

Introduction

HIV/AIDS as an emergent disability: The response of vocational rehabilitation

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It is with great pleasure that I welcome you to this special issue on HIV and employment. Since the onset of the HIV pandemic in the early 1980s, the nature and course of this illness has changed in dramatic ways. As such, the response of the field of vocational rehabilitation has also grown to meet the ongoing needs of individuals with HIV/AIDS, especially as the need for employment and vocational rehabilitation has become a primary concern for many living with this illness. Within the past several years, there has been a groundswell of interest in the vocational rehabilitation of individuals with HIV/AIDS among a wide range of diverse professionals. In April of 2003 the Matrix Research Institute (now the Matrix Center at Horizon House, Inc.) organized the *Working Positive Summit* conference [endnote] to bring together leading HIV and employment researchers, educators, and service providers from across the nation to share knowledge and provide recommendations for next steps. Uniformly, conference attendees recommended the formation of a national organization to facilitate ongoing exchange regarding the best practices for employment research, education, services, and advocacy. From this effort, the *National Working Positive Coalition* (NWPC) was established. In my role as chairperson of the NWPC Research Working group, I have had the pleasure of sharing many ideas with other group members and it was through such a dialogue that the idea for this special issue materialized.

One of the most helpful ways to understand many of the current advances and challenges regarding the vo-

ccational rehabilitation of individuals with HIV/AIDS is to view this illness from the perspective of an emergent disability. Emergent disabilities are defined by two main characteristics: the disorder has either newly appeared in the population, or it has previously existed but is rapidly increasing in geographical range or incidence [8,38]. HIV/AIDS meets both these criteria. When HIV first appeared in the United States in the early 1980s, little, if anything, was known about this disease except that many people were dying. Since HIV was first recognized, the CDC has continued to note new or emerging demographic patterns of this disorder [7].

The most prevalent feature of HIV/AIDS as an emergent disability is its constant evolution and the need for ongoing adjustment in services as medical advancements are made. A review of the vocational rehabilitation literature reveals the response of rehabilitation and AIDS service professionals to these changes. During the very early period of HIV emergence, many people were not aware of their illness until they became seriously ill and were not able to work. Consequently, there was little attention paid to HIV/AIDS in the field of vocational rehabilitation. However, as early as 1988, the *Journal of Applied Rehabilitation Counseling* published one of the first manuscripts providing an overview of AIDS for rehabilitation professionals, highlighting counseling interventions and vocational implications [40]. As we gained a better understanding of HIV/AIDS and improved medical man-

agement, an increasing number of manuscripts were published to provide rehabilitation professionals with more background and context for the HIV/AIDS pandemic (e.g. [15,19,20,35]). Specific publications also addressed how to incorporate HIV in rehabilitation instruction [11,14]. In 1995, Hunt conducted the first study of HIV/AIDS training in rehabilitation counselor education programs and found that 79% of the programs surveyed provided at least some basic HIV information in their course content and that the majority of programs provided course work that was indirectly related to HIV (e.g., multicultural counseling, human sexuality, substance abuse). In a follow-up study, Hunt and Robertson [29] found that 93% of the responding programs reported including basic information on HIV. While this research focused on rehabilitation programs, other studies assessed counselors' attitudes, experience, knowledge, and comfort regarding HIV/AIDS [2,17].

About the same time that one notes an increase in focus on HIV in the vocational rehabilitation literature, one can find a similar trend in the HIV/AIDS literature and among other fields related to HIV and employment (e.g., occupational therapy, employment counseling, law, business, nursing, social work, neuropsychology, counselor education). Hoffman [25] provided an extensive literature review on the effect of HIV on work and employment. Brooks and Klosinski [6] published one of the seminal pieces that highlighted action steps needed by AIDS service organizations to address the emerging employment issues and concerns of individuals with HIV/AIDS. Other themes noted in this literature are the effect of neuropsychological impairment on employment [42], workplace issues and employment assistance programs [16,39], and effect of employment on quality of life [3].

