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EXECUTIVE SUMMARY

Work is a fundamental part of life. It means much more than a paycheck; it offers purpose and the opportunity to lead an independent, self-directed life for all people, including people living with HIV/AIDS. Moreover, we know that poverty, discrimination, and social marginalization are powerful drivers of the HIV/AIDS epidemic. Accordingly, employment is an essential piece of the coordinated response to HIV/AIDS, both within the U.S. and around the globe.

Never has this been truer than at this critical juncture in the history of the HIV/AIDS epidemic. Advances in treatment in recent years have made entering, re-entering, or remaining in the workforce an option for more and more people living with HIV/AIDS. Many already possess or are developing the requisite skills for employment success and have the health, stamina and desire to apply them in the workplace. In fact, some of the key qualities that employers seek in new hires—problem solving, flexibility, resilience, strength and resolve—are also attributes of many people living with HIV/AIDS. What’s more, research conducted in recent years clearly indicates the benefits garnered when people at risk of or living with HIV/AIDS are able to pursue meaningful work.

Consequently, the conversation about HIV/AIDS is expanding, to include a national focus on employment. In the U.S., this evolution is evidenced by the inclusion of the U.S. Department of Labor among the six lead Federal agencies responsible for implementing President Obama’s National HIV/AIDS Strategy for the United States—the nation’s first-ever comprehensive plan for responding to HIV/AIDS. It is also indicated by the growing number of HIV/AIDS service providers across the country offering employment and training services. Efforts by the International Labour Organization (ILO) and within other nations also signal a new, more holistic approach to addressing the complex issue of HIV/AIDS.

This emerging paradigm shift was the impetus behind the Institute on HIV/AIDS and Employment hosted on July 28, 2012 by the U.S. Department of Labor (DOL)/Office of Disability Employment Policy (ODEP) and the National Working Positive Coalition (NWPC). Held at DOL’s national office, this symposium was an affiliated independent event of the XIX International AIDS Conference (AIDS 2012) in Washington, D.C.

More than 75 people participated in the Institute, representing a diverse cross-section of stakeholders, including local, national and international HIV/AIDS and disability experts, service providers, researchers, rehabilitation and workforce system professionals, employers, government and non-government officials, community leaders, labor leaders, advocates, and people living with HIV/AIDS. (For a list of participants, see Appendix A.) By providing a forum for sharing of research and best practices, the event brought a global context to a dialogue initiated in April 2011, when DOL/ODEP hosted the HIV/AIDS Employment Roundtable, which explored ideas for improving employment opportunities and outcomes and reducing stigma and discrimination for people living with HIV/AIDS in the U.S.

In addition to three distinguished introductory speakers, the Institute featured four panel presentations: 1) Research, 2) Direct Service Provision, 3) U.S. Federal Initiatives and 4) HIV/AIDS and the Workplace. (For the Agenda, see Appendix B.) This report summarizes the event’s proceedings, capturing key points and recommendations and extracting common themes for participants and other stakeholders to consider in taking the conversation about employment and living with HIV/AIDS to the next level. In addition, it maps these common themes to four strategies for collaborative action that emerged as a potential framework for moving forward: 1) policy change, 2) research, 3) education and outreach and 4) training and skill building.
INTRODUCTION

The Institute on HIV/AIDS and Employment kicked off with welcoming remarks from Dylan Orr, Special Advisor to the Assistant Secretary of Labor for the Office of Disability Employment Policy, and Mark Misrok, President of the National Working Positive Coalition's Board of Directors, both of whom shared the basis for the event and set the stage for the day’s discussions. Subsequently, participants heard from three distinguished speakers:

- Kathy Martinez, Assistant Secretary, Office of Disability Employment Policy, U.S. Department of Labor (DOL)
- Dr. Grant Colfax, Director, White House Office of National AIDS Policy (ONAP)
- Alice Ouedraogo, Director, International Labour Organization (ILO) Programme on HIV/AIDS and the World of Work

Kathy Martinez

Assistant Secretary Martinez thanked everyone for their participation and noted that just two days before, July 26, 2012, was the 22nd anniversary of the Americans with Disabilities Act, which underpins much of the discussion about full inclusion and equal access to employment for people living with HIV/AIDS. She shared that when the ADA was being drafted, the disability community vowed not to support any version of the law that excluded people living with HIV/AIDS, and that as head of DOL’s Office of Disability Employment Policy (ODEP), she is committed to furthering this common bond.

She then noted that on the ADA anniversary, the U.S. Senate Foreign Relations Committee passed the U.N. International Convention on the Rights of Persons with Disabilities, clearing it for a vote by the full Senate. If ratified, the U.S. would join more than 100 countries around the work who are already parties to it, she said. She then added that DOL/ODEP is particularly interested in its Article 27, which specifically requires that signatory nations recognize the rights of people with disabilities to work on an equal basis with others, including the opportunity to earn a living by work freely chosen and in an open, inclusive and accessible environment.

In the U.S., people with disabilities consistently have a far higher rate of unemployment and significantly lower labor force participation rate than people without disabilities. ODEP’s goal is to change that, Assistant Secretary Martinez said, noting the intrinsic value of work to individuals, families and communities. She stated a particular commitment to ensuring that people living with HIV/AIDS are included in ODEP’s efforts. Like all people, people living with HIV/AIDS who want to work should be able and empowered to do so.

Assistant Secretary Martinez then shared details about three particular ODEP efforts, Add Us In, the Disability Employment Initiative, and workplace flexibility. Add Us In works to identify and develop strategies to increase employment opportunities within the small business community for individuals with disabilities. ODEP has awarded grants to eight consortia under the program to date. Represented within these consortia are a number of minority and LGBT organizations, which play an especially important role since the incidence of disability, including HIV/AIDS, is higher among these communities.

Through the Disability Employment Initiative, ODEP, in collaboration with DOL’s Employment and Training Administration (ETA), is working to increase the capacity of the nationwide network of American Job Centers (formerly called One-Stop Career Centers) to serve people with disabilities, especially those who are unemployed, underemployed and/or receiving Social Security disability benefits.

ODEP is also supporting several projects to encourage and assist employers to foster workplace flexibility. The concept of workplace flexibility entails creating workplaces that support and acknowledge the realities
of workers’ lives including disability, health care, and care giving needs. As described by Assistant Secretary Martinez, it is not about how you get the job done, but that you get the job done.

Assistant Secretary Martinez ended by saying that DOL is proud to be one of the lead Federal agencies responsible for implementing President Obama’s National HIV/AIDS Strategy for the United States and is committed to ensuring that Secretary of Labor Hilda L. Solis’s vision of “good jobs for everyone” includes people living with HIV/AIDS.

Dr. Grant Colfax

Dr. Colfax began by noting that July 2012 marked the second anniversary of the U.S.’s National HIV/AIDS Strategy as well as the anniversary of the ADA, a coincidence that represents the synergies between the disability and HIV/AIDS communities. He also referenced the excitement of the XIX International AIDS Conference that ended the day before, noting the shifting nature of the conversation of the HIV/AIDS epidemic from one solely about prevention and treatment toward one about an AIDS-free generation.

He noted that there was a lot of discussion at the conference about full inclusion and equal access relative to health care, prevention and treatment, but there was also a notable increased focus on social factors and the social determinants of health, and employment is a critical piece of the puzzle. He added that the U.S.’s National HIV/AIDS Strategy has three primary health goals—to reduce HIV incidence, increase access to care and optimize health outcomes, and reduce HIV-related health disparities. He emphasized that employment has a role to play in each of these goals because when people are employed, their health outcomes improve.

Dr. Colfax also noted that the Affordable Care Act is expected to increase health insurance coverage for more than 30 million people and will greatly assist in reducing HIV-related health disparities; as an example starting in 2014 people living with HIV/AIDS can no longer be denied health coverage based on their status. Employment plays a key role in expanding this coverage and ensuring people get access to the care they need, he said. It is also essential to prevention, he said, noting that a study discussed at the AIDS 2012 conference reveals that, among gay black men, employment is a strong predictor of HIV status or suppressed viral loads.

Dr. Colfax also shared some current data regarding populations disproportionately impacted by HIV/AIDS, noting that among the estimated 50,000 new infections in the U.S. each year, gay men represent 64 percent and women account for 23 percent, and among those women, Latinas and African American women represent nearly 75 percent.

He concluded his remarks by saying that an additional goal of the U.S.’s National HIV/AIDS Strategy is to increase collaboration among Federal, State and local governments and community organizations, and that today’s event is an example of that in action. He also noted that the Office of National AIDS Policy (ONAP) is releasing an implementation progress report for the Strategy that details the various Federal efforts that have taken place since its inception, including the production by DOL of several materials about employment and living with HIV/AIDS from the perspective of individuals, employers and service providers.

Alice Ouedraogo

Alice Ouedraogo thanked the U.S. Department of Labor and the National Working Positive Coalition for including the International Labour Organization in the Institute, and noted that the day’s event, as well as the AIDS 2012 conference, showed that many nations are working toward common goals of eradicating new HIV-infections, HIV-related deaths and HIV-related discrimination. And while the world has never been closer to the end of AIDS, many challenges remain, she said, noting that about 34.2 million people worldwide live with HIV, almost 50 percent of them are women, and that there were an approximated 2.5 million new infections in 2011. This last statistic in particular is unacceptable, she said, because while HIV
is not curable, it is preventable. She also noted that in 2011, an estimated 1.7 million people lost their lives to HIV/AIDS – a number almost three times the population of Washington D.C.

Ms. Ouedraogo noted that at the 2010 International Labour Conference, International Labour Organization (ILO) member states adopted by overwhelming majority Recommendation 200 (“Recommendation concerning HIV and AIDS and the World of Work”), a labor standard that acknowledges the need to strengthen workplace prevention efforts and facilitate access to treatment, care and support for people living with or otherwise affected by HIV/AIDS. Recommendation 200 builds upon the ILO “Code of Practice on HIV/AIDS and the World of Work” adopted in 2001. Printed as a booklet and translated into 53 languages, the Code of Practice has made a big impact, serving as a guiding document for workplace policies and programs. Recommendation 200 takes into account changes and experiences since then, strengthens the key principles of the Code of Practice, adds to it, and turns them into an international labor standard.

The ILO believes the workplace plays a critical role in preventing and treating HIV/AIDS, not only because it has the power to reach workers where they spend a great deal of their time, but also because it has a multiplier effect, with messages received trickling down to families and communities, she said, noting that this is critical in reducing stigma and discrimination.

Recommendation 200 calls for the design and implementation of national workplace policies and programs with all concerned stakeholders, and the inclusion of the U.S. Department of Labor in the U.S.’s National HIV/AIDS Strategy provides a good example, she said, as in many countries labor is not involved in the HIV/AIDS response. Recommendation 200 also says there should be no discrimination based on HIV status or because someone belongs to a segment of the population or lives in a region of the world perceived to be at greater risk or more vulnerable to HIV; this component is critical because data from both the U.S. and other nations make clear that stigma continues to be a barrier to employment for people living with HIV/AIDS.

Ms. Ouedraogo also shared that since the inception of the ILO’s HIV/AIDS program, it has been engaged with DOL, through its Bureau of International Labor Affairs (ILAB), to provide technical support on the development and implementation of HIV policies to more than 700 workplaces in 24 countries, together reaching more than 1 million women and men.

Ms. Ouedraogo concluded her remarks by quoting a man in India living with HIV, “If you take away our jobs, you will kill us faster than the virus.” This statement encapsulates the critical need to incorporate the issue of employment into efforts to eradicate HIV/AIDS, she said, and it is critical that this mean not only development of policies, but also implementation of those policies into sustainable practices and programs.
In the U.S. and around the globe, many people living with HIV want and need to work. Due to advances in treatment in recent years, many people with HIV are living healthy lives and have the capability and stamina to contribute to the workforce. Working has been positively correlated with improved physical and mental health for people living with HIV in a number of initial research studies in this area. Preliminary findings indicate that going to work after not working was associated with a decrease in health risk behaviors for some, indicating that more research is needed to better understand the impact of employment on reducing the risk of HIV transmission.

