TECHNICAL REPORT

Summary Findings for Research Component R3:

HIV/AIDS, SUBSTANCE ABUSE & EMPLOYMENT

Rehabilitation Research and Training Center
on
Drugs and Disability

School of Medicine
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Dayton, Ohio

September, 2003

Funded by the National Institute on Disability and Rehabilitation Research
U.S. Department of Education
Washington, D.C.

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TABLE OF CONTENTS

INTRODUCTION

Rehabilitation counselors and individuals living with HIV/AIDS face a challenging dilemma: a significant number are feeling better, yet many are concerned about transition issues as they reach out to once again embrace work and careers. Returning to work is unexplored territory for many and we have little precedent to guide them, especially now that complex medication therapies are part of the equation. This research study undertook to:

(1) outline the issues that are confronting people living with HIV and AIDS as they work to move out of disability benefit dependence into the world of work today, as well as
(2) identify vocational rehabilitation strategies.

Many no longer view HIV/AIDS as the acute deadly disease of the early 1980's but consider it a long-term chronic illness, one for which preparation for long term care is essential. National statistics showed marked declines in AIDS incidence and deaths beginning in 1996 and continuing into 1998. As the number of deaths related to AIDS declined, the number of people living with the disease increased substantially. Decreases in AIDS deaths were attributed to better prophylaxis for opportunistic infections (OI), and treatment with highly active antiretroviral therapy (CDC 1998, 2001). Despite improvement in health as a result of the availability of new treatments, efforts at workforce entry have not been easy for this population (Martin, 1999). People who have undertaken a medication therapy regimen experience problems with compliance, lifestyle changes, physical or health problems as a result of medication treatments, as well as uncertainty about the advisement of workforce entry or reentry (Bogart, Kelly, Gray-Bernhardt, 2000). Estimates show the U.S. losing over $1.8 billion in productivity each year due to the absence of individuals with HIV and AIDS from the work force. Meanwhile, approximately $1.5 billion is currently being paid by public and private disability insurers to sustain people living with the disease (National AIDS Fund, 2001).

Vocational rehabilitation services can assist individuals living with HIV or AIDS to address the work-related concerns and to return to the workforce. Research has shown significant correlation between long-term health and employment among people with HIV/AIDS, as they report improved quality of life and functional status (Chammas, 1999; McReynolds, 2000; Swindells, Mohr, Justis, Berman, Squier, Wagner, & Singh, 1999; Yelin, Greenblatt, Hollander, & McMaster, 1991). Those with flexible schedules and higher levels of education fared better in this research. Yet going to work is a "Catch-22" for many people living on insurance and public agency benefits (Greene, 1998; Larson, 1999). Contemplation of benefit loss can create dissonance in the decision-making process.

When individuals living with HIV or AIDS consider transitioning back into the work world, a number of other barriers to success are reported in the literature. One relates to the lack of knowledge of their rights as individuals with disabilities in the workplace. Other studies report negative feelings and emotions associated with having a disease and the psychosocial issues that impact individuals' ability to work or be productive on the job (Brashers, Neidig, Reynolds, & Haas, 1998; Gilden, 1997; Livneh & Antonak, 1997; McReynolds, 2000). This is compounded by the fact that an increasing number of individuals living with HIV or AIDS lack resources and have poor or nonexistent work histories because of homelessness, substance abuse, mental health problems and a host of other related factors (Heath & Rodway, 1999; Martin, 1999).

Whether or not to disclose HIV+ status is a dilemma faced by the majority of individuals. The stigma and lack of knowledge that exists in the general community and in the workplace can cause reactions which lead to fear of discrimination, loss of social relationships, possible job losses, or loss of health insurance benefits (Brooks & Klosinski, 1999; Adam & Sears, 1996).

One issue under research relates to medication management and how it impacts the lives of people entering the workforce, maintaining work, or considering a new career (Crespo-Fierro, 1997; McReynolds, 2000). These complex therapies require multiple medications that need to be rigorously taken and are to be ingested at different times of the day, sometimes on an empty stomach, sometimes with food. These medications may cause fatigue, diarrhea, nausea or a host of other symptoms. Some medications must be refrigerated. Disclosure to employers becomes a concern for many as they may require reasonable workplace accommodations so they can continue the medication regimen.

In order to assist people in exploring these work transitions, rehabilitation counselors must have a better understanding of this issues individuals living with HIV or AIDS face in today’s environment. The understanding and information dissemination must originate with the experience of the individuals themselves and be updated regularly because of rapidly changing treatment dimensions.

Vocational rehabilitation professionals will need to confront issues related to serving people with HIV or AIDS, as professionals and as a field. People with HIV or AIDS are and will continue to be present on caseloads throughout the country because of the disability of HIV or AIDS or another primary disability, such as substance abuse (Hunt, 1996). Until recently, however, the need to provide vocational rehabilitation services to people with HIV or AIDS was not well met. Studies have also shown that rehabilitation counselors need specialized training and experience to work with this population (Glenn, 1997; Hunt, 1996; WID, 1994).

The field of rehabilitation has begun to research and develop policies, programs, and practices for serving people with HIV or AIDS, but many questions remain unanswered. They can begin to be answered through research involving two key partners present in every rehabilitation effort, the consumer and the rehabilitation counselor. There is a great deal of work to be done in this arena, however. Some state vocational rehabilitation systems still do not have disability classifications that include HIV or AIDS. Also, it has been noted that by the time an individual with HIV qualifies under the “order of selection” criteria, they may already be too ill to seek employment (personal conversation, J. Gutterman, Ohio Rehabilitation Services Commission, 1999).

RESEARCH DESIGN

The major goal of this study was to examine relationships between vocational rehabilitation services, HIV/AIDS as a disability, and substance abuse. The following research questions were developed to guide the final study activities:

1. What percentage and what are the demographic characteristics of consumers living with HIV or AIDS that report moderate or severe problems with substance abuse?
2. How do substance abuse problems relate to employment outcomes for consumers living with HIV or AIDS?
3. What barriers to obtaining and maintaining gainful employment exist for persons living with HIV or AIDS?

4. What strategies are people living with HIV or AIDS using to find employment?
5. What vocational services and transitional techniques can vocational rehabilitation counselors use to assist consumers living with HIV or AIDS in entering or re-entering the work force?
6. Is there a relationship between client-reported ability to work and reported levels of substance abuse among consumers with HIV or AIDS?
7. Is there a relationship between client-reported ability to work and satisfaction with vocational rehabilitation services as well as level of disease progression among consumers with HIV or AIDS?
8. Is there a relationship between rehabilitation counselors' perceptions, levels of knowledge, training/experience, and self-reported skill levels and consumers' with HIV or AIDS vocational rehabilitation outcomes and reported satisfaction with services?

The design of this research project involved a process of receiving consumer and expert input and guidance at key stages. We identified experts in the areas of vocational rehabilitation, HIV/AIDS, qualitative research methodologies, and employment. These individuals were convened in a formal meeting to review the proposed plan. A list of the consultants is included in Appendix 1. Input provided by the panel included the following:

- A qualitative strategy would be a good approach as long as it is focused. There are a number of software programs that can be used with the analyses of the resulting qualitative data.
- The approach to HIV should be to cast it as a "chronic disease" as opposed to a fatal illness.
- The approach to substance abuse should be in terms of a treatment/ recovery model.
- Since benefits will be an issue for many consumers, we could develop a "cheat sheet" of benefits - a field guide for HIV/AIDS benefits.
- Recruitment of people with HIV to vocational rehabilitation may need to be part of the model since we may not be able to identify enough people who are already in that system.

- The study can be used to impact policy. For example, AIDS Service Organizations need training related to vocational rehabilitation and to development of policy concerning referral to and working with VR.
- Keeping managed care on the table is important as is educating systems on work initiatives already in place.
- A traditional benefits analysis may not work the same because of the “in & out” health status of some people with HIV/AIDS.
- One consideration for a hypothesis is that work may be a prevention factor and not a risk factor for some people living with HIV/AIDS as it may smooth out schedules such as medication regimens and doctor appointments.
- Another factor is co-morbidity – particularly Traumatic Brain Injury, Mental Illness, Substance Abuse, and general cognitive functioning level.
- Be sure to collect data on why a person wants to work - is it a “push to work” or a “pull to work?”
- It is anticipated that the “5 year gap” in employment history will be one potential barrier to an employer offering a job. How does VR compensate?
- Another potential hypothesis relates to whether the chronic disease model defines barriers and solutions for people with HIV within the VR system.
- Some potential sources of recruitment include: clinical trial units, magazines & newsletters, Arms of Love in Springfield, internet, clinics, interfaith clergy, AIDS Service Organizations, etc.
- The flyer could utilize a four color layout with photos and should define the study and eligibility, include amount of stipend, mention dates and locations for interviews, and possibly have a peel off set of flyers so someone can just take one from a display.

All of the expert consultants provided feedback on the first interview form. Three individuals who were HIV+ and consumers participated as consultants serving as “test participants” for each of the interviewers that provided a means for field-testing the initial instrument. Several who remained involved throughout the study provided feedback on the recruitment flyer and the two subsequent interview questionnaires.

NOTE: The study was originally designed to recruit respondents directly from Ohio's vocational rehabilitation system thereby ensuring that all selected respondents would be at least applicants for vocational rehabilitation services. This would allow us to ask specific questions of the respondents about their experiences in vocational rehabilitation, to track the services they received, as well as to evaluate their vocational progress and outcomes. We planned to obtain written consent from respondents to communicate directly with their vocational rehabilitation counselors in order to obtain additional information and compare the information provided by respondents and counselors. We were unable to recruit respondents as planned in our proposal. This was due (1) to the fact that HIV/AIDS is not a separate disability category in Ohio's vocational rehabilitation system's client database, and (2) less formal systems of respondent recruitment would not satisfy human participants confidentiality guidelines. To address the issue, we modified the original research questions and developed survey instruments to answer these modified questions.

METHODOLOGY

This study required the involvement two participant groups:

(1) individuals living with HIV or AIDS who are or could be consumers of federal-state vocational rehabilitation services, and
(2) vocational rehabilitation counselors employed in the federal-state vocational rehabilitation system.

The following section outlines the process for recruitment of these two groups, demographics of the final respondents, and human participants protection information.

Participants

Participants Representing Consumers

Recruitment. An initial recruitment flyer was developed utilizing input from the expert panel. The flyer was pretested with consumers from a local AIDS Service Organization. The flyer contained the title and purpose of the study; the eligibility requirements for inclusion in the study; the types of information to be collected; the way that the information was to be collected;

information about remuneration for participating; and contact information. We also provided an anticipated timeline. A copy of the flyer is provided in *Appendix 2*.

Copies of the flyer were distributed to contacts at 19 sites around the state of Ohio for direct distribution and/or display. A list of these recruitment sites is in Appendix 3. In addition, SARDI advertised the same information in a statewide newsletter and at the Ohio AIDS Coalition conference held in March, 2000. Recruitment for the study officially began on March 30, 2000.

Interested individuals were asked to call a local or toll free number, to fax, or to e-mail SARDI and to complete a brief screening form. As a part of that screening, respondents were asked the following: Name; Mailing Address; Telephone Number; Best time to be reached; Is it OK to leave a message?; Race/Ethnic Background; Gender; Age; Highest grade completed/highest level of education; Current employment status; If not newly employed, why do you want to consider work at this time?; Can you provide proof of your HIV status?; Were you ever in state vocational rehabilitation and when?

Respondents were selected on April 24, 2000. Interested individuals calling after that date were advised that the required number of respondents for the study had been selected but that they could provide contact information if they were interested in participating in future studies or were interested in receiving results of the study. A total of 71 individuals completed the screening prior to or on April 24, 2000. An additional 18 completed the screening information after the deadline with the understanding that we would keep their information on file in case the need arose for additional respondents.

A meeting to select participants was scheduled for April 24, 2000, and included the four interviewers and Principal Investigator. A list of potential respondents with basic demographic information was provided to everyone at the meeting. The screening forms were also available. The general consensus of this meeting was to select a minimum of 50 and a maximum of 55 respondents for the study. We had to prioritize selecting a larger portion of the many women who qualified for the study since the number of women screened was significantly less than men. It also appeared that slightly less than half of the individuals screened were African American, and very few were Hispanic or from other minority groups; therefore, we attempted to select as many of the individuals in these minority groups as qualified for the study.

The first group reviewed was the female respondents. All women who had signed up met the requirements and were selected for the study. The resulting respondent group included 10 women between the ages of 26 and 59. Only one of these women reported exposure to the state vocational rehabilitation system. Seven were African American, two were Caucasian, and one was Hispanic.

The next group discussed was males of Hispanic race or identified as "other" in the race category. First we dealt with those identified as "other" in the race category. One male identified himself as bi-racial, 25 years old, and had never been in the vocational rehabilitation system. Another individual identified himself as a Pacific Islander, who was 36 years old and had never been in the vocational rehabilitation system. Both of these individuals were selected for the study.

Five men identified themselves as Hispanic. Four of these individuals were selected to participate. The one individual not selected in this group was a gentleman who was unable to complete a two-hour interview in English. It was decided that fluency in oral English needed to be an added requirement for this protocol due to the lack of an interviewer fluent in Spanish. The four men who were selected were between the ages of 35 and 44. Two of them reported experience with state vocational rehabilitation.

The remaining applicants were divided by race - African American and Caucasian. We first identified that our priority was to select those individuals who reported exposure to the vocational rehabilitation system. These individuals were all included in the study. We then reviewed education levels and age to diversify our participant sample on these two variables.

A total of 16 African American males were selected for the study. Their ages ranged from 29 to 47. Nine of these individuals had some type of exposure to the vocational rehabilitation system. A total of 19 Caucasian males were also selected for the study. Their ages ranged from 29 to 55. Seven of these individuals had some exposure to the vocational rehabilitation system.

The selection process yielded a total of 51 individuals. Three additional screenings were completed on women within several days. It was decided that we would accept all three women into the study to increase the number of female participants. One of these newly added women was African American and two were Caucasian. One indicated involvement with the state vocational rehabilitation system.

Letters were sent to all persons not selected to participate in the study. They were advised that they could contact us by phone or mail if they were interested in receiving the results of the study.

Final participant pool of consumers. A total of 54 individuals were selected for the study sample. These potential respondents were subsequently divided among the interviewers who called and/or sent letters to each individual on their lists. One African American male selected could not be reached either by phone or mail, and therefore was excluded from the study prior to the informed consent and first interview. This left a sample size of 53 respondents. A summary of several basic demographic characteristics of the resulting sample is provided in *Table 1.*

Two of the individuals did not complete the second interview during the course of the study. One of these two individuals was a Caucasian female. She was unable to be reached as her phone had been disconnected and her mail was returned with no forwarding information available. The second respondent was a Caucasian male who had scheduled the second interview and confirmed his interview time two days prior to that scheduled time. However, we were unable to contact him at the scheduled time and there was no answer to repeated phone calls. A letter was sent, but it was returned as "undeliverable."

An additional two participants did not complete the third interview. One of these gentlemen had been difficult to reach to schedule each of his first two interviews. His address was transient. At the time of the second interview, we had been unable to reach him at his phone number or his identified address. He happened to call approximately one week after the other second interviews had been completed and we did complete his second interview. We were again not able to reach him for the third interview. Repeated attempts to reach him through messages and letters were unsuccessful. The other participant who did not complete the final interview was incarcerated. We did contact him through a letter sent to the prison, and he was willing to participate in the final interview. However, to accommodate his situation, we would have had to change the approved protocol, and for that reason, we did not complete the final interview with him.

