With advances in HIV antiviral medications and subsequent improvement in health status, many people with HIV face the decision whether to return to work. This decision is complicated by the interplay of four sets of factors: medical, financial/legal, psychosocial, and vocational. These factors both pressure individuals to move toward work-related changes and raise barriers that keep people from identifying and meeting work goals. This article outlines a client-focused model for assisting people with HIV to consider and act upon decisions about work. Unlike vocational models, which define success in terms of the benefit to society—that is, removing individuals from government entitlement programs—this model asserts that success should be based upon improvements in life circumstance such as financial gain or an increased sense of well-being.

Four Phases of Considering Work

The client-focused model identifies four phases of considering work: Contemplation, Preparation, Action, and Resolution. While the process is non-linear, it typically starts with a perceived pressure for change by the person with HIV. This pressure may be internal, based, for example, on improved health, boredom, a desire for more income, or a wish for more meaning in life. External pressures may include increased living expenses, threats of eviction, changes in the structures of legislated benefits, or family expectations.

In responding to pressures to change, a person with HIV faces a sequence of decisions, each with related activities. These decisions define the first three phases in the client-focused model.

- Phase 1—*Contemplation*. Decision: Is any change feasible? Activity: Weigh pros and cons of changes.
- Phase 2—*Preparation*. Decision: What kind of change is best? Activity: Set a goal and make a plan to achieve it.
- Phase 3—*Action*. Decision: How do I achieve the goal? Activity: Implement and refine the plan.

During Phases 2 and 3, individuals may reconsider their decisions and return to an earlier phase of consideration. During any phase, individuals may defer the decision or choose not to make any change.

Phase 4, *Resolution*, is characterized by a reduction in the internal or external pressures that prompted the initiation of the considering work process. Among the possible resolution outcomes are: finding and adapting to a new work situation, deferring a decision to make a change in the work situation, deciding not to change the work situation and resolving the pressure to change through non-work means, or deciding not to change the work situation and accepting the current situation and pressures. In the case of a deferred decision or a decision not to change, a successful outcome might be to find means other than work to resolve the perceived internal or external pressures. These means may include reducing financial pressures by limiting expenses or increasing non-work related income—for example, by asking family for financial assistance—or by reducing psychosocial pressures such as boredom or loneliness by finding other projects or increasing social connections.

Facing the Challenge of Considering Work

Throughout the phases of considering work, clients may request assistance from a range of service providers, including physicians, employment professionals, benefits counselors, and mental health providers. Using the client-focused model is helpful in two ways: providing clients with a map to understand a process that may appear...
Work. Can’t live without it; sometimes, can barely struggle through it. Work can be fulfilling, even exciting, but it remains an often stressful pursuit over which we feel like we have little control.

In the mid-1990s, many HIV-positive people, buoyed by renewed health, rejoined the workforce. But for many people with HIV, the normal ambivalence about working is amplified a thousand times: living with HIV, even when it is “manageable,” can be a full-time job. Adding a paid job to the mix requires balancing antiviral treatment schedules and side effects with a 40-hour commitment, dealing with gaps in work history, facing potential employment discrimination, and taking on all the stresses that come with the commitments and human interactions of the workplace.

As Peter Goldblum and Betty Kohlenberg point out in this issue of FOCUS, government-funded vocational programs generally compensate providers based on the number of clients who get jobs rather than on the number who make decisions that best reflect their needs, desires, and abilities. The goal of limiting the burden of social programs on tax money is understandable, but like so many attempts to reduce costs, these programs may sacrifice long-term quality for short-term savings.

The promise of combination treatment has led to the perception not only that HIV may be manageable but also that it is easy to manage. While some people tolerate their medications well, many spend significant amounts of energy dealing with complicated regimens and debilitating side effects. That they even consider taking on a job while they are overwhelming; and helping other clinicians provide appropriate assistance.