The nature of the relationship between employment and health status is not entirely clear as each may impact the other. From an employment perspective, HIV presents in a similar manner to other episodic disabilities that wax and wane, and public policies need to reflect this in order to avoid unnecessary job loss. Discrimination continues to be one of the most significant barriers to employment for people living with HIV, and the problem may be greater in countries with no protections in place. The decision to disclose one’s HIV status in the workplace setting may have different economic and social ramifications for different socio-economic demographic groups and among other demographic variables, including geography and workplace setting.

Demographic shifts in the epidemic have changed the nature of employment services that people living with HIV need; many require training in “soft” as well as technical skills. People living with HIV are not well informed about employment services available to them. Perceived meaningfulness of one’s work positively correlates to sustained employment. There is a need for more research into the topic of HIV/AIDS and employment, and community-based participatory research may lead to more valid results.

By providing a “captive audience,” the workplace is an effective channel for messages about HIV prevention, treatment and support. Similar to those with mental illness, employment plays a key role in the recovery process and can be incorporated into more AIDS Service Organizations. Preliminary evidence supports the effectiveness and benefits of supported employment on the vocational and health outcomes for people living with HIV.

By providing guidance on what type of information they need, Federal agencies concerned with education and employment can assist researchers in developing more effective proposals.

For a bibliography of research related to employment and HIV/AIDS, see Appendix C.

Speakers:

- Liza Conyers, Pennsylvania State University
- Sergio Rueda, Ontario HIV Treatment Network, University of Toronto
- Celeste Watkins-Hayes, Northwestern University
- Ken Hergenrather, George Washington University
- Lisa Razzano, University of Illinois, Chicago
- Gavin Reid, Global Network of People Living with HIV (GNP+)
- David Martin, Harbor-UCLA Medical Center
The National Working Positive Coalition (NWPC) Research Working Group, which Liza Conyers chairs in addition to being an associate professor of education at Pennsylvania State University, is an interdisciplinary team of researchers who share an interest in better understanding the employment and economic well-being of people living with HIV/AIDS.

Research on this topic is still in a relatively early stage that continues to expand and adapt to the changing needs of individuals with HIV/AIDS. Initial research focused on assessing the needs of people living with HIV/AIDS to determine the extent to which employment services were needed in the face of a life-threatening illness. Today, it is clear that many people living with HIV/AIDS want and/or need to work.

One early qualitative study was conducted at Multitasking Systems of New York, Inc., one of the first HIV/AIDS employment service programs. Funded by the Office on Special Education and Rehabilitative Services (OSERS) National Institute on Disability and Rehabilitation Research (NIDRR), this program was developed in 1989 by two physicians at New York University (Drs. Laubenstein and Greene) who noticed that their patients with HIV/AIDS who continued to work were less susceptible to depression and lived longer than those who disengaged from work.

This study provided an early indication of the potential role that employment could play in reducing stigma and improving the outlook for some participants as noted by this quote, “I feel happy. I work just as anybody else who is healthy works. So I feel there is nothing wrong with me.” The study also revealed the need for a variety of employment service options, because some participants did not want to be associated with HIV/AIDS service organizations while others only felt comfortable in that context. Furthermore, it highlighted the perceived risks of working related to potential loss of receipt of disability benefits among some participants.

A different research project (funded by a NIDRR) analyzed data from a national database to compare charges of employment discrimination filed with the U.S. Equal Employment Opportunity Commission (EEOC) by people living with HIV/AIDS with those filed by people from other disability groups. Results showed that a higher proportion of charges filed by people living with HIV/AIDS were deemed to have merit when independently reviewed by EEOC investigators, indicating a need for a better understanding of how to reduce HIV-related discrimination. Two employers have demonstrated significant leadership in this area: Levi Strauss & Co. and Chevron. Discrimination is also something that needs to be considered relative to service providers who may also have biases that lead them to discourage people living with HIV/AIDS from considering work.

A National Working Positive Coalition Vocational Development and Employment Needs Survey (NWPC VDENS) - conducted in 2008-2009 by Dr. Conyers in collaboration with the NWPC and the New York State Department of Health AIDS Institute and funded by NIDRR and the New York State Department of Health’s AIDS Institute - provides a broader perspective on the employment needs and experiences of people with HIV/AIDS in the U.S., taking into consideration a wide range of demographic variables.

Within the survey’s sample of more than 2,506 volunteer participants, 21 percent reported unstable health during the past 12 months and 15 percent expected their health to be unstable over the next 5 years. Furthermore, 90 percent reported additional health concerns beyond their HIV diagnosis. These findings highlight the episodic nature of HIV. Employment practices and public policies must take this into consideration so that health fluctuations do not lead to unnecessary loss of employment, and so that, when a break in employment is necessary, return to work can be effectively facilitated when health improves.

Among employed respondents, 63 percent were working full time, 26 percent were working part time, and 12 percent were working less than 14 hours per week. Again, these data indicate the need for practices and policies that facilitate workplace flexibility. Data also revealed that many participants face financial
challenges despite being employed; among those who were working, 19 percent earned less than $15,000 per year.

The NWPC VDEN Survey’s findings also suggest that working positively impacts individuals’ health and reduces health risk behaviors. Among employed participants who were unemployed prior to their current job, 49 percent reported that their self-care increased since their current job, 46 reported an increase in CD4 count, 21 percent reported an increase in medication adherence, 34 percent reported a decrease in alcohol and drug use, and 30 percent reported a decrease in unprotected sex. A smaller percentage reported negative health outcomes, highlighting the need for more research to better understand what characteristics, whether individual or work-related, may contribute to both positive and negative outcomes.

When unemployed participants were asked if they could work, only a quarter of men and third of women reported they could not work, signaling an increased need for employment services to help people living with HIV/AIDS address barriers that are impeding their engagement in the workforce. However, the study also revealed that people living with HIV/AIDS have little knowledge of employment services and supports that may be available to them. Only 17 percent knew about One-Stop Career Centers (now American Job Centers); 31 percent knew about the vocational rehabilitation (VR) system; 23 percent knew about the Ticket to Work program and trial work period, a work incentive program for Social Security Disability Insurance (SSDI) recipients; and 10 percent knew about extended Medicare. Within these figures, women were less likely to know about employment-related policies and services than men. It is likely that employment and VR services may have a key role to play in improving economic and health outcomes for people living with HIV/AIDS. However, findings from the NWPC VDENS are based upon a volunteer sample and more research is needed to better understand the relationship between employment and health outcomes.

Future plans for research examining the relationship between employment, health and prevention include evaluation of a microenterprise employment project for women in the rural south, examining health and employment outcomes among a sample receiving medical care in South Central Pennsylvania and program evaluation of an integrated housing and employment intervention program funded by the U.S. Department of Housing and Urban Development (HUD).

Sergio Rueda, Ontario HIV Treatment Network, University of Toronto

Also interested in examining the relationships between employment and health in people living with HIV/AIDS, Sergio Rueda was part of a team that conducted a systematic review of the impact of return to work on individuals’ health. Analyzing multiple studies from the general population, they found that, overall, people were in better health after going back to work and worse when they remained unemployed.

The analysis also found, although to a lesser degree, that poor health interferes with people’s prospects of returning to work and maintaining employment. These findings indicate that the association between work and health isn’t necessarily linear. Employment may be good for health and/or health may be a condition for employment; clearly multiple factors interact and reinforce each other.

Within this review, there were some suggestions that earlier reemployment may be associated with better health and employment outcomes than delayed return to work. However, this clearly depends on individual needs. Return to work did appear to partially or completely reverse the negative health effects associated with job loss.

None of the studies analyzed as part of this project examined the effectiveness of policy interventions or system improvements, pointing to a wide open area for research not only related to HIV/AIDS, but also other episodic conditions.
The various studies done specifically with people with HIV did indicate that employment status was positively and strongly associated with both physical and mental health. However, a preliminary analysis also revealed a steeper decline in health following job loss among people with HIV who were suffering from poorer physical health to begin with, indicating that healthier people may be more resilient to the negative health effects of unemployment.

Finally, another study done by this group of researchers looked at job security and found that for men living with HIV, a greater level of job security offered a mental health benefit over and beyond simply having a job.

Overall, this body of research suggests that with work comes health, and also that the quality of work may make a difference to health.

**Celeste Watkins-Hayes, Northwestern University**

Celeste Watkins-Hayes’ research focuses on women living with HIV/AIDS and nuances on the basis of socio-economic factors in order to highlight how public policies and services can be more responsive to this population.

Women do not make up the majority of people living with HIV/AIDS and thus their related needs may not be the focus when public policies are made. However, when considering the needs of people living with HIV/AIDS, gender power dynamics come into play on many levels and can affect women’s wages, job prospects, and labor market experiences. At the same time, women often have primary caretaking responsibilities for children, and thus may have access to a broader array of services and support. These issues are amplified for African American women, who are disproportionately impacted by HIV/AIDS.

The Health, Hardship and Renewal (HHR) study being led by Dr. Watkins-Hayes is exploring how HIV-positive women make ends meet by examining the economic and social experiences of a racially and economically diverse group of more than 100 women in the Chicago area. The study reveals that for women with HIV, whether and how to disclose their status is a matter of economic survival. But, the implications of disclosure vary depending on socio-economic status. Middle-class women report high potential for downward mobility through job loss. Low-income women report increased economic stability because they can tap into an array of HIV support services.

These findings are illustrated in the stories of two women. The first, Katie, a 35-year-old mother of one, was diagnosed in 2005 while pregnant. She was earning $120,000 per year in a high-level position and did not disclose due to fear of losing her job. Protecting her job meant living in silence. Another, Jada, a 43-year-old woman making $25,000 per year working in a university cafeteria, was diagnosed in 1995. She reported that her connection to an HIV/AIDS service provider has brought housing stability and ancillary benefits. She lives in a low income housing development for single women living with HIV who have children, and particularly noted the benefit of living near other single mothers with HIV with whom she can share information and experiences. For her, coping with the HIV diagnosis psychosocially, medically and financially are linked, whereas for Katie, they are disconnected.

For middle-class women, an HIV diagnosis heightens financial vulnerability, and while low-income women may also fear stigma from disclosing one’s status, economic survival may hinge on doing so. Privacy is a luxury they cannot afford, but ultimately this may be to their benefit because of increased support and improved mental health. When asked how many other people they know also living with HIV, middle-class women typically say three, while low-income women say 10 or more.

These findings should by no means be interpreted to mean that HIV can be a positive thing for low-income women; rather, they highlight the need for the safety net and reveal the challenges that some women must face as they struggle to survive economically and build social capital while living with a debilitating and potentially deadly disease. This is of particular relevance given the current budgetary environment.
for social services. These findings also highlight the need to increase support for middle-class women with HIV/AIDS who often go to great and stressful lengths to hide their status in order to avoid economic vulnerability, which can have implications for their mental health and other health outcomes.

**Ken Hergenrather, George Washington University**

Ken Hergenrather researches the topic of HIV/AIDS and employment using community-based participatory research, which means collaborating with partners and organizations, and ensuring that the individuals impacted by the research are involved in the process. In the Washington, D.C., area, these partner organizations have included Whitman-Walker Health and the District of Columbia (DC) Rehabilitation Services Administration (RSA).

Community-based participatory research ensures community participation in the entire research process, from development to methodology to data analysis and interpretation and, ultimately, how to use the findings to shape effective policy and communicate with lawmakers. Of course, different populations will be involved at different degree levels, but the general premise is that when those impacted by research are involved, the results are more valid and there is a higher level of understanding of what they truly mean. Community-based participatory research has particular importance related to community health and wellness because it emphasizes a multidirectional transfer of expertise and shared decision making, leading to more effective policy and social change.

