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ABSTRACT

This training manual addresses the vocational rehabilitation (VR) of persons with the Human Immunodeficiency Virus (HIV) or AIDS (Acquired Immune Deficiency Syndrome) and related conditions. It considers the medical, cultural, social, legal, psychological, and economic implications of this condition; and how these factors relate to the vocational rehabilitation process. VR management issues considered include Federal responsibility, the role of state VR agencies, procedural barriers to service, organizational structure, and advocacy. Basic information includes the historical context of the epidemic's course; the spectrum of HIV, symptoms, and opportunistic infections; routes of transmission; and infection precautions for caregivers. Also discussed are cultural and social issues, characteristics of the population, psychosocial issues, the counselor, the co-worker, and HIV and attitudes. Counselors are encouraged to look at AIDS as just another disability. Service delivery is considered in terms of case finding, the initial interview, functional limitations, eligibility, and development of the Individualized Written Rehabilitation Program. Legal issues such as confidentiality and the duty to warn are also addressed. Appendixes include resources (e.g., AIDS hotlines for all states), a glossary, and a reprint of "Aids Rehabilitation: A Resource Guide" by Thomas Backer. Contains 14 references. (DB)

SIXTEENTH INSTITUTE ON REHABILITATION ISSUES

VOCATIONAL REHABILITATION SERVICES TO PERSONS WITH H.I.V. (AIDS)

Institute on Rehabilitation Issues
CONSUMER STATE REGION-FEDERAL RESEARCH AND TRAINING

RESEARCH AND TRAINING CENTER

UNIVERSITY OF WISCONSIN-STOUT
STOUT VOCATIONAL REHABILITATION INSTITUTE
SCHOOL OF EDUCATION AND HUMAN SERVICES
MENOMONIE, WISCONSIN

OCTOBER, 1989

Report from the Study Group on

VOCATIONAL REHABILITATION SERVICES TO PERSONS WITH H.I.V. (AIDS)

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Savannah, Georgia

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Prime Study Group I
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Acknowledgement

Acknowledgements are most appropriate to all those participating in this publication on behalf of all of the personnel in the field of rehabilitation who will benefit from this document. It is the hope of all concerned that persons with HIV will receive timely, appropriate, and more complete services from people in the field of rehabilitation as a direct result of the information provided herein.

The diagnosis of thousands of cases of "AIDS" across the country and the continuing incidence of new cases poses a serious challenge to rehabilitation professionals. We are grateful that this timely topic was proposed by NIDRR, RSA, CSAVR, and selected by the Executive Committee of the Institute on Rehabilitation Issues. Their mandate was to discuss, raise issues, review information, and publish a training manual for rehabilitation professionals in RSA, the state vocational rehabilitation agencies, rehabilitation facilities, independent living centers, and others concerned about providing quality rehabilitation services to persons with disabilities including those with HIV.

We extend our appreciation to the individuals who met that challenge - first to the Prime Study Group members - who willingly gave of their expertise, time, energy, and writing ability. We are all grateful for the knowledge, wisdom, and support embodied in these true professionals. These are the people who committed their efforts to the significant research and writing of this document, while maintaining their primary job duties. There is little doubt that their involvement, dedication, and contribution resulted in greater awareness of the rehabilitation issues and heighten sensitivity to the needs of persons with HIV.

We also extend our appreciation to those persons who attended the Annual IRI meeting as Study Group members. They reviewed the second draft of the document on October 16 and 17, 1989, in Savannah, Georgia. Hard work, knowledge of rehabilitation, and willingness to criticize constructively was the hallmark of their efforts, which produced a stronger document. Their input was heard and incorporated in the final draft of this book.

The product of any IRI document is the effort of several people. Each of the above people, in their own way, helped in the writing of all chapters. However, we would like to acknowledge the persons who produced the first two drafts of the chapters, assimilated new information and suggestions into their work, and presented their efforts for criticism by other Prime Study Group members and by the Study Group.

An introduction was originally prepared by Charles E. Young, Administrator of the Oregon Commission for the Blind. A basic information chapter "HIV 101" was written by Alan Emery, Ph.D. AIDS Consultant, San Francisco, California and Catherine Maier, Womens Service Program Coordinator of the San Francisco AIDS Foundation. The chapter on Psychosocial issues was prepared by Catherine Maier; Alan Emery; and Mary Grigsby, Coordinator AIDS Counseling Division, Oaklawn Community

Services, Dallas, Texas. The legal issues regarding services to persons with HIV were documented by Curt Decker, J.D., Executive Director, National Association of Protection and Advocacy (NAPAS), Washington, D.C. To offer assistance and guidance to the front-line providers of service, a chapter was developed which covers the service delivery process from a counselors perspective. This chapter was team written by Leigh-Ann Meissner, Program Specialist, Texas Rehabilitation Commission; Katherine Williams, Acting Administrator, Vocational Rehabilitation Services Administration, Washington, D.C.; Mary Grigsby; and Fred Shaw, Deputy Director, Field Operation, Department of Rehabilitation, Sacramento, California. The chapter on Management Issues, added late in the writing process, was originally prepared by Charles Young, reviewed for the first time at the Annual meeting, and extensively changed as a result of that input by the Editorial Committee. The chapter on Attitudes was written by Richard Pimentel of Milt Wright and Associates, Northridge, California. Resources, hot lines, and agency listings, as well as a glossary were provided for the reader's use by several sources. We salute these writers and the people on the Study Group who came to the Institute on Rehabilitation Issues Annual meeting to react to the document for making it a better and more useful training document.

During our deliberation the State Vocational Rehabilitation Agency of California offered the able input of Robin Timm, Rehabilitation Counselor. She provides services to a general caseload while furnishing quality rehabilitation services to several persons with HIV. Likewise the Commission on Rehabilitation Service of Massachusetts offered to our group the services of Senior Counselor, Domenic Stagno and a client of that agency. These individuals met with the Prime Study Group and gave significant first-hand input into the issues surrounding vocational rehabilitation services to persons with HIV. We thank these persons individually and their respective agencies for making this a much more accurate and meaningful book.

Finally, we wish to personally thank the dedication of the other two members of the Editorial Committee. Catherine Maier, Womens Service Program Coordinator of the San Francisco AIDS Foundation is clearly a most dedicated and knowledgeable professional. She maintained the course even as San Francisco recorded and then began recovering from a most devastating earthquake. Domenic Stagno, Senior Counselor, Massachusetts Rehabilitation Commission brought his several years of front line case management experience in vocational rehabilitation and experience in working with persons with HIV to our efforts.

To all who have helped we say a sincere thank you. To those who make use of this book we sincerely hope it is helpful, instructive, and enlightening so that persons with HIV may receive timely, quality, and appropriate services. Your services will assure access to physical and mental restoration, training, counseling and coordination of services, and ultimately employment which are vitally needed by persons with HIV.

As stated, the entire document was the combined result of the Prime Study Group, Study Group, Editorial Committee, and guests. As in all IRI documents, no one individual member is responsible for the content of a particular chapter. However, any errors of omission or commission must be attributed to the final editors, Dave Corthell and Mike Oliverio.

David W. Corthell, Ed.D.
University Sponsor

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INTRODUCTION

or
Why You Should Read This Book

"THE CENTERS FOR DISEASE CONTROL (CDC) NOW CONSIDERS HIV TO BE A CHRONIC ILLNESS!"

The mission of Vocational Rehabilitation is to serve individuals with physical and/or mental disabilities when the functional limitation caused by those disabilities interferes with obtaining or retaining employment. Services are also provided to enable clients to live independently through Centers for Independent Living.

The Centers for Disease Control (CDC) now considers the HIV disease to be a chronic illness rather than one which is immediately life threatening. The number of people in the United States with AIDS is now more than 100,000. AIDS experts and medical authorities project that this number is only the tip of the iceberg and that many more people have HIV but not AIDS. AIDS researchers project that the number of people with HIV will continue to grow. The need for vocational rehabilitation services by persons with HIV will increase proportionately.

Vocational rehabilitation professionals have been providing services for clients with HIV. However, to effectively and sensitively serve this growing population in the future requires a point of reference. The Institute on Rehabilitation Issues (IRI) responded to the suggestion of RSA, NIDRR, and CSAVR to study and produce this HIV/vocational rehabilitation training manual.

In this book the authors will generally refer to HIV (Human Immunodeficiency Virus), or persons with HIV. HIV was chosen rather than the specific diagnoses of AIDS (Acquired Immunodeficiency Syndrome), ARC (AIDS Related Complex), HIV Symptomatic or HIV Asymptomatic.

The virus does not follow an orderly progression. It does, instead, vary in it's progression and impact from person to person. New, although usually expensive, and not universally available treatments, have enabled people with HIV to live longer with this chronic, yet manageable condition.

Surgeon General Koop stated that, "HIV is expected to impact every household in America in the 1990's." It is known that HIV affects every cultural, social, economical, sexual, racial, and geographical group in this country.

Consider the following facts identified in 1989:

- AIDS is the leading cause of death of women in New York City.
- More males, living in San Francisco, have died from AIDS than the number of San Francisco men who perished in World War I, World War II, the Korean War, and the Vietnam conflict combined and doubled.
- AIDS among those between the ages of 13 and 19 increased by 51% this past year.
- HIV is a growing public health problem and spreading on our college campuses.

Each of us knows certain facts about HIV. It has been impossible to avoid information about the disease. However, some of the information available is false, outdated, or misleading. Therefore, it is the Prime Study Group member's intent, and the intent of this book, to present valid, updated information that will assist in the successful vocational rehabilitation of people with HIV.

The following book will address the specific needs and concerns of persons with HIV. It addresses and explains the medical, cultural, social, legal, psychological, and economic implications of this condition, and how these factors relate to the vocational rehabilitation process. Some of these issues are similar to issues and needs of other disability groups and some are unique to HIV.

People with HIV are classified as disabled under federal anti-discrimination statutes. Vocational rehabilitation is an eligibility program and not a mandate program. Many persons with HIV meet the criterion of eligibility, and sometimes HIV clients will have a primary disability other than HIV. For example, hemophilia, substance abuse, or any other physical or mental disability may be the primary disability but the person also is HIV+. Persons who are HIV+ will be eligible for services if they meet the eligibility requirements of: a physically or mentally disabled, which results in a vocational handicap, and that following appropriate services there is reasonable expectation that the individual will obtain or retain appropriate employment.

Specific needs, associated with this disability, will often require vocational rehabilitation services from facilities, and independent living centers to address and provide necessary services. It was the intent of the authors that this book provide sensitive, significant and useful information for all rehabilitation personnel in a broad range of positions so they may enhance services to clients with HIV.

The proactive response and actions of Vocational Rehabilitation Administrators and Managers to this manual and to HIV as a medical or mental disability will assist agency staff, programs, and rehabilitation facilities in providing sensitive, specific, nondiscriminatory, and effective rehabilitation services to clients with HIV.

CHAPTER I

VR MANAGEMENT ISSUES AND HIV

> Management sets the direction and tone for delivering services in any agency. It is the responsibility of management to identify changes in the field and prepare the agency including staff for the new issues to be faced by the organization. The issues surrounding HIV have already begun to impact vocational rehabilitation services. It is the understanding of the Prime Study Group that several states have taken the position that no new policy statements are necessary to serve persons with HIV. Instead, this new group will be served if they meet the general eligibility requirements of the state vocational rehabilitation program.
>
> A significant (although not unanimous) number of the members of the IRI Study Group felt the Rehabilitation Services Administration, the National Institute on Disability Rehabilitation Research, and state Vocational Rehabilitation Administrators should take a more proactive stance on the issues surrounding HIV. Members of the IRI groups believe that the management/administrative issues must be addressed before the other issues surrounding this topic.
>
> The benefits of providing management leadership to the agency are numerous. Advanced planning, specific policy development, and training will avoid crisis management of these issues and, reduce staff anxiety when confronted with this topic. Proactive planning will protect the agency from outside pressures and demands. Such a stance will allow the agency to become a leader in this issue that has major impact on the disability community.

Many state agencies have had employees with HIV and/or served clients with HIV as a primary or secondary disability. However, <u>every</u> state agency will be confronted with the issue of HIV in the next few years. HIV is pervasive, is infecting more and more people, and is found in people of all ages, occupations, and educational levels. It is clearly an issue that is not going to go away. Therefore, organizations of all types must eventually develop policies and procedures to deal with the disease.

The Prime Study Group strongly recommends that management address their response to this disease before being faced with making decisions that affect larger numbers of current employees or clients. The comprehensive response to HIV developed by management should, as a minimum, include:

- Drafting and promulgating an agency policy on HIV;

- Providing training to all staff on the policy, the medical aspects of HIV, psychosocial issues, attitudes, legal issues, and case service procedures;
- Develop similar benefit agreements; and
- Implementing recommendations from this publication and/or those developed by the agency.

Such actions will communicate the necessary management support for serving persons who are eligible for vocational rehabilitation services including those with HIV.

Federal Responsibility

The Rehabilitation Services Administration (RSA), as the oversight agency for vocational rehabilitation, should consider development of comprehensive policies on rehabilitation services to people with HIV. These policy issues would include but are not limited to:

- Eligibility criterion for service for people with HIV;
- New services that may be necessary;
- Protection of confidentiality;
- Review of client coding and tracking systems; and
- Training of state agency medical consultants, state agency staff, and others.

RSA should also develop specific HIV guidelines for all other rehabilitation services provided under the Rehabilitation Act, including Independent Living Programs and Centers. For example, a recent study (Scharlau, 1988) found that: between 9% and 18% of Centers for Independent Living did not believe a person with AIDS would be eligible for services; approximately half indicate staff or board members have expressed concern about serving clients with AIDS; between 30% and 51% of CIL's had provided inservice training on AIDS, but the training was usually from one to four hours long, and primarily covered medical aspects; 83% to 93% felt that serving persons with AIDS will be a nationwide CIL issue.[1]

RSA should be exploring interagency cooperative agreements with relevant federal agencies to enhance sensitive delivery of service to people with HIV. These agencies would include but are not limited to:

- Other divisions of the Department of Education;

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[1] Note: First percent is for CIL's in cities of less than 200,000 and the second percent is for CIL's in cities of over 200.000.

- The Public Health Service; and

- Office of Human Development Services of the Department of Health and Human Services, Department of Labor, and Department of Housing and Community Development.

In the past, RSA has provided training to central and regional office staff in order to assure proper monitoring of state rehabilitation services on new laws, policies, or issues. It is felt that the provision of services to persons with HIV is surrounded by several complex issues. Consequently, RSA is urged to consider national training regarding the complex issues of services to persons with HIV.

Periodically RSA identify projects for funding under its discretionary and training budgets. In the area of HIV, RSA should consider allocating training monies for the provision of training for state medical consultants. The specific information needed by state medical consultants includes: how HIV has become a chronic rather than terminal illness; new treatments which are extending productive life; current diagnostic procedures, and other aspects of HIV medical management. Other in-service training should be provided either through national training priorities (RFP's) or through the RCEP system.

RSA, under Special Projects and Demonstration for Providing Vocational Rehabilitation Services to Individuals with Severe Handicaps - Invitational Priority (Federal Register, Vol. 54, No.178, September 15, 1989), has issued an RFP for up to three grants to "... respond to the need for service delivery to individuals with AIDS, projects that are designed to promote vocational and independent living outcomes for individuals with AIDS who are considered disabled." This beginning effort is to be commended. It is hoped that more such RFP's in the area of services and training in HIV will be announced.

The National Institute on Disability and Rehabilitation Research (NIDRR) funds research in rehabilitation. As of late 1989, NIDRR has funded one research project for a one year time period on "Serving Children with AIDS: Developing a Family and Community Service Protocol." The Prime Study Group recommends that NIDRR support further research in providing vocational rehabilitation and independent living services to persons with HIV. Of particular interest would be research findings on the required new services and model programs. It is hoped that such research results will be available before rehabilitation agencies are inundated by a large number of people with HIV seeking services.

State VR Agencies

State vocational rehabilitation agency management are only required to respond to RSA policy directives. However, this does not preclude a state agency from developing their own policy in response to HIV. Members of the Study Group believe that state agencies should develop HIV-specific policies. Such agency policies would include the following issues:

1. Eligibility of people with HIV including provision of equipment and services, purchase of experimental drugs and treatments, and referrals to other rehabilitation services such as Independent Living.
2. Clear delineation of the right of all employees with HIV to the full benefits of their employment and the expectation of nonbiased staff reactions.
3. Delineation of the vocational rehabilitation agencies responsibility, through staff development efforts, to provide comprehensive training to staff. This should include administrators, managers, supervisors, counselors, and support staff. Pertinent training is needed regarding specific job needs and include sensitivity to the issues surrounding HIV. The Prime Study Group recommends that training also be provided in the areas of sexuality, death and dying, and substance abuse to strengthen all staff's skills in providing services to and understanding of this population.
4. Take a leadership role in providing model HIV in the workplace policies and sensitivity training to vendors, other rehabilitation agencies, and potential employers (especially those who regularly employ people with disabilities referred by the VR agency).
5. Reenforcement of confidentiality requirements recognizing the stigma that at present surrounds people with HIV.

Procedural Barriers To Service

Vocational rehabilitation administrators should review the current procedures for serving clients and the potential barriers to effectively serving persons with HIV. Clearly, persons with HIV present several challenges to rehabilitation professionals. For example, present coding systems for tracking may not accurately provide a picture of the number of persons with HIV who are currently being served by the agencies. Because of the multiple problems faced by persons with HIV, rehabilitation closures may not be achieved as rapidly as with other persons.

A potential problem is the long-term nature of services needed by this population, as well as the potential for amended plans, and inability of a client to successfully fulfill the goals and objectives as outlined in the IWRP. Providing services to persons who will often require multiple services, over a protracted time period, may result in a perception that working with such clients will not receive equal credit and support of the agency. This could be viewed as a disincentive to serve this population and needs management's attention. For example, a comparable system of support and rewards, for personnel working with persons who have HIV, could be developed within the traditional vocational rehabilitation process.

Outreach

It is recognized that vocational rehabilitation agencies are often under funded and unable to serve all clients who could benefit from rehabilitation services. However, it is essential that the vocational rehabilitation agencies make known to other agencies, who work with persons who have HIV as well as employers, the availability of vocational rehabilitation services to this population. Outreach also develops information about other services and resources available to the vocational rehabilitation counselor for referrals and could provide potential for improved interdisciplinary approach to serving the client. As identified, potential similar benefits should be made known to the agencies' staff.

Organizational Structure

Vocational rehabilitation agencies are housed in a variety of different departments of state government. Each agency defined the job role of their staff. In some cases agencies may need to consider the role of counselors as coordinators of services versus counselors skilled in providing psychosocial interventions to person with HIV. Some agencies provide services only through general caseloads while others may have specialty caseloads. Serving persons with HIV may require a review of how best to structure service delivery for this new population. Some areas of consideration may include:

Benefits of specialty caseloads:

- Current knowledge and expertise in one area of service which is complex and changing rapidly.
- Familiarity with resources and personal working relationships with community agencies.
- Increased sensitivity to the population which leads to improved trust with clients and referral sources.
- Creates an internal resource for other divisions of the agency such as staff development.

Problems with specialty caseloads:

- Isolation and stigmatization of counselors with specialty caseloads.
- Potential burnout of specialty staff.
- Identification of counselor by potential employers and other providers of service as the "AIDS" counselor resulting in "de facto" breaches of confidentiality and increase in stigma.

- Leads to misperception by other counselors that this population is not their service responsibility.

- Potential of lack of service in some less populated area of the state lacking the specialty counselors.

- Inaccurate assessment of average counselor expenditures resulting from a few expensive cases.

Supervision

It is the responsibility of management to enforce the policies developed through supervision and, if necessary, disciplinary action. Incident of inappropriate behavior by any staff (e.g., breach of confidentiality, refusal to accept persons with specific disabilities, inappropriate behavior towards clients, etc.) must be adequately addressed. This intervention could include one to one supervision, further training, review of job requirements and responsibilities, reprimand, or in the most severe cases, dismissal.

Cooperative Agreements With Community Resources

Responsibility for developing cooperative arrangements with community resources, which provide comparable benefits specific to persons with HIV, (see the Appendix for listing of potential agencies) begins with the administration of the agency and flows to the regional and area offices. Such arrangements need to be nurtured, reinforced, and made operational at every level.

Review of Release of Information Forms

Many state agencies use medical release forms that are not adequate for the special issues relating to HIV. Legal departments of each agency should review the present release forms and modify those forms as necessary to assure that clients have given valid informed consent to obtaining and releasing this sensitive information.

Some states have health and safety codes that are more restrictive than the federal statutes regarding confidentiality of records. Often these take the form of prohibiting unauthorized disclosure of information. As a rule, staff should be aware that if medical information is shared with <u>any</u> person or facility, the client must agree and sign a release <u>each</u> and <u>every</u> time information is shared with and outside agent or agency. For example, the State of California's procedure, on release of confidential materials, states, "Failure to adhere to these laws may result in assessment of civil penalties, plus court costs. Each illegal disclosure made is a separate and actionable offence." Consequently, their procedure requires, "To enter a client's references of having AIDS symptoms, laboratory work-up, or the diagnosis of AIDS in the case file, the counselor must obtain a specific signed Release of Information for this purpose from the client/applicant ..."

Advocacy for Persons with HIV

Vocational rehabilitation, a traditional resource to employers, can take a leading role in disseminating information to break down barriers to employment of individuals with HIV. Agencies can establish employer advisory groups and offer technical assistance or educational programs at the worksite to help desensitize the co-workers of eligible clients with HIV. This effort could assist employers and their work force to be more receptive to working with individuals who may meet negative attitudes towards them and their disease. However, the vocational rehabilitation agency also needs to have a clear policy on how it will treat employees with HIV in order to give confidence and credibility to agency staff making such educational presentations to the public.

Vocational rehabilitation agencies will often purchase services from outside agencies for their clients with HIV. In such cases, the state agency should confirm that the vendor is competent in providing those services. In some cases the state rehabilitation agency will need to provide training, or make training readily available, to rehabilitation facilities, Client Assistance Projects, private rehabilitation facilities, Centers for Independent Living, and other sources of rehabilitation services within the state.

Finally, it is recommended that consumers with HIV be contacted by the state rehabilitation agency for their input regarding several matters. They could most appropriately advise the agency on staff training issues, advisory groups, community support networks, and other issues specific to this disability.

Chapter II

HIV 101

The Course of the Epidemic/Historical Context

A new and deadly virus made its first appearance during the 1960's, or perhaps even earlier. It was not until 1981 that there was any hint of its passage, and it was 1984 before the virus was finally identified. During the last decade the virus has spread to virtually every country in the world.

In early 1981 physicians in New York, Los Angeles, and San Francisco and a few other urban areas unknowingly encountered the first manifestations of this perplexing virus. At the time none of these doctors could know that these few patients represented the beginning of a medical challenge that would alter the course of medical history, if not history in general. Some of these doctors contacted the Centers of Disease Control (CDC) in Atlanta, to ask for help. In the summer of 1981 the CDC organized its Task Force to track the course and incidence of this disease.

The general public, however, did not become aware of this disease and its medical, social, psychological, and political implications until 1983. Because the earliest cases of these new confounding infections were found in white homosexual males and Haitians, the media began to focus attention on gay lifestyles and people from Haiti, sanctioning the general public's fears and prejudices about homosexuality. The pointed focus on the lifestyles and culture of the first people to get the disease, rather than on the disease itself, led the American public to believe that this was not something they had to confront directly or take seriously.

During the early years of the epidemic the virus was named by its various discoverer as "Gay Related Immunological Disease" (GRID), "Human T-Lymphotropic Virus Type III" (HTLV-3), "Lymphadenopathy Associated Virus" (LAV), and "AIDS Retro Virus" (ARV).

In 1986 an international scientific committee gave it the official designation "Human Immunodeficiency Virus," or "HIV". To the public it became known as "the AIDS virus," and one of the medical conditions it causes became known as "AIDS" - Acquired Immune Deficiency Syndrome.

To date, gay men have the highest incidence of infection. However, two other groups significantly affected by HIV disease are intravenous drug users (IVDU's, and women. Most of these women are poor, uneducated, disenfranchised, and have little or no political power, socioeconomic power or power in their personal lives. Women who are IVDU's or partners of IVDU's are ostracized and stereotyped. IVDU's are viewed by society and by social services and care providers as uneducable, immoral criminals, while women with HIV are seen as irresponsible and promiscuous. Many IVDU's and women with HIV are

Table I-1

The Chronology of AIDS

1977	AIDS virus arrives in New York
1978	AIDS virus arrives in Los Angeles and San Francisco
1981	First medical cases reported to CDC
1982	First organization on AIDS created in New York
1983	The name "AIDS" established
1984	The "AIDS virus" discovered: Pasteur (France) announces LAV; Gallo (USA) announces HTLV-3; Levy (USA) announces ARV
1985	U.S. government declares AIDS "top health priority"; predicts AIDS vaccine ready within six months
1985	CDC issues Guidlines for AIDS in the Workplace
1986	Surgeon General issues report on AIDS
1987	Virus renamed "HIV" (Human Immunodeficiency Virus)
1987	Presidential Commission on AIDS appointed
1988	AIDS diagnoses in the U.S. surpass 60,000; 50 new cases added each working day; no cure or vaccine in sight. Surgeon General's report sent to every US postal address.
1989	AIDS diagnoses in the U.S. surpass 100,000; treatments for HIV infections improving and encouraging; no cure or vaccine in sight. AIDS considered a chronic illness as opposed to a terminal illness.
1993	Projected 450,000 Americans diagnosed with AIDS - one every 36 seconds; treatments for HIV infections continue to improve. No cure or vaccine in sight.

ethnic minorities. These groups, most affected by HIV, are categorized in disfavored ranks in society. They are socially and politically targeted and discriminated against as the least deserving of attention and services. However, these groups most affected by HIV are not the only people who contracted the virus.

People with HIV disease represent every racial and ethnic group, every socioeconomic level, and include people of every sexual orientation, both men and women. Most people with HIV are between the ages of 20 and 49 - the peak years of productivity, when most people are planning for the future.

HIV is frequently called "the disease of losses." It is an infectious disease that is responsible for the loss of health, finances, employment, housing, control of bodily functions, cognitive and intellectual functioning, loved ones, and hope. People with this virus are not only anxious, isolated and depressed, but their psychological well being is further eroded by manifestations of the disease, fatigue, and pain, and by the fear of death, rejection, discrimination, prejudice and unending loss.