The loss of the four individuals resulted in an overall attrition rate of 7.5%. This left a final sample size of 49 for the study.

Table 1. Demographic Characteristics of Original Respondents (N = 53)

Characteristic	**Related Categories**	**Percentage Distribution**	**Frequency**
Age	25 – 30	09.4%	5
	31 - 35 years	15.1%	8
	36 - 40 years	22.6%	12
	41 – 45	34.0%	18
	46 or older	18.9%	10
	Range: 25 – 59		
Gender	Male	75.5%	40
	Female	24.5%	13
Race/Ethnicity	Caucasian	43.4%	23
	African American	43.4%	23
	Hispanic American	9.4%	5
	Other/Multicultural	3.8%	2
Marital Status	Never Married	54.7%	29
	Married	3.8%	2
	Widowed	3.8%	2
	Divorced	24.5%	13
	Separated	11.3%	6
	Other (living as married)	1.9%	1
Education	< 12 years	15.1%	8
	12 years	43.4%	23
	> 12 years	41.5%	22

Participants Representing Vocational Rehabilitation Counselors

State vocational rehabilitation counselors participated in this study in two ways. One group responded to a survey to ascertain knowledge, perceptions and perceived level of skills in serving individuals living with HIV or AIDS. The second group was involved in a focus group activity designed to gain information about barriers and techniques in providing vocational rehabilitation services to individuals with HIV or AIDS.

Recruitment of survey participants. All individuals employed by the Ohio Rehabilitation Services Commission as Vocational Rehabilitation Counselors were recruited to complete an anonymous mailed survey. The purpose of this survey was to help document and describe the perceptions of rehabilitation professionals regarding HIV and AIDS and levels of related knowledge and skills. Counselor respondents were contacted via mail with a cover letter, a copy of a survey to complete, and a post-paid return envelope. A copy of the cover letter and the counselor survey can be found in *Appendix 4.*

A total of 315 surveys were sent to counselors by the Training Director of the Ohio Rehabilitation Services Commission. Completed surveys were received from 65 individuals for a response rate of approximately 20%. A reminder e-mail message was sent to counselors from the State Office; however, this did not result in the receipt of additional surveys. This response rate is very low and surprising given the study's endorsement by the Director of ORSC. However, after the surveys were mailed, we received input from several individuals employed by ORSC who suggested that we might not get a favorable response rate because the issue of HIV/AIDS is not well-addressed by the system currently and because the staff have been asked to complete several surveys in recent months.

Recruitment of focus group participants. The Training Coordinator for the Ohio Rehabilitation Services Commission recruited counselors to participate in the focus group session, which was conducted in November, 2001. She was asked to identify respondents from different geographical areas of the state and to attempt to obtain as diverse a group as possible. She then sent out announcements via e-mail asking for volunteer participants.

Demographics of survey participants. *Table 2* provides demographic information about the vocational rehabilitation counselors who chose to participate in the survey portion of this study.

Table 2: Demographics of Vocational Rehabilitation Counselors (N=65)

Demographic Variable	Frequency	Percentage
Gender		
Male	20	30.8
Female	45	69.2
Age		
21-29	9	13.8
30-39	14	21.5
40-49	13	20.0
50+	29	44.6
Education		
Some College	2	3.1
Bachelor’s Degree	7	10.8
Some Graduate Coursework	9	13.8
Master’s Degree	45	69.2
Ethnic Background		
African-American	4	6.2
Caucasian	60	92.3
Other	1	1.5
Years of Rehabilitation Experience		
1-4 years	17	26.2
5-9 years	9	13.8
10-14 years	4	6.2
15+ years	35	53.8
Certified Rehabilitation Counselor		
Yes	30	46.2
No	35	53.8
Area Served		
Urban	37	56.9
Rural	27	41.5
Disability		
Yes	18	27.7
No	47	72.3

Demographics of focus group participants. Participants in the group included seven counselors representing both the Bureau of Vocational Rehabilitation (BVR) and the Bureau of

Services for the Visually Impaired (BSVI). Respondents volunteered to participate and were provided lunch during the focus group. The respondents included four females and three males. Six respondents were Caucasian and one was African-American. Two respondents worked for BSVI and the other five worked for BVR. All respondents were state vocational rehabilitation counselors.

Assurance of Human Participants' Protection

The SARDI Program has a great deal of experience addressing human participants concerns. Our procedures are standardized for every population and are reviewed by the Wright State University (WSU) Human Participants Committee and Institutional Review Board. The data collection protocol and instrumentation were approved by the WSU Human Participants Committee before initiation of data collection activities. Respondents in the study were protected in several ways. For example, potential consumer respondents were informed that the study was being conducted independently and that refusal to participate would not affect services to which they were entitled in any way. All participants signed a written informed consent and were provided a copy. A copy of this Informed Consent appears in Appendix 5. Questionnaires and other instruments contained no personal identifiers, with the exception of a numeric ID code that referred back to the informed consents. The informed consents were maintained in a separate, locked file away from completed study instruments. Consumer requests for results of the study were provided via an abstract describing group results. All respondents were provided with the names, addresses, and telephone numbers of the Principal Investigators. Finally, all personal interviews were conducted in private locations.

The group of vocational rehabilitation counselors participating in the survey process was informed about the study by a cover letter that accompanied the mailed survey. That letter described the purpose of the study and the fact that all state vocational rehabilitation counselors in Ohio were being asked to participate. Potential respondents were informed that their responses would be anonymous and voluntary. They also were informed that completing and returning the survey to us implied their consent to participate. The survey questionnaire contained no personal identifiers. Participants who have specifically requested results of the study and provided an appropriate address will be provided an abstract describing group results. All respondents were provided in the cover letter with the names, addresses, and telephone numbers of the Principal Investigators. The sample of vocational rehabilitation counselors recruited to participate in the focus group were also asked to read and sign an informed consent document. A copy is provided in *Appendix 6*.

Measures and Instrumentation

The following section describes the measures and instruments used to gather data for the research study. It is divided into two parts. Part one describes the various instruments used in a three part process used to gather data from participants representing the consumers or individuals living with HIV or AIDS. The second part outlines the tools used to gather data from the participants representing vocational rehabilitation counselors.

Instruments Used to Gather Consumer Data

Three different interview questionnaires were developed for use with the consumer respondents in this study. Each questionnaire combined qualitative, open-ended questions with quantitative items, some of which were from standardized instruments. Development of each questionnaire included the following process: (a) obtaining input from the Expert Panel and from the interviewers, (b) drafting questions for each suggested section of the questionnaire, (c) sending the draft instrument to the Expert Panel and interviewers for feedback, (d) revising and field testing the questionnaire, and (e) submitting the final version for human participants approval prior to initiating each round of interviews.

Interviews. Questionnaires were developed for use in three interview formats. ***Interview One***. Sections of the first questionnaire were suggested by the Expert Panel. The intent of this initial interview was to gather background data in a number of critical areas: Demographics; Education, Employment, and Income; Involvement in Vocational Rehabilitation; Physical Health; Emotional Health; Alcohol and Other Drug Use; and Life Satisfaction. ***Interview Two.*** The second interview involved collecting data in the same critical areas. In addition, we obtained a legal history. Respondents were also asked to answer several questions relating to Social Supports, Family, and Leisure Activities. ***Interview three.*** The third interview questionnaire included all of the areas from Interview One, along with several additional sections dealing with utilization of resources and spirituality, tradition, and cultural identity. Respondents were also asked to answer questions related to summarizing the past year during which they were involved in the study. Copies of these three interview forms can be found in *Appendix 7.*

Instrument scales for consumer data. The following instruments scales were used during the three interviews.

- *Addiction Severity Index* (ASI; McLellan et al., 1980), a comprehensive clinical/research instrument used to assess problems across seven life areas: medical, employment/education, alcohol use, drug use, legal, family/social, and psychiatric. This study utilized the alcohol use and drug use areas. Previous research has shown the ASI to be reliable and valid (Kosten, et al., 1983; McDermott, et al., 1996; McLellan, et al., 1980; McLellan, et al., 1985).
- *Michigan Alcoholism Screening Test* (MAST; Selzer 1971), which is a 25-item self-report instrument designed as a screen for alcoholism. Several investigations have demonstrated acceptable reliability and validity for the MAST (e.g., Gibbs, 1983; Magruder-Habib, Stevens, and Alling, 1993; Storgaard, Nielsen, and Gluud, 1994).
- *Satisfaction with Life Scale* (SWLS; Diener et al., 1985) is a five-item self-report scale that has respondents indicate degree of agreement with five statements regarding satisfaction with their lives. It has been shown to be both reliable and valid (Pavot and Diener, 1993).
- *The Alcohol Use Disorders Identification Test* (AUDIT) (Babor et al., 1992; Saunders et al., 1993) was developed by the World Health Organization to identify persons whose alcohol consumption has become hazardous or harmful to their health. The AUDIT is a 10-item screening questionnaire with 3 questions on the amount and frequency of drinking, 3 questions on alcohol dependence, and 4 on problems caused by alcohol. The target population for the AUDIT is adults in a variety of settings including primary care, emergency room, psychiatric care, DUI offenders, forensic units, and employee assistance programs in industrial settings. Psychometrics conducted include reliability studies (test -retest and internal consistency) and validity tests including content and construct. Conley (2001) found that the AUDIT had good correlation, r = 0.61, with the Michigan Alcoholism Screening Test (MAST) for a sample of 126 individuals participating in a DUI treatment program.
- *Center for Epidemiologic Studies Depression Scale* (CES-D) is a 20-item instrument developed by the National Institute of Mental Health to detect major or clinical depression in adolescents and adults. The CES-D has 4 separate factors: Depressive Affect, Somatic Symptoms, Positive Affect, and Interpersonal Relations. The questions are easy to answer and cover most of the areas included in the diagnostic criteria for

depression. It has been used with urban and rural populations, and in cross-cultural studies of depression. Studies using the CES-D indicate that it has very good internal consistency, acceptable test-retest stability, and construct validity (Radloff,1977).

- *Mankoski Pain Scale* (Copyright © 1995, 1996, 1997 Andrea Mankoski). This instrument was developed by Andrea Mankoski who granted the study a right to copy with attribution. Ms. Mankoski devised this pain scale to help describe the subjective experience of pain in more concrete terms to her doctors and family. It has been published in the Australian Endometriosis Association's newsletter and is used extensively by the online community.
- *SF-36 Health Survey* (Ware, et. al., 1992; McHorney, et. al., 1993). The SF-36 Health Survey was developed for the Medical Outcomes Study and has been tested and validated extensively. The SF-36 was designed for use in clinical practice and research, health policy evaluations, and general population surveys. The SF-36 includes one multi-item scale that assesses eight health concepts: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of physical or emotional problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions. The SF-36 survey was constructed for self-administration by persons 14 years of age and older, and for in person administration by a trained interviewer or by telephone.
- *Medication and Other Drug Use Survey*. This survey was developed specifically for use as part of an epidemiological study conducted by the Rehabilitation Research and Training Center on Drugs & Disability. The survey questionnaire contains 102 items regarding alcohol and other drug use, disability, attitudes toward disability and substance use, family background, employment and work-related background, rehabilitation services, psychosocial functioning, and demographic characteristics. The instrument has proven to be extensive, yet user-friendly. Several key independent variables also considered include social/demographic characteristics, employment and work-related experiences, disability background, rehabilitation history, peer or family influences, and psychosocial factors such as self-esteem, depression and risk-taking.

Instruments Used to Gather Vocational Rehabilitation Counselor Data

The researchers utilized a questionnaire to solicit perceptions, knowledge, experience/training, and skill levels relating to HIV and AIDS. The instrument was a compilation of items derived from a previous study of rehabilitation counselors (Glenn, 1997). The sections utilized were subjected to Chronbach's alpha reliability analysis with results indicating high internal consistencies: perception , 0.88; knowledge, 0.81; experience/training, 0.68; and skills, 0.97 (Glenn, 1997). A section adapted from the World Institute on Disability's 1994 survey instrument (26 items) measured perceptions that vocational rehabilitation counselors have toward persons living with HIV/AIDS.

In the second section, counselors' knowledge was measured by a series of questions developed by Peterson (1988) and used by Hunt (1996) and Glenn (1997) in national studies of rehabilitation professionals. This instrument included 38 questions about the rehabilitation counselor's knowledge of the course of HIV and AIDS; situations that place a person at risk for contracting the disease; legislation affecting the rights of persons with HIV or AIDS; stressors related to HIV and AIDS; and medical treatment modalities. These questions require true/false responses.

Self-reported skill levels were assessed using a scale from a previous study of rehabilitation counselors (Glenn, 1997). This measurement was designed to investigate specific information related to counseling, planning and resource acquisition and other aspects of the rehabilitation counseling process. Skill levels were rated by counselors for 14 items, with a seven point Likert scale for each item.

In addition to the survey, an interview questionnaire was developed for a focus group interview of practicing rehabilitation counselors. The questionnaire obtained details of the vocational rehabilitation services and the rational for these services that were provided to consumers living with HIV/AIDS as well as the number and nature of client contacts, the nature and types of referrals, and client progress reports.

Data Collection

Data collection for the study began in May, 2000 and lasted for 17 months. The majority of the consumer interviews were completed by the end of the summer of 2001. The data collection involving the initial group of vocational rehabilitation counselors occurred in the spring of 2001 and the focus group was completed in November, 2001.

Consumer-Generated Data

All consumers who called in response to the recruitment flyers and advertisements participated in a brief screening by telephone. As noted earlier, the screening was used to gather information that would be pertinent in the selection process and included information about demographics, current employment status, experience with state vocational rehabilitation, and reasons for wanting to become employed. The study involved collection of both qualitative and quantitative data. Data were collected from volunteer participants, with their consent, at three points during the study. Baseline data collection (T1) occurred for 53 participants as part of one-on-one interviews completed during April and June, 2000. The first follow-up interviews (T2) occurred during October and November, 2000 (n = 51) and the final second-follow-up interviews (T3) occurred during May through July, 2001 (n = 49). Participants were randomly assigned to one of three SARDI staff counselors/interviewers throughout the study. During each interview, participants provided descriptive responses to qualitative questions and provided anecdotal experiences to the interviewer, which were manually recorded and audio-taped for later transcription, with the participants' permission. Additionally, participants responded to Likert-type scale and "Yes-No" quantitatively-scored questions, including items from the Michigan Alcoholism Screening Test, an alcohol use inventory (AUDIT), the SF-36 health survey, etc.

Vocational Rehabilitation Counselor-Generated Data

All vocational rehabilitation counselors employed by the Ohio Rehabilitation Services Commission were recruited to participate in the initial counselor-related data collection effort via a mailed, self-administered, paper/pencil survey. Cover letters and surveys were sent to all counselors along with a post-paid return envelope. Surveys were mailed in February and March, 2001. Survey questions focused on barriers to service delivery and successful rehabilitation outcomes, vocational rehabilitation counselor perceptions about people living with HIV/AIDS, and counselors' self-reported skill levels for providing rehabilitation services to this population.

