**An Overview of Research Findings Related to Implementation of the NHAS**

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Thank you council members for your invitation, and to all present today for your interest and time. In addition to my role as a professor at Penn State University, I am also Chairperson of the Research Working Group of the National Working Positive Coalition (NWPC). The NWPC is a coalition of persons living with HIV/AIDS, service providers and researchers who are concerned about employment opportunities for people with HIV/AIDS and evaluating the availability and quality of services within the broader context of economic well-being and improved health.

Today I was asked to provide an overview of research findings related to HIV and employment issues to help set the context for this morning's discussion and consideration of needed public policy initiatives to effectively implement the employment provisions of the National HIV/AIDS strategy.

**National HIV/AIDS Strategy and Employment**

As many of you are aware, the primary objectives of the National HIV/AIDS Strategy include (a) reducing the number of new HIV infections, (b) increasing access to care and optimizing health outcomes and (c) reducing health-related disparities. The two primary questions we will consider today are, "How is employment related to these goals?" And "Is there any reason that PACHA should devote time and resources to further examining and measuring the role of employment in the NHAS?"

Although objectives related to employment are integrated throughout the NHAS, many are not aware of the research that supports the inclusion of employment as a critical component of addressing the goals of the strategy and what research still needs to be done to gain a better understanding of the relationship between employment status and HIV health and prevention outcomes.

**National Working Positive Coalition Vocational Development and Employment Needs Survey**

To fill in this context, I will begin by sharing some key descriptive findings from the NWPC Vocational Development and Employment Needs Survey and discuss these findings along with related research. The NWPC-VDENS survey was funded by a Mary Switzer Fellowship through the National Institute on Disability and Rehabilitation Research (Department of Education) as well as additional funds from the New York State Department of Health, AIDS Institute (to increase data collection within New York State). This survey was implemented in 2008 and participants were recruited from AIDS Service Organizations from around the United States.

The sample for the NWPC study included 2,506 people with HIV/AIDS. Although it was a volunteer sample, efforts were made to ensure that the sample represented the demographic diversity of the HIV/AIDS epidemic as reflected in the sample demographics:

Age: mean age 46

Gender: 65% male, 34% female, 1% transgender

Race: 37% Black, 37% White, 18% Latino, 7% other

Sexual orientation: 48% heterosexual, 44% gay, 8% bisexual

Education: 38% have a high school education or less

Never use: email (25%), Internet (22%)

History of: homelessness (43%), incarceration (26%), drug abuse (38%),

Employment Status: 32% employed, 68% not working

53% reported an income of less than $15,000 per year

**Impact of HIV Diagnosis on Employment Status**

A primary finding from this study is the devastating impact than an HIV diagnosis can have on the employment and economic wellbeing of those impacted. For example, 63% of respondents reported that they were working at the time they were diagnosed. However, only 32% reported being employed at the point of completing the survey.

Qualitative research studies reveal that many individuals stopped working or lost their jobs at the point of diagnosis (Conyers). A range of factors contribute to this including perceptions of a shortened life expectancy, poor health, and being overwhelmed by the traumatic nature of the diagnosis.

Evidence also suggests that PLWHA who face job loss may be particularly vulnerable to falling out of HIV care. For example, during the period of 2006 to 2009 the number of PLWHA applying to the New York State AIDS Drug Assistance program (ADAP) claiming unemployment benefits increased from 179 to 723 (Conyers, Carrera & Lobosco, 2009). According to the National Alliance of State & Territorial AIDS Directors, National ADAP Monitoring Project Annual Report (2014), in June, 2013, ADAP utilization reached its highest level in ADAP history serving over 152,000 clients. These trends not only highlight the critical importance of the ADAP program but also underscore how vulnerable people with HIV can be to losing needed medical services when they lose or change jobs.

Lack of early intervention to prevent unnecessary HIV related job loss can be very costly to the individual and to society. Research indicates that less than half of one percent of SSI and SSDI recipients actually exit these programs each year to work (Marini, 2001). In light of the negative impact of interrupted employment trajectories, it is essential to develop policies that may limit premature departure from the workforce (Williamson & McNamara, 2003) and to fund more research to examine this issue

within the HIV/AIDS context. The longer a person is out of the work force, the less likely it is that they will transition back to employment.

Currently, I am not aware of any research that specifically tracks transitions in employment status from point of diagnosis or any intervention studies that are designed to provide employment resources or supports at the point of diagnosis to help reduce unnecessary job loss. This type of research, including examining the impact on employment transitions on health and engagement in health risk behaviors associated with HIV transmission would be helpful to better inform public policy regarding the role of employment in the implementation of the strategy.