Spectrum of HIV, Symptoms, and Opportunistic Infection

Definition

According to the 1989 monthly CDC HIV/AIDS Surveillance Report, "Acquired Immunodeficiency Syndrome (AIDS) is a life-threatening manifestation of infection with the Human Immunodeficiency Virus (HIV)." The HIV disease complex is caused by a retro virus that suppresses or compromises the human body's immune system. The presence of HIV indicates a "spectrum of infection," ranging from HIV positive, to ARC, to AIDS.

HIV Positive (+)

If a person is exposed to the HIV, he or she may become reported as HIV positive (HIV+). The "AIDS antibody test" is not a test for AIDS or HIV. It is a blood test that has been developed to detect antibodies in the blood which indicates HIV exposure. A person may have a HIV+ antibody test but may not have symptoms, in which case he or she is designated as "HIV+ asymptomatic."

Some symptoms of HIV are common, general, and unrelated to the virus. They may be caused by a host of infections other than HIV. Consequently, the reader is cautioned not to try to diagnose themselves, clients, or co-workers as they read this section. Proper diagnosis requires specialized medical tests, interpreted by a physician who has specialized knowledge or training.

ARC

ARC (AIDS Related Complex) is a group of symptoms that do not fit the CDC's definition for AIDS. Symptoms of ARC may include but are not limited to: fatigue and malaise, swollen lymph nodes or lymphadenopathy, continuous unexplained fever or night sweats, weight loss, bouts of diarrhea, candidiasis or thrush on the tongue or throat, transient recent memory loss, confusion and disorientation. Haryleukoplakia, or corrugated lesions on the tongue, may also be present. The virus may cause Herpes Zoster (Shingles), which is manifested by painful sores usually on the trunk.

Idiopathic Thrombocytopenic Purpura (ITP), a syndrome of unknown origin, causes bruising and easy bleeding in people with a diagnosis of ARC. It has been estimated by epidemiologists that there are three to five times as many people with ARC than there are people with AIDS.

AIDS

The diagnosis of AIDS is determined by physicians when they determine the presence of one or more specific opportunistic diseases. The agents of these diseases are usually present within the body or the environment but only have the opportunity to cause disease if the immune system has been impaired, hence the term opportunistic diseases. The most common opportunistic infection that determines an AIDS diagnosis is Pneumocystis Carinii Pneumonia (PCP), a rare parasitic infection of the lungs that results in a dry cough, shortness of breath and difficulty in breathing.

The second most common opportunistic infection or disease of AIDS was originally seen in older men as a benign lesion. Kaposi's Sarcoma (KS), a cancer of blood vessel walls occurs in persons with HIV as pink or purple painless lesions on the skin. These lesions may be present internally including major organ involvement.

Another protozoal or parasitic infection resulting in an AIDS diagnosis is Toxoplasmosis (Toxo). This is a systemic infection that results in abscesses of the brain and may cause severe headaches, disorientation, and seizures.

Mycobacterium Avium Intracellular (MAI) is a bacterial tuberculosis that may infect the lungs or other body tissues, and is also an indicator of AIDS. Symptoms can include wasting and weakness.

Although Candidiasis, a fungal infection, may affect various membranes such as the tongue, nail beds, or anus, it is only an indicator of AIDS if it is present in the esophagus. When candidiasis is present in the esophagus swallowing becomes extremely painful.

Another fungal infection indicating AIDS is Cryptococcoses. This fungus enters the respiratory track, infects the lungs and spreads to the meninges becoming Cryptococcal Meningitis. Common symptoms are confusion, headaches, nausea, memory loss and seizures.

Three viral infections maybe indicators of AIDS: Cytomegalovirus (CMV), Herpes Simplex, and Progressive Multifocal Leukoencephalopathy (PML).

CMV has a variety of symptoms resulting in colitis (MV Colitis), pneumonia, infection of the brain (CMV Encephalitis), or infection of the retina of the eye (CMV Retinitis). CMV Retinitis may result in blindness. CMV Encephalitis may cause headaches, confusion and dementia. CMV Colitis may cause vomiting, diarrhea, nausea, and weight loss. Cytomegalovirus is only noted as AIDS related if it is disseminated, or spread, throughout the body and severe.

Herpes Simples Virus is only defined as AIDS when it is chronic, more than a month in duration, does not heal, is not in remission, or is present on nonmucous skin.

Progressive Multifocal Leukoencephalopathy (PML) is a papovavirus that infects the coating around nerves in the brain causing loss of memory, impaired motor control, mood swings, and seizures. Also there may be weakness of limbs specifically on one side of the body, vision and speech impairment, and inability to concentrate.

The 1987 Revision of The Centers Of Disease Control's Case Definition For AIDS adds dementia and wasting syndrome as AIDS indicators. AIDS Wasting Syndrome is identified by more than 10% weight loss accompanied by either diarrhea of more than 30 days, or weakness and fever for more than 30 days. A physician must make this diagnosis of wasting syndrome, as weight loss is a common symptom of HIV.

Using CDC's criteria for this diagnosis, HIV Encephalopathy (AIDS Dementia), must be diagnosed by a physician and confirmed by the presence of HIV in spinal fluid, or exams of the head by CAT Scan, or MRI. AIDS Dementia has two categories. The first is AIDS Dementia that is severe with the person needing total care, which is considered a late stage in the disease process. The second category of AIDS Dementia is manifested by a neurocognitive impairment where the person with AIDS Dementia has trouble remembering and needs continued assessment. This neurocognitive impairment may be accompanied by an intellectual deficit that interferes with daily functioning.

Table II-2 summarizes the common diseases associated with AIDS and ARC along with the associated symptoms.

Routes of Transmission

Anyone can contract HIV if they engage in the activities that transmit the virus. HIV is transmitted from one person to another in specific body fluids, and must enter the bloodstream to infect someone. The body fluids of a person with HIV which can transmit the HIV virus are: semen, blood, vaginal secretions, urine, and feces.

One of the routes of transmission of HIV that may result in an HIV+ status is sexual activity. Semen is the agent that carries the

Table II-2

Common Diseases of AIDS and ARC, with Symptoms

Name	Type	Common Symptoms
AIDS:		
Pneumocystis carinii pneumonia (PCP)	protozoan	dry cough, shortness of breath
Kaposi's sarcoma (KS)	cancer	pink, purple or brown spots
Toxoplasmosis	protozoan	fever, weakness, confusion, seizures
Cryptosporidium	protozoan	severe diarrhea
Mycobacterium avium intracellular (MAI)	bacteria	weakness. wasting, constitutional symptoms
Cryptococcol meningitis	fungus	headaches, confusion, nausea, seizures, memory loss
Progressive multifocal leukoencephalopathy (PML)	virus	memory loss, motor control problems, mood changes, seizures
Herpes simplex	virus	sores that do not heal or are on nonmucous skin
Cytomegalovirus	virus	must be disseminated in different organs, variety of symptoms
Candida albicans	fungus	white coating on throat or lungs for AIDS, in mouth for ARC
Direct neurological complications	HIV	motor control problems, memory loss, seizures, headaches, confusion, dizziness, mood swings

Table II-2 (continued)

Common Diseases of AIDS and ARC, with Symptoms

ARC:

Thrush	fungus	same as Candida, white coating mouth
Hairy leukoplakia	virus	"hairy" or corrugated lesion on tongue
Shingles	virus	painful sores on body, usually on trunk
Idiopathic thrombocytopenic purpura (ITP)	unknown	bruising, easy bleeding
Persistent lymphadenopathy		swollen lymph nodes

virus of an infected person during sexual intercourse (both vaginal and anal). Semen is also the infectious agent in oral sex (fellatio). Researchers have determined that vaginal secretions of an infected woman contain a lower concentration of HIV than do semen or blood. However, the virus can he transmitted from a woman to another person through vaginal intercourse or oral sex (cunnilingus). Researchers do not know if pre-ejaculation fluid contains the virus or causes infection. Donor insemination is another route of sexual transmission, although credible donor sperm programs test for HIV.

There is evidence that female to female transmission through sexual activities is possible. The Annals of Internal Medicine (1986) records one probable case and one possible case of female to female transmission. The agent of transmission is believed to be menstrual blood of an HIV infected woman entering the bloodstream of another woman through a cervical lesion.

The HIV virus is also transmitted through intravenous (IV) needles, which accounts for the high numbers of IV drug users who are HIV+. Partners of IV drug users, not using safer sex practices, are at high risk of contracting HIV. Needle sticks that occur in medical settings are also an intravenous transmission route. However, HIV infection of health care workers through this route is reported as rare. Injecting the virus directly into the blood stream is the most effective way of transmitting the virus.

Blood transfusions were at one time another route of intravenous transmission of HIV. Since 1985 all donor blood in the United States has been screened for the presence of HIV. However, some people are now being diagnosed with HIV disease due to their exposure to the virus through blood transfusions prior to 1985.

Hemophiliacs receive infusions of Factor VIII, which is a clotting factor made up of the blood of many donors. Before blood specialists began to heat-treat Factor VIII to kill the virus many Hemophiliacs had become infected. A high percent of Hemophiliacs in the United States were infected with HIV because of receiving infected Factor VIII prior to heat treatment of blood and blood products.

Children are also affected by HIV because an infected mother may transmit the virus to her baby during pregnancy, during birth through blood exchange, or through breast milk while nursing. The chance of the mother transmitting the infection to her child is about 50/50. Perinatal transmission of the virus is responsible for 80% of the cases of children with AIDS. The mother's or father's IV drug use is associated with 80% of these cases, while other children contracted HIV through transfusions or infusions with Factor VIII.

The course of an infection in a newborn differs from that of an adult. Although a child of an HIV infected mother is always born showing HIV antibodies, these antibodies may be the mother's antibodies, meaning that the infant may not be infected. While the child may remain symptom free, it is usually not known until about 15 months of age if the child's antibodies are their own or their mothers. Four to six months of age is the average onset of symptoms of an HIV infected child, progressing to AIDS at approximately 10 or 11 months of age. Symptoms in an infant with HIV are developmental delay, failure to thrive or grow, chronic diarrhea, chronic infections and pneumonia, and neurological problems. Seventy five percent of infants with HIV die in the first two or three years of life, while some live to nine or more. However, "Planning for services must take into account larger numbers of children with infection who are surviving longer because of the effective use of immunomodulation and chemotherapies" (Diamond, 1989).

HIV may also be transmitted from an infected person's urine or feces. This may occur through sexual practices, or from improperly following infection control guidelines while caring for a person with HIV who is incontinent or who vomits (see guidelines table II-3).

The following infection control guidelines were developed for those giving direct care to people with HIV. These guidelines are included in this manual as they may sometimes be pertinent in the workplace and social settings. They reflect a common sense approach to basic hygiene.

Debunking Myths

Misinformation, confusion, and myths still abound concerning all aspects of HIV, the people who are infected by it and, the people affected by it.

Physicians are the people we look to for medical expertise and advice. However, medicine is a profession of specialists, trained to diagnose and treat specific diseases and medical problems. The diagnosis and treatment of HIV is also a specialty and many physicians are not familiar with this new specialty. Therefore, it is important that medical consultations about clients with HIV are contracted with physicians who specialize in HIV on every phase of the HIV spectrum.

There is considerable confusion and misunderstanding around the issue of HIV antibody testing. For example, it is assumed by many people that confidential testing insures confidentiality. It does not. The confidential records of a physician, which contain the name of a person who was tested, may be subpoenaed, thereby breaking confidentiality. Consequently, some persons seek anonymous testing. Anonymous testing does not include the person's name, but a random number. The person given that number is insured confidentiality regarding the test results. Anonymous versus confidential testing is a controversial issue and legally differs from state to state.

Information about HIV changes frequently, therefore it is essential for counselors, administrators, managers, and medical consultants to stay informed and up-to-date. The Resources Section of this manual lists many sources to assist you. Keeping current will help to dispel the confusion, myths, and misinformation around HIV disease.

Table II-3

Infection Precautions for Those Giving Direct Care to People with AIDS in the Home

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People caring for persons with AIDS in the home use standard precautions designed to prevent blood and other body secretions from entering the body through any body opening, including cuts or open areas on the skin. Handwashing before given direct care protects the person who is susceptible to infection. Handwashing after direct care protects the caregiver.

Here are specific precautions to use when giving direct care to someone with AIDS:

1. WASH YOUR HANDS. Hands do not need to be gloved for handling patient clothing and other articles that are not soiled. Hands do not need to be gloved to touch the patient's intact skin (for example, backrubs). Keep your hands away from mouth and face while working. Wash hands before eating.

2. Wear disposable gloves when handling any secretions or excretions, especially blood. Avoid direct skin contact with blood.

3. People who do not have AIDS can use the same bathroom as someone with AIDS. As in any living situation, good sanitary practices (not spilling excrement on toilet seats, etc. and cleaning the bathroom regularly) make it safe for everyone. Washing hands after use of the facilities is protective to others. Mopping of bathroom floor and cleaning of other surfaces with standard household cleaning agents is sufficient for normal cleaning.

4. Dishes used by people with AIDS can be used by other people once they have been washed in hot soapy water. Allow to drain dry.

5. Kitchen floor and other kitchen surfaces can be cleaned using standard housecleaning agents. Sponges used to wash dishes and clean food preparation surfaces should not be used to clean other surfaces. Sponges and mops used to clean the floor should not be rinsed in food preparation sink.

6. Wash soiled linens and towels in a washing machine using the hot water cycle and detergent. Dry on high in dryer.

7. As you see, the surfaces and utensils used by a person with AIDS normally only require standard cleaning practices. Even used kitchen utensils are adequately cleaned when washed in hot soapy water, and the washing machine on the hot cycle will clean clothes and linens.

Table II-3 (continued)

Infection Precautions for Those Giving Direct Care to People with AIDS in the Home

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Surfaces (toilets, counters, floors) which have been visibly soiled with blood, fecal material or other body secretions, on the other hand, require disinfection. Household bleach is the best disinfectant because it is effective not only against AIDS but against organisms not killed by other household disinfectants (for example, use on the tub or shower floor as directed to control the fungus which causes Athlete's foot).

In order to use bleach safely, follow these instruction:

a. Wearing gloves and using paper towels, remove soil and disease causing organisms, washing with hot water and the appropriate household cleaning agent (detergent, scouring powder, etc.).

b. Following cleaning, rinse surface to remove all soap or other cleaning agent.

c. Apply a bleach solution to the surface (1/4 cup bleach to 1 gallon water). This strength is sufficient to disinfect against AIDS and other organisms; stronger solution will cause fumes which are harmful to the respiratory tract.

d. Bleach should <u>never</u> be combined with other cleaning agents because the resulting fumes can be extremely harmful.

8. When your clothing is likely to be in contact with secretion/excretions wear a gown, lab coat, or smock.

9. Use plastic bags to dispose of soiled tissues, dressings, bandages, and soiled gloves. Close and secure the bag tightly when discarding. Needles and other sharp items should be placed in puncture-resistant containers before discarding. Dispose of the bag in the garbage, as you would other solid waste.

10. Bedpans and urinals should be handled in a sanitary manner. Excrement need not be treated before being flushed down the toilet.

11. Diarrhea and vomitus: Using gloves, clean up patient and linens immediately. Put soiled linens in plastic bag until ready to launder. Clean and disinfect surfaces as above, placing disposable items in a plastic bag as above.

12. Pregnant women are sometimes advised to avoid direct physical contact with people with AIDS because patients may be shedding CMV virus in body secretions. (CMV may cause birth defects.)

Table II-3 (continued)

Infection Precautions for Those Giving Direct Care to People with AIDS in the Home

However, if someone caring for a person with AIDS becomes pregnant, having used the listed precautions will have provided more protection against CMV than we ordinarily have in our daily contact with people, some of whom may be asymptomatic excreters.

13. AIDS is not transmitted through the air. However, a person with AIDS who has an active and persistent cough may harbor other organisms which could be spread by the airborne route. The main concern to healthy caregivers is the possibility of the cough being caused by TB. The other respiratory diseases that people with AIDS get are usually only of importance to people who are immunosuppressed. Should a cough develop, ask patient to cough or sneeze into a tissue or handkerchief, not directly into the air.

14. At the end of physical care, WASH YOUR HANDS. Use lotion on clean hands. (Clean hands will not contaminate lotion bottle.) Lotion is important to replace the natural oils removed by handwashing, Dry, chapped hands leads to open areas through which disease-causing organisms may enter. In addition, those areas may develop mild infections which could then be transmitted to the patient.

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Questions and Answers

Many people still have questions and concerns about HIV infection. There is still much confusion, misinformation, and myth surrounding the disease. The following questions are representative of those that are frequently asked about HIV across the United States. The answers to these questions reflect the current unanimous agreement of health experts on HIV from around the world.

Q. What on the job concerns should rehabilitation staff members have?

A. The HIV virus is not airborne and <u>cannot</u> be transmitted through:

- sneezing
- sharing a drinking glass, utensils
- shared office equipment and supplies
- ordinary work place activities
- shaking hands
- papers
- toilet seats

A person with HIV disease, however, may be at risk of catching your cold, flu, or other infectious airborne diseases. Rehabilitation counselors usually do not need to take any special precautions on the job while working with clients or co-workers who have HIV. However, there may be circumstances where a client becomes ill and body fluids are present. Infection precautions (see table II-3) must then be observed.

Q. Can mosquitoes transmit HIV?

A. There have never been any cases of anyone getting HIV from mosquitoes. A mosquito only spreads diseases that use mosquitoes as part of the disease's life-cycle. Malaria, for example, has to spend part of its life in an anopheles mosquito in order to mature. HIV does not use mosquitoes as a condition of its life cycle - HIV is not transmitted by mosquitoes.

Syphilis, hepatitis and other blood-borne diseases like HIV are not spread by biting insects. Mosquitoes don't go immediately from person to person. In fact a mosquito will usually bite and feed about once ever 48 hours. Even if the virus were present in a mosquito, it would be in incredibly tiny quantity and would die before the next bite.

Recent studies also show that the virus cannot stay alive in cultures of mosquito cells. Also, if mosquitoes were transmitting HIV, we would see many more cases of HIV in those parts of the country where mosquitoes are common.

The answer is -- NO, mosquitoes do not transmit HIV.

Q. What about swimming pools and hot tubs?

A. Swimming pools and hot tubs do not spread HIV.

There are at least three reasons why swimming pools and hot tubs are safe. Remember that in order to do any harm, HIV must get from inside the body of an infected person to inside the body of someone else in sufficient quantity to be harmful and without the virus dying in the meantime.

First, it is unlikely that the virus would be able to get into the pool or hot tub in any dangerous quantity. The person with HIV, who has an open wound in a swimming pool, would have to bleed into the water in very large amounts. Even then the virus would immediately spread through the water and be diluted to the point of ineffectiveness. The chlorine in the pool would also kill the virus.

Even if the pool were improperly chlorinated or not chlorinated at all, the virus would still not hurt anyone unless significant quantities of the virus were to enter someone's body. You would have to drink huge quantities of the water - probably more than a person is even capable of drinking - and then the virus would have to get into your bloodstream.

So, the virus doesn't really have a chance in a swimming pool or hot tub. In short, pools and hot tubs are safe.

Q. **Why isn't the virus transmitted through food handing?**

A. The basic principles of transmission apply here as well. To do any harm, the virus must get from inside the body of the infected person to inside the body of someone else in sufficient quantity to be effective and without the virus dying in the meantime.

How would dangerous quantities of the virus get on the food? Saliva would provide insufficient quantities. Heavy bleeding could provide sufficient quantity. If the food were uncooked, the blood would be clearly visible. However, you would not eat the food if you saw blood on the uncooked food. If the food were cooked, the heat used in the cooking process would kill the virus. If the virus were on the food for sometime before serving, the virus would probably die of its own accord.

The Centers for Disease Control says that all epidemiologic and laboratory evidence indicates that blood-borne and sexually transmitted infections are not transmitted during the preparation or serving of food or beverages. The CDC guidelines about HIV in the workplace clearly state that food service workers known to be HIV+ need not be restricted from work unless they have evidence of another infection or illness for which any food service workers should also be restricted.

Clean serving utensils also pose no risk. Soap and water kill the virus. The kind of dish washing equipment used in restaurants, company cafeterias, or even home dishwashers, will easily kill HIV, as will hand washing with hot water and soap.

Q. Is there any chance of getting HIV by donating blood?

A. NO! Each donor is given his or her own blood donation bag with its attached disposable needle. These sets come in sterile wrapping from the factory and can only be used once. The needle is used for that donor and then discarded. There is no transfer of blood between donors, nor between the donor and the person collecting the blood. The strictest of safety standards are adhered to in the blood donation and testing process. In the entire world nobody has been identified as contracting HIV from donating blood, and many millions of donations are made each year.

Q. What about exposure to someone's blood?

A. Large quantities of blood should be treated carefully regardless of HIV. Although **intact** skin is an effective barrier against the HIV and most other diseases, blood-borne diseases are common enough and serious enough so that blood should be dealt with carefully.

An effective way to clean up quantities of spilled blood is by using an ordinary solution of regular household bleach - one part of bleach to ten parts of water, just as it says on the label.

Minor amounts of blood are not a cause for concern. For example, the tiny bit of blood that can result from a minor paper cut or pin stick is not likely to transmit HIV. Nevertheless, blood can transmit syphilis, hepatitis and other diseases as well as HIV, so use common sense about blood contact in the event of a serious accident.

Q. What are the risks of contracting HIV infection through blood transfusion?

A. In 1985, the HIV antibody screening test was implemented throughout the country. Since that time, the risk of HIV infection from blood transfusions has been greatly reduced. Although the blood supply is not absolutely safe it is safer than it's ever been. When medically indicated, it's much safer than turning a transfusion down.

Q. Is it advisable to provide my own blood for possible transfusion before having surgery?

A. One option available to certain qualifying individuals requiring a blood transfusion for an elective surgery is an autologous donation - one that uses the patient's own blood. Using your own blood eliminates the risks associated with blood transfusions; HIV, hepatitis, antibodies, and immunologic reactions.

With a physician's approval and foresight, a patient can usually store up to one pint per week for four to six weeks prior to surgery. The six-week limitation arises because of the restriction on how long blood can be stored fresh. Although, in some instances, the more expensive frozen blood storage may overcome this limitation. Patients should contact their physician for more information about this option. Autologous blood donations are not recommended to be stored for speculative blood banking "just in case."

For pregnant women concerned about the possibility of a transfusion due to Caesarean surgery, it is possible to donate one's own blood during the second trimester and have it stored frozen. The process is expensive and insurance will not pay for it unless the blood is actually used. The decision is really up to the woman concerned.

Q. **What about the HIV antibody test?** What are antibodies? What is the test good for? Who should take the test? Should everyone have to take the test? If a person gets a "positive" result from the test, does that mean he or she is contagious?

A. "Antibodies" are substances that are produced by the immune system to help eliminate a specific foreign invader than can cause disease. The body produces specific antibodies for each specific invader. Production of antibodies is an essential element of the human immune response.

Polio antibodies are designed to help attack and destroy polio. Measles antibodies are designed to deal only with measles. HIV antibodies are produced by the body as a response to the presence of the HIV virus. Each different antibody can be identified in the blood.

Unlike measles antibodies, which can protect the body from measles, and unlike polio antibodies, which can protect the body from polio, HIV antibodies do not provide protection against HIV for reasons that are not yet understood. However, since the body produces these antibodies anyway whenever it is infected with the HIV virus, the HIV antibody serves as a marker (signal or flag) that the HIV virus has been there at one time or another. However, the presence of HIV antibodies does not mean that the HIV virus is still there-only that it had been there at sometime in the past.

A test is available to determine whether the antibody to the HIV virus is in the blood. The test was designed for use by blood banks to screen their blood supply. If a given unit of blood contains HIV antibodies, the blood bank throws away that unit of blood rather than take any chances that the virus itself might still be there. The Food and Drug Administration licensed the test solely for that purpose, to act as a screening device for throwing away suspicious blood. It was not intended or licensed as a test for throwing away people.

The HIV antibody test <u>is not</u> a test for HIV. The test will not indicate whether the person tested still has the active virus in their system. It is not predictive of person's present or future health. It is only an indicator of past exposure to the HIV virus. However, a negative test result is a pretty good indicator that the person tested has never been exposed to the virus. A positive test means that the person encountered the virus at some point in his or her life.

Because the results of this test can produce many social, emotional, and political reactions in people, we believe it is always best to get the test in a setting that provides counseling before and after the test is done.

In California and some other states, the antibody test can be taken anonymously and confidentially. In other states, there is no confidentiality and test results are reported to public health authorities. If you are considering taking the test, you may wish to find out if your test result will be reported, and to whom.

A person who has HIV antibodies should not donate blood, and should always take precautions about sexual transmission. Also, women who are antibody positive and who are considering pregnancy should seek the advice of a physician.

Q. Can using a condom protect me from getting HIV?

A. While using condoms is definitely a way of reducing your risk of exposure to HIV, condoms may not be a foolproof, completely safe method for avoiding infection.

There have been no studies to date that have determined whether condoms can actually prevent transmission of HIV. There are two reasons for this. First, it is impossible to produce in a laboratory setting the exact conditions that exist during vaginal or anal intercourse. Second, no individual would knowingly want to risk being exposed to the virus for the sake of a laboratory test.

However, in 1985 researchers at the University of California conducted laboratory tests based on the Food and Drug Administration's approved methods for testing condoms. Their findings indicated that HIV cannot penetrate latex condoms, unless the condom is ruptured. This study was patterned after a study conducted in 1983, which demonstrated that the herpes virus could not pass through latex condoms. In the research, a teaspoon of fluid containing unusually heavy concentrations of live HIV was pumped under pressure into each of several condoms. The outside of the condoms was then dipped into a virus-free culture fluid for 30 minutes. The culture fluid was then tested over a three-week period. No viruses were present in the fluid even after this extensive testing period. The condoms completely stopped the passage of HIV. Previous scientific tests have shown that condoms stop transmission of herpes simplex, gonorrhea, and syphilis.

More recently, research in both the United States and Canada has shown that condoms made of natural skin (such as lambskin) may not be as effective in preventing leakage of HIV as latex condoms. Furthermore, another recent study has raised concern that many condoms may not meet the U.S. Food and Drug Administration's minimum standards for leaks.

Q. Why should I trust the medical authorities? They have been wrong before!

A. Because HIV is such a highly publicized and highly politicized disease, the medical authorities have been more careful about this disease than any in history.

Since 1981, regulations have required the reporting of every case of AIDS diagnosed anywhere in the United States to the Centers for Disease Control in Atlanta. Other studies have traced cases back more than ten years. Considerable expertise and expense have been devoted to learning about HIV, particularly the way in which the disease might be transmitted from person to person.

