoniazid (INH)
- ☐ Itraconazole (Sporanox[®])
- ☐ Leucovorin (Wellcovorin[®])
- ☐ Pyrazinamide (PZA)
- ☐ Pyrimethamine (Daraprim[®])
- ☐ Rifampin (Rifadin[®], Rifamate[®])
- ☐ Sulfadiazine
- ☐ Other: _____
- ☐ Other: _____

21. What is your current HIV status?

- ☐ HIV Positive, no symptoms
- ☐ HIV Positive, with symptoms or infections
- ☐ Confirmed AIDS diagnosis

22. What was your **last T-cell** or CD4 count?

_____ μL^3

When was your last T-cell or CD4 count taken?

_____|_____
Month Year

23. What was your **last viral load**?

_____ RNA copies/ PCR

_____ DNA copies/ bDNA

When was your last viral load test taken?

_____|_____
Month Year

24. When did you first find out you were HIV positive?

_____|_____
Month Year

25. Have you ever been told that you have an AIDS diagnosis?

- ☐ Yes → Date _____
Month Year
- ☐ No

26. How many times have you been hospitalized for an AIDS-related illness?

_____ Times

27. Before you were diagnosed with HIV/AIDS, were you regularly employed?

- ☐ Yes → What did you do?
 - ☐ **Professional** (for example, teacher, lawyer, registered nurse)
 - ☐ **Technical** (for example, drafting, lab technician, optician, physical therapist)
 - ☐ **Managerial** (for example, supervisor, project director, event coordinator)
 - ☐ **Clerical** (for example, administrative assistant, word processor, receptionist)
 - ☐ **Sales** (for example, retail, wholesale, marketing)
 - ☐ **Service Occupations** (for example, gardener, waiter, delivery services)
 - ☐ **Skilled Trade** (for example, chef, cashier, contractor)
 - ☐ **Student** (go to school full-time)
 - ☐ **Other:** _____
- ☐ No

The following questions are about your current employment status.

28. Are you working regularly now?

☐ Yes → If you are working now, are you working:

☐ Full time → *Please go to Question 41*

☐ Part time, 20 - 32 hours per week → *Please go to Question 41*

☐ Part time less than 20 hours per week → *Please go to Question 41*

☐ Temporary (for example, odd jobs) → *Please go to Question 29*

☐ No → How long has it been since you last worked?

Months

Years

Did you stop working because of your HIV disease?

☐ Yes

☐ No

If you are not working now, are you: (choose only one)

☐ Retired → Please stop at this question and return the survey in the enclosed pre-addressed, stamped envelope. Thank you.

☐ Disabled or unemployed and looking for a job → *Please go to Question 29*

☐ Disabled or unemployed and not looking for a job → *Please go to Question 29*

☐ Completely disabled (not able to work) → Please stop at this question and return the survey in the enclosed pre-addressed, stamped envelope. Thank you.

29. Please tell us how much you agree or disagree with the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable
a. I am afraid I will lose my disability benefits (income) if I return to work.	(1)	(2)	(3)	(4)	(5)	(N/A)
b. I think my health will improve if I go to work.	(1)	(2)	(3)	(4)	(5)	(N/A)
c. I think I will be able to take my medication as prescribed in the workplace.	(1)	(2)	(3)	(4)	(5)	(N/A)
d. I believe I will be able to take time off from work to see my doctor if I go to work.	(1)	(2)	(3)	(4)	(5)	(N/A)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable
e. I am afraid I will lose my health insurance (including Medi-Cal) if I go to work.	(1)	(2)	(3)	(4)	(5)	(N/A)
f. I am concerned over changes in my health from day to day.	(1)	(2)	(3)	(4)	(5)	(N/A)
g. I am afraid my co-workers will find out I have HIV.	(1)	(2)	(3)	(4)	(5)	(N/A)
h. I think I will be able to keep up with the physical demands of work.	(1)	(2)	(3)	(4)	(5)	(N/A)
i. I am afraid my job skills are out of date.	(1)	(2)	(3)	(4)	(5)	(N/A)