The Helping Overcome Problems Effectively (HOPE) pilot program is one example of community-based participatory research conducted by researchers at The George Washington University (GWU) in partnership with Whitman-Walker Health. The purpose of the study was to look at the mental health and employment outcomes of African-American gay men living with HIV/AIDS. It involved “HOPE” interventions over seven weeks. During each three-hour session, participants learned various skills such as problem solving, job seeking skills such as how to create a resume, and how to better communicate with health care providers. Each session was in a group setting, where individuals had the opportunity to learn from and share ideas with each other.

At the time of the interventions, not all of the men were working. At a three-month follow up, three were enrolled in college, one had obtained employment and three were actively seeking employment. There were also significant decreases in depression and anxiety and increases in self-efficacy, self-esteem, medication compliance and job-seeking skills. Perhaps most compelling were the results from structured interviews, during which participants expressed significant gratitude for the skills acquired, with some noting that they are working to pass along lessons learned to others they know with HIV or other life challenges.

Based on the HOPE study, participants created a model for better communicating with physicians and other health care providers, with a focus on planning and asking questions and confirming understanding of answers received. This led to one participant’s physician quipping that he was nervous when the participant arrived for his appointment because the participant had a notepad with questions and no one had ever come to an appointment prepared like he had. Direct participant involvement was key to the development of a model that can now be used throughout the HIV community.

Another study explored influences upon public vocational rehabilitation (VR) counselors serving people living with HIV/AIDS. Of 156 counselors who completed a self survey, 55 percent reported having had a person living with HIV/AIDS on their case load. Findings indicated that counselors’ placements were influenced by a number of factors, including medication noncompliance and workplace discrimination, including on the part of employers. In addition, in instances where a health care provider said an individual should not work, that opinion trumped the counselor’s role. In addition, counselors reported difficulty in finding flexible work arrangements that would accommodate treatment needs.
So overall, it appears that more education is necessary. Given this, GWU was awarded funding through its Region 3 Technical Assistance and Continued Education (TACE) Center to provide training to VR counselors in the Mid-Atlantic Region on effective employment practices for working with people living with HIV/AIDS. This program will be piloted in Fall 2012 with the intention of replication through other TACE Centers. It is hoped that this program, as well as others, will help disband the discriminatory factors that prevent people living with HIV/AIDS from working.

Lisa Razzano, University of Illinois, Chicago

Lisa Razzano is a faculty member in the Department of Psychiatry at the University of Illinois (UIC), Chicago, and works with the Department’s Center on Mental Health Services Research and Policy (CMHSRP). In so doing, she has launched a lot of work related to HIV/AIDS and recovery from a mental health perspective, with the focus on recovery being not just the absence of symptoms, but also the ability to thrive within one’s community. Clearly, employment is a key part of recovery in this context.

The CMHSRP has done a lot of work on evidence-based supported employment, including leading a national multisite study of supported employment programs, the Employment Intervention Demonstration Program (EIDP). Overall, there have been multiple randomized controlled trials of supported employment conducted in the field, with more than 15 published studies with intervention and control work with substantial-sized samples. These models have also been generalized in other nations, including Great Britain, Singapore, Australia, and Japan. There are also other key models from the disability perspective that have applicability in the context of people living with HIV/AIDS, especially related to conditions that are episodic in nature.

The applicability of the supported employment model may also be particularly beneficial because of its emphasis on competitive employment, rapid job placement and customized job development. The key is to move away from transitional or sheltered work models and to integrate a host of support services, including housing, family support and medication assistance. Benefits counseling is also an important aspect in order to ensure employment is not paradoxically detrimental to a person’s financial health.

Within this context, a study funded by NIDRR was conducted that explored the effects of medication adherence on employment. Chicago House, an HIV/AIDS service provider that offers employment services, partnered in this study with UIC in 1999, and in so doing developed a model based on supported employment called “Increase Individual Independence and Income,” or “iFOUR.” Over a two to three year period, this model was piloted at Chicago House. Participants were followed for two years; variables looked at included employment outcomes, mental health indicators, social support indicators, empowerment, residential stability, financial stability, and whether or not participants had accessed additional services and supports, among others.

The sample for the study was 350 individuals and generally reflected the demographics of the HIV/AIDS community in Chicago, with an overrepresentation of African-Americans, followed by Whites and Latinos. It included males and females and people of various sexual orientations and gender identities. The goal was to get a slice of the current generation of people living with HIV/AIDS in the community rather than one particular segment of that population. The project also sought to focus on the factors that promote workforce participation in the general population, so a specific subsample within the HIV community, for example MSMs, was not the target sample in this case.

Six months after participation in the iFOUR program, 49 percent of people had returned to competitive work, meaning they earned minimum wage or above and worked in integrated settings where most people did not have disabilities. At 9 month follow up, this number rose to 63 percent. Over the evaluation period, 43 percent of people were able to achieve full-time employment.
In considering the findings from the iFOUR study, it is important to note that Chicago’s unemployment in recent years is higher than the national average. Communities looking to replicate need to take into consideration local labor market conditions, and the nature of workforce needs, including seasonable variations.

Participants in the iFOUR study also revealed improvements related to depression, anxiety, health beliefs, medication adherence, treatment engagement, and other health indicators. There were not substantial changes in the symptomology of HIV, indicating that individuals were able to both manage their conditions and maintain employment in tandem; that treatment did not need to keep them out of the workforce. This message may be particularly important to service providers.

Based on the results of the initiative study, further research on the iFOUR program was funded in 2011 by NIDRR, this time using a randomized control trial (RCT) design. As part of this study, there is an enhanced four-week workshop that adapts the supported employment model to be more HIV relevant. One of the interesting issues moving forward with this study will likely be disclosure, which continues to be an enormous barrier to workforce participation for many people living with HIV/AIDS. It may be necessary to receive accommodations, yet it is one of the things they report being most concerned about due to stigma and discrimination. These studies, conducted in concert with an AIDS service organization, also demonstrate that the tremendous growth and potential for AIDS service organizations to evolve into the field of employment.

Gavin Reid, Global Network of People Living with HIV (GNP+)

GNP+, for which Gavin Reid serves as Community Development Manager, works to improve quality of life for people living with HIV/AIDS by working with independent and autonomous regional and national networks of people living with HIV on all continents. Its work is important in all areas, especially in consideration of the number of people who continue to die as a result of the epidemic, a large portion of whom are from Mr. Reid’s country, South Africa.

It is known that the workplace is an effective channel for messages regarding prevention, testing, treatment, care and support. In this context, working can be transformational; in addition to allowing people to support themselves, it builds self-esteem and plays an important role in mental health and well-being. Mr. Reid is a personal testament to this fact. When diagnosed in 1993, he was a tax accountant with a large firm. He chose to disclose, and although he felt well supported by his employer, he resigned from his position. His confidence quickly decreased, and he experienced depression over several years out of the workforce.

People living with HIV tend to have two main fears. The first relates to the ability to stay healthy, access medication and what will happen if significant illness develops. The second relates to discrimination and how they are perceived by others. Stigma significantly discredits an individual in the eyes of others and, often, this perception becomes indistinguishable from one’s own identity, leading to self stigma. This has been experienced by many populations throughout history based on factors such as race/ethnicity, sexuality and illnesses, including mental illnesses.

The People Living with HIV (PLHIV) Stigma Index, developed in collaboration by many partners, including GNP+, collects information on stigma, discrimination and the rights of people living with HIV that will help further advocacy efforts. The goal of the index is to broaden understanding of the extent and forms of stigma and discrimination faced by people living with HIV in different countries. It is hoped that it will serve as a tool for advocating for changes in laws, policies, programs and practices. Currently 40 countries participate. Following a decision of the 28th UNAIDS Programme Coordinating Board (PCB), the PLHIV Stigma Index has been recommended as the main tool by which the UNAIDS family will quantify people living with HIV–related stigma, and one that they will support at a country and regional level.
People living with HIV serve as interviewers for the PLHIV Stigma Index, as well as the program managers, budget holders, data entry clerks, analyzers and advocates. So in this way, the process is as important as the product, because the index itself is helping to build capacity among individuals and organizations and helping increase their ownership for and pride in advocacy efforts.

A recent collaboration has led to an evidence brief on the index supported by the ILO. This evidence brief was conducted in nine countries. Findings show that HIV-related stigma is seen to directly lead to the loss of jobs, people being out of work, change in job or refusal of promotion, as well as a discriminatory attitude from co-workers. Examples of statistics that emerged included 30 percent of respondents reporting loss of jobs (in Kenya and Zambia this number was 40 percent); 27 percent were refused the opportunity to work in Nigeria; and 4 percent in Estonia and 28 percent in Kenya and Zambia had the nature of their work change or were refused a promotion.

These statistics are backed up by numerous anecdotal stories about and quotes from people living with HIV. In developing countries, employment status is further complicated by the fact that people tend to be paid on a day to day basis, with no Social Security safety net. Thus, stigma impedes people from feeling they can access support, even in instances where there are, in theory, protective policies in place. To break down this pervasive stigma, we need to partner and form networks of supportive employers and unions and for people with HIV to be engaged at all levels of an organization.

Stigma impacts everything—quality of care and someone’s willingness to access care, continue treatment and stay healthy. The PLHIV Stigma Index provides evidence for the need for action on this issue by international agencies and civil society groups within individual nations. For more information, see http://www.gnpplus.net/en/programmes/human-rights/plhiv-stigma-index.

David Martin, Harbor-UCLA Medical Center

David Martin is the Director of HIV Mental Health at Harbor-UCLA Medical Center and a professor of psychiatry and behavioral sciences at the Geffen School of Medicine at UCLA. He is interested in interventions that help people change their behavior related to prevention and treatment, as well as in workforce reentry and HIV.

To date, controlled studies of workforce entry for people with disabilities have been limited, so there is a need for more research, including research related to HIV. In particular, studies need to explore the episodic nature of the condition, because within the disability context, there tends to be an assumption of “disability for life.” This assumption is supported by research conducted many years ago and repeated recently that revealed that once people qualified for Social Security Disability Insurance, their likelihood of returning to work was very small.

Some more valid parallels may be found in the literature about alcohol and drug abuse and return to work. For example, a paper published in 1995 revealed that graduates of drug and alcohol abuse treatment programs who went on to work were much less likely to relapse than people who did not.

First efforts at workforce reentry for people living with HIV stem back to 1996, during the days of what is referred to as the Lazarus Syndrome. Highly motivated, typically white, well-educated gay men were, with the use of protease inhibitors, able to successfully reenter the workforce. But the demographics of return to work today are very different, reflecting changes in the demographics of the HIV epidemic since that time.

In fact, for many people living with HIV today, the goal is workforce entry, not reentry. Many studies reveal a severe lack of what is commonly referred to as “soft skills” among many who participate in various programs provided by HIV service providers. This deficiency needs to be addressed in service delivery and in research, in order to better understand how to strengthen capacity.
In a randomized clinical trial addressing this issue for which results have not yet been published, people living with HIV participated in 13 group sessions. There was a difference at 24-month follow up in terms of employment-related activities, although there was not an indication that the peer interaction of the group sessions led to enhanced workforce reentry efforts, which was contrary to what the researchers had expected. For those people who were successful at workforce reentry, those who had participated in the sessions were less likely to stop working.

Another study using the same cohort had several findings of importance, including that locus of control was very important in predicting employment at 24 month follow up. Not surprisingly, additional predictors were whether or not the work was perceived as meaningful and met individuals’ financial needs. These are important factors to keep in mind because many people with disabilities who return to work are underemployed for their skill set, sometimes leading to a situation where work is less financially viable than collecting disability benefits.