The focus group questions related to counselor knowledge of HIV or AIDS, attitudes, and perceived skills in working with this population. We also explored counselor perceptions related to barriers to employment for people living with HIV or AIDS.

Data collection for the study was completed by Master's level research staff who were selected based on three characteristics: (1) psychology, social science, rehabilitation, or nursing backgrounds with at least five years of post-baccalaureate experience, and (2) either experience providing clinical services to people who are living with HIV or AIDS or who are living with other disabilities, or experience collecting data from consumers with disabilities, including those experiencing alcohol and other drug use problems. All personnel, independent of their backgrounds, completed training that focused on HIV and AIDS, federal benefits, drugs of abuse, and interviewing techniques. The interviewer training consisted of formal protocol training, instrument training, mock interviews, and routine monitoring. De-briefing sessions were held with the interview team after each set of consumer interviews to process the data collected and to discuss themes and commonalities.

Analysis

The analysis involved consumer and counselor generated data. This section outlines the analyses utilized in each part of the study.

Analysis of Consumer – Generated Data

There were two types of procedures used to analyze the consumer-generated data, quantitative and qualitative.

Quantitative analysis procedures. Quantitative data were analyzed for correlations (e.g., Pearson's r) among hypothesized related variables (e.g., substance use levels and depression). Data collected at multiple times were analyzed via paired-samples t-tests and chi-square tests of independence. Additionally, the impact of combined independent variables upon dependent/ outcome variables were assessed using one-way and two-way analyses of variance, as well as linear regression and logistic regression analyses.

Frequency and correlational analyses were used to ascertain the percent of consumers with HIV or AIDS that report moderate or severe problems with alcohol. The responses were correlated with five vocational rehabilitation service variables, including: (1) VR services applied for or used; (2) Number of participants having received VR services; (3) VR services applied for since last interview; (4) Ever been a consumer of VR services; and (5) Participated in VR services since the last interview. VR service items were also cross-tabulated with several T1-

T2 measures of substance abuse for a final frequency report. Demographic information was identified for those reporting severe problems with alcohol and drug use.

Independent t-tests of two HIV groups were conducted for the variables (a) positive income differences from T1-T2; (b) increased benefits; (c) more job applications; (d) improved job satisfaction if working; and (e) positive employment changes (e.g., unemployed to employed, part-time to full-time work). The two population groups were (1) participants with short MAST scores ≤ 5 , n=19, compared to participants with short MAST scores >5, n=32; and (2) Participants with no reported drug use in the past year (n=19) compared to participants with at least one reported drug used in the past year (n=24).

Independent t-tests of the same two groups were conducted for each of the following variables (a) current work situation at T1; (b) HIV caused change in employment; (c) T2 any change in employment situation; (d) general impressions of current health; (e) my health is excellent; (f) I expect my health to get worse; (g) current health compared to one year ago; (h) number of days during the past month in which I felt bad; and (i) composite health status combined with data from T2 health items.

Correlational analyses of several T1 and T2 health, work and rehabilitation questions were done to address relationship between consumer-reported ability to work, satisfaction with vocational rehabilitation services, and level of disease progression.

Qualitative analysis procedures. Qualitative responses were compiled to assess participants' perceived barriers to employment, as well as common experiences related to employment history, social interactions, vocational rehabilitation training, and levels of substance use over time.

Analysis of Vocational Rehabilitation Counselor – Generated Data

Information collected during the interviews for counselors were linked with the results of qualitative data analyses to add contextual background and explanatory detail to the quantitative findings. Qualitative data were synthesized in an effort to identify recurring themes and issues that link HIV, substance abuse, and vocational rehabilitation services outcomes. Grounded theory procedures and techniques enabled theoretical interpretations grounded in empirical findings (Strauss & Corbin, 1990). Aspects of interviewer bias (a nearly inevitable side effect of qualitative research) were explored through data review, case presentations, and design team discussions. Audiotape recordings, after transcription fidelity checks, were used in content analyses. Specifically, Folio VIEWS or Q.S.R. Nudist software was used to support an analysis of transcript data (Ray, 1997).

RESULTS

The results of the data analyses are organized for review by research question. Each question is highlighted with the analysis of data collected from both consumers and rehabilitation counselors.

Research Question 1

What percentage and what are the demographic characteristics of consumers living with HIV or AIDS that report moderate or severe problems with substance abuse?

Findings from Consumer Data/Quantitative

Several VR services items were compared to the short form scores of the MAST (Michigan Alcoholism Screening Test). There are variations in the level of interpretability for the short and full MAST scores recorded at T2 (variable shrtmast). For the short MAST, the cutoff score for alcoholism problems is either >3 or >5. A cutoff score of >5 was used in this study to reduce the chances of false positives. *Table 3* provides the summary of the information learned in this analysis.

Sixty three percent of the study participants living with HIV or AIDS have some problems with alcohol, according to the s-MAST scores. Sixteen of the 51 participants (.314) have ever used VR services; of these, thirteen (.812) have alcohol-related problems. Between T1 and T2, an estimated 31 HIV participants (23 in T1, 8 in T2) (.608) have ever applied for VR services; of these, 22 (17 in T1, 5 in T2) (.709) had alcohol-related problems. For the 35 non-VR users (.686), 19 (.543) had alcohol-related problems. The correlations were highly significant ($p < .01$) between four of the five VR services variables, with the exception of the item “VR services applied for since the last interview.”

Table 3. Participants living with HIV or AIDS that report moderate or severe problems with alcohol (N=51)

	sMAST ≤ 5	sMAST > 5	Total
VR Services applied for or used (T1 variable q33)			
No	13 (.255)	15 (.294)	28 (.549)
Yes	6 (.118)	17 (.333)	23 (.451)
Total	19 (.373)	32 (.627)	51 (1.000)
Number of participants having received VR services (T1 variable q35asum)			
No services	17 (.333)	23 (.451)	40 (.784)
≥ 1 service	2 (.039)	9 (.176)	11 (.216)
Total	19 (.373)	32 (.627)	51 (1.000)
VR Services applied for since last interview (T2 variable 00146)			
No	16 (.314)	27 (.529)	43 (.843)
Yes	3 (.059)	5 (.098)	8 (.157)
Total	19 (.373)	32 (.627)	51 (1.000)
Ever Been Consumer of VR services (T2 variable 00147)			
No	16 (.314)	19 (.373)	35 (.686)
Yes	3 (.059)	13 (.255)	16 (.314)
Total	19 (.373)	32 (.627)	51 (1.000)
Participated in VR Services since the last interview (T2 variable q65)			
No	16 (.314)	28 (.549)	44 (.863)
Yes	3 (.059)	4 (.078)	7 (.137)
Total	19 (.373)	32 (.627)	51 (1.000)

Likewise, the VR services items used with the s-MAST scores were cross-tabulated with several T1-T2 measures of substance abuse. The basic measure of drug abuse was established as a composite for each subject having used any of several drugs (e.g., marijuana, cocaine, heroin, etc.) during the past month or during the past year. There were also questions asking for use of the same substances since the last interview (T1). Related results are summarized in *Table 4*.

Table 4. Participants living with HIV or AIDS that report drug use @ T1 (N=51)

Drug Use	No	Yes	Total
VR Services applied for or used (T1 variable q33) **versus Drug Use in the last year** (T1 variable q98bsum)			
No	14 (.275)	14 (.275)	28 (.549)
Yes	13 (.255)	10 (.196)	23 (.451)
Total	27 (.529)	24 (.471)	51 (1.000)
VR Services applied for or used (T1 variable q33) **versus Drug Use in the last month** (T1 variable q98csum)			
No	20 (.392)	8 (.157)	28 (.549)
Yes	16 (.314)	7 (.137)	23 (.451)
Total	36 (.706)	15 (.294)	51 (1.000)
Number of participants having received VR services (T1 variable q35asum) **versus Drug Use in the last year** (T1 variable q98bsum)			
No services	21 (.412)	19 (.373)	40 (.785)
≥ 1 service	6 (.118)	5 (.117)	11 (.215)
Total	27 (.530)	24 (.470)	51 (1.000)
Number of participants having received VR services (T1 variable q35asum) **versus Drug Use in the last month** (T1 variable q98csum)			
No services	29 (.569)	11 (.216)	40 (.785)
≥ 1 service	7 (.137)	4 (.078)	11 (.215)
Total	36 (.706)	15 (.294)	51 (1.000)

Forty percent of the participants living with HIV or AIDS used drugs on a yearly basis, 29 percent within the month preceding the T1 interview. Twenty-three of the HIV participants

(.451) had ever used VR services; of these, seven (.304) had drug-related problems on a monthly basis, ten (.435) for a yearly basis. Only eleven (.215) reported receiving VR services; of these, five (.455) had used drugs within the past year. Similar questions were asked of the participants at T2 for comparison. Those results are presented in *Table 5*.

Table 5. Participants living with HIV or AIDS that report drug use @ T1 (N=51)

Drug Use	No	Yes	Total
VR Services applied for since last interview (T2 variable 00146) vs Drug Use since last interview (T2 variable q114sum)			
No	28 (.549)	15 (.294)	43 (.843)
Yes	6 (.118)	2 (.039)	8 (.157)
Total	34 (.667)	17 (.333)	51 (1.000)
VR Services applied for since last interview (T2 variable 00146) vs Drug Use in last month (T2 variable q115sum)			
No	30 (.588)	13 (.255)	43 (.843)
Yes	6 (.118)	2 (.039)	8 (.157)
Total	36 (.706)	15 (.294)	51 (1.000)
Ever Been Consumer of VR services (T2 variable 00147) vs Drug Use since last interview (T2 variable q114sum)			
No services	24 (.471)	11 (.216)	35 (.686)
≥1 service	10 (.196)	6 (.118)	16 (.314)
Total	34 (.667)	17 (.333)	51 (1.000)
Ever Been Consumer of VR services (T2 variable 00147) vs Drug Use in last month (T2 variable q115sum):			
No services	26 (.510)	9 (.176)	35 (.686)
≥1 service	10 (.196)	6 (.118)	16 (.314)
Total	36 (.706)	15 (.294)	51 (1.000)

Eight participants living with HIV or AIDS had newly applied for VR services by interview T2, bringing the estimated total to 31 (23 in T1 and 8 in T2) (.608). This statistic does not consider individuals that may have repeatedly applied during their lifetime. No interview questions address first ever VR applications. Of the eight new applicants, two (.25) had substance use during the roughly five month period preceding the T2 interview. One-third of these participants had used drugs during the interview interval. These results were reiterated in the following T2 monthly drug use results:

The consistency reported here is expected due to the short time scale (five-month interval versus last month). This indicator (Ever been a consumer of VR services) strongly addresses the question: What percentage of VR customers with HIV/AIDS report moderate or severe problems with substance abuse? Roughly one-third of the HIV participants have ever used VR services. Of these sixteen participants, six (.375) have substance use issues, compared to .257 (9/35) of nonusers of VR services who report substance use within the past month, or .314 (11/35) of nonusers of VR services who reported substance use within the five month interval between T1-T2.

Note: As of T2, 44 HIV participants (.863) reported that they were not currently consumers of VR services. The subjective interview questions found many participants either unfamiliar with VR or had frustrations with the VR system. Eleven (.25) of these participants had used drugs within the past month. Only seven (.137) of the HIV participants had participated in VR services since the last T1 interview; three of these individuals (.429) had used drugs during this five month interval and during the past month preceding T2.

Next, the relationship between alcohol and gender and drug use and gender of the surveyed consumers was addressed. Related data reported in *Tables 6and 7*, respectively, are for the entire n=51 sample of HIV participants, since only about one-third of these individuals reported having ever used VR services and it was not possible to look at that issue concurrently due to the small sample sizes.

Table 6. Gender of participants living with HIV or AIDS (T1 variable 002) versus short MAST score (T2 variable shrtmast) (N=51)

Gender	sMAST ≤ 5	sMAST > 5	Total
Female	6 (.118)	6 (.118)	12 (.235)
Male	13 (.255)	26 (.510)	39 (.765)
Total	19 (.373)	32 (.627)	51 (1.000)

Table 7. Gender of participants living with HIV or AIDS (T1 variable 002) versus T1 drug use in the past year (T1 variable q98bsum), T1 drug use in the last month (T1 variable q98csum) (N=51)

	Past Year:			Past Month:		
Gender	**None**	**Some**	**Total**	**None**	**Some**	**Total**
Female	8 (.157)	4 (.078)	12 (.235)	11 (.216)	1 (.020)	12 (.235)
Male	19 (.373)	20 (.392)	39 (.765)	25 (.490)	14 (.275)	39 (.765)
Total	27 (.529)	24 (.471)	51 (1.000)	36 (.706)	15 (.294)	51 (1.000)

Three-fourths (.75) of the HIV study participants were male. This compares to a 1996 CDC estimate of .91 male for the Dayton, Ohio HIV population. Greater longevity among individuals living with HIV or AIDS, a four-year span since the CDC study, and a growing HIV epidemic among women, probably explain this .16 discrepancy. The sample appears to be representative based upon gender. Of the male participants, one-half reported drug use within the past year and 35.9 percent reported drug use within the past month. Two-thirds of the male participants had short MAST scores indicating alcohol problems. Of the 12 female participants, four individuals reported drug use within the past year, and one individual reported drug use within the past month. One-half of the female participants had s-MAST scores indicating alcohol problems.

The next set of relationships explored was between alcohol use and drug use and consumers' ages. The related results are summarized in *Tables 8 and 9*.

Table 8. Age of participants living with HIV or AIDS versus s-MAST score (N=51)

Age	sMAST ≤ 5	sMAST > 5	Total
20-29	3 (.059)	1 (.020)	4 (.078)
30-39	6 (.118)	12 (.235)	18 (.353)
40-49	8 (.157)	18 (.353)	26 (.510)
50-59	2 (.039)	0 (.000)	2 (.039)
Over 60	0 (.000)	1 (.020)	1 (.020)
Total	19 (.373)	32 (.627)	51 (1.000)

Table 9. Age (calculated T1-2 variable age) versus T1 drug use in the past year (T1 variable q98bsum), T1 drug use in the last month (T1 variable q98csum) (N=51)

	Past Year:			Past Month:		
Age	**None**	**Some**	**Total**	**None**	**Some**	**Total**
20-29	3 (.059)	1 (.020)	4 (.078)	3 (.059)	1 (.020)	4 (.078)
30-39	8 (.157)	10 (.196)	18 (.353)	12 (.235)	6 (.118)	18 (.353)
40-49	14 (.275)	12 (.235)	26 (.510)	19 (.373)	7 (.137)	26 (.510)
50-59	1 (.020)	1 (.020)	2 (.039)	1 (.020)	1 (.020)	2 (.039)
Over 60	1 (.020)	0 (.000)	1 (.020)	1 (.020)	0 (.000)	1 (.020)
Total	27 (.529)	24 (.471)	51 (1.000)	36 (.706)	15 (.294)	51 (1.000)

Eighty-six percent of the sampled participants living with HIV or AIDS were between 30 and 49. One-half of the participants are between 40 and 49, compared to 1996 CDC estimates of 0.27 for the same age range among participants in the Dayton, Ohio area. Exactly half of participants age 30 to 49 report drug use on a yearly basis. Thirty percent of individuals in this age range report drug use within the past month. Sixty-eight percent of the participants age 30 to 49 had s-MAST scores indicating alcohol problems.