Medical. Many people with HIV no longer trust their physical capacities or their stamina to be consistently available and have difficulty making the primary decision about whether any change is possible in their employment situation. They may require assistance in the contemplation phase to assess the medical feasibility of returning to work and to determine the impact of HIV on their physical capacity to work. Even after a decision to make a work-related change, the instability of improved health, difficult side effects, and challenging medication regimens may undermine efforts to return to work. During the action phase, medical consultation regarding management of medication side effects may be helpful. In the resolution phase, adjustment to new work schedules may interfere with antiviral treatment adherence, and clients may need support and guidance to develop strategies and motivation to maintain proper medication practices. They may also benefit from advocacy to help employers appropriately accommodate their medical needs.

Legal/Financial. Disability benefits and insurance structures also affect considerations about returning to work. In fact, the steps taken to return to work can be influenced more by the rules of governmental and private benefit systems than by workplace requirements. Methods and timing of regaining work-related skills (and of testing a return to work) are often shaped by complicated limitations on earnings, sometimes discouraging return to work efforts.

During the contemplation phase, clients often need information about the impact that returning to work will have on their benefits, including the risk of a formal review of disability benefits and a possible cessation of benefits. In the preparation phase, benefits issues may inform the selection of work goals, for example, finding employment with disability coverage. Clients may also need help understanding the benefits implications of potential jobs and locating appropriate job opportunities. Benefits considerations may affect the pace of returning to work during the action phase. In this context, a successful work-related outcome might include deciding to experiment with unpaid volunteer work or going to school prior to returning to work to avoid jeopardizing current benefits. In the resolution phase, if employment is started,
complex benefits regulations related to reporting income can lead to mistakes that can cause income disruptions. During this period, it is essential to continue documenting ongoing symptoms in medical chart notes to support the legitimacy of restarting disability should the employment experiment falter. Helping clients understand and apply their legal rights for adequate workplace accommodation under the Americans with Disabilities Act may also increase their chances for success in new work situations.2

Psychosocial. Psychological and social factors, including psychological functioning, motivation, and social support structures, affect all phases of the considering work process. Some people with disabling HIV are also unable to work due to psychiatric disorders. In these cases, both medical and psychiatric conditions must be assessed to determine feasibility of work. Other psychological phenomena may interfere with an individual’s ability and motivation to work, including fear, low self-esteem, depression, and anxiety.

In the contemplation phase, helping clients appraise their personal resources to cope with increased stress and understand the nature of available social support is essential. Providing clients with an overview of the client-focused decision-making model can make the tasks at hand clearer and less overwhelming. Providing positive role models of others who have successfully made work-related changes may increase client hopefulness. Individuals may need assistance in the preparation phase in selecting specific work-related environments taking into consideration their abilities to cope with the potential work demands. Setting short-term goals for exploring work options and reinforcing success will help clients gain a sense of self-efficacy.3

In many cases, individuals in the action phase are better served if work-related stress increases incrementally, thus enabling them to become more stress-resilient over time. Carefully monitoring emotional reactions and stress-related symptoms can assist clients to develop specific stress management techniques. Helping clients achieve their work goals in this phase may also require more active motivational techniques to confront fears and skill deficits. In cases where the resolution of the process to consider work includes returning to work, psychological adaptation may require reexamination of earlier expectations and assistance in coping with new work situations.

Vocational. Once a client makes the decision to return to work or change jobs, the major vocational challenge is choosing a job. Helping clients identify the right job goal is the hallmark of the preparation phase. For people with HIV, proper job selection is vital given that work is a major cause of stress, and stress can weaken health. Living with HIV may have changed a person’s work-related values, leaving him or her reluctant to return to unsatisfying occupations. Living with a disease in which little is under their control, many people with HIV value having a measure of control over the decision of whether and how they might work; exercising this control is essential to both physical and mental health.