Despite the research conducted, there is still not a lot of understanding about what kinds of interventions are most effective in helping individuals achieve employment. Some promising practices are emerging, but much work remains to be done. Reflecting this, Federal agencies such as DOL and DOJ, which do not fund this nature of research, can play an important role in furthering it by serving as a sounding board for investigators as they develop studies; that way they can develop better proposals and explain to potential funders how particular studies will address the information needs of particular agencies.
Panel 2: Direct Service Provision

Models of Direct Service Provision – Panel Discussion of HIV Employment Initiatives

Key Points and Recommendations:

- Employment services for people with HIV cannot operate in isolation; they should be part of a holistic approach that ensures individuals’ basic needs, such as food and housing, are also met.
- Employment can be a critical part of rehabilitation for people with HIV, just as it is for people with a range of health conditions.
- Coexisting disorders must be addressed when assisting people with HIV prepare for or return to work.
- Employment services need to be diversified to address individuals’ different levels of needs.
- HIV employment services providers may be able to also assist non-HIV positive individuals who have mental health disabilities or other disabilities, and/or other barriers to employment.
- Departments of rehabilitation, workforce development, housing, and health are among potential funding sources for employment services for people living with HIV.
- Entrepreneurship is a viable employment option for people living with HIV, in developing and industrialized nations, urban and rural areas, and resources exist to assist in promoting it.
- Offering employment services within the HIV service provider context requires a shift in thinking that can be challenging in light of the need to balance protecting disability benefits and resources for those in need, while also expanding opportunities for those who want and/or need employment supports.
- There is a gap in services for transgender individuals living with HIV, who may face increased discrimination.
- In all areas, cultural differences come into play relative to discrimination.
- The development of formal laws and policies prohibiting discrimination is critical; the next step is to ensure their implementation, enforcement, and effectiveness. There are still countries with laws and policies negating protections and/or with no legal protections in place.
- One approach to improving employment outcomes for people living with HIV is to increase their access to government-run employment programs; however, confidentiality must be ensured.
- In countries where people living with HIV are not able to access health care due to exclusionary policies, one approach has been to develop specific HIV health care initiatives that also incorporate employment services.
- The issue of employment did not figure prominently at the AIDS 2012 conference.

Speakers:

- Melissa Popiel, Canadian Working Group on HIV & Rehabilitation (Toronto, ON)
- Brett Andrews, Positive Resource Center (San Francisco, CA)
- Nadia Bello, AIDS Committee of Toronto/Employment Action (Toronto, ON)
- April Watkins, GMHC (New York, NY)
- Stan Sloan, Chicago House (Chicago, IL)
- Richard Howard, ILO Program on HIV/AIDS and the World of Work
Melissa Popiel, Canadian Working Group on HIV & Rehabilitation (Toronto, ON)

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, charitable organization that responds to the rehabilitation needs of people living with HIV/AIDS. CWGHR’s work is multi-faceted, encompassing research, education, policy and practice. In so doing, it brings together the traditionally separate worlds of HIV, disability and rehabilitation, working with multiple stakeholder groups, including individuals living with HIV/AIDS; HIV/AIDS service organizations; rehabilitation and other health care providers; employers; government agencies; insurance companies; pharmaceutical companies; disability-related organizations, researchers and academics.

CWGHR defines disability broadly, based on the International Classification of Functioning (ICF) categories, as involving one or more of the following life impacts: physical impairments, activity limitations, and participation restrictions. Rehabilitation can help overcome these barriers and can include services that can prevent a decline in health and move beyond, to support wellness and active living. Physical, psychosocial, emotional and/or vocational supports can be important components of a rehabilitation program. Examples of the range of rehabilitation supports include basic supports, such as housing and food, to less tangible supports, such as family relationships and friendships, cultural and religious affiliations and employment, etc.

CWGHR takes a holistic approach, working to increase access to rehabilitation supports, and considers employment to be an important part of rehabilitation. In doing so, it works across disability perspectives, especially those related to other episodic disabilities. Episodic disabilities are complex chronic illnesses that are unpredictable in their occurrence, length and severity.

One specific CWGHR initiative related to rehabilitation, which includes a chapter on employment, is called the E Module for Evidence-Informed HIV Rehabilitation. The E Module is an online resource developed in 2011 that assists rehabilitation practitioners working in a variety of environments to access comprehensive information to increase their capacity to work with people living with HIV. It is an update of a printed guide developed in 1998 and reflects the changing profile of the epidemic and how these changing needs can be addressed through evidence-based HIV rehabilitation practices. Specific topics include: aging, concurrent health conditions, cognitive rehabilitation, evidence-informed interventions, service access, advocacy and employment. Although the E Module was developed within the Canadian context, there may be sections that are applicable or adaptable to other areas of the world. Access to the E Module can be found at: http://cwghrcampus.hivandrehab.ca/documents/CWGHR_E-moduleEvidence-InformedHIVRehabilitationfinal.pdf.

In working to improve employment opportunities for people living with HIV, CWGHR considers all connections individuals may have—employers, insurers, occupational therapists and social supports, etc.—to encourage those involved to not operate in isolation, and then it works with these connections to ensure they have the capacity to support employees. This involves significant employer education and outreach. Some of the educational initiatives CWGHR has developed include online courses for employers and human resources professionals that have been accredited through human resources associations in Canada. A new in-person training program is currently under development for front-line managers, which is to be piloted in late 2012. CWGHR also offers in-person trainings for employer audiences including front-line managers, on issues such as legal rights, accommodation practices, how to effectively communicate and creating a workplace culture inclusive of people with HIV and other episodic disabilities. A business case about employing people living with episodic disabilities is also currently under development.

Another CWGHR initiative is the Episodic Disabilities Employment Network (EDEN), an online resource network for people living with HIV and other episodic conditions in Canada. The EDEN website, launched in 2012, features videos, links, blogs and an interactive forum for discussing employment challenges. One frequent topic of conversation among users is disclosure, especially as it relates to the workplace. To assist with finding answers to questions, there is a feature called “Ask HR,” through which users can submit
questions and get a response from a certified human resources practitioner. For additional information on EDEN, visit www.edencanada.ca.

CWGHR views employment as a continuum along which employees may be involved in the workforce to varying degrees at different times, depending up on their health status. This may include leaving the workforce, as necessary. There is a need to provide ongoing training and support for not only individuals living with HIV, but also those who support them with access to employment opportunities and with employment advancement. For more information about CWGHR, see www.hivandrehab.ca.

**Brett Andrews, Positive Resource Center (San Francisco, CA)**

The Positive Resource Center (PRC) serves people living with HIV/AIDS in the San Francisco Bay Area. It started in 1991, when a group of community volunteers created a work referral service to match people with HIV/AIDS who were unemployed with opportunities for part-time, temporary jobs in the community. A couple of years later, the group received funding from the City of San Francisco to build employment services for people with HIV. Not long after, coinciding with the advent of combination therapy with protease inhibitors, clients began requesting expanded employment services.

In 1996, the Positive Resource Program, as it was then known, became part of AIDS Benefits Counselors, a benefits counseling agency that helped people living with HIV/AIDS to get disability and medical benefits. The merged organization became the PRC. Joined together, the two entities offered a continuum of benefits counseling and employment services, responding to the evolving needs of people living with HIV/AIDS.

Today, even though California has significant budget problems, the City of San Francisco is doing well, partly due to the high-tech industry. In a city of 800,000, the Department of Public Health has a budget of 1.2 billion; however, the Office of Economic Workforce Development has a budget of 15 million. In its early years, PRC worked a lot with the office of Economic Workforce Development, advocating for funding for services for people living with HIV/AIDS. Today, funding comes from both offices; however, the major funder is the California Department of Rehabilitation (DOR), which PRC has partnered with for 14 years. Recently, the organization went through the process of becoming certified by the Commission of Accreditation of Rehabilitation Facilities (CARF).

In helping clients work toward employment PRC uses a comprehensive approach, often starting with addressing basic needs, because many have additional barriers to employment, such as alcohol and drug use and mental health disabilities. The employment program is divided into three different streams. The first is for individuals just considering work and involves series of workshops that address career exploration, legal rights and other topics. The second focuses on skill building. As part of this, there is a 12-station computer lab that allows clients to learn basic skills or participate in a six-week “next step” program, which provides comprehensive training on the Microsoft Office suite. The computer lab will soon be refurbished through a $50,000 grant from AT&T. The third group encompasses skilled and trained clients seeking job search and placement services following job loss due to the economy in recent years. A lot of PRC’s clients are dealing with self stigma and shame; many exhibit signs of post-traumatic stress disorder (PTSD). PRC allows them a safe place to work through those issues in a culturally appropriate setting. Mock interviews play a large role in employment preparation, because many clients need to build confidence. The decision whether or not to disclose is a common topic of discussion.

Overall, PRC serves about 560 clients per year and has a 20 percent placement rate in jobs averaging $20 per hour, which is twice San Francisco’s minimum wage. Around this issue, San Francisco is unique in that many employers already have a high level of understanding and education about the needs of people living with HIV because of impacted friends and family. In fact, a lot of PRC’s placements occur within small businesses and the nonprofit sector. PRC’s client population is primarily low income. About 90 percent are
men, 8 percent are women and 2 percent are transgender. In 2010, PRC expanded its services to include people with only mental health disabilities.

PRC is currently assisting with a study being conducted by University of California, San Francisco that is looking at the short- and long-term effects of employment activities on people living with HIV/AIDS. Early findings indicate the critical nature of barrier removal, starting with the absolute basics; two of the major issues to emerge were food insecurity and unstable housing.

DOR is an organization that many people may not think about partnering with to provide employment services to people living with HIV. Early discussions PRC had with DOR about the specific challenges facing people with HIV were productive, leading the Bay Area’s DOR district administrator to identify three VR counselors who specifically focus on people living with HIV. In addition, PRC has collaborated with DOR to provide an annual HIV training for other VR counselors. In 2010, training on the Affordable Care Act and how it will impact medical benefits was also introduced.

All of these efforts have given PRC a strong reputation for employment services in San Francisco. As a result, PRC will be serving on a council advising the Mayor on strategies for implementation of his 17-point jobs plan. San Francisco has a 7.5 percent unemployment rate, but among people with disabilities, it is about 25.5 percent, and he understands how important it is to meet the needs of that subpopulation. One of the challenges PRC sees, in general, in ensuring employment services are accessible to people living with HIV is siloed funding.

For more information about PRC, see http://positiveresource.org/

Nadia Bello, AIDS Committee of Toronto/Employment Action (Toronto, ON)

The AIDS Committee of Toronto’s Employment Action program (EA) is the only full-scale employment service for people living with HIV/AIDS in Canada, and has been operating for twelve years. EA offers all aspects of vocational counseling, including pre-employment services, job development, self-employment, retention, work trials, benefits assistance, back-to-school and computer training.

Toronto is a city of about two and a half million people. It has an estimated two new infections per day, one of whom is likely a gay man and the other of whom is likely a woman of color, a newcomer to Canada, or a First Nation’s person. Employment Action serves about 130 people a year, including women, men and youth, newcomers to Canada and long-term survivors. For many of these clients, barriers such as housing, food security, language skills and immigration status can be larger barriers to employment than HIV itself.

Employment Action places about 40-45 clients a year in a wide range of jobs, from entry-level food service positions to a vice president of a local community college, with an 85 percent retention rate. Clients are tracked for three years following a placement and offered support. Although part of the AIDS Committee of Toronto, Employment Action operates under its own branding and uses a nondisclosure model, walking a fine line between client confidentiality and advocacy. Employment Action’s mandate is to serve all people living with HIV, but only receives funding from the Ontario government through placements that qualify for Employment Supports under the Ontario Disability Support Program.

A fairly new Employment Action program is called “Positive Work for Positive Women,” a microfinance project aimed at increasing financial independence for African, Caribbean, and Black women. This project is the first of its kind in Canada and thus far has been a great success. It provides entrepreneurship grants of up to $5,000 per individual. The program has been running for a year and a half. Fifteen women have graduated and are now running a wide range of businesses, from making and selling foodstuffs to providing services such as tutoring and sewing.
Plans are now underway for a third year, during which the microfinance concept will be offered to all clients, not just a particular community. There has been a lot of interest in entrepreneurship from Spanish-speaking and/or gay men. This program has helped illustrate that microfinance, typically a strategy employed in developing nations, has a place in industrialized nations, including in urban areas with sizable newcomer communities. Microenterprise is also a viable employment option for people living with HIV/AIDS. It also may have a particular role to play during a recessionary economy.