30. Please give us your response to the following statements:

- a. I am afraid I will be exposed to new diseases at work. ☐Yes ☐No ☐Not Applicable
- b. I am worried about changes I would have to make in my daily routine if I work. ☐Yes ☐No ☐Not Applicable
- c. I am afraid I will lose my housing assistance if I go to work. ☐Yes ☐No ☐Not Applicable
- d. I will have the transportation I need if I go to work. ☐Yes ☐No ☐Not Applicable
- e. I will have child-care available if I go to work. ☐Yes ☐No ☐Not Applicable
- f. I am afraid I will not have the rest periods I might need while working. ☐Yes ☐No ☐Not Applicable

31. Please tell us how much you agree or disagree with these statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable
a. I am concerned that I might not be able to get adequate health insurance if I go to work.	(1)	(2)	(3)	(4)	(5)	(N/A)
b. I think I am healthy enough to work.	(1)	(2)	(3)	(4)	(5)	(N/A)
c. I think I am too disabled physically to work.	(1)	(2)	(3)	(4)	(5)	(N/A)
d. I am very interested in working.	(1)	(2)	(3)	(4)	(5)	(N/A)
e. I am afraid the stress of work will affect my health.	(1)	(2)	(3)	(4)	(5)	(N/A)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable
f. I am worried about AIDS/HIV-related discrimination in the workplace.	(1)	(2)	(3)	(4)	(5)	(N/A)
g. I feel I have enough education to get a job I would like.	(1)	(2)	(3)	(4)	(5)	(N/A)
h. I feel I have the job skills that are needed to go to work.	(1)	(2)	(3)	(4)	(5)	(N/A)

32. Are you thinking about going to work now or in the future?

- ☐ Yes → Please go to question 33
- ☐ No → Please stop at this question and return the survey in the enclosed pre-addressed, stamped envelope. Thank you for taking the time to answer these questions.

33. How important are the following factors in your desire to go to work?

	Not at all Important	Somewhat Important	Neutral	Important	Extremely Important
a. Increasing my income.	(1)	(2)	(3)	(4)	(5)
b. Getting out of debt.	(1)	(2)	(3)	(4)	(5)
c. Owning a business.	(1)	(2)	(3)	(4)	(5)
d. Feeling useful and/or productive.	(1)	(2)	(3)	(4)	(5)
e. Ability to contribute to society.	(1)	(2)	(3)	(4)	(5)
f. Being around people.	(1)	(2)	(3)	(4)	(5)
g. Being physically active.	(1)	(2)	(3)	(4)	(5)
h. Increasing my free time.	(1)	(2)	(3)	(4)	(5)
i. Feeling normal.	(1)	(2)	(3)	(4)	(5)
j. Increasing my sense of accomplishment.	(1)	(2)	(3)	(4)	(5)
k. Reducing the burden on my family.	(1)	(2)	(3)	(4)	(5)
l. Contributing to the support of my family.	(1)	(2)	(3)	(4)	(5)
m. Getting out of my home.	(1)	(2)	(3)	(4)	(5)

34. When do you hope or plan to enter the work force? (Choose only one)
- ☐ Now (as soon as possible)
 - ☐ In 3 to 6 months
 - ☐ In 7 to 12 months
 - ☐ Next year
 - ☐ Not sure
35. Have you discussed with your doctor the possibility you might go to work?
- ☐ Yes → Is he or she agreeable to the idea of you looking for work?
 - ☐ Yes
 - ☐ No → Why not? _____
 - ☐ No
36. How many hours do you think you could work in a week?
- ☐ 1-10 hours
 - ☐ 11-20 hours
 - ☐ 21-30 hours
 - ☐ 31- 40 hours
37. Do you hope to find work that is:
- ☐ Temporary
 - ☐ Permanent
38. Do you need services to help you find work?
- ☐ Yes
 - ☐ No
- If Yes → Please select the **five** most important services that would help you find work.
- _____ **Career counseling** (Counseling to help you choose a job)
 - _____ **Job training** (Training for a specific job: for example, lab technician, paralegal, floral design)
 - _____ **Job placement** (Helping you find a job)
 - _____ **Job search skills** (for example, resume preparation, interviewing skills)
 - _____ **Benefits counseling** (for example, understanding changes to your benefits if you go to work)
 - _____ **Additional education** (for example, high school equivalency, additional college-level courses, English as a second language)
 - _____ **Support groups** (for example, groups for people with HIV looking for work)
 - _____ **Skills training** (for example, computer-skills, accounting, administration)

39. What kind of work do you think you would be **most** interested in?

(Choose only one)

