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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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January 1999

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.

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Acknowledgments

We would like to acknowledge the contribution of the following people to the successful completion of the Employment Issues Survey: Ferd Eggan, City of Los Angeles AIDS Coordinator; Charles Henry and Gunther Freehill, Los Angeles County Department of Health Services, Office of AIDS Programs and Policy; Staff of AIDS Project Los Angeles: Dr. Lee Klosinski, Director of Education, Craig Thompson, Executive Director; Volunteers of AIDS Project Los Angeles; Dr. Marty McCombs and Dr. Bill Tanner, AIDS Project Long Beach; Sue Scott and John Roscoe, AIDS Service Center; Dean Goishi and Terena Poohtey, Asian Pacific AIDS Intervention Team; Oscar DeLaO and Noe Zuniga, Bienestar; Dr. Susan Lawrence and Ken Siewert, Catalyst Foundation; Barbara Draden, Minority AIDS Project; Dr. Mark Henrickson and Nick Rogga, Northeast Valley Health Corporation; Jennifer Andrews and Estella Garcia, Saint Mary Medical Center - CARE program; Hywel Sims and Selena Inouye, Santa Monica AIDS Project; Stewart Sokol and Norma Padilla, South Bay Free Clinic; Mario Perez and Daniel Gould, Tarzana Treatment Center; Valerie Lathern and Alberta Haines, Prototypes/Women's Link. We would also like to acknowledge the Harbor-UCLA Medical Center's Department of Health and Human Services HRSA Grant BRH970176, Special Projects of National Significance, for its contribution in covering a portion of the photocopying cost associated with the survey.

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 500 (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 Egan, 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 500 (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.

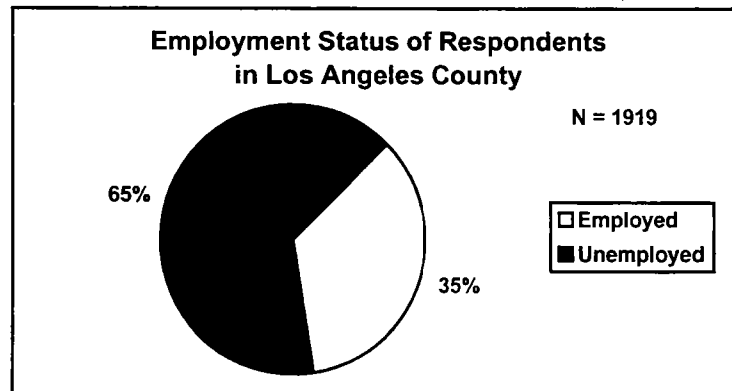
Health profile of survey respondents

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 500 (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.

