Regaining Lost Abilities:  
The Prospect of Returning to Work  
Michael Bettinger, PhD, MFCC

While some people with AIDS have continued to work throughout most of the course of their illness, others have retired because of the complications related to HIV infection. With the success of combination therapy and the protease inhibitors, many people with HIV disease have regained lost abilities, and a once rare question has become common: “Should I return to work?” This prospect involves a host of practical questions, but it also raises psychological issues related to the meaning of work in a person’s life, the changes in perspective that follow the adjustment to a life-threatening disease, and a person’s relationship to the future.

For most people, work is important for reasons beyond financial well-being. Along with gender, ethnicity, and sexual orientation, it is one of the primary ways people identify themselves. “What do you do (for a living)?” is almost always one of the first questions people ask each other in social situations, not simply because it is an easy way to break the ice and offer topics for continuing the conversation, but also because the answer provides a short-hand for each party in the interaction to define the other parties. At the end of one’s life, obituaries usually note three things in the headline: the name of the deceased, his or her age, and what kind of work he or she did.

Work is central to self-image and self-esteem, and is one of the basic marks—perhaps one of the defining conditions—of adulthood. In the United States, with the exception of those over 65 and those raising children, adults are presumed to have jobs. And as the recent debate over welfare reform suggests, American society does not look kindly upon those who do not have jobs for which they get paid.

To be disabled is to be considered incapable or less able to work and therefore ineffective. Mental health professionals have long regarded work as a form of therapy for people with disabilities, because working, even in a low-status profession, helps endow an individual with a sense of accomplishment and the feeling that he or she is not only a part of the greater adult community, but also a productive member with an identity beyond that of “patient.” This shift in identity enhances self-esteem and often alleviates symptoms of depression.

Disability and the Return to Work

For adults who find themselves unable to work due to the effects of HIV infection and for those who now have the opportunity to return to work, there are psychological and practical, as well as financial consequences, that blend with and reinforce each other.

Most fundamentally, retirement because of disability often damages self-image and self-esteem, especially if it occurs at a time of life, in early to mid-adulthood, when a person would not have expected to face such limits. While peers continue to be active and productive, a person disabled by HIV disease may not only lose the identity of a worker but also see him or herself as essentially defective. For a person with a long-term disability, it may take several years to grieve this loss and to mitigate potentially concurrent symptoms of depression before he or she adjusts to the circumstances, forms a new self-image, and bolsters self-esteem. Until recently, most people with HIV disease have not had the time to make psychological adjustments beyond con-
Over the past year, there has been a substantial decline in demand for a monthly disability workshop run by the AIDS Health Project (with AIDS Benefits Counselors) in San Francisco. Some months, as few as three people show up for a forum that once drew as many as twenty.

In response, AHP has conceived the workshop, alternating from month to month between the usual focus on how to decide about, apply for, and use disability benefits, and a new focus on how to adapt to renewed ability, make career decisions, and negotiate retraining and returning to work.

This programmatic revision is a tiny indication of the most significant psychosocial change since the beginning of the epidemic. Up to now, AIDS has been defined by debilitation, the most readily observable sign of HIV progression. Death itself is certainly the most powerful reminder of AIDS, but even for those of us who have watched many friends die, death is an event that happens to a person once. Disability, however, is a process that assaul ts him or her every day. While the resurrections “from the dead” characteristic of the current treatment success are cause for pure and absolute amazement, they are only the prelude to the return of ability, a story that is experienced not in a single moment but which is repeated in every moment.

Accompanying this change are a host of practical concerns related to disability benefits, employment rights, and job hunting, concerns that Betty Kohlenberg addresses in this issue of *FOCUS*. But, the change also challenges the ways in which people with HIV think about their time, their values, and themselves.

**The Taint of Disability**

In his article in this issue of *FOCUS*, Michael Bettinger observes that in work-oriented societies, disability is tainted. Not working means many things—none of them affirmative—ranging from not producing or contributing to not being self-reliant to not being “normal.” These judgments reflect the values that define American culture and the cultures of many other societies.

Many people with HIV disease have transcended these values and the devaluation that comes with disability. Adjusting to a threat to life has meant learning to live in the moment, offering many people with HIV disease the insight to buck traditional work-focused conceptions of self-worth and achievement.

It is ironic that treatment success may force many people who have come to terms with living with HIV to reconsider hard-won psychological adjustments. Suddenly, the tide of culture pushes them away from living in the moment toward living for the future and perhaps for a distant future. Suddenly, the future is not about the probability of decline, but about the possibility of continued well-being.