Shown in *Tables 10 and 11* are the relationships between alcohol use and drug use and ethnicity.

Table 10. Ethnicity of participants living with HIV or AIDS versus s-MAST score (N=51)

Ethnicity	sMAST ≤ 5	sMAST > 5	Total
Caucasian	8 (.157)	13 (.255)	21 (.412)
African-American	9 (.176)	14 (.275)	23 (.451)
Asian/Pacific Island	0 (.000)	1 (.020)	1 (.020)
Hispanic	1 (.020)	4 (.078)	5 (.098)
Multiracial/Other	1 (.020)	0 (.000)	1 (.020)
Total	19 (.373)	32 (.627)	51 (1.000)

Table 11. Ethnicity of participants versus T1 drug use in the past year (T1 variable q98bsum), T1 drug use in the last month (T1 variable q98csum) (N=51)

	Past Year:			Past Month:		
Ethnicity	**None**	**Some**	**Total**	**None**	**Some**	**Total**
Caucasian	11 (.216)	10 (.196)	21 (.412)	13 (.255)	8 (.157)	21 (.412)
Afri. Amer.	11 (.216)	12 (.235)	23 (.451)	17 (.333)	6 (.118)	23 (.451)
Asian/Pacif	1 (.020)	0 (.000)	1 (.020)	1 (.020)	0 (.000)	1 (.020)
Hispanic	4 (.078)	1 (.020)	5 (.098)	5 (.098)	0 (.000)	5 (.098)
Mult/Other	0 (.000)	1 (.020)	1 (.020)	0 (.000)	1 (.020)	1 (.020)
Total	27 (.529)	24 (.471)	51 (1.00)	36 (.706)	15 (.294)	51 (1.00)

Forty-five percent of the participants living with HIV or AIDS are African-American, and 41 percent are Caucasian. Ten of the Caucasian participants (.476) reported drug use within the past year, eight of them within the past month of the T1 interview. Twelve of the African-American participants (.522) reported drug use within the past year, six of them within the month preceding the T1 interview. The five Hispanic participants had only one reported drug use within the past year. Thirteen of the Caucasians (.619), fourteen of the African-Americans (.609), and four of the five Hispanics (.800) had short MAST scores indicating alcohol problems.

The next demographic characteristic considered was marital status. The related relationships between alcohol use and marital status and between drug use and marital status are presented in *Tables 12 and 13*, respectively.

Fifty-five percent of the participants had never been married. Of this group, 57 percent (16/28) reported drug use within the past year, and 39 percent (11/28) reported drug use within the month preceding interview T1. The six separated participants reported low drug use. Forty-two percent (5/12) of divorced participants reported drug use within the past year, although only 20 percent of divorced participants reported using drugs within the month preceding T1. One-half of those participants never married had s-MAST scores indicating alcohol problems. Both the separated and divorced groups had .83 of participants with s-MAST scores indicating alcohol problems.

Table 12. Marital status of participants living with HIV or AIDS versus s-MAST score (N=51)

Marital Status	sMAST ≤ 5	sMAST > 5	Total
Never Married	14 (.275)	14 (.275)	28 (.549)
Married	1 (.020)	1 (.020)	2 (.039)
Living as Married	0 (.000)	1 (.020)	1 (.020)
Separated	1 (.020)	5 (.098)	6 (.118)
Divorced	2 (.039)	10 (.196)	12 (.235)
Widowed	1 (.020)	1 (.020)	2 (.039)
Total	19 (.373)	32 (.627)	51 (1.000)

Table 13. Marital Status T1 versus drug use in the past year (T1 variable q98bsum), T1 drug use in the last month (T1 variable q98csum) (N=51)

Marital	Past Year:			Past Month:		
Status	None	Some	Total	None	Some	Total
Never Married	12 (.235)	16 (.314)	28 (.549)	17 (.333)	11 (.216)	28 (.549)
Married	1 (.020)	1 (.020)	2 (.039)	1 (.020)	1 (.020)	2 (.039)
Living as Married	1 (.020)	0 (.000)	1 (.020)	1 (.020)	0 (.000)	1 (.020)
Separated	4 (.078)	2 (.039)	6 (.118)	5 (.098)	1 (.020)	6 (.118)
Divorced	7 (.137)	5 (.098)	12 (.235)	10 (.196)	2 (.039)	12 (.235)
Widowed	2 (.039)	0 (.000)	2 (.039)	2 (.039)	0 (.000)	2 (.039)
Total	27 (.529)	24 (.471)	51 (1.00)	36 (.706)	15 (.294)	51 (1.00)

Years of education was the next background variable considered. The relationships between alcohol use and years of education and drug use and years of education are described via *Tables 14 and 15*, respectively. For the purposes of these analyses years of education has been subdivided into the following four categories: (a) less that 12th grade, (b) 12th grade, (c) grades 13 or 14, and (d) grade 15 or higher.

Table 14. Years of education completed by participants versus s-MAST score (N=51)

Years Education	sMAST ≤ 5	sMAST > 5	Total
< 12	3 (.059)	4 (.078)	7 (.137)
12	9 (.176)	14 (.275)	23 (.451)
13-14	2 (.039)	12 (.235)	14 (.275)
≥ 15	5 (.098)	2 (.039)	7 (.137)
Total	19 (.373)	32 (.627)	51 (1.000)

Table 15. Years of education completed by participants versus drug use in the past year (T1 variable q98bsum), T1 drug use in the last month (T1 variable q98csum) (N=51)

Years	Past year:			Past Month:		
Education	None	Some	Total	None	Some	Total
< 12	5 (.098)	2 (.039)	7 (.137)	5 (.098)	2 (.039)	7 (.137)
12-14	19 (.373)	18 (.353)	37 (.725)	25 (.490)	12 (.235)	37 (.725)
12	12 (.235)	11 (.216)	23 (.451)	15 (.294)	8 (.157)	23 (.451)
13-14	7 (.137)	7 (.137)	14 (.275)	10 (.196)	4 (.078)	14 (.275)
> 15	3 (.059)	4 (.078)	7 (.137)	6 (.118)	1 (.020)	7 (.137)
Total	27 (.529)	24 (.471)	51 (1.00)	36 (.706)	15 (.294)	51 (1.00)

Three-fourths of the participants living with HIV or AIDS have at least a high school education and/or some college. Fifty percent of this group reported drug use within the past year, and 12 (.327) of this group reported drug use in the month preceding the T1 interview. Seventy percent of this group had a short MAST score indicating alcohol problems. Eighty-six percent of the participants having some college experience (13-14 years) had short MAST scores indicating alcohol problems.

The next set of relationships studied dealt with consumers' self-reported work situation. The associated results are presented in *Tables 16 and 17*.

Table 16. Current work situation of participants versus s-MAST score (N=51)

Work	sMAST ≤ 5	sMAST > 5	Total
Full Time	0 (.000)	7 (.137)	7 (.137)
Part Time	3 (.059)	3 (.059)	6 (.118)
Under the Table	3 (.059)	8 (.157)	11 (.216)
Seeking Work	8 (.157)	7 (.137)	15 (.294)
Not Seeking Work	5 (.098)	7 (.137)	12 (.235)
Total	19 (.373)	32 (.627)	51 (1.00)

Table 17. Current work situation versus drug use in the past year (T1 variable q98bsum), T1 drug use in the last month (T1 variable q98csum) (N=51)

	Past Year:			Past Month:		
Work	None	Some	Total	None	Some	Total
Full Time	6 (.118)	1 (.020)	7 (.137)	6 (.118)	1 (.020)	7 (.137)
Part Time	2 (.039)	4 (.078)	6 (.118)	3 (.059)	3 (.059)	6 (.118)
Under the Table	4 (.078)	7 (.137)	11 (.216)	5 (.098)	6 (.118)	11 (.216)
Seeking Work	8 (.157)	7 (.137)	15 (.294)	12 (.235)	3 (.059)	15 (.294)
Not Seeking	7 (.137)	5 (.098)	12 (.235)	10 (.196)	2 (.039)	12 (.235)
Total	27 (.529)	24 (.471)	51 (1.00)	36 (.706)	15 (.294)	51 (1.00)

The seven participants (.137) in the study that worked full-time at T1 all had s-MAST scores indicating alcohol problems. However, only one of these full-time worker participants had used drugs in the past year, including the one month preceding T1. Fifty percent of the part-time worker participants had s-MAST scores indicating alcohol problems; another fifty percent of this group indicated drug use in the month preceding T1. Seventy-three percent of the under-the-table work participants had high s-MAST scores; another 64 percent of these participants indicated yearly drug use. Therefore, the under-the-table workers may be at risk for both alcohol and substance abuse. Approximately one-half of the participants who were unemployed and seeking or not-seeking work had high s-MAST scores and drug use within the last year. However, drug use for the past month was low for both categories of unemployed participants (.20 of those seeking work, .13 of those not seeking work).

Findings from Consumer Data/Qualitative

Problems with drinking too much alcohol. During the first interview respondents were asked, “Has there ever been a time in your life when you think that you had a problem with drinking too much alcohol?” They were to respond with one of the following: 1) definitely, 2) probably, 3) maybe, and 4) definitely not. Respondents were then asked to explain their answers.

Twenty of the 53 respondents, or roughly 38%, responded with “4” indicating that they definitely have never had a problem with alcohol. Five African American females and seven African males were in this group. In addition, one Caucasian female, five Caucasian males, one Hispanic male, and one male classified as “another race” were in this group.

The majority of the group stated that they rarely drank alcohol or drank only minimally such as on special occasions. Several individuals indicated that they had had a consequence and then reduced their use. For example, one individual stated, “When I was younger, I did get sick a couple of times. I don’t like getting hangovers.” Another individual shared something similar, “I got drunk enough to vomit once. I sure don’t want to do that again.” Two respondents reported that they had family members who were alcoholic and this was a deterrent for them.

Five respondents, or 9% of the sample, responded that “maybe” they had had a problem with drinking at some point in their lives. One participant in this group was an African American female. The other four were male – two African American and two Caucasian. One of the individuals stated that she can drink “a lot.” She says that she “only drinks beer” and that she likes beer. Her mother has been concerned about her drinking and calls her an alcoholic. Another individual reported that during the past three months, he had been drinking daily. One individual stated that when his partner was dying he drank “a lot,” and another person said, “I must be in a state of denial.” The other participant in this category shared that he knew he shouldn’t drink with medications but did anyway. Up until the time in 1996 when he shared with his family that he is HIV+, he had been drinking to get drunk rather than socially. He reports that now he does not have a problem with drinking.

Three individuals, 6% of the sample, reported that they "probably" have had a problem with alcohol. One African American male and two Caucasian males responded to this category. One individual stated that he "probably" has a problem because once he starts drinking he at times cannot quit. Another participant shared that he almost flunked his senior year of college because of "way too much partying." He also reported an alcoholism and substance abuse history on both sides of his family. The remaining participant, who stated that he probably had a problem with drinking, said that he drank a lot when he was younger – about 25 years old. He said that he drank to forget his problems and to avoid facing up to his problems. He went to bars very frequently. He said he did go to AA (Alcoholics Anonymous) on his own then, on and off for about a year. He also said that he had stopped drinking during that time period.

Twenty-five, or 47%, of 53 respondents reported a "1" indicating that they definitely experienced a problem with drinking too much alcohol at some time in their lives. Six respondents in this category were female (two African American, three Caucasian, and one Hispanic). Nineteen respondents in this group were male (five African American, 10 Caucasian, three Hispanic, and one identified as being of another race).

Some of the most reported consequences were needing to attend AA or alcohol treatment programs (n=5), arrests for Driving Under the Influence or other charges (n=5), drinking to medicate or relieve negative feelings such as depression (n=5), drinking daily (n=4), and being "out of control" with drinking (n=4). Some of the respondents described problems with drinking in their youth and then making significant changes to their drinking patterns. Others reported continued problems with alcohol. Some respondents described problems and consequences related to drinking soon after they were given a diagnosis of HIV+ or AIDS. One participant described receiving a driving under the influence charge (DUI) in 1975, when he was laid off from his driving job. He was drinking a lot during that period and states that he was lucky that he didn't lose his license and his job. One woman stated, "My kids were born with low birth weight; I had fights with my husband; there were money problems; I was evicted. I knew I had a problem."

Another participant admitted that he had been sexually abused as a child. He stated that he definitely has had a problem with drinking too much alcohol in his life. When asked why he thinks that, he responded, "I would be sitting in my yard pulling weeds, and I would wake up to the neighbor sitting me up in the dandelions. I was so violent, I would beat up homeless people who trespassed on my property. I tried to strangle my lover." He has a sister and a brother who were also sexually abused by their father. When the siblings get together now, as adults, they take their rage out on each other and cannot really talk about their father without getting mad at one another. He indicated that he drinks to cope with his feelings of rage and to medicate the depression and other problems in his life.

Another individual was arrested for DUI about five months after being diagnosed HIV+. He stated, "It was one of those days when I was depressed, mad, feeling sorry for myself. After getting the DUI, I knew I had a problem or couldn't deny it any longer. I recognized that it had been a problem for the last 10 years. I was not dealing with the HIV; my friends were dying; I had a lot of guilt and anger; I didn't have to feel or think. I remember hoping maybe I would die but not from this disease."

Research Question 2

How do substance abuse problems relate to employment outcomes for consumers living with HIV/AIDS?

Findings from Consumer Data/Quantitative

Positive vocational rehabilitation outcomes could be operationally defined via experiences such as the following five T1-T2 variables: (a) positive income differences from T1-T2; (b) increased benefits; (c) more job applications; (d) improved job satisfaction if working; and (e) positive employment changes (e.g., unemployed to employed, part-time to full-time work). Using an alpha = .05 level of significance for two-tailed t-tests, there were no significant differences between the low and high alcoholism s-MAST participants for any of the five vocational rehabilitation outcome variables. Likewise, there were no significant differences between the non-drug-users and drug-users for any of the five variables. Furthermore, t-tests between users and non-users of vocational rehabilitation services for these five variables were not significant at alpha = .05.

Findings from Consumer Data/Qualitative

Employment problems prior to diagnosis of HIV or AIDS. In the third interview, respondents were asked whether or not they had experienced any employment difficulties prior to their diagnoses. Seven of the individuals indicated that they had experienced some type of employment problem while 42 individuals reported that they had not had any difficulties. Several individuals had been diagnosed as HIV+ while they were very young and had not had many opportunities to work prior to the diagnosis. A number of individuals reported very solid work histories prior to their diagnoses describing steady and consistent work. The majority of individuals reporting no prior work problems stated that they were able to find employment relatively easily. One participant stated, "I had no problem applying for and getting a job. I was never unemployed prior to 1992 when I was diagnosed HIV+."

One individual stated that he had experienced some slight mental health issues prior to his diagnosis. "These issues did not become severe until my diagnosis of HIV." Another individual commented that he has always been dissatisfied with his employment situation, both prior to his diagnosis and now. Another individual commented, "I really have no problem getting jobs. I do have a problem keeping them."

Two individuals reported having some difficulty in getting along with others at work. One individual described that he "butted heads" with his supervisors. He indicated, however, that this was just "typical stuff" and that everyone has this problem. Another participant reported that she has had problems with supervisors (persons in authority) in previous jobs. She gets angry and "goes off at them." She has been fired because of this. This same individual has physical problems because of her other disabilities which have caused problems with her work.