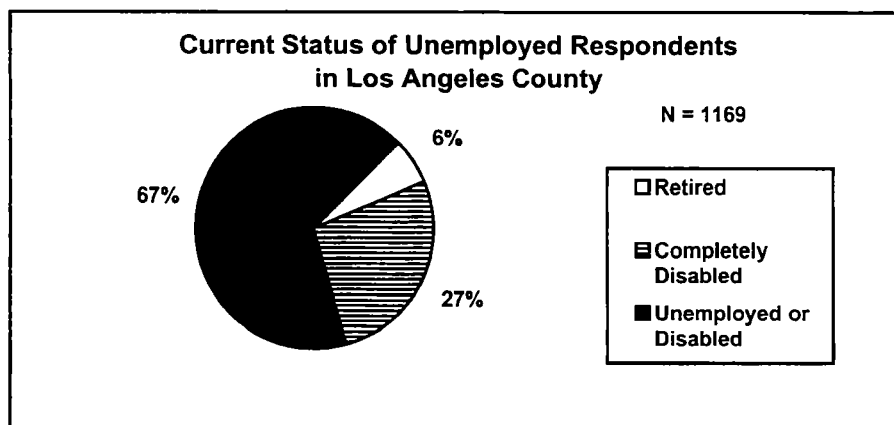
Figure 1



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

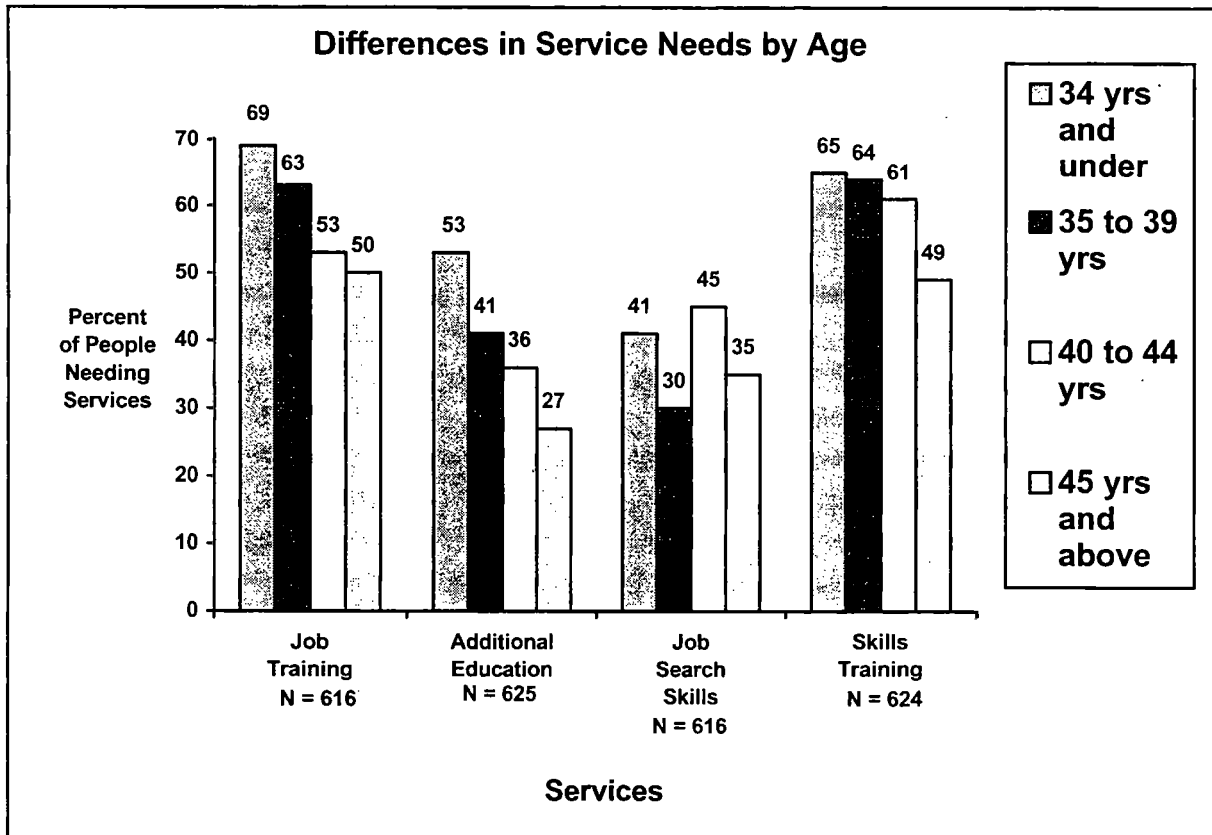


Figure 4

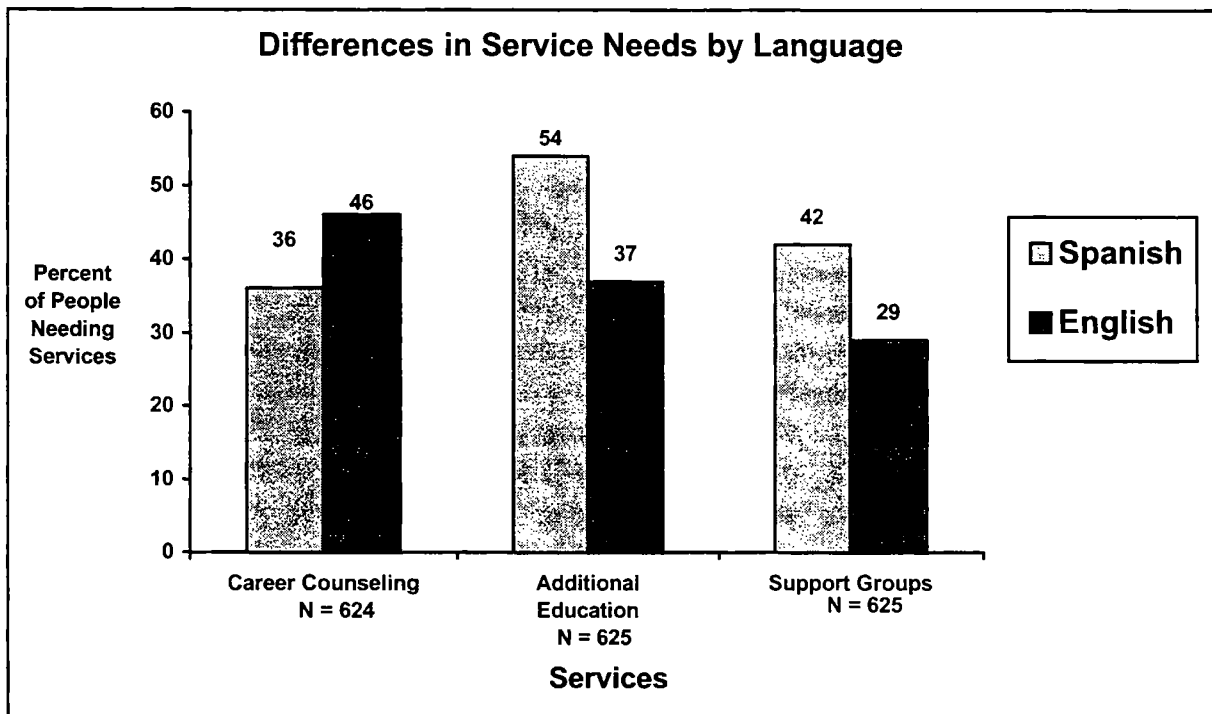
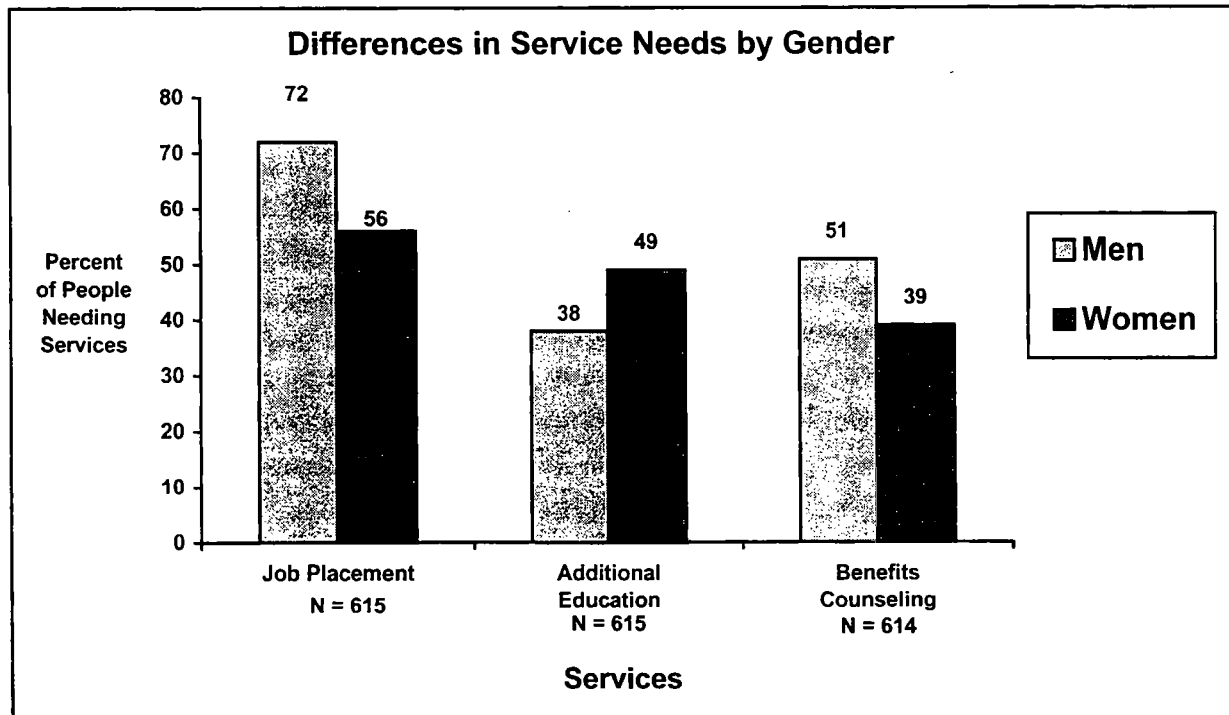


Figure 5



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.

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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%
ddI, 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 [®] (Ritanovir)	
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!