Taking action to achieve a chosen vocational goal, requires knowledge and skill in confronting employment barriers. For example, after periods of disability, many people have employment history gaps that are difficult to explain to employers. Diminished physical capacity may narrow occupational options and require the acquisition of new work skills. Clients may also require counseling regarding fears about age discrimination and their abilities to learn new work skills and to compete with younger workers. This counseling may need to be continued through the transition back to work and into the resolution phase, during which clients may need further assistance regarding skill development and emotional support.

Conclusion

The client-focused model provides not only specific guidance for assisting clients, but also a philosophical approach that identifies a range of successful outcomes that can be incorporated into HIV counseling and vocational program design and evaluation. These outcomes take into consideration the unpredictable nature of HIV disease and HIV-related medicine. Ideally, the client-focused approach will influence policy discussions regarding new federal programs that provide incentives for people with disabilities to return to work.4 In this way, it can broaden the range of successful outcomes and make these programs more relevant to people living with HIV disease.

Authors

Peter B. Goldblum, PhD, MPH is Coordinator of the Considering Work Project at the UCSF AIDS Health Project, a program that provides psychosocial support services to individuals with HIV who are considering work.

Betty Kohlenberg, MS, CRC, ABVE has been in private practice as a vocational counselor in San Francisco for more than 20 years. Since 1995, she has been the vocational consultant to Positive Resource Center and is the facilitator of the Making a Plan (MAP) Program groups.
Classic vocational rehabilitation models implicitly assume that returning to work is a linear process of behavior change and skill acquisition, but experience in counseling people with HIV shows that the process of considering work is more organic, affected by the unpredictability of HIV and a variety of psychosocial and other challenges. To ensure that vocational counseling takes into account this complexity, the process must not only meet the special needs of clients with HIV, but also incorporate professional tools for counselors and counseling programs.

To help individuals consider employment or a future without employment, the Positive Resource Center, a San Francisco agency that provides employment counseling for people living with HIV, runs a group counseling program. This article reports on the outcomes of the first five cohorts of the Making a Plan (MAP) group program.

Challenges of Considering Work

According to the Client-Focused Model for Considering Work, people with HIV must confront issues regarding four interrelated factors when they think about returning to work: medical, financial/legal, psychosocial, and vocational. A review of these factors uncovers the range of impediments to the vocational planning process:

- **Medical**: lack of trust in physical capacity, unstable health, difficult medication regimens and adherence problems, benefit provider interference with physician-patient relationship, and lack of patient and physician knowledge about reasonable accommodations to help people with HIV succeed in handling work.
- **Legal/Financial**: complicated return-to-work rules, earnings limitations, threat of loss of essential benefits, major variations in rules for different benefit systems, and income reporting difficulties, including confusion on how to report overpayments and income gaps.
- **Psychosocial**: anxiety, depression, renewed life challenges, facing rejection, social stigmatization and discrimination, fear of work and failure, and loss of HIV community support.
- **Vocational**: difficulty identifying vocational goals and incorporating interests and values into job choices, lack of skills, gaps in employment history and knowledge about the labor market, lack of knowledge about legal rights, necessity for reasonable accommodations, potential employer discrimination, discomfort with interviewing and other employer interactions, ambivalence about HIV disclosure, and fear of competition.

Developing the Making a Plan Program

The Making a Plan counseling program offers HIV-positive people career counseling support to help them identify training and employment goals and plan for the implementation of these goals. From September 1999 through December 2000, the Positive Resource Center conducted five Making a Plan (MAP) groups with a total of 67 participants. The groups were open to all clients who committed themselves to attending eight, weekly, two-hour sessions.

Of the 67 participants, all but one were male. Their ages ranged from 26 to 56 years of age, with a mean age of 42. Their mean education was 15 years. Of the 60 participants who were unemployed, the time since last work ranged from one month to 16 years, averaging five years.