**Impact of Employment Transitions on Health and Access to Care**

A number of research studies that are not specifically related to HIV have found that employment transitions are associated with changes in health-related lifestyle and that health risk behaviors increased for those on a downward employment trajectory, while an upward employment trajectory was associated with no changes or healthy lifestyles (Liukkonen, Virtanen, Vahtera, Suominen, Sillanmaki & Koskenvuo, 2009; Virtanen, Vahtera, Broms, Sillanmaki, Kivimaki & Koskenvuo, 2008).

Findings from the NWPC-VDENS provided support for improved health and reduced health-risk behaviors among respondents who transitioned to work. Employed participants who were unemployed prior to their current job were asked if health outcomes or behaviors associated with prevention increased, decreased or did not change since being employed. For the majority of respondents, employment either had no impact or a positive impact on improved health and reduced health-risk behaviors.

Regarding health outcomes, 49% reported self-care increased since their current job and 40% reported no change. Only 10% reported self-care decreased. With respect to CD4 count, 46% reported an increase in CD4 count and 37% reported no change. 18% reported a decrease in CD4 count. Regarding medication adherence, 21% reported an increase and 71% reported no change. 8% reported a decrease in taking medications as prescribed.

With respect to behaviors associated with increased risk of HIV transmission, 35% reported that use of alcohol decreased since their current job and 63% reported no change. Only 2% reported an increase. We see a similar trend with drug use. 34% report a decrease in drug use and 63% report no change. Only 3% reported an increase. Regarding unprotected sex, 30% reported a decrease in unprotected sex, and 63% reported no change. Only 6% reported an increase. Finally we also asked about number of sex partners and found that 35% reported a decrease in number of sex partners and 61% reported no change. Only 4% reported an increase.

When unemployed participants were asked what they thought would happen regarding health and prevention outcomes, we note similar trends in their responses where the vast majority anticipated that transition to work would lead to either no change or

improved health outcomes and reduction in health risk behaviors associated with HIV transmission.

There is an urgent need to better understand this relationship between employment and health, first for the individuals themselves and their wellbeing, and also for society as a whole, which will benefit from increased overall productivity and lower health and social costs associated with positive employment and associated health outcomes.

In a systematic review of the research literature related to return to work and health outcomes for people in the general population (not specifically people with HIV) found that overall, people were in better health when then went back to work and worse when they remained unemployed (Rueda et al). However, the relationship between work and health is not linear and multiple factors need to be taken into consideration when doing research in this area.

A series of studies conducted in Canada by members of the Ontario HIV Treatment Network (OHTN), which specifically focused on people with HIV/AIDS, indicated that employment status was positively associated with both physical and mental health. However, there was a steeper decline in health following loss of employment among participants who had poorer health status prior to job loss, indicating that healthier individuals may be more resilient to the negative effects of job loss. Additionally, in a study that examined the role of job security found that, for men living with HIV, a greater level of job security offered mental health benefits over and above just having a job.

In summary, although research findings provide support for the positive association of work and health, it is also clear that we cannot expect positive outcomes for everyone. The psychosocial aspect of the work environment and degree of employment permanence are key factors that impact the extent to which varied employment settings are conducive to positive health outcomes for people with HIV/AIDS. More research is needed to better understand the positive effects of employment as well as the psychosocial aspects of the work environment that lead to more or less positive health outcomes.

These findings also suggest that when evaluating the impact of employment services for people with HIV/AIDS, the outcome measures should be more comprehensive than whether or not the person got a job. It should also include assessment of the impact of employment on the health and economic well being of the individual over time.

**Lack of Knowledge of Vocational Supports and Services**

The NWPC-VDENS survey also revealed that PWHA have very limited knowledge of employment services and resources. The two most prominent federally funded services are the American Job Centers (funded by the DOL and designed to serve all job seekers with and without disability) and the State Federal Vocational Rehabilitation system (funded by the Department of Education, Office of Special Education and Rehabilitation Services, and designed

specifically to serve individuals with documented disabilities, which create significant barriers to employment). Only 17% of survey respondents reported knowledge of the American Job Centers (formerly called the One Stop Career Centers) and only 31% of the respondents were familiar with Vocational Rehabilitation services.

PLWHA are not only poorly informed of vocational supports, but they also lack information about key federal incentives to facilitate the employment of people with disabilities. With respect to knowledge of SSI and SSDI (or SSA, for both) work incentives, only 23% reported knowledge about the Ticket to Work (which provides free access to vocational rehabilitation services) and the Trial Work Period (which allows individuals with SSDI to work up to 9 months without impacting their disability benefits income). Even more striking, only 10% of the respondents knew about Extended Medicare and how they could continue to have access to Medicare over an extended time while transitioning back to work. Respondents also reported low levels of knowledge of the Family Medial Leave Act and the Reasonable Accommodations provisions of the Americans with Disabilities Act.