Both the rehabilitation and HIV/AIDS literature have increasingly focused on the employment-related experiences of HIV positive individuals, involving a more diverse range of research participants (youth, ethnic minorities, different stages of the employment process) and incorporating theoretical perspectives. A number of recent studies underscore the meaning of work, identity, and career development [4,9,17,28,32,35,41]; job seeking behavior [22,23]; the impact of vocational services and employment [10]; comparisons between HIV and cancer [12]; workplace disclosure [12,13]; program development and outcomes [5,30,31]; job placement [23]; employment discrimination [37]; and perceived barriers to employment [34]. The legal and business literature also document the extent to which peo-

ple with HIV are covered by legislation such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act. In light of the wide range of initiatives emerging across many disciplines, we decided that it would be best if the content of this volume (a) covered various stages of the transition to work from consideration of work through employment, (b) illustrated both advancements and challenges associated with employment and research, (c) addressed important individual as well as contextual factors, and (d) remained user-friendly to practitioners and fellow researchers alike. Because of the overwhelming response to this topic and the high quality of all of the manuscripts that were submitted, this special issue will conclude with articles in the 22.3 issue of the *Journal of Vocational Rehabilitation*.

The issue begins with *HIV 101: A Primer for Vocational Rehabilitation Counselors*. Berry and Hunt provide a comprehensive review of the current status of HIV/AIDS so that vocational rehabilitation counselors can have a solid understanding of what HIV is, the medical terms used to delineate the health status of individuals with HIV/AIDS, the psychosocial issues that relate to the provision of vocational rehabilitation services and the increasing importance of the role of vocational rehabilitation practitioners for this population.

One of the prominent themes in the HIV/AIDS vocational and psychosocial literature is the Lazarus syndrome, in which, after years of anticipating their own premature deaths many individuals who respond favorably to medical treatments are suddenly faced with the prospect of not dying and having to unexpectedly plan for a future. However, the primary focus of this literature is on the need for individuals with HIV/AIDS to change their outlook, whereas only limited attention has been directed to the need for HIV/AIDS service providers to engage in a similar paradigm shift regarding their conceptualization and provision of services. In *Developing Employment Services for Individuals with HIV/AIDS: Participatory Action Strategies at Work*, Paul-Ward, Braveman, Kielhofner, and Levin make a compelling argument for the need to shift the focus in all phases of services for people with HIV/AIDS to place a greater emphasis on self-determination. The authors describe the development of a 3-year federally funded demonstration project, *Enabling Self-Determination for Persons Living with AIDS*, which includes a review of the theoretical foundation of this project and the challenges encountered along the way. This manuscript appears second in the

issue because it targets the need to initiate change in one of the earliest phases of the rehabilitation process, residential facilities. It provides vital documentation of the ever-widening gap between traditional HIV/AIDS services, that provide basic sustenance requirements (housing, case management, nutrition), and the current needs of individuals with HIV/AIDS to be able to plan for a viable future.

Although only a few vocational rehabilitation programs for people with HIV/AIDS exist nationwide, the next two contributions to this volume provide evidence that many people with HIV/AIDS are able to achieve their vocational goals with the proper support services. In each manuscript, the authors provide a strong theoretical foundation for their specific approach to the vocational rehabilitation process and how they adapted specific substance abuse and psychiatric vocational rehabilitation interventions to the ever changing needs of people with HIV/AIDS. In the first manuscript, *Tailoring a Vocational Rehabilitation Program to the Needs of People with HIV/AIDS: The Harbor-UCLA Experience*, Martin, Chernoff, and Buitron provide an extensive discussion of the evolution of the UCLA approach to vocational rehabilitation by describing three of the employment programs that they have developed since 1996.

Although the first program was developed from basic vocational rehabilitation principles, each subsequent program drew upon the experiences of the prior programs so that the services became increasingly tailored to meet the unique needs of people with HIV/AIDS. In particular, the authors demonstrate the successful integration of substance abuse rehabilitation theory into vocational rehabilitation services. This article serves as an excellent resource as it offers detailed descriptions of both the theoretical foundation for these projects and details regarding the content and structure of the interventions. Based on their extensive experience in the field, the authors provide recommendations for future research and program evaluation, including a reconsideration of definitions of successful outcomes and the timeline for goal attainment.