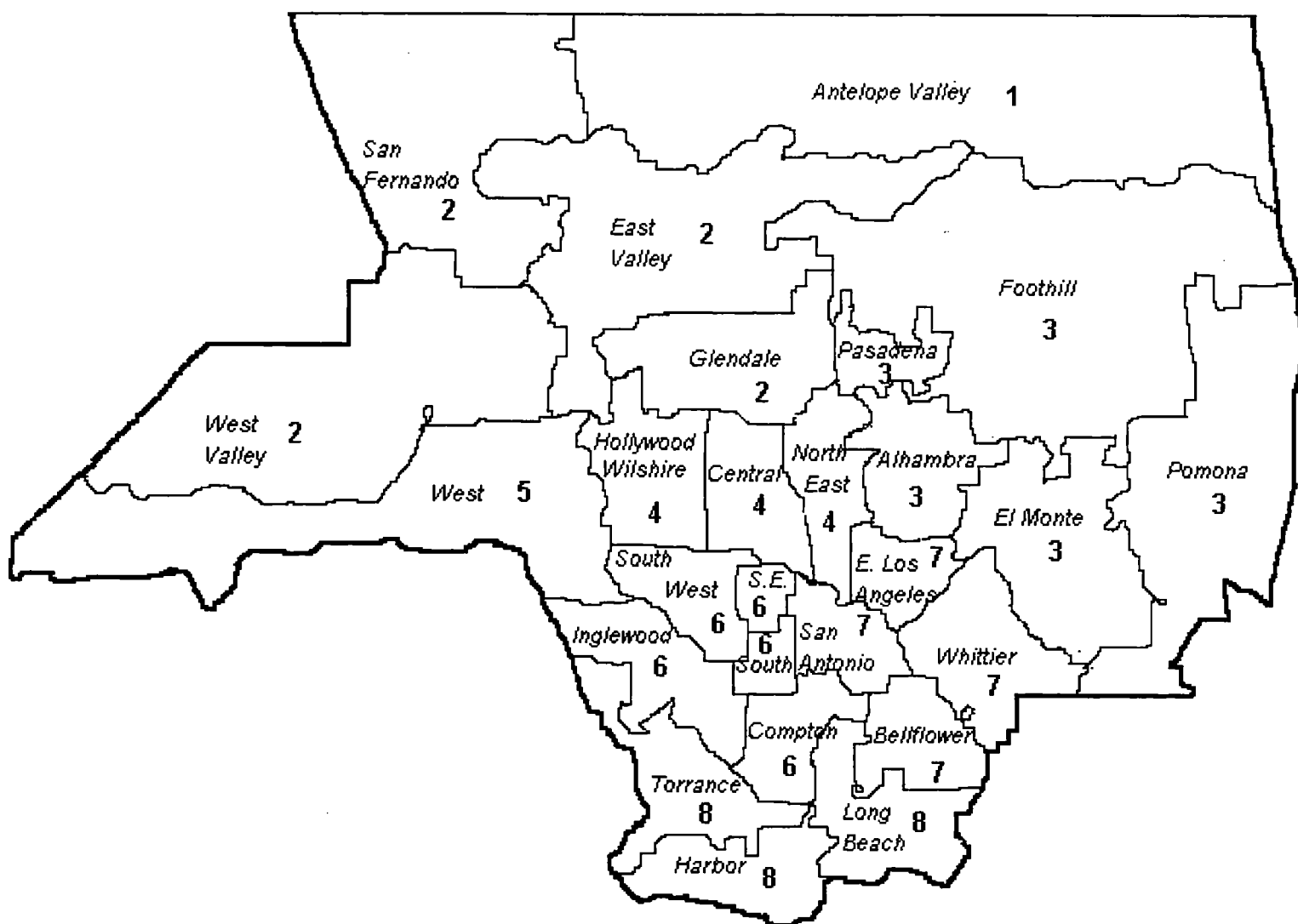
Please return the survey in the envelope provided

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

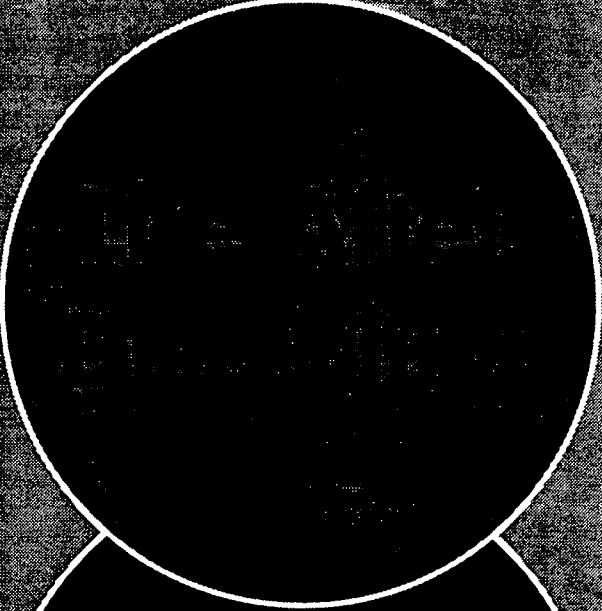
Southwest
Southeast
South
Compton
Inglewood

Region 7

East LA
San Antonio
Whittier
Bellflower

Region 8

Torrance
Harbor
Long Beach



Returning To Work

GMHC

GAY MEN'S HEALTH CRISIS

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I N T R O D U C T I O N

As new treatments offer newfound health and a new sense of hope that AIDS will become a chronic but manageable disease, many people with HIV who have been on disability leave are considering returning to work. If you are one of the many people contemplating a return to work, you know that there are a lot of uncertainties affecting your decision. This brochure will attempt to answer some of the legal, financial and practical questions that may be arising for you as you consider whether and how to reenter the workforce.

Although this brochure is designed to be used by people from every state, please be aware that states and local municipalities can differ with regard to matters involving government entitlements and private insurance benefits. GMHC serves residents of New York City. If you live outside of New York, are currently receiving any kind of disability benefit and are considering a return to work, it is a good idea to contact your local HIV/AIDS organization to find out how your specific benefits will be affected.

Similarly, this brochure relies on laws valid as of the Fall of 1997. Laws and regulations do change, and it is important to seek advice from your local HIV/AIDS organization to find out the current state of affairs with regard to insurance, government entitlements, and employment rights.

GOVERNMENT ENTITLEMENTS: SSDI, SSI, AND MEDICARE

Government entitlements are benefits provided by federal, state and/or local governments to assist people in need. Some entitlements, such as food stamps, public assistance, ADAP (the AIDS Drug Assistance Program) and Medicaid, are "means-based" benefits, provided to people below a certain income and asset level. GMHC's Client Advocacy Department provides Fact Sheets on most means-based and other government entitlements. These Fact Sheets can answer most of your questions about eligibility for, and applying for, these benefits; these Facts Sheets also address the effect of working on eligibility for these entitlements.

This brochure will focus specifically on the effect of returning to work on the following government entitlements: Social Security Disability Insurance ("SSDI"), Supplemental Security Income ("SSI"), and Medicare.

What is the difference between SSI and SSDI?

Both benefits are provided to people defined as disabled by the Social Security Administration ("SSA"). SSI is a means-based entitlement, provided to people of limited means who do not have a substantial work history. SSDI is provided to people who have worked and paid FICA taxes for a certain amount of quarters over a certain number of years.

If I return to work, will I lose my SSI benefits?

Since SSI is a means-based entitlement, if you return to work, the SSA will look at your SSI budget. If you receive SSI, you are entitled to gross (pre-tax) earnings of \$85 per month (the "disregard") before your benefits are affected;

if you receive a combination of SSI and SSDI, the monthly disregard would be \$65. Once you earn in excess of the disregard, your SSI check will be reduced by one dollar for every two dollars of gross income earned in excess of the disregard.

If I return to work, is it possible that I would lose all of my SSI benefits?