Clearinghouse: Work and AIDS

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Crystal S, Fleishman JA, Hays RD, et al. Physical and role functioning among...
Seven individuals had some form of employment. Of the total group, 58 were White, six were Hispanic, and three were African American. The Making a Plan groups focus on five areas: identifying barriers to employment; testing and interpreting vocational interests and values; making decisions about vocational goals; learning about informational interviewing; and researching labor market and training opportunities. In addition, they offer referrals in three areas: HIV-specific resources to overcome employment barriers; other Positive Resource Center programs, including resume writing, interviewing, and employment rights; and community resources such as self-employment support, computer training, and higher education. The groups are facilitated by a vocational counselor.

Weekly curricula are designed to identify each participant’s position with regard to each of the interrelated factors and to specify barriers to employment with the goal of creating a plan to overcome them. MAP activities specifically focus on employment, but the program supports non-employment outcomes that may evolve through the informed exploration of these barriers. Participants are expected to attend consistently, participate actively, follow through with assignments between meetings, and make and implement decisions.

To evaluate the efficacy of the Making a Plan program, the Positive Resource Center conducted two forms of evaluation: pre- and post-intervention survey analyses of outcomes and a post-intervention focus group. The evaluation was designed to identify the needs of participants for vocational counseling services; client-perceived barriers to returning to work in three areas (vocational, psychosocial, and legal/financial) areas; and ways in which the group counseling process had produced changes in client needs.

All 67 MAP group participants filled out the pre-intervention questionnaire at the beginning of their first meeting. Of these, 43 participants (64 percent) filled out the post-intervention questionnaire. Questionnaires surveyed three different issues: needs and concerns, perceived barriers to returning to work, and feelings. In addition, nine participants—who were demographically similar to the full participant group—offered additional evaluative data during the focus group.

**Needs and Concerns**

Initial MAP participant concerns focused on career choice, values, physical capacities and the anticipated stress of work. The desire for meaning in work was significantly stronger than concern about specific issues regarding job availability or the impact of earnings on the status of disability benefits.

Participants reported significant changes in needs and concerns over the course of the program. In the context of a vocational counseling program, the greatest effect was in areas that could be addressed immediately: the lack of knowledge or information about self and vocational processes, and related feelings. By the end of the program, participants experienced a decreased need for career planning help, an increase in the personal knowledge needed to choose a suitable job, a major increase in labor market knowledge, and an increase in confidence about job skills. Some concerns remained relatively unchanged by program participation, mostly in terms of anticipated problems. Among these were the stress of working while living with HIV, concerns about finding meaningful work, and worries about having the basic physical ability to work.

Interestingly, some vocational concerns—for example, the need for continuing help in choosing the right job or career—might have been heightened, perhaps due to an increased awareness of the desire and need for satisfying employment. This

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**Contacts**

Peter B. Goldblum, PhD, MPH, UCSF AIDS Health Project, Box 1312, San Francisco, CA 94143-1312, 415-476-7842, 415-476-3655 (fax), pgoldbl@itsa.ucsf.edu (email).

Betty Kohlenberg, MS, CRC, ABVE, Kohlenberg & Associates. 1255 Post Street, Suite 943, San Francisco, CA 94109, 415-665-6902, 415-576-5304 (fax), bettyk@dnai.com (email).

See also references cited in articles in this issue.
phenomenon suggests a need for ongoing support extending even after the start of employment.

Perceived Barriers and Emotional Changes

Overall, group employment counseling reduced vocational barriers while increasing motivation for more counseling and assistance during the considering work process. At the end of the program, there were three statistically significant changes: participants were more sure about what kind of jobs they wanted, more competent in discussing work history gaps, and more aware of their needs for benefits information. Participants also indicated that they were aware of employment barriers and the related needs to acquire computer skills, to update job skills, to handle stress, and to learn to interview. Health-related concerns remained stable throughout the program.

Affective states are often influenced by issues unrelated to employment, making it difficult to determine how MAP participation altered them. Anxiety and apprehension were the most prevalent feelings both before and after the program, although participation resulted in statistically significant reductions in feelings of being unprepared, hesitant, and anxious. Participants also reported feeling more capable and less stressed and pressured, although the program did not specifically focus on creating these changes in affect.

