



Employment Needs of Individuals with HIV/AIDS: Service Providers' Viewpoints

Jaimie Ciulla Timmons and Sheila Lynch Fesko

Introduction

Individuals with HIV/AIDS often confront challenges when addressing employment concerns related to their health status. Since AIDS Service Organizations (ASOs) and vocational rehabilitation (VR) systems are likely to be involved in meeting the employment needs of this population, the Institute for Community Inclusion at Children's Hospital has surveyed both to determine their responsiveness to the employment-related concerns of individuals with HIV/AIDS. The goal of this project is to identify promising practices used to respond to the employment needs of persons with HIV/AIDS and use this information to improve the existing employment services available. This report summarizes the experiences of AIDS Service Organizations and vocational rehabilitation systems concerning the provision of work-related services to individuals with HIV/AIDS.

Participants

In order to understand the provision of employment-related services by AIDS Service Organizations, a statewide survey of 264 ASOs in Massachusetts was conducted with 89 ASOs responding. Participating organizations were asked the extent to which support around employment was provided, the type of work-related services delivered, and where consumers were referred for assistance with employment.

State VR agencies were also surveyed as part of a national study on the impact of the 1992 Rehabilitation Act Amendments. State agency Administrators and Rehabilitation Counselors were asked to identify outreach practices for individuals with HIV/AIDS and the range of supports offered to this population. A total of 255 Administrators and 266 Rehabilitation Counselors responded to the survey.

Employment-related perspectives of individuals with HIV/AIDS were also obtained. Five focus groups were conducted and surveys focusing on employment-related experiences were completed by individuals with HIV/AIDS in Massachusetts. A total of 103 individuals participated in the study.

Findings

AIDS Service Organizations

AIDS Service Organizations indicated that the employment needs of individuals with HIV/AIDS are becoming increasingly important, but incorporating work-related support into the variety of services provided to their consumers has been difficult.

Sixty-three percent of the ASOs surveyed indicated that consumers they served had work-related concerns, yet only a little more than half (56%) of the sixty-three percent said they were able to provide support concerning employment.

Exactly half of the participating ASOs indicated there are employment-related services that would be beneficial to individuals with HIV/AIDS that they are unable to provide.

While recognizing the breadth of work-related concerns of individuals with HIV/AIDS, ASOs have been most successful in meeting health and income related support needs that influence employment.

ASOs delivered employment support mostly around health insurance and Social Security issues. This remains consistent with what individuals with HIV/AIDS identified as crucial areas of need.

ASOs cited job accommodation and job search services as other important needs of individuals with HIV/AIDS, but indicated an inability to respond sufficiently.

Since ASOs have not traditionally provided employment support services, they often refer people with employment-related issues to other agencies.

ASOs indicated that they primarily referred employment-related issues to legal resources. While these services might be helpful with advocacy and discrimination issues, they are not as useful for people with job search and accommodation needs.

ASOs also indicated that the state vocational rehabilitation service system was not a commonly utilized resource because it is perceived as large, difficult to maneuver, and therefore a poor match to address employment needs.

Vocational Rehabilitation

The ASOs surveyed reported infrequent referrals to the state VR system. Additionally, only 23% of the individuals with HIV/AIDS reported the use of VR services in dealing with employment-related issues. It is useful to compare these findings with the results of the VR study.

VR counselors and administrators report limited outreach to individuals with HIV/AIDS.

Fifty-eight percent of the counselors and administrators surveyed reported seeing no change in efforts to address the specific rehabilitation needs of individuals with HIV/AIDS since the 1992 Rehabilitation Act Amendments.

In addition, 71% of surveyed counselors and administrators reported seeing no change in outreach to employers concerning issues pertaining to individuals with HIV/AIDS.

Of the 266 counselors providing direct job-related services, 65% reported having no one on their caseloads with HIV/AIDS.

Despite the need for job accommodation assistance reported by individuals surveyed, 96% of VR counselors reported that they have never provided technical assistance to an employer about issues related to employees with HIV/AIDS.

When VR counselors were asked to list employment issues or support needs for clients who have HIV/AIDS, it was somewhat inconsistent with what surveyed individuals reported they needed.

VR counselors reported disclosure and job accommodation as primary client support needs, while surveyed individuals identified the need for assistance primarily around Social Security benefits and job placement.

Implications and Recommendations

The results of this project suggest the need to expand the capacity of ASOs and VR systems to address the full range of work-related support for individuals with HIV/AIDS. ASOs and VR systems can increase their capacity to respond to the employment

needs of their consumers with HIV/AIDS through consideration of the following recommendations:

AIDS Service Organizations can:

Consider the establishment of more formal linkages with state resources such as the VR service system, the Division of Employment and Training and One Stop Career Centers.

Identify one person (or a consultant) who can become an expert in the Social Security regulations regarding employment and work incentives.

Inquire specifically about employment-related concerns at the time of intake, ultimately leading to a prompt referral to an appropriate resource.

Consider an increase in training on job accommodation and job search strategies to enhance the capacity to respond to the employment needs of consumers.

Vocational Rehabilitation systems can:

Increase outreach efforts, building partnerships with agencies such as ASOs that provide a variety of services to this population.

Increase outreach efforts and consultation to both individuals with HIV/AIDS and employers concerning job accommodation needs and issues.

Maintain an awareness of obstacles encountered and continue to appreciate the central role employment plays in people's lives. The ongoing provision of support and encouragement will allow individuals with HIV/AIDS to maintain or obtain employment in a manner that is consistent with their physical and emotional needs.

This project is funded by grant #H133B30067-95 from the National Institute on Disability and Rehabilitation Research as well as grant #H235R50067 from the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Rehabilitation Services Administration. For further information on this study, please contact: Jaimie Ciulla Timmons, Institute for Community Inclusion (UAP), Children's Hospital, 300 Longwood Avenue, Boston, MA 02115 (617) 355-6506 V; (617) 355-6956 TTY; ici@a1.tch.harvard.edu.