

GMHC treatment ISSUES

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Working Positive Returning to Life

By Eric C. Ciasullo

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If you think about it, it's nothing short of amazing that some of us have made it this far. We have endured despite the threat of death, despite the symptoms and the stigma and all of the sheer indignities of HIV. We have fought back the fear and the depression, the sense of vulnerability, the discouragement—and the discouragers. For those of us who have endured in the face of this debilitating illness and who have stood up to the relentless physical, emotional, addictive and political pressures, our very lives are a victory.

Having beaten such incredible odds, the next steps are both achievable and inevitable. More and more of us are getting to a point where we're ready to claim our future. No matter where we're starting or what we've been through, all of us have some capacity to move toward greater autonomy, toward more personally meaningful social engagement, and toward something more stable and satisfying than subsistence level income. More and more of us are thinking about work.

I'm a gay man with AIDS. That's one of the ways I can be identified, but it's also true that I've been many other things in my life. I've been a student and a teacher, a protégé and a mentor, a son to two parents and a brother to two siblings, a boyfriend—briefly—to several guys, a partner to two men, and after years in the wilderness, a husband to just one. I've been an ROTC cadet, a frat boy, and a Catholic seminarian. I've been a waiter and a writer and a counselor to homeless and incarcerated youth.

In the context of this epidemic, I've been a street-based activist, a social services advocate, a member of planning councils and boards of directors, a prevention educator, a case manager, a program director, and now a public health administrator.

Like all of us, there are a lot of things that contribute to who I've been and who I am. But to many government officials, I am first and last a person with AIDS. To them and many others, the diagnosis in my medical chart stands out as the single defining element of my life and my identity.

When I was diagnosed with HIV in 1990 the evidence was clear that I was looking at a three to five year prognosis. In 1991, my T-cells dropped below 200, anticipating what would soon become an official AIDS diagnosis. In the fall of 1992, a few weeks before I turned 30, when the headaches and the fatigue and the other disabling side effects became just too much, I went out on "permanent" disability.

When I tested positive we were deep in the Reagan/Bush years, more than five years away from the emergence of protease

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inhibitors, and it never occurred to me that I would see 35, never mind 40. It never occurred to me that I'd see a Democrat elected president, not to mention a second Bush. It never occurred to me I'd see the turn of the century, or fall in love, or buy a house, or think about having children. Yet these things are all true today.

Back then, I had stopped thinking about the future at all. I took care of sick friends, and I grieved their deaths. I grieved my own death prematurely. I used the AIDS Drug Assistance Program (ADAP) to access preventative medications for every opportunistic infection imaginable. Between them and the large quantities of medical marijuana I smoked for the nausea (and the boredom), somehow I endured beyond every realistic expectation.

Then, along came the protease inhibitors and triple combination therapy. To be honest, I initially experienced a sense of horror as I realized that I wasn't going to die any time soon. I used to refer to that as "the threat of imminent survival." Having experienced so much grief and having prepared so completely for my own death, I really didn't know whether I could muster up the psychic energy necessary to prepare for life.

But I did it—with a lot of luck. I had maintained some limited involvement in the politics of social services for youth and people with HIV and I stumbled onto a few consulting gigs. People offered me the occasional part-time job related to my prior work experiences. Eventually, as I started to exist more in the "Land of the Living," a passion and excitement for life started to creep back in. I started to contend with some of the financial wreckage, the vocational confusion, and, let's call it out, the depression, fear and drug abuse that stood between me and employment.

I made some good decisions and a fair number of bad ones. I started out slowly, and in 1998, after more than six years on "total and permanent" disability, I was offered a job as an AIDS services administrator.

It hasn't been easy. I needed external support to deal with some of the issues that had been swept under the carpet along the way. Like a lot of people who make that transition, I had an emotional crash after about six months when I realized that work wasn't going to fix everything that was broken in my life. Then, after about two-and-a-half years, my third combination of anti-virals stopped working. I started a new course of treatment that made me so sick I had to take two extensive leaves of absence that kept me out of work for almost a year. Fortunately I

work for a large employer that understands its responsibilities under the ADA (Americans with Disabilities Act) and the Family Medical Leave Act about medical privacy and reasonable accommodations.

The reality is I still have AIDS, and my fifth combination of HAART has five drugs—four classes—which has created another whole set of challenges along with the need for still more pills with still more side effects. Honestly, sometimes there are so many side effects I lose track.

I suppose I could stay home all day and write down my symptoms, and discuss them endlessly over a bong with some of my friends who aren't working. But the truth of the matter is that my life is infinitely better now that I work. Don't get me wrong, it can be really challenging taking care of myself as well as I need to. I don't eat well enough, I don't get enough exercise and sometimes I'm late with my meds. But overall, I think organizing my life around work that I care about leaves me physically, mentally, and spiritually more healthy than organizing it around managing symptoms and pursuing healthcare. And it's great to get a decent paycheck.

I recently went to a large conference for HIV service providers. There were workshops on fundraising and management, lipodystrophy and hepatitis C, microbicides research and vaccine development; workshops on providing food and housing and healthcare, adherence and nutritional education and treatment support to people with HIV/AIDS in all of our incredible diversity. The CDC has recently discovered that people with HIV have prevention needs and a role to play in prevention, and so there were even workshops on HIV prevention for positives.

But there was nothing on vocational counseling. There was nothing on employment; nothing on supporting our efforts to seek and maintain economic independence. Nothing to help us to make informed choices when risking the relative security of our medical, housing and financial benefits by simply seeking employment; nothing to overcome the barriers to social integration we face. There was nothing for someone taking their first step toward getting a first job. For that matter, there weren't even any workshops dealing with the challenges of providing health and supportive services to those of us who never left the workforce, to those of us working again, or to those of us struggling to find our way back onto benefits after our employment efforts have faltered.

It never occurred to me I'd see the turn of the century, or fall in love, or buy a house, or think about having children.

Other than a giddy moment around the advent of triple combination therapy when some overly optimistic prognosticators predicted that people with HIV were all going to surge back into the workforce, it seems as if too many of our advocates and allies have determined that employment is something we shouldn't or can't achieve. At the very least, they seem to view the challenge of employment as a marginal issue. It still hasn't captured their imaginations, commanded their attention, called forth their creativity, or in any significant manner compelled them to marshal their considerable political resources.

Let's be clear, the federal government now spends billions of dollars a year for HIV healthcare and supportive services—and we need these resources. It's true that many of us have a vital need for publicly-funded medical services, access to drug therapies, and assistance with food and housing and other basic needs. But it's also true that with our allies we have created what many of us now refer to as an AIDS Industrial Complex, one which is predicated on our postures of passivity and dependence. Services and programs designed to assist us in our efforts to become or remain self-sufficient are left bankrupt beggars at the gate. Indeed, transition-to-work services are not a permissible use of Ryan White funds.