**Moments of Time**

The task of considering the future may be an unfamiliar luxury for both counselors and their clients with HIV disease; it is also a weighty responsibility. Integrating treatment success requires attention, intention, and planning.

The challenge extends beyond the individual, however, and once again, it is crucial for mental health professionals to consider the implications of change on communities. Where communities hardest hit by HIV have sometimes broken along the fault line between seropositive and seronegative, treatment success is now revealing potential fractures among three groups: seronegative people, seropositive people who have regained ability and are improving, and seropositive people who remain disabled and whose health may be declining.

By disturbing an established order, times of great change present opportunities to reconceive ways of living that once seemed fixed. Now is the time to anticipate the broader effects of treatment success and to work toward reconfiguring a community that leaves no one group isolated. The implications of this change are substantial and will affect both prevention and support strategies for the foreseeable future.
These feelings may be fed by the practical challenges of dealing with resumes that are no longer so impressive and with professional skills that are no longer up-to-date. In addition, individuals re-entering the market at the same level they had been at when they stopped working, may now be competing for jobs with people who are younger than they are; our age-conscious society may not only make them less employable but also raise anxieties about aging (something people with symptomatic HIV disease have up to now rarely considered). In this area at least, people with HIV disease share some of the challenges faced by women returning to the work force after an absence for child-rearing.

Being disabled can lead to severe economic problems and concerns about money that can only divert attention away from or exacerbate the psychological challenges of confronting the future as an able person. A person with HIV disease may have “spent down” life savings, cashed in retirement plans, maxed out credit cards and life insurance policies, and sold personal possessions. Being disabled and anticipating a shortened life span, a person with HIV disease may have adjusted to these conditions and to receiving government support.

But when envisioning a normal life span, this financial instability can be frightening and heighten anxiety about the decision to return to work and the process of job hunting. For some people, a “clean slate” may be inspiring, but for most, having let go of the means and form of a previous life becomes unsettling in the context of extended life. Adding to this confusion is the uncertainty about whether health recovered by combination therapy will be permanent and by the fear that working will mean that disability income will be lost forever.

Finally, many people disabled by HIV disease have become used to a different way of life: a greater control over time, a slower pace and more adaptable schedule, the absence of the dysfunctional interpersonal “dramas” that arise in every work setting, and in our work-crazed society, a healthier balance of work and rest. For some, adjusting to disability, uncertainty, and a threat to life also nurtures clarity about what is important and what is unimportant, a deeper understanding of the preciousness of life, and a desire to live in the moment.

This change in perspective is often reflected in terms of work and career. So it has not been unusual for a lawyer with HIV disease to return to school to become a therapist or for a business person to become an artist or for an artist to become a teacher. But recovering health, regaining ability, rejoining the work force, and undertaking activities previously deferred may end this way of living, transporting a person with HIV disease back to where he or she was before becoming ill. Further, staying in or returning to the job a person previously held can, under these circumstances, lead to feeling trapped, frustrated, and disappointed.

Adapting to Change

Mental health providers can help clients who are considering a return to work by seeking to understand the practical and emotional tasks they face and by helping them sort through the conflicts inherent in undertaking these tasks. Part of this process is psychological and part is practical. To deal with the practical aspects of resuming a career or training for a new one, providers should refer clients for vocational counseling. To approach the psychological issues, clinicians can begin by asking clients to explore the meaning of working (or not working), concentrating, in particular, on self-image and self-esteem and the emotional issues that make returning to work difficult. Thus, for clients who want to return to work, the psychological task is to redefine themselves as workers, acknowledging but disengaging from the image of themselves as being disabled.

Despite a natural capacity to adapt and readapt, clients are likely to take comfort in the organization of their lives around HIV disease and to have difficulty changing this perspective. A similar phenomenon is seen among recently released prisoners who have a difficult time adapting to life outside of prison. Some commit other crimes or violate parole in order to be sent back to the familiar world of incarceration. In this way, some clients with HIV disease may find it difficult to readjust to a world focused beyond medical appointments, medication schedules, and other HIV-related activities. They may want to change, but may not want to have

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to act or be different, experiencing difficulty letting go of what they have become used to, even when the familiar is painful.

Any significant change in a person’s life, including a positive one, brings up feelings of loss and a need to grieve for what has been lost. In this case, a world organized around HIV disease and the self-image as a disabled person. To successfully grieve a loss involves forming a new relationship with what has been lost, whether this is a person who has died, or, as in this case, an illness that is no longer what it was.