The need for information about innovative employment programs was evident at the AIDS 2012 conference, which featured one single workshop on employment despite a week-long agenda. There were many examples of successful private-public partnerships discussed at the conference, with models that moved beyond corporate social responsibility to understanding HIV as a human resources issue; however, a missing piece within them seemed to be actively recruiting people with HIV. Service providers such as Employment Action and many others can help address this void. Employment is also a key part of the conversation about HIV and aging, because it relates to planning for retirement at a time when people with HIV are leading longer, healthier lives.

For more information about Employment Action, see http://employmentaction.crescan.com/.

April Watkins, GMHC (New York, NY)

GMHC has been around for 30 years providing an array of services to the HIV/AIDS community. At first, GMHC’s focus was mainly on providing dignified care to those who were dying at alarmingly high rates. But, with treatment advances it became clear that approaches to supporting people living with HIV needed to expand. Ten years ago GMHC created their workforce development initiative, which they named MATCH. MATCH stands for moving ahead toward career horizons. Within this program they began providing vocational and employment services for HIV positive individuals. This addition to GMHC’s service menu was not initially welcomed, as some thought participants would not be interested in working or willing to give up the benefits GMHC fought hard to acquire for them. MATCH started with one small performance-based contract and shortly grew into a very substantial workforce development program ranking number one in the NPAC Alliance, where they began offering services to HIV negative individuals as well. GMHC Participants embraced the concept, and MATCH is now the most requested service at GMHC besides meals.

MATCH emphasizes informed choices when it comes to employment, and this includes considering how employment may impact benefits. Not surprisingly, a common fear of clients is whether working will actually be financially viable for them, especially if they become sick. So, the program has an extensive assessment process, which includes benefits counseling from GMHC’s advocacy department, along with financial coaching and budgeting assistance.

MATCH offers a range of services, and clients do not necessarily have to go through all of them. Some of the services include GED preparation, life coaching, career counseling, and computer classes in addition to traditional employment placement assistance. Within these various components, there is room for clients to make the determination as to whether or not they want to work. MATCH also provides supportive services such as a clothing closet called “Power Suited by MATCH,” which gives professional attire for interviews, and often provides professional attire once a participant becomes employed.

GMHC is a volunteer-based organization, and thus a majority of the supportive services are provided by volunteers. GMHC solely depends on government funding for the services provided by the MATCH program, which operates strictly through performance-based contracts. There continues to be a need for greater understanding about the critical value of employment services, despite positive outcomes and clear indications that people living with HIV want and need to work.
Since January 2012, MATCH has enrolled 1,001 clients, of whom 566 were African American, 262 were white men and 173 fell under different categories. In terms of gender, 563 were female, 436 were male and 2 were transgender. These numbers illustrate that contrary to people’s assumptions, the majority of GMHC’s participants are not gay white men, but rather represent the shifting demographics of the HIV epidemic.

HIV service organizations need to evolve alongside their participants, who are living longer, healthier lives and many of whom have work experience. But, this requires battling an outdated mindset, in which people see employment services as converse to their previous fight for benefits. MATCH balances these opposing viewpoints by emphasizing that working is strictly voluntary. MATCH also knows that employment is a prevention module and most people living with HIV/AIDS are living longer because of employment, and the lack of potential risky behavior.

For more information about MATCH, see http://www.gmhc.org/get-support/stay-healthy/workforce-development-program-

Stan Sloan, Chicago House (Chicago, IL)

Chicago House has also experienced aversion to employment services in the context of HIV due to the history of early advocacy efforts focused on ensuring benefits for people who were too sick to work. But fortunately, the trajectory of the disease has now changed, and thus the way society thinks about the social support services for people living with HIV must as well.

Chicago House was founded in 1985 as the Midwest’s first provider of HIV/AIDS housing. It has continually tried to stay one step ahead, which has proven challenging, but successful. In 1992, it became an early provider of housing for families, and in 2001, it partnered with the AIDS Foundation on prevention efforts. Then, in 2005, Senator Richard Durbin (Illinois) visited Chicago House and subsequently offered to assist in whatever way he could. The need for an employment program was emphasized, and not long after Chicago House got a $200,000 grant to develop a pilot project drawing on research by Lisa Razzano and others.

Since that time, Chicago House’s employment program, dubbed iFOUR (Increase Individual Independence and Income), has had over 800 people participate, with a placement rate of 47 percent and employment rate of 41 percent. The program’s clientele face multiple barriers to employment, including homelessness, alcohol and drug abuse, felony convictions and mental health disorders. The participants are 75 percent male and 75 percent African American.

The crux of iFOUR is a four-week training program that emphasizes the whole person, focusing not just on job preparation, but also the full spectrum of supports necessary to obtain and maintain employment. The program follows a circular model, rather than a linear model, so if clients leave it, they can return and pick back up at any point in the process. Once clients graduate from the four-week training program, they work one-on-one with a career counselor.

During each of the four weeks of the program, four days are dedicated to broad employment issues, and one day focuses specifically on employment in the context of HIV. As part of this, attorneys advise on benefits, including how to get back on them, if necessary, as well as issues around disclosure and accommodations.

About four years ago, Chicago House received a grant from the U.S. Department of Housing and Urban Development (HUD) that stipulates that clients receiving housing under it have to participate in the employment program. For clients participating in this program, called Gaining Ground, the placement and retention rates are significantly higher (67 percent employment rate and 83 percent job retention rate), and illustrate the critical nature of addressing all of a person’s needs. Furthermore, after three years, which is
how long people can stay in the supported housing, more than 50 percent are able to pay their own leases with no subsidies.

In evaluating these results, it is important to consider that the average age of iFOUR participants is 42, many of whom dropped out of high school, have a history of homelessness, and have never really worked. As a result, even with training, placements can prove challenging due to lack of experience. To assist, in 2008, Chicago House opened its own enterprise, Sweet Miss Giving’s Bakery, as a transitional jobs/internship program. While the bakery’s products received rave reviews and it brought a lot of attention to Chicago House, from a business perspective, it did not prove viable. However, a national wholesale baker entered into a licensing agreement to take a part of the product line to a larger audience and is now running the transitional jobs/internship program itself, with a small portion of each sale going back to Chicago House.

The experiences of five transgender African-American women who participated in the bakery program revealed a severe gap in services for, and significant discrimination toward, transgender individuals. As a result, Chicago House’s former hospice facility is being turned into the first transgender housing program in the Midwest, with its own employment program modeled after iFOUR.

For more information about Chicago House, see http://chicagohouse.org/. For more information about research outcomes related to the iFOUR program, see Lisa Razzano’s presentation in the Panel 1 section of this report.

Richard Howard, ILO Program on HIV/AIDS and the World of Work

Despite differences in nations across the globe, there are striking similarities in how HIV/AIDS affects various populations. This shows in how it is increasingly affecting the most marginalized and vulnerable communities and how employment has emerged as critical to assisting affected individuals improve their health and quality of life. The term “the end of AIDS” is beginning to be used, but clearly, this goal must be accompanied by goals of ending unemployment and discrimination for people living with HIV.

On this issue, the International Labour Organization (ILO) operates on two levels. The first is the broad policy level in which it works to ensure that policies enable access to employment for people with HIV. The other level reflects the opposite extreme, working to help individuals and businesses at the local level. These efforts address prevention, access to employment and service provision.

In Asia, as in many places, the HIV epidemic has changed dramatically over the past 15 years. Initially, it consisted of a few cases of infections among primarily gay men, typically through tourism. In the 1980s and 1990s it was not nearly as widespread as it was in the U.S. But it eventually became big, spreading rapidly, through injecting drug users. It started with middle-class young men and then multiplied down the socio-economic scale. It stayed a predominantly young male problem, and unemployment was a major issue, especially in light of its origins in drug use. It also is a problem among sex workers, the majority of whom in the region are not trafficked, but rather choose to go into sex work because they perceive they have no other options for income. Programs focused on economic empowerment have been shown to increase HIV treatment adherence and reduce pass on infections.

Problems within particular groups are apparent, for example among transgender people in Indonesia, who have extremely limited employment options. Also, gay men face particular challenges in the workplace as a result of discrimination due to not being married, which is highly valued in many Asian societies. In the workplace, not being married is viewed as suspect, and many gay men leave work as a result of the stigma they face.

At the macro level, the ILO has had success developing formal policies that prohibit discrimination based on HIV status; however, it has been less successful at preventing or addressing discrimination when it
does occur. As an example, under a U.S. Department of Labor (DOL)/Bureau of International Labor Affairs (ILAB)-funded grant, the ILO ran a large program to develop national policies in China, while at the same time the Chinese civil service prohibits people with HIV from teaching school and working in gyms and restaurants. Furthermore, access to legal aid and recourse is typically limited. All in all, increasing access to employment free of discrimination is challenging.

Another ILO focus is on increasing options for people living with HIV who cannot, or do not want to, pursue formal sector employment. One approach to doing this is through government-run employment service programs, which are highly prevalent in China. For example, one such program offers people a series of four trainings to assist them in turning a business idea into reality. Under the DOL/ILAB program, the ILO is working to ensure that people living with HIV have access to this program. This has involved training service providers so that they know this type of program exists and how to assist people living with HIV in accessing it. The main challenges involved ensuring confidentiality in referral.

In other nations, work has focused on ensuring access to basic employment supports, including health. This issue is of particular importance in Indonesia, where people with HIV often cannot access the universal health program for the poor because many provincial regulations have actual written exclusions prohibiting people with HIV from accessing services. As a result, the ILO has set up some “one-stop” shops where people with HIV can access social support services, as well as employment services.

Skills training is a key aspect to addressing HIV and employment in Asia. Connected to this, the ILO recently worked to simplify its many skills programs into one participant-driven, “turn-key” microenterprise development program. This program is a series of five modules that a non-governmental organization (NGO) can take and tailor to the needs of the community it serves. Thus far, this program has proven highly successful and adaptable for very different groups with very different needs, for instance, sex workers in Bangkok, women’s groups in the Philippines, a disability group in Vietnam and market vendors in Nepal. It is hoped that this program will also prove fruitful in working with various groups of people living with HIV, especially those who may not be able to access government-run programs. Key to this will be to link the program with access to funds through microfinance programs.


Panel 2 Discussion

Following Panel 2, participants posed the following questions or comments:

• A representative from the ILO in Chile said that the presentations thus far were among the best he heard all week, including at the AIDS 2012 conference. The focus of his work in South America revolves around assisting members of the LGBT community living with HIV to improve their employment outcomes. He previously worked in Asia and brought a lot of what he learned there to South America, and now feels there is a great deal to also learn from what is going on in North America. He is particularly interested in learning more about barrier removal programs and the differences in barriers to employment faced by people living with HIV who are LGBT and those who are not. He hopes the conversation continues among Institute participants.

• Another participant agreed that the Institute presentations filled a void at the AIDS 2012 conference and also inquired as to where the various resources, including the ILO’s five-part microenterprise curriculum, could be accessed. He is particularly interested in learning more about successful microenterprise models such as those shared by Richard Howard. He also asked if any of the panelists have recommendations for transgender specific employment services. It was noted that Cecelia Chung’s presentation on the fourth panel may address the latter of these comments.
• Another ILO representative remarked on the issue of the representation of employment at the AIDS 2012 conference and suggested that Institute participants should start thinking now about how to more fully address employment at the AIDS 2014 conference in Melbourne, Australia.