SSI recognizes a "break-even point" where if your gross earnings exceed a certain amount, you will stop receiving SSI. Because some people's earnings are not consistent from one month to the next, it is possible that in some months, you will reach the break-even point, but in other months, you would not. If you incur twelve consecutive break-even point months, you will have to file a new application for SSI before you are entitled to any additional SSI benefits.

What about SSDI? If I return to work, am I still eligible?

SSDI has a trial work period ("TWP") which allows a person to work for up to 9 months in any 60 month period and still collect SSDI benefits. The nine months do not have to be consecutive. During the TWP, you can earn any amount of money you are able to earn and still collect the full amount of SSDI. Any month in which you earn over \$200 in gross monthly earnings will be counted towards the trial work period.

What happens when the trial work period ends?

At the end of the TWP, if you continue to work, the SSA will continue to pay benefits for three more months in which your earnings exceed \$200. This is known as the "grace period." If you continue working beyond the

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grace period, SSDI benefits will stop during

months in which your gross monthly earnings exceed \$500.

If I work for over a year, but become disabled again, do I have to reapply for SSDI?

Following the TWP, the SSA recognizes an extended period of eligibility ("EPE") for 36 months. During the EPE, if you gross at least \$500 per month, you are considered to be performing substantial gainful activity ("SGA"), and will not receive SSDI benefits during this time. However, if you either become disabled again and stop working *or* if your earnings fall below \$500 per month during the EPE, you do not have to reapply for SSDI or go through a waiting period before benefits begin. Obtain a letter from your employer stating the date you stopped working or the date your monthly gross earnings fell below \$500, and submit that letter to the SSA. Your SSDI benefits should resume shortly thereafter.

I've heard people talk about a continuing disability review. What is that?

The SSA conducts continuing disability reviews ("CDRs") to determine if a recipient of SSI or SSDI is still medically disabled and eligible for these benefits.

To be eligible for SSDI, you (and your doctor) represent to the SSA that you will be unable to work for at least 12 months. Therefore, if you return to work within the first twelve months after the SSA has determined that you are disabled, it is very likely that the SSA will perform a CDR. If the SSA determines that you are not disabled, it is possible that the SSA will try to charge you for overpayments.

If you return to work *after* you have been receiving SSI or SSDI for at least a year, and you are performing substantial gainful activity

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(your monthly gross earnings exceed \$500) following the TWP, the SSA will probably conduct a CDR. If, as a result of a CDR, the SSA determines that you are no longer disabled, benefits will stop.

I've been receiving Social Security benefits for a long time, and have already become Medicare eligible. What will happen to my Medicare if I return to work?

During the TWP, while you are still receiving your SSDI checks, you will still be Medicare eligible and your employer's policy will be secondary to Medicare. If you continue performing substantial gainful activity (your gross monthly earnings exceed \$500) after the TWP, and stop receiving SSDI checks, you will continue to be eligible for Medicare during the EPE, but you will be responsible for paying the monthly premiums which are usually deducted from your SSDI check.

I purchased an individual health insurance policy prior to my Medicare start-date to cover my prescription costs. If my new employer has a group health insurance plan, should I give up my individual policy?

Most individual health insurance policies prohibit an insured from retaining the policy if the insured becomes eligible for group health insurance. It is important to read your policy carefully to determine whether the individual health insurer would require you to drop the policy in favor of your new employer's group plan.

If my new employer offers a group health insurance plan, should I bother keeping my Medicare coverage?

If your employer has *fewer* than one hundred employees covered by the group plan, you may have to retain your Medicare coverage. Health insurance plans offered by these smaller employers are *secondary* to Medicare if a person is already Medicare eligible. This means that Medicare has to be used first to cover medical expenses, and the group health insurance plan can only be used to cover medical expenses not covered by Medicare. If your employer covers *more* than one hundred employees under its group health insurance plan, Medicare is secondary, and the group health insurance plan would be your primary source of insurance coverage.

If I am required to give up my individual health insurance policy once I join my employer's plan, but become disabled again in a couple of years, what kind of health insurance will I be entitled to?

If you become disabled again during the EPE, you will remain eligible for Medicare whether or not you have continued to pay the premiums while you were working. This means that as soon as you receive your first SSDI check during the EPE, you will automatically be receiving Medicare coverage.

Unfortunately, if you become disabled again during the EPE, you will probably not be eligible for a COBRA continuation of your employer's health insurance plan because federal law prohibits a person from "duplicating" Medicare coverage with group health insurance. (COBRA is a federal law requiring employers to allow employees to continue coverage under the employer's health insurance plan at the

employee's expense for a specific period of time following the cessation of the employee's employment.) Similarly, once you are Medicare eligible, you are not entitled to purchase an individual health insurance policy. This means that ADAP, a Medigap policy, or a Medicare HMO may be the only possible options for coverage of prescription expenses.

If you become disabled from work *after* the EPE, you will be entitled to COBRA continuation of your employer's health insurance plan for 29 months at which time you will be Medicare-eligible again.

For more information about SSI, SSDI, Medicare or other government entitlements including Medicaid, ADAP, public assistance, and food stamps, please contact the Client Advocacy Department of GMHC, or your local AIDS organization. GMHC's Client Advocacy Department provides Fact Sheets on most means-based and other government entitlements; the Fact Sheets can answer most of your questions about eligibility for, and applying for, these benefits. To request GMHC's Fact Sheets about specific government benefits and entitlements, or if you have specific questions about these benefits and entitlements, you can contact the Client Advocacy Department through its Financial Hotline: 212/367-1125.

PRIVATE DISABILITY INSURANCE

Some people have private long term disability ("LTD") insurance. An *individual* LTD plan is an insurance policy usually purchased directly from an insurer or insurance broker, and requires you to pay the monthly or quarterly insurance premiums to retain the policy for your future needs. A *group* LTD plan is a policy that is provided most typically by an employer, and either the employee, through payroll deductions, or the employer pays the premium.

If you are receiving any type of private LTD benefit, whether it is through a group or individual insurance plan, it is important to read the summary plan description which describes how your policy works. Since the language in the policy can sometimes be confusing, you can also consult with an attorney or benefits counselor who can help you interpret the terms of your LTD policy.

This section will attempt to answer common questions about the effect of returning to work on private disability insurance benefits. It is important to remember that an insurance policy is a contract; while there are provisions that are common in disability policies, you will have to read the policy or the summary plan description of the policy that covers you in order to determine how returning to work will effect your specific LTD insurance coverage.

I get LTD benefits through an LTD plan offered by my former employer. Will I continue to collect LTD benefits once I return to work?

Group LTD plans typically provide 60% of your gross income less any SSDI you are receiving. Once you are deemed eligible, payments under group LTD plans usually continue for as long as you remain disabled. Unlike SSDI, however, most group LTD plans do not have a trial work period. The general rule is that if you return to full-time work, you lose most or all of your LTD benefit. Some group LTD plans offer a partial or residual benefit which would allow you to work part-time or perform a percentage of your former work duties and still be able to collect part of the LTD benefit. As with all insurance policies, it is important to read the summary plan description to determine whether your particular plan has any return-to-work provisions.