Each case of AIDS reported in the United States is carefully analyzed as to the possible methods by which the disease was acquired by that patient. Each patient is questioned about possible methods of exposure.

In addition, large group studies have been conducted over time with several thousand volunteer participants, some of whom have the disease, and others who do not, but who are members of high risk groups. Risk activities are documented and statistically correlated. These continuing studies are conducted by independent research groups in several different cities. The data collected by each group from thousands of participants is carefully analyzed, and correlated with data from other studies.

Studies have also tracked the health of doctors, nurses, and other health care workers in hospitals where patients with HIV infections are treated. Additional studies have carefully monitored the health of children living in the same household with a child who has HIV.

Similar studies are conducted in Europe, Canada, and Australia. Scientists from these different countries exchange data and compare findings. The results of all of these separate research and analysis projects are striking in their consistency. Researchers are confident that the methods of transmission were accurately identified, and that no future surprises can be expected.

Q. If, as you say, the medical evidence is so definite and this disease isn't a danger to us, why is HIV disease still such a big deal? Parents are picketing schools, people with HIV are being fired, the military is testing everyone, and laws are being proposed to bar people from food-handling jobs.

A. HIV raises a lot of fundamental and very sensitive questions and issues that have nothing to do with disease or medicine - questions and issues about which many people have extremely strong and very vocal opinions. HIV also has many elements that make it a sensational topic for the press: sex, blood, homosexuality, drugs, death, and promiscuity to name a few.

Much of the excitement about HIV doesn't really relate to the disease itself. It relates to strongly-held beliefs and opinions about the activities that are often responsible for transmitting the virus, and about the kind of people who most often get HIV.

HIV is a relatively new disease for most people. Since there is no cure, it's scary. We're all afraid of something we aren't used to and that we don't fully understand. Of course, parents are even more concerned about a new disease where their young children are concerned. They are often not willing to listen to the evidence unless someone will give them an ironclad guarantee that there is absolutely no possible risk under any circumstances. No one is going to give them ironclad guarantees about any aspect of their child's safety and well-being away from the home. Neither can the parents themselves absolutely guarantee the safety and well-being of the child even when the child is at home.

We can expect that HIV will remain a controversial disease for some time, so long as it remains connected with our beliefs and traditions and differing points of view about morality and religion.

Q. If HIV is a venereal disease, why isn't it curable like other venereal diseases?

A. Not all sexually transmitted diseases are curable even today; most were not curable until this century. Sexually transmitted diseases have been a problem for many centuries. Gonorrhea and syphilis were epidemic diseases in many countries from about the 16th century into the 20th century. These diseases were incurable, painful, disfiguring and often led to death.

Syphilis was especially difficult, usually leading to insanity and death. Many famous people had the disease. Beethoven and Mozart are said to have died from syphilis. Winston Churchill's father died of syphilis. Syphilis wasn't consistently curable until 1944.

Herpes, a sexually transmitted disease caused by a virus, is still incurable. A few years ago, the press gave a great deal of attention to the epidemic of herpes. Little is written about it today, even though there are just as many new cases of herpes diagnosed today as there were then. The press and the public simply lost interest in the disease which does not cause death.

CHAPTER III

NEEDS: ISSUES AND CONCERNS

"The Psychosocial Issues
What Does It Mean To Me As A Counselor"

Cultural and Social Issues

Cases of AIDS first appeared in the United States among homosexual men, then among intravenous drug users, and then sexual partners of these drug users.[1] The disease quickly became associated in the public mind with only certain groups of people in certain parts of the country.

The deaths from AIDS of Rock Hudson, Liberace, attorney Roy Cohn, Washington Redskins football player Jerry Smith, and U.S. Congressman Stewart McKinney from Connecticut helped to dispel the myth that only "those" people contracted AIDS. The Surgeon General of the United States, Dr. C. Everett Koop, admonished Americans to "put those feelings behind us," and he reminded us that "we are fighting a disease, not people."

Heterosexuals who have contracted AIDS are the subject of frequent front page stories in newspapers and magazines. Safer sex and condoms have become familiar topics from the breakfast table to the comic strips.

As HIV can be a sexually transmitted disease (STD) it raises issues of morality in the general public. Some fundamentalist evangelists vociferously declared that AIDS was God's punishment on sinners of various types. HIV quickly became a political no-win issue with politicians distancing themselves from the topic as far as possible. Thus, a catastrophic medical and public health issue became a battleground over morals, religion and politics. The general public was asked to confront individual rights, changing sexual behaviors, and the role of government in public health in a context of myth, confusion, misinformation, and fear.

The turmoil of politics, religion, values and morals surrounding HIV resulted in a lack of action. The turmoil thwarted prevention of this disease, blocked medical treatment and research, resulted in AIDS-phobia, stereotyping, and discrimination. HIV hysteria has spread to include prohibiting children with HIV infection from attending school, to employees being fired from jobs, to landlords evicting tenants, to

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[1] The term "intravenous drug user" (IVDU) is being replaced by the term "injection drug user," (IDU) so as to make clear that "skin popping," or injecting under the skin, not directly into a vein, can still be a route of transmission of HIV.

violent acts toward affected families, to proposed legislation leading to quarantine.

All this controversy has been directed toward the people with HIV. Yet, HIV is a very fragile virus, which is difficult to transmit. An infectious disease, which can be prevented and managed.

Characteristics of the Population

Gay and Bisexual Men

Gay and bisexual men have been the groups most affected in the United States by HIV up to the 1990's. These men are Caucasian, Black, Hispanic, Asian, Native American, they represent every minority group, every culture and subculture, and every transmission route of the virus. This group includes blue collar workers, lawyers, actors, judges, rehabilitation counselors, athletes, teachers, military persons, scientists, clergy, persons with disabilities, executives, artists, politicians, doctors, high school and college students, senior citizens, friends, husbands, fathers, grandfathers, brothers, sons, and lovers.

HIV appeared in this country at a time when the gay population in several major cities had become organized and had developed some political and socioeconomic power. Thus the gay communities in these cities had a foundation upon which to create networks and services for the support of gay men with HIV. Not only did these organizations and agencies help to provide essential services and to alleviate the isolation of gay men with HIV, they became the models for effective, compassionate and timely services and support for all people with HIV.

Injection Drug Using Men

Men who are injection drug users, contrary to belief, can fit into any one or more of the above categories as they come from every walk of life, culture and subculture, and age group. Injection drug users sometimes are "recreational drug users," not necessarily addicts.

Because of years of drug abuse, addicts often require many services from a wide variety of agencies such as social, medical, emergency, criminal justice, drug treatment, and others. Although these men are outside the mainstream of society and do not have socioecon[illegible] political influence, there is a sense of community and commonality among them. They also have power on the streets and in their relationships with women. This power may take the form of making decisions about living arrangements, drug use, safer sex, etc.

A diagnosis of HIV requires additional services for this complex and difficult population. An unpopular and disfavored group to begin with, they are a challenge for the service provider, and they are often ignored. Heterosexuals of color (especially Black and Hispanic men) who are injection drug users represent a disproportional large percentage of men who are HIV+.

Injection Drug Using Women

The number of women with HIV is growing. Most of the women affected by the virus are injection drug users or sexual partners of injection drug users. A woman from the drug culture presents the service agencies with many complex problems. For example, if she has children, then family service agencies become involved. Like most men from the drug culture, these women have limited educations, no careers or benefits, and no political or socioeconomic power. Like men, these women with HIV, who are injection drug users, are disproportionately women of color (especially Black and Hispanic women).

Unlike men, these women were frequently disenfranchised before they contracted the virus. They have very low self-esteem and their identity is experienced primarily through their relationship with a man. These women typically have no sense of shared community and no personal power.

Heterosexual Men (not injection drug users)

It is part of the HIV myth that one must be promiscuous to get HIV. Heterosexual individuals have been known to contract HIV from one or a few heterosexual sexual encounters.

Since the sexual revolution of the 60's, heterosexual male sexual behavior outside of monogamy and/or marriage has become common in the American culture, even though it is in conflict with society's basic values. This conflict between behaviors and values becomes a smoke screen which reinforces the belief that heterosexual men are not at risk for HIV. The smoke screen promulgates the belief that heterosexuals do not engage in the sexual behaviors that transmit HIV. This belief encourages heterosexual men to deny their own risk for HIV infection, and creates isolation and lack of support for heterosexual men with the virus.

Some heterosexually identified men occasionally engage in homosexual sexual behavior, often surreptitiously. Many of these men do not believe themselves to be at risk for HIV because they see themselves as heterosexual, not bisexual or gay. This perception of identity as heterosexual, even when engaging in occasional homosexual behavior, sharply increases these individual's risk of HIV. This perception also increases the risk of infection for their female sex partner(s).

Heterosexual men with HIV also represent every socioeconomic, religious, ethnic, and educational group. They are found in every age group from teenagers to senior citizens, and are represented by various members of families from across the United States.

Heterosexual Women (not injection drug users)

The sexual behavior of heterosexual women was also profoundly influenced by the sexual revolution of the '60's. Unlike heterosexual men however, society has neither accepted nor ignored the sexual behavior of heterosexual women outside of monogamy, or especially outside of marriage. Women with HIV who contracted the disease through heterosexual behavior are usually judged to be promiscuous regardless of how many or few sexual contacts they had, even if they contracted HIV from their husband.

A major HIV myth is that men can sexually transmit HIV to women, but that women cannot sexually transmit HIV to men. This creates another smoke screen which reinforces confusion, denial, and discrimination toward both men and women with HIV. HIV is bidirectional. A woman with HIV can also transmit the disease to a man.

Women are usually relationship caretakers. Women with HIV will attempt to protect their families, their children and their relationships by denying their HIV status. They explain their illness away by lying, by calling it cancer or another more socially acceptable serious illness. Like women who are IV drug users, these women have only one commonalty - their disease. They are without a shared community or a political voice. Without a sense of power over their lives, they become severely isolated, and perhaps are even more isolated than IDU (Injection Drug User) women. As a result, these heterosexual women do not get the support needed from family, friends, service agencies, and society in general.

Lesbians

Lesbians are the focus of multiple HIV myths. Four of these myths are: lesbians do not contract HIV; lesbians do not have sex with men; lesbians do not inject drugs; and a woman cannot sexually contract HIV from another woman. These myths present major obstacles to all lesbians.

Instead of turning to the lesbian community for support, a lesbian with HIV is likely to withdraw and deny her HIV status. She may fear that her sexual behavior with men, and/or her injection drug use will be perceived as inappropriate and unacceptable by her community. Due to her fear of being ostracized by the lesbian community, and having no commonalty with heterosexual women, she becomes isolated.

The one probable case of female to female transmission of HIV, presented in the Annals of Internal Medicine (1988), strongly suggests that a woman with HIV can transmit the virus through sexual activity to other women as well as to men. Some lesbians choose not to believe this scientific evidence and thereby perpetuate the myth that a woman cannot sexually contract HIV from another woman, and increase their risk of contact with the virus.

Lesbians with HIV represent all socioeconomic, political, ethnic, racial, and religious groups. Some of these women have careers, benefits, education, and a sense of power in their lives. Confirmation of their HIV status commonly leads to fear of rejection, isolation, and ultimately loss of personal power.

Transfusion and Infusion Recipients

During the early days of the HIV epidemic hemophiliacs and recipients of blood transfusions also developed HIV through their medical dependence on blood and blood products. These two groups were affected by HIV between 1977, when the virus arrived in this country, and the spring of 1985, when blood screening programs were put into effect.

Large numbers of persons with hemophilia contracted HIV between 1977 and 1985. Persons with hemophilia were at high risk of contracting HIV prior to 1985 when HIV blood screening tests and heat treatment of Factor VIII, the blood clotting substance used by persons with chronic bleeding disorders, became routine. Whitney reports that, "As of March 1, 1989, 1,045 persons with hemophilia have been diagnosed with AIDS, according to the CDC. Of the 20,000 persons with chronic bleeding disorders, it is estimated that over 50% are HIV-positive due to exposure to contaminated blood products" (Whitney, p. 228).

The other category of people contracting HIV during the early days of the epidemic were those individuals who received blood transfusions of infected blood prior to 1985, when blood screening programs were placed in operation at blood banks.

Unlike other populations with HIV, transfusion and infusion recipients as well as children and infants with HIV are seen as "helpless victims" once their transmission mode is known. Their families and friends, in an attempt to protect them from stigma, may surround them in silence and in effect isolate them from existing HIV support networks. Unlike other groups, they are not blamed for contracting this disease and so are put into a "better" category than "those people." However, they receive the same discriminatory treatment by society (Whitney, 1989). As a result, "...people with hemophilia and their families who, in many instances, have run into the closet as a means of protecting themselves from harassment" (Whitney, p. 227). The resulting separateness and isolation presents a barrier for transfusion recipients with HIV in seeking medical, psychological and social services assistance.

Psychosocial Issues

The social and political factors of HIV along with the fear and anxiety of contagion account for complex psychological issues, needs, and concerns of those with HIV. People with HIV suffer from stigma and discrimination directed towards them. The stigma and discrimination results from what is perceived as their inappropriate and unacceptable behavior and the fact that they represent culturally disenfranchised and/or oppressed populations.

People who are HIV positive and asymptomatic suffer from fear of becoming ill, or symptomatic. They experience ongoing anxiety about their daily health, denial, shock, loss of loved ones, depression, stress, sleep and eating changes, and sometimes severe changes in mood and behavior. They may or may not be mentally disabled by being HIV+. This section, while focusing on the psychological issues of those diagnosed with AIDS and ARC, will describe reactions which may be experienced by people who are HIV+ and not diagnosed with AIDS or ARC.

Denial

The first reaction of those who are HIV positive and given a diagnosis of AIDS or ARC is usually denial. Denial may be manifested by the complete rejection of the diagnosis and disbelief. Often many days, weeks or months go by before the individual faces the reality of their diagnosis and its implications on their life. Denial in the early stages after diagnosis is a much needed coping mechanism. If it continues, however, denial sets up unrealistic expectations and impedes the individual's ability to cope with and accept the limits of their disability.

A client in denial about his/her HIV status often will present to the counselor a guarded, protected picture of his/her health and abilities. It is important for the counselor to recognize this denial with care and sensitivity, and encourage more realistic acceptance of the disability. This early alliance will set the groundwork for working effectively with this client.

Fear

Fear is the state of being upset or agitated by the presence of, or nearness of, danger, evil, pain, etc. Fear is the psychological response to what is happening now or something that is known (e.g., the diagnosis).

The most common fear of a person with HIV is the fear of a complete and painful disability leading to death. Although HIV is now considered by medical authorities to be a chronic, manageable disability, the fear is very real to those who experience it and must be respected as such by the counselor. As with any possibly severe disability, these dire projections for the future may become a reality. Many times these fears are based on the individual's own experience of friends or acquaintances suffering and dying from AIDS.

In our culture fear of death and death itself are not discussed openly, nor are disease, disability, suffering, and the deterioration leading to death. The fear of death is exacerbated by the cultural taboos against accepting death as a normal part of life. Disease, disability, suffering, deterioration, and death are all natural processes of life that are rarely talked about. The counselor can more effectively deal with a client on these issues after confronting their own personal fears in this area.

The realities of dealing with day-to-day existence for a person with HIV, or any disease or condition that is considered life-threatening, evoke fear. The ever-present, daily fears include being physically, financially, mentally, and socially incapacitated. Acceptance and discussion of a client's fears by a counselor may help to alleviate some of these fears.

Anxiety

Anxiety is the state of worrying about what may happen in the future, not concern about what is happening now. Anxiety is not always present, may be free-floating, and may he precipitated by perceived future events such as the changing predictions of medical treatments, which are often sensationalized by the media. Anxiety is harder to deal with than fear as it is more elusive and less tangible.

Much of the anxiety for people with AIDS or ARC stems from the perception of the continuum of the disease starting with becoming HIV+, then leading to ARC, progressing to AIDS, and finally death. Long-term diagnosed survivors who work and also care for their basic daily needs, refute this perception of an unalterable progression. As the number of long-term survivors increases, individuals who are diagnosed with HIV are beginning to feel less anxious about their futures, and more hopeful about their lives. People who have HIV and have been diagnosed with AIDS call themselves "PWA's" (People with AIDS). They are now talking about living with AIDS and identify themselves as "PLWA", or People Living With AIDS. As early as March, 1988, Constance Wofsy, M.D., an internationally recognized AIDS authority, reported that HIV would become a manageable, chronic illness, like diabetes.

These factors have helped to alleviate the anxiety of HIV diagnosed individuals. However, anxiety, or future fear, is still frequently present in people with AIDS and ARC. People with ARC often suffer from a higher degree of anxiety than people with AIDS. They experience the anticipatory stress of waiting for something worse to happen (AIDS). This anxiety may increase to the point where the person becomes disabled. Psychological intervention and medication may have to occur at this time before the person can return to work.

Depression

Depression is an all-encompassing feeling of sadness and hopelessness, resulting in a severe reduction of available energy. At some time or another every person with AIDS or ARC suffers from depression. The depth and length of depression differs from individual to individual, as does one's ability to function and adapt in a depressed state. While depressed one may experience fatigue, decreased interest in surroundings, and lack of pleasure in once pleasurable pursuits (anhedonia). There may also be drastic changes in sleeping patterns such as early morning wakening or insomnia. Eating patterns may also change ranging from not eating to over eating.

Depressed people in general may turn to alcohol or drugs to alleviate the pain of sadness and hopelessness. This use of drugs or alcohol is particularly dangerous for a person with HIV as the substances are known to compromise an already lowered immune system. If an individual continues to self-medicate depression by the use of substances, it may be an unconscious form of attempting suicide. Psychological intervention is strongly recommended for people with HIV who are self-medicating their depression with alcohol or drugs, as well as all diagnosed individuals who have recurring or ongoing bouts of depression.

The declaration of HIV as a manageable, chronic disability by doctors, counselors and care providers is helping to bring hope into the lives of people with HIV, thereby helping to alleviate depression.

Anger

Depression when turned inward is sometimes described as anger. However, this is only one aspect of anger. Anger is the logical human response to distress or sorrow; an emotional response, or a fighting back, against a situation wherein the individual may be frightened or pained, and not in control of the outcome. Anger may also be the individual or group response to a social or political injustice wherein disenfranchised and/or oppressed groups have little power. Anger is precipitated in people with HIV by one or all of the above.

Commonly anger is exacerbated in people with HIV by the many medical appointments, the days and weeks of repetitive paperwork and red tape needed to file for assistance. The fatigue that is present in people with HIV is worsened by these numerous appointments. Anger is also fueled by the frequent hostile and discriminatory treatment from care and/or service providers and the general public. "AIDS-phobia" is often unconsciously projected by well meaning care and service providers. This judgmental and discriminatory treatment increases the alienation, frustration, and anger of individuals with this disease. Anger may be expressed by hostile outbursts toward others including families, friends and care providers, or toward the individual him/herself. Suicide attempts or gestures can be a way of expressing anger by directing it at oneself.

Anger sometimes precipitates the use of, or the abuse of, alcohol or drugs and again becomes self-destructive. Anger can be manifested by withdrawal from friends, loved ones, and community, as a way to protect them from the individual's hostile verbal attacks. This leads to isolation and compounds the fear, depression and anxiety already present.

Rehabilitation Counselors realize that a client's anger may be justified and a healthy expression of emotion. While not personalizing the client's anger, the counselor can express understanding and can then be seen as an ally. He/she can assist the client in setting limits as to the extent of appropriate display of anger. The counselor can easily recognize the client's frustration. Recognition of those feelings, accompanied by acknowledgment of the anger and limit setting, can facilitate the client's appropriate expression of anger. This process assists the client in taking some control of his or her life. It is, in effect, the client saying "I have had enough!" and the counselor being willing to hear it, and go beyond it with the client. Personal sensitivity and compassion by a counselor can play a significant role in defusing the very natural anger in a client with HIV, and thereby assist that client in getting on productively with his/her life.

Guilt and Shame

Guilt is a feeling of remorse due to having committed a wrong doing or an offense. Shame is a painful feeling of having lost the respect of others because of perceived improper behavior or wrong doing. Guilt and shame causes people to feel worthless and less-than. Both of these feelings are experienced by people with all disabilities.

Society has often responded to the AIDS epidemic by condemning the people who have HIV. Either their sexual behavior - whether it be homosexual, heterosexual, or bisexual - is the focus of the condemnation, or the person is assumed to be a "drug addict." This judging or blaming leads the person to feel guilty and ashamed.

A person with HIV feels guilty because the message received from society is "it is your fault that you got the disease," or "you got what you deserve," or "you asked for what you got," or worse yet, "you deserve to die for what you have done." The message is so powerful and pervasive that many people with HIV end up questioning the validity of their own sexual experience and orientation. Their sense of self erodes and caves in, and self-doubt takes over. The process results in feelings of guilt. A person with HIV feels ashamed because the general public often sees him or her as deviant, and socially and morally reprehensible. Therefore, that person feels outside of the norm, unacceptable, different, and ashamed.

Some gay men who are not infected, or who are HIV-positive, but asymptomatic, and who live in high incidence urban areas, feel a sense of "survivor guilt." Survivor guilt can be described in the question "why him and not me?" These men are often overwhelmed and feel helpless after the years of sickness, suffering, and deaths of lovers and countless friends. It is a slow chipping-away at the individual's self-esteem and sense of well being. Over time it becomes difficult for these men to accept or hope for their own survival and they express it in statements like "he was a good person and I'm not" or "I have done more wrong, so why not me?"

Many women with HIV feel guilty, sexually dirty, and ashamed. It is assumed by the general public that they must have been promiscuous and "one of those kind of women" to have contracted the disease. They become demeaned by this pervasive public judgment and ultimately believe that they have done something wrong or unacceptable. A woman with AIDS is commonly treated with little or no respect by care providers because of the assumptions made about her or her behavior.

Heterosexual men who have HIV also feel guilt and shame as society assumes that they are gay or bisexual. In the male heterosexual culture the labeling of bisexuality or homosexuality as deviant and deserving of punishment is the accepted norm. The heterosexual man with HIV, therefore, feels that others see him as having done something wrong or outside the norm. He too feels guilty and ashamed.

Guilt and shame lead to isolation, withdrawal, and the perceived necessity to lie to others about one's diagnosis, sexual orientation, or personal behaviors.

Loss

Loss is such an emotional issue for most people, including mental health professionals, that it is often played down and its importance and impact on a person's life is devalued or ignored. Like death and dying, the discussion of loss is usually reserved for literature, fiction, and the intellect.

HIV is a disease of losses. A person with HIV may lose his or her income, housing, husband or wife, lover, friends, family, appearance, insurance, occupation, mastery of skills, strength, cognitive ability, intellectual and motor functions, bodily functions, self-respect, and hope.

People suffering from AIDS Dementia experience yet another HIV related loss. The early stages of AIDS Dementia are very stressful for the client as "they know that they don't know." This loss of memory, cognitive, and intellectual functioning, is met with great fear. It has been described by people with AIDS Dementia as the ultimate loss.

Rehabilitation counselors are aware that loss is also present in most acquired severe disabilities. However, most losses due to disabilities other than HIV, are not compounded by the extent of loss of acceptance, loss of respect, and in particular, outright condemnation by society. A vocational rehabilitation counselor can make a difference for people with HIV by acknowledge or addressing the specific and compounded losses of HIV clients. To not do so is to deny the human effect of this disease.

What Does it Mean to Me as a Counselor?

There continues to be a high level of fear related to persons with HIV. This fear is often due to misinformation regarding transmission of HIV and the natural fear of dealing with people from different cultures and sub-cultures. In addition, HIV is a condition which confronts us as individuals and as a society with certain taboo subjects, such as sex, sexuality, drug abuse, and death. To begin to put HIV information into practical use, counselors must address the preconceptions they have acquired culturally and socially regarding these issues. The next step is to accept and own the biases held.

The role of a counselor is to be accepting and supportive of all clients even though he/she may continue to be uncomfortable with some of their issues. Acknowledging this internal conflict will begin to give the counselor the permission to be human and explore their conflicting feelings. Falling for the old myths that counselors are "supposed" to love and accept everyone unconditionally suggests that counselors are somehow superhuman and above having feelings about different people and lifestyles. It may also cause counselors to feel guilty when they realize they are uncomfortable and have negative emotions about some of these issues.

Counselors need not lose sight of their basic training of honoring and respecting clients as individuals whose beliefs and values may conflict with their own. Viewing the client as a whole person not a label or a disease is important. As has been experienced in the past, continuous self-monitoring of counselors' response to clients is perhaps the most effective, long-term way of confronting uncomfortable feelings and biases.

What Does it Mean to Me as a Co-worker?

Often co-workers will not know of an individual's HIV status. However, rumors and suspicions about fellow employee's HIV status are likely to occur whenever an individuals life style differs from that of co-workers. It is not uncommon for gay persons to be the subject of such rumors. Any time they miss work or look a little tired people start to suspect they have HIV. Even knowing someone is gay is enough to suspect they have HIV for some people. A person with HIV who is not gay will automatically be assumed to be so and may suffer the hate and bias of homophobic co-workers. Another population that is at risk of such rumors are those who volunteer in some HIV related service or who have friends or family diagnosed as HIV+. An apparent guilt by association is placed on these people who are either automatically assumed to be homosexual or HIV+. "Why else would they associate with people with HIV?" The stigma and sensationalism surrounding HIV make it difficult for even the most sensitive, caring people to not be drawn into the company rumor mill and gossip about co-workers.

Unfortunately in many companies it isn't until someone is actually diagnosed with AIDS that the employers and employees begin to address the issue. For the persons who are HIV+ and asymptomatic or are suspected of being HIV+, through company rumors, there is often no HIV education to assist in dispelling myths and calming fears.

The co-workers of persons with HIV will be forced to face their beliefs and biases about many uncomfortable issues. With the advances of modern day science and the increase in the practice of institutionalizing the elderly and sick, most people are not accustomed to being faced with disease, deterioration, and death. Thus, when people are confronted with any life-threatening illness the tendency is to pull back, close down, and feel very uncomfortable, (Emery, 1988). They don't know what to say or do and often feel awkward. They don't know whether to talk about the illness or not, to ask about how the person is feeling, or pretend it isn't there. There may also be a desire to help among co-workers coupled with the reality that there is nothing they can do, creating feelings of frustration and helplessness.

As the person deteriorates co-workers may become angry at having to be faced with the reality of the situation on a daily basis. The presence of the person with HIV is a visible reminder of their own mortality and fear. They may secretly want that person to die and "get it over with." Feelings of guilt and anxiety usually accompany these thoughts which compound the confusion and frustration.