In *Providing Effective Employment Supports for Persons Living with HIV: The KEEP Project*, Escovitz and Donegan document parallels in the barriers to employment experienced by people with psychiatric disabilities and those with HIV/AIDS and draw upon psychiatric rehabilitation principles and practices to meet the employment needs of individuals with HIV/AIDS. They describe the successful employment outcomes of their three-year demonstration project, the *Kirk Em-*

ployment Empowerment Project (KEEP). During the course of this project, 77% of the participants were employed at least once and 63% of the participants remained in their job for 90 days or longer. This project is noteworthy both because of its demonstration of the successful application of psychiatric rehabilitation principles to the vocational rehabilitation of people with HIV/AIDS and because the results counter common assumptions about the unemployability of traditionally marginalized groups of people with HIV/AIDS. The study participants consisted of a large proportion of ethnic minorities and people with significant vocational disadvantages (limited education, psychiatric illness, history of substance abuse and/or incarceration, and poverty). Consistent with the place-train philosophy of many psychiatric rehabilitation programs, Escovitz and Donegan challenge vocational rehabilitation providers to place primary emphasis on the development of job-related decision-making and problem solving skills and sustaining support post-employment rather than on extensive training in job-seeking activities. The successful rehabilitation outcomes of both the UCLA and KEEP projects far exceed the return-to-work rate (2.5%) of people with disabilities generally [21] and challenge the notion that individuals with HIV/AIDS do not need or will not benefit from vocational rehabilitation services.

In the spirit of remaining user-friendly to practitioners in the field, *Vocational Counseling for People with HIV: The Client Focused Considering Work Model*, by Kohlenberg and Goldblum provides a useful model for vocational rehabilitation practitioners to conceptualize the process of considering employment. This model draws upon many of the key theories previously discussed in the research studies (self-determination, stages of change) and applies them to the clinical practice of vocational rehabilitation.

To conclude the first section of this special issue on HIV/AIDS and Employment, we are presented with the shared perspectives of person living with AIDS and a service provider/researcher regarding the current state of HIV/AIDS service systems. *Positive Futures: A Need for a Paradigm Shift in HIV/AIDS Services*, co-authored by Ciasullo and Escovitz, advocates for a shift away from HIV/AIDS services that focus exclusively on stabilization and maintenance to those that incorporate a rehabilitation-focused, futures-oriented model. Unlike the maintenance approach, the rehabilitation paradigm presumes the possibility of wellness, as well as capacity and agency, and is oriented towards self-determination and autonomy. The authors note that the

rehabilitation paradigm is predicated on the principle of providing the necessary resources and supports (health insurance, vocational training) to achieve success and of accommodating setbacks associated with episodic illness to minimize any deterioration in health or access to needed social or residential services. Ciasullo and Escovitz draw upon civil rights as a core foundation of HIV/AIDS advocacy and delineate clear policy initiatives that could lead to healthier futures for individuals as well as for our system of services.

The second section of this special issue (to appear in the next volume of the Journal) focuses on barriers to employment and workplace experiences of employed individuals with HIV/AIDS. Despite medical advancements, it is essential to recognize that not all individuals with HIV/AIDS have access to treatment or respond when treatments are available [1]. Razzano and Hamilton examine the relationship between employment status and a variety of demographic, health, and benefits variables in *Health-related Barriers to Employment Among People with HIV/AIDS*. This study provides evidence that health-related barriers to employment do continue to exist among many people with HIV/AIDS. This study also illustrates (a) the importance of assessing perceived health limitations, rather than diagnostic categories or biological indicators alone, and (b) the high reliance of individuals with HIV/AIDS on Medicaid as a primary means of health care. Razzano and Hamilton's study has important implications for HIV/AIDS research and policy. While it is important to emphasize self-determination and vocational services for this population, it is equally important to recognize the importance of basic HIV/AIDS services and supports for people who are not yet healthy enough to make a transition to employment. Furthermore, more research is needed to assess the extent to which lack of access to health insurance is itself a barrier to employment. Finally, vocational rehabilitation professionals and researchers alike need to understand that due to medical advances, the diagnosis of AIDS, once a clear predictor of serious health decline, can no longer be relied upon as a reflection of health status or functional ability.

When considering barriers to employment, it is also critical to consider contextual factors such as the extent to which people with HIV/AIDS must contend with negative social bias and employment discrimination. Conyers, Unger, and Rumrill investigate this issue in *A Comparison of Equal Employment Opportunity Commission Case Resolution Patterns of People with HIV/AIDS and Other Disabilities*. This study is one

of the first to provide empirical evidence documenting that, after official review by the EEOC, people with HIV/AIDS are less likely to have charges of employment discrimination dismissed as groundless and are more likely to have findings of reasonable cause compared to people with other disabilities. Although previous studies have reported high levels of perceived discrimination among participants with HIV/AIDS, this study is unique in that it is based upon the objective evaluation (by trained EEOC personnel) of charges of discrimination. The findings of this study are discussed within the context of the services that vocational rehabilitation counselors need to provide to both reduce HIV/AIDS stigma in the work environment and to better inform their clients of the limitations of employment legislation.