I've been out on group LTD for about two years, but I'm thinking of interviewing for full-time jobs. If I accept one, and get sick again in a few months, can I go back out on LTD?

The answer depends on a number of factors. If you return to work for the same employer from which you went out on disability, and you become disabled again within a few months, some group LTD policies would allow you to return to the LTD benefit without a waiting period. However, if you go to work for a new employer, you would most likely be required to walk away from your old employer's LTD plan forever.

If your new employer provides a group LTD benefit, there may be a pre-existing condition limitation that would prevent you from eligibility for the benefit if you need to go out on an HIV-related disability leave before the limitation period expires. For example, if your new employer's LTD plan has a 12-month pre-existing condition limitation, you would not be eligible to make a claim for LTD benefits under this policy for an HIV-related disability until you had been covered by the policy for 12 full months.

I get LTD benefits through an individual LTD policy. Can I work part or full time and still collect my LTD benefits through this individual plan?

Private individual LTD insurance policies work differently than group LTD insurance. Although most individual LTD plans will stop paying benefits after you have returned to full-time work, some individual LTD plans will allow you to work part-time and receive part of your LTD benefit. As always, read your insurance policy carefully to determine how it will work for you.

I've been on disability through an individual LTD policy for a long time. If I go back to work and then become disabled again in the future, can I make another claim for LTD benefits under that policy?

Most individual plans will remain in effect if you return to work and then become disabled again; since this is an individual policy, the policy should be yours to keep as long as you make the premium payments. Again, read your policy carefully so that you fully understand your rights under the policy.

DEBT MANAGEMENT

Many people who have been out on disability for a long time owe a considerable amount of money to creditors. Creditors, including credit card companies, department stores, health care providers and other non-tax-related credit providers may attempt to collect such debts in a variety of ways. If you owe money to a credit card company, for example, and you stop making your minimum monthly payment, the credit card company may send you letters or even call you at home in attempting to collect the debt. Ultimately, the credit card company may sue you.

If you owe money and cannot make a payment, the credit card company can easily win a lawsuit against you to repay the debt. If the credit card company wins, the judge issues a "Judgment" in favor of the credit card company and against you. The credit card company can then enforce the Judgment by attaching your assets and using them to pay off the debt.

However, there are some assets that are exempt from attachment on a Judgment. For example, a creditor with a Judgment cannot reach SSDI, SSI or LTD. If any of these is your

only source of income and you have no other assets, then a credit card company may deem you to be "Judgment-proof," because the Judgment cannot reach you. In that event, the credit card company will probably cease its collection efforts.

Your salary, however, is not exempt from collection on a Judgment. Therefore, while you may have been Judgment-proof while you were disabled, once you go back to work and earn a salary, you may no longer be considered Judgment-proof, and creditors may resume collection.

Please note that the above laws apply to most, but not all, creditors. For example, the IRS may attach your SSDI, SSI or LTD to pay your tax debt.

I owe a lot of money to several credit card companies, but I have been judgment-proof for several years. Now I am thinking of returning to work. What can my creditors do?

If a creditor has already obtained a Judgment against you, it can attach your salary. Through a process called "garnishment", a creditor can take 10% of your gross salary from each paycheck until your debt is paid off.

How does a creditor garnish my salary?

A creditor with a Judgment against you will contact your employer through the Sheriff's office and inform your employer that it has a judgment against you. The Sheriff will then order your employer to pay up to 10% of your gross salary to the creditor until the debt is paid off. Only one creditor can garnish your salary at any one time, so the most your salary can be garnished is 10% at any one time. Any other

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creditors must wait in line for each preceding

creditor to be paid off before they can begin their own garnishment of your salary.

Can I avoid salary garnishment by filing for bankruptcy?

A bankruptcy is a determination by a judge that your financial condition is such that you cannot pay your debts. There are several types of bankruptcy, the most common of which is a personal bankruptcy in which the judge discharges all of your debts so that you can become financially stable.

When you file a bankruptcy petition, a bankruptcy judge looks at your assets at the time you file your petition, and will not look any further. Therefore, your future salary is not considered an asset to a bankruptcy judge. If you have no assets other than your present salary, your debts may be discharged, and your future salary will not be garnished. In addition, under certain circumstances, your tax debts may be discharged. Be aware that declaring bankruptcy is a very complicated and serious matter with long-term financial repercussions. Prior to filing for bankruptcy, you should consult with an attorney.

Is there any other way to avoid salary garnishment?

Since there are costs associated with garnishment, creditors would rather have debts paid by the debtors themselves. Therefore, a creditor might look favorably on an offer of payment either in the form of a lump sum or in monthly installments. After you have decided to return to work, you can approach your creditors and offer a plan to "work out" the debt. Creditors will sometimes accept less than full payment to satisfy old debts. In formulating your offer you should carefully consider your financial limitations. By working out the debt directly

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with the creditor you avoid involving your employer and may even save some money in the process.

I owe a lot of money in back taxes. When I was out on disability and living on a restricted income, my tax debt was placed in an "uncollectible" status, although interest and penalties continued to accrue. Will I have to repay the government all of that money if I go back to work?

Yes; the city, state and federal tax authorities are creditors who can garnish your salary. However, government creditors are usually "first in line" and can garnish your wages before credit card companies or other non-governmental creditors. Further, the Internal Revenue Service can garnish a far greater portion of your taxes than other creditors.

If you have tax debts you should therefore try to avoid garnishment, and there are two ways to do so. You may attempt to work out a monthly payment agreement with the IRS. Or, you may offer the IRS a lump sum to settle the tax debt altogether. This is called an "Offer in Compromise." Depending upon your specific circumstances, the IRS may accept an offer of far less than what you actually owe. You should consult with a tax professional before deciding on how to deal with your tax debts.

Once I have returned to work, are contributions to a retirement plan subject to collection on a judgment?

It depends. Pension and/or retirement plans are exempt from collection on a judgment and may not be attached by a creditor who has a judgment against you.

However, pension and/or retirement plans are legally subject to collection by the IRS for

tax debts. For public policy reasons, though, the IRS rarely takes pension funds. Tax law is very complicated, and if you have tax debts you cannot pay, you should consult with a tax professional.

GETTING A NEW JOB: YOUR RIGHTS

Once you have decided to return to work, and have figured out how returning to work will effect your financial status and benefits, the next step may be finding a job. If you have been on a long term disability leave, your former job was probably filled long ago, and your former employer will likely have no legal obligation to reinstate you to your prior position or to find another job for you in the company. Certainly, you can call your former supervisor or human resources office and inquire about the possibility of returning to that place of employment. But if you can't or don't want to return to your former employer, it's time to start pounding the pavement!

Obviously, there are many practical matters to consider when facing a job search. The answer to many questions, such as how to explain the gap in your resume, are going to be specific to your own situation. You might want to seek the assistance of a vocational or outplacement counselor as you reenter the workforce.

Do I have to tell a prospective employer that I have been out on disability?