Some people may have moral and religious beliefs that interfere with their treatment of the person with HIV in a respectful and compassionate manner. They may have difficulty separating the individual from the disease. The moral and religious beliefs of all employees must be respected, but at the same time they cannot be allowed to be used for condemnation or the ostracism by others.

If the person with HIV deteriorates he/she may begin missing greater amounts of work and may not be able to perform his/her job at the level required. Resentments and anger may start to build as co-workers must take on more of the workload. It is normal for the co-workers to feel put upon and burdened by this situation even though they may fully understand the limitations of the disabled person.

It will be important for employees to find others at work who will listen, show understanding, and who are willing to talk about the situation honestly. This type of nonjudgmental support best comes from within the company or agency where people know the individual diagnosed and have a better understanding of the dynamics involved. An employee may find that they cannot go to family members or friends outside the agency or company for support due to prejudices and the stigma attached to AIDS. For this person the emotional support at the job becomes even more important.

CHAPTER IV

HIV AND ATTITUDES

Now that many organizations are developing and implementing policies and procedures related to HIV, they are finding that their staff at all levels have strongly held opinions and beliefs, not only about HIV and AIDS itself, but also about people who have or are suspected of having contracted these conditions.

Because of these attitudes, even the best planned organizational policies and efforts, on the part of the rehabilitation professional, may be met with strong resistance. The issues that surround HIV invoke primordial fears of death and disease. Our society's traditional attitudes toward drug abuse, sex - both heterosexual and homosexual - raise strong feelings. It is these feelings that often underlie the expressed fear of "catching the disease," even when the medical profession assures us that there is virtually no risk of contagion through casual contact.

This chapter explores attitudes and how they may impact positively or negatively on the rehabilitation process. Attitudes impact rehabilitation in three specific ways:

1. Attitudes of the counselor and/or the rehabilitation organization itself.
2. Attitudes of employers and co-workers of the person with HIV.
3. Attitudes of persons with HIV.

It is hoped that a better understanding of attitudes will enable the rehabilitation counselor to be more effective in delivering services to persons with HIV.

Attitudes and Disability

Over the last twenty years, rehabilitation has made tremendous progress in the area of evaluation, training, and counseling persons with disabilities. Technical and mechanical advances now allow persons with disabilities to use their abilities in ways unimaginable even a few years ago. Yet with all these advances, persons with disabilities still represent one of the most unemployed and underemployed groups in this country. Many people from the rehabilitation, disability, and employer communities believe that the last great battle will be fought on the field of attitudes.

Until recently, employers and others saw a person with a disability, and the disability itself as the same thing. Society has come a long way in dealing with persons who have disabilities. The reference to a person with a disability instead of "the disabled" or the "handicapped" today is common usage. It was not always so.

Confronting attitudes about people with disabilities in the past was very similar in some ways to contemporary attitudes towards people with HIV. The attitude that people have disabilities as a punishment is an age old concept.

The mission that rehabilitation has adopted is to educate ourselves, employers, and persons with disabilities about the underpinnings of these attitudes, so that we can all understand the reactions these attitudes cause in ourselves as well as others. This understanding is the start of overcoming negative attitudes. The battle is by no means over, but as a result of the recent victory in the change to the term "persons with disabilities" from the term "the disabled," we hold a position of higher ground.

Today persons with disabilities are presented in a more positive light in movies, television, and literature. Changing the attitudes towards persons with disabilities means increasing the opportunities for them. Attitudes create the climate in which the rehabilitation process occurs.

AIDS Education in America

It is a standard observation in the field of HIV education, that it takes five to seven educational experiences on the basic facts of HIV before a sufficient level of learning and acceptance is reached. Most people experience far fewer than five to seven training sessions. Therefore, many persons who had some HIV training remain very unsure and skeptical about what they have been told.

To some degree, improving the presentation of factual material is of some benefit. However, without addressing the underlying attitudinal resistance to the facts, the search for the perfect HIV course is like trying for the pot of gold at the end of the rainbow. The key to HIV training is to integrate attitudinal training with factual training.

It is More Than a Virus

When starting an HIV workshop it can be revealing to write the word AIDS or HIV on a flip chart. An otherwise blank sheet of paper with the word AIDS or HIV on it is a dramatic thing to see. Trainers then ask the group to word associate, to call out ideas and words that come to mind when they think of AIDS or HIV. Figure IV-1, represents the responses of a typical group.

When the diagram is examined it becomes clear that such issues of sex, death, IV drugs, homosexuality, etc. are closely associated with HIV and AIDS in our society. It is important for the rehabilitation

More Than A Virus

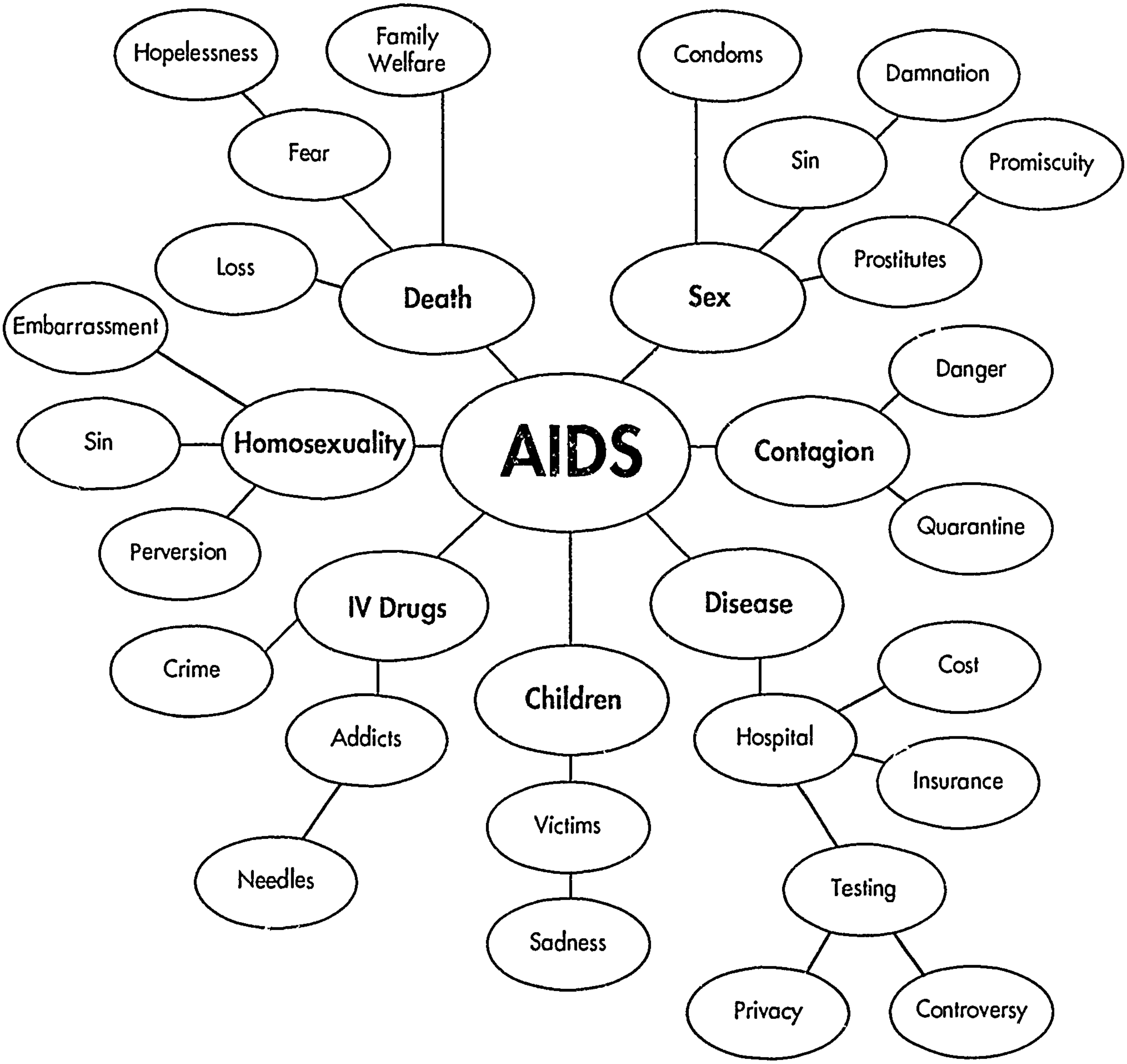

Figure IV-1

counselor to understand that the way they feel about HIV and AIDS is a summation of how most people feel about the issues associated with HIV. Ultimately how we feel about a person with HIV is how we feel about HIV itself.

A useful way to think about this process, is to relate back to the late 60's and attitudes about the Viet Nam war. When service personnel came home, they came home to a society in confusion and turmoil. For many, home was certainly physically safer but no less hostile. The average Viet Nam veteran came home, threw away his/her uniform, put the medals on the dog's collar and spent the next twenty years trying to forget that they even served. They came home to a society that did not separate how it felt about the war from the people who fought.

Americans have finally reached a catharsis in the last five years about Viet Nam. Television shows and books about Viet Nam abound. Memorials and parades are common. Society doesn't seem to feel any better about the war, but it does feel better about the people who fought it. It took twenty years.

Persons with HIV face a very similar situation. Today, they live in a society that does not distinguish between its feelings about HIV and the people who have it. Yet persons with HIV and HIV itself are no more the same thing than the veteran was the government's policy on Viet Nam.

is no question that society will have to reach a catharsis HIV. The problem is when or how soon, because it is only after ration of the two ideas that people will <u>act</u> rather than <u>react</u> creating effective programs and policies. Society may not have the luxury of waiting twenty years to come to grips with their attitudes.

The Big Three

One of the greatest challenges that the counselor will face is the way that people react to the ways that HIV can be transmitted. Trainers, who provide workshops on attitudes towards AIDS, do an exercise for professional groups where they write on a flip chart some of the terms people free associate to the word AIDS (see figure IV-1 for common words). Words like: homosexual, heterosexual, IV drug, blood transfusion, multiple sexual partners. Then they ask participants to role play, with the group assuming they are HIV positive. They must select two of the ways of getting it from the list. The first, how they would want it if they had to have it, and the second, the way that they would least want to get it.

It is common in these groups to have no one select homosexual or IV drug use as a way they want it, with 80 or 90 percent selecting one of these two as the way they would least want it. Next, the trainers select each category (homosexual, IV drug use, etc.) and explore why each person picked the category they did. What comes out in a large group of 50 or more, is that there are negative feelings about all the ways of becoming infected with HIV. The work implications of this are serious. They are what can be called the big three:

1. When it is discovered that someone is infected, the first thing we speculate about is how they got it.

   Since we do not know everything about everyone, we sometimes guess wrong. Even if we guess right, what use is this information in the workplace? Most likely people believe that someone contracted HIV in a way they did not like, rather than in a way that was more socially acceptable.

2. People who are perceived to be in high risk groups are treated as if they have HIV.

   When a person is identified as being in a high risk group, that individual finds him or herself being treated as if they are HIV positive. Gays, IV drug users, hemophiliacs, blood transfusion recipients, Haitians, and the sexual partners of these people have experienced poor treatment, employment terminations, ostracism, and worse, regardless of their HIV status.

   HIV attacks the body, but HIV also attacks society. HIV is a virus whose fear cycle attacks society, suppressing our sensibilities and making us susceptible to opportunistic prejudices and hatreds that would never gain a foothold in an attitudinally healthy environment.

   When HIV gives license to the expression of people's prejudices and hatreds, the focus becomes high risk groups instead of high risk activities. This is a very dangerous focus. Being in a generalized risk group does not infect someone with HIV anymore than not being in a group makes one immune. It is high risk activities that causes people to be HIV positive.

   Persons who are considered to be in high risk groups may be at no risk of becoming HIV positive. Examples might include homosexuals in mutually monogamous relationships for the last twelve years or IV drug users who don't share needles with anyone.

   The opposite is also true. People who are not perceived to be in high risk groups can be at terrible risk of infection because of their activities. For example, a heterosexual man or woman who engages in unprotected anal and vaginal intercourse or student athletes who share their steroid needles in the locker room are practicing high risk activities.

3. People who take public stands in their organizations for effective HIV policies and treatment of persons with HIV are looked upon with suspicion.

   When employers are asked if they believe that their organizations will have an employee who becomes HIV+ most say yes.

When asked if they have policies and procedures to deal with this when it occurs, few say yes. How many of these employers would tolerate being without a disaster plan for their company? It seems that employers and organizations are waiting for the crisis to occur before they do anything. Why? The fact that they expect the problem is going to happen should be reason enough. They appear to be waiting for a situation that forces them to deal with issues of HIV.

People who chose to get involved with the issue of HIV are sometimes suspected. Employers and counselors who have attended HIV or AIDS training report being kidded by co-workers. This may seem like good natured harassment on one level, but it also sends another message. "If you get too involved, we will also wonder about you." This problem can impact on the rehabilitation counselor in ways ranging from: employers wanting to take a strong stand for hiring or reinstating a former employee with HIV but are afraid to do so; to the counselor or rehabilitation organization itself who may be afraid to take a high profile proactive stand on HIV. When it comes to working with people with HIV, there might be a certain amount of guilt by association.

You do not have to be black to have fought for civil rights, you do not have to be a woman to believe in equal pay, you do not have to have a disability to advocate for persons with disabilities, and you do not have to have HIV or be at risk for HIV to want to assist.

Guilt and Innocence

The rehabilitation professional will find that the concepts of guilt and innocence are factors in the way that our society deals with persons with HIV. A good illustration of this is the term "innocent victim!" It is one of the most commonly used references towards persons with HIV who are not perceived to have engaged in high risk activities. The term itself says a lot: the word innocence infers guilt; guilt infers crime; crime infers punishment; and finally punishment infers deserved. Every time the term "innocent victim" is used, at some level, it is inferred that there are persons, or a class of persons who deserve their HIV.

Concepts of guilt and innocence are stereotyped factors which stand in the way of dealing with persons who have HIV. Spending time and energy assessing or discussing innocence or guilt is futile. It impedes the process of selecting the appropriate services and the delivery of those necessary services. It also significantly interferes with getting to know the real person.

All professionals need to be aware of how their attitudes impact on their professional responsibilities. When the professional rehabilitation counselor looks at attitudes, the counselor should consider also determining their own attitudes. When counseling clients, such an exercise will facilitate knowing whether they are responding to their own attitudes or the client's problems. The professional counselor will recognize that:

1. The profession of rehabilitation demands standards for services. It considers the needs and resources of the client as well as the potential value of delivered services as the primary justification for providing those services. For no client is "negligence" a factor in determining eligibility for or quality of services provided.

2. Responsibility should be differentiated from deserved. There are persons, who through their action, may be considered responsible for their HIV status, just as with many other medical and/or disabling conditions. It does not follow that responsibility infers deserved. It may be true to say that there are many persons who are responsible for their HIV - but none who deserve it. This becomes an important point to consider when it is realized that some employers, rehabilitation, and medical professional feel more uncomfortable delivering services to the "guilty victims" than to the "innocent" ones.

3. Accepting and serving the person is not equal to condoning or accepting the behavior. This is one of the most troubling concerns voiced by persons who are bothered by the innocence versus guilt issue.

Death versus Chronic Illness

Many people perceive those infected with HIV as dying. The counselor needs to keep in mind that people who are HIV positive are not necessarily dying or even symptomatic. Remember, HIV is changing from being considered a fatal illness to being considered as a chronic, treatable illness. However, employers, friends, and people who consider them for employment may be afraid of dealing with persons with HIV because they are uncomfortable with the concept of death. This perception surfaces a number of issues.

A significant issue is anticipation grieving. Grieving is the process that people go through when they have lost a close friend, relative, or a loved one, and it can be a difficult and painful process. When people find out that a friend is going to die, they tend to go through a similar process before that person dies. This process is called anticipatory grieving. It is very much like the grieving process and includes feelings of depression, anger, denial, gradual acceptance, and a distancing from the person.

Another issue that impacts in the workplace, as well as rehabilitation, is that very few people want to be next to or close to a person who is perceived to be dying. When friends are perceived to be dying, they are mourned. When strangers are perceived to be dying, few people seek them out as friends. This is a phenomenon seen in war.

The new combat soldier has to prove himself, not only in battle but over time to the old veterans; prove that he is competent enough not to die too quickly, before the seasoned veterans even bother to learn his name. Why? It just hurts too much to have your friends die.

This issue seems to surface not only in the workplace but in social gatherings and in the rehabilitation counseling relationship. It happens also with adults with leukemia, cancer, heart attacks, etc. The majority of people in this country who are HIV positive are asymptomatic and can be expected to live healthy, productive lives for many years.

Intimacy

Frequently, in the course of a new relationship, people share intimate information gradually. People have comfort levels about the amount of information that they are willing to know about someone else and are willing to share with another person about themselves, or wish others to know about them. Regardless of HIV status, when someone new suddenly shares information at an intimacy level, people become uncomfortable. They may feel the need to close down that person's revelations. Such early intimate revelation may make it very difficult to continue the relationship with them. That information can become the identifying characteristic about them. Many people simply can't deal with this much intimacy with someone with whom they do not have a close relationship.

When a counselor perceives that this may be happening in the workplace or during the application for employment, the counselor would be well advised to look for the following:

1. Are the people in the workplace reacting to real information or are they reacting to their own assumptions, superstitions, etc.

2. Are the people in the work place unable to share with the counselor or with the persons with HIV disease that this information is making them feel uncomfortable?

Counselors should advise employers who are having this problem to: (a) not assume things about the other person; and (b) if they are very uncomfortable with knowing things or believe they know things about someone, as difficult as it may be, let them know they are uncomfortable. Communicate with the employee and try and work it out. It becomes important to the future relationship of worker and co-worker. It is at this level, that a professional rehabilitation counselor might very well be involved, just as they might in acclimating any person with a disability to the workplace, that makes co-workers feel uncomfortable.

Empowerment

Counselors and supervisors don't necessarily need new information on how to work with persons with HIV. Instead they need to learn they already knew how to work with persons with disabilities and HIV is another disability. If they can work with people, they can work with people with disabilities and likewise with this disability. Co-workers and supervisors can learn that the needs of people with HIV are not unique. They have the same basic human needs. The reasons and the intensity of those needs may be unique to HIV, but the basic nature of needs are common to all people. The need to maintain dignity, belonging, self-determination, and achievement are all the same, however, HIV can attack all four of these needs.

HIV attacks dignity by making private things public. It attacks dignity when people with HIV are perceived not as individuals but as stereotypes and by ostracism of that person from the group. It affects self-determination, throwing people who are in ill health into situations where they aren't allowed to have input into decisions that are made for them. HIV affects achievement and the ability to achieve by stalling opportunities to achieve. It also affects the history of achievement by making HIV the disease more important than the person or what he or she has achieved.

The rehabilitation counselor is in a unique position, not only to help the person with HIV fulfill these needs, but to teach employers, co-workers, and supervisors how to help the person accomplish this also. For example:

1. The rehabilitation counselor helps a person with HIV maintain their dignity. The counselor helps the person maintain their dignity by not making assumptions about the person. They work with the individual rather than lumping people into some generalized category. Teaching employers and co-workers how to react in a like manner would be very helpful.

2. The counselor can impact on the idea of belonging. Through the counseling process the counselor can help reestablish the person with HIV into the workplace or put them into a new workplace where they can belong.

3. The counselor acts on self-determination. The counseling process can be effective, in helping the individual develop goals and achieve them. The employer and co-worker can help by giving positive feedback to the person when improvement is noted.

4. Counselors can also impact to insure achievement. It is only possible, however, when the separation of HIV and persons with HIV has been made intellectually as well as emotionally.

The idea of dealing with attitudes and fears in the workplace has been successfully applied in the field of disability. It was accomplished in a social environment full of prejudices, myth, stereotypes, and fears. HIV vocational rehabilitation is new but our familiar tools can work here as successfully as they have with persons with other severe disabilities.

Counselor Attitudes

All people have attitudes including counselors. Strong negative attitudes may interfere with the objectivity so necessary to proper case management. The following are suggestions of ways a professional counselor, who is concerned about their attitudes towards persons with HIV, can address this problem.

1. Look at AIDS as just another disability. This is not as simple as it seems for the counselor must remember all he/she has learned about the disabilities. Being nonjudgmental and seeking the individual behind the disability is the goal of all counselors.

2. Work for an objective AIDS vocabulary. Behavior is not changed by changing attitudes. Attitudes are changed by changing behavior. Language is not attitude, it is a behavior.

   The language of AIDS, victims, sufferers, survivors, etc. was the language of disability. The counselor should concentrate on using "persons with AIDS" or better "persons with HIV." The attitudes of the language becomes the attitude of the person using it. Neutral language leads to neutral attitudes.

3. Understanding it's OK to feel sorry for certain "victims." Babies born with HIV, blood transfusion recipients, hemophiliacs, all bring out our sympathy. However, the counselor should understand that sympathy for these groups do not require apathy towards others.

   It might be useful for the counselor to consider that, "regardless of how someone became infected everyone who is HIV+ is treated about the same." The only way to insure that the group the counselor feels is the most deserving is treated well is to insure that everyone is treated well.

4. Meet someone with HIV. It is easy for one to stereotype a group that one has never met. One of the most important things that a counselor who will be working with persons with HIV can do is meet someone with HIV.

   It is advised that the counselor not meet this person in a counselor client relationship. But more on an equal footing, where both can talk freely. The various AIDS hotlines and foundations in each city may be happy to assist with a referral. Ask if you can meet and talk with a person with HIV who is meeting their needs.

5. <u>Do not surrender till you have tried it</u>. Actors act, writers write, and counselors counsel. Be aware of potential problems, but the counselor should not evaluate his/her ability to work in this area until they have tried it. Most counselors, once caught up in the familiar aspects of the job, consider working with persons with HIV, to be no different than working with anyone. That is our goal.

6. <u>What if nothing works</u>? A recent study indicated that over 50% of persons over 40 years of age would be willing to risk their jobs rather than work with someone with AIDS. What should the counselor who just cannot work with someone involved with HIV do?

   First, they should be congratulated on their professionalism. Here is someone who cares enough about doing a good job that he/she is bothered if they feel that something over which they have no current control is preventing them from doing a quality job. They may be able to work on their attitudes through the help of co-workers, and communications with clients. They need to feel comfortable that their personal feelings will not color decisions or negatively impact the overall rehabilitation process. The danger is not the counselor who feels this way, but rather the counselor who feels that his/her attitudes are "right" and will work with this population "as long as they make me."

Chapter V

SERVICE DELIVERY: A COUNSELOR'S PERSPECTIVE

Introduction

A National Commission on AIDS has been formed to set policy and priorities in dealing with the public health crisis of HIV. This current commission has both the scientific expertise and experience to assure that the consequences of HIV are addressed.

"For every known AIDS patient, 15 other Americans - 1.5 million or more - are infected with the AIDS virus" (Kessler, 1989). In the years to come, many more people will develop disabling conditions and will need the resources of the vocational rehabilitation system.

Regardless of what is being done by a National Commission, community services agencies and state Department of Health and Public Health, little will happen in the vocational rehabilitation system unless vocational rehabilitation administrators, counselors, and the agencies they serve, understand and accept their role in assisting this growing population of persons with disabilities.

Vocational rehabilitation service providers need to dispel fear and prejudices by beginning to provide outreach to this population. Management must be active in this outreach in order to insure that people with disabilities caused by HIV have equal access to the rehabilitation system.

Understanding the HIV Client

Many of the issues and concerns for the HIV population are similar to those for other disabilities. The techniques and skills acquired through work with past clients will be carried over in work with HIV. However, many new skills, knowledges, and techniques are necessary to work effectively with persons with HIV.

The moral stigmatization and discrimination of clients with HIV, is one way HIV differs from most other disabilities. In the United States the highest populations with HIV are among those who are already disenfranchised and viewed as outcasts by society. Among these populations are IV drug abusers, minorities, women, and homosexuals. Many people with HIV internalize the negative messages society places on them by feeling shame and guilt.

One of the most effective ways for people to control shame and guilt feelings is to become a member of a support groups where they can meet other persons with HIV. Support groups allow clients with HIV to gain a sense of normalcy and self-worth. Clients need to be supported in the belief that they are valuable and have a right to care for themselves. The counselor can be instrumental in this by treating HIV clients like any others - with respect and dignity.

Persons with HIV need to be treated in a sensitive and nonjudgmental manner. The fears and rejection they experience from friends, family members and society in general are emotionally damaging. Often this results in self-imposed isolation which may contribute to depression. Because of low self- esteem and overwhelming isolation the likelihood of these clients seeking out vocational rehabilitation services on their own is very slim. The counselor's outreach to local AIDS agencies is necessary and will result in cross referrals. Direct outreach to HIV clients is also of the utmost importance.

Another way to address the isolation of the HIV client is to help them develop an emotional support system. Frequently this means clients must start over in developing relationships at a time when they are not emotionally or physically stable. Working with clients in this phase requires particular sensitivity to their experiences of loss and despair.

Clients with HIV frequently feel anger. The many targets of this anger may shift from the government for doing too little, to a physician for not having all the answers, to the vocational rehabilitation counselor for the process taking so long. At times the client anger is expressed as an attitude of entitlement and outrage because their needs are not being met (Barret, 1989). As with others with disabilities, this anger is not directed personally at the counselor but is instead misdirected anger about their situation. Keeping this in mind helps to allow clients to vent their anger and enables counselors to redirect that anger.

The many losses a person with HIV experiences, particularly the loss of control over their lives, is a recurrent theme and constant source of pain, anger, and frustration. As with many illnesses, decisions are taken out of the hands of the client. Sometimes the client's body and his/her mental capacity is deteriorating. As there is little they can do about it, they feel helpless. Involving and empowering clients in all phases of the vocational rehabilitation process and in all decisions will help them to regain a sense of responsibility and control.

As with any disability, basic living needs must be addressed before any real progress can be made towards helping the client find employment. Additionally, for the HIV client a need for basic HIV related education may also exist. It is important to have a well established HIV network to locate the appropriate organizations and agencies which provide necessary resources. Information and ideas for developing and maintaining such a network can be found later in this chapter and in the resource section in the appendix section of this book.

Finding out what the diagnosis means to clients and how they experience the impact of HIV on their lives may be helpful in determining their overall attitude toward their disability.

It is important for persons with HIV to maintain a well balanced life involving adequate diet, sleep, exercise, pursuit of interests, social support, and knowledge of the effects drugs and alcohol have on their immune system. Since stress may act as an immune suppressor, relaxation techniques and stress management training can be helpful as well. Some clients may benefit from referrals to alternative therapies such as visualization, acupuncture, and massage. Self-care also empowers reducing the client's feelings of loss and helplessness.