• A representative from Lambda Legal noted that a common theme to all the presentations was disclosure, and that educating people about if and how to disclose, and the potential ramifications of doing so even where legal protections are in place, is an essential part of the conversation about HIV and employment. He noted that at the AIDS 2012 conference, one of the keynote speakers remarked about how everyone living with HIV needs to come out as such. While in reality that is the place we want to get to in order to get rid of stigma and discrimination, it is not yet the reality, but he believes we need to figure out how to get there. A representative from ActionAIDS in Philadelphia asked if it was felt that PRC’s and Chicago House’s high placement rates were due more to clients’ preparation or good relationships with employers. Stan Sloan said that because of disclosure, Chicago House doesn’t actually do job development, only job preparation, because working directly with employers could violate clients’ privacy. Instead, they focus more on the back end, helping people retain employment once they have it. So placement rates may be more the result of supporting people once on the job. Brett Andrews echoed this sentiment, saying he believes that removing barriers to employment is just as much if not more essential then the job itself. At PRC, this begins with an extensive intake process to determine what those barriers are, which may be at the most basic level, for instance, food, housing or even the need for glasses. That is why PRC’s relationship with the California Department of Rehabilitation is so beneficial; it is able to assist in addressing many of the issues uncovered. He also remarked about the important component of PTSD and self-shame, and that the more that conversation can happen and be normalized, the better off the program will be.

• Richard Howard asked Brett Andrews what kind of services are provided that actually help people prepare to go through the job application and interview process as people with HIV, noting that the ILO’s programs in Asia do not really help people apply for jobs. Brett Andrews replied that PRC has a job club that meets monthly, and as part of that, clients who have already been through the program come in to talk about their experiences with current participants. In addition, PRC does mock interviews.

• A participant suggested that the HIV community may be able to benefit from partnering with disability-related groups that focus on employment and struggle with similar issues in terms of lack of understanding and stigma, including but not limited to those representing the mental health community and those representing other episodic disorder communities. This approach is also relevant given the increasing rates of coexisting disorders, which will continue to increase as the population with HIV ages.
U.S. Federal Initiatives

Key Points and Recommendations:

- In the U.S., a range of Federally funded employment and training programs and resources are available to assist in facilitating employment opportunities for people living with HIV/AIDS.
- In the U.S., people living with HIV/AIDS are protected from discrimination in employment under several laws, including, but not limited to, the Americans with Disabilities Act, as amended (ADA), Family and Medical Leave Act (FMLA) and Rehabilitation Act of 1973, as amended (Rehab Act).
- A variety of educational resources exist to assist individuals, service providers and employers in understanding their rights and responsibilities under these laws and other topics related to HIV/AIDS and employment.
- When disclosing in order to obtain job accommodations, an individual does not necessarily have to be specific about his or her status as HIV positive.
- Outreach is a key complement to enforcement; if people are unaware of their rights and how to seek recourse if they experience discrimination, laws are not effective.
- The right to live free from discrimination based on one’s HIV status is a civil rights issue.
- Stable housing is positively associated with improved health outcomes for people with HIV/AIDS.
- Housing and employment services can be used in combination as a means to improve overall outcomes for clients.

Speakers:

- Dylan Orr, U.S. Department of Labor
- Allison Nichol, U.S. Department of Justice
- Lauren Deigh, U.S. Department of Housing and Urban Development
Dylan Orr, U.S. Department of Labor

The U.S. Department of Labor (DOL) is one of six lead Federal agencies responsible for implementing President Obama’s National HIV/AIDS Strategy for the United States. This strategy includes some employment-specific goals, which include helping individuals living with HIV/AIDS to obtain job skills and employment; increasing supports for employers to hire and retain people living with HIV/AIDS; integrating people living with HIV/AIDS into broader employment initiatives for people with disabilities; and decreasing HIV-related discrimination.

DOL, through its Office of Disability Employment Policy (ODEP), has been working to advance these goals in a number of ways, including through two of its technical assistance centers for employers, the Job Accommodation Network (JAN) and Employer Assistance and Resource Network (EARN). Over the past year and drawing upon information gleaned from the April 2011 HIV/AIDS Employment Roundtable, DOL/ODEP developed and published a suite of “Employment and Living with HIV/AIDS” materials, including a resource guide for individuals; a business case for employers; a series of individual, employer and service provider success stories; and an online toolkit with information for individuals, employers and service providers. As part of this, DOL/ODEP is also maintaining a working list of HIV/AIDS service providers that offer employment and training services; it is hoped that this list will grow over time. All of these materials are available at http://www.dol.gov/odep/topics/HIVAIDS.

DOL also offers other resources and protections that can benefit people living with HIV/AIDS in the workplace. For instance, its Office of Federal Contract Compliance Programs (OFCCP) enforces three laws, one of which is Section 503 of the Rehabilitation Act of 1973, as amended (Rehab Act), which prohibits discrimination and requires affirmative action in the employment of qualified individuals with disabilities, including those living with HIV/AIDS. Given that one in four people in the U.S. works for a Federal contractor, Federal contractors should be considered as a job source for people living with HIV, and Federal contractors in fact have affirmative action obligations to hire people with disabilities.

Furthermore, the Family and Medical Leave Act (FMLA), enforced by DOL’s Wage and Hour Division, provides eligible employees of covered employers up to 12 weeks of unpaid, job-protected leave per year for specified reasons, including management of a serious health condition or to care for a family member with a serious health condition. Of particular importance to people with HIV may be that FMLA leave can be taken intermittently. Furthermore, under a recent interpretation by DOL, parents do not need to have a biological relationship with a child to be eligible for FMLA for purposes of caring for that child, expanding coverage to many families, including LGBT families.

The Americans with Disabilities Act, as amended (ADA), the employment provisions of which are enforced by the Equal Employment Opportunity Commission (EEOC) for private employers, also provides protections to people with HIV/AIDS. In addition to prohibiting discrimination in employment based on disability, including HIV/AIDS, this law requires employers to provide reasonable accommodations to assist people with disabilities in performing the essential functions of their job. Leave may also be a reasonable accommodation under the ADA.

In addition to people knowing about and educating one another about the legal protections that exist, to the extent that people can educate one another about the many employment and training services that are available, the better off we will be. For example, the nationwide network of American Job Centers (formerly called One-Stop Career Centers) funded by DOL’s Employment and Training Administration (ETA) can assist in increasing employment opportunities for people with HIV/AIDS. HIV/AIDS service providers may want to reach out to their local center in order to learn more about what they offer so that appropriate referrals can be made. These centers and all other recipients of financial assistance under the Workforce Investment Act (WIA) are prohibited from discrimination on the basis of disability. Other DOL-sponsored programs that may also be of interest include Job Corps, Registered Apprenticeship, YouthBuild and the Workforce Recruitment Program, a Federal internship program for college students and recent graduates with
disabilities. People should also be aware of and connect to their local vocational rehabilitation providers funded by the Department of Education and the Ticket to Work Employment Networks funded by the Social Security Administration.

**Allison Nichol, U.S. Department of Justice**

Under the National HIV/AIDS Strategy for the United States, the U.S. Department of Justice (DOJ) is responsible for reducing the level of stigma and discrimination faced by people with HIV. This responsibility is mainly exercised through enforcement of portions of the ADA, the Rehab Act and the Fair Housing Act. (DOJ shares enforcement responsibility for the ADA with EEOC; DOJ covers State and local government employers while EEOC covers private employers.)

Disclosure comes into play relative to a lot of this work. Over the years, disclosure has led to negative outcomes for many people; however, it may also be necessary in order to obtain legal protections. A key thing for people with HIV/AIDS, and their service providers, to understand is that it may not be necessary for an individual to specifically disclose that he or she has HIV, but rather just a medical condition that requires an accommodation, whether it be time off for treatment or breaks for medication or other such arrangements.

To complement its enforcement activities, DOJ conducts outreach and education to prevent discrimination from occurring in the first place and to assist people in understanding their rights and responsibilities when it does. Over the last year, this outreach has been focused on parts of the American South where infection rates are spiking and cultural barriers may prevent people from disclosing their status in order to seek legal protection.

The goal is to reinforce that discrimination based on HIV/AIDS status is a civil rights issue. Often, this message is completely new to people living with HIV and their employers and service providers, who do not always understand that people living with HIV are protected by disability laws. DOJ’s ADA website has a section dedicated to HIV/AIDS at www.ada.gov/aids that can be an effective tool for educating about this issue. It also offers people the ability to file a complaint. Another important resource is a recently released technical assistance guide called Questions and Answers: The Americans with Disabilities Act and Persons with HIV/AIDS, available at http://www.ada.gov/aids/ada_q&a_aids.pdf.

DOJ has had 35 HIV/AIDS-related cases in its pipeline in the last year. The U.S. is lucky that it has legal protections in place, but it is important for residents to remember that DOJ cannot enforce what it does not know about. So education is an essential complement to enforcement.

Additional efforts by DOJ under the National HIV/AIDS Strategy for the United States include participating on a new workgroup addressing issues related to the intersection of violence against women and girls, gender-related disparities and HIV/AIDS as well as the issue of the criminalization of potential exposure. DOJ sees all of these issues fitting together because they all foster a negative environment and fuel further stigma.

**Lauren Deigh, U.S. Department of Housing and Urban Development**

The Housing Opportunities for Persons with AIDS (HOPWA) program, administered by the U.S. Department of Housing and Urban Development (HUD), provides grant funding to states, cities and community organizations to provide housing assistance to low-income persons living with HIV/AIDS (PLWHA) and their families. HOPWA funds may be used for a wide range of housing and related services that increase housing stability and help prevent homelessness for this special needs population. Although HOPWA is the only Federal housing program specifically targeted at the HIV/AIDS community, PLWHA also benefit from other HUD housing programs, including those directed at low-income persons with disabilities, the elderly, and people who are homeless or at risk of homelessness.
HUD is one of six lead agencies implementing the National HIV/AIDS Strategy (NHAS) goals to reduce new infections and improve health outcomes for persons living with HIV/AIDS. HOPWA contributes to the NHAS actions to increase housing stability and access to services for PLWHA, as well as to achievement of HUD’s goal to use housing as a platform to improve the quality of life for underserved populations.

Housing is positively associated with HIV prevention, effective participation in and adherence to HIV treatment and care, and improved health outcomes for people with HIV/AIDS. Housing has also been shown to yield cost savings; research shows that it may reduce hospital emergency room visits and hospitalizations and other institutional costs.

Support services are critical program components that help households to become and remain stably housed and to increase access to health care needed to improve their health and quality of life. For beneficiaries evidencing stable arrangements, many projects have begun innovative efforts to help persons move toward more self-sufficiency and to increase their economic security. Employment-related services are eligible HOPWA costs. These efforts to promote greater self-sufficiency are shown to be effective for participants as well as efficient in appropriate service delivery.

In 2011, HOPWA created a pilot technical assistance initiative to build HOPWA service provider capacity to directly provide or link clients to employment-related services. HUD collaborated with Department of Labor’s Office of Disability Employment Policy in the design and delivery of this initiative.

“Getting to Work” is a 12-month capacity-building and technical assistance initiative. Nine teams applied, each consisting of the HOPWA grantee and a service provider, and all are participating. Each team attended an on-site orientation, conducted an organizational self-assessment, and developed an individualized plan based on the unique needs of their organization’s structure, resources, and population. The provider organization receives monthly technical assistance via phone and group webinars, as well as tools and resources to assist their efforts.

With these plans, common concerns are building organizational support and the need to shift thinking away from a strictly caretaking role. Other programs did not know who their potential external collaborative partners were, and some lacked the internal resources to extend their work to this area. Not surprisingly, another key concern among case managers and individuals is the impact of work on benefits, so education around this issue has also been a key component.

Designed as a capacity-building initiative, the data collected from the participants included process measures, such as how many new partnerships were formed and with which types of organizations, as well as how many persons received job assessments, and how many persons were placed in part-time, full-time, or seasonal jobs.