The law does not require that you disclose your HIV status to an employer or prospective employer, and it also does not require that you disclose the fact that you have been on disability leave. However, if you lie on your application for employment, you could be terminated at a later time if the lie is discovered. Prior to

going on a job interview, it is important to consider how you will explain a gap on your resume.

The response to an inquiry about the gap on your resume will be very specific to your own circumstances. Some people choose to tell a prospective employer that they took time off from full time work to pursue personal interests or an entrepreneurial opportunity. Some people have done volunteer work and can bolster their resume with information about projects on which they have worked. And some people may decide that it is easier to tell a prospective employer that they were on a personal leave or a disability leave but can return to work at this time. An outplacement or vocational counselor may have other ideas to assist you with explaining the gap on your resume in the manner that is most comfortable for you.

What if I'm returning to the same employer I left to go out on disability?

If you are returning to the same place of employment from which you took your disability leave, you may have to provide a return to work certification from your doctor explaining that your disabling condition no longer prevents you from working, and that you are ready and able to do your job. Even if you are going to be interviewing for a new job with a different employer, it is a good idea to consult with your doctor to see what s/he thinks about the long range effects of work on your health.

For more information about private insurance, debt management, or the legal implications of returning to work, call the GMHC Legal Department at 212/367-1040, or your local AIDS organization.

Gay Men's Health Crisis is the world's oldest and largest not-for-profit AIDS organization, providing services to people with AIDS and their loved ones, educating the public and advocating for fair and effective AIDS policies.

For more information or for a free copy of our Catalog of AIDS Educational Resources, please call the Hotline.

HOTLINE: 212/807-6655
TTY: 212/645-7470 (deaf access)
WEBSITE: www.gmhc.org

FIRST IN THE FIGHT
AGAINST AIDS

GMHC

Written by Marla Hassner and Robert Newman

*Editorial assistance by
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Randy Retkin, Rick Starr*

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October 3, 1997

Ms. Sandy Thurman
Director
White House Office of National AIDS Policy
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Washington, DC 20006

Dear Sandy:

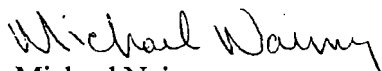
Thank you for meeting with us on Wednesday, October 1st to discuss employment services for people living with HIV/AIDS. The media "hype" surrounding recent medical breakthroughs has reinforced the *reality* that MTS clients have been proving since 1988 – an HIV/AIDS diagnosis does not have to mean the end of a person's productive work life.

Your leadership role in recognizing this issue will ensure that employment is included as an option for people looking to both enter and return to the job market. We greatly appreciate your sense of urgency in arranging a meeting with the Secretaries of Health, Education and Labor to provide the broadest range of support for this initiative. We will contact your office as you requested on Friday, October 10th to follow-up on the date tentatively planned for this meeting.

Please contact us at 212.679.8234 or fax 212.679.8310 if we can provide any additional information on our Transitional Employment Model or materials from the public policy roundtable held in July.

We are grateful for your belief in the MTS mission and thank you for your leadership in helping our clients prove that *"Employment is a Treatment That Works."*

Sincerely,


Michael Naimy
Co-Executive Director


Darla Pasteur
Director of Development

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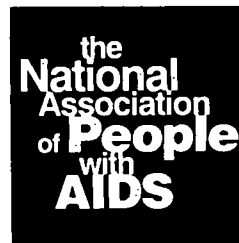
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MAKING DECISIONS
ABOUT EMPLOYMENT, BENEFITS
AND HEALTH INSURANCE

RETURNING TO WORK
WITH HIV/AIDS

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38 East 29th Street, New York, NY 10016



RETURNING TO WORK WITH HIV/AIDS: PUBLIC POLICY ROUNDTABLE

Executive Summary

Public Policy Roundtable I
July 21-22, 1997
New York City

Returning to Work with HIV/AIDS: Public Policy Roundtable July 21-22, 1997

Executive Summary

Recent treatment breakthroughs and the subsequent success of triple combination therapies for people with HIV disease have combined to change the face of HIV/AIDS across the country. For the first time in the HIV epidemic, the thought of staving off the ravages of HIV disease has moved from fantasy to fact. Access to the new therapies (in conjunction with primary medical care and a constellation of social services) has allowed countless persons with HIV/AIDS (PWAs) to dramatically improve their health and also envision a future that is not automatically equated with disease and death.

Cautiously, this change in outlook has brought with it the idea of regaining their health, and, for some, of joining the workforce. HIV/AIDS has disabled tens of thousands of hard-working individuals who are considering or may soon be able to consider returning to work. For many PWAs, their diagnosis and poor health forced them to leave the labor market. These disabled PWAs qualified for public benefits and health care programs such as Supplemental Security Income, Social Security Disability, Food Stamps, Medicaid, and even Medicare.

Returning to work (or entering employment for the first time) is a major step for any individual with a disability. Numerous challenges face PWAs as they begin to consider this option. In order to successfully transition men and women from disability into the workforce, there are key policy, programmatic, educational, and funding issues that must be considered, addressed and resolved.

In July, 1997, MTS, Gay Men's Health Crisis (GMHC), and the National Association of People with AIDS (NAPWA) held a two-day Public Policy Roundtable in New York City to begin a national focussed dialogue on these work-related issues. The sixty-five community leaders attending the roundtable included individuals living with HIV/AIDS (some of whom have successfully returned to work), key policy advocates from around the country, representatives from foundations which fund AIDS and Disability projects, and a contingent of community advocates from Canada.

From this initial meeting, it is clear that there is tremendous opportunity, energy and excitement around this issue. There is also a substantial amount of work that must be done if we are to successfully assist PWAs as they transition into the workforce. The three sponsoring organizations agreed to review the roundtable findings and recommendations, issue this summary report and plan the next steps.

It is our hope that as we move forward, we move collectively, with the intention of improving the lives, health and well being of all PWAs.

Guiding Principles and Public Policy Priorities

During the Public Policy Roundtable, the participants reached a consensus on the principles which should guide all efforts to assist PWAs enter or re-enter the workforce and on the major Public Policy Priorities.

I. Guiding Principles for Initiatives to Assist Persons with HIV/AIDS (PWAs) Enter or Re-Enter the Workforce.

1. Working must be addressed within the broader context of the Determinants of Health including: Health Care, Stable Housing, Nutrition, Income Security, Psychosocial Support, Physical Environment, Safety, and Access to Appropriate Employment.
2. The PWA must be at the center of the decision-making process.
3. Decisions about working/not working must be made without coercion.
4. Employment should be available as an option in the care continuum.
5. Programs and services must be flexible and responsive to the individual's life experiences.
6. Service providers should not make assumptions about the capacity of "hard-to-reach" populations, or any group's ability to participate in, or benefit from, employment services.
7. The PWA must control confidentiality and disclosure.
8. Decisions by private and public payers about an individual's capability of working cannot be based solely on current clinical evidence.

