
The role of research in identifying vocational development and employment needs of individuals with HIV

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Objectives

- Review medical, economic, and social forces compelling people with HIV/AIDS toward employment.
- Discuss current research designed to identify the vocational development needs of people with HIV/AIDS and the challenges to employment.
- Discuss the need for advocacy, policy and program development.

Medical Factors

- Antiretroviral combination drug therapies have led to improved health, better prognoses, and an increased interest in employment for many people living with HIV.
- Impact of chronic illness
 - How will I survive financially?
 - What do we help people live for beyond constraints of poverty?
 - How to plan for a positive future?

Medical Complexities

- Many women and people of color have **not benefited equally** from medical advances and face greater barriers to employment.
- For some, work conditions could compromise health outcomes.
- Important to identify varied needs within and among the many different demographic groups affected by HIV.

Organizational Culture

- Many AIDS Service Organizations (ASO) were established during crisis years
 - Strong organizational culture of caring for people with HIV/AIDS, not self-determination
 - Now, many ASO are established bureaucracies with well defined funding streams
 - Typically do not include funding for vocational rehab
 - Few staff trained in vocational counseling
 - Few staff are aware of community resources
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Impact of Organizational Culture

- One research participant described her service provider's response to her interest in employment:
 - *“She said, ‘you can’t go back to work.’ Her main focus was on trying to get me to see how grateful I should be...and that if I went back to work, I would get sick and die.”*
- Emerging trend towards increasing self-determination in AIDS service systems
 - Some providers report significant challenges in getting consumers to become less dependent

Economic Factors

- With advances in medical treatments, it has become increasingly difficult for people with HIV to qualify for disability benefits and services.
 - ❑ Services are provided to those with most severe disability
 - ❑ Questionable access for those who are asymptomatic
- Despite flat funding for ASO, the demand on these services has expanded due to increased numbers of people living with HIV/AIDS.
 - ❑ Agencies have to do more with less resources
 - ❑ Important to connect with vocational services in the community

Consequences: Need for Work

“Poor single mothers who do not possess partner support, access to pensions and financial assets, or eligibility for health and disability benefits may have no other choice than to remain in or re-enter the labor market following an HIV diagnosis.”

Mildred Williamson, PhD, MSW

Former Interim Executive Director

AIDS Alliance for Children, Youth & Families

2007

(Mildred Williamson, 2007)

Social Factors

- Youth
 - Strikes many during key vocational development years

- Poverty
 - Social inequalities in health care
 - Unequal access to quality education; high drop out rates
 - Lack of access to support

- Restricted opportunities
 - Employment discrimination
 - Lack of jobs in local communities

- Criminal justice - high rates of incarceration

Unique Context for Women and People Of Color

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Implications for vocational development

- Need to invest in vocational development options that will lead to jobs that can meet **individual and family** needs.
- Need to be aware of ways in which consumers can retain health insurance and other benefits while working.
- Need to understand benefits of participating in vocational development even if there is not an immediate outcome.

Current Research Study

- **Mary Switzer Fellowship**
 - National Institute on Disability and Rehabilitation Research
 - U.S. Department of Education

- **Follow-up on employment needs pilot study**
 - 2004 Internet-based needs assessment

- **Survey Revisions**
 - Focus groups with women and people of color
 - Increased focus on health and prevention
 - Pilot-tested at AIDS Alliance for Children, Youth & Families

Pilot Data: Clear Differences

■ People of Color

- ❑ 84% reported race limited employment opportunity
- ❑ 75% reported use of employment services was limited “a lot” by their race and/or cultural background

■ White

- ❑ Compared to only 27% of white respondents
- ❑ Compared to only 29% of white respondents

Health, Economics, and Prevention

- Many respondents reported major health challenges
 - 49% mental health issues; 41% substance abuse
- 88% of employed respondents reported that work improved health and outlook on the future
- 98% of respondents reported “increased income” major factor in interest in work
- **59%** of employed respondents reported that employment **reduced engagement in risky health behaviors**

Despite Perceived Positive Health & Prevention Outcomes of Employment...

- 76% of respondents reported that they never received any state vocational rehabilitation services.
- Majority not familiar with laws and resources designed to assist people to attain work and/or maintain work.

Research Objectives

- Identify the unique issues and concerns regarding considering and maintaining work among people with HIV.
- Identify the issues related to the use and/or non-use of vocational rehabilitation services among people with HIV.
- Identify the relationship between employment, HIV prevention and health status of people with HIV/AIDS.

Why is research so important?

- Must identify need to advocate for services
 - Vocational rehabilitation service delivery responds to identified consumer needs
 - Examples: orthopedic, psychiatric, developmental...
- Need to inform policy makers of complexity
 - Polarized views
 - “Everyone should be going back to work”
 - “This group is incapable given other multiple challenges”

Why is research so important?

■ Implications for public health

- Potential of employment as prevention – to better understand the ways in which employment can influence the level of engagement in health-risk behaviors.
- Benefits of helping people gain or maintain access to jobs with quality health insurance.
- Need to identify job conditions that may foster positive health outcomes, including maintaining medication adherence on the job.

Grounding Research in Theory

- HIV studies have not taken advantage of vocational development theory and research that can:
 - Help explain and predict outcomes & inform program development
- Social Cognitive Career Theory
 - Accounts for impact of environmental barriers
 - Identifies links between person, environment & behavior
- Career Barrier Research
 - Examines racial/ethnic disparities, poverty, gender, sexual orientation

Benefits of Research Participation

- Participants

- Can reflect on personal experiences and help to inform policy and program planning for others.

- Agencies

- Can identify consumer needs and assist with advocacy to establish services.

- Format

- Easy to complete; self administered
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Resources for Participating Agencies

- We can design data collection to be able to provide each participating agency with a summary of their consumer's responses to the survey.
- This information can be used for grant-writing or advocacy
- Can provide information on state vocational rehabilitation services and other vocational supports as they are identified.

Levels of Participation

- Verbal Agreement
 - Post general flyers in agency
 - Send electronic flyer/link on list-serves to friends
- Email agreement
 - Establish specific agency link & agency flyer
 - Distribute paper format of survey
 - Peer recruiters; central pick-up & drop off contact
- Additional training – PSU IRB online module
 - Provide 1:1 assistance with survey
 - Distribute survey in group format

Resource for Research Participation

Any one who would be interested in participating in this research project can contact:

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Links/Access to Survey

- General Link
 - <https://surveymk.com/nwpc>
- Spanish Link
 - <https://www.surveymk.com/snwpc>
- Agency Specific Links
 - Can be designed upon request
- Paper and Pencil Surveys
 - Available upon request