Often people with HIV turn to spiritual practices and beliefs. For some this may be the first time they have explored spirituality, for others it may mean returning to the religious beliefs of their childhood. Those who live on the fringes of society may often feel disenfranchised from their religious backgrounds. Others may turn to metaphysics or alternative spiritual practices. HIV longevity studies point to the importance of the integration of the medical, psychological, spiritual and social components. All of these, coupled with a positive attitude, can enhance one's health while possibly increasing longevity.

One difficult aspect of this disease is the fact that the majority of people with HIV are under 40 years old. This is a time in their lives when they would normally be building toward the future. As with other disabilities, the acceptance of the disability and its limitations is important. People with HIV are forced to face the possible threat of death, not in some distant future, but at a much younger age. It is difficult to witness any person become disabled, sometimes deteriorate, and perhaps die. It is even more difficult when that person is young. The counselor can be supportive to the client by being willing and available to talk about death. Many people with HIV have watched their friends die throughout the course of the epidemic and are fearful of a prolonged, painful death. Being familiar with the grief process while respecting individual differences will be helpful to the client.

Working with persons with HIV can be demanding and yet rewarding. As with all clients, there is much to be learned from this population. Being witness to the strength and courage with which many people face their disabilities can be intensely moving. For a rehabilitation counselor, enabling a client, through appropriate services, find employment and enhance their life is fulfilling and meaningful.

It is important that rehabilitation counselors take care of themselves emotionally when working with clients with HIV. Having someone to turn to for support and understanding, discussion of strong feelings, and to air concerns helps reduce stress. Vocational rehabilitation counselors may need to develop support groups in their offices. If support groups are not available, they may need to find peers in other state vocational rehabilitation offices or community agencies. Without support, counselors can become overwhelmed by grief, losses, frustration, and ultimately burn out. Topics for groups to consider are, dealing with grief, death and dying, loss, frustration, and feelings of helplessness.

Counselors also need to recognize their own emotional reactions to clients. It has been the experience of most HIV service providers that professional distance and rigid boundaries, with HIV clients, are not effective due to the needs of the client for emotional and compassionate support and services. Feelings of helplessness and inadequacy can arise from not being able to help the client. The counselor's unresolved issues of death, sexuality, and what constitutes appropriate behavior may surface when working with HIV clients. Often these issues are denied by the counselor and are expressed as anxiety, guilt, despair, and indifference. The urge can be great to become overwhelmed and abandon compassion. As with other clients, the effective vocational rehabilitation counselor learns to recognize the value of both objectivity and compassion in effective counseling.

Case Finding

Obtaining referrals of clients with HIV has already occurred in some areas of the United States. Concerned counselor have reached out to persons with HIV and are receiving increasing numbers of referrals. It is hoped that this effort will continue and increase in scope. Typically, however, persons with HIV are not coming to or calling for services at vocational rehabilitation offices. To increase referrals, counselors must go to the client and do the required outreach to bring these clients into the system. Initially, one or two counselors may work as a team sharing referrals and resources, using local, regional, or state referral resources. It will be these counselors who will ultimately help persons with HIV effectively access the system designed for them.

Most state vocational rehabilitation staff realize that they will eventually be working with many HIV clients. Some of these clients will come with other traditional disabilities and seek services. These clients may already be HIV positive, become HIV positive, or become symptomatic while receiving services. After receiving quality vocational rehabilitation services, clients with HIV tell others with HIV about the quality services and resources of the state agency. Thus the number of persons with HIV applying for services will grow rapidly.

Initial Interview

Counselors actually begin assessing a person's feasibility for services with the first contact; whether that be on the telephone or from walk-ins seeking information. The following section will provide the counselor with the necessary questions and answers to encourage and enable the caller or walk-in to pursue the vocational rehabilitation process, insuring that appropriate clients are not screened out.

As with any new client, the initial interview focuses on establishing good rapport and a positive working relationship. This may require special effort on the part of the counselors due to the lack of trust and skepticism disenfranchised clients feel towards service agencies. The repeated experiences of discrimination and rejection experienced by persons with HIV may be expressed by the client cancelling or missing appointments. In order to form an alliance the counselor may have to make further appointments.

The initial interview in vocational rehabilitation plays a key role in the assessment. Counselors may need two or three sessions to adequately collect appropriate information as well as established trust and rapport. There are certain components to address in the initial interview with the HIV client. Among these are:

- Obtain release of information
- Motivation
- Support systems
- Functional limitations and disability information
- Work history/aptitudes and abilities
- Job retention skills
- Confidentiality of records
- Communication

These components are addressed in all initial interviews. One important difference unique to working with the person with HIV is the requirement of a specific release of information for all health and other information related to their HIV. There are strict confidentiality laws governing release of HIV status without the specific written authorization from the client. The general release of information forms vary from state to state. So it will be the administrator's responsibility to consult with state legal departments to develop release forms that both protect the client and meet the needs of counselors in assessment. Further information on this topic can be found in the next chapter on Legal Issues.

Awareness of Disability/Functional Limitations

The presence of a positive HIV antibody test alone does not constitute a vocational handicap. If the client is experiencing functional limitations, counselors must then determine if it is the HIV that is the cause of the limitations.

The following questions are guidelines for assessment.

- What does the applicant know about HIV disease? What are the current symptoms? Changes in functions, i.e., sleeping, eating, physical activity level.

- What are the past HIV related illnesses if any?
- Is the applicant involved in medical treatment, i.e., scheduled clinic appointments, keeping all appointments? How often does he/she attend clinic?
- If currently receiving medical services, what is the treatment plan? How does the client feel about the medical treatment plan and provider?
- Have there been any hospitalizations? If so, how many and for what? What was the course of the hospital treatment?
- What has been communicated to the applicant regarding their medical condition and what is their understanding and responsibility in maintaining a healthy life?
- Is medication being taken? Does the applicant have the resources/ support systems in place to continue to obtain necessary medication? Is the applicant involved in alternative treatment? Are there any side effects from the medication currently being taken?
- Does the applicant understand the importance of the medication and adhere to the regimen required? Are the medications and/or treatments affecting ability to work, i.e., time and frequency of treatments, side effects of medications?
- When was the last episode of an illness where normal activity was interrupted? What were the responsible actions taken to get the necessary medical treatment? What has been the recuperation time between illnesses? What is the applicant's preventive measures to ward off future illnesses?
- What reoccurring symptoms is the applicant experiencing?
- Does the applicant have questions about HIV that have not been adequately answered?

Functional Limitations

Functional limitations, for persons with HIV, will vary on an individualized basis. Counselors need to begin assessment of these limitations by exploring fatigue, stamina, need for sleep, diarrhea, unplanned and unexplained weight loss, sustained fever, headaches, respiratory problems such as shortness of breath, working indoors versus outdoors, extreme temperature changes, night sweats, shingles, and memory skills (long and short-term). Soft neurological signs that counselors need to be aware of are: inability to track conversation, confusion, impaired short-term memory, and aphasia.

As with any disability group, counselors should ask about a history of mental health problems and make note of any psychological limitations. In assessing the client with HIV, counselors should address the client's level of anxiety and anger. Both may be significantly elevated as a result of the diagnosis and negative experiences that have followed. This can result in the client developing interpersonal problems causing additional limitations with regard to work or receiving services. When present, these problems should be noted under the discussion of vocational handicap in the eligibility determination.

Motivation To Work

Motivation is a factor that requires careful assessment for any disability group. HIV is considered to be the "disease of losses." Due to these physical, social, and psychological losses, clients may need time, understanding, and encouragement from the counselor to become fully motivated.

Support Systems

The evaluation of existing support systems is necessary. Does the client have a family, (including significant others), a therapist, a support group, spiritual support, doctors, social workers, agencies, living arrangements, and how stable are his or her support systems? If the client has adequate support, their chances of a successful involvement in a vocational rehabilitation program is significantly increased. A vocational rehabilitation counselor may initially be the sole support for the client until further support resources are developed. Counselors can obtain information from the National AIDS Hotline information number 1-800-342-AIDS or the local health department. More complete information about services may be found in the appendices in the back of this document.

Work History/Aptitudes and Abilities

The work history of an HIV client plays an important role in the initial interview, as it does with other disability groups. Assessing whether the applicant/client has transferrable job skills, that would readily put him/her back into the job market, is vital. Questions that are to be addressed include:

- Educational level; whether the applicant is a high school graduate/G.E.D. or whether the individual has some college/-technical skills?
- What employment did the applicant have previous to HIV and what have they done about returning to work since the diagnosis of HIV?
- When is the applicant's best working time, i.e., morning, afternoon, evening, part-time, full-time, flexible hours?
- What kind of work does the applicant want to do?

- What kind of work is the applicant capable of doing?

Work encompasses a large part of our lives. Without work many people feel lost, depressed, and helpless. It is a traumatic experience for anyone who has worked to find him/herself without a job and/or unable to work due to prejudice or functional handicaps. The counselor must be sensitive to the severe changes in life-style and socioeconomic level since the onset of the HIV disability.

Transferrable skills that the applicant may possess such as hobbies, interests, and skills need to be explored thoroughly in light of the current job market. Assessment of available training options also need to be explored early on in the diagnostic process.

Job Retention Services

Persons with HIV often require job retention services. If so, these services should be addressed early in the process and not wait until after the delivery of other services. Individuals currently working may be in imminent danger of losing their job due to the functional limitations of HIV related illnesses. If there appears to be a vocational handicap, it is very important to intervene and to facilitate reasonable accommodations to allow that person to continue to maintain their current employment. This may involve modifications to the job and utilizing counselor creativity to remove or reduce the vocational handicap. Working with the employer, to promote his/her understanding of the client, as well as assessing whether part-time or full-time work is more appropriate, is vital to job retention.

Confidentiality of Records

All persons who apply for vocational rehabilitation services, sign release forms. Confidentiality is always discussed and assured. It is important that counselors understand the specific confidentiality and legal issues surrounding HIV and protect that confidentiality. Staff must have specific written permission to obtain or share information with each individual source of information, agency, or service provider. In short, release forms must be signed by the applicant prior to sharing information with any individual or agency. The specifics of confidentiality issues will be covered more fully in the chapter on Legal Issues.

Communication

Communication is critical to the vocational rehabilitation program from beginning to end. Listening to and talking with the applicant in the initial interview and throughout the diagnostic process is essential. The counselor must find out how the client is experiencing and dealing with HIV. Has this changed over time - for the better or worse? Questions are based on the individuality of the client and are phrased in a sensitive, flexible, and creativity manner.

Gathering Diagnostics

Using the information gathered in the initial interview, the counselor begins to determine what diagnostic information need to be obtained to substantiate a physical or mental disability that is a vocational handicap to employment. In addition, more information is required to answer question about reasonable expectations that the person will benefit from vocational services in obtaining and maintaining employment. When obtaining information to substantiate a physical or mental disability, counselors identify appropriate medical professionals that have knowledge and experience working with the HIV population. The local or state Department of Health, local AIDS organizations, or a teaching hospital can be resources in identifying physicians who treat and have experience working with HIV patients.

The definition "medically stable" can have various meanings to various medical personnel, but a key to consider is whether the applicant's condition is stable enough to consider work. Communicate this information to the physician. Counselors need to document and determine whether the HIV is stable, slowly progressive, or episodic in nature, and how often are the episodes. The experienced counselor is familiar with similar determinations in disorders such as multiple sclerosis. Counselors also need to be cognizant of definitions when reading medical reports and communicate questions to the appropriate medical personnel. At the same time, counselors should keep in mind the answers that were received from the client in the initial interview.

The following are questions commonly asked of physicians and other evaluators:

- What symptoms and/or illnesses has the applicant experienced, and what is the time factor between each?
- What symptom of HIV is the person experiencing currently?
- Specifically, how is the client limited in function?
- What is the individual prognosis over the next few years?
- What is or what should be the client's medical treatment plan?

Answers to these questions will assist in counselor assessment in the determination of the degree of medical stability of the client. If the client is not already followed by a provider, this information may assist the client in developing appropriate medical/psychological care and follow-up.

In working with HIV clients, appropriate medical evaluation will be needed. Due to the sometimes severe emotional impact of HIV on the client, counselors should keep in mind that a psychological interview and possibly psychological testing and assessment may be necessary to assess additional limitations. The limitations that are seen, may include but are not limited to anxiety, depression, cognitive or intellectual impairment, and anger. These emotional/psychological factors may be disabling and indicators of a clients meeting the functional limitation requirement of eligibility. As mentioned in Chapter II, clients may show signs of various degrees of HIV dementia. If these symptoms are present, a complete neuropsychological assessment would be an appropriate diagnostic procedure. As part of the diagnostic work-up it is important to include any emotional changes, difficulties, problems, and symptoms. Past psychological/psychiatric history will help the counselor and the current psychologist/psychiatrist put the current assessment into perspective.

Eligibility/Ineligibility

As in all other disabilities, a person with HIV must meet the eligibility criteria for rehabilitative services. The guidelines for the determination of eligibility in cases with this diagnosis do not differ from the protocols used in other disabilities. The criteria for eligibility are as follows:

1. There must be documented evidence that establishes the diagnosis of a disability by a physician.
2. The resulting medical or psychological disability must be a substantial handicap to employment and there must be a reasonable expectation that rehabilitation services will result in gainful employment.

In chronic progressive disabilities, counselors need to use available resources to help determine if there is a reasonable expectation that the provision of rehabilitation services will result in gainful employment (i.e., feasibility). In gathering diagnostic information to determine eligibility, questions need to be directed to those persons conducting the assessment or evaluation for the counselor. These questions are specific to work related limitations. Upon receipt of all diagnostic reports, counselors may use the expertise of specific diagnosticians to further explore work feasibility, as well as consulting with their supervisor, medical consultants, and/or primary physician to help to them in making the eligibility decision.

Ineligibility

In cases where the applicant is found ineligible due to the determination that: (1) the individual's disability does not constitute a substantial barrier to employment; or (2) the individual cannot be expected to achieve suitable employment as the result of providing vocational rehabilitation services, the counselor will provide resource information that is available to more appropriately meet the needs of the client. Such services may include but not be limited to:

- Follow-up medical care
- Additional support in counselling for HIV infected individual.

- Post testing counselling. Services are available through the State Department of Health to provide the necessary AIDS counselling and support that a person might need.

- Independent living services referral.

- Referral to the Client Assistance Program.

Counselors can refer to the Resource/Appendix section of this document for additional information that could assist an applicant/client in getting the necessary services he or she may need.

Development of the IWRP

When the diagnostic phase is completed and eligibility has been determined, the development of the Individualized Written Rehabilitation Program (IWRP or Plan) takes place. An IWRP is developed when the counselor, client, and client representative, if applicable, has concluded the planning phase of the rehabilitation process. The IWRP is a document of mutual agreement and commitment. It clearly sets forth the responsibilities of the agency and the client in pursuing the defined program of rehabilitation which moves toward employment.

The client's restrictions and limitations, as noted by the counselor, are made known to the client through counseling and guidance. This information is used to understand the various mental and emotional aspects, as well as physical problems and limitations that will need to be removed, reduced, or avoided through planning.

The IWRP incorporates the appraisal of the client's assets and limitations to achieve an identified vocational objective to obtain and maintain employment. The IWRP is not a legal contract but an agreement, subject to amendments as needed to meet the vocational objective. Included in the IWRP is:

- Rationale for choosing the vocational objective.

- Planned frequency of client contact.

- Intermediate rehabilitation objectives, for example to make all clinic appointments, refill AZT prescriptions, attend support groups, be on time for classes.

- Client progress toward program objective evaluation. This entry explains the criteria used by the counselor to evaluate the client's progress toward the vocational objective, e.g., client is receiving supportive short-term psychological services and progress is evaluated by periodic reports from the service provider.

Service Delivery
Implementation of the IWRP

Once a plan is developed, appropriate methods of monitoring are included, and the plan is initiated, the service delivery phase of rehabilitation service begins. Services may be: 1) arranged and coordinated by vocational rehabilitation, and/or 2) directly provided by vocational rehabilitation as needed to reach the vocational goal. These services may be at cost to vocational rehabilitation through the use of similar benefits that are provided by other agencies or benefits for which the client may be eligible. These comparable benefits might include the use of medicaid/private medical insurance, financial aid for schooling (grants, scholarships), and any other helpful services for which the client may be eligible or entitled through other agencies.

Vocational rehabilitation counselors know the importance of a strong, well developed network which provides resources for clients and/or identifies and answers technical or service provision questions. Difficulties in establishing an HIV network may arise when there are no formal agencies in the community dealing with HIV related concerns and other organizations are reluctant to become involved. An important part of networking is educating resources, referral sources, employers, and training centers about the disease.

The same skills used to develop working relationships with agencies concerning other disabilities must be called upon again in working with HIV. Local health departments are a good place to start and may refer the counselor to further community resources.

There may be limited resources available to certain segments of the population such as minorities, women, children, and injection drug abusers. The services available for people in these subpopulations will vary from state to state and locals within states. Counselors need to be alert in determining the clients' needs and identifying gaps in resources. Where resources are not available, counselors may use their creativity and ingenuity in encouraging community efforts in identifying and establishing necessary services.

A resource list has been provided at the end of this book. It will be beneficial to become familiar with the HIV related services provided nationally. HIV related materials such as pamphlets, videotapes, and brochures are available from many agencies. These materials may prove helpful both for in-service training and client awareness programs.

Job Placement

People with disabilities, which require the services of the state/federal rehabilitation program, have many needs in common. However, some disabilities have unique features that cause specific problems that need attention. Such is the case for persons with HIV. The following section will discuss some of the unique issues involved in job readiness and job placement that are faced by persons with HIV.

Workplace Issues

Probably the most significant impact HIV has in the workplace is in the emotional response of the other employees. It is strongly recommended that a culturally sensitive and up-to-date education program be presented to staff members to dispel their fears and the myths about HIV that created those fears. Although any HIV/employee training program must be based upon clear, accurate, medical facts and legal advise, these alone are often not enough. Time needs to be made available for concerns to be expressed and discussed so that deeper issues are allowed to surface. Employees' concerns, fears, and objections about working near or with people with HIV, need to be voiced and acknowledged. However, it must also be acknowledged that a person with a disability must be treated with respect and compassion. Such treatment is the right and humane thing to do, no matter what the disease (Emery, 1988).

Another aspect of dealing with HIV in the workplace is the issue of grief. Due to the stigma associated with HIV many companies have not acknowledged the death of employees from this disease. Much of the denial seen in society about death is played out in the work setting where often times work goes on as usual without addressing the loss to the staff, collectively or individually. Unrecognized grief results in the decrease of productivity. Unexpressed anger may be unleashed in a variety of inappropriate ways. Employees need time and a place to deal with their emotions and their loss. This may happen in a variety of ways including providing time to talk about the individual and what he/she meant to others, hosting some type of celebration of his/her life, or the employees may come up with their own means of completing their relationship with the person. People grieve in very individual ways, therefore it is important that each individual is respected and no one is forced to participate in ways with which they are not comfortable.

In some areas of the country where there may be several AIDS related deaths in one company in a short period of time, employers are dealing with the issues of compounded grief. For these situations it is important to bring in some type of professional help. Many companies today have employee assistance programs with mental health professionals who can provide grief counseling for employees. The placement counselor will need to approach employers and offer referrals to these community resources. For example, local hospice services are trained in the area of death and dying, and some mental health professionals in the community specialize in grief counseling. Literature on grief and the grieving process may help employees process their grief.

Placement Plan

The counselor and client working together develop a workable placement plan. It should define the strategies and responsibilities of each person, set time lines, and reporting responsibilities. A placement plan may include several components usually found in "Job

Seeking Skills" training programs or all of such a program. For those clients with significant work histories the services needed may include: specific training for specific skill deficits; office services to prepare and copy resumes, use of a phone to call prospective employers, clerical services, etc.; if not earlier accomplished, work/issues and value clarification may be appropriate; or the client may only need help in organizing and conducting the job hunting process.

Follow-up

When an HIV client becomes employed and successful employment achieved, the case might be put into Status 32, Post Employment Services. Such a move might enable the client to feel that the counselor will continue to be supportive and available to assist, should any problems arise on the job. In placing HIV clients in Status 32, vocational rehabilitation agency administrators should recognize that reduction of caseloads for counselors will be necessary. Such a reduction in caseload will enable counselors to perform the additional work required by the clients with complex problems while receiving credit towards their job performance review.

Additional Factors to be Considered for Persons with HIV

Rehabilitation professionals will recognize that HIV clients may be faced with significant challenges in the accomplishment of their goals and objectives that are unique to their disability. Consequently the agency, which enables persons with HIV to receive services, will be aware of and sensitive to these situations. To accomplish quality services for this population, the agency should equip staff with:

- Knowledge about the disease and the many specific issues, needs, and concerns of a persons with HIV.

- The knowledge of available HIV resources, referrals, and "similar benefits."

- The knowledge that clients' everyday and rehabilitation activities can be affected by frequency of treatments, side effects of medication and exacerbation of the disease.

- The opportunity, with justification, of modifying completion dates on the IWRP and frequent evaluations of the rehabilitation plan for that express purpose.

- The ability to change original objectives depending upon the course of the disease.

CHAPTER VI

LEGAL ISSUES IN HIV

As the HIV epidemic has spread, examples of the variety of legal problems faced by persons with HIV has proliferated. Advocates and persons affected with HIV began to look for a legal framework to afford protection to this extremely vulnerable group of people. Fortunately, that framework could be found in the protection afforded to persons with disabilities under laws which has been developing over the past two decades. While some advocates understood the parallels between having a disability and having a chronic disease, it was not generally accepted that both could be interchanged for purposes of protection under the law.

The battles for determining whether persons with HIV would fit within the traditional disability framework were numerous. They including the courts, Congress, state and local governing bodies, and the Executive branch of the federal government and the agencies of the Executive branch. Not surprisingly then, the courts became the primary focus for this discussion of the theory that people with HIV would be covered by the federal and state statutes which provides coverage for people with disabilities. If such protection was afforded, the question remained how far and under what circumstances would this coverage extend.

Rehabilitation Act: Section 504

The foundation of nondiscrimination protection for people with disabilities is Section 504 of the Rehabilitation Act of 1973 as amended. Section 504 provides as follows:

> No otherwise qualified handicapped individual in the United States, as defined in (29 U.S.C. 706 (7)) shall, solely by reason of his handicap, be excluded from the participation, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program or activity conducted by an Executive agency or by the United States Postal Service.

This language was the first line of defense for legal protection. The first test of the applicability of Section 504 came in a case not specifically related to HIV. The U.S. Supreme Court in School Board of Nassau County v. Arline (107 S. Ct. 1123 1987) was faced with a situation of a woman with a contagious disease (tuberculosis) who wished to return to her job as a school teacher. The Court held that Section 504 did protect a person with a contagious disease but that the person must also meet the criteria of being otherwise qualified.

The concept of "otherwise qualified" means that an individual with handicaps must meet the qualification standards of the program or activity from which the individual is seeking benefits or services. In the case of an individual with a contagious disease, the Court in Arline noted that such an individual would not be "otherwise qualified" for an employment position if the individual posed a significant risk of communicating the disease to others in the workplace and reasonable accommodation could not limit the risk. Guidelines were set out by the court to determine significant risk. These guidelines include the examination of medical evidence to: (a) determine the nature of the risk (how the disease is transmitted), (b) the duration of the risk (how long is the carrier infectious), (c) the severity of the risk (what is the potential harm to third parties), and (d) the probabilities the disease will be transmitted and will cause varying degrees of harm. This four part test that was adopted by the Court was recommended by the American Medical Association.

Thus, the Court maintained the traditional two-part test of Section 504 as it had already applied to other disabilities. First, a determination must be made as to whether the person is an individual with a handicap, second, the determination must be made as to whether the individual is "otherwise qualified."

Two further clarifications of this doctrine from the other two branches of government firmly place people with HIV under the protection of Section 504. The U.S. Department of Justice, at first, strongly opposed the coverage of contagious diseases in the Arline case. Despite that opposition, however, the Department of Justice reversed itself and in an opinion in September, 1987, stated that they accepted the Court's interpretation and furthermore, extended the protection to persons who were asymptomatic HIV+. Since the Court only referred to full blown AIDS in a now famous footnote, the Department of Justice's opinion helped settle the question about Section 504 coverage when the person is HIV+.

The U.S. Congress also provided guidance to deal with the issue in two separate pieces of legislation. In the Harkin-Humphrey amendment to the Civil Rights Restoration Act (1988), Congress intended to clarify the application of Section 504 in the employment context in terms of persons with contagious diseases. The amendment states that:

> For the purposes of Section 503 and 504, as such sections relate to employment, such term does not include an individual who has a currently contagious disease or infection, and who, by reason of such disease or infection, would constitute a direct threat to the health or safety of other individuals or who, by reason of the currently contagious disease or infection, is unable to perform the duties of the job.

It appears that this amendment is in concert with the Arline decision and codifies the existing standards applicable to Section 504. In another action, Congress included specific language to deal with contagious diseases in the Fair Housing Act Amendments of 1988. In that legislation passed by the 100th Congress, the legislators again adopted the concept of "direct threat" as a disqualifier for coverage. Any person who by virtue of having a contagious disease poses a "direct threat" to another person is not protected by the Act. The four-part test adopted by the Court in Arline would then be used to determine whether indeed a direct threat existed. This four part test has ben upheld in other cases by other courts (Chalk v. U.S. District Court, 840 2nd 701 (9th Cir. 1988).

Further interpretation of the role of Section 504 in providing protection for persons with HIV appeared in a case involving special education in Martinez v. School Board of Hillsborough County, Florida (666 F. Supp. 1524 (M.D.) Fla. 1987). The Court in that case required a lower court to first determine whether reasonable accommodations as mandated by Section 504 could reduce the risk of transmission before deciding whether the child could be excluded from special education services.

These decisions also have impact on protections provided in states that have developed nondiscrimination statutes and enforcement procedures to assure compliance with those protections. At least 36 states currently have language that covers persons with disabilities. The state agencies who have the responsibility to enforce those statutes look to the federal definitions to define these terms. States court cases, based on state statute, have also consistently held that a person with a contagious disease such as HIV are handicapped for the purposes of the statute.