II. Public Policy Priorities

To facilitate individuals entering or re-entering employment, barriers created by current governmental policies and regulations must be addressed. The key issues are:

1. Welfare Reform/Workfare Programs in all states must accommodate the special needs of PWAs.
2. Current Public and Private Disability-Related Benefit policies should be modified to provide a safety net of benefits when an individual tries to transition into the workforce.
3. Education is needed in the Public and Private sectors for service providers and employers about the employment needs and capabilities of PWAs.
4. A comprehensive national strategy should be developed to coordinate the efforts and resources of federal agencies such as HRSA, HUD, DOL, etc. to respond to the employment and training needs of PWAs.

III. Cross Cutting Issues

Roundtable participants identified a list of issues that affect all Public Policy Priorities.

1. Employers and potential employers must be involved at all levels.
2. Retraining and education are key components in all employment efforts.
3. Needs of Special Populations must be addressed by availability of a broad set of employment and training options.
4. Definition of Disability should be broadened by employers and government agencies.
5. Long-term drug efficacy is unknown. Flexibility in employment and benefits is crucial.
6. There must always be a balance between advocacy for employment and access to drugs and treatments.

Roundtable Format

The roundtable began with a panel of consumers who described their experiences in returning (or trying to return) to work. Additional panels followed with presentations from organizations offering employment options and services to PWAs, from experts on governmental regulations, and descriptions of state and national initiatives. The first day of the conference ended with participants identifying the major Public Policy issues.

On the second day, attendees broke into five working groups to analyze the public policy issues and recommend action steps. Each group focussed on one priority only. The priority and charge given to each group were:

Work Group Charge

1. Identify Key Issues.
2. Identify what needs to be done.
3. Identify Action Steps.
4. Address Cross Cutting Issues.
5. Identify Principles.

Work Groups

1. Welfare Reform/Workfare
2. Benefits/Housing.
3. Education and Advocacy
4. Funding.
5. Canadian Issues

Work Group Results

1. Welfare Reform/Workfare Work Group

Key Issues: All people with disabilities need accommodations. Services for everyone should include: Case Management; Life Skills Training including budgeting and managing income; Psychosocial support; and English as a Second Language (ESL) programs. Special populations need special services. **Women & Youth:** Appropriate childcare and supportive services including HIV-specific childcare where medications are administered. **Ex-offenders:** Transitional support services when leaving incarceration. **People with substance abuse histories:** Substance abuse counseling to facilitate recovery.

What Needs to Be Done: Exemptions must be identified at the Federal level. We recommend in general that the Americans with Disabilities Act (ADA) be enforced and specifically that Welfare Reform:

1. Exempt beneficiaries from placements that their health care providers document would be inappropriate or dangerous.
2. Eliminate or reduce participation percentage requirements for disabled adult beneficiaries.
3. Require localities to plan disability accommodations for workfare programs as required by the ADA and implement state oversight and monitoring of compliance.
4. Exempt disabled welfare beneficiaries from rules mandating cut off of Medicaid or other basic benefits for failure to comply with work requirements.
5. Maximize and expand the federal exemption for state use of good cause exemption for TANF program to allow continuation of benefits.
6. Exempt disabled beneficiaries from arbitrary lifetime time limits.
7. Develop Work Opportunities by establishing set aside funding for disability specific welfare to work programs including cash grants and tax credits.

Next Steps

1. Outreach to other existing coalitions of advocates who focus on work related issues.

2. Invite state and local agencies involved with HIV/AIDS to the table.
3. Hold a community forum for PWAs to discuss return to work and impact of reform.
4. Build Welfare Reform state coalitions specifically to address work requirements and employment opportunities for people with disabilities, including PWAs.

2. Benefits Work Group

Key Issue #1: Private Long Term Disability (LTD) carriers should develop options to allow for trial work periods.

What to Do

1. Investigate what work incentive products are offered as part of LTD coverage.
2. Analyze the business model(s) used by LTD carriers.
3. Use local AIDS organizations to work with local insurance companies. Develop a common script.
4. Reach out to and understand other disability organizations.
5. Create an environment for voluntary change on the part of LTD carriers.

Next Steps

1. Identify existing LTD HIV/AIDS policies and network with LTD carriers.
2. Define recommended modifications to LTD policies.
3. Determine best approaches to working with the LTD insurance industry.

Key Issue #2: One uniform work incentive program for both Social Security Disability (SSD) and Supplemental Security Income (SSI) should be developed. It should be based on the current SSD program and designed in a manner that doesn't undermine health insurance coverage.

What to do

1. Make work incentives more flexible.
2. Develop Buy-in options for Medicare and Medicaid.
3. Assess and prioritize AIDS-specific issues and identify overlap with other disabilities.
4. Identify any model state programs.

Next Steps

1. Form working group to identify, assess, and coordinate current efforts.
2. Coordinate efforts with other national disability organizations such as the National Council on Disabilities and CCD.
3. Hold conference to identify universal goals within disability and HIV/AIDS communities.
4. Analyze state Medicaid programs aimed at medically needy and low-income populations.

Key Issue #3: SSI and SSD beneficiaries who return to work should be able to purchase Medicaid coverage to cover gaps in employer health coverage (i.e., prescription drugs, pre-existing condition clauses, etc.)

What to Do

1. Design a Medicaid purchase option so that ADAP programs become the payers of last resort for those without prescription drug coverage.
2. Continue Medicaid expansion efforts to change the link between disability and eligibility.

Next Steps

1. Advocate for Medicaid expansion and purchase option at state and national levels.
2. AIDS Action Council will broadcast current White paper and seek national "buy in" from state, local and national AIDS organizations to strengthen bargaining position.
3. Plan conference for state organizations and a session at national AIDS conference.

Key Issue #4: Housing regulations at state and local levels need to be flexible to accommodate part-time and full-time employment.

What to Do

Create new regulations so that employed PWAs can remain in subsidized housing rather than risk eviction.

Next Steps

1. Identify states and locales where this is an issue.
2. Identify state advocacy groups.
3. Document the inconsistencies in current regulations vis-a-vis the goals of employment initiatives such as Workfare and state's housing programs.

Key Issue #5: PWAs must have access to support services such as training and childcare in order to transition into the workforce.

What to Do

Tie re-training, education, and other employment readiness programs to support services.

Next Steps

1. Identify stakeholders and advocates in these support areas.
2. Investigate current efforts to access support services benefits.
3. Plan strategy to modify eligibility as needed.

3. Education and Advocacy Work Group

Key Issue #1: Government workers should be knowledgeable about HIV/AIDS and treatment.

What to Do

1. Mandatory training of government workers in HIV/AIDS, work transition and public benefits;
2. Educate vocational rehabilitation professionals at state agencies including educational institutions to work with PWAs.
3. Train ASOs to work with vocational rehabilitation and similar agencies.

Key Issue #2: PWAs Need Access to Education and Training Services

What to Do

1. Determine in which states the Order of Selection limits vocational rehabilitation for PWAs.
2. Examine and remove barriers to education in federal programs (SSA, HRSA, JTPA, etc.).

Next Steps

1. Develop and expand outreach to PWAs regarding educational and training opportunities and vocational rehabilitation services.
2. Create linkages to all populations, particularly institutionalized and other "hard to reach" groups.
3. Revise Departments of Rehabilitation Order of Selection to include PWAs in affected states.
4. Investigate potential Small Business Administration support for people with disabilities.