Certainly the dialogue at this AIDS conference presumed that we continue to inhabit what some call a disability identity—and that this identity is in fact total and permanent. The implication is that we must maintain this posture if we are to continue to be beneficiaries of the system's good efforts and good intentions, and of the increasingly insufficient resources of an increasingly out-of-touch and disinterested federal government.

To be honest, I believe that a perverse and simplistic contradiction currently exists around issues of employment and people with HIV, one which careens back and forth between paternalism and a pernicious form of judgment. Informally, I hear many service providers say with concern and conviction that most of their clients aren't thinking seriously about employment, and that even if they are, it just isn't a very realistic possibility. Painfully, I hear others speak with scorn of those of us who (in their opinions) aren't working and could, or aren't working and should—resentful that we left or haven't yet found our way into or back into the workforce. We are described by them in ways that sound suspiciously similar to Reagan-era descriptions of so-called welfare queens, as if the meager incomes and scraps of services we receive are so freaking fabulous, or as if we we're gleefully

self-satisfied at scoring some disability jackpot that allows us to live carefree lives.

Seemingly, many of these good people have somehow failed to grasp the nature of the complexity in our lives; the reality that, despite persistent disabling symptoms of HIV disease and HIV treatments, a great majority of us experience external pressure and/or a real desire to work. Most of those not working don't feel fortunate but rather feel stuck in relative poverty or financial chaos. Many of us feel bored and isolated and stigmatized by the marginalization of not working. We feel simultaneously sustained and trapped by disability benefits. Because we continue to be vulnerable to the uncertainties of HIV, we may be deeply uncertain of our ability to compete in the job market. Sometimes we are paralyzed by the fear of losing our housing and healthcare if we try to work but then end up unable to sustain employment. And we are worried about whether we can work well enough and consistently enough to really improve upon whatever stability we might have obtained from the increasingly fragile benefits system.

So, our symptoms and uncertainties are real and based on very concrete challenges and dangers. Nevertheless, for the majority of us who have benefited and will hopefully continue to benefit from the new therapies, the question of work is going to assume greater importance, not less.

Let's look at a few facts. What limited data we have suggests that as many as three quarters of people with an AIDS diagnosis are not employed, and that some smaller number, perhaps one quarter, of people who are simply HIV-positive are disabled by the virus. In places like San Francisco, that would mean that as many as half of all people with HIV/AIDS are not working. Nevertheless, a San Francisco

The National Working Positive Coalition (NWPC) will be presenting a day-long, pre-conference institute at this year's U.S. Conference on AIDS (USCA), October 21–24 in Philadelphia, PA.

Scheduled for Wednesday, October 20, the program, titled "Working for a Future" will review current knowledge about the value of productive activity, effective rehabilitation service practices, research findings, and advocacy priorities related to work activity and employment for people living with HIV/AIDS.

Details will be forthcoming on the NWPC website (www.workingpositive.net).

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needs-assessment a few years back suggested that as many as one in three non-employed/disabled people with HIV/AIDS had an urgent desire and intention to return to the workforce. (In Los Angeles at around the same time, it seemed that two out of three were seriously thinking about employment.) And the San Francisco assessment showed that the need and desire to work was expressed equally across obvious distinctions like race, sex and gender, sexual orientation, and income level.

The people and the organizations that say they are concerned about our welfare had better take notice, or they're going to become increasingly less relevant in our lives.

If these numbers hold true nationally, then one- to two-thirds of people with HIV/AIDS in this country may fit the following profile: we aren't working; we're totally dependent on family, friends and social supports for food, shelter and healthcare; but we're thinking about or actively trying to find a way to become employed, trying to find our way into the mainstream of American life. Why aren't these efforts capturing the attention of our allies and advocates?

One reason is that we just don't know if these numbers hold true. More than seven years after the emergence of triple combination therapy, we still have never had any kind of comprehensive national survey of people with HIV designed to determine our attitudes and needs regarding employment. Almost everything we think we know continues to be anecdotal, and this is simply unacceptable. It's long past time that the federal government invested the resources necessary to help us better identify and diminish the

barriers to our full social inclusion and economic empowerment.

When we talk about a "changing epidemic," it seems to me that this dynamic concerning work should be capturing a great deal of our attention. And let me say this quite frankly, the people and the organizations that say they are concerned about our welfare had better take notice of this, or they're going to become increasingly less relevant in our lives.

Karen Escovitz from the Matrix Center in Philadelphia has written an eloquent and concise articulation of the need to pay greater attention to this issue of HIV and employment. She says simply, "Work is the single most normative experience for adults in our society. And if we believe that individuals have futures, most of those futures have to include work."

What I most appreciate about Karen's insight is that it's not rocket science. Any casual reflection on the nature of work in our society will reveal that work has not just economic, but similarly significant social and even spiritual dimensions. For many who are employed in the HIV/AIDS service field, work plays a vital role in their own sense of worth and self-esteem. Why would anyone assume that recipients of such services would place any less value on the social and financial remuneration that work brings?

As I tried to demonstrate earlier, each of us is so much more than a virus and a diagnosis. But if we're not supported in our efforts to develop viable futures as actors in our own lives, if we're not given opportunities to confront the obstacles to work (that might include but isn't limited to

National Working Positive Coalition (NWPC) Guiding Principles

- People with HIV/AIDS have the right to explore and engage in work opportunities as a central function of their efforts to live full, independent and satisfying lives.
- Individual choices of people living with HIV/AIDS related to work must be respected. The diversity of positive work outcomes including, but not limited to, paid employment must be recognized.
- Vocational services must be responsive to the diversity of work experiences and cultural backgrounds of people living with HIV.
- Consumer choice and control of decision-making related to work must be the foundation of services, research, program design and policy-making.
- People with HIV/AIDS must have access to necessary supports to explore, consider, pursue and engage in work. Systemic barriers to vocational development of people with HIV/AIDS must be removed.
- Individual experiences of living with HIV and transitioning to work are non-linear and change over time. Any service, research, program design or policy related to HIV and work must take this dynamic into account.
- Communication, cooperation and collaboration are essential between people with HIV/AIDS and those who are crucial to positive outcomes for people with HIV/AIDS. The NWPC respects the unique contributions of all.

www.workingpositive.net

paid employment), how are we ever to have lives that are really worth living?

The sad and frightening truth is that the most experienced and innovative programs attempting to assist HIV-positive people with work entry/re-entry issues have been hobbled by uncertain, patchwork, and diminishing funds. Programs that showed early excitement after initially being funded as demonstration projects have not subsequently been invited to apply for anything that approaches stable government funding streams.