The Effects of Making a Plan Groups

Overall, MAP participant concerns can be divided among the factor areas defined earlier. Within the vocational factor, participants were concerned about choosing the right job, fitting the job to their values, interviewing, and being accepted by employers. Within the psychosocial factor area, they were concerned about anxiety and stress, and within the financial/legal factor area, they were concerned about benefits, medical insurance, and income. In addition, medical and financial factors were strongly related to the vocational process, that is, instability in these factors interrupted vocational activities.

Both the questionnaire results and the focus group findings suggest that the MAP process can respond to some but not all of these concerns. First, the group counseling process (and its follow-up activities) can have a significant practical effect by increasing vocational and other activities, most prominently supporting the process of choosing a job goal and the ease of talking about work history gaps.

Second, while the process had less effect on psychosocial concerns, it was associated with an improved emotional state, that is, decreased hopelessness. In addition, participants tended to report reduced anxiety and depression, a generally more positive self-evaluation, and an increase in support from service organizations and other support systems, in spite of a perceived worsening of finances and health. The impetus for these changes was likely the heightened sense of activity, engagement in future planning, and hopefulness that accompanies vocational progress and control.

It is notable that even with strong initial indicators of employability—participants tended to be older than 40 and so were covered by age discrimination laws, had more than a high school education, and had significant amounts of work experience—participants experienced a wide variety of outcomes beyond getting a job. These included returning to school, moving out of town, and deciding not to work due to declines in health or continued indecision. The freedom to reach any decision was clearly stated in the introduction to the process and this openness was explicitly valued by participants.

Conclusion

With enormous swings in health status and unpredictability of medication effectiveness, people with HIV need the flexibility to identify whatever activity level and employment status will help them maximize their health and quality of life. Choices other than immediate employment—including delaying or deferring work re-entry—can be valid, positive, and successful outcomes of vocational planning programs. People with HIV have major concerns about returning to work and perceive a wide variety of barriers to employment that can be resolved or mitigated through a group counseling process facilitating a successful return to work.

Authors

Betty Kohlenberg, MS, CRC, ABVE has been in private practice as a vocational counselor in San Francisco for more than 20 years. Since 1995, she has been the vocational consultant to Positive Resource Center and is the facilitator of the Making a Plan (MAP) Program groups.

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Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
Recent Reports

Concerns about Returning to Work

In a survey of people living with HIV, unemployed participants were hesitant about workforce participation due to fears about job skill decline, loss of health care coverage, and problems with HIV drugs.

Researchers surveyed 478 participants at two Arizona HIV clinics. Respondents had a mean age of 39.7 years, were mostly White, non-Hispanic males, had publicly funded health coverage, and had been living with HIV for an average of seven years. Sixty-four percent of the respondents had attained an educational level of at least vocational school, community college, or some college, while 21 percent had a high school diploma or GED, and 15 percent had not attained a high school diploma. About 40 percent were working either full- or part-time, 10 percent were students, retirees, or homemakers, and 50 percent were unemployed. Respondents who were younger had better health status, had a higher CD4+ cell count, and had at least a high school diploma or GED, and were more likely to be employed.

Unemployed participants were significantly more likely to have heightened concerns about work than respondents with jobs. In addition to concerns about job skills and health care, they were worried about stress, gaps in employment history, exposure to other people's germs and infections, discrimination in the workplace, and requalification for public benefits if a participant were to lose a job. The requalifying process could result in a delay of necessary HIV-related drug therapy. Among employed participants, the most common concern was "excuses to cover up for health care needs," followed by concerns about health care and life insurance benefits.

Rebuilding Life after Facing Death

The experience of living with HIV after facing imminent death can be characterized in terms of three major themes—back to living, realizing life has changed, and readjusting life—according to a qualitative Canadian study. A conceptual map can be used to illustrate the progression of these themes.