With this loss, clients often experience symptoms of depression or act out in order to prevent depression. To make up for lost time, they may express a sense of urgency concerning deferred life activities. The life partner a person never had, the forgotten sex life, the trips never taken, the house never purchased, the books never read, the family relationships never repaired may all resurface, and with a vengeance. Also, since improvement in health rarely occurs without some setbacks, clients who experience HIV-related symptoms or infections, may emotionally regress to a “disabled” mentality for a period of time. Finally, regaining ability is likely to be complicated by survivor guilt, which may lead clients to act in ways that threaten their survival.

Throughout this process, clients may question the value of old ways of living, including ones they are about to re-engage. The experiences gained during disability, of learning to live in the moment, for example, may help clients devise new (and perhaps unconventional) ways of living that are better suited to long-term adjustment. For some clients, however, this process of questioning about the future may be a way of perseverating, of avoiding the difficult process of adjustment to new health and life.

Clinicians should heed such resistance, which may take many forms, and remain attuned to the pain clients may suffer as they grieve the loss of a way of living and negotiate new lives. Counselors should also seek to help clients reestablish a balance between living in the present and planning for a future. This might involve helping clients understand and retain what they value about living in the moment while, at the same time, defining long-term needs and strategies for satisfying them.

Conclusion

This time of change is exceedingly confusing for many people who are living with HIV disease. It is made more difficult by a society that is most comfortable with binary notions: one is either seropositive or seronegative, ill or well, with AIDS or without AIDS, able or disabled.

But these polar concepts are too limited for dealing with the new reality of HIV. There is a wider spectrum of illness and wellness than ever before, and as clinicians, we need to advocate for a broader range of possibilities, to support the confusion many of our clients are experiencing, and to work toward a “between”—a place where answers are not apparent but possibilities can be considered. To ensure that clients can make informed decisions about returning to work and considering the future, we need to encourage them to inhabit this place, even if only for now.

Authors

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References


It's Back to Work We Go: HIV and Re-entering the Job Market

Betty Kohlenberg, MS, CRC, ABVE

In the first years of AIDS, there was little talk about vocational planning. The immediate demands of opportunistic conditions usually precluded employment and the statistics discouraged planning for the future. Today, new antiviral drug combinations, earlier intervention, improved treatment for HIV-related conditions, and dietary changes are leading to longer periods of good health for people with HIV disease, time in which to think about returning to work.

For people with HIV disease who have adjusted to the idea of dying, the prospect of living raises new fears and challenges in all aspects of their lives, including perhaps most prominently employment. Among these, risk and uncertainty may accompany the idea of returning to old jobs or adopting new occupations, explaining a complicated personal situation to employers and co-workers, or handling the complexities of disability benefits.

Coordinating Benefits with Working

The most common question about returning to work concerns earning income while maintaining disability benefits and medical insurance coverage. An essential first step toward job reentry is to clarify the amount and type of earnings allowed by current providers of disability income.

People receiving Supplemental Security Income (SSI), the federal benefit for people with disabilities who have very low incomes, may continue to receive a portion of their SSI payment while working if they are still disabled; however SSI payments will decrease based on their additional income. To arrive at the adjusted benefit, the Social Security Administration subtracts from the current SSI benefit the first $65.00 of earnings in a month and one-half of the remaining sum. For example, if a person earned $550.00 in a given month, the Social Security Administration would subtract $65.00 plus $242.50 from the client’s standard monthly benefit of $640.00. The adjusted SSI benefit, which would also take into account some additional criteria, would equal roughly $400.00.

People receiving Social Security Disability Insurance (SSDI), the federal benefit for people with disabilities who have paid into the Social Security system five years out of the past 10 years of employment, may earn up to $500.00 a month and still receive their full monthly SSDI payment. The SSDI system will also allow unlimited income without impacting benefits to people who undertake a “work trial” of up to nine months. These months do not have to be continuous, and any month in which a person earns over $200.00 is considered to be a work trial month.

People with HIV disease who have Long-Term Disability (LTD) benefits from private insurers should review their policies to clarify terms of coverage. Commonly, long-term disability policies cover the first two or first five years following disability. After this initial period, benefits continue only if the disability prevents the individual from engaging in work in any occupation for which he or she is suited by The Body, AIDS and HIV in the Workplace. The Body Web Site. www.thebody.com.

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See also references cited in articles in this issue.
reason of education, experience, and physical capacity. In some cases, insurers may offer financial incentives for individuals to return to work or may fund rehabilitation efforts if they can predict that an insured individual might be able to return to work at his or her former income level.