Two individuals reported they had had employment problems prior to their HIV diagnoses related to their use of alcohol and other drugs. One woman said, "I was a drug addict and I didn't take my jobs seriously. I worked to get money for drugs." Another participant indicated that his alcohol and drug use interfered with most of his jobs.

Research Question 3

What barriers to obtaining and maintaining gainful employment exist for persons living with HIV/AIDS?

Findings from Consumer Interviews/Qualitative Data

Opinions about the potential loss of benefits. The potential loss of benefits is an area of concern for individuals living with HIV or AIDS. The cost of medication and medical care can be overwhelmingly high. Most respondents were receiving some type of benefit such as Medicare or a prescription drug program to help meet these medical expenses. In addition, many received benefits such as SSI or SSDI to help cover basic living expenses such as rent, utilities, food, etc. All benefits mentioned have ceilings on the income a person can earn and still maintain benefit eligibility.

The biggest concern among the study participants regarding benefits was the loss of coverage of medical needs, especially medication, which can reach into thousands of dollars per month. Most of the respondents were aware that they could earn up to a specific amount of income without losing any benefits. Some were able to state specific amounts stipulated by the contributing agency. One mentioned that his employer knows about his benefits and doesn't ask him to work extra hours. Several stated they would lose only medical benefits upon becoming employed, while a few said they would remain eligible for medical benefits but would lose all other coverage. Eight respondents stated that they would definitely lose all benefits if they became employed, while three stated that they would definitely not lose any benefits.

Several addressed the fear of losing benefits upon employment and then becoming too sick to work, whereby they would have to reapply for benefits and wait for coverage to begin. One person said, "It is like playing Russian Roulette. I had a friend who went to work and he lost everything. When he got sick and lost his job, he had to go through all the paperwork and delays to get his benefits back. It was not worth it."

Several consumers spoke of their concerns about losing benefits, although they had not sought out any specific information regarding limits or guidelines. One consumer stated that trying to get a definite answer from an agency was confusing because "no one can give the same answers…different people have told me different things."

One participant described her experience with having to choose between employment and benefits. Because she had a pre-existing condition (HIV+), she was not immediately eligible for full health coverage under her employer's medical insurance. She was covered under transitional Medicaid (she was employed but they were still covering her until she could get coverage under her work), but her Medicaid was due to end prior to her eligibility for full insurance coverage. She contacted the Human Resources supervisor, the director of Human Resources, and the Assistant to the Governor in an attempt to keep her Medicaid coverage until she could become fully insured by her employer. She was denied and had to make the very difficult choice of leaving her job in order to retain her Medicaid coverage. She stated, “It hurt a lot. I had to give up my home and move back in with my mother.” She has been unemployed since this incident**.**

Experiences telling employers about HIV status. A total of 24 respondents indicated that they had told an employer about their HIV status. Seventeen of the respondents stated that their experience in this regard was positive or at least not problematic. Four respondents indicated that their HIV status helped them obtain employment because their employers were AIDS Service Organizations or were known to be “HIV friendly” employers. One individual stated that disclosing his HIV status enabled him to collect disability from his employer.

Another participant indicated that he told his cousin who hired him but he did not disclose his condition to any of his co-workers. Several other respondents relayed similar stories. One man told his store manager about his HIV status. The manager had wondered why the participant had asked for so many days off for doctor’s appointments and she frequently asked him if he was OK. He did tell her, and she was supportive indicating that her best friend had died from AIDS. She promised that she would keep his HIV status confidential and the participant states that it appears to have stayed private between them.

The disclosure of HIV was problematic at first for a couple of respondents, but then became a positive factor in their employment. One person was a bartender and told her boss after work one night when they had both been drinking. The next day another employee told her that their boss wasn’t comfortable with her working at the bar anymore because customers would find out and not come back. The participant left the job, but a week later was called back because the boss realized that he had lost a good worker. When she returned to work, everyone was supportive of her and her situation.

Another participant had an unusual occurrence. His employer actually was the one to tell him that he was HIV+. He was working for the plasma donation center and wanted to donate plasma. On several occasions, the doctor had told him that his lymph nodes in his neck were swollen so he could not donate. About the fourth time he tried, his lymph nodes were not swollen and he was allowed to donate. One week later, his supervisor called him in and told him that he had tested positive for HIV. The supervisor was very supportive of the situation and didn’t think that it should effect his working there. However, several co-workers found out about his being HIV+ and really protested his being there. One co-worker complained when he made coffee.

They told the person's supervisor that they didn't want him making coffee or being around them. He left his position by mutual agreement with his employer.

Six of the respondents stated specifically that they had negative experiences when telling an employer about their HIV status. One man stated that his disclosure was the ultimate reason why he left this job. Once he had disclosed, his employer began to treat him differently. His driving route was changed and his supervisor started to make other changes that angered the participant. He states that he only worked about three more months after his disclosure. He ended up quitting, but states that this decision was mutual. He believes that his boss would have found a reason to fire him if he had not quit.

Another participant informed the vice-president of operations, but not his immediate supervisor. He had returned from a local AIDS Service Organization where he just learned that he was HIV+. He was upset and, not knowing what to do, he interrupted the vice-president while he was on the telephone. This person hung up the phone and told him to take as much time as he wanted to return to work. The participant indicated reports of his HIV status leaked to other employees. "Everyone became germ-o-phobic." For example, he stated that his supervisor would come around him with a handkerchief covering his mouth and nose. He was written up several times and then was fired. He had never had any problems at this job prior to disclosing his HIV status.

Another participant filed an ADA complaint against his employer. He was working full time in 1997 with complete health and dental insurance coverage. He stated that his employer knew that he was gay and it was not an issue. His job required that he be around chemicals used in the workplace and, when he started to feel sick repeatedly, his employer suggested that he see a physician. He did see a physician and was diagnosed as HIV positive. He did not tell his employer but the doctor indicated that she needed to report his PCP condition to the employer. The participant decided to disclose his HIV status at that time. He told the employer that he was able to work but that it was difficult because of his health problems. The employer said, "We'll just deal with it (HIV)." Later that same night, the employer called him and indicated the company was worried that someone could come in and sneeze on him and could make him sick. The employer wanted a guarantee from the physician that he wouldn't get sick in order for him to return to work. He stated that he knew immediately what was happening; he did not go back to work but kept documentation of doctor's excuses. A month later, the employer called and said he was losing money because the participant wasn't working and, because he couldn't do his work, he (employer) would have to let him go. The employer offered him insurance, through COBRA, for $400 month. The participant asked the employer to send a certified letter so that he could collect unemployment. This did happen. He applied for unemployment and welfare. He also called the Ohio civil rights court and filed a complaint under ADA "HIV discrimination." In November, 1999, the case ended and the participant won because the court found probable cause that he had been discriminated against. He was awarded $20,000 of which he received about $6,000 after paying bills, attorney's fees, etc. He was told that he could appeal for more money and would probably win but that it could take 10 years. His attorney advised him to take the offer, stating "do you have another 10 years?"

Opinion about disclosing HIV status to employers. Twenty-six of the 53 respondents indicated that they would tell an employer about their HIV status, at least under certain circumstances. Three individuals stated that they would disclose their status but only if it were necessary (for example, if they were injured on the job). Two individuals stated that they would wait awhile until they were well established on the job and then they would determine if they would tell anyone or not. An additional 12 respondents indicated that they wanted to be open about living with HIV or AIDS, but they would "wait and see." Many of these individuals indicated that they would prefer to be open, but would want to feel comfortable in their jobs first. They would have to feel that their employers would be supportive and not scared about the situation. For example, one female participant stated that she would be hesitant now to tell an employer about her HIV status. She said she would wait until after she had the job and would see how things went. She said that she would adopt the "don't ask, don't tell" rule. She would be honest if asked, but she wouldn't volunteer the information – at least not until she felt comfortable.

Twelve respondents stated that they would definitely tell their employers about their HIV status, either at the time of the interview or after being hired. One participant stated he would share this information because of his health situation. Another individual indicated he would want his boss to know but not his co-workers. He would need to feel comfortable with his boss, however, and believe that the boss was trustworthy prior to sharing his status. Another person stated he wouldn't be able to keep it secret in his community because he is an outspoken advocate for people living with HIV/AIDS. Also, he has been on television and in the newspapers. Other respondents who indicated they would share their HIV status responded that they were very open about living with HIV or AIDS and would extend that openness to any employment situation.

A majority of the respondents who indicated they would not be willing to disclose their HIV status to an employer simply stated, "It's none of their business." Eight respondents cited fear of discrimination as a reason for not sharing their health situations with employers. Other reasons provided were: the stigma of being known as a person with HIV or AIDS; previous bad experiences in disclosing to others; and the fear and ignorance of others in regards to HIV and AIDS. For example, one participant said, "I learned about my HIV status while in prison. I was treated as an outcast. I know there is this kind of ignorance on the outside, too. I would not divulge my HIV status to an employer so as not to subject myself to potential prejudice." Another participant said, "Right now I would not be willing to tell an employer about my HIV status. I am not ashamed of it; I just don't think I need to tell anyone that does not need to know. Why subject myself to that potential prejudice?"

Perceived barriers to employment. Respondents were asked, during the second and third interviews, to list the barriers that they have to remaining employed or to obtaining employment. The responses from the two interviews were combined and reported in *Table 18*. A total of seven individuals indicated, during either the second or third interview, that they had no barriers to employment. One participant noted, "I don't have any barriers myself. Ignorance is a barrier – people who are ignorant of my disease and my abilities. Ignorance and fear: those have been around for a long time."

The majority of respondents, however, were able to identify some type of barrier to their obtaining and/or maintaining gainful employment at the time of the interviews. General physical health concerns were identified by many of the respondents. Some had recurring health concerns at the time of the interview, however, a number of individuals stated they were always concerned that they may get sick in the future. One participant said, "My main concern is staying healthy. I know that my peripheral neuropathy could get worse. I need to maintain my appearance so that I don't look like an AIDS patient." Another participant reported, "Health issues are my biggest barrier. Smaller companies throw up red flags when they find out about the disease because they fear that their rates [insurance] would go up." He continued with a story about a job interview.

Table 18. Identified barriers to employment reported by participants (N=49)

Identified Barriers	N	Percentage
- General Health Concerns	17	33.3%
- Potential Loss of Benefits	15	29.4%
- Need for Additional Training or Education	9	17.6%
- Issues of Reduced Strength and Stamina	8	15.7%
- Side Effects of Medications	8	15.7%
- Length of Time Since Last Job	7	13.7%
- Discrimination	6	11.8%
- Depression	6	11.8%
- General Mental Health Concerns	5	9.8%
- Fear of Disclosing HIV Status	4	7.8%
- Transportation Problems	4	7.8%
- Reduced Level of Motivation	3	5.9%
- Stress	3	5.9%
- Housing and/or Child Care	2	3.9%
- Peripheral Neuropathy	2	3.9%
- Other	8	15.7%
- No Barriers	7	13.7%

"When one interviewer asked me if I have any major health problems, I responded, 'None that would interfere with my job.' I haven't heard anything further from that employer."

A number of individuals were also concerned about their benefits and whether (1) they would be able to make enough money to cover their health related expenses or (2) if they would be able to find employment with a comprehensive benefits package that would cover their needs. Several relayed stories of people who returned to work, became ill, and lost their benefits. Other respondents felt pressured from Social Security personnel or from others to return to work because they appear to be asymptomatic. This pressure occurs even when the participant believes he or she has significant barriers to employment related to living with HIV or AIDS. One participant indicated, "My barrier to employment is my lack of stamina although Social Security has determined that my disease can be controlled by drugs. The drugs slow you down and nobody wants you if you can't stay at work. Social Security tells me that I should return to cooking, but that job is too dangerous." Another individual stated, "The federal government and state agencies are my biggest barrier to employment because of all of their policies about benefits and health insurance. I would lose my medical coverage if I went back to work. Drug companies are also a barrier because medications are so expensive."

Some respondents reported barriers not noted by any other participant. Each of the following barriers was reported once:

- Physician advised individual not to work;
- Memory problems;
- Lack of opportunities in the community;
- Companies utilize drug testing;
- Potential for relapse [from substance abuse recovery];
- Difficulty getting along with others;
- Inability to meet employer expectations; and
- Being around others who are ill.

The individual who indicated she lacks opportunities lives in a small community with no public transportation system. She rides her bicycle or walks to interviews and to complete other tasks. A friend drives her to her appointments that are out of town. She indicates that many people know that she is HIV+ and that this likely hinders her ability to find employment. She has been hired several times since her diagnosis, but has been fired after relatively short periods of employment. She is motivated to work but she believes that she has used all of her options in her community. She is trying to find a car so that she can look for work in other communities, however, her financial situation is creating additional difficulties in this pursuit. She further indicates, "Even in Alcoholics Anonymous here in town there is discrimination because I am HIV+."

Perceptions of employment situation if never diagnosed with HIV. Respondents were asked during the third interview to consider where they thought they might be in the area of employment if they had never contracted the virus. Many of the participants had difficulty considering this question. One participant stated, "I've blocked it out of my mind. I can't give a good answer right now." She reported she has been trying to find employment for a long time now and is contemplating a return to school in the near future. Five respondents indicated they did not know what they would be doing for employment if they had never contracted the AIDS virus. One individual stated he has had employment problems because of a prison record, which occurred prior to his diagnosis.

A total of 17 of the 49 respondents stated they would be in the same type of employment or at the same position they had been in prior to their diagnosis. One individual stated, “I would probably be in the same type of work, something in lawn/landscaping or restaurant work. I don’t think I would be as satisfied as I am now. I know that sounds weird, but it is true. I am happier now than prior to my diagnosis.”

An additional three individuals indicated that they would have stayed in school or in a training program and would have pursued employment in the area of their training. For example, one individual stated that he would have been “an RN in a big old hospital. I would’ve pursued my career.” He reported that he didn’t continue his pursuit of nursing as a career because the hospital environment is not safe for him anymore because of his health. Another individual reported, “I would probably be with the same employer I was with. I think that I would better know how to keep coping through my depression if I had not been diagnosed HIV+.”

Six respondents indicated they would have pursued the employment goals that they had prior to their diagnoses. Two additional individuals reported prior training in a field and would likely have obtained employment in those areas. Four respondents stated that they knew they would have been working in positions with decent pay and benefits, although they were not certain of the types of work they would be doing. Ten of the respondents reported that they would have continued in a similar field but would have improved their positions within the company with the majority of these individuals reporting that they would probably be in some type of management or supervisory roles in their companies. One male participant said, “I would be in management. I was initially very ambitious, but now my ambition has decreased. The new medications that I am taking now have given me new hope.” The remaining two respondents indicated that they probably would be working in totally different areas than they had in the past.