**Lack of Access to Trained Professionals**

In addition to their own lack of knowledge relating to employment services and federal incentives, the vast majority of respondents to the NWPC survey indicated that their service providers were not knowledgeable about employment services and resources. In fact, only one fourth of respondents agreed that their service providers were knowledgeable in this area.

The lack of access to qualified vocational rehabilitation professionals within the HIV/AIDS service system is also due to the restrictions limiting and/or prohibiting funding of vocational services within the Ryan White HIV/AIDS Program, and the overall tendency to isolate human service needs and services, rather than providing more comprehensive integrated services (Ciasullo & Escovitz, 2005).

Research indicates that when individuals with disabilities have access to a masters level rehabilitation counselor compared to other professionals, they achieve higher rates of successful employment outcomes. Consequently the 1992 Amendments to the Rehabilitation Act require that states hire qualified personnel to address the unique needs of individuals with disabilities. Unlike many other professionals, rehabilitation counselors are required to take courses regarding employment policies and services for people with disabilities, including knowledge of work place accommodations, assistive technology, work incentives, evidence-based vocational interventions as well as medical and psychosocial aspects of disability, including stigma and discrimination. With this background rehabilitation counselors have the skills and knowledge to address barriers to employment for people with HIV/AIDS. The highest level credential for a rehabilitation counselor is Certification in Rehabilitation Counseling (crccertification.com). This certification requires a level of competency in all of these areas associated with successful employment outcomes for people with disabilities. However, despite this needed skill set, rehabilitation counselors are rarely found within

the AIDS services, as they are not currently eligible for Medicaid or Medicare reimbursement or as a billable service for many insurance providers. Consequently, community-based agencies cannot afford to cover their full salary. The lack of reimbursement of services for professionals with the unique skill set to help people with HIV/AIDS maintain employment or transition to work is an example of an structural barrier to employment resources and information for people living with HIV/AIDS. To increase access to knowledgeable professionals, it would be important to consider ways to implement the reimbursement of these services within the HIV/AIDS system of care.

**Impact of Health Status on Access to Employment Services and Income Supports**

Despite advancements in HIV treatment, there is great diversity of health status among those affected. From the NWPC-VDENS study sample, 67% reported a diagnosis of HIV and 33% reported AIDS. 21% reported unstable health during the past 12 months and 15% expected their health to be unstable over the next 5 years. Remarkably, 90% reported additional health concerns beyond their HIV/AIDS diagnosis.

This diversity of health outcomes has important implications for gaining access to vocational services and/or disability benefits and supports. Increasingly, people with HIV/AIDS may be determined to be too healthy to qualify for Social Security benefits and also not qualify for vocational rehabilitation services because they are not found to have a significant number or level of functional limitations to meet the eligibility criteria to be classified as a person with a disability by the state federal vocational rehabilitation eligibility requirements.

Ironically, one would have to wait for their health status to decline before meeting the eligibility requirements of federal vocational rehabilitations services. From what we know about the research on treatment as prevention where reduction in viral load reduces risk of HIV transmission, failure to provide employment services while people are well enough to work is poor public policy. Without connection to either income supports or employment services, engagement in HIV care is increasingly tenuous.

As you are considering issues related to the implementation of the Affordable Care Act for people with HIV, it would be important to consider ways in which people with HIV/AIDS could have access to vocational resources and supports during these critical points of employment transition. Interest and need for employment may be a critical factor in helping retain people in care, increase treatment adherence, and viral suppression.

To date, only one study has specifically examined the impact of use of state vocational rehabilitation services related to the outcomes of the NHAS. This study was grounded in a model of health care utilization to investigate the impact of vocational rehabilitation as an enabling factor to (a) increase use of medical and mental health services, (b) increase supplemental employment services, and (c) reduce health-risk behaviors associated with HIV transmission. The findings of this study supported the hypothesis that use of

vocational rehabilitation services plays an important role in the implementation of the NHAS.

The State Federal Vocational Rehabilitation services system is the most comprehensive employment resource for people with disabilities, including many people with HIV/AIDS. These services include comprehensive rehabilitation evaluation to determine skills, interests, and abilities, as well as case management, vocational counseling, employment services, assistance with finding and keeping a job, and on the job training, apprenticeships and non-paid work experiences. Rehabilitation counselors can also authorize medical referrals and supportive rehabilitation services, including mental health counseling, if these services will remove barriers to employment. Research findings indicate that use of VR services increases the chances of successful employment among those who use these services.

According to the Centers for Disease Control and Prevention [8], retaining individuals with HIV/AIDS in care is a significant public health challenge as it is estimated that 3 out of 4 PLWHA do not achieve the full benefits of the treatment needed to keep the virus under control. Given the extent of valuable services provided by the VR system, it makes intuitive sense that use of VR services would improve access to health care and supplemental employment services for eligible PLWHA and reduce risk of HIV transmission. Successful engagement in vocational rehabilitation services not only increases the potential for being linked to important resources but it also increases the likelihood of improved economic outcomes through employment [11]. For example, one study (Hayward and Schmidt-Davis) found that only 27% of persons who were eligible for VR services but who did not use it were working after one year, compared to 83% of persons who participated and obtained an employment outcome (Hayward & Schmidt-Davis, 2003).