Individuals returning to work may continue to receive Medicare coverage for up to 39 months. If the new employer offers group health insurance, an employee may attain this benefit regardless of pre-existing conditions, in many cases after a waiting period that may not exceed 12 months.

**Building Up to Work**

Medical professionals currently recommend that people who are using the new antiviral regimens return to work only after a period of six months of improved health. Because many people living with HIV disease receive fairly stable benefits, mental health providers should encourage clients considering reemployment to use this initial period of improving health as a time of careful exploration and to plan a gradual—rather than a premature—return to work. Since this may well be the first long-term vocational planning a person has ever undertaken, supportive counseling is critical.

A potential job’s time and energy demands may intimidate people with HIV disease. Sustaining stamina, managing stress, and keeping enough control over disease. Sustaining stamina, managing stress, and keeping enough control over medical professionals currently recommend that people who are using the new antiviral regimens return to work only after a period of six months of improved health. Because many people living with HIV disease receive fairly stable benefits, mental health providers should encourage clients considering reemployment to use this initial period of improving health as a time of careful exploration and to plan a gradual—rather than a premature—return to work. Since this may well be the first long-term vocational planning a person has ever undertaken, supportive counseling is critical.

The pre-vocational period is also an ideal time to explore new occupational areas and sharpen job-hunting skills. Taking vocational tests, developing interviewing skills, writing a new resume, going on informational interviews about occupational or career options, investigating training opportunities, and learning about employment rights—all focus attention on the future and on choosing and shaping a new life. Career counseling agencies, especially those who have expertise in helping people with HIV disease, such as Positive Resource in San Francisco or AID Atlanta’s Reconstruction program, can bolster this process by offering workshops, job referrals, counseling, and training programs.

**HIV in the Interview**

Some people with HIV disease cannot begin to imagine working until they figure out how to answer a prospective employer’s questions about their health status and the time they have been out of the workforce. Having and responding to HIV disease is a life-altering experience with profound emotional as well as physical effects. For many people, any discussion of the future, even about work, will naturally center on these issues.

Employment interviews, however, focus by law not on a person’s disability, but on his or her ability to perform the essential functions of a job. To keep the discussion centered on their skills and the job, people with HIV disease need to practice how to talk comfortably and positively about themselves, without undue emphasis on medical issues or the ways in which HIV has transformed their lives. Further, understanding their legal rights under the Americans with Disabilities Act: Making the ADA Work for You. Northridge, Calif.: Milt Wright Associates, 1990.

**References**


Correction

In the June 1997 issue of FOCUS, an editorial error led to an incorrect citation in “The History of Hope: The HIV Roller Coaster” by Michael Sherhoff. The quotation by Steven Schwartzberg, cited on page 5, should have read: Schwartzberg S. A Crisis of Meaning: How Gay Men Are Making Sense of AIDS. New York: Oxford University Press, 1996. We apologize for any inconvenience this error may have caused.
Disabilities Act of 1990 (ADA), as well as under state and local disability rights laws, leads to increased confidence in interviewing and in asking for reasonable accommoda-
tions once employed.

The ADA precludes employers of 15 or more employees from asking about the existence, nature, or severity of a person’s health conditions. Any medical examinations related to a job must take place after the job offer, be required for all entering employees, and target only job-related physical conditions consistent with the employer’s business needs.

Other anti-discrimination laws at state and federal levels cover people living with HIV. Section 504 of the Rehabilitation Act of 1973 requires that a person with a disability (a “handicapped individual”) not be excluded from participation in any program or activity receiving federal financial assistance, including employment, recreation, education, and transportation. It also entitles employees with disabilities to reasonable accommodation. The Family and Medical Leave Act of 1993 covers employees of employers with 50 or more employees with 5 or more employees and provides for 12 weeks of unpaid leave for medical or family rea-
sons. The California Fair Employment and Housing Act covers employers with five or more employees and precludes discrimi-
nation based on medical conditions, including HIV infection.

If possible, job applicants should avoid discussing medical issues; not mentioning a medical problem in a job interview does not preclude an employee from asking an employer to accommodate the impairment later. An applicant who can offer an explana-

Close It: End the discussion about medical issues, and move on to the more important subject of why you are interest-
ed in the job for which you are interview-
ing, why you are able to do the job, and how you have to have the skills to do the job. Finish up by explaining why you think you’d be right for the job and how you came to this conclusion. You might complete the discussion by saying: “. . . I’ve taken some computer classes. I was enjoying the number-crunching part, so I concentrated on spreadsheets and Excel. I got so good at it, the teacher used to ask me to help the slower students. I learned a lot about how the software works and how to fix problems.” This conversational transition should take you beyond the subject of your illness and toward the subject of the job, returning the discus-
sion to your skills and interests. A well-
told explanation can turn the description of a medical leave into a forceful and convincing story of initiative, resourcefulness, intelligence, and skill.