We know from experience that people with HIV/AIDS have discrete and particular needs for targeted services. The time has come for our friends in the larger HIV/AIDS community to join with us in pressing decision makers at CDC, HRSA, and Departments of Labor and Education to recognize the essential role of employment and employment services in the health and wholeness of people with HIV/AIDS in the only manner that has any meaning—through strategic, coordinated, and sustained funding.

* * *

Last year, a group of people working on these issues organized ourselves as the National Working Positive Coalition, or NWPC. Our mission is to advocate for work opportunities and improved services, to coordinate the sharing of relevant information, and to promote experience- and evidence-based best practices in employment services for people living with HIV/AIDS. Working on behalf of the larger group, some of us have developed a core set of principles that we believe must guide our work together and must set the stage for national efforts and discussions about HIV and employment.

Twenty years ago a small group of people with AIDS caucused as part of the Second National AIDS Forum in Denver. They formed the country's first national AIDS organization, NAPWA, the National Association of People

With AIDS. They also crafted a set of revolutionary guidelines for the empowerment and treatment of people with AIDS that came to be called the *Denver Principles*. These Principles were revolutionary because they rejected the words and roles of "victim" and "patients," insisting that we be recognized as "people living with AIDS," and that as people we have the full range of human rights and needs as everyone else, and that we must be involved in the decisions that affect our lives.

My fantasy is that in the not too distant future, people living with HIV/AIDS will really be seen as full members of the community, agents of our own destinies, folks with futures and aspirations and a right to meaningful inclusion in the lives of our larger communities. When that happens, our friends and allies and advocates may still be needed to assist us with the work of moving forward. My hope is that in the same way that the Denver Principles shaped the last generation's work on AIDS a new generation's efforts will be informed by the revolutionary shift in thinking represented by the values of this nascent National Working Positive Coalition.

I believe that we are at the beginning of a new era in the history of this epidemic. Here's what I mean by that. The first 15 years of the epidemic were about dying—first quickly, then a little more slowly, but it was all about dying. The next five years were about not dying—and I know that people are still dying, but if we're honest with ourselves, the impact of treatment in the developed world is that mortality due to HIV has been greatly diminished. It's my hope and belief that this next era of the HIV/AIDS epidemic is about living, really learning to live, fully, with HIV.

Eric C. Ciasullo is a founding member of the National Working Positive Coalition (NWPC).

Resources:

Gay Men's Health Crisis (GMHC), New York, NY "Transition to Work" (212) 367-1007
 Positive Resource Center, San Francisco, CA (415) 777-0333
 Cascade AIDS Project, Portland, OR "Working Choices" (503) 223-5907
 Housing Works, New York, NY "Second Life Job Training" (212) 966-0466 x1172
 AIDS Project Los Angeles (APLA), Los Angeles, CA "Work Services Project" (213) 201-1471

Choosing an Employment Program

By Bob Huff

More and more AIDS service organizations (ASOs) are hearing an increasing demand from clients for help in preparing to enter the job market. Counselors at GMHC report a growing number of calls from people interested in "testing the waters" for a return to work. But there's more to helping people get ready for work than simply referring them to a resume writing class or to the State's vocational rehab office. Few ASOs are set up to offer the kind of sustained, multi-dimensional vocational rehabilitation support that people with a complex illness like HIV require. "Typically ASOs don't understand employment, while State Departments of Rehabilitation don't understand HIV," says San Francisco vocational counselor Betty Kohlenberg, "There are only a few programs that successfully offer vocational services in an HIV-aware setting." The fact that Ryan White CARE Act funds may not be spent on vocational services does not help matters.

Vocational support can be important for people with HIV in all kinds of life situations. Some clients may have extensive work histories in highly responsible positions but need help to decide what they would like to do in this new phase of their lives. Others may have no conventional employment history or may be leaving prison and will need additional kinds of support. Lynn Wiles, of the Cascade AIDS Project in Portland, Oregon, runs support groups for her clients as part of their "Working Choices" program: "We have people just out of prison sitting next to people wearing suits and ties. It makes for interesting groups."

Most service providers contacted prefer to avoid describing their initiatives as "return to work." Jeffrey Rindler, director of the volunteer and work center at Gay Men's Health Crisis in New York says, "At GMHC we call our program "Transition to Work" because many people we serve have never worked before."

Generally, motivations reported for investigating work seem to be similar. "The clients I talk to will usually have strong reasons for wanting to return to work, like having more cash in their pocket and the opportunity to do something more rewarding and fulfilling with their time," said Michael Buitrón, a counselor at the Work Positive Assistance Project at the Harbor-UCLA Medical Center in Los Angeles. Often, a fulfilling occupation is identified as taking on a "helping" role. Brian Varner, an AIDS advocate

in Knoxville, is pursuing a graduate degree in medical ethics: "I want to return to work to help others in similar situations, to advance my career, and to change my self image from 'incurable AIDS victim' into 'contributing member of society'."

Approaches to Vocational Counseling

The overriding objective of most well-considered programs is not seeing that every client obtains paid employment, because work may not be best for everyone. It's about making sure that each individual understands her or his own needs, motivations and opportunities and is able to make an informed decision about what will best support her or his overall health and well-being. Betty Kohlenberg, who runs her "Making a Plan" or MAP program at San Francisco's Positive Resource Center, calls this a *client-focused* model. "The best outcome is one that is best for the client—not for the agency or the funder."

Reshard Riggins, a vocational counselor at GMHC agrees, "I want people to understand at the outset that they have nothing to lose by exploring their options. Our goal is to allow them to define what they want to do."

The MAP program is a structured, eight-week program where, Kohlenberg says, "the outcomes are not determined, but the program is. We know what people need to do to get to the point where they can make an informed decision." The Cascade AIDS Project will soon begin offering Kohlenberg's MAP program.

But others say that, once a person has expressed a desire to work, there is no substitute for learning on the job. Karen Escovitz, of the Matrix Center in Philadelphia, ran a demonstration program called "Project KEEP" that got people out into the real-world job market and gave them plenty of support as problems came up. "We helped people get started then let them learn in process. You learn your job by doing your job. There's no substitute for that," said Escovitz.

Project KEEP participants found their jobs in the competitive employment market. An innovative program for homeless people with HIV pioneered by Housing Works in New York City provides training and employment opportunities through a wide range of agency-owned enterprises, including cafes, retail stores and a catering service. The result for many participants is education, work experience and a paycheck, all delivered within a supportive environment.

"I thrive on being able to be useful and to learn, and to help others know that they are important and that HIV/AIDS is not the end of the life cycle..."

For many clients paid employment is not the first step or even the ultimate goal. GMHC's Rindler says, "For some, a volunteer experience is what they are looking for. This allows people to get some experience with structure while they work on their skills."