The program was not expecting many job placements to result during this one-year initiative, but the early results of the Getting to Work initiative are very positive. Within the first six months, at the half-way point of the initiative, 44 new partnerships had formed – 3 were with Workforce Investment Boards and 3 with vocational rehabilitation, and the rest were with organizations like Goodwill, nonprofits, community colleges, and other vocational service providers. In addition, 335 new persons have received employment-related services, 235 of whom received some employment readiness assessments and 70 of whom received job skills training. Of these, 20 full-time, 23 part-time and 4 seasonal placements have been reported. Three projects initially had a part-time person to work on this initiative; within six months, several other projects were provided (by the grantee) new funding or staff resources for this project.

By law, ten percent of HOPWA funding is designated for areas not eligible for formula funds and for Special Projects of National Significance (SPNS). These projects are designed to test innovative models with potential for replication. Some SPNS have addressed employment and other related work for special populations, including ex-offenders, youth, and women with children.
A new 2011 HOPWA/SPNS initiative, called Integrated HIV Housing Plans (IHHP), is also working to develop models for integrating housing with employment and other supportive services, in order to assist low-income people living with HIV/AIDS achieve more long-term stability. Seven projects are funded under this initiative, four of which are working on employment initiatives to expand efforts or to develop new capacity. At the end of three years, the seven projects funded under this initiative will develop an Integrated HIV/AIDS Housing Plan (IHHP) that will be made public for potential replication in communities across the nation.

HOPWA employment initiatives and other models of integrated HIV service delivery are featured in HOPWA 20, Housing Innovations in HIV Care at [www.hudhre.info](http://www.hudhre.info).

**Panel 3 Discussion**

Following Panel 3, an employment attorney with experience at both DOJ and DOL, as well as a Federal contractor, said that the Federal government should serve as a model for private employers in providing training and education for its staff around HIV/AIDS issues, along with other disability issues. She noted that currently, required training for Federal Equal Employment Opportunity (EEO) counselors does not include the topic of HIV/AIDS discrimination.
Key Points and Recommendations:

- The Job Accommodation Network (JAN) offers free and confidential guidance on workplace accommodations for people with disabilities, including people living with HIV/AIDS.
- Inquiries to JAN indicate that the challenges faced by people living with HIV/AIDS in the workplace vary greatly, but are often accommodated easily and at low or no cost.
- Individuals living with HIV/AIDS are often unaware that they are protected under disability nondiscrimination laws.
- The Centers for Disease Control and Prevention’s (CDC) “Business Responds to AIDS/Labor Responds to AIDS” (BRTA/LRTA) program engages business and labor in HIV prevention and awareness.
- Care must be taken to ensure that prevention messages in the workplace do not inadvertently negate messages about the importance of hiring and supporting existing employees living with HIV/AIDS.
- Integration of HIV/AIDS into larger workplace policies and programs in recent years may dilute efforts to specifically address it.
- The “Let’s Stop AIDS Together” campaign aims to humanize HIV/AIDS; it may be possible to develop a specific component of it targeted at private-sector employers.
- The conversation about HIV/AIDS and employment must take into context the differing needs of diverse communities.
- In certain contexts, laws or policies may serve as barriers for certain populations, such as ex-offenders.
- Employers may be willing to implement HIV/AIDS policies and programs, but not know how to do so.
- Levi Strauss & Co. (LS&Co.) has been a leader in the response to HIV/AIDS for 30 years and in 2006 committed to providing for all of its employees and their families, worldwide, HIV prevention, testing, treatment and care.
- Businesses need to understand that HIV/AIDS is a human resources issue, not just a corporate social responsibility issue.

Speakers:

- Lou Orslene, Job Accommodation Network
- Robert Bailey, CDC’s Business Responds to AIDS/Labor Responds to AIDS
- Cecilia Chung, Health Commissioner, San Francisco Department of Public Health
- Paurvi Bhatt, Levi Strauss & Co., Employee HIV/AIDS Program
Lou Orslene, Job Accommodation Network

The Job Accommodation Network (JAN), one of five technical assistance centers funded by the U.S. Department of Labor’s Office of Disability Employment Policy (ODEP), is the leading source of free, expert and confidential guidance on workplace accommodations under Title I of the Americans with Disabilities Act (ADA) and other disability employment issues. This guidance is provided over the phone, through emails and through JAN's online chat. JAN also offers extensive information through its website, www.AskJAN.org, including accommodation ideas by disability. In 2011, JAN’s consultants fielded more than 40,000 inquiries and conducted more than 150 trainings. Employers comprise about half of JAN's customers. The second largest group served is individuals with disabilities, including job seekers and people concerned about maintaining their employment in the face of health challenges. In fact, in 2011, the majority of inquiries related to work retention or return to work.

JAN averages only 50 inquiries per year in which people specify that they are a person living with HIV/AIDS, or are contacting JAN in reference to a person living with HIV/AIDS. However, it is important to note that many of the people who contact JAN often do not identify specific diagnoses, but rather discuss conditions or symptoms that are causing challenges at work. The nature of these contacts reinforce research findings that people living with HIV/AIDS are often unaware of available employment services and that they are protected under the law based on their HIV status.

When people contact JAN for assistance, they are often already at a crisis stage, with a situation that is either preventing them from getting a job or threatening an existing job. Of contacts that are HIV/AIDS related, the symptoms causing problems in the workplace vary greatly, and while some relate directly to HIV/AIDS, many are instead the result of adverse reactions to medications. In these situations, the conversation often turns to disclosure; however, JAN does not advise on whether or not someone should disclose. In situations when employees report feeling pressured to disclose in order to request a reasonable accommodation under the ADA, JAN may advise that they can share health conditions related to their diagnosis without specifying the actual diagnosis.

One example of an HIV/AIDS-specific inquiry was an employer who called in reference to a secretary who could only go to an HIV clinic during working hours. The suggested accommodation was a flexible schedule, which the employer did provide. Another option provided during the contact was to allow the secretary to use intermittent leave under the Family and Medical Leave Act (FMLA). Another example was a computer operator who was experiencing weight loss and chronic diarrhea. The suggested accommodation was an ergonomic chair with extra padding and for the individual to change her position frequently to prevent sores. In addition, the employer moved her workstation closer to the restroom. Another example was a machine operator who was experiencing difficulty remembering steps to changing parts. Under JAN's suggestion, the employer provided a step-by-step checklist with written instructions. Sometimes employers ask about what other employers are doing around this issue or what they can do to be more inclusive, so JAN often advises that they implement appropriate training for supervisors and employees, and clear and inclusive policies on HIV in the workplace.

One of JAN's strengths is meeting people, whether employers or individuals or others, where they are, and thus much of the guidance provided by JAN is very basic, whether it related to HIV/AIDS or another disability. It is hoped that each inquiry JAN addresses plays a small role in fostering more inclusive workplaces.

Robert Bailey, CDC's Business Responds to AIDS/Labor Responds to AIDS

The Centers for Disease Control and Prevention’s (CDC) Business Responds to AIDS/Labor Responds to AIDS (BRTA/LRTA) program is a public/private partnership that promotes and assists the involvement of business and labor in HIV prevention, awareness and policies in the workplace to promote the development of comprehensive workplace HIV/AIDS programs. It began in 1992 as an outgrowth of the U.S.
Government’s first Federally funded HIV/AIDS information campaigns. The premise was that the workplace offered a captive audience for messages regarding prevention and for debunking pervasive myths. Today, there are five components to the BRTA/LRTA program: policy development; training for managers, supervisors and labor leaders; education for employees/workers; education for employees’/workers’ families; and community service, volunteerism and philanthropy. In the early years, the focus was on larger companies, but in recent years this has shifted to small companies. Efforts include education aimed at increasing testing, access to care and de-stigmatization. Over the years, BRTA/LRTA has partnered with groups such as Lambda Legal on specific cases and the American Bar Association on various policy initiatives. Very positive results have also come from partnerships with private companies, including Fox Entertainment, which a few years ago worked to extend benefits to cover people with HIV during times when they are not able to work. Two other example of partnerships with the private sector included Fox Entertainment, which negotiated insurance and other benefits for its employees to cover periods of time when an employee might be out of work due to an episodic condition like HIV, and Polaroid, which developed a three-part series about how to support a co-worker living with HIV/AIDS. BRTA/LRTA also offers a series of educational materials for leaders and managers, workers, businesses and families and is currently working to revamp its website, www.hivatwork.org to be a more robust resource. As part of this, it is converting several printed resources to be online only. At one time, BRTA/LRTA was able to offer direct technical assistance to employers, but resources no longer allow for that service.

BRTA/LRTA sometimes has to walk a fine line to ensure its prevention efforts do not inadvertently work against its efforts to assist employers in supporting people living with HIV/AIDS. Another challenge stems from all health conditions being lumped together in disability policies or wellness programs. While this sort of inclusivity can be beneficial, it also dilutes the focus on HIV/AIDS.

The CDC is also involved in outreach efforts beyond the workplace context. One example is “Let’s Stop AIDS Together,” which many AIDS 2012 participants may have seen promoted in Washington, D.C. during the conference. This campaign works to raise awareness about HIV and its impact on the lives of all Americans and fight stigma by highlighting that people with HIV are real people living and working in communities across the nation. It may be possible to segment this campaign’s audience and target specific messages at the private sector.

Cecilia Chung, Health Commissioner, San Francisco Department of Public Health

Clearly, the topic of HIV/AIDS and employment must take into context the differing needs of diverse communities. But, this can prove challenging in certain contexts, where laws or policies may serve as barriers for certain populations, one example being ex-offenders because employers are able to ask about applicants’ criminal histories.

In San Francisco, early efforts at reaching diverse communities included, among other things, LGBT job fairs. But, it was noticed that these job fairs were never attended by transgender individuals. After discussions with the transgender community, it was determined that a transgender-specific job fair was needed. The first year it was piloted, 18 employers sign up and 150 transgendered individuals participated. In this case, there was an easy solution to extending an initiative’s effort. This success eventually led to the city’s Transgender Empowerment Initiative, started in 2006. This initiative is a collaborative program between multiple organizations, including city and county agencies, non-profits and One-Stop Career Centers (now American Job Centers). The Transgender Empowerment Initiative operates on a model similar to the Positive Resource Center and encompasses two components: traditional employment and self-employment. Through the latter, clients work to develop a business plan and are paired with a transgender business owner to serve as a mentor. Recently, the program added a life skills component for individuals who are considering going to work, but are not quite ready to do so yet.
Currently, San Francisco is exploring passing an antidiscrimination ordinance related to individuals with arrest records. Such an effort should be of benefit to the HIV/AIDS community.

**Paurvi Bhatt, Levi Strauss & Co., Employee HIV/AIDS Program**

The employer perspective is often a missing piece in the HIV/AIDS puzzle, and oftentimes this is not due to unwillingness to help, but rather lack of understanding about how to do so. Furthermore, in recent years, the topic of HIV/AIDS and employment appears to be falling through the cracks; it is not adequately discussed within spaces for the HIV/AIDS community, the disability community, nor the employer community.

For more than 30 years, Levi Strauss & Co. (LS&Co.), headquartered in San Francisco, has been a leader and one of the very few employer voices in the response to HIV/AIDS. The company's effort began in 1992, when several concerned employees wanted to distribute educational materials to co-workers about HIV in the lobby, but feared discrimination if they did so. To stem this concern, senior company leaders worked shoulder to shoulder with employees to deliver the much-needed HIV/AIDS educational information. Over time, efforts broadened.

However, in 2006, the company determined that it was not delivering on its commitment and instead resting on its laurels. To change this, it revamped its efforts and made a public commitment through the Clinton Global Initiative to provide all of its employees — not just in the U.S., but worldwide — and their families with HIV prevention, testing, treatment and care. Through research, the company has found that one of the hardest places to deliver HIV messages at work is in the U.S., something that many people find surprising.