At this juncture in the legal and legislative flurry of activity, the balance has most definitely tipped in favor of protection and inclusion of persons with HIV under the traditional framework of disability law. Further evidence of this shift is found in the Americans with Disabilities Act. The Act, as introduced, includes protection from discrimination for persons with HIV in private employment, public accommodations, public and private transportation and telecommunications. The legislation contains the concept of a person not being eligible for protection if they pose a direct threat of infection similar to the Fair Housing Act of 1988. The Senate passed its version on September 7, 1989, with the support of the Bush Administration. As this document goes to print, the House of Representatives is considering its version of the bill.

As a federally funded program, the Vocational Rehabilitation Program must accept the concepts as established by law and its interpretation the courts. Rehabilitation must look at the person with HIV as a viable candidate for involvement in the vocational rehabilitation process. At the point of application, the traditional eligibility requirements for services would be applied.

The Rehabilitation Services Administration (RSA) of the Department of Education issued a guidance memorandum in 1986 which does not adequately address HIV as it exists in the nineties. This policy is under extensive review and new RSA policies are expected by the end of 1989.

State and Local Activities

A patchwork of laws and regulations exist throughout the states in dealing with HIV infection. Approximately 36 states have some type of legislation protecting people with disabilities from discrimination as do a variety of localities. The states also faced a problem as to whether HIV was a "disability" or "handicap" within the definition of their laws. The Arline decision and the subsequent Department of Justice opinion strengthened the argument for inclusion of persons with HIV since most states look to the federal law for guidance on the interpretation of the definition of disability. Some states, like Maryland, promulgated interpretative guidelines that clarify state statutes and indicate that HIV is included within the definition. Several localities have passed AIDS specific non-discrimination laws as well. On the other hand, Tennessee specifically, deleted HIV from their disability statute through action by the state legislature.

These local statutes are important for several reasons. First, they often provide a more efficient and low cost remedy for cases of discrimination. State and local human rights commissions can provide investigation and complaint resolution without the person with a disability having to secure an attorney and file costly and time-consuming litigation. Also the visibility of those agencies and their out-reach efforts sends a message to the community at large that discrimination against people with HIV is not tolerated.

Vocational rehabilitation personnel should be aware of these laws in order to properly counsel their clients who encounter discrimination.

Confidentiality and the Duty to Warn

Two parallel concepts relating to HIV that have given rise to the most heated debate are the need for: (1) confidentiality and (2) the impact of confidentiality on the publics right to know and duty to warn people who could potentially be put at a risk of exposure to the disease.

The issue of confidentiality as it relates to vocational rehabilitation services should easily fall under the strong legal statements that protect client confidentiality in the Rehabilitation Act of 1973 as amended. Federal regulations (34 C.F.R. 361.49(c)(1) provide for the confidentiality of the client's records. Further it allows the client or client representative to request information from those records. This concept of confidentiality has been an underlying principle of the vocational rehabilitation program since its inception. Those principles would apply to clients with HIV. Vocational rehabilitation professionals need to be aware of the importance of protecting the client with HIV their right to confidentiality as it relates to services inside the agency. The protection of confidentiality is required as well in the larger community.

Specific issues related to the need for certain groups to know of the HIV antibody status of a client of a state vocational rehabilitation agency are yet to be resolved. Questions arise as to informing other rehabilitation services providers of the antibody status of clients who are being referred for placement. Also the issue of prospective employers wanting this information will arise. This issue troubles both counselors and other rehabilitation service professionals such as staff of supported employment programs and those working in Projects with Industry.

The administration does have the authority to release information, at its discretion, which would protect a client or others when the individual could endanger the safety of himself or others (34 C.F.R.361.49 (e)(4). Some rehabilitation personnel may argue that their relationship with colleagues and employers will be jeopardized if antibody status is not disclosed by them when it is later discovered the client was HIV+. There is no valid medical reason for employers or providers to be given this information. Thus, the regulation cited above would not apply to clients with HIV. Any such breach of confidentiality would be subject to legal and disciplinary actions.

In order to assure uniform practice by vocational rehabilitation professionals and support staff, state and other rehabilitation services agencies must develop policies which emphasize the clients' right to privacy and strict adherence to rules of confidentiality. Also education programs for all persons within the rehabilitation community must be provided on an ongoing basis to keep the staff current on the developments in the field (see Administration Issues).

Testing

Since the discovery of the HIV virus and the development of the test for the antibodies (ELISA) and the confirmatory test (Western blot), the debate has continued as to the appropriate role of testing. Public health authorities and others have argued that it is important to know the extent of the disease in the population at large and to know whether certain individuals are infected who may have exposed others. On the other hand, other public health officials and consumer groups argue that testing should not be conducted on a mandated basis until: (a) effective treatment and therapies are available and (b) there are effective protections against discrimination in all of its forms.

Obviously, persons claiming discrimination based on their disability must show they are within the class of individuals protected under the Act. The vocational rehabilitation professional should not be faced with testing issues except with regard to counseling. For clients concerned about their antibody status, initial counseling should be offered by the staff and referrals to testing and counseling programs would be made (see Appendix for appropriate agencies). Testing for HIV antibodies would not be appropriate routine part of the diagnostic or evaluation process. It, in and of itself, does not constitute a disability nor is it a functional handicap.

Other Rehabilitation Services

Independent Living Services

Title VIII of the Rehabilitation Act creates a four part independent living service program to provide services for persons with disabilities that are too severe to benefit from vocational rehabilitation services. Three parts of the program presently receive appropriations while the fourth has never been funded by the Congress.

Part A authorizes formula grants to state vocational rehabilitation agencies (or another agency specifically designated by the Governor and approved by the Secretary) for the provision of comprehensive independent living services. Such services must be designed to meet the current and future needs of individuals whose disabilities are so severe that they do not have the potential for employment but may benefit from vocational rehabilitation services which enable them to function independently. Priority must be given to persons who have disabilities and are not currently served by other programs under the Rehabilitation or Developmental Disabilities Act. Independent living services may include: (1) counseling, including psychological, psychotherapeutic and related services; (2) housing, including appropriate accommodations and modifications of any space to serve persons with handicaps; (3) appropriate job placement services; (4) transportation; (5) attendant care; (6) physical rehabilitation; (7) therapeutic treatment; (8) needed protheses and other appliances and devices; (9) health maintenance; (10) recreation services; (11) services to children of pre-school age, including physical therapy, development of language and communication skills, and child development services; and (12) appropriate preventive services to decrease the needs of individuals served under this program for future independent living services.

Part B. Centers for Independent Living. In states having approved independent living plans, RSA may make grants to vocational rehabilitation agencies to establish and operate centers for independent living. Each center must have a board which consists primarily of persons with handicaps who are substantially involved in the policy development and management of such centers. The centers may provide the following services: intake, counseling, and evaluation of client needs; referral and counseling for attendant care; advocacy regarding legal and economic rights; skill training, housing and transportation referral and assistance; health programs; community group living arrangements; individual/group social and recreational activities; and attendant care and training of personnel to provide such care.

Part C. Services for Older Blind Individuals. This special program provides independent living service to persons over age 55 whose visual impairment is severe enough to make gainful employment extremely difficult, but for whom independent living goals are feasible. Authorized services under Part C include outreach, treatment, provision of eyeglasses and other aids, mobility training and guide, and other services.

Part D. Protection and Advocacy Services for the Severely Disabled. This section creates a protection and advocacy program for severely disabled individuals but has never been funded. This program allows the Commissioner to make grants to provide protection and advocacy services to severely disabled persons with little specific direction on how the program would function. The potential exists for these programs to provide protection and advocacy services to persons not presently eligible under the existing protection and advocacy services programs or client assistance programs. Since the concept of the independent living program is to serve persons not eligible for traditional rehabilitation services, this section if funded could fill a severe gap in legal advocacy services.

Impact of HIV Infection

Reviewing the services anticipated by the Independent Living Program demonstrates the parallels between many of the service needs of people with HIV, especially people who have developed full blown AIDS becomes obvious. The priority established for the program, in serving persons with disabilities that are not served by vocational rehabilitation or Developmental Disabilities Acts, clearly applies to this population. Many of the traditional Independent Living Center (ILC) services would be necessary for persons with HIV who are struggling to maintain a stable home environment. Respite services and attendant care certainly would enable someone with a chronic disease to stay at home rather than use expensive acute hospital care. Advocacy services provided by ILC's will also be an important service for people with HIV. ILC's will also find, as have other programs funded under the Rehabilitation Act, that some of their present clients, are discovering that they are HIV+ or even have full blown AIDS. Such discovery will further increase their need for a variety of services to manage the new problems associated with having a previous disability and also HIV.

Cooperative Agreement with Community-Based Organizations

One of the best ways to ensure that the services available under the independent living program are made available to persons with HIV is through formal interaction between Aids Service Organizations (ASO) and ILCs. Prior to the development of these formal agreements, ILCs, like all other service providers must develop a plan to work with this population which includes development of policy and training of staff. While ILCs understand the discrimination faced by persons with disabilities and should be excellent providers of services, the unique problems posed by HIV require that everyone be sensitized to the special needs of this population. Also ASOs are most likely unaware of the services available under the Rehabilitation Act and outreach to those organizations in the community should come from ILCs as well as to inform them of the role of rehabilitation.

Rehabilitation Facilities

There are over five hundred freestanding rehabilitation hospitals; outpatient rehabilitation facilities including comprehensive outpatient rehabilitation facilities (CORF); there are over 5,000 rehabilitation facilities which provide supported employment, sheltered employment, placement, and residential services; uncounted home health care agencies; and skilled nursing facilities in every local that focus on serving persons with disabilities. Over 50% of referrals to rehabilitation facilities come from state vocational rehabilitation agencies with the remainder coming from developmental disabilities board, state mental health agencies, special education agencies, or self-referral.

Eligibility of Persons with HIV infection

Eligibility for services in facilities for this population should be determined as for any other client of vocational rehabilitation. Assumedly the client has been referred to the facility because it has been determined that the client is suitable for the type of service offered. The mere presence of the HIV cannot affect the eligibility status of the client. If the client, however, is experiencing illness or other impairment which make it impossible for the client to meet the requirements of the program, those factors would be taken in to account as with other disabilities. Since there is no transmission through casual contact, precautions in the workplace would follow those set out by the Office of Occupational Safety and the Centers for Disease Control.

Confidentiality

As stated above, the requirements of confidentiality should be strictly observed. However, practically speaking, confidentiality is often breached by the person themselves and those who they tell. As a result of this ever widening circle of people who know the antibody status of the client of rehabilitation services, it will be critical for the facility to guarantee that no adverse action is taken against the persons by agency staff or other client on the basis of HIV status.

Management of Clients

Clients in rehabilitation facilities who are known to be HIV positive should not require that additional precautions be taken. Certainly in certain types of work such as food handling the normal precautions required by health regulations would suffice. Again the OSHA workplace guidelines offer the best directions on what steps should be taken for all employees.

Some clients in rehabilitation facilities exhibit acting out behavior. Consequently, a facility may be concerned that a client with HIV may engage in such behavior. If that behavior would result in the exchange of body fluids which cause HIV transmission (blood and semen), the facility should seek guidance from appropriate experts on how best to manage the client's behavior. If clients are engaged in the type of activity which leads to risk of infection (e.g., promiscuous sex, injection drug use), program review and reevaluation may be necessary. Each situation should be treated as an individual case and evaluated on that basis.

Role in Education

While it may not be the primary role of rehabilitation facilities to educate clients about behavior issues (except in residential settings or comprehensive programs on life skills) facilities have the opportunity to provide vital information and education about HIV and how to prevent its transmission. In addition to employing good workplace practices, facility staff should be instrumental in providing current information for clients on "safer sex." Facilities can provide counseling services or identify and refer clients who need such service to those agencies that provide this service.

Institutions and Rehabilitation Services

Some state vocational rehabilitation agencies place staff at institutions serving persons with mental retardation and mental illness. Persons who are institutionalized and are also HIV+ present severe problems for those institutions. The issues of confidentiality, segregation, and lack of access to certain services due to their condition are especially difficult to manage in this setting. The rehabilitation professional working in this setting must be aware of these issues and not inappropriately screen out any clients who may be antibody positive from services which may lead to better vocational opportunities or integration into the community.

Confidentiality. Again confidentiality is especially difficult to maintain in large public institutions. However, the same standard must be maintained by facility employees.

Segregated Services. It has been reported that institutions will segregate persons with HIV from the rest of the institutional population under the mistaken belief that they are "protecting" the other residents. This practice violates basic 504 protections unless there is a demonstrated direct threat posed by the individual. Vocational rehabilitation agency professionals working in these settings should be watchful of these practices and raise questions with administrators if such activity exists.

Rehabilitation Hospitals

One area of rehabilitation services which has dealt frequently with HIV appears to be rehabilitation medicine. In 1987, the Association of Rehabilitation Nurses adopted a position of appropriate care for persons with HIV in rehabilitation facilities. Also the American Congress of Rehabilitation Medicine created a Task Force on HIV and is preparing standards of care for this population.

Persons with HIV come to the hospital through trauma related injuries, other unrelated disabilities, and through children who contracted HIV from their mothers. Such persons will often require therapy for neurological illness. As stated in an article "Rehabilitation and AIDS: Primary Care and System Support" (Furth, Maloof, Flynn and Shea - 1988 MMJ):

> These illnesses may be divided into two broad categories: those related to the virus itself and those resulting from an opportunistic infection. Guillain-Barre' syndrome, transverse myelitis, stroke, and neuritis may be caused by HIV; and many of these patients can improve with rehabilitation. Other conditions associated with the virus may be less responsive to therapy, for example, dementia (which affects 30 to 60 percent of patients with AIDS) and progressive multifocal leukoencephalopathy, an opportunistic viral infection. Other opportunistic infections such as toxoplasmosis and Mycobacterium tuberculosis can cause brain abscesses that may respond to antimicrobial therapy (p. 469-471).

The authors go on to suggest that many aspects of rehabilitation programs designed for AIDS patients are the same as for patients without HIV. These programs must accommodate two features that distinguish patients with HIV: the intense psychosocial and educational needs these patients have and the necessity of following guidelines to prevent transmission of the disease.

Education of the patient and the family are imperative to develop the support systems necessary for the patient as well as preventi further infection of other parties. Since an important component o any rehabilitation program is the reintegration of the person into the family and community after discharge from a rehabilitation hospital, it is important to remember that discharge can be a "re-isolating" experience for these patients. Post discharge counseling is necessary to help the patient through this period. Again, the hospital should work through the ASOs in the community to provide ongoing support which is essential.

Issues within the hospital for managing the patients and staff also must be given careful consideration. Certainly universal precautions must be strictly observed. Many patients in these setting have open wounds and bodily secretion that could cause transmission if not appropriately managed. Training of all health care professionals so they are totally familiar with the disease and how it is transmitted should be established. Policies and guidelines that deal with patients in multiple therapy settings and sharing equipment and group participation must be in place. Since HIV is not transmitted casually, blood and body fluid precautions should suffice to protect staff and others. Rehabilitation hospitals should be able to "mainstream" patients with HIV. If, however, patients with conditions that require more barriers, a rehabilitation program can be offered in their rooms or with a limited amount of easily cleanable equipment. Rehabilitation staff should rely on the infectious control and epidemiology staff for guidance and training.

Projects With Industry

Under the PWI grant program (authorized by Part B of Title VI) Rehabilitation Services Administration contracts with: state agencies, non-profit rehabilitation facilities, and nonprofit community organizations, businesses, labor unions, and trade associations, to provide job training, placement assistance, and pre and postemployment supportive services for individuals with disabilities to increase competitive employment and opportunities.

Impact of HIV Infection

Again the PWI program should anticipate that clients may be or may become HIV seropositive raising serious questions for administrators of the program. As many PWI programs work extensively in the food service industry, the pressures from private employers not to hire or continue to employ a person with HIV and another disability will increase. Employers who already are nervous about hiring a person with a disability will raise a myriad of questions when faced with the reality of HIV. Some of those questions will include: the long-term prognosis of the client; the cost to the employer in investing in a person with a potentially terminal illness; the public relations impact on the business; and the problems with other staff. PWI program managers may also worry about credibility with "good employers" who will drop out of the program when faced with these new challenges.

Once again the need for training, clear policy and follow-up to ensure the issues are addressed before they erupt into a crisis, will be the best defense against many of the problems that will inevitably occur.

Supported Employment

First funded in 1987, the purpose of the "Supported Reemployment Services for Individuals with Severe Handicaps Program" (Part C of Title V) is to assist state rehabilitation agencies in establishing collaborative efforts with other public and private organizations to provide opportunities for placement for persons with severe disabilities in supported employment. Supported employment is defined as "competitive work in integrated work settings for individuals who need on-going support in order to perform such work." Under this program state agencies provide training and time-limited post-employment services leading to supported employment for persons with severe disabilities for whom competitive employment has not traditionally occurred or where such work has been interrupted or intermittent.

The impact of HIV on supported employment programs will be the same as in the PWI section above.

Client Assistance Programs (CAP)

The Client Assistance Program is a mandatory formula grant program in each state and territory. CAPs provide information and referral to persons with disabilities about services under the Act and has the authority to pursue legal administrative and other appropriate remedies on behalf of client and client applicants of rehabilitation services. CAP agencies are located in a variety of settings (35 are connected to the Protection and Advocacy Programs for the developmentally disabled and mentally ill individuals while others are in other nonprofit agencies or state vocational rehabilitation agencies.

CAPs provide individual advocacy services on behalf of persons who may be having problems with the vocational rehabilitation system. All programs under the Act are within the jurisdiction of CAP.

Impact of HIV

The CAP agency provides legal advocacy services for persons who have a disability, if they are seeking services from a vocational rehabilitation program. The mandate of the CAP effort is to pursue legal, administrative, and other appropriate remedies. The mandate allows this program to be the first line of defense for any individual who believes they face discrimination or denial of service within the rehabilitation system. CAPs have received training through national training seminars on the issues of HIV and have had several cases involving the denial of service to individuals with HIV. To date, those cases have involved denial of eligibility on the grounds that the person was too ill ("He will die soon") to be eligible for vocational rehabilitation services.

As people with HIV live longer, due to improved treatment, the cases may move beyond the threshold issues of eligibility. Vocational rehabilitation agencies should also view CAP and protection and advocacy programs as a resource for referrals to deal with the legal problems associated with the disease. CAP agencies have several roles to play in assuring that persons with HIV obtain the full range of services that are provided by the rehabilitation system and to which they are entitled. These include outreach to the general public to inform them of their eligibility for vocational rehabilitation services, initial counseling with appropriate referrals, negotiation and mediation of issues, individual legal representation if necessary, and assuring that the system has in place the necessary policies and protections for this population.

APPENDIX A

RESOURCES

APPENDIX A

RESOURCES

Aids Information Hotlines

Alabama	1-800-455-3741
Alaska	1-800-478-2437
Arkansas	1-800-445-7720
Arizona	1-800-334-1540
California	
Northern California	1-800-FOR-AIDS
Southern California	1-800-922-AIDS
Caroline Islands/Micronesia	011-691-9-619
CDC Printed Materials	404-329-3534
CDC Recorded Information	404-329-1290
Colorado	303-331-8305
Connecticut	203-566-1157
Delaware	302-995-8422
District of Columbia	202-332-AIDS
Florida	1-800-FLA-AIDS
Georgia	1-800-551-2728
Guam	011-6710734-2947
Hawaii	808-922-1313
Hawaii	808-961-7276
Honolulu	808-924-AIDS
Kauai	808-245-4495
Maui	808-244-4288 or 808-667-0655
Oahu	808-735-5303
Idaho	208-334-5944
Illinois	1-800-AID-AIDS
Indiana	317-633-8406
Iowa	1-800-532-3301
Kansas	1-800-232-0040
Kentucky	1-800-654-AIDS
Louisiana	1-800-992-4379
Maine	1-800-851-AIDS
Marianas Islands/Saipan	011-670234-8950
Marshall Islands	011-692-9-3487
Maryland	1-800-638-6252
Massachusetts	1-800-235-2331
Boston	617-424-5916
Michigan	517-335-8371
Wellness Network, Inc. Hotline	1-800-872-AIDS
Minnesota	1-800-248-AIDS
Mississippi	1-800-826-2961
Missouri	314-751-6438
Montana	406-444-4740
Billings	406-252-1212
National AIDS Hotline	1-800-342-AIDS
Nebraska	1-800-782-AIDS

Nevada	
Las Vegas	702-383-1393 or 702-369-6162
Reno	702-329-AIDS
New Hampshire	603-271-4490
New Jersey	1-800-624-2377
New Mexico	505-827-0006 or 505-984-0911
New York	1-800-462-1884
North Carolina	919-733-7301
North Dakota	1-800-592-1861
Ohio	1-800-332-AIDS
Oklahoma	
Enid area	405-242-5555
Oklahoma City area	405-271-6434
Oregon	503-229-5792
Portland	503-223-5907
Pennsylvania	1-800-692-7254
Puerto Rico	809-765-1010
Rhode Island	401-277-6502
South Carolina	1-800-322-AIDS
South Dakota	1-800-472-2180
Tennessee	1-800-342-AIDS
Texas	
Austin	512-458-7405
Dallas	214-559-AIDS
Houston	713-524-AIDS
Utah	1-800-843-9388 or 801-466-9976
Vermont	1-800-882-AIDS
Virginia	1-800-533-4148
Washington	206-361-2888
West Virginia	1-800-642-8244
Wisconsin	1-800-334-AIDS
Milwaukee area	414-273-AIDS
Wyoming	307-777-7953

State Aids Agencies and Hotlines

Alabama Department of Health
AIDS Program
State Office Building, Room 662
434 Monroe Street
Montgomery, AL 36130
205-261-5017
1-800-228-0469

Alaska Department of Health
AIDS Health Program
3601 C Street
Anchorage, AK 99524
907-561-4406

Arizona Department of Health
Office of Health Education
431 N. 24th Street
Phoenix, AZ 85008
602-230-5836

Arkansas Department of Health
AIDS Activities
4815 W. Markham
Little Rock, AR 72205
501-661-2135

California Department of Health
Office of AIDS
P.O. Box 160146
Sacramento, CA 95816
916-445-0553

Colorado Department of Health
AIDS Education Risk Reduction Program
4210 E. 11th Street
Denver, CO 80220
303-331-8320

Connecticut Department of Health
AIDS Program
150 Washington Street
Hartford, CT 06112
203-566-5058

Delaware Department of Health and Social Services
AIDS Program Office
3000 Newport Gap Pike
Building G
Wilmington, DE 19808
302-995-8422

District of Columbia Commission of Public Health
Division of AIDS Education
1875 Connecticut Avenue, N.W., Room 838-C
Washington, DC 20009
202-673-3425

Florida Department of Health-Rehabilitation
Health Education and Risk Reduction
1317 Winewood Boulevard, Room 453
Building 6
Tallahassee, FL 32399
904-487-2478

Georgia Department of Human Resources
STD Control Program
878 Peachtree Street, N.E.
Atlanta, GA 30309
404-894-5147

Hawaii Department of Health
Public Health Education
3627 Kilauea Avenue
Honolulu, HI 96816
808-735-5303
808-922-1313

Idaho Department of Health and Welfare
AIDS Program
450 W. State Street
Boise, ID 83720
208-334-5930

Illinois Department of Health
Health Education
525 W. Jefferson
Springfield, IL 62761
217-782-2016

Indiana Department of Health
Office of AIDS Activity
1330 W. Michigan
Indianapolis, IN 46206
317-633-8406

Iowa Department of Public Health
AIDS Education
Lucas Building, 3rd Floor
Des Moines, IA 50319
313-281-4938

Kansas Department of Health and Environment
Office of Health Education
Forbes Field Building 321, Room 13
Topeka, KS 66620
913-296-5587

Kentucky Department for Health Services
AIDS Health Education
275 E. Main Street
Frankfort, KY 40621
302-564-4804

Louisiana Office of Prevention Medicine and Public Health
  Services
325 Loyola Avenue, Room 615
New Orleans, LA 70012
504-568-5005

Maine Bureau of Health
Office on AIDS
Station House, Station 11
Augusta, ME 04333
207-289-3591

Maryland Department of Health and Mental Hygiene Epidemiology
201 W. Preston Street
Baltimore, MD 21201
301-225-6707

Massachusetts Department of Public Health
AIDS Health Education
150 Tremont Street
Boston, MA 02111
617-727-0368

Michigan Department of Health
Special Office of AIDS Prevention
3423 N. Logan
Lansing, MI 48909
517-335-8371

Minnesota Department of Health
AIDS Program
717 S.E. Delaware Street
Minneapolis, MN 55440
612-623-5414

Mississippi Department of Health
AIDS Education Program
P.O. Box 1700
Jackson, MS 39215
601-960-7725

Missouri Department of Health
AIDS Program
P.O. Box 570
Jefferson City, MO 65102
314-751-6438

Montana Department of Health and Environmental Services
AIDS Program
Cogswell Building
Helena, MT 59260
406-444-2457

Nebraska Department of Health
AIDS Prevention Program
P.O. Box 95007
Lincoln, NE 68509
40[illegible]-471-2937

Nevada State Health Division
Department of Human Resources
505 E. King Street, Room 200
Carson City, NV 89710
702-885-4800

New Hampshire Department of Health and Welfare
6 Hazen Drive
Concord, NH 03301
603-271-4490

New Jersey Department of Health
AIDS Division
C.N. 360, 363 W. State Street
Trenton, NJ 08625
609-984-6000

New Mexico Department of Health and Environment Epidemiology
P.O. Box 968
Santa Fe, NM 87504
505-827-0086

New York State Department of Health
AIDS Institute
1315 Empire State Plaza, 25th Floor, Room 2580
Albany, NY 12237
518-474-8160

North Carolina Health Department
AIDS Control Program
P.O. Box 2091
Raleigh, NC 27602
919-733-3419

North Dakota Department of Health
AIDS Project
State Capitol Building
Bismark, ND 58505
701-224-8378

Ohio Department of Health
AIDS Activity Unit
246 North Nigh Street
Columbus, OH 43266
614-466-5480

Oklahoma Department of Health
STD Division
P.O. Box 53551
Oklahoma City, OK 73152
405-271-5601

Oregon Department of Health
AIDS Program
1400 S.W. 5th Street, Room 710
Portland, OR 97201
503-229-5792

Pennsylvania Department of Health
Disease Control
P.O. Box 90
Harrisburg, PA 17108
717-787-3350

Puerto Rico Department of Health
Call Box STD, Caparra Heights Station
San Juan, PR 00922
809-754-8118

Rhode Island Department of Health
AIDS Control Program
75 Davis, Room 105
Providence, RI 02908
401-277-2362
401-277-6502