Conclusion

As a result of dealing with HIV disease, many seropositive people report significant changes in values and priorities regarding work. Not just a source of income or a time-filler, work must be a place in which they can exert control over stress and time demands. The ongoing uncertainty about life expectancy makes it important to find a work setting in which a seropositive person can feel connected, contribute to the community, or express his or her creativity.

Mental health practitioners can provide supportive counseling and values clarification to strengthen their clients’ abilities to integrate new conceptions of work into reality. Further, equipped with practical information about disability benefits, employment rights, training opportunities, and interview answers, mental health practi-
tioners can help their clients make complex decisions about whether, when, and how to re-enter the labor market and discover opportunities for life-enhancing work.
Recent Reports

Americans with Disabilities Act

Employers regulated by the Americans with Disabilities Act (ADA) must follow the same rules for psychiatric disabilities that they follow for physical ones, according to new government guidelines. Since most ADA regulations apply to all disabilities, the new guidelines offer insights relevant to an employee or job applicant with any disability.

According to the new regulations, a psychiatric disability is any mental or psychological disorder that “substantially limits a major life activity.” This includes many DSM-IV disorders, but specifically excludes substance abuse. A disorder may be a disability even if treatment, including psychiatric medications, mitigates its effects.

The ADA prohibits employers from asking before hiring any question that may “elicit information about a disability,” except if an applicant voluntarily requests “reasonable accommodation” or if an employer “reasonably believes” that an applicant will need accommodation. In such cases, employers may ask if applicants need accommodation and what measures would fulfill this need.

After making a job offer, an employer may ask disability-related questions and require a pre-employment medical exam only if the employer “subjects all entering employees in the same job category to the same inquiries or examinations regardless of disability.” If as a result, an employer bars or releases a person from a job, the employer must prove this action to be “job-related and in line with business necessity.”

An employee or someone acting on his or her behalf may at any time during employment request accommodation. He or she may make the request using “plain English,” and need not write it, mention the ADA, or use the phrase reasonable accommodation.

Vocational Rehabilitation for People with HIV
SSI-Vocational Rehabilitation Project, AIDS Administration, Maryland Department of Health and Mental Hygiene, Baltimore (unpublished description).

Historically, vocational rehabilitation programs have excluded seropositive people because they were considered terminally ill. As this perception changes, there is a need to provide education, training, and support to seropositive people who want to work. A Maryland program, staffed by counselors working exclusively with seropositive people, fills this void.

One of the project’s goals is to develop an HIV-specific disability assessment tool. Generic disability assessment tools usually include basic questions, for example, “Can you take a bus?” But simple yes/no answers obscure common HIV-related disabilities, such as weakness or fatigue. For example, a seropositive person, asked “Can you prepare your meals?”, may answer yes, even though all he or she can do is cook frozen dinners.

The Maryland project focuses on four groups of seropositive people. The first consists of people already receiving Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). Many in this group have improved health and want to return to their former jobs, but cannot because of demanding job duties. For example, fatigue may preclude waiting tables, or treatments that require staying out of the sun may preclude outdoor work.

People in the second group want to work but, due to HIV-related limitations, must continue receiving SSI benefits. The third group, the focus of the project’s “early intervention” effort, includes people who currently work but in environments that lead to a decline in health and to disability. Finally, people in the fourth group are ready to work, but either have no job skills or have never worked. In all of these cases, assessment identifies capacity to work, skills and skills deficits, training opportunities, and appropriate jobs.

Next Month

When the media have considered the dark side of combination therapy, they have focused on the possibility of transmitting HIV strains rendered drug-resistant by the failure to follow strict medication regimens. These discussions invoke the archetype of the poor, inner-city, “unreliable” drug user. In the August issue of FOCUS, Andrea Barthwell, MD, President of Encore Medical Group in Chicago, explores the myths and the truths regarding HIV-related treatment for substance users.

Also in the August issue, Luther C. Brock, Sr., Coordinator of Community Education and Outreach for the AIDS Community Research Consortium, discusses the successful HIV treatment of drug users in East Palo Alto, California.
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