One of the biggest fears people have when considering work is that they may not be able to stick with it. Kohlenberg stresses that continuity of employment support services is essential, especially due to the episodic nature of HIV disease and treatment side effects than can lay down unexpected speed bumps in a person's plans. "Employment counseling needs to be continuously available. Things change for people with HIV. People drop in and out of work. They need to know some one will 'be with me and won't be mad at me if I blow it'."

In spite of these challenges, people with HIV are increasingly saying they want to work. As one client told Reshard Riggins, "I'd rather die working than live without dignity."

"Of course, this is not everyone's attitude and there is no reason it should be," said Riggins, "We want people to get the information they need and understand what is best for them. After going through this process, if someone decides not to go to work, that is a success."

Benefits

After fear of failure, the biggest worry for most persons living with HIV/AIDS, whether working or on Social Security disability, is fear of losing their medical coverage. But the rules about eligibility are complicated and can be different in different states and different cities.

All the experts agree: if you are receiving disability benefits, you would do well to carefully understand your situation before you plunge back into the world of work. And if you're currently working but worry about how long you can keep up the pace, time spent with a benefits counselor now may smooth the road considerably in the future if you find you need to change jobs or stop working. Jane Gelfand, a benefits attorney at Positive Resource Center in San Francisco, describes benefits counseling as "harm reduction" because so much can go wrong with a person's life and health if they lose the stability that benefits provide.

Some people report frightening difficulties when trying to restart benefits after a period of work. Dan Dunable, an AIDS advocate in Atlanta, isn't sure it's worth taking the risk: "I went off SSDI and returned to full-time employment. Since then I have had to leave full-time employment twice. And each time I applied for

reinstatement of my SSDI or made any changes, it created a nightmare."

Others live in fear that they will inadvertently go over the maximum monthly earnings allowed by Social Security and get in trouble. Melvin is an AIDS treatment advocate in Westchester, New York with a per-diem hospital job: "I had to get my director to fill out a lot of papers and make sure that I didn't earn over \$800.00 per month. I don't get medical coverage, holidays, sick days or personal days from my job. Worrying about getting sick and losing my Medicaid is very stressful."

The Social Security system is complex and sometimes capricious. A knowledgeable advocate can help assure that you are treated fairly. Jane Gelfand warns that Social Security personnel sometimes don't understand or follow all of their own regulations. But, she says, if every denial is challenged, persistence usually pays off. Yet outside of a handful of cities, few have access to the support of a dedicated benefits attorney to help them battle the system.

If Social Security can seem daunting, people on Long Term Disability (LTD) insurance obtained from a job have even fewer protections. As for-profit entities with few government controls, LTD insurers have been known to terminate benefits without warning, which creates a source of continuing anxiety for people with these policies who are legitimately disabled.

Making it Work

People with HIV/AIDS considering work face many other uncertainties, ranging from outdated computer skills to age discrimination to whether to disclose their HIV status. Brian Varner wonders if the gaps in his resume out him: "I'm not married with kids, so it doesn't take much effort on the part of an interviewer to conclude that I'm a gay man with AIDS."

Those who have been on both sides of the fence can be a good source of support and guidance. Ed Lortz, a retired, part time financial consultant in San Francisco, has this advice for those contemplating employment: "It is important to learn to distinguish between *stress* and *challenge*. Stress will kill you, challenging yourself will keep you alive." Also important, he says, is to tailor your living expenses to your level of income, "Financial stress will kill you just as fast."

Sam Soriano, a volunteer AIDS activist in Seattle thinks the challenges are worth it: "I thrive on being able to be useful and to learn, and to help others know that they are important and that HIV/AIDS is not the end of the life cycle but can be used to be productive and purposeful."

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Project KEEP

By Karen Escovitz

Project KEEP was a three-year demonstration project to identify and develop service strategies for overcoming barriers to obtaining and maintaining employment for persons living with HIV/AIDS. After an initial community consultation and design phase to identify real and perceived barriers, comprehensive employment support services were provided to unemployed adults living with HIV/AIDS during a two-and-a-half year period. In order to reflect the demographics of HIV/AIDS in urban settings, participants were recruited from Empowerment Zone areas of Philadelphia.

Description

Project KEEP implemented services based on vocational rehabilitation practices proven effective in helping people with psychiatric disabilities to achieve and maintain employment. The components of such supported employment programs typically include:

- Commitment to competitive employment as an attainable goal for clients
- Rapid job search and placement, rather than lengthy pre-employment assessment, training and counseling
- Assistance finding jobs according to client preferences, strengths and work experience
- Ongoing availability of follow-along, post-employment supports
- Employment services that are integrated with other rehabilitative services

In keeping with these principles of a supported employment program, Project Keep did not emphasize job readiness training, but rather

assisted "all who say they want to work" to find employment in the competitive job market. The rapid attachment approach, along with comprehensive individualized supports, allowed participants to use real-world work experience as an opportunity to develop job maintenance and coping skills.

Methods

Baseline interviews were conducted by research staff and follow-up interviews were collected at six-month intervals. Employment tracking data was collected at job start, at any significant change in job characteristics, and at job end. Time spent in each service category was tracked. Services and support were available to participants throughout the project duration with at least monthly follow-up by support counselors. Counselors were available to be reached by pager when problems occurred on the job. Services provided included:

- Assessment and evaluation
- Job search assistance
- Benefits and legal counseling
- Disability management education
- On-site job support (negotiations with employers, etc.)
- Job-related problem solving
- Specific skills training
- Referral to auxiliary services
- Coordination and collaboration with other service providers

The target of 100 participants was rapidly enrolled and dropouts replaced from a waiting list. During the course of the project, 148 individuals obtained services.

Participant Demographics	
Number of participants	N=148
Age, mean (range)	38 years (20-65)
Gender	
Male	60%
Female	38.5%
Transgender	1.5%
Race/Ethnicity	
African American	72.8%
Latino	19.7%
White	6.8%
Other	0.7%
Education	
No high school diploma	29.3%
High school grad	53%
Post high school	17.7%

Baseline Characteristics	
Years since HIV diagnosis, mean(range)	5 (2.0-16.4)
HIV+/AIDS	26%
HIV+/No AIDS	74%
Comorbidities	
Concurrent psychiatric disability	34.5%
Substance abuse treatment in prior month	31.0%
Any employment experience	92%
Months unemployed, mean(range)	33.7(1-300)
Social Security status	
SSDI	18.2%
SSI	20.2%
Both	9.5%
Other benefits	
Public assistance	34.5%
No cash benefits	17.5%

General Findings

Best practices for helping people with psychiatric disabilities find employment were effective in this population.