Researchers interviewed seven men between the ages of 40 and 45 years on combination treatment at a Montreal immunodeficiency clinic. At the time of the first interview, the men had been diagnosed HIV-positive for an average of 7.6 years and had been living with an AIDS diagnosis for between 1.4 and 5.6 years. Prior to the initiation of combination treatment, each participant had been told by his physician that his death was imminent. All experienced significantly improved health following antiviral treatment.

Before each participant began combination therapy, most of the participants had taken steps, including ceasing employment, to prepare for imminent death. Some had undergone out-of-body experiences, a flooding of forgotten memories, and the desire for death. However, after starting combination treatment, each experienced renewed energy, weight gain, and decreased viral load, leading to a belief that he was going to live.

Participants next recognized that they were living within two realities. They experienced a new sense of uncertainty about the long-term effectiveness of treatment, compounded by the paradox of appearing healthy while still living with AIDS. As part of this process, they realized how small their worlds had become as they had prepared to die; renewed energy allowed them to shift focus beyond physical health to other needs and to the world around them.

Finally, participants realized that they had to readjust their lives by changing their daily routines. They redefined themselves in terms of how they were functioning in the present, not in terms of what they used to be and their relationships to others. They also tried to reintegrate into society and look into the future. All seven men did this by returning to work or
Many stated that they derived personal satisfaction from work and that returning to work was one of the most significant tools for reintegrating themselves into the community. They said, however, that some employers did not provide programs to assist them in finding work that accommodated their needs, and that their physical limitations and treatment regimens interfered with their ability to work.

**Assisting People to Return to Work**


A qualitative study of unemployed people with HIV found that all participants believed that work would return a sense of normalcy to their lives. Specific reasons for wanting to return to work fell into three categories: psychological and emotional benefits, financial benefits, and the social and physical nature of work.

Study participants were 30 randomly selected clients from the AIDS Project Los Angeles who answered questions regarding issues such as HIV disclosure decisions, health concerns, health insurance considerations, and job discrimination. The majority of the participants were receiving some form of government-sponsored income assistance. The mean age of participants was 39 years (ranging from 21 to 57 years). Time unemployed ranged from less than one year to 13 years. Overall, participants reported being in a good state of health based on a health status scale.

Participants cited a range of obstacles to returning to work, the most common of which were health and medical concerns that caused uncertainty about short- and long-term health. Another significant concern was finances and medical benefits. Many participants feared that they would receive inadequate medical coverage from new employers. In addition, participants experienced fear, anxiety, shame, and low self-esteem associated with concerns about disclosing their medical status to coworkers and exposing co-workers to HIV.

Participants had a general perception that employers were not likely to be sensitive to HIV-related issues, and this raised further concerns about stigma, prejudice, and discrimination. Finally, participants lacked confidence about their skills, experience, and education, believing that they would have to accept low-paying positions and to abstain from certain types of employment such as work that requires a high level of physical activity.

**The Benefits of Working**

McReynolds CJ. The meaning of work in the lives of people living with HIV disease and AIDS. Rehabilitation Counseling Bulletin. 2001; 44(2): 104–115. (Kent State University, Ohio.)

In a study of attitudes about work among people with HIV, participants identified work as a means of surviving HIV in four ways: work provides access to affordable insurance and health care; it serves as a distraction from the disease; it enables people to contribute to society; and it serves as a measure of health.

Researchers conducted a two-hour focus group of four men and one woman who were interested in employment-related issues, and seven in-depth audiotaped interviews with five men and two women who were employed or retired.

The ability to work created many opportunities for each participant. Employment provided access to group health insurance to pay for medications and office visits to treating physicians. Work also served as a way for participants to keep their minds off the daily stress of living with a chronic illness, and the work place acted as an effective mediator between participants and society. Working provided a sense of meaning in life, because it allowed participants to maintain and create social connections. Finally, work was a measure of participants' involvement in the process of living, as opposed to dying, enabling them to partake in an activity that is valued by society.