Findings from Vocational Rehabilitation Counselor Data

Participants were then asked to discuss how successful they believe ORSC has been in providing services to people who are living with HIV/AIDS. The general consensus was that this is a population that has seen little success so far in vocational rehabilitation. One participant indicated that he had not had any successful closures among people with HIV/AIDS. There was some discussion about how the disease can interfere with the rehabilitation process due to fatigue and side effects from medications. A number of consumers have wanted to attend school in pursuit of a degree. Very few consumers with this disability wanted to attend short-term training and job placement. The progressive nature of the disease has interfered with longer-term programming. Another participant described a consumer who had multiple co-existing disabilities who was frequently hospitalized and who had numerous other medical problems. Another participant described a consumer who was generally very problematic. This particular consumer did a lot of blaming and threatening, and these mental health issues created a significant barrier to vocational rehabilitation. The general unpredictability of the disease also creates problems. One participant stated that she had one successful closure of someone who was living with HIV. The participant saw this consumer later, and the consumer indicated that he was currently having health problems and that his health was no longer stable and was interfering with his employment. Fear from consumers and from potential employers continues to be an issue. Also, on the surface, it seems that the future of consumers won't be successful and this creates the belief from ORSC counselors that they won't be able to get "26" closures from this population so they are more likely to put their energy into other clients.

There was some discussion about other disabling conditions that have a similar progression as HIV/AIDS and have similar impacts on vocational planning and barriers to employment. Fibromyalgia, multiple sclerosis, and hemophilia were three disabilities mentioned by the counselors. People undergoing hemodialysis may also have barriers that are similar to those experienced by people living with HIV/AIDS.

Participants were then asked what they consider the barriers to the vocational rehabilitation process for people living with HIV/AIDS or in working with this population. The following barriers were identified:

- Participants indicated that the outcome expectations are not always reasonable for this population. Not only are "26 closures" the expectation, but also the consumer needs to be earning a higher wage and work a certain number of hours per week. Part time work may be the best option for some people living with HIV/AIDS, yet they aren't considered successful closures by RSC policy. The traditional definition of success doesn't always work with this population.
- Some counselors and employers view people living with this disease as "not going anywhere" and having no real future.

- Sometimes consumers have a fear of state agencies. This may be due to a negative experience with an agency in the past or may be due to fears related to disclosure of their HIV status.
- There have been relatively few referrals of people living with HIV/AIDS and a high number of "no shows."
- Referral agencies may also have had negative experiences with RSC in the past and may be hesitant to make referrals.
- Consumers entering the system are in a hurry. They have expectations that are not always reasonable related to the amount of time it may take to become ready for employment and the actual earning potential that they may have. Consumers want the process to be immediate and they want a guarantee that they will become employed.
- The consumer's benefits are also an issue. Consumers may be afraid of losing their Social Security and their medical coverage. Some consumers may not have the earning potential to make up for the loss of these benefits.
- Although the system can be flexible, the process can be slow.
- The lack of pre-existing information can slow down the process at times. If the consumer cannot maneuver through the system, the process is slowed down considerably.
- Sometimes it is difficult to get medical information from the consumers. Information related to limitations is particularly difficult to obtain. Medical sources are very good about supplying the diagnoses, but it is difficult to find documentation of limitations or evidence that supports the consumer becoming involved in rehabilitation. If these details are missing, the consumer needs to be evaluated further.
- The employers are often fearful. The employer may assume that a consumer is more disabled than he or she actually is just because that individual is involved with ORSC.

Focus group participants were asked to look over a list of potential barriers and potential problems areas that a consumer may endorse. This same list was provided to participants in another component of this research study who are living with HIV or AIDS. Focus group participants were asked to circle the 10 barriers that they consider the most severe or the most common issues that this population will need to address. The problem areas identified by the focus group participants are as follows:

- Fatigue

- Need for flexible hours
- Anxiety about working
- Medication schedule
- Length of time since last job
- Health concerns
- Hard to get motivated
- Level of education
- Side effects from medication
- Discrimination
- Depression
- Need for part time work
- Disclosure issues
- Use of alcohol or other drugs
- Potential loss of benefits
- Difficulty dealing with stress
- Difficulty concentrating
- Memory problems
- Need for new training
- Sigma of HIV/AIDS
- Lack of family support

The focus group participant responses were also analyzed to determine the issues that were considered to be the biggest issues faced by consumers with HIV or AIDS. Eleven issues were identified due to "ties" between items. *Table 19* shows the top barriers identified by focus group participants compared to the top barriers identified by consumers who participated in the interview component of this study.

Fatigue was the most commonly identified barrier to employment identified by both groups of participants. Medication-related problems were not rated as highly as a barrier to employment by participants who are living with HIV or AIDS as compared to rehabilitation counselors.

TABLE 19. Comparison of rankings of potential barriers to employment by consumers and vocational rehabilitation counselors

Potential Barriers	Consumer Ranking (N = 51)	Counselor Ranking (N = 7)
- Fatigue	1	1
- Fear of Being Exposed to Illness	2	
- Discrimination	3	2
- Need for New Training	4	
- Disclosure Issues	5	8
- Potential Loss of Benefits	6	5
- Need for Flexible Hours	7	8
- Health Concerns	8	5
- Length of Time Since Last Job	9	
- Stigma of HIV/AIDS	10	2
- Side Effects of Medication		5
- Medication Schedule		2
- Depression		8
- Need for Part Time Work		8

Research Question 4

How are people living with HIV/AIDS finding employment?

Findings from Consumer Participants

Reasons for wanting employment at this time. The majority of the thirty-six individuals, who were not working in any regular paid capacity at the time of the first interview, indicated that they would like to work in some capacity. Two individuals stated that they were not interested in working at all right now. The other respondents gave a number of reasons for wanting to work. They have been categorized in *Table 20*.

Some respondents were very eager to enter or return to the workforce. One participant had been employed full time for seven months at a nursing home. She left that position about six weeks prior to the first research interview and indicated that she had been very depressed since that time. She had been working as a nursing assistant and left the position because she was not state certified as a nursing assistant. She completed the training program, but could not test for her certification because she did not graduate from high school and does not have her GED. She indicated she attended GED preparation classes and had too much difficulty with the math portion. She states that she feels “worthless” sitting at home. According to her, “It makes you get sicker thinking about what’s going on in your life. Working is therapy and makes you feel normal.”

Table 20. Reasons for wanting employment as given by participants living with HIV or AIDS (N=36)

Reason	Number Responding	Percentage
- Money	20	56%
- Something to do/have free time	10	28%
- To improve self-esteem/sense of accomplishment	4	11%
- Feel healthier and able to work now	6	17%
- To be independent or self-sufficient	2	6%
- For emotional stability/ to take mind off of problems	2	6%
- Have always worked	4	11%
- To give back to society in some way	3	8%
- Graduating from school	1	3%

Another participant indicated she wants to feel as though she is accomplishing something and wants to feel “whole” again. The money is also an incentive because her “Social Security just isn’t enough.” She commented that she would like to “periodically buy a new dress just because she likes it. With Social Security, this isn’t really possible.”

Several respondents have found unique ways to meet their needs. For example, one participant had a strong work history prior to his diagnosis with HIV. He stopped work for a period of time due to illness and the emotional impact of the diagnosis. He currently receives SSDI benefits. After a couple of years staying at home, he became bored and wanted to find something to keep him busy. He also wanted to have some extra spending money so he could go to movies or out to eat without having to short change himself in other areas such as groceries. This participant also indicated that his daughter was becoming concerned about him and said that he was becoming a recluse who needed something to do. He was nervous about the types of jobs that he may be able to do because of his need for flexible hours and his need for part time work in order to keep his benefits B particularly health benefits. His daughter suggested that he apply for a job as a hiker for her employer, a car rental company. At first the participant was afraid that being a "hiker" would be physically demanding and require him to be on his feet and walking all of the time. When he found out that the job mainly involved driving, he applied for a position. Currently he works a couple of days per week transporting cars to where they are needed within a limited distance. The participant states that he definitely likes his current job situation. He states that the work is not physical and that "it gets me out of the house." He further says the hours are flexible. His boss also knows he receives SSDI, although she doesn't know why, and that he is only able to earn a certain amount of money. He fits in with his co-workers because most of the other people in this position are retired or on disability and are only able to work a limited number of hours per week due to physical or financial reasons.

Experiences looking for work. At the time of the initial interview, a total of 32 respondents were not working in any capacity (volunteer work was not included as employment). Nineteen of the individuals reported that they were actively seeking employment. At the second interview, 16 of the 30 respondents who were not working indicated that they were actively looking for a job. At the final interview, 19 out of 26 unemployed respondents were looking for work. Six of the study respondents reported an active job search at all three interview times.

Respondents were asked to describe some of their experiences in seeking employment. Some of the experiences were positive and others were negative. A number of respondents described the job search as "frustrating." One person stated, "I do not like the process of looking for work. I hate the interview process and the waiting for an answer. I get pessimistic and it is not related to HIV. I know my work history gets in the way, and I can get somewhat frustrated."

Several expressed the fact that looking for work was frustrating because they would either complete applications or send out resumes and they were not contacted in return. Others described feelings of inadequacy and a lack of confidence during the job search. One individual stated that he is "personally uncomfortable looking for work." Another said, "I was not enthused while looking for work. I always felt like I wasn't going to get the job. I think these behaviors are related to depression and self-esteem issues." Another participant summed up his experience as follows: "I can tell that I am not going to get the job even before the interview is over. I begin to wonder what it is I did wrong. It is awful."

One participant describes his experience looking for work as "emotionally fearful." He said, "I don't want to go into a confrontation about not working the past six years. I have to come up with a story or lie or some kind of cover-up, and I don't feel good about doing that. I would like to be able to tell the truth. But if I tell the truth, nine out of 10 times, I'm not going to be hired."

Several individuals expressed frustration with having to rely on public transportation in order to apply for jobs and then to travel to work. Several respondents discussed the difficulty in explaining a significant gap in their employment histories. One participant said, "I have to write down that I haven't worked in two years because of illness. That does not feel good." Returning to school to help close the gap in employment was a thought expressed by several respondents.

Other respondents indicated they are confident in their ability to find appropriate employment and in their interviewing skills. One participant stated, "When I look for a job I am confident. I know the system. I have a 'don't ask, don't tell' philosophy about my HIV status." Another participant said, "Finding a job is not a problem for me. I am diverse in what I know how to do. I often have side jobs doing electrical, plumbing, painting and computer work for people. Many of the nurses at the VA [where he receives medical care] are my customers for the side jobs." One man stated he hadn't had any negative experiences and generally could get hired, but health problems (not all HIV related) prevented him from keeping jobs for any length of time.

A concern for many of the respondents is the need for flexibility in hours. A number of the respondents are or have been looking for employment that allows them to work part time or have flexible hours due to the physical toll and needs of their illness. Of this group seeking flexibility, one stated, "Who wants an employee who can work 11-4?" Health problems were also a concern. One participant stated, "The job that I did settle on only lasted three weeks because I could not physically keep up." One women was offered a job working in a laundry facility where some of the duties would be managerial but most would be general labor. She worked for two days and had to quit because of health problems and difficulty meeting the physical demands of this particular job. She did state that she believes her ability to work in physically demanding jobs will improve if she exercises and builds strength in her knees and back. Another participant was offered a job with a video rental company, but this occurred at a time when his health and memory problems began to worsen. He was unable to actually start the job; however, he never did call the employer to let him know that he wouldn't be taking the position.

One participant described a very negative experience when he did choose to disclose his HIV status. He indicated that in the beginning of the interview process, he did not disclose his HIV status. He discussed his professional background and asked if he would be able to work "under the table." This did not seem to be a problem for the employer, but it did create an atmosphere where the employer repeatedly asked, "What do you do for a living?" and "Where have you been professionally for the past three years?" The participant believed that he had no other option but to disclose his HIV status. He indicated that he thought that both interviewers seemed interested in possibly hiring him until he disclosed that he is HIV+. At that time, the interviewers asked, "What does that do to you?" The participant felt that the interviewers were "scared" about his having HIV. He was not contacted by them after this interview.

One respondent, an African American electrical engineer, stated that she had approximately 20 job interviews during the five months between contacts with the research study. She said that she was doing a lot of driving back and forth to interviews and, although she denied that this was frustrating, her affect indicated otherwise. She stated that employers frequently acted very interested in her and then would say things like "the company has been forced to implement a hiring freeze" or "we don't really have time to train you in the components of the job that will be new for you." At the time of the second interview, she had been unemployed for close to one year. She believes that even this short of a time away from the field has probably hurt her in her job search and that she is considered entry level. She interviewed with one company three times and was told they wanted to hire her. After a delay, she was advised that the job was given to someone with more experience. She does not think that discrimination is an issue. She attributes her difficulty in finding employment solely to her lack of experience. At the time of the third interview, this respondent had recently started a job as an engineer and appeared to be very happy with her new employment.

One participant described the frustration that she has experienced in regard to deciding whether or not to apply for a job. Her husband told her about an opening for a cleaning person for a janitorial company where he works as a supervisor. The position would be part-time without benefits, but it would give the participant the opportunity to see if she would be able to handle employment at this time. She would then apply for her former position with a university where she was a cook. This is her employment goal. One of her dilemmas is whether or not to disclose her HIV status. Her husband told her that he would support her no matter what she wanted to do. However, he had heard some of the people in this small company talk about HIV, didn't think they were educated about it and might not hire her if they knew she was HIV positive. She was named "Volunteer of the Year" by a local AIDS Service Organization and has been open about her HIV status. She believes it is important to speak out about HIV. She is also afraid that if the employer finds out about her HIV status they will fire her husband. Her husband still is supportive of any decision. She summarized her difficulties by saying, "Isn't it enough that I have to fight this disease but do I have to fight ignorance too?"

A few individuals shared some of the strategies that they use when looking for work. The most common strategy was to avoid disclosing HIV status. Several people disclosed that they had not been working recently because of a disability. Some actually mention a co-existing disability that they have, while others do not provide any other details. One individual stated to the interviewer that she was currently on disability and would be re-evaluated soon. For this reason she wanted to get back into the work force as soon as possible.

Another strategy employed was to be prepared for the questions that may be difficult to answer and develop an answer in such a way that it wouldn't leave an opening for any further questions on that topic. Another individual did not think that his HIV status should be an issue to any employer and he does not mention disability at all. He did state that he looks over any potential employer's insurance plans carefully to make sure he will be able to be covered. Another participant indicated that she did not disclose her HIV status when she was looking for work. She also chose not to put HIV under the pre-existing condition portion of the paperwork. Her health care provider through work doesn't know about her HIV status and she is using the VA for her HIV needs.

Another strategy was to utilize personal resources as well as those resources that are available in the community. One participant described how he takes his resume and military honorable discharge papers with him when he is seeking employment. He uses the Catholic Charity Employment Services, who developed his resume for him, to seek referrals to employers.

One individual utilized the Internet to locate job opportunities and to post his resume. Another parlayed his success in painting his own and a friend's apartment into some potential opportunities painting other apartments. Another participant stated, when she decided that she was ready to return to work, she signed up with a temporary agency. She completed one application for them and one interview. She was given some basic office tests and then they set her up with a position relatively quickly. She states she knew she could get work through the temp agency without the other concerns and she didn't have a problem with completing the interview or application. Another participant has been investigating work-at-home situations listed on the Internet. Still another, through the help of his cousin, has found a job that allows him to work flexible hours which is important because of his health status.

Research Question 5

What vocational services and transitional techniques can VR counselors use to assist consumers living with HIV or AIDS in entering or re-entering the work force?