There were few significant correlations between medical indicators (CD4 count, AIDS status, recent hospitalization) and employment outcomes.

Individuals with longer periods of unemployment and those with concurrent psychiatric diagnosis tended to take longer to find a first job, although these factors were not correlated with overall employment rate, which suggests that effective employment support enables people to overcome these barriers. Medical indicators, low education level and self esteem were not associated with time to the first job.

Findings Related to Benefits:

Employment rates were similar for those receiving SSI and SSDI, although those receiving disability benefits worked fewer hours than those not receiving benefits.

Participants who stated they were not afraid of losing benefits (53%) were more likely to become employed and work more hours than those who said they were afraid of benefit loss.

Correlations with Total Hours Worked

	Corr	Sig
Overall functioning score at baseline	.18	.034
Received offsite vocational counseling*	.571	.001
Received onsite job support**	.26	.01

*primarily post-employment job-related problem solving, disability management and coping skills development.

**primarily mediating misunderstandings between employer and employee

Discussion

The majority of participants in this demonstration project were people of color and people from impoverished backgrounds and neighborhoods; they were representative of the populations in which HIV is spreading most rapidly in U.S. urban areas. Most participants experienced barriers to employment in addition to HIV/AIDS, including psychiatric disability, substance abuse, domestic violence, low education levels, history of incarceration, and unstable housing. Despite multiple disadvantages, Project KEEP participants provided with access to comprehensive and proactive individualized supports were able to achieve a high rate of employment and retention in competitive jobs.

It is important to note that Project KEEP participants were self-selected individuals actively seeking to explore employment possibilities and were therefore likely to represent community members who are most motivated to work or

Results

Outcomes	
Some employment	114/148 (77%)
No employment	24/148 (23%)
Hourly wages, mean (range)	\$8.49 (\$2.50-\$44.23)
Participants remaining in job \geq 90 days	63%
Total jobs held (per employed participant)	278 (2.4)
Jobs held \geq 90 days	52%
Job characteristics	
Full time	54.3%
Part time	45.7%
Reported income	79.5%
Under-the-table income	20.5%
Jobs with benefits	12.6%
Jobs without benefits	87.4%

those who have less medical impairment. Furthermore, over 90 percent of participants had some work history. This supports recent findings that even limited prior work experience is a good indicator of capacity for vocational success.

It should also be noted that the services demonstrated to be most effective were not necessarily those traditionally associated with "back-to-work" programs or vocational services for persons with disabilities. These programs typically stress pre-employment activities such as job readiness and job-seeking skills (resume writing and interview techniques, etc.), rather than the job-keeping skills that will help individuals manage work in their lives once they become employed. Follow-along services are generally limited or unavailable once a person becomes employed. Project KEEP findings strongly support the value of a service approach that emphasizes post-employment support, including disability management and job-related problem solving. It is also critical that the ongoing services be available as needed to support individuals when changes occur in medical condition, job situation or life circumstances.

The type of back-to-work efforts most common in the HIV community often emphasize benefits counseling and decision-making about financial and legal issues and typically lead participants through a cost/benefit analysis of their options. These programs, while addressing important components of transitioning to work, may not adequately consider the intangible benefits, such as alleviating boredom and gaining a sense of purpose and social integration.

Karen Escovitz, MSS, is a Project Director at the Matrix Center @ Horizon House, Inc., in Philadelphia. For more detailed information about Project KEEP or for training/technical assistance regarding employment for people with HIV/AIDS, she can be reached at: karen.escovitz@hhinc.org

Group Employment Counseling "Making a Plan"

By Betty Kohlenberg

People who begin to think about work often find themselves swirling in indecision.

"Making a Plan" (MAP) is a career counseling program for closed groups of eight to twelve clients who attend a two-hour session weekly for eight weeks. The MAP group counseling program began as a project of the Positive Resource Center (PRC), a San Francisco agency offering employment services exclusively for people living with HIV/AIDS. The groups were a response to an increased client need within an environment of limited staff availability, stemming from a recognition that among the barriers that keep people with HIV/AIDS from returning to the workplace is the problem of insufficient career counseling resources to adequately serve those clients who wish to expand their personal options and develop new work goals. MAP programs at PRC are repeated approximately four to five times annually.

The group counseling program offers people with HIV career counseling support while they identify and plan training and employment goals in a series of eight weekly group sessions. The development of a personal plan for pursuing training and employment is an explicit goal of program participation, though there are also a range of somewhat more implicit goals of psychosocial support and amelioration of cognitive and affective barriers to considering work. All participants are expected to focus on employment, as is indicated by the group name—"Making a Plan"—which was proposed and adopted by the first group's participants. The weeks' activities are structured, focusing on exploration of the individual's characteristics leading to the choice of a job goal, and further exploration of the needs of the world of work. The most common result is a plan of the steps needed to prepare the individual for entry into the chosen field.

While the activities are structured, the outcomes of the program are not. A wide range of outcomes—as long as they are made on an informed basis—is acceptable at the end of MAP, including: starting a new work situation; removing the pressure to return to work; deciding not to change the work situation; deciding to defer a decision to change the work situation; or resolving the pressure to change through non-work means.

During the period September 1999 through February 2004, 20 MAP groups were conducted at Positive Resource Center with a total of 210 participants. The MAP groups were advertised and made available to all clients of PRC who could commit themselves to attending eight weekly two-hour sessions. Service Coordinators at PRC specifically recommended participation to clients whom they identified as in need of and ready for the structured support of the program. Clients who were not interested in working, who were not physically or psychologically able to work or who would not be consistently available during the eight scheduled weeks were encouraged to enroll in later groups. No one who self-identified as interested and willing to participate was excluded from participation.

The MAP groups are based on the "Client-Focused Model for Considering Work for People with HIV," an approach that takes into account a full range of life concerns, categorized as 1) medical, 2) legal/financial, 3) psychosocial and 4) vocational domains.

Consideration of all four domains of influence allows a person thinking about work to understand the effects of employment decisions on all aspects of his or her life and allows him or her to make an informed decision. Not weighing the consequences of entering the work force on each of these domains could potentially cause serious harm to a person living with HIV/AIDS, since work-related activity and income can trigger the loss of important benefits, including income, health insurance, housing and medical care. Loss of benefits can be particularly serious in the event of subsequent deterioration in health status. People who begin to think about work are often overwhelmed by the complexity of considering all of these aspects of their lives simultaneously and often find themselves swirling in indecision and lack of information, unable to move ahead.

As a closed career counseling group of limited duration, the MAP program focuses on increasing participants' awareness of the specific inter-related factors involved in making a decision about employment and positively impacting those factors. This format can be an efficient way of conducting counseling, particularly where staff resources are limited.