South Carolina Department of Health
AIDS Project
2600 Bull Street
Columbia, SC 29201
803-734-5482

South Dakota Department of Health
AIDS Program
523 E. Capital
Pierre, SD 57501
605-773-3357

Tennessee Department of Health and Environment-Disease Control
100 - 9th Avenue, North
Nashville, TN 37219
615-741-7387

Texas Department of Health
Epidemiology-Health Promotion
100 W. 49th Street
Austin, TX 78756
512-458-7405

Utah Department of Health
Epidemiology
288 N., 1460 W.
P.O. Box 16660
Salt Lake City, UT 84116
801-538-6191

Vermont Department of Health
AIDS Education
60 Main Street
P.O. Box 70
Burlington, VT 05402
802-863-7245

Virgin Islands Department of Health
AIDS Committee
P.O. Box 7309
St. Thomas, VI 00801
809-776-8311

Virginia Department of Health
AIDS Activity Program
109 Governor Street, Room 722
Richmond, VA 23219
804-786-6267

Washington Department of Health
Epidemiology-AIDS Program
1610 N.E. 150th Street
Seattle, WA 98155
206-361-2888

West Virginia Department of Health
151 - 11th Avenue
South Charleston, WV 25303
304-348-5358

Wisconsin Department of Health and Social Services
AIDS Program
1 W. Wilson Street
P.O. Box 309
Madison, WI 53701
608-267-5287

Wyoming Division of Health and Medical Services
AIDS Program
Hathaway Building, 4th Floor
Cheyenne, WY 82002
307-777-7953

Additional Resources

AIDS Action Council
729 Eighth Street, S.E., Suite 200
Washington, DC 20003
202-547-3101

AIDS Action Committee
661 Boylston Street
Boston, MA 02116
617-437-6200

AIDS Project Los Angeles
7362 Santa Monica Boulevard
Los Angeles, CA 90046
213-876-AIDS

American Association of Physicians for Human Rights
P.O. Box 14366
San Francisco, CA 94114
415-558-9353

American Foundation for AIDS Research
40 W. 57th Street, Suite 406
New York, NY 10019

American Medical Association
535 North Dearborn Street
Chicago, IL 60610

American Red Cross
AIDS Education Office
1730 D Street, N.W.
Washington, DC 20006
202-737-8300

Gay Men's Health Crisis
354 W. 18th Street
New York, NY 10011
212-547-3101

Hispanic AIDS Forum
c/o APRED
853 Broadway, Suite 2007
New York, NY 10003
212-870-1901 or 212-870-1864

Minnesota AIDS Project
2025 Nicollett Avenue South, #200
Minneapolis, MN 55404
612-870-7773

Minority Task Force on AIDS
New York City Council of Churches
475 Riverside Drive
New York, NY 10015
212-749-1214

Mothers of AIDS Patients (MAP)
P.O. Box 1763
Lomita, CA 90717-5763
213-542-3019

National AIDS Network
729 Eight Street, S.E.
Washington, DC 20003
202-564-2424

National Association of People with AIDS
P.O. Box 65472
Washington, DC 20035
202-483-7979

National Coalition of Gay Sexually Transmitted Disease Services
c/o Mark Behar
P.O. Box 239
Milwaukee, WI 53201
414-277-7671

National Council of Churches/AIDS Task Force
475 Riverside Drive, Room 572
New York, NY 10115
212-870-2421

National Gay Task Force
AIDS Information Hotline
212-807-6016 (NY state)
1-800-221-7044

National Leadership Coalition on AIDS
1150 - 17th Street, N.W.
Washington, DC 20036

National Sexually Transmitted Diseases Hotline/American Social
  Health Association
1-800-227-8922

San Francisco AIDS Foundation
P.O. Box 6182
San Francisco, CA 94101-6182
415-863-AIDS

Service Employees International Union
A.F.L.-C.I.O.
1313 L Street, N.W.
Washington, DC 20005
202-898-2300

The Surgeon General's Report
US Public Health Service
P.O. Box 23961
Washington, DC 20026

US Public Health Service
Public Affairs Office
Hubert H. Humphrey Building, Room 725-H
200 Independence Avenue, S.W.
Washington, DC 20201
202-245-6867
1-800-342-AIDS

Resources Outside The United States

Australia/New Zealand

National AIDS Coordinating Committee
Commonwealth Department of Health
P.O. Box 100
Woden 06, Australia

Victorian AIDS Council
P.O. Box 174 Richmond
Melbourne 3121, Australia

New Zealand AIDS Foundation
Auckland Hospital
Auckland, New Zealand

Canada

AIDS Committee of Toronto
556 Church Street
Toronto, Ontario

AIDS Vancouver
1033 Davie Street
Vancouver, BC

Centretown Community Resources
100 Argyle Avenue
Ottawa, Ontario

Comite SIDA du Quebec
3757 rue Prud'homme
Montreal, Quebec

APPENDIX B

GLOSSARY

APPENDIX B

Glossary of Terms Associated with AIDS/HIV

Absolute T4 Count: The actual number of T helper lymphocytes per measurement of blood. The number of T4 cells is significantly lower in people whose immune system has been affected by HIV.

Acquired Immunodeficiency Syndrome (AIDS): The most severe manifestation of infection with HIV. The immune system is destroyed or incapacitated to such an extent that the person becomes susceptible to life threatening infections from bacteria, viruses, other organisms, and cancers.

Acute: Having a rapid onset and a short, often relatively severe course. (See "Chronic")

AIDS-Related Complex (ARC): A less severe form of HIV infection than AIDS. It is characterized by the presence of fever, weight loss, swollen lymph nodes, or other general symptoms as well as abnormal laboratory tests of the immune system. ARC sometimes progresses to AIDS.

Antibiotic: A soluble substance derived from a mold or bacterium that inhibits the growth of other organisms and is used to combat disease and infection.

Antibody: A protein produced by the body as a defense mechanism in response to a foreign substance (antigen) such as a virus or bacteria. The antibody will react only against that antigen which induced its formation.

Antigen: substance which kills or inhibits micro-organisms (viruses, bacteria, fungi, and/or parasites). Includes antibiotics. Most antibiotics are specific to a type or class of micro-organism.

Antimicrobial Agent: A substance which kills or inhibits microorganisms (viruses, bacteria, fungi, and/or parasites). Includes antibiotics. Most antimicrobials are specific to a type or class of microorganism.

Antiviral: A substance that stops or suppresses viral activity.

Asymptomatic Infection: Infection with a disease-causing agent in which the person feels or shows no outward symptoms or signs.

Autologous Transfusion: A blood transfusion in which the patient receives his or her own blood donated several weeks before an elective surgical procedure.

Bacterium: A microscopic organism composed of a single cell. Some bacteria can cause disease in man but most are harmless. Bacteria are often classified on the basis of morphologic features, growth requirements, and sensitivity to antibiotics.

Candidiasis: Any infection caused by the yeast Candida which takes advantage of the immune deficient state. It may cause overwhelming and difficult to treat infections of the digestive tract and other organ systems. In persons with AIDS, Candida often causes an inflammation of the mouth, throat, and esophagus (see "Thrush").

Carrier: An individual infected with a disease-causing agent who experiences or demonstrates no outward signs or symptoms of illness caused by the disease agent.

Casual Contact: Contact between two people which does not involve the exchange of body fluids (e.g., hugging, shaking hands).

Cell-mediated Immunity: A type of immune response in which viruses, bacteria and other foreign substances are attacked and destroyed by white blood cells. This type of immune response occurs in addition to the antibody response.

CD4: See "Helper Cells."

CD8: See "Suppressor Cells."

CDC (Centers for Disease Control): A federal health agency (located Atlanta, Georgia) that is a branch of the U.S. Department of Health and Human Services. CDC provides national health and safety guidelines along with statistical data and other diseases.

Chronic: Persisting over a long period of time: months or years.

Cofactors: Other substances, microorganisms, or characteristics of individuals which may make them more susceptible to a specific infection or disease.

Contagious: Ability of a disease-causing organism to be transmitted from one person to another, directly or indirectly. HIV is not easily transmitted between or among people; it is only spread during activities that expose individuals to the blood (and fluids containing blood cells, like semen) of another person.

Cryptococcosis: Infection with the fungus Cryptococcus neoformans which can affect the brain, lungs, liver, intestinal tract, and skin. Severe cases may be associated with AIDS.

Cryptosporidiosis: Infection with the parasite Cryptosporidium. In persons with immune deficiency, it may cause severe protracted diarrhea and respond poorly to treatment.

Cutaneous: Pertaining to the skin.

Cytomegalovirus (CMV): A common virus that may produce symptoms similar to mild flu or infectious mononucleosis, or may produce no noticeable symptoms at all. In the immunodeficient individual, CMV infections can result in serious infection of the lungs, esophagus, and eye.

Disinfection: A process that kills or destroys most disease-producing microorganisms.

ELISA (or EIA): Enzyme-linked immunosorbent assay; a sensitive serological screening method used to detect antibodies to HIV. Repeatedly reactive (positive) results are followed by a second level test, the Western blot. ELISA techniques are also widely used to detect infections with other agents.

Encephalitis: Inflammation of the brain.

Encephalopathy: Any degenerative disease of the brain.

Epidemiology: The study of occurrence, distribution, causes, and control of a disease in a population.

Exposure: The act or condition of coming in contact with, but not necessarily being infected by, a disease-causing agent.

False Negative: An erroneous test result that indicates absence of a condition (for example, no specific antibodies detected) when, in fact, the condition is truly present.

False Positive: An erroneous test result that indicates absence of a condition (for example, specific antibodies detected) when, in fact, the condition is truly absent.

Helper/Suppressor Ratio: The ratio of helper T cells to suppressor T cells. The normal ratio is generally 2:1; this becomes inverted in persons with AIDS and some symptomatic HIV infected persons. Also termed T4/T8 ratio and CD4/CD8 ratio.

Helper T Cell: A type of lymphocyte which is responsible for orchestrating the immune system. This is the population of cells most seriously affected by HIV. Also known as T4 cells and CD4 cells.

Hemophilia: A hereditary disorder characterized by inadequate amounts of specific blood clotting factors.

Herpes Simplex: A group of viruses that produce watery blisters, often painful, on the skin and mucous membranes, especially the borders of the lips (cold sores) or the mucosal and cutaneous surface of the genitals. In persons with AIDS, severe lesions may occur which cover large areas of the body and last more than one month.

Herpes Virus Group: A group of viruses that includes the herpes simplex viruses, varicella-zoster virus (the cause of chicken pox and shingles), cytomegalovirus, and Epstein-Barr virus (principal cause of infectious mononucleosis).

Histoplasmosis: Infection with the fungus Histoplasma capsulatum. In healthy persons it usually causes no symptoms or a limited respiratory illness. In persons with AIDS, the fungus may cause a severe infection involving multiple body organs.

HIV: See "Human Immunodeficiency Virus."

Human Immunodeficiency Virus (HIV): The virus that causes AIDS. Also referred to as HIV-1. Some individuals infected with HIV remain well for years. This virus was previously referred to as Human T-lymphotropic virus type III/Lymphadenopathy-associated virus (HTLV-III/LAV).

Human Immunodeficiency Virus-2: A virus which is related to but distinct from the well characterized HIV-1. HIV-2 has been identified in western Africa and western Europe and causes a spectrum of disease similar to HIV-1.

Humoral Immunity: A type of immune response to a foreign agent (e.g., bacteria) that involves the production of antibodies.

Immune Response: The activity of the immune system against foreign substances.

Immune System: The body's system of defense mechanisms in which specialized cells (mainly lymphocytes) and proteins (antibodies) work together to eliminate disease-producing microorganisms and other foreign substances.

Immunocompetent: Refers to an individual with a normal, healthy immune system.

Immunodeficiency, Immune Deficient, Immunocompromised, Immunosuppressed: Refers to a breakdown of the body's normal functioning immune system. May be inherited or caused by particular drugs, radiation, or microorganisms (including HIV).

Immunology: Branch of science dealing with the body's resistance to disease and to invasion by foreign substances.

Incubation Period: The time between infection by a disease-causing organism and the onset of illness. The incubation period for AIDS is estimated to be three months to seven years, the upper limits are likely to be longer with longer time of observation.

Infection: The condition in which the body (or part of it) is invaded by a microorganism (such as bacteria or virus) which multiplies and produces an injurious effect.

Interstitial Pneumonitis: A condition in which lymphocytes and other white blood cells accumulate in lung tissue and usually impair the breathing process. It may occur in children with AIDS.

IDU: Injection drug users - includes "skin popping" or injecting under the skin.

Intravenous: Injected into or delivered through a needle into a vein.

IVDU: Intravenous drug user.

In Vitro: Literally, within glass. The term refers to those experiments conducted in an artificial laboratory environment.

In Vivo: Literally, within a living body. The term refers to those experiments conducted in animals or humans.

Kaposi's Sarcoma (KS): A tumor of the walls of the blood vessels, usually appearing as pink to purple spots on the skin. It may also occur in the mouth or intestines.

Latency: The period when an infection is inactive.

Lymphadenopathy: An abnormal condition of the lymph nodes, where the nodes enlarge and may become tender.

Lymphadenopathy Syndrome (LAS): A condition characterized by persistent (more than three months), generalized lymph node enlargement. This may be caused by several different microorganisms, including HIV.

Lymphocytes: White blood cells, normally present in the blood and lymph nodes which bear the major responsibility for carrying out the functions of the immune system. Lymphocytes can be divided into two major groups:

> **B Cells:** Derived from bone marrow, responsible for humoral immunity, and involved in the production of antibodies. They are also referred to as B lymphocytes.
>
> **T Cells:** Derived from the thymus gland (in the neck). T cells have many different functions relating to cell mediated immunity and antibody production. They are also referred to as T lymphocytes.

Lymphoma: A cancer of the lymph nodes.

Meningitis: Inflammation of the membranes of the spinal cord and/or brain.

Microorganism: A form of life which has microscopic dimensions (size). Includes bacteria, fungi, viruses, and some parasites.

MMWR (Morbidity and Mortality Weekly Report): The weekly scientific publication of the U.S. Public Health Service Centers for Disease Control that provides health care providers and public health professionals with timely information and recommendations about current public health problems.

Mucocutaneous: Anything that concerns or pertains to mucous membranes and the skin (e.g., nose, mouth, vagina, lips, eye, anal area).

Mucous Membrane: A moist layer of tissue that lines body cavities having an opening to the external world (e.g., the lining of the mouth, nostrils, vagina, anus/rectum, urethra).

Mycobacterium Avium Intracellular (MAI): A bacterium related to the organism that causes tuberculosis in humans. In persons with AIDS it may cause disease in multiple organs and responds poorly to therapy.
Opportunistic Diseases: Those diseases which are caused by microorganisms that are commonly present in the environment but which cause disease only when the immune system becomes depressed.

Pathogen: Any disease-producing microorganism or substance.

Parasite: A plant or animal that lives, grows, and feeds on or within another living organism.

Parenteral: Involving introduction into the bloodstream.

Passive Surveillance: The process of monitoring health problems through the receipt of reports on those problems.

Perinatal: The period around, during, or just after birth.

Persistent Generalized Lymphadenopathy (PGL): Chronic, diffuse, noncancerous lymph node enlargement that is a manifestation of HIV infection. The presence of lymphadenopathy alone does not increase the risk of subsequent AIDS in a person with HIV infection. A common sign of a Stage III HIV infection.

Placebo: An inactive substance with no direct beneficial effects. Usually used in clinical studies for comparison, to measure the effectiveness of an experimental drug or regimen.

Pneumocystis Carinil Pneumonia (PCP): A parasitic infection of the lungs; the most common opportunistic infection in persons with AIDS.

Predictive Value Positive: Likelihood that a person with a positive test result truly has the condition being evaluated by the test (see "Sensitivity" and "Specificity").

Predictive Value Negative: Likelihood that a person with a negative test results truly does not have the condition being evaluated by the test (see "Sensitivity" and "Specificity").

Prenatal: Before birth.

Prevalence: Total number of persons in a given population with disease or other health-related event during a specified period of time, usually expressed as a percentage.

Prophylaxis: Measures taken to prevent something from happening, may involve use of a substance or materials (e.g., vitamins, condoms, vaccines, immune globulins).

Replication: The process of duplicating or reproducing, as in duplicating DNA or RNA, such that an identical new molecule is formed. This process is necessary for the reproduction of viruses.

Retrovirus: A class of viruses that contain the genetic material RNA and that have the capability to copy this RNA into DNA inside an infected cell. The resulting DNA is then incorporated into the genetic structure of the cell.

Reverse Transcriptase: An enzyme produced by retroviruses that allows the production of a DNA copy of their RNA as a first step in the retrovirus' natural cycle of reproduction.

RNA (Ribonucleic Acid): A compound associated with the control of chemical activities inside a cell. Some viruses such as retroviruses carry RNA instead of the more familiar genetic material DNA.

Sensitivity: In biologic testing, the percentage of people who test positive who in fact do have the condition being tested for (see "Specificity").

Seroconversion: The initial development of antibodies in a susceptible individual following exposures to a particular antigen.

Serologic Test: Most typically, a test which detects the presence of antibody in blood or body fluid to a particular microorganism. Serologic tests are useful to identify many infections, including HIV.

Seropositive: In the context of HIV, the condition in which antibodies to the virus are found in the blood.

Serum: The clear liquid portion of blood which separates from the cellular portion when the blood clots. The serum contains antibodies and is used when performing serologic tests.

Sexually Transmitted Disease (STD): Infection that is transmitted or spread primarily through intimate sexual contact between an infected person and an uninfected person; included are chlamydia, syphilis, gonorrhea, and many others.

Side Effects: The action or effect of a drug or regimen other than that desired. The term usually refers to undesired negative effects such as headache, diarrhea, skin irritation, or liver damage. Experimental drugs must be evaluated for both immediate and long-term effects.

Signs: Any objective evidence or manifestation of an illness in the body (e.g., fever, blisters, sores, redness, enlarged lymph nodes). Signs can be identified by someone other than the patient. They are not subjective. For example, a measured temperature of 101 and skin rash are signs; fatigue is a symptom (see "Symptoms").

Specificity: In biologic testing, the percentage of people who test negative who in fact do not have the condition being tested for (see "Sensitivity").

Sterilization: A process by which all forms of microorganisms, including bacteria, viruses, and fungi, are destroyed.

Subclinical Infection: See "Asymptomatic Infection" and "Carrier."
Suppressor T Cell: A type of lymphocyte which helps regulate response. Also known as T8 and CD8 cells.

Surveillance: Continued examination of all aspects of occurrence and spread of disease or other health-related events that are relevant to the effective control of the disease or event (e.g., CDC Surveillance).

Symptoms: Any perceptible, subjective change in the body or its functions that indicates disease or phases of disease, as reported by the patient (e.g., itching, tingling, tiredness). (See "Signs.")

Syndrome: A pattern of symptoms and signs, appearing one by one or simultaneously, that together characterize a particular disease or disorder.

T Cells: See "Lymphocytes."

T4 Cell: See "Helper T Cell."

T8 Cell: See "Suppressor T Cell."

Thrush: An infection of the mouth (e.g., gums, tongue, mucous membranes) by the yeast Candida. Generally appears as a cream colored, curd-like growth. Such infection generally indicates that an individual is immunocompromised.

Titer (or Titre): A laboratory measurement of the amount (or concentration) of a specific material in something else. Antibody titer is a quantitative measurement of the amount of antibodies present in the blood--the titer may fluctuate (increase or decrease) during the course of an infection and during latency. Viral titer is a quantitative measurement of the amount virus present. As with antibody titers, the amount of virus present will increase or decrease depending upon when the sample was taken during the natural course of the infection.

Toxicity: The extent, quality or degree of being poisonous or harmful to the body. Toxicity studies determine the potential harmful effects (side effects) of a drug by careful clinical observation and extensive laboratory tests.

Toxoplasmosis (Toxo): A condition due to infection with Toxoplasma gondii, which may cause encephalitis. Seen frequently in persons with AIDS.

Viremia: The presence of virus in circulating blood, which implies viral replication.

Virucidal (Virucide): An agent that destroys or inactivates a virus.

Virus: An intracellular parasite that invades a cell and may disrupt or subvert normal cellular functions, causing the cell to behave in a manner determined by the genetic information contained in the virus.

Western Blot: A serologic test to detect antibody. To perform a western blot, viral antigens are separated according to their electrical charge and reacted with serum. If antibody is present an antigen-antibody complex forms a blot on the paper on which the reaction takes place. In testing for antibody to HIV, a western blot is more specific and accurate than the ELISA test.

This glossary is based on a publication of:

Wisconsin AIDS/HIV Program
Wisconsin Division of Health
1 West Wilson Street
P. O. Box 309
Madison, WI 53701-0309

APPENDIX C

AIDS & REHABILITATION

A RESOURCE GUIDE

AIDS & REHABILITATION: A RESOURCE GUIDE

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The AIDS* health crisis is impacting on rehabilitation professionals and organizations throughout the United States. Medical, vocational, residential and community-based service agencies receive referrals to serve persons who are HIV-positive or have symptoms of HIV-disease. Administrators, counselors and other professionals find that their everyday jobs now require knowledge of the disease and its consequences. As medical treatments improve, persons with AIDS are living long enough and are healthy enough to need the full range of rehabilitation services - not unlike the dramatic expansion of service for persons with head injury just a few years ago, and for spinal cord injured persons a few years earlier.

At the same time, rehabilitation organizations have to cope with the disease among their own staffs, and respond to the fears staff may have about working with HIV-infected persons as co-workers or clients. AIDS policies and programs thus must concern both service provision and appropriate response to staff needs.

The purpose of this publication is to provide both concepts and practical resources for rehabilitation professionals and organizations responding to the AIDS health crisis. It identifies some main challenges AIDS will present to rehabilitation in the 1990's, and offers some strategies and information resources for appropriate response.

"AIDS & Rehabilitation: A Resource Guide" was created through the collaborative effort of a number of individuals and organizations, as listed on the back cover. It is intended for use in conjunction with many information sources and technical assistance resources - both ones listed here and others that each user will need to identify. A wide variety of such resources are essential for problem solving in this complex, rapidly evolving field.

This publication also is intended to inspire creative collaborations between public and private rehabilitation organizations, as well as linkages with community groups such as AIDS service agencies. It is through both the diligent use of available resources and creative partnerships that responses to the demands of the AIDS health crisis will be found.

ABOUT AIDS AND REHABILITATION

Most rehabilitation professionals have now had some "AIDS 101" education, and virtually everyone knows some of the basic facts through the mass media. Yet the shortfalls in understanding and planning for appropriate action are great. Perhaps most disturbing, many professionals and institutions in the health and human services fields don't comprehend how serious these shortfalls are. More than just basic education is needed; the AIDS health crisis requires a coherent, organized response at a number of levels. As Helen Hayes, the great American actress, put it in her autobiography, "it's what you learn after you know it all that really counts."

For rehabilitation administrators and individual practitioners, practical challenges are now arising every day. Consider these scenarios:

- *One of your staff comes to you and confides that he has just been diagnosed with HIV disease. You know your health insurance won't cover many of his expenses, and your small agency will be disrupted if he has to take much time off. What do you do?*

Many professionals are now using the term "HIV disease" instead of AIDS; both will be used interchangeably here.

- *A mentally retarded client you've placed in a supported employment setting also has some symptoms of HIV illness. Both the job coach on-site and the employer need to be prepared for the time off from work and other accommodations this person may require. What do you do?*

- *A client who is known to be HIV-positive bites another client in a fight. The injured client's family might sue your facility if they knew the health status of the patient who bit their family member. What do you do?*

These are just a few of the issues rehabilitation professionals will have to confront in the 1990's. As the number of AIDS cases increases, public and private rehabilitation organizations throughout the United States must respond. This publication briefly overviews four of the most important challenges now facing the rehabilitation field regarding the AIDS health crisis: *changing attitudes, getting educated, mobilizing resources*, and *building programs and policies*.

By examining these challenges, we can frame a more comprehensive response to the AIDS health crisis in rehabilitation organizations and individual practices. Some organizations may already have excellent AIDS policies and programs, but even these can be improved. And many others are just at the beginning of a response.

"AIDS 101" Resources

- Alyson, S.(Ed.), (1988). You can do something about AIDS. *Contact*: The Stop AIDS Project, 40 Plympton St., Boston, MA 02118.

- Institute of Medicine, National Academy of Sciences (1988). Confronting AIDS: Directions for public health, health care and research. Washington, D.C.: National Academy Press.

- Shilts, R. (1987). And the band played on. New York: St. Martin's Press.

- Your local AIDS service agency should have informational resources. An excellent catalog of general AIDS education materials is available from San Francisco AIDS Foundation, 333 Valencia Street, P.O. Box 6182, San Francisco, CA 94101-6182. (415) 864-5855.

AIDS & Rehabilitation Basic Resources

- Backer, T.E. (1988). The future of rehabilitation in the workplace: Drug abuse, AIDS and disability management. Journal of Applied Rehabilitation Counseling, 19 (2), 38-41.

- Framrose, B. (1989) Coping with AIDS in the rehab environment. Rehabilitation Management, 2 (3), 57-63.

- Pivo, K.R. (1988). AIDS in the regional center system: Analysis and suggested guidelines. California Regional Center Journal, 1-8. Reprint information regarding this article can be obtained through the Dept. of Community Affairs, Harbor Regional Center, 21231 Hawthorne Blvd., Torrance, CA 90503.

- The Federally-sponsored Institute on Rehabilitation Issues for 1989 is developing a publication on AIDS for rehabilitation professionals, which will be available at the end of 1989. *Contact*: Research & Training Center, University of Wisconsin, Stout, Menomonie, WI 54751. (715) 232-1380.

- The American Academy of Physical Medicine and Rehabilitation and American Congress of Rehabilitation Medicine have initiated a Joint Task Force on AIDS and Rehabilitation. Over the next year, this Task Force will be conducting research, developing courses on AIDS for rehabilitation professionals, and preparing print publications targeted especially to rehabilitation professionals working in medical settings. *Contact*: Stephen F. Levinson, MD, PhD, Chair, NIH Department of Rehabilitation Medicine, 9000 Rockville Pike, Bethesda, MD 20892.

- The National AIDS Information Clearinghouse is a centralized source for information about AIDS services and resources. Information specialists with broad knowledge of AIDS issues provide direct access to this database. The Clearinghouse supplies free, government-approved HIV educational materials -- brochures, posters, point-of-purchase displays, etc. Selected materials are available in Spanish. *Contact*: P.O. Box 6003, Rockville, MD, 20850. (1-800-458-5231).