Although there has been an increasing amount of investigation into prevocational and return to work initiatives in major cities in both the rehabilitation and HIV literature, less attention has been focused on the experiences of people who are currently working or who live in small towns or rural areas. To address this gap in the literature, Conyers and Boomer provide a comprehensive review of the patterns of job accommodation and factors associated with workplace disclosure of HIV/AIDS among a sample of employed individuals with HIV from southcentral Pennsylvania. This study found that part-time employees tended to request job accommodations more frequently than full-time employees and that many people with HIV/AIDS did not disclose their HIV status at work.

Finally, this special issue on HIV and employment concludes with a case study that is designed to help integrate and apply much of the content presented. In *Teaching the HIV Positive Client How to Manage the Workplace*, Breuer provides an annotated case study that illustrates many of the complex issues that individuals with HIV/AIDS face both when seeking employment and on the job. This manuscript provides clear strategies for responding to common employment concerns such as responding to illegal interview questions, evaluating disclosure of HIV status, use of leave time, and managing medication adherence at work. This information is presented in a format that educators, trainers, and individuals with HIV/AIDS can easily adapt for their individual learning and training needs.

Since its inception in April of 2003, the National Working Positive Coalition (NWPC) has developed into the preeminent organization to produce and disseminate knowledge regarding the employment-related needs and concerns of individuals with HIV/AIDS. The

mission of the NWPC is to (a) promote research, development, and implementation of effective practices in employment services for individuals with HIV/AIDS, (b) coordinate sharing and dissemination of this information, and (c) advocate for work options and opportunities for people living with HIV/AIDS. As chairperson of the Research Working Group, I would like to invite any rehabilitation professionals who are interested in the NWPC mission and goals to join this network and contribute to the advancements in this field. The board of the NWPC consists of persons living with HIV/AIDS, service providers, educators, and researchers. During the past year, board members have made presentations at national conferences such as the Center for AIDS Prevention Conference in San Francisco, the National HIV/AIDS Social Work Conference, and the National Council on Rehabilitation Education (NCRE) conference. Most recently, NWPC sponsored *Positive Futures*, the first full day pre-conference institute, on HIV and employment at the 2004 US Conference on AIDS.

Currently, the NWPC is sponsoring a national employment needs survey to assess current status of employment among people with HIV/AIDS and to identify the needs they face as they consider employment or contend with workplace issues. Results of this survey will be available on the website of the National Association of People with AIDS (NAPWA.org) in March of 2005. Members of the coalition are actively working on a wide range of projects including: improving services, gaining a better understanding of vocational rehabilitation providers' experiences of working with this population, and doing more in-depth analyses of employment discrimination. However, it is important to note that this special issue does not provide an exhaustive review of all of the work being done in this area.

As an organization, the NWPC recognizes the importance of integrating our efforts with the many initiatives and organizations currently designed to address the employment issues of individuals with disabilities generally and to continue to welcome new members who share our mission and values to further advance employment opportunities for individuals with HIV/AIDS. For more information about how to join the NWPC please visit our website at workingpositive.net.

Developing this special issue has been a great source of enjoyment for me. However, reaching this goal would have been much more difficult without the assistance and advice from my co-editor, Phil Rumrill. As I was conceptualizing this volume, I contacted Phil

to see if he would be willing to co-edit this special issue with me to provide mentorship and guidance. Phil read through all of the manuscripts and served as copy-editor on half of them. His expertise in multiple sclerosis and chronic illness and his experience as an editor of prior special issues and books were instrumental in this process. I am deeply grateful for his collegiality and the support that he provided along the way. I would also like to thank several individuals who provided feedback on my own contributions to this issue (K.B. Boomer, Lynn Koch, Brandon Hunt, Karen Escovitz, Phil Rumrill, Roselyn Costantino) including the external reviewer for the EEOC and Disclosure manuscripts, Bryan Cook. I appreciate the time and effort that these individuals devoted to improve the quality of these manuscripts. This issue also would not have been possible without the tremendous contributions of each of the authors and reviewers who are acknowledged below. I thank Paul Wehman for his interest in this topic and willingness to devote an entire issue and one-half to HIV/AIDS and to Roberta Martin for her technical expertise and support. Above all, I would like to thank the many individuals who live with HIV/AIDS on a daily basis and whose experiences have helped us all to become more informed of the challenges that they face and the accomplishments that they have achieved in their efforts to plan for a positive future.

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