For more information: www.bkohlenberg.com

Betty Kohlenberg, M.S., CRC, ABVE, counsels people in career transitions in the San Francisco Bay area.

Frequently Asked Questions Rehabilitation and Employment Services for PLWHA

By Eric Ciasullo and Karen Escovitz

National Working Positive Coalition (NWPC)

Isn't it just a few people living with HIV/AIDS that are able or want to transition to work?

No. First, it is important to recognize that the vast majority of PLWHA are in their prime work-potential years. Second, increasing numbers of PLWHA are living longer lives and experiencing longer periods of time with minimal or manageable symptoms. All of these individuals could benefit from rehabilitation-oriented services that are designed to support the restoration of adult functioning.

Furthermore, hundreds of thousands of PLWHA in the United States are already in the workforce. Dramatic new efforts to reinforce the importance of HIV testing are intended to inform hundreds of thousands more that they are infected. As HIV is understood more as an episodic—perhaps lifelong—disability, many HIV-positive workers are likely to need work-related services that support them in their efforts to remain self-sufficient whenever possible.

Studies in Los Angeles and San Francisco suggest that many PLWHA have a very strong interest in employment. A 1999 needs assessment conducted by the San Francisco Dept. of Public Health suggested that as many as one out of three unemployed/disabled PLWHA had an intention or desire to enter/re-enter employment within the following 6 to 18 months.

There is an urgent need for current national data on these issues. However, all trends point towards the increased need for employment-related services.

Why would a person with HIV/AIDS receiving disability and medical benefits under Social Security, Medicare or Medicaid want to work?

Permanent reliance on state disability benefits creates a status quo in which poverty is normative, stigma is inevitable, and PLWHA are marginalized as disabled dependents.

Work confers meaning, purpose, and identity. Work is the single most normative experience for adults in our society, containing profound economic, social, and even spiritual dimensions. Even unpaid work can play a vital role in creating a sense of worth and self-esteem and diminishing stigma. Many long-term benefits recipients seek to become engaged in productive activity to combat boredom and isolation.

Benefits recipients may be interested in supplementing their income by working part-time, and can be helped to do so without disrupting the necessary medical benefits upon which they rely. For those who transition to work full-time, it's possible that their activities will improve the benefits they'll be eligible for, should they need them in the future.

Aren't there already agencies that provide rehabilitation services for individuals with disabilities? Why should they be HIV-specific?

PLWHA and their advocates have only recently begun to engage vocational rehabilitation (VR) service systems. These systems are in the earliest stages of identifying and addressing our specific needs. Among other things, there are fundamental issues of cultural competence that still need to be addressed, and decades of stigma yet to be unlearned. VR service providers frequently have a limited understanding of the ways HIV disease impacts vocational development and the trajectory of rehabilitation. Moreover, VR systems are not designed to well serve individuals with any sort of episodic disabilities, having been designed originally to support the needs of injured combat veterans.

Vocational services that are HIV-specific can provide a substantial bridge to these other service systems, and empower PLWHA to use them effectively. They can play a powerful role in assisting rehabilitation efforts, which by their nature are often marked by great uncertainty, anxiety and self-consciousness, and complicated by medical needs and side effects. It is common to hear PLWHA state that they're much more comfortable taking the initial steps toward rehabilitation in an environment where they're confident that their needs are understood, where they can be less conscious about visible and hidden manifestations of HIV disease, among people who have many of the same issues.

Doesn't the Social Security Administration provide guidance for persons on disability and wanting to transition to work?

The complexity of SSA rules and regulations can not be overstated. While recent legislation created meaningful incentives that make it safer

Permanent reliance on state disability benefits creates a status quo in which poverty is normative, stigma is inevitable, and PLWHA are marginalized as disabled dependents.

Regardless of work history, learning how to integrate self-care, disability management, and adherence with the demands of work life can be challenging.

for recipients to explore working, this legislation also made SSA rules and procedures yet more complicated and difficult to understand. The incentives impact differently on two wholly separate (though occasionally overlapping) income programs (SSI and SSDI), and two wholly unique health insurance programs (one of which, Medicaid, is administered differently in each of the 50 states). Even SSA leadership acknowledges that local representatives are often poorly informed about existing work incentives. Recipients of disability income frequently need specialized intermediaries that can interpret SSA guidance, and advocate for individuals with atypical needs. As it stands, current HRSA guidance doesn't really limit the ability of client advocates to assist their clients in understanding the impact of work on benefits, though some EMAs may fail to realize their need and capacity to do so.

Isn't it a simple process for people to transition to work after being disabled?

No. The process of entering or re-entering the work world is a complex process of rehabilitation influenced by many factors including: the episodic nature of the disease process; periodic changes to medical regimens; unresolved mental health issues and/or problems associated with substance abuse; education and training prior to onset of disability; work history, or lack thereof; awareness of and access to vocational counseling and training opportunities; and the willingness of employers to comply with the ADA in the provision of workplace accommodations.

For many people, HIV-related illness causes an interruption in work history or training, or delayed entry into the workforce. Furthermore, the nature of HIV disease itself and its physical changes may require a person to pursue entirely new career directions. Many PLWHA seeking rehabilitation services have limited and/or outdated job skills, especially in fields where there is rapid technological change.

Regardless of work history, learning how to integrate self-care, disability management, and adherence with the demands of work life can be challenging. These activities are further complicated by real and perceived issues of stigma and discrimination, along with difficult decisions related to workplace disclosure. All of these challenges can be met more successfully with quality HIV-specific support services.

What are the potential pitfalls for people living with HIV in attempting to transition to work?

Issues related to a non-static health status, psychosocial pressures to work and not work, unresolved challenges related to mental health and substance use need to be considered alongside the questions of vocational exploration and training. Fear, anxiety, and depression are common obstacles in this process. Issues of bad credit, debt and back taxes may be resolved in a less burdensome manner prior to employment than afterwards. Careful consideration needs to be made to the impact of work on health, as well as on various health and financial benefits. It can be quite challenging to maintain efforts at medical monitoring, adherence, exercise, and nutrition while working or training for work, and individuals may need assistance in assessing their capacities for such activities, and the best pace at which to do so.

Some PLWHA will need assistance in identifying and requesting reasonable accommodations from their employers, so that they can succeed in jobs for which they're qualified. Others will need assistance transitioning into the job, along with ongoing support for some period of time (and/or periodically) in adjusting to the balance of maintaining work and health, and responding to problems as they arise.

Is there enough information available for people with HIV/AIDS wanting to transition to work to be able to effectively negotiate the process without specialized assistance?