Fundamentals on AIDS in Rehabilitation and Workplace Settings

Based on guidelines from the Centers for Disease Control, the U.S. Public Health Service, the Surgeon General, the National Academy of Sciences, and the American Medical Association, persons involved with rehabilitation services for persons with AIDS or those who are HIV-positive should be aware that:

1. The AIDS virus (HIV) is usually fragile and harmless outside the body, out in the environment, in the air, or on environmental surfaces.

2. HIV is transmitted by: (a) sexual intercourse; (b) direct blood-to-blood contact; and (c) maternal transmission. HIV requires a moist, temperature controlled environment in which to survive.

3. There is no known risk of transmission to coworkers, clients or consumers in offices, schools, factories or construction sites.

4. AIDS is not transmitted through preparation of food or beverage.

5. Casual contact with saliva or tears does not transmit HIV. Normal amounts of saliva or tears do not have sufficient quantities of HIV to cause infection.

6. Food service workers need not be restricted solely due to HIV infection.

7. People with AIDS need not be restricted from using public telephones, equipment, toilets, or water fountains because of fear of transmission.

8. HIV is not transmitted by any ordinary daily contact related to living with or caring for people with AIDS.
9. HIV is not transmitted by any ordinary contact related to working with people with AIDS unless in special circumstances where sufficient contact with infected blood or body fluids can occur.
10. A person with AIDS is subjected to more danger in the workplace than coworkers or the public are subjected to the danger of AIDS because of his/her increased susceptibility to infection.
11. HIV is not transmitted by sneezing or coughing.
12. There is no medical or scientific reason to treat AIDS in the workplace differently than any other life-threatening condition.

(Adapted by Robert H. McDaniel, PhD, University of San Francisco, from Managing AIDS in the Workplace, 1988, by Sam B. Puckett and Alan R. Emery; and AIDS Policies and Programs for the Workplace, 1989, by Kathleen C. Brown and Joan G. Turner.)

THE FIRST CHALLENGE: CHANGING ATTITUDES

Attitude change about AIDS among rehabilitation professionals must precede progress on other fronts. We must accept that AIDS is a rehabilitation issue, that persons with AIDS have a disability and are entitled to the services we can render. The attitude that "if we acknowledge that AIDS is a disability, the slice of the pie for other disabilities will be smaller" is simply unacceptable, both for legal and professional reasons.

Also, we must accept the medical reality that AIDS has become a chronic rather than an acute illness. No longer is "there only one fate for an AIDS patient" - there are thousands of people living with AIDS today, many of them working and otherwise being productive members of society. Improved medical, psychosocial and community services have prolonged useful lifespan for a great many persons with HIV disease. Thus, rejecting persons with AIDS as "infeasible for rehabilitation" is not medically correct or professionally acceptable.

Changing attitudes means reducing the irrational fear and prejudice that still surrounds AIDS. In rehabilitation we know something about this - we constantly deal with many such emotions concerning other types of disabilities. Most surveys of attitudes about AIDS, in workplaces and in the general community, indicate that the most basic fear still is about casual contact. There are still significant percentages of people who would fear sharing a bathroom, a desk or a meal with a person with AIDS. But remember that only 20 years ago, people were concerned about catching cancer through casual contact in workplaces, so real attitude change is possible.

Fears and prejudices about AIDS are also rooted in attitudes about homosexuality, in more general resistance to dealing openly with sexuality, and in negative attitudes about drug abusers. These are increased if an individual has another type of disability as well. Because AIDS has claimed so many people in their prime years of life, it provokes unreasoning fears about one's own mortality - an extraordinarily difficult issue to wrestle with.

Irrational fears and prejudice exist among rehabilitation professionals as well - coworkers may require just as much help as clients, family members or employers. For instance, over the last several years, efforts have been made at a major university medical school to start an AIDS education program for nursing students. This program has never happened, largely because those in charge fear parents of nursing students storming their offices saying, "how dare you teach our innocent daughters about safe sex?" Pioneering research about the attitudes and skills of California physicians regarding AIDS indicates a direct connection between prejudicial attitudes and (a) inadequate (or incompetent) provision of AIDS education to patients and (b) physicians' sexual history taking skills.

Education, as well as interaction with persons with AIDS (PWAs), can make a difference. For instance, in an April 1989 national study of advertising industry workers, a much higher percentage of respondents said they would feel "comfortable" working alongside a person with AIDS if their company already had experienced at least one case of AIDS.

THE SECOND CHALLENGE: GETTING EDUCATED

Six issue areas that need to be considered in educational programming for rehabilitation settings are developed here: (1) The symptoms of HIV disease and how these affect the rehabilitation process; (2) HIV transmission and how to provide education for clients, families, staff, boards, employers and communities; (3) Legal issues as related to staff, clients and family members; (4) Costs and benefits issues; (5) Minority issues; and (6) Drug abuse and AIDS.

1. The symptoms of HIV disease and how these affect the rehabilitation process

The great degree of variability in symptoms of people with HIV infection has to be taken into account during rehabilitation and for job placement. This includes the neuropsychological symptoms which are so prevalent among persons with HIV disease. Just diagnosing these can be enormously complicated - is a belligerent and angry person that way due to AIDS dementia, because of preexisting psychopathology, or as a response to the very real problems of the disease... or all three? We have to learn about the many cognitive, motor and affective symptoms associated with AIDS if we are to serve clients properly. And we have to learn how these symptoms interact with the symptoms of other disabilities such as brain injury or cerebral palsy - an almost unexplored field of research.

Resources On HIV Disease Symptoms

- Psychology and AIDS. (1988). Special Issue of American Psychologist, 43(11).

- Buckingham, S.L., & Van Gorp, W.G. (1988). Essential knowledge about AIDS dementia. In Social Work, 33, 112-115.

2. HIV transmission and how to provide education for clients, families, staff, boards, employers and communities

In addition to resources for "AIDS 101" education for lay persons (a few of these were mentioned above), there are tremendous resources already available to employers concerning AIDS in the workplace. These resources can often be adapted to rehabilitation settings, as can materials for health care professionals dealing with issues such as resuscitation, biting and scratching clients, and other situations where there is some risk. The CDC has issued standards for health care professionals which can be used as a foundation (see Resources, below), but these may need to be augmented for specific types of rehabilitation facilities.

Resources On AIDS In The Workplace

- * AIDS in the Workplace, a five-part multi-media education package which includes the video "An Epidemic of Fear." *Contact*: San Francisco, AIDS Foundation, 333 Valencia St, 4th Floor, P.O. Box 6182, San Francisco, CA 94101.
- * Working Beyond Fear, a training program with both a video and live lecture presented by the American Red Cross, designed to educate businesses about AIDS. Contact your local Red Cross Chapter.
- * WAIDS, a computer bulletin board devoted to worksite AIDS policies and programs, including an extensive bibliography, sample employer policies, upcoming conference listing, and other information. Maintained by the Human Interaction Research Institute, the bulletin board may be accessed free of charge with any IBM-compatible microcomputer and a telephone modem. *Contact*: 213/825-3736.
- * AIDS: Corporate America responds, a 1988 overview of worksite issues and responses. Available from Corporate Relations, Allstate Insurance Company, Allstate Plaza, Northbrook, IL 60062.
- * Backer, T.E. (1988). Managing AIDS at work. Healthy Companies, 1 (2), 22-27.
- * Puckett, S.B., & Emery, A.R. (1988). Managing AIDS in the workplace. Reading, MA: Addison-Wesley Publishing Company.
- * AIDS education & business guide. *Contact*: American Foundation for AIDS Research, 40 W. 57th Street, New York, NY 10019.
- * National Leadership Coalition on AIDS. A group of Fortune 500 companies, medical professionals, foundations and community organizations. The Coalition operates the CDC-funded AIDS in the Workplace Resource Center. *Contact*: 1150 17th Street, NW, Washington, DC 20036.
- * One of Our Own, a 30-minute video with management guide and other print materials, which deals primarily with worker attitudes. *Contact*: Dartnell Corporation, 4060 Ravenswood Avenue, Chicago, IL 60640.
- * HIV in the workplace; An employer response plan for HIV in the workplace; and Basic HIV infection control for general work settings. October, 1988. All three publications are available for $15.00 a set. *Contact*: Oregon Health Division, P.O. Box 231, Portland, OR 97207, (503) 229-5792.
- * Backer, T.E., & Crofford, B.J. (1989). AIDS in the workplace bibliography. Los Angeles: Human Interaction Research Institute.
- * Service Employees International Union (1988). The AIDS book: Information for workers. Washington, DC: Author.
- * Brown, K.C. & Turner, J. G. (1989). AIDS policies and programs for the workplace. New York: Van Nostrand Reinhold.

Protection Against Occupational Exposure To Hepatitis B Virus (HBV) & Human Immunodeficiency Virus (HIV)

As with all communicable diseases, there are precautions that need to be taken. Here are some specific preventative measures rehabilitation professionals should use when working with clients, when hands-on contact is required:

1. WASH YOUR HANDS. Gloves may be useful to protect hands where there will be excessive amounts of body fluid contact or where breaks in the skin occur.

2. Hands do not need to be gloved for handling client clothing and other articles that are not soiled. Hands do need to be gloved to touch the client's intact skin (e.g., backrubs).

3. Keep your hands away from mouth and face while working. Wash hands before eating.

4. People who do not have AIDS and HBV can use the same bathrooms as someone with the virus. As in any living situation good sanitary practices (not spilling excrement on toilet seats, etc. and cleaning the bathroom regularly) make it safe for everyone. Washing hands after use of the facilities is protective to others. Physical cleaning of surfaces actually visibly soiled with blood, fecal material, or other body secretions removes soil and disease-causing organisms. A good disinfectant for soiled surfaces is household bleach mixed with water (1 part bleach to 9 parts water). Bleach is also particularly useful on the shower floor to control the fungus which causes athlete's foot.

5. Dishes used by people with HBV and AIDS can be used by other people once they have been washed in hot soapy water. Allow to drain dry.

6. Wear disposable gloves when handling any secretions or excretions, especially blood. Avoid direct hand contact with blood.

7. When your clothing is likely to be in contact with secretions/excretions, wear a gown, lab coat or smock.

8. Use plastic bags to dispose of soiled tissues, dressings, bandaids, diapers, and soiled gloves. Close and secure the bag tightly when discarding.

9. Wash soiled linens and towels in a washing machine using the hot water cycle and detergent. Dry on high in dryer.

10. Diarrhea and vomitus: Using gloves, clean up client immediately rinsing soiled surfaces with soapy water. Put soiled linens in a plastic bag until ready to launder.

11. At the end of physical care, WASH YOUR HANDS. Use lotion on clean hands. (Clean hands will not contaminate lotion bottle.) Lotion is important to replace the natural oils removed by handwashing. Dry, chapped hands leads to open areas through which disease-causing organisms may enter. In addition, those areas may develop mild infections which could be transmitted to the clients.

(Adapted from North Bay Rehabilitation Services, San Francisco, CA)

Rehabilitation Resources

- AIDS and the deaf community: Deafpride Advocate, Spring 1989, entire issue. *Contact*: Deafpride, 1350 Potomoc Avenue, SE, Washington DC, 20003.
- AIDS: Training People with Disabilities to Better Protect Themselves. A training video and manual providing step-by-step instructions on how to teach people with developmental disabilities about AIDS. *Contact*: Young Adult Institute, 460 West 34th St, New York, NY 10001. (212) 563-7474.
- Kain, C. (Ed.). (1988). No longer immune: A counselor's guide to AIDS. Washington, DC: American Association for Counseling and Development.
- Perspectives. An in-house training program designed to deal with AIDS in the workplace, including a training manual with trainer's guide, audio tapes and pre-assembled trainee packet. *Contact*: Milt Wright & Associates, 17624 Romar St., Northridge, CA 91325. (818) 349-0858.

Health Care Resources

- AIDS Professional Education Videotape Series. Includes "Overcoming Irrational Fear of AIDS: A Coping Strategy for Health Care Providers," "Psychosocial Interventions in AIDS," and "The Buffer Zone: The Mental Health Professional and the AIDS Epidemic." *Contact*: Carle Medical Communications, 611 West Park Street, Urbana, IL 61801.
- Centers for Disease Control (1987). Recommendations for prevention of HIV transmission in health care settings. MMWR: 36 (2S), 3S-17S.
- Gerbert, B., Maguire, B., Badner, V., Altman, D. & Stone, G. (1989). Fear of AIDS: Issues for health professional education. AIDS Education and Prevention 1(1), 39-52.

3. Legal issues as related to staff, clients and family members

Rehabilitation professionals in any setting need to know about AIDS as a protected handicap, about reasonable accommodation, employment discrimination and other issues - both for staff and for clients. AIDS is being treated as a disability by the courts and by such agencies as Social Security - more than 42,000 PWAs had received SSI or SSDI benefits by the end of 1988. Sections 503 and 504 of the Rehabilitation Act of 1973 also clearly apply, as do various state or local ordinances.

CDC guidelines recommend no employment restrictions for employees with AIDS. The Occupational Safety & Health Administration (OSHA) Guidelines on safe workplaces also apply - and court cases say refusal to perform job duties where there does not seem to be risk justifies firing.

Rehabilitation organizations are also employers, and must deal with many employment-related legal issues. One is workers who refuse to serve a client with AIDS or work alongside someone who is HIV positive. The legal interpretations about co-workers and casual contact are now fairly clear, but with regard to clients whose physical condition or behavioral problems may pose some risk, some issues have yet to be resolved.

Another area of concern is confidentiality issues for both workers and clients regarding HIV status. For instance, what does confidentiality mean for a PWA who is also mentally retarded or has a brain injury, or severe mental illness?

A third area is insurance benefits questions, such as extension of benefits under COBRA, or maintenance of SSI and SSDI benefits (especially health insurance coverage) during periods of employment (including how to "massage the system" to take advantage of structures such as the trial work period, so that persons with AIDS can have the psychological and practical benefits of working without risking their benefits).

A fourth area is new aspects of workers compensation - for instance, a worker who became HIV-positive after receiving a blood transfusion required because of surgery for an industrial injury.

Finally, rehabilitation organizations must deal with a host of issues regarding AIDS testing - from staff who demand that clients be tested to those who ask that the organization pay for voluntary testing for staff.

All of these issues will almost surely require legal review by your organization, at the federal, state and local levels.

Resources on Legal Issues

- AIDS and Persons with Disabilities: Legal Issues and Resources is a Federally-funded project intended to help overcome barriers (discrimination) to services for persons with developmental disabilities, often children, who are HIV-positive. Resources include (1) a report on legal issues affecting persons with developmental disabilities; (2) guidelines and model procedures to protect confidentiality; and (3) a computerized data base on AIDS. *Contact*: Sharon Rennert, ABA Commission on the Mentally Disabled, 1800 "M" Street, NW, Washington, DC 20036. (202) 331-2282.

- Albert, P., Graff, L., & Schata, B. (Eds.), (1988). AIDS practice manual: A legal and educational guide. San Francisco: National Gay Rights Advocates and National Lawyers Guild AIDS Network.

- Banta, W.F. (1988). AIDS in the workplace: Legal questions and practical answers. Lexington, MA.: Lexington Books, D.C. Heath and Company.

- DREDF -- Disability Rights Education and Defense Fund, Inc. 2212 Sixth St., Berkeley, CA 94710. *Contact*: Linda D. Kilb, staff attorney, (415) 644-2555, (TDD) 644-2629.

- The National AIDS Information Clearinghouse, 1-800-458-5231, can provide information on legal referrals.

- Employment Law Center of the Legal AID Society of San Francisco has a special AIDS and employment project dealing with workplace related issues. 1663 Mission St., Suite 400, San Francisco, CA 94103. (415) 864-8848.

- Gostin, L.O. (1989). Public health strategies for confronting AIDS: Legislative and regulatory policy in the United States. In Journal of the American Medical Association, 261(11), 1621-1630.

4. Costs and benefits issues

While costs of medical treatment for AIDS are going up as the number of cases increases -$3.5 billion is estimated in 1989 - average costs are going down because there is less in-hospital care. As better treatments prolong life, rehabilitation costs, including vocational rehabilitation, also go up. These developments are happy in some ways, and problematic in others. Health insurance for persons who are HIV infected but asymptomatic is becoming increasingly difficult to get. Rehabilitation agencies and professionals will need to know about such costs and benefits considerations both for the organization and the clients it serves.

Resources on Costs And Benefits Issues

- Geisel, J. (1989) AIDS claims soar, but still fraction of total: Survey. NARPPS News, 11 (1), 28-29.
- Fruen, M.A. (1988). AIDS: A looming financial commitment. In Business and Health, 5 (3), 24-27.

5. Minority issues

There are major differences between racial and ethnic groups about health, death/dying, sexuality and communicating about all these issues - all of which enormously complicate the already complicated business of AIDS education. This necessitates culturally-sensitive programs, which we must consider for both staff and clients. The situation is further complicated by the predominance of blacks and hispanics in the current ranks of AIDS cases, especially among women and children.

Resources on Minority Issues

- Blakeman, R., McCray, E., Lumb, J.R., et al. (1987). The incidence of AIDS among blacks and hispanics. Journal of the National Medical Association, 79(9), 921-28.
- De La Cancela, V. (1989). Minority AIDS prevention: Moving beyond cultural perspectives towards sociopolitical empowerment. AIDS Education and Prevention, 1(2), 141-153.
- Guinan, M.E. & Hardy, A. (1987). Epidemiology of AIDS in women in the United States. Journal of the American Medical Association, 257(15), 2039-2042.
- Rogers, M.F. & Williams, W.W. (1987). AIDS in Blacks and Hispanics: Implications for prevention. Issues in Science and Technology, 3 (3), 89-94.
- Schinazi, R.F. & Nahmias, A.J. (1988). AIDS in children, adolescents and heterosexual adults: An interdisciplinary approach to prevention. New York: Elsevier Science Publishing Co.
- The Centers for Disease Control have a special Minority Information Packet available on request. *Contact*: The Department of Health and Human Services, Public Health, Centers for Disease Control AIDS Program, 1600 Clifton Road, Atlanta, GA 30333. (404) 639-2076.
- Multicultural AIDS Resource Center helps community-based organizations with AIDS education and prevention training, focusing on issues regarding people of color. Pamphlets are available in different languages. *Contact*:

1540 Market St., San Francisco, CA 94102. Within California, call (800) 545-6662. Outside of CA., call (415) 861-2142.

6. Drug abuse and AIDS

The largest category of new cases of AIDS now is among inner-city IV drug abusers. As these persons present for rehabilitation services, we will be required to deal with the additional challenges drug abuse presents. A parenthetical note for AIDS education: a great concern now amongst educators is the lack of attention to non-IV drugs, including alcohol, as risk factors. Any type of substance abuse lowers impulse control, which increases the chance of risky behavior, whether unsafe sex or subsequent injection of drugs.

Resources on Drug Abuse And AIDS

- Des Jarlais, D. C. (1988). Policy issues regarding AIDS among intravenous drug users: An overview. AIDS and Public Policy Journal, 3(2), 1-4.
- Keeping hope alive: Proceedings of the American Medical Society on Alcoholism and Other Drug Dependencies Forum on AIDS and Chemical Dependency. (1988). *Contact*: Manisses Communications, 3 Governor St., P.O. Box 3357, Wayland Square, Providence, RI 02906-0357.
- Turner, C.F., Miller, H.G., & Moses, L.E. (Eds.). (1989). AIDS: Sexual behavior and intravenous drug use. Washington, D.C.: National Academy Press.

THE THIRD CHALLENGE: MOBILIZING RESOURCES

Within the rehabilitation community, new service programs and materials are emerging all the time. For instance, several cities now have publicly-funded AIDS education programs for their deaf populations (see description below). Programs are proliferating for developmentally disabled persons as well (one such program is described below). And many rehabilitation organizations have some type of AIDS education for their own workforces.

As a result, if an organization or individual is looking to set up some sort of AIDS response program, it may be possible to identify a somewhat similar program already ongoing in the same geographic area. A site visit or even telephone inquiry can provide many ideas for transfer and adaptation.

Program development therefore should begin by surveying locally available resources. The nearest AIDS community services agency may be the right place to start, since this entity may have knowledge of what rehabilitation-specific programs are in the community (on the other hand, some community-based service agencies know very little about rehabilitation, and there may be an important opportunity to provide some education about rehabilitation concerns).

Supported employment programs have been dealing with both the attitudinal problems and work accommodations needed for very severely disabled people to be employed in regular workplaces. Many of the methods developed for these programs could also be used for supporting employability of persons with AIDS - e.g., a job coach dealing with a worker's symptoms of AIDS dementia, or filling in on the job itself when the worker is absent without warning because of the medical variability of the disease. Also, job seeking skills training workshops can be adapted to help persons with AIDS learn to present their disability in positive terms, and to deal directly with concerns about their ability to contribute productively to the workplace.

Examples of Rehabilitation-Specific Programs

- AIDS Education for the Deaf - a nonprofit agency which provides peer counseling, a TDD service, captioned videotapes and other services for AIDS education, prevention and services in the Los Angeles deaf community. *Contact*: Heidi Kleiger, AIDS Education for the Deaf, 8350 Santa Monica Boulevard, Suite 203, West Hollywood. CA 90069. (213/654-5942).
- Association of Regional Centers Agencies AIDS Education Project - funded by a grant from the State of California Office of AIDS, this program provides AIDS training for developmental services agencies, and providing information and support to AIDS agencies that may serve developmentally disabled clients. *Contact*: Ellen Fishman, Project Director, ARCA, 428 J street, Suite 410, Sacramento, CA 95814. (916/446-7961).

Resources on Resource Identification

- National AIDS Hotline, sponsored by Centers for Disease Control (CDC), Atlanta, GA. (800) 342-AIDS.
- National AIDS Network, 1012 14th Street, NW, Suite 601, Washington, DC. 20005. (202) 347-0390. Services include community and professional education, referrals to AIDS service organizations, directories and newsletters.

THE FOURTH CHALLENGE: DEVELOPING PROGRAM AND POLICY

Any organizational AIDS program needs to be based on strategic planning. The main steps are as follows:

(1) Get top management support to ensure needed resources.

(2) Create an employee advisory committee to help develop this program.

(3) Use community resources.

(4) Analyze worker and community attitudes and possible high-risk behaviors that will need modifying.

(5) Put the organization's AIDS policy down in writing.

(6) Modify benefits to ensure needed services for workers with AIDS and their families. The best and most cost-effective approach is likely to include case management.

(7) Modify the worksite if needed to protect the health and safety of all workers - including those who are HIV-infected.

(8) Get involved in community activities and fundraising. Be a good role model for employees who may decide to help.

The policies from which your program will spring - how you'll handle staff who are HIV-positive or have symptoms, how you'll deal with clients, etc. - are the essential starting place for any good program.

Citizen's Commission on AIDS: Ten Principles for the Workplace

1. People with AIDS or HIV (Human Immunodeficiency Virus) infection are entitled to the same rights and opportunities as people with other serious or life threatening illnesses.

2. Employment policies must, at a minimum, comply with federal, state, and local laws and regulations.

3. Employment policies should be based on the scientific and epidemiological evidence that people with AIDS or HIV infection do not pose a risk of transmission of the virus to coworkers through ordinary workplace contact.

4. The highest levels of management and union leadership should unequivocally endorse nondiscriminatory employment policies and educational programs about AIDS.

5. Employers and unions should communicate their support of these policies to workers in simple, clear and unambiguous terms.

6. Employers should provide employees with sensitive, accurate, and up-to-date education about risk reduction in their personal lives.

7. Employers have a duty to protect the confidentiality of employees' medical information.

8. To prevent work disruption and rejection by coworkers of an employee with AIDS or HIV infection, employers and unions should undertake education for all employees before such an incident occurs and as needed thereafter.

9. Employers should not require HIV screening as part of pre-employment or general workplace physical examinations.

10. In those special occupational settings where there may be a potential risk of exposure to HIV (for example, in health care, where workers may be exposed to blood or blood products), employers should provide specific, ongoing education and training, as well as the necessary equipment, to reinforce appropriate infection control procedures and ensure that they are implemented.

(Source: Citizens Commission on AIDS for New York City and Northern New Jersey)

Policy Resources

* The University of San Francisco's Rehabilitation Administration Program sponsored a July 1989 conference, <u>National Forum on AIDS in Rehabilitation</u>, which has produced policy guidelines in three areas: (1) general rehabilitation services for persons with AIDS (medical, vocational, residential, etc.); (2) community-based job placement or employment assistance for persons with AIDS; and (3) retaining/employing rehabilitation personnel with AIDS. *Contact*: USF, McLaren College of Business, Ignatian Heights, San Francisco, CA 94117. (415) 666-6333.

* <u>A Conference on Developmental Disabilities & HIV Infection</u> resulted in an April 1989 set of "Public Policy Affirmations Affecting the Planning

and Implementation of Developmental Services for Children and Adults with HIV Infection." *Contact*: American Association of University Affiliated Programs, 8630 Fenton St., Suite 410, Silver Spring, MD 20910. (202) 588-8252.

THE FUTURE

The future holds both some bright promise and some troublesome developments. Researchers in several settings are preparing trials for AIDS vaccines, and improved medical treatments are emerging all the time. On the darker side, it is clear from recent research that the next wave of AIDS cases will be among the very young - teenagers and college students, and this will have some sad but important implications for those of us conducting activities such as transition programs aimed at disabled teenagers. And AIDS will continue to be a disease of homosexuals, the poor and people of color. The stigma and other life challenges these people face will also make our task of rehabilitation more challenging. As the number of infants born with AIDS increases, this population also will place increasing demands on the rehabilitation system.

This document has mentioned a number of major organizations in the rehabilitation field that are currently developing programs or policies related to AIDS, and indeed this publication itself is sponsored by several highly visible organizations. Such involvement is likely to increase in the future, as the need for rehabilitation services by persons with HIV infection increases. Professional, governmental and regulatory agencies will need to work together with service organizations in both the public and private sector.

Ultimately, meeting the many challenges of the AIDS health crisis is a management issue for rehabilitation organizations of all sorts. In his book, THRIVING ON CHAOS, Tom Peters identifies an essential trait of successful managers in both public and private organizations. That trait is resiliency, the ability to accept and respond to the complexity and challenge of constant change. This capacity is certainly needed to cope with the challenges of AIDS - mixed with other challenges of rehabilitation for the 1990's.

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The Human Interaction Research Institute, a nonprofit center for research on organizational change and health services, has since January 1987 been conducting research and policy studies on AIDS in the workplace. Many of the resources presented have emerged from this program. Further information is available by contacting the Institute at the address given on the front cover.

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