- ☐ **Professional** (for example, teacher, lawyer, registered nurse)
- ☐ **Technical** (for example, drafting, lab technician, optician, physical therapist)
- ☐ **Managerial** (for example, supervisor, project director, event coordinator)
- ☐ **Clerical** (for example, administrative assistant, word processor, receptionist)
- ☐ **Sales** (for example, retail, wholesale, marketing)
- ☐ **Service Occupations** (for example, gardener, waiter, delivery services)
- ☐ **Skilled Trade** (for example, chef, cashier, contractor)
- ☐ **Student** (go to school full-time)
- ☐ **Other:** _____

40. Are you planning to go back to the same kind of work you have done before?

- ☐ Yes
- ☐ No

Do you have any additional comments regarding your concerns or needs in finding work?

Question 41 begins on back page

Answer the following questions only if you are working right now.

41. Have you told your employer of your HIV status?

- ☐ Yes
☐ No

42. Do any of your co-workers know that you have HIV?

- ☐ Yes
☐ No

Please give us your response to the following questions:

- | | Not at All | A Little | Some | A lot | A Great Deal |
|--|------------|----------|------|-------|--------------|
| 43. How much has work interfered with your ability to take your medications as prescribed? | (1) | (2) | (3) | (4) | (5) |
| 44. How much has work interfered with your ability to see your doctor? | (1) | (2) | (3) | (4) | (5) |
| 45. How well have you been able to keep up with the physical demands of your work? | (1) | (2) | (3) | (4) | (5) |
| 46. How much has your health interfered with your ability to work? | (1) | (2) | (3) | (4) | (5) |
| 47. How much do you think your working has negatively affected your health? | (1) | (2) | (3) | (4) | (5) |
| 48. How much AIDS/HIV-related discrimination have you experienced at work? | (1) | (2) | (3) | (4) | (5) |
| 49. Does your employer pay for your health insurance? | | | | | |
| ☐ Yes | | | | | |
| ☐ No | | | | | |
| 50. Do you have private disability insurance? | | | | | |
| ☐ Yes | | | | | |
| ☐ No | | | | | |
| ☐ Not Sure | | | | | |
| 51. Have you talked with your doctor about your working situation? (Working with HIV) | | | | | |
| ☐ Yes | | | | | |
| ☐ No | | | | | |

THANK YOU FOR YOUR PARTICIPATION!

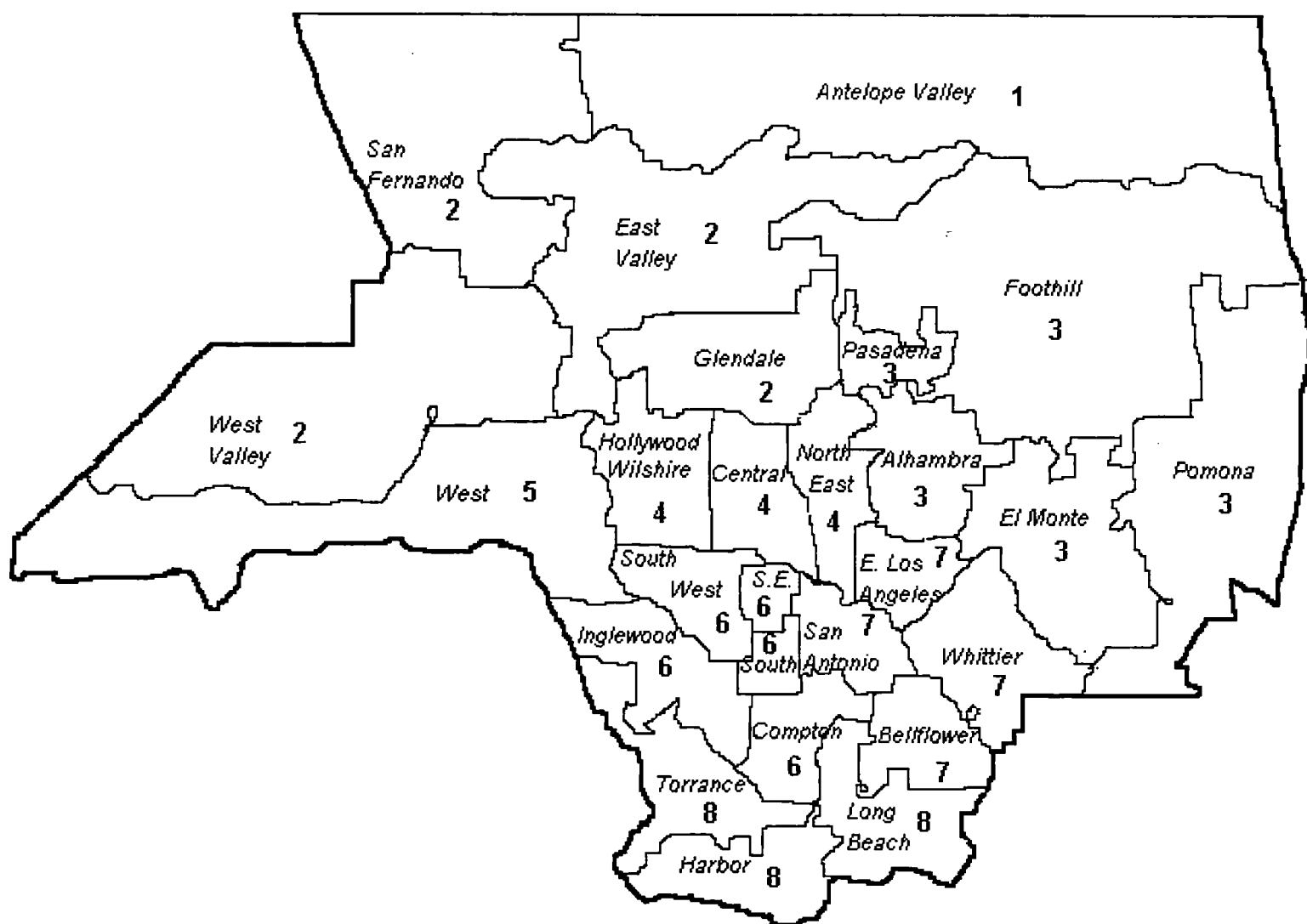
Please return the survey in the envelope provided