No. Current systems of governmental and non-governmental workforce development and rehabilitation are rarely client-centered, frequently complicated, often perceived as inaccessible to people with disabilities in general, and communities impacted by HIV/AIDS in particular. Without very effective self-advocacy, PLWHA often have great difficulty realizing the benefits of these programs. The need for specialized assistance in leveraging these services is the fundamental motivation for advocates who seek some limited capacity for CARE-funded rehabilitation and employment services.

Don't the "Ticket to Work" and "Work Incentives Improvement Act" programs under the Social Security Administration provide sufficient assistance?

No. The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) provides important reforms to work incentives available to Social Security recipients, including "easy-back-on" provisions, an elimination of work-related Continuing Disability Reviews (CDR), extended Medicare coverage, and a provision allowing states to create "working while disabled" Medicaid buy-ins. These improved work

incentives create the context in which many PLWHA are willing to take the risks associated with seeking employment.

The "Ticket to Work" program offers the possibility of greater consumer choice in identifying rehabilitation service providers. However, there are no guarantees that these providers will know anything about HIV or the work-related needs of PLWHA. Moreover, the program assumes that providers, called Employment Networks (EN), will have the wherewithal to wait the years it might take for reimbursement under a highly problematic formula. For many AIDS service organizations interested in providing work-related services, this reimbursement formula makes the program an irrelevant source of potential revenue.

Furthermore, "Ticket to Work" reimbursement relies on the achievement of employment that leads to suspension of benefits – leaving out those who need access to vocational services which might yield unpaid work and/or limited employment intended to subsidize financial benefits. As of spring 2003, less than 1 percent of disabled beneficiaries who had been mailed their Tickets actually assigned their Tickets to an EN.

Why should we add Transition to Work as a permissible service under the Ryan White CARE Act?

Services rendered under the CARE Act were originally designed within a context of crisis—one that held little hope for stabilization or improvement of health. We had little expectation that a majority of those PLWHA needing services would have the potential to live for decades after diagnosis.

Now that we recognize that the HIV disease process is neither stagnant nor one of inevitable decline, HIV services need to be re-engineered to reflect the new realities of the illness. Rather than anticipating (and at times creating) increased services dependency over time, the system needs to be changed to optimize autonomy and self-sufficiency whenever possible. Those who are wholly dependent on services may need support in recognizing their capacity for achieving greater autonomy, and assistance in developing necessary strategies and skills.

Services must always be delivered within a context of consumer control and consumer choice, one which recognizes a full spectrum of desirable outcomes including paid and unpaid work, full- and part-time work, work that includes benefits and work that is done while receiving Social Security benefits. Engagement in productive activity has been demonstrated time and time again to carry many and substantial benefits to people living with a wide variety

of disabling conditions, including social integration, diminished isolation, improved sense of purpose and identity, improved mental health and quality of life, routine and structure to one's time, etc. In addition, targeted research efforts may demonstrate that structured engagement in vocational and employment activities positively impact health outcomes.

Finally, it needs to be stated that a growing population of PLWHA relies on the CARE Act for a broad range of health and social services. "Transition to work" services provide an avenue for compassionately reducing CARE Act caseloads by supporting improved autonomy for those individuals who want to and are able to make such changes. This can redirect diminishing resources towards those whose medical status makes them least able or least likely to care for themselves. Just as expenditures for benefits counseling and advocacy services have ensured that the CARE Act is the payer of last resort, local communities who choose to leverage CARE Act funds for transitional services may discover that they are better able to serve those most in need.

Current systems of governmental and non-governmental workforce development and rehabilitation are rarely client-centered.

Patching the Medical Safety Net

By Thomas P. McCormack

It's true that there's now a fairly comprehensive—but terribly complex and hard-to-grasp—set of federal and state laws and rules that encourage disabled SSDI and SSI recipients to try returning to work. (Email the author at tomxix@ix.netcom.com for a detailed paper summarizing them and offering case management suggestions and further resources.) But all these bureaucratic protections still fail to solve the greatest fear of disabled persons thinking about trying to work again: "What if I try to work again and someone at Social Security says that I'm no longer disabled enough to stay in the system? What guarantee do I have that I won't lose my medical care?"

"What if I try to work again and someone at Social Security says that I'm no longer disabled enough to stay in the system? What guarantee do I have that I won't lose my medical care?"

Actually, Congress did offer states one way to meet this fear in a little-known provision of Section 202 of the 1999 Ticket to Work and Work Incentives Improvements Act (TWWIIA). That section is best-known for giving matching funds to States that offer Medicaid, at small premiums, to working persons with medically disabling conditions with earnings up to at least 250 percent of poverty (about \$46,000 a year for one person in 2004), or even more. And Section 204 says that states can, on a demonstration project basis, give Medicaid to "pre-disabled" workers at risk of full disability, also using those generous income rules. States can even get extra federal money by offering one or more of these options. Yet as of early 2004 only Mississippi and the District of Columbia (for HIV-positive persons); Rhode Island (for multiple sclerosis patients); and Texas (for schizophrenia and bipolar patients) had successfully applied for such funding—and Mississippi alone has fully implemented the coverage. This

leaves about \$100 million authorized and available for such patients but unclaimed and unused by the states.

Furthermore, all states that cover the main, basic option under TWIIA can also give Medicaid under the same rules to eligible workers who recover from their disabilities while in the basic Medicaid working disabled program as long as they still have a potentially serious condition (like HIV or chronic mental illness). Again, few states have implemented this important Medicaid coverage option. And here, too, extra federal money is available to help states do this.

To fully guarantee that the medical coverage safety net for those attempting to return to work is stronger and surer, disabled persons and their advocates need to make at least two things happen: First, they must lobby their states to offer coverage for the working fully-disabled. Second, and most important, they must lobby their states to offer coverage under Section 202 for "ex-disabled" persons—which would guarantee health coverage to anyone leaving SSDI or SSI to try working, even if they're found to be no longer disabled!

And to really put the icing on the cake, disabled persons and their advocates can also press for two more reforms: State Medicaid coverage of working "pre-disabled" persons under Section 204 of TWWIIA; and getting Congress to permanently extend Section 204 past its scheduled "sunset" at the end of Fiscal Year 2006—because doing so would accomplish much of what the HIV community hopes to obtain from the Early Treatment for HIV Act (ETHA).

Thomas McCormack is Public Benefits Policy Consultant to the Title II Community AIDS National Network (TICANN); www.ticann.org in Washington, DC.