Key Issue #3: Employers should be Included in Employment and Training Programs and Receive Incentives for Hiring PWAs.

What to Do

1. Expand Tax Incentives for hiring people with disabilities, particularly SSA beneficiaries.

2. Work directly with private employers and employees to provide and coordinate training programs on supplemental health benefits programs.
3. Include local chambers of commerce and business community in job creation for people with disabilities and HIV.
4. AIDS Service Organizations should act as employer models by committing to hire PWAs, and developing model programs with flexibility and creative accommodations (flex time, job sharing, part-time, etc.).
5. Require state, county and city universities and colleges (and private institutions which receive federal funding) to develop opportunities for PWAs.

Next Steps

1. Investigate expansion of Empowerment Zones to target employers hiring PWAs who reside in these zones.
2. AIDS Service Organizations develop and deliver up-to-date training on HIV/AIDS, treatment and employment information to the employer community.

Key Issue #4: Research is needed to Demonstrate the Health and Monetary Benefits of Employment for PWAs.

What to Do

1. Increase studies of monetary benefits and savings from social security-to-employment programs in both the public and private sector.
2. Research study on relationship of employment and health for PWAs and other disabilities.

Next Steps

1. Advocate for evaluation of state training and educational programs in enrollment of and responsiveness to people with HIV/AIDS.
2. Encourage ASOs to evaluate "return to work" and "affirmative action" for PWAs and report on ASO employment of PWAs.
3. Advocate for research on the feasibility and economics of job accommodations such as flex time, job sharing, and telecommuting.

4. Funding Work Group

Key Issues

1. Development of a comprehensive national strategy for a federal response for HIV employment. This needs to include two main areas: streams of funding (HOPWA, CARE, JTPA, Vocational Rehabilitation, etc.) and oversight mechanisms/agencies (Departments of Education and Labor, HRSA, Housing and Urban Development, etc.).
2. Develop a national coalition to secure a comprehensive response to the employment needs of people with HIV disease.
3. Establish national technical assistance program to aid local CBOs to establish and fund HIV employment programs.
4. Obtain clarification from HHS (ie HRSA) concerning eligibility of vocational rehabilitation services under the CARE Act.
5. Develop coalition with larger disability community to facilitate and coordinate use of vocational rehabilitation funds for people with HIV disease.
6. CARE Act funding for outreach to vocational and rehabilitative service agencies.

What to Do

1. Obtain HRSA guidance that is clear and usable.
2. Educate PWAs and local Planning Councils on program.

Next Steps

1. Meet with HRSA officials, Title I providers, CAEAR Coalition, etc.
2. Identify most effective model(s).
3. Draft language to clarify permissible uses of CARE funds for HIV employment.
4. Mobilize CARE Act planning councils to secure clarification.
5. Identify existing disability coalitions and common strategies to expand vocational rehabilitation resources and educate federal policy-makers about emerging needs of people with disabilities for employment services.

5. Canadian Work Group

Key Issue: The group developed a list of principles based on the Ottawa Charter for Health Promotion that guides most HIV services in Canada. These guiding principles give a sound context for addressing return to work issues for PWAs in a holistic and humanitarian context. The principles were adopted by the Roundtable (see first page).

What Needs to Be Done:

Advocacy and Education

1. Develop an advocacy strategy in collaboration with other community partners, including cross disability organizations and health care providers.
2. Educate community organizations and health care providers on return to work issues for people living with HIV/AIDS.
3. Meet and advocate with federal and provincial policy-makers and senior bureaucrats responsible for return to work programs.
4. Meet and advocate with private insurers to ensure policies/programs are based on community return to work principles.
5. Meet and advocate with business and labor associations to ensure appropriate return to work policies are in place for people living with HIV/AIDS.
6. Advocate with the Health Protection Branch and pharmaceutical companies to undertake extensive post-marketing surveillance to ensure longitudinal clinical data on efficacy and toxicity.
7. Ensure return to work issues are appropriately addressed in the third phase of the National AIDS Strategy.

Research: Develop national research on the needs of people living with HIV disease with respect to return to work issues.

Next Steps

Establish a national working group on return to work issues that will be responsible for:

1. Integrating existing community work into national initiatives.
2. Developing position statement on return to work issues.
3. Developing specific advocacy initiatives on return to work issues.
4. Integrate return to work information into HIV and rehabilitation module currently in development.

List of Attendees

Public Policy Roundtable I

July 21-22, 1997

New York City

CONFERENCE ATTENDEES

Jeanne Argoff	Dole Foundation
Cornelius Baller	National Association of People with AIDS
Zaida O. Castillo	Proceed
Paul Causey	AIDS Benefit Counselors
Sophia Chang	Henry J. Kaiser Family Foundation
Paul Costello	Bailey House
Jeff Crowley	National Association of People with AIDS
Barbara Davis	Actors' Fund
Ray Diaz	Samaritan Village
Paul DiDonato	Funders Concerned About AIDS
John Dunn-Mortimer	Northern California Grantmakers
Mark Etzel	AIDS Project Los Angeles
Robert Greenwald	AIDS Action Committee of Mass.
Susan W. Haikalis, LCSW	San Francisco AIDS Foundation
Catherine Hassens	Lambda Legal Defense & Ed. Fund
Marla Hassner, Esq.	GMHC
Sean Hosein	C.A.T.I.E.
John Huckaby	AIDS Foundation of Houston
Rob Humrickhouse	Howard Brown Health Center

Ronald Johnson	New York City AIDS Policy Coordinator (Mayor's Office)
Steve Johnson	Northwest AIDS Foundation
Mark King	AID Atlanta
Michael Kink	Housing Works
Betty Kohlenberg	Kohlenberg & Associates
Rodney Kort	Canadian AIDS Society
Gil Kudrin	Night Sweats & T-Cells
Roger LaRade	AIDS Committee of Toronto
Joan Lowell	Actors Work Project
Ken Lowery	Consumer Information & Conflict Resolution
Christine Lubinski	AIDS Action Council
David J Martin, PhD	Harbor-UCLA Medical Center
Tom McAulay	Persons With AIDS Society of British Columbia
Vincent McGee	Irene Diamond Fund
Mark Misrak	ABC/Positive Resource
Jeff Monford	National AIDS Fund
Mary Alice Mowry	Dane County Employment Initiative
Marjorie Mueke	Ford Foundation
Michael Naimy	MTS
Catina Perkins	National Association of People with AIDS
Jose Rodriguez	Ohio AIDS Coalition

Eddie Sanchez	Proceed
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Sextus Tansinsin	
Sheila Thomas	Wellesley Hospital & Health Centre
Stephen Triplett	
Barbara Turk	MHRA/HIV Care Services
Paul Vander Waerdt	ABC/Positive Resource
Jason Wussow	Center for Health Care Strategies, Inc.

**Attending Organizations
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**Public Policy Roundtable I
July 21-22, 1997
New York City**

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