Appendix C

Participating AIDS Service Organizations by HIV Planning Regions

Los Angeles County Employment Issues Survey Mail-Out Schedule

Selected AIDS Service Organizations	HIV Planning Region	Total Clients Mailed Surveys	Total English Surveys Mailed	Date Mailed	Total Spanish Surveys Mailed	Date Mailed	Total Survey Undeliverable	Total Surveys Ineligible	Total Surveys Eligible	Total Response Rate
Catalyst Foundation	One	68	66	8/28	2	8/28	0	0	22	32%
Northeast Valley Health Corporation	Two	202	151	8/6	51	8/6	6	0	51	26%
Tarzana Treatment Center	Two	46	46	8/25	N/A	N/A	0	0	19	41%
AIDS Service Center	Three	777	704	7/9	73	7/ 14	46	5	303	42%
AIDS Project Los Angeles	Four	2406	2061	6/24	345	7/ 1	45	6	927	39%
Asian Pacific AIDS Intervention Team	Four	34	34	7/24	N/A	N/A	0	0	13	38%
Santa Monica AIDS Project	Five	54	52	8/17	2	8/17	0	2	47	87%
Minority AIDS Project	Six	391	342	8/14	49	8/14	59	3	89	27%
Prototypes Women's Link	Six	89	75	8/28	14	8/28	1	0	22	25%
Saint Mary Medical Center - CARE	Eight	592	542	8/25	50	8/25	57	2	205	38%
AIDS Project Long Beach	Eight	206	195	7/31	11	7/ 31	22	0	85	46%
South Bay Free Clinic	Eight	88	75	7/ 27	13	7/ 27	0	0	50	57%
Bienestar Latino AIDS Project Van Nuys Hollywood Long Beach East Los Angeles	Two Four Eight Seven	700	130	8/3	570	8/3	36	3	158	24%
TOTAL		5653	4473		1180		272	21	1991	37%



HIV Planning Regions, Los Angeles County

Region 1

Antelope Valley

Region 2

San Fernando
East Valley
West Valley
Glendale

Region 3

Alhambra
El Monte
Foothill
Pasadena
Pomona

Region 4

Hollywood/Wilshire
Central
North East

Region 5

West

Region 6

Southwest
Southeast
South
Compton
Inglewood

Region 7

East LA
San Antonio
Whittier
Bellflower

Region 8

Torrance
Harbor
Long Beach



Lambda Legal Defense and Education Fund, Inc.