Despite the many benefits of State Federal Vocational Rehabilitation Services there are also many challenges so this system cannot be the sole focus of employment services and resources for people with HIV/AIDS. As aforementioned, many people with HIV may not quality for VR services due to lack of documented functional limitations. Second, due to limited funding, many states are not able to meet the needs of all of the people with disabilities seeking services. Finally, current policy initiatives are placing a greater emphasis on VR to serve students in transition from high school to work, without providing additional funding to meet this demand. Should this move forward, it will be more difficult for older individuals and people with chronic illness to be prioritized for access to rehabilitation services.

Currently, the Department of Education is not specifically mentioned within the implementation plan of the NHAS. In light of the significant role that they play in the provision of employment services to people with disabilities it would seem that their engagement in the implementation of the NHAS is warranted.

**Evidence-based Interventions Exist**
Despite the underutilization of vocational rehabilitation and workforce development services, several research studies demonstrate that vocational services can be effective. These interventions represent a range of approaches including vocational groups, prevocational services, applying models from psychiatric rehabilitation, individual counseling approaches and integrating programs within housing services. Despite their success, many of these interventions ended at the end of a grant cycle rather than being integrated into the HIV system of care.The knowledge and expertise developed through projects funded by NIDRR and NIH need to be integrated into current service systems and further research needs to be done to establish additional evidence-based practices.

**Specific Findings for Unemployed Participants**
When the unemployed participants were asked if they were able to work, 43% of men and 38% of women said yes, however they were not currently employed. About one third of respondents (32% men and 29% women) reported that they were not sure if they could work, indicating a strong need for vocational counseling and prevocational services to help individuals develop their skills and assess a variety of options. A quarter of the men (25%) and 34% of women indicated that they were not able to work. That more than a quarter of respondents are not able to work underscores the need to retain important safety nets for this population including income benefit supports, housing subsidies and access to health care.

Findings from the NWPC survey indicate that people with HIV/AIDS who are not employed are not one monolithic group and may be at various phases of considering work and are in need of targeted interventions to help them address barriers to employment. As we are better able to understand the diverse needs of this group, we will be better able to tailor interventions appropriately. For example, I am currently working with Vanessa Johnson to investigate the impact of an integrated HIV prevention and vocational development intervention for African American women with HIV/AIDS.

Unemployed respondents reported three main motivations to work: increase income (87%), feel useful and productive (84%) and gain access to benefits (75%). However, about 17% to 28% of the sample reported concerns regarding the potential of loss of housing and income benefits, discrimination, losing health insurance, health deteriorating and others finding out their HIV status. Only 32% reported confidence in their ability to work. 34% indicated that they need job skills and only 27% agreed that their service providers were knowledgeable about employment.

These findings indicate that there is a clear need for employment services for individuals who may be able to work or who are unsure of their ability to work. There is a critical need to help these individuals access information to make informed employment decisions and do not prematurely foreclose consideration of work due to lack of adequate information or resources designed to help people with disabilities be able to work. Effective models, such as the Client-Focused Considering Work Model, exist to help guide this process.

**Employment Discrimination Rarely Reported**

Participants reported multiple types of discrimination related to HIV status, gender, ethnicity, sexual orientation and age. Of those who reported discrimination, only 3.5% reported to EEOC. 4.4% reported to Legal Aid, 7.7% reported to employer and 18.2 reported to friends or family. One study found that when charges of HIV discrimination were filed with the EEOC, a higher proportion of those charges were found to have merit after independent review when compared to charges of discrimination filed by people with other types of disability (Conyers et al. 2006). Employers are a key partner in reducing HIV and other forms of disability stigma. Clearly there is a need for more employer-based education to both reduce levels of discrimination and increase efforts to hire people with HIV/AIDS

**Conclusion**

As I conclude, it is important to note that many of the points that have addressed today as they relate to HIV/AIDS are shared among people with disabilities more broadly. As the HIV/AIDS movement has had a remarkable impact on improving health care services and policies, it is my sincere hope that through your leadership, we may be able to address critical issues in employment and disability policy more broadly to provide more consistent access to knowledgeable service providers with expertise in employment and disability issues and the intersection of health, work and public health outcomes related to vocational rehabilitation service delivery. The disability rights movement has laid the foundation to increase the professional training to address the employment needs of individuals with disabilities, which is inclusive of people with HIV/AIDS. Perhaps now we can work together to bring these efforts to greater fruition to further advance the rights of all people with chronic health conditions and disability.

Thank you for your time and consideration of this topic.