Findings from Consumer Data/Quantitative

This issue was addressed indirectly in the consumer interviews since there was no questionnaire item for interviews T1 or T2 that specifically addressed the question. "Ability to work" was measured by variables dealing with the subject's current work situation, changes in employment, and general health condition. The variables tested were:

(a) Current work situation at T1,
(b) HIV caused change in employment,
(c) T2 "Any change in employment situation?"
(d) General impression of current health,
(e) "My health is excellent,"
(f) "I expect my health to get worse,"
(g) Current health compared to one year ago,
(h) "Number of days during the past month in which I felt bad,"
(i) Composite health status, combined data from T2 health items q54, q56, q58a, q59, q61, q62, q63 (T1 items q24, q26, q28, q29, q32, q34, q36).

Using an alpha = .05 level of significance for two-tailed t-tests, there were no significant differences between the low and high alcoholism s-MAST participants for any of the nine vocational rehabilitation outcome variables. The "Current Work Situation" variable from T1 yielded t = -1.745 (p = .087) between the two s-MAST groups. There was significant heterogeneity of variance for the responses to the "HIV caused change in employment" and "Any change in employment situation" variables. Likewise, there were no significant differences between the non-drug-users and drug-users for any of the nine variables.

Findings from Consumer Study/Qualitative

Perceived accommodation needs. Each participant, in the first interview, was asked "What accommodations do you think are necessary in order for you to stay at or return to work?" The most commonly reported accommodation need was a flexible work environment. Other accommodations mentioned included: flexible scheduling; a liberal sick policy; access to a restroom, and ability to rest when necessary. Physical restrictions posed barriers for some respondents who said that they tired more easily now or were simply no longer able to perform certain actions due to strength and/or endurance limitations. Several stated that working part-time would allow them to be both gainfully employed and able to take care of themselves. Some said they did not require any special accommodations at this time either because they did not need them or because their employer already provided them. *Table 21* provides details regarding what consumers believe to be their needed accommodations.

One individual indicated that he needed to find a full time job in order to keep his mind occupied and off of his illness and health concerns. Another participant stated that in order to return to work "there needs to be more understanding about HIV/AIDS in the public. They need to take the black flag and stigma from the disease."

Several individuals indicated that they needed training in another field in order to become employed, while one individual stated that she needed training in techniques to improve or accommodate for her memory difficulties. Another respondent indicated that he would like to have assistance in job placement.

Findings from Vocational Rehabilitation Counselor Data/Qualitative

The focus group participants indicated that the strengths in the federal state vocational rehabilitation system as identified include the facts that the system can be flexible and that

Table 21. Accommodations identified by participants as necessary for employment

Accommodations Needed	N	%
- Flexible Hours	22	41.5%
- Ability to Alternate Standing and Sitting	8	15.1%
- Part Time Employment	8	15.1%
- Easy Access to a Rest Room	6	11.3%
- Ability to Take Frequent Breaks	4	7.5%
- Access to Transportation and/or Handicapped Parking	5	9.4%
- Stress-Free Environment	4	7.5%
- Ability to Take Medications at Work	4	7.5%
- Physical Accessibility (elevator, power doors, climate control, etc.)	3	5.7%
- Visual Needs (large print, large computer screen, etc.)	3	5.7%
- Limited Physical Labor (lifting, etc.)	3	5.7%
- Other Personal Needs (counseling, liberal sick policy, medical insurance, training, etc.)	7	13.2%
- Day Time Hours	2	3.8%
- Ability to Work From Home	2	3.8%
- No Needs Because Employer Already Providing	3	5.7%
- No Needs At This Time	5	9.4%

consumer choice is a positive component in the rehabilitation process. The consumers are able to consider their long-term goals and are able to have a say in the steps taken to reach those goals.

The participants all agreed that state vocational rehabilitation can and should provide services to this population. Vocational rehabilitation may not have been successful so far, but they are still able to provide appropriate services if some of the barriers identified are addressed. AIDS Service Organizations may also be able to assist; however, at this time, the state agencies are best equipped to provide services. A team approach would probably be the best approach for most consumers who are living with HIV/AIDS.

The accommodations participants have used so far when working with people living with HIV or AIDS include utilizing ergonomic adaptations for the computer and rehabilitation technology for vision problems (some of which were not related to the HIV diagnosis). They have also pursued asking for frequent breaks and exploring job - sharing opportunities.

Research Question 6

Is there a relationship between client-reported ability to work and reported levels of substance abuse among consumers with HIV or AIDS?

Findings from Consumer Data/Qualitative

Current work situations. Consumer respondents were asked to describe their current work situation during the first interview. A total of 12 respondents indicated that they were currently working either full or part time in positions where they paid taxes. Five individuals were working full time, defined as 40 or more hours per week. An additional seven respondents were working in part time positions of less than 40 hours per week with a relatively consistent number of hours per week or per month.

The remaining 41 respondents were technically classified as unemployed. However, at the time of the first interview, one individual was performing seasonal work and another was providing childcare for a relative, both on a full time basis. They were receiving their pay "under the table." Three other respondents were working part time, one seasonal, in "under the table" capacities. Two final individuals reported working for "under the table" money sporadically as work is available. One additional participant was working part time in a volunteer capacity for a nursing practicum as part of an educational requirement. Another individual reported that he was a homemaker, and one other individual reported being a full time student.

Sixteen, or 50% of the 32 respondents who reported not being employed, indicated that they were not working as a direct result of illness due to HIV or AIDS. They reported that AIDS-related fatigue and other AIDS-related illnesses such as pneumonia, stress, loss of concentration, wasting syndrome, and side effects of medication made it difficult to obtain or keep employment. One person stated she had been fired due to absenteeism related to her HIV. One additional participant was not working due to having a hip replacement. His unemployment is related to health problems not directly related to his HIV. Three individuals reported that they are not working due to major depression resulting in an inability to work. One woman reported that she became suicidal while in the hospital after learning of her diagnosis. Of the 19 respondents unemployed due to direct physical or mental health problems, five had been unemployed at least five years or longer (one had been unemployed for 10 years, citing he stopped working because of his HIV status and physician's orders).

Fear of losing needed benefits, such as Medicaid, is another factor in respondents' lack of employment. Four consumers stated directly that they were afraid of losing benefits if they tried to return to work. One man noted that his medical expenses were $35,000 per year, and he cannot find adequate employment in the small rural area where he lives to meet these expenses. Some of the other reasons for unemployment include recent lay offs (n = 2), recently quitting job for personal reasons not related to HIV (n = 1), AIDS stigma due to disclosure at interviews (n = 2), lack of transportation (n = 1), lack of necessary education (n = 1), and need to stay home with children (n = 2).

Twelve respondents categorized as unemployed indicated that they did perform volunteer work on a regular basis. Many of them volunteered with local AIDS Service Organizations. Some reported weekly volunteer work, while others did not work as often. However, each of them did report consistency in their volunteer work.

Expressed satisfaction with current work situation. Of the 17 respondents working at T1 (including those with "under the table" wages), 12 reported that they were satisfied with their current employment situation. The remaining five indicated that they were not satisfied, with four stating that they did not like the actual work that they were doing. One of these respondents called his current employment a "survival job" that he is performing until he can find something better. The other individual who reported dissatisfaction indicated that he likes the type of work that he is doing but he reports feelings of guilt because he is working "off the books" while he is collecting Social Security. He wants to work in a legitimate job, but fears he will lose his benefits. He states, "It's a hard situation to control. I feel trapped. A person feels better if he can work on his own."

Changes in employment since HIV or AIDS diagnosis. Of the 53 respondents at the T1 interview, nine stated that they had not gone through any changes in their employment status due to their HIV or AIDS. The remaining 44 individuals gave a variety of reasons for changes in their employment status. The actual diagnosis and health problems or concerns were the most commonly cited reason for leaving employment.

Thirty-five of the 44 respondents whose employment status had changed reported having quit their jobs since being diagnosed with HIV. Seventeen respondents, or 48.6%, indicated that they quit because of health reasons and twelve said they left their jobs because of their HIV diagnosis (but did not give any further information). Fatigue, decreased strength and energy, memory and concentration problems, side effects from medications, stress, and peripheral neuropathy were given as some of the health-related issues that resulted in leaving employment.

One participant stated that he left his job after his diagnosis of HIV and that he is still having difficulty adjusting mentally and emotionally to being HIV positive. Another individual stated that his ambition overall decreased after his diagnosis of HIV and stopped working for this reason. Another participant indicated that he hated his job and quit because he knew that he would be able to collect disability benefits. Another individual felt that he should quit his job because of the chance that he would lose Medicaid, and he needed these benefits in order to pay for his medications.

One participant quit work because he was afraid that he would become ill being around other people at his place of employment. Another participant stated that she was “very ignorant” about HIV when she was first diagnosed and believed she would die soon. Thus, she immediately quit her job and told her employer that she had been diagnosed with HIV and would not be living very much longer. A short time later, after learning more about HIV, she returned to her employer and asked to be rehired. Her employer refused to take her back. This woman was a fast food restaurant manager, a position that has very high turn over. She believes she was not re-hired due to her HIV status.

Six of the 44 consumers reporting changes in employment indicated that they had made changes in the type of employment or in their actual work schedules. Regarding type of employment, the change most frequently noted was moving to a less physically or mentally demanding situation. Schedule changes included moving from full-time to part-time hours, and time-of-day adjustments such as from third shift to first shift.

Three additional respondents stated that they believed they were fired or “forced out” of their jobs because of their diagnoses. One said that his employer was supportive at first, but later fired him for being sick and unable to do his work after he had been off sick for a couple months. Another said that he believes that he was let go from his position after he revealed his HIV status to management.

Another participant described an unfortunate situation that resulted in his being forced to leave his job. He worked at a fast food restaurant for almost a year as a part time crew leader, performing some of the duties of an assistant manager. He states he liked this job because he was able to be creative and he worked for his nephew who knew he was HIV positive. He indicated that his nephew was going to help him get his own store to manage. One day, he was injured on the job when he was cut across his eye by a blade (used to cut meat) and had to get stitches. He stated, “I took myself off the line and used universal precautions." He went back to work the next day and opened the store as usual. Not long after this incident, however, he noticed that his hours began to decrease. His nephew informed him that he "had to tell" other employees about the HIV because he felt they had a right to know. Soon, even the customers started to know. The participant’s nephew was ordered by the General Manager to cut his hours even though he asked for his usual 40-hour week. The participant indicated that he saw others getting overtime while his hours were being cut. This decrease in hours forced him to resign. He did file a lawsuit stating, "If you hit them in the pocket, it might educate them." The lawsuit asked for wages that he would have received if he had continued working as usual following the injury. At this time, the company has offered him $22,000. He thinks that he will accept the offer. He stated, "All money is not good money." He indicated that the money would help for the pain and suffering and stress that the situation has caused him, and having the money would help to "get me back on my feet."

Changes in employment between interviews. Less than half of the respondents remained stable in their employment situations during the course of the study. Approximately 57% of respondents reported some type of change in their employment in the areas of amount of time worked, employer, and type of work. Twenty one respondents reported no change at all in their employment situations throughout the course of the study. Seventeen of these individuals remained unemployed without employment of any kind. Three individuals remained employed fulltime with one of them continuing with “under the table” wages. The final participant in this group remained employed on a part time basis.

Research Question 7

Is there a relationship between client-reported ability to work and satisfaction with vocational rehabilitation services as well as level of disease progression among consumers with HIV or AIDS?

Findings

We were unable to measure this data due to insufficient numbers of individuals living with HIV or AIDS in our study who were participating in vocational rehabilitation services.

Research Question 8

Is there a relationship between rehabilitation counselors' perceptions, levels of knowledge, training/experience, and self-reported skill levels and consumers' with HIV or AIDS vocational rehabilitation outcomes and reported satisfaction with services?

We were unable to conduct an analysis of this correlation. We were unable to match the individuals who responded to the counselor questionnaire with clients who are living with HIV or AIDS. We did perform an analysis of the information learned from the rehabilitation counselors in the survey and focus group activities.

Findings from Vocational Rehabilitation Counselor Data/Quantitative

Information regarding levels of knowledge, perceptions and perceived levels of skills were obtained through a survey. Survey participants were asked to estimate the number of consumers living with HIV or AIDS that they have served in their work as a vocational rehabilitation counselor. Sixty percent indicated they had served no consumers with HIV or AIDS. Twelve percent had served one person; 14 percent had served two; 8 percent had served 3; 1 percent served four; 3 percent had served five; and 1.5 percent or one participant reported serving 30. *Table 22* provided the detailed information.

Participants were also asked to rank their perceived level of experience in providing vocational rehabilitation services to individuals living with HIV or AIDS. They were provided a Likert scale of 1 to 6, with seven being "a great deal." The findings outlined in *Table 23* show that 23 percent of the participants have no experience in serving this group of individuals. Sixty three percent report little or below average experience. Approximately 8 percent have above average experience.

Table 22. Estimated number of consumers with HIV or AIDS served, as reported by vocational rehabilitation counselor participants

Number of Consumers Served	Frequency	Percent	Valid %	Cumulative %
0	39	60.0	60.0	60.0
1	8	12.3	12.3	72.3
2	9	13.8	13.8	86.2
3	5	7.7	7.7	93.8
4	1	1.5	1.5	95.4
5	2	3.1	3.1	98.5
30	1	1.5	1.5	100.0
Total	65	100.0	100.0	

Table 23. Ranking of level of experience serving consumers with HIV or AIDS as reported by vocational rehabilitation counselor participants

Level of Experience	Frequency	Percent	Valid Percent	Cumulative %
None	15	23.1	23.1	23.1
2	27	41.5	41.5	64.6
3	14	21.5	21.5	86.2
4	4	6.2	6.2	92.3
5	4	6.2	6.2	98.5
6	1	1.5	1.5	100.0
Total	65	100.0	100.0	

The participants also indicated the level of training they had received regarding HIV or AIDS. They reported level of training using a Likert scale of 1 to 6, with one being no training. The results of the related analysis summarized in *Table 24* indicate that twelve percent of the respondents had received no training with 3 percent receiving a lot. Sixty percent of the group reported average to below average levels of training.

Participants were also asked to rank their perceived level of skill in addressing rehabilitation-related issues with consumers living with HIV or AIDS. They ranked each area on a Likert scale of 1 to 7 with one being none to 7, a lot. Frequency data from the surveys is summarized in *Table 25*.

Table 24. Level of training related to HIV or AIDS as reported by vocational rehabilitation counselor participants

Level of Training	Frequency	Percent	Valid Percent	Cumulative %
None	8	12.3	12.3	12.3
2	18	27.7	27.7	40.0
3	17	26.2	26.2	66.2
4	8	12.3	12.3	78.5
5	12	18.5	18.5	96.9
A Lot	2	3.1	3.1	100.0
Total	65	100.0	100.0	

Findings from Vocational Rehabilitation Counselor Data/Qualitative

Participants in the vocational rehabilitation counselor focus group were first asked about their experience in working directly with this population and what training they had in the area of providing vocational rehabilitation to people living with HIV or AIDS. The level of experience in working with people living with HIV or AIDS varied. One individual has served as the principal contact for referrals for his office of people who are living with HIV or AIDS. Another individual had worked on an HIV hot line and was very knowledgeable about the disease but has only seen a few consumers with HIV during his time with RSC. Two individuals indicated they had experience through other aspects of their lives or at prior jobs with people who were living with HIV or AIDS. Several have had one or two consumers apply for services with them but have not had much experience working on vocational issues with this particular disability. One individual stated that he had conducted a presentation for an AIDS Service Organization but that this activity did not seem to result in many referrals to RSC.