NEWS RELEASE

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FOR IMMEDIATE RELEASE

Monday, May 24, 1999

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Workers Do Not Forfeit ADA Protections by Seeking Disability Benefits

U.S. Supreme Court ruling is great news for people with HIV and AIDS

(NEW YORK, May 24, 1999) — The United States Supreme Court, in the first of several decisions this term affecting people with HIV and AIDS, ruled unanimously Monday that workers with disabilities do not automatically lose employment discrimination protections if they apply for Social Security disability benefits.

Lambda Legal Defense and Education Fund said the decision is great news for people with HIV or other disabilities who may need protection through the Americans with Disabilities Act (ADA) as well as support from the Social Security Disability Insurance (SSDI).

Lambda, which had filed a friend-of-the-court brief on behalf of 48 major medical, public health, disability and civil rights organizations, praised the 9-0 ruling in *Cleveland v. Policy Management Systems* for respecting the needs of people with disabilities.

"This ruling spares people with disabilities from having to make the impossible choice between food and work," said AIDS Project Director Catherine A. Hanssens, author of Lambda's *amicus* brief.

The decision vacates and remands an August, 1997, ruling by the Fifth Circuit Court of Appeals that dismissed Texas resident Carolyn C. Cleveland's wrongful termination lawsuit under the ADA solely because she had applied for Social Security benefits after she had been fired.

The Court said that the Fifth Circuit erred when it interpreted the request for disability benefits as an admission by Cleveland that she was unable to work because of her disability and hence beyond the scope of the ADA. The justices rejected the application in ADA cases of *judicial estoppel*, the legal doctrine that prevents parties to a lawsuit from making contradictory claims in separate court proceedings.

In a 12-page decision that drew significantly on Lambda's brief, Justice Stephen Breyer wrote, "The Social Security Act and the ADA both help individuals with disabilities, but in different ways." He continued, "In our view...the two claims do not inherently conflict to the point where courts should apply a special negative presumption.... That is because there are too many situations in which an SSDI claim and an ADA claim can comfortably exist side by side."

Justice Breyer noted that in all other types of cases, plaintiffs are given an opportunity to explain statements that may appear in conflict, but are not.

"We do not see why the law in respect to the assertion of SSDI and ADA claims should differ," he said.

Lambda's brief highlighted the complementary goals of the ADA and Social Security benefits which encourage the employment of people with disabilities. The ADA protects them while on the job, requiring reasonable accommodations to help them keep working. Social Security provides some income for those who are unable to work because of their disabling conditions.

— more —

Lambda Legal Defense and Education Fund is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men and people with HIV/AIDS through impact litigation, education and public policy work. Headquartered in New York, and with offices in Los Angeles, Chicago, and Atlanta, Lambda has regional and national expertise in all aspects of sexual orientation and HIV-related law and policy.

Supreme Court Rules on SSDI and ADA
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Cleveland suffered a stroke in 1994 that left her with residual medical problems and a speech impediment. Managers at her Dallas employer, Policy Management Systems, mocked her disability, refused to consider her request for reasonable workplace accommodations as required by the ADA, then fired her. The company insisted that she forfeited her right to ADA protections when she filed for Social Security disability benefits. Monday's ruling grants Cleveland the opportunity to bring her dismissed claims to court.

"People with disabilities, including those with HIV, increasingly rely on both the ADA and Social Security. This decision ensures that the courthouse door will not be closed to them when they suffer discrimination," said Legal Director Beatrice Dohrn.

During a term in which the federal disabilities rights law has faced the greatest scrutiny yet from the High Court, rulings are expected in three other ADA cases in which Lambda played active roles. Hanssens also co-authored an *amicus* brief in *Kirkingburg v. Albertsons*, a case involving a Portland, Oregon truck driver with monocular vision.

Additionally, Lambda participated in *amicus* briefs in *Sutton v. United Airlines*, a case involving twin Colorado sisters denied jobs because of their extremely poor vision, and *Murphy v. United Parcel Service*, brought by a delivery driver fired for having high blood pressure.

All three cases test whether the ADA also protects people whose disabilities can be controlled, corrected, or otherwise mitigated. Noting that the ADA provides some of the strongest workplace protections for people with HIV, Lambda participated in all three cases to ensure that those protections are not eroded.

Lambda is the nation's oldest and largest legal organization for lesbians, gay men, and people with HIV/AIDS.

(Cleveland v. Policy Management Systems, No. 97-1008)

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