In the U.S., LS&Co. offers HIVConnect, a program modeled on an employee assistance program (EAP), but tailored to HIV. Through it, LS&Co. employees can use a toll-free phone number to reach counselors for direct phone counseling, assistance in navigating HIV-related resources, and referral to the HIV-related social and health services they need. HIVConnect counselors draw upon a wide range of best practice health and social service resources to assist employees with managing HIV at work and in their lives. In addition, the company provides HIV workplace education for all of its retail, distribution center, and office-based employees using creative education techniques adapted for each setting and in partnership with local AIDS service organizations.

Businesses need to understand that HIV/AIDS is a human resources issue, and not solely a corporate social responsibility issue. A sole focus on the philanthropic and community perspective can unintentionally underutilize the human resources community, who have the tools and interest to get involved once engaged. LS&Co. would like to see other employers and the HR community join in the business response to HIV/AIDS in the US. We need their leadership on this effort.

To learn more about Levi Strauss and Co. and its workplace efforts to address HIV/AIDS, visit [www.hivaids.levi.com](http://www.hivaids.levi.com).

**Panel 4 Discussion**

_Following Panel 4, participants posed the following questions or comments:_

- A participant asked Robert Bailey if there are mechanisms and links through which research on the topic of HIV/AIDS and employment is shared with businesses. In response, Robert Bailey mentioned the Business Coalition on Health, through which the CDC does distribute research findings and other information to businesses. He also mentioned that over the last year, the CDC has been mandated to better package its research findings for use by the public, not just other researchers. This is part of the impetus behind revamping the BRTA/LRTA website, which he hopes will launch by the end of the year.
The same participant then asked Paurvi Bhatt for strategies for better engaging businesses, especially in countries where the business case is less strong due to lower prevalence of HIV/AIDS. Paurvi Bhatt responded that outside of the business case, employers may respond to the fact that this is likely an issue that employees care about. At LS&Co., this is especially the case among its young retail based workforce. It offers a way to engage employees and build their organizational commitment.
Common Themes and Strategies for Collaborative Action

Broadly, the key points and recommendations from each of the Institute’s panels fell into seven common themes, as outlined below.

1. **Reduce HIV/AIDS stigma and discrimination** – Research and anecdotal experiences of service providers and individuals make clear that stigma and discrimination based on one’s status as HIV positive still pervades. This stigma may be present not only in the actual workplace, but also the employment services setting, and it may be more acute for certain populations, with cultural issues often coming into play. Furthermore, self-stigma is a problem among many people living with HIV/AIDS. Government and employer policies, including laws and regulations, play an important role in reducing stigma and discrimination, but they are only one piece of the puzzle; increased education and outreach is needed.

2. **Expand the conversation about HIV/AIDS to include employment** – In the U.S. and around the globe, many people living with HIV/AIDS want and need to work, and due to advances in treatment in recent years, have the capability and stamina to do so. In addition, working is positively correlated with improved physical and mental health for people living with HIV/AIDS, and may have an impact on decreasing HIV transmission through increased medication adherence and/or reduced health-risk behaviors for some. Employment can also reduce reliance on disability benefits and other public programs and resources. However, as the conversation expands to include employment, it is critical that it not negatively impact the benefits, resources and support available for those who are not able to work and who are dependent on health and income benefits for survival.

3. **Build capacity among service providers to effectively serve individuals living with HIV/AIDS** – Service providers are critical to increasing employment opportunities for people living with HIV/AIDS. HIV/AIDS-specific providers can offer employment/training assistance or partner with workforce development and vocational rehabilitation providers to do so. Similarly, workforce development and vocational rehabilitation providers can learn more about effective strategies for serving people living with HIV/AIDS. Housing service providers also have a role to play, and benefit to gain from, facilitating employment services for people living with HIV/AIDS. Furthermore, entrepreneurship is a viable option in both developing and industrialized nations, and resources exist to help promote it.

4. **Increase job readiness among individuals living with HIV/AIDS with varying levels of experience and education** – As with other populations, employment services for people living with HIV may need to be diversified to address different levels of needs. Furthermore, they cannot operate in isolation. They must be part of a holistic approach that addresses all barriers to employment and includes training in “soft skills.” In some countries, one approach to improving employment outcomes for people living with HIV is to increase access to government-run employment programs. In all efforts, confidentiality must be ensured. In the U.S., research indicates that people living with HIV are not well informed about employment services.

5. **Educate about the disclosure dilemma** – Disclosure is a personal decision that people living with HIV/AIDS confront on an ongoing basis throughout their lives relative to a variety of circumstances, including employment. In the workplace and other settings, the decision may have different ramifications for different groups. There are varying points of view on the topic, none of which are right or wrong. On one hand, disclosure may help de-stigmatize HIV/AIDS by debunking myths, thereby reducing discrimination and creating more inclusive workspaces. On the other hand, stigma does clearly exist and thus disclosure may lead to discrimination, including loss of employment opportunities, despite legal protections. In some situations, accessing employment-related resources and protections may be possible without specifying one’s HIV status.

6. **Adopt an episodic disability paradigm** – From an employment perspective, HIV presents in a similar manner as other episodic disabilities that wax and wane and thus public policies need to reflect this in order to avoid unnecessary job loss. In the U.S., disability laws and regulations, including the
Americans with Disabilities Act (ADA), the Rehabilitation Act of 1973, as amended, and the Family Medical Leave Act (FMLA) provide nondiscrimination and workplace protections, including reasonable accommodations, which can include flexible scheduling, as well as job protected leave. People living with HIV/AIDS and those working with them should be aware of how these laws and additional services can be utilized to manage working with a chronic illness over time. It is also important that newly developing services and policies expand beyond the physical disability paradigm to account for the needs of individuals with chronic illnesses, where their symptoms are often less stable and may wax and wane over time.

7. **Augment the existing research exploring HIV/AIDS and employment** – More research is needed to identify effective practices for assisting people with HIV/AIDS to obtain and retain employment and to document the benefits of doing so, from both an individual and societal perspective. Furthermore, government agencies that don’t typically fund HIV/AIDS research but nevertheless benefit from it, such as those concerned with education and employment, can greatly assist researchers in developing more effective proposals by sharing how the research will contribute to their information needs. Community-based participatory research appears to be particularly beneficial in working with the HIV/AIDS community.

Taken together, the above themes map to four main strategies for action that may serve as a potential framework for moving forward.

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<td>1. Reduce stigma and discrimination</td>
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<td>2. Expand the conversation about HIV/AIDS to include employment</td>
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<td>3. Build capacity among service providers to effectively serve individuals living with HIV/AIDS</td>
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<td>4. Increase job readiness among individuals living with HIV/AIDS with varying levels of experience and education</td>
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<td>5. Educate about the disclosure dilemma</td>
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<td>6. Adopt an episodic disability paradigm</td>
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<td>7. Augment the existing research exploring HIV/AIDS and employment</td>
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In a short period of time, the Institute on HIV/AIDS and Employment did a great deal to advance the dialogue about HIV/AIDS and employment, elevating the conversation to an international level. Participants were clearly engaged and enthusiastic to learn and share their experiences. To build upon this momentum, potential next steps include the following:

- Share the event report with all participants and other key stakeholders.
- Map out the relevant U.S. Federal and State agencies and community stakeholder organizations whose missions and activities relate to key issues and gather their leaders for a high-level strategy meeting to discuss the key points and recommendations in the context of current plans and priorities.
- Facilitate ongoing dialogue between event participants (national and international) to encourage the continued sharing of ideas and experiences around the topics discussed. This sustained dialogue could be achieved through means including virtual discussion through the use of DOL ODEP’s ePolicyWorks online workspace.
- Hold a series of small follow-on working meetings, each focused on one of the common themes as a way to flesh out corresponding recommendations and develop implementation plans.
- Continue to encourage collaboration and coordination between Federal and State agencies, researchers, advocates, and community stakeholders to develop effective practices and solutions.
- Publish a series of articles or blog posts, perhaps through AIDS.gov, based on the common themes.
- Make the Institute a biannual event, corresponding with the International AIDS Conference schedule, or, alternatively, work to integrate it into the conference, starting with AIDS 2014 in Melbourne, Australia.
- Incorporate identified action steps into agency/organizational strategic planning processes as appropriate.
# APPENDIX A – PARTICIPANT LIST

## Institute on HIV/AIDS and Employment

An Affiliated Independent Event of the XIX International AIDS Conference

Hosted by the U.S. Department of Labor and the National Working Positive Coalition

<table>
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<tr>
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Institute on HIV/AIDS and Employment
An Affiliated Independent Event of the XIX International AIDS Conference

Hosted by the U.S. Department of Labor and the National Working Positive Coalition

U.S. Department of Labor, Frances Perkins Building, Great Hall
200 Constitution Ave NW, Washington, DC 20210
Saturday, July 28, 2012, 10:00 a.m. to 3:15 p.m.

Agenda

9:00 a.m. to 9:45 a.m. Pre-Institute Networking and Check-In
*Program begins promptly at 10:00 a.m.

10:00 a.m. to 10:10 a.m. Welcome/Introduction
Kathy Martinez, Assistant Secretary, U.S. Department of Labor, Office of Disability Employment Policy (ODEP)

10:10 a.m. to 10:20 a.m. National HIV/AIDS Strategy
Dr. Grant Colfax, Director, White House Office of National AIDS Policy (ONAP)

10:20 a.m. to 10:30 a.m. Common Global Goal - Recommendation Concerning HIV and AIDS and the World of Work
Alice Ouedraogo, Director, International Labour Organization (ILO) Programme on HIV/AIDS and the World of Work

10:30 a.m. to 12:00 p.m. Research
1. Findings from research projects on people living with HIV/AIDS and employment/vocational rehabilitation:
   Liza Conyers, Pennsylvania State University; David Martin, Harbor-UCLA Medical Center; Sergio Rueda, Ontario HIV Treatment Network, University of Toronto; Lisa Razzano, University of Illinois/Chicago; Celeste Watkins-Hayes, Northwestern University; Ken Hergenrather, George Washington University; Gavin Reid, Global Network of People Living with HIV (GNP+)
2. Discussion of research findings, and current/planned/proposed projects (full group)

12:00 p.m. to 12:15 p.m. Break and Networking

12:15 p.m. to 1:30 p.m. Direct Service Provision
1. Models of direct service provision - panel discussion of HIV employment initiatives:
   Melissa Popiel, Canadian Working Group on HIV & Rehabilitation (Toronto, ON); Brett Andrews, Positive Resource Center (San Francisco, CA); Nadia Bello, AIDS Committee of Toronto/Employment Action (Toronto, ON); April Watkins, GMHC (New York, NY); Stan Sloan, Chicago House (Chicago, IL); Richard Howard, International Labour Organization (ILO) Programme on HIV/AIDS and the World of Work
2. Discussion of models of direct service provisions (full group)
1:30 p.m. to 1:45 p.m.  Break and Networking

1:45 p.m. to 2:30 p.m.  U.S. Government Initiatives
1. U.S. Federal Initiatives:
   Dylan Orr, U.S. Department of Labor; Allison Nichol, U.S. Department of Justice; Lauren Deigh, U.S. Department of Housing and Urban Development

2. Discussion of government initiatives (full group)

2:30 p.m. to 3:15 p.m.  HIV/AIDS and the Workplace
1. HIV/AIDS and the workplace:
   Lou Orsline, Job Accommodation Network (job accommodations and the Americans with Disabilities Act); Robert Bailey, CDC's Business Responds to AIDS/Labor Responds to AIDS (promoting comprehensive workplace programs); Cecilia Chung, Health Commissioner, San Francisco Department of Public Health (diverse communities within the HIV/AIDS community and employment); Paurvi Bhatt, Levi Strauss & Co., Employee HIV/AIDS Program (a U.S. business response model)

2. Discussion of initiatives addressing HIV/AIDS employment issues in the workplace (full group)

3. Closing comments
Abbreviated List of References Related to Employment and HIV/AIDS