States Offering Medicaid to Working, Fully Disabled Person Earning up to \$46,000 per Year

Alaska	Illinois	Massachusetts	New Hampshire	Texas
Arizona	Iowa	Minnesota	New Jersey	Utah
Arkansas	Indiana	Mississippi	New Mexico	Vermont
California	Kansas	Missouri	New York	Washington
Colorado	Louisiana	Nebraska	Oregon	Wisconsin
Connecticut	Maine	Nevada	Pennsylvania	

States Offering Medicaid to a Working "Ex-disabled" Person Earning up to \$46,000 per Year

Arizona	Connecticut	Pennsylvania
Colorado	Indiana	Washington
	Kansas	

States Offering Medicaid to a Working "Pre-disabled" Person with HIV Earning up to \$46,000

Mississippi	District of Columbia
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Approval of Sculptra Recommended

By Bob Huff

One of the more disabling side effects of anti-retroviral therapy is loss of fat in the face known as facial wasting, or lipoatrophy. Fat loss in the cheeks and temples has been associated with the use of nucleoside reverse transcriptase inhibitors (NRTI) and most strongly with the use of Zerit. Many people who have enjoyed a dramatic recovery of health after starting therapy have found that the onset of facial wasting can be as identifying and stigmatizing as the wasting of AIDS. Some people with severe facial wasting have reported being unable to leave the house and conduct their normal business due to depression and extreme discomfort about their appearance. For many people with long-term exposure to HIV drugs, facial wasting has posed a significant barrier to fully participating in society or returning to work.

On March 25, 2004, an advisory committee to the Plastic and Reconstructive Surgical Devices Branch of the federal Food and Drug Administration (FDA) met to consider the evidence submitted in support of a new, implantable substance intended to build up fat-depleted tissues in the face. The substance, poly-L-lactic acid, is called Sculptra by its sponsor, Dermik Laboratories, although it has been better known in Europe and in HIV community press reports as New-Fill. The proposed indication for Sculptra is to "correct shape and contour deficiencies" resulting from facial fat loss in people with HIV. The FDA granted an expedited review of the Sculptra application because they felt the product addressed a debilitating condition, represented an unmet medical need, and was in the best interest of patients.

According to observers at the hearing, despite a rather sparse presentation of data demonstrating the efficacy of Sculptra, it may have been dramatic testimony by individuals who had suffered the debilitating effects of facial wasting and

who had benefited from treatment with the product that convinced panel members to vote for approval in the "best interest of patients."

Did it Work?

In a 50-person French efficacy trial, the main study outcomes were total cutaneous thickness (TCT) as measured by ultrasound and a series of photographs taken at baseline and after various stages of treatment. TCT generally showed the greatest improvement early in treatment and the selected photographs presented could be described as convincing demonstrations that the treatments were effective at restoring a normal appearance in the cheeks. Patients also reported improved quality of life soon after receiving treatments. A 30-person study conducted in London produced similar improvements in skin thickness and patient satisfaction as well as reductions in depression and anxiety. In several open-label U.S. studies, photographs showed less striking changes than were seen in the French photos; nonetheless, patient satisfaction with the treatment was high.

The FDA and the panel was generally convinced of the product's safety. Only a few adverse events associated with Sculptra have been reported, primarily bruising, injection site reactions or the development of nodules or granulomas at the injection site. Poly-L-lactic acid is a synthetic polymer supplied in the form of microparticles of irregular shape that are injected below the skin. Eventually, the substance seems to degrade into harmless chemicals within the body. Unfortunately, gradual degradation may mean that periodic touch-ups will be required to keep treated areas from fading away. Longer-term studies will be needed to address this concern. Additional questions about cost and recommended training for providers who will administer Sculptra are still to be determined.

I delivered my story about how I wanted to remain anonymous with this disease and how lipoatrophy stripped me of that ability... How, if it wasn't for lipoatrophy, I could essentially live a fairly normal life with HIV. How people who were unaware of my diagnosis, such as family members, friends and co-workers, became concerned about my "failing health" and how I passed up consulting job opportunities since I would never be comfortable with face-to-face interaction.

— "Anonymous," on her testimony to the FDA panel.

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Why Work?

By Karen Escovitz

Work is the single most normative experience for adults in our society. It is not a marginal or "special" issue. It is a central issue for most HIV-positive people just as it is for most other people. It is of critical importance for HIV-positive people who are not symptomatic, for those who are symptomatic but not disabled enough to qualify for disability benefits, for those who receive disability benefits but who want to do more with their lives, for those who cannot subsist on the pittance they receive from Social Security,

for those whose futures are restored to them (whether temporarily or permanently) by successful treatment, and for those who want to make a positive contribution to their communities and to society. It is of critical importance for all HIV-positive people who do not want to be perpetually marginalized.

We know from research with people with other disabilities and chronic medical conditions that work provides structure, opportunity for social integration and support, distraction from symptoms, a sense of purpose and identity, worth and fulfillment, opportunities for growth and learning as well as income that enables a person to be a consumer of more than just services. We know that work is key to recovery from depression and other mental illnesses, that working decreases dependency on service systems and reduces the need for crisis-level services. The research is starting to verify that people with HIV benefit similarly from work, whether full-time, part-time, paid or volunteer.

As the experience of this virus is changing for so many, there is a strong need for the HIV services and research world to catch up. I would not suggest that we abandon issues like housing, nutrition, prevention or primary care. Unfortunately, I believe there will always be people who need those immediate services to meet immediate needs. Nevertheless, the time has come for us to equip ourselves to help HIV-positive people imagine, plan for, and move into their futures. And if we believe that individuals have futures, most of those futures will have to include work.

The good news is that there is starting to be good research and practice information available on how to provide effective employment supports. There are a few places around the country where people are really benefiting from good programs. Whenever I meet colleagues who are involved with efforts to help HIV-positive people with employment, we lament that

we all have the same difficulties. We find that work-related issues are barely represented on the schedules of the major HIV conferences, work hasn't made its way into funding priorities, it is not high up on the service agendas — yet consumers in our communities are expressing an overwhelming need for help with employment.

In Philadelphia, where we ran Project KEEP (the Kirk Employment Empowerment Project), the vast majority of our participants were African-American or Latino, from impoverished and under-resourced communities; and most experience multiple barriers to employment including concurrent mental illness and/or substance abuse, history of incarceration, homelessness, etc. Many were gay and a few were transgendered. Some lived with other disabilities or medical conditions. Nearly all of them lacked important information and support to navigate complicated benefits situations, negotiate for job accommodations, or help them manage the barriers well enough to pursue their own employment aspirations. The HIV service system seems to be doing a pretty good job of providing most of these folks with decent medical care. They have case management to help them with housing and nutrition and transportation and other immediate needs. But they see work as a key to their future, and there are few currently in the HIV service system designated to help with this.

It seems to me that if treatments continue to be as effective as they are now, or more so, there will be increased need for services and supports that are future-oriented, rehabilitative in nature, and focused on moving consumers into increased self-reliance, autonomy and self-management. If so, employment is key, and we will all need to know as much as possible about it.

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