The amount of training that had been received also varied among participants. It appears several people consider their training in working with people who are living with HIV or AIDS as “on-the-job training.” There have been some general workshops and some general training related to HIV and AIDS. One participant indicated that he has taken the training offered by RSC and was interested in additional training. Another individual stated that a training workshop related to HIV and AIDS was canceled recently because there were not enough people registered to attend. Another described a very comprehensive training on medical aspects of HIV and AIDS that was very interesting but “overwhelming” because of all of the

Table 25. Perceived level of skill in rehabilitation counseling-related areas related to serving individuals with HIV or AIDS as reported by vocational rehabilitation counselor participants (N=65)

Perceived Level of Skill	Valid N*	Mean	Median	Mode	SD	Min	Max
Addressing Legal Issues re HIV/AIDS	65	2.09	2.00	1	1.21	1	7
Address Med Tx and Med Adherence	65	2.15	2.00	1	1.23	1	7
Accessing Comm Res and Services	65	3.31	3.00	4	1.41	1	7
Determining Voc Implications	65	3.89	4.00	4	1.29	1	6
Employer Practices Affect Employment	65	3.18	3.00	4	1.30	1	6
Conduct Job Development	65	3.26	3.00	4	1.45	1	6
Counseling Ind w HIV/AIDS	65	3.15	3.00	2	1.51	1	6
Counseling Families of Ind w HIV/AIDS	65	2.92	3.00	2	1.51	1	6
Counseling re Death/Dying	65	2.55	2.00	1	1.50	1	7
Counseling re Gay/Lesbian Issues	65	2.26	2.00	1	1.40	0	7
Counseling re Relationship Issues	64	2.34	2.00	1	1.30	1	5
Counsel fr Diff Ethnic/Rac Backgr	65	2.45	2.00	1	1.30	1	6
Counsel re Lifestyle Issues	65	2.55	2.00	2	1.41	1	7
Counsel re Ethical Dilemmas	65	2.51	2.00	2	1.30	1	5

* Numbers vary due to missing data in surveys.

Information provided in a short period of time. Training received to date has not been specific to addressing the vocational rehabilitation needs of this population.

Participants were then asked to discuss how successful they believe RSC has been in providing services to people who are living with HIV or AIDS. The general consensus was this is a population that has seen little success so far in vocational rehabilitation. One participant indicated he had not initiated any paperwork that would identify consumers with HIV or AIDS as being successful in their vocational rehabilitation. There was some discussion about how the disease can interfere with the rehabilitation process due to fatigue and side effects from medications. A number of consumers have wanted to attend school in pursuit of a degree. They reported that very few consumers with this disability wanted to attend short-term training and job placement. The progressive nature of the disease has interfered with longer-term programming. Another participant described a consumer who had multiple co-existing disabilities who was frequently hospitalized and who had numerous other medical problems. Another participant described a consumer who was generally very problematic. This particular consumer did a lot of blaming and threatening, and these mental health issues created a significant barrier to vocational rehabilitation. The general unpredictability of the disease also creates problems. One participant stated that she had one successful closure of someone who was living with HIV. The participant saw this consumer later, and the consumer indicated that he was currently having health problems and that his health was no longer stable and was interfering with his employment. Fear from consumers and from potential employers continues to be an issue. Also, on the surface, it seems that the future of consumers won't be successful and this creates the belief among RSC counselors that they won't be able to get "26" closures from this population so they are more likely to put their energy into working with other consumers.

There was discussion about other disabling conditions that have a similar progression as HIV/AIDS and what the participants have discovered about vocational planning and barriers to employment with consumers who have these disabilities. The group mentioned Fibromyalgia, multiple sclerosis, and hemophilia. People undergoing hemodialysis may also have barriers that are similar to those experienced by people living with HIV/AIDS.

Participants were then asked what they consider the barriers to the vocational rehabilitation process for people living with HIV/AIDS or in working with this population. The following barriers were identified:

- Participants indicated that the outcome expectations are not always reasonable for this population. Not only are "26 closures" the expectation, but also the consumer needs to be earning a higher wage and work a certain number of hours per week. Part time work may be the best option for some people living with HIV/AIDS, yet they aren't considered successful closures by RSC policy. The traditional definition of success doesn't always work with this population.

- Some counselors and employers view people living with this disease as “not going anywhere” and having no real future.
- Sometimes consumers have a fear of state agencies. This may be due to a negative experience with an agency in the past or may be due to fears related to disclosure of their HIV status.
- There have been relatively few referrals of people living with HIV/AIDS and a high number of “no shows.”
- Referral agencies may also have had negative experiences with RSC in the past and may be hesitant to make referrals.
- Consumers entering the system are in a hurry. They have expectations that are not always reasonable related to the amount of time it may take to become ready for employment and the actual earning potential that they may have. Consumers want the process to be immediate and they want a guarantee that they will become employed.
- The consumer’s benefits are also an issue. Consumers may be afraid of losing their Social Security and their medical coverage. Some consumers may not have the earning potential to make up for the loss of these benefits.
- Although the system can be flexible, the process can be slow.
- The lack of pre-existing information can slow down the process at times. If the consumer cannot maneuver through the system, the process is slowed down considerably.
- Sometimes it is difficult to get medical information from the consumers. Information related to limitations is particularly difficult to obtain. Medical sources are very good about supplying the diagnoses, but it is difficult to find documentation of limitations or evidence that supports the consumer becoming involved in rehabilitation. If these details are missing, the consumer needs to be evaluated further.
- The employers are often fearful. The employer may assume that a consumer is more disabled than he or she actually is just because that individual is involved with RSC.

The strengths in the system, as identified by the participants, include the fact that the system can be flexible and that consumer choice is a positive component in the rehabilitation process. The consumers are able to consider their long-term goals and are able to have a say in the steps taken to reach those goals.

Focus group participants were also asked about the training needs that they have in order to work more successfully with this population. Participants indicated that HIV training is currently voluntary. Some counselors need basic training about how HIV can and cannot be transmitted because some staff members have fears about working with this population. They believe they are at risk for contracting the virus through their regular working relationship with consumers who are HIV positive. Counselors with these fears and misperceptions are not likely to voluntarily participate in training related to HIV and AIDS. Participants indicated that they need additional information about the symptoms of HIV and AIDS as well as the limitations associated with this disease. Some of the other topics of interest include discussing issues of risk for consumers who return to work such as working with children or working with others who have colds or who come to work sick.

The participants suggested the following dissemination avenues for transferring relevant information to rehabilitation counselors:

- Develop fact sheets that can be distributed and read by staff at their leisure.
- Provide training in conjunction with area meetings since these are mandatory.
- Present information at monthly staff meetings or bi-monthly staff meetings.
- Provide a listing of Internet resources that can be accessed by staff.
- Utilize existing resources such as the Return To Work Guide published by the National AIDS Fund.
- Training will need to be ongoing because a brief training will not provide enough information on how to work with this population.

DISCUSSION

There were a number of areas of significance found in this study that addressed HIV, substance abuse and employment issues. This discussion will address those that have implications for delivery of services to individuals living with HIV or AIDS in the federal-state vocational rehabilitation system.

The first area of concern is that, in this study, only an estimated one-third of participants living with HIV or AIDS had ever used VR services. The participants were recruited through the community service organizations and could be considered representative of this population. Many individuals living with HIV or AIDS gravitate toward using specialized services to (1) receive more competent care; (2) to work with professionals sensitive to the issues of HIV or AIDS; and (3) to avoid potential problems related to the stigma of the disease.

The employment pictures painted by the participants in this study are not dissimilar from those of other people with disabilities. The onset of the disability has brought about changes in job status, unemployment is higher than the national average, and there are numerous medical and psychosocial issues that require attention. What is pervasive in this report is the level of concern about potential discrimination and the stigma attached to this disease.

Discrimination is a central theme, whether perceived or real. It has been stated that individuals with living HIV or AIDS fare better in the workplace when they have supervisors who are gay, or work in small organizations characterized by personal, face-to-face relationships with management (Adams & Sears, 1996). Yet, they also fare well in large organizations with formal policies mandating equitable treatment. People without these environmental supports are otherwise left to the preconceptions and arbitrary action of individual employers (CSAP, 1994, Adams & Sears, 1996).

An understanding of confidentiality regulations that impact disclosure is often not trusted and rightly so. State and federal laws prohibit discrimination on the basis of HIV status but laws related to privacy of HIV-related information are state specific. Companies are required to provide privacy of workers' medical information and keep it confidential and separate from personnel files. Yet, not all employers have an understanding of the critical nature of guarding the privacy of the HIV+ employees. It can result in inappropriate sharing of information about a coworker's health status (Vest, Vest, Perry, & O'Brien, 1995).

Fear can be the source of economically-based discrimination. Many employers fear that employees will be less productive as they get sicker, the illness will interfere with business (customers will go elsewhere or coworkers might refuse to work with people with HIV), or their health-related costs will increase. Discrimination based on these fears is not legal (Bogart, et al., 2000). In addition to fear, stigma and beliefs about the moral character of the population are a concern. Given the large numbers of people who are gay or substance abusers, living in poverty and members of a minority population, we find multifactored stigmatization occurring, which may result in exclusionary practices (Garcia, Cartwright, & Glenn, 1997; Hunt, 1997).

Vocational rehabilitation (VR) agency personnel serve individuals who have a disability and it impacts their ability to obtain or maintain employment. Fifty percent of the study participants living with HIV or AIDS reported not being employed and indicated that they were not working as a direct result of illness due to HIV or AIDS. Less than half of the employed respondents remained stable in their employment situations during the course of the study. We could assert that this might mean a large number of individuals living with this disease could benefit from the services provided by VR. Yet, two-thirds of the group had never utilized the services. Many were either unfamiliar with VR or had experienced frustrations with the system.

Participants in the study working as vocational rehabilitation counselors expressed concern about the lack of applicants for services as well as the lack of success with vocational rehabilitation experienced by individuals living with HIV or AIDS. They were also able to identify barriers to success that are inherent in the system. These must be considered by those who implement policy. Some of the barriers that are of interest include:

- *VR requirements.* VR outcome expectations are not always reasonable for this population. Not only are "26 closures" the expectation, but also the consumer needs to be earning a higher wage and work a certain number of hours per week. Part time work may be the best option for some people living with HIV/AIDS, yet they aren't considered successful closures by VR policy. The traditional definition of success doesn't always work with this population.
- *Perceptions of the service and employment community.* Some counselors and employers view people living with this disease as "not going anywhere" and having no real future.
- *Perceptions of the consumers.* Sometimes consumers have a fear of state agencies. This may be due to a negative experience with an agency in the past or may be due to fears related to disclosure of their HIV status. This includes those service professionals who would refer people to the agency.
- *Loss of necessary benefits*. The consumer's benefits are also an issue. Consumers may be afraid of losing their Social Security and their medical coverage. Some consumers may not have the earning potential to make up for the loss of these benefits.
- *The time.* Although the system can be flexible, the process can be slow. If the consumer cannot maneuver through the system, the process is slowed down considerably.

- *Lack of understanding/knowledge of vocational limitations.* Sometimes it is difficult to get medical information from the consumers. Information related to limitations is particularly difficult to obtain. Medical sources are very good about supplying the diagnoses, but it is difficult to find documentation of limitations or evidence that supports the consumer becoming involved in rehabilitation. If these details are missing, the consumer needs to be evaluated further. The employers are often fearful. The employer may assume that a consumer is more disabled than he or she actually is just because that individual is involved with ORSC.

This group needs vocational rehabilitation assistance from people who are competent in their ability to help them. Counselors must have the skills to assist people in making appropriate job choices (Yelin, et al, 1991) and assist with understanding the factors that influence transition to work, (e.g., medication therapies, understanding the disease, and management of stresses and concerns of the disease) (Glenn, Garcia, Li & Moore, 1998; McReynolds, 2001). This comes from education, ongoing training and experience. Other studies have shown rehabilitation counselors need specialized training and experience to work successfully with this population (Glenn, 1997; Hunt, 1996; WID, 1994). Yet, this study shows rehabilitation counselors are receiving below average amounts of training and have little to no experience working with the population.

Vocational rehabilitation professionals need to confront issues related to serving people with HIV and AIDS. They are and will continue to be present on caseloads throughout the country because of the disability of HIV or AIDS or another primary disability, such as substance abuse (Hunt, 1996). This study highlights the significance and correlation of alcohol and drug abuse among people living with HIV or AIDS. Sixty three percent of the study participants living with HIV or AIDS have some problems with alcohol. The correlations were highly significant between four of the five VR services variables, with the exception of the item "VR services applied for since the last interview." Forty percent of the participants used drugs on a yearly basis and 29 percent had used drugs in the month prior to participating in the first study interview.

The field of rehabilitation has begun to research and develop policies, programs, and practices for serving people living with HIV or AIDS, but many questions remain unanswered.

Even if the questions are answered, they will need to be continually reevaluated given the changing trends of the disease and treatments.

The concerns regarding employment that are found in this study point to the need for reevaluation of policies and procedures, as well as further research. The potential loss of benefits is a definite area of concern for individuals living with HIV or AIDS. The cost of medication and medical care can be overwhelmingly high. Most respondents were receiving some type of benefit such as Medicare or a prescription drug program to help meet these medical expenses. In addition, many received benefits such as SSI or SSDI to help cover basic living expenses such as rent, utilities, food, etc. All benefits mentioned have ceilings on the income a person can earn and still maintain benefit eligibility.

Fear, stigma, and moralistic attitudes lead the study participants to recommend caution in the area of disclosure of HIV status for individuals looking for work or employed. This caution was understandable but problematic given the potential need for job accommodations and protection under the Americans with Disabilities Act. Study participants identified specific job accommodations that would assist them in obtaining and maintaining employment. These include modified work schedules, access to refrigerators or food and water, time to rest or liberal sick leave. It is hard to hide the fact that you are taking medication of any sort, especially when the medication schedule is complex.

There are numerous psychosocial issues that will impact an individual’s ability to work or be productive on the job as noted by the study participants. Stress related to relationship problems join fears about personal health and mortality issues. These issues can interfere with normal cognitive function, lead to loss of sleep as well as physical or mental health deterioration.

The responses in this study show individuals living with HIV or AIDS and employers alike have concerns about the physical demands of work and the functional limitations associated with the disease. Previous research suggests that individuals living with HIV or AIDS who held physically demanding jobs were more susceptible to job loss than those with college educations and flexible scheduling. (Massagli, Weissman, Seage, & Epstein, 1994). There was definite concern expressed about the potential loss of medical benefits in some job choices. Medications are expensive and require health insurance or disability benefit structures for funding (Reid, Kitchen, & Deutsch, 1999).

Rehabilitation counselors and consumers alike are key to solving problems and implementing practices that will have more success. The participants in the qualitative portion of this study were very knowledgeable about both barriers and ways to address accommodations. They were also the individuals most invested in making VR work for people with disabilities and increasing employment opportunities. Yet, the general population of vocational rehabilitation counselors did not believe they were sufficiently skilled in providing